PARENTAL PERSPECTIVES ON SOCIAL SUPPORT NEEDED DURING THEIR CHILD'S TRANSITION FROM PRESCHOOL TO SCHOOL WITHIN AN EARLY INTENSIVE BEHAVIOURAL INTERVENTION PROGRAM

By

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ABSTRACT

The purpose of this study was to examine the experiences of parents of children with autism during the transition from preschool to school within an Early Intensive Behavioural Intervention (EIBI) program. Qualitative interviews within grounded theory framework were conducted to gain a better understanding about parents' perceptions of the social supports they received during the transition period.

Data collection involved semi-structural interviews with six families whose children completed EIBI program at St.Amant and were enrolled in school. Due to the small sample size, a metasynthesis of five qualitative studies about the transition experiences of families with children with autism was added. This metasynthesis provided additional information to the data collected from interviews in order to strengthen the trustworthiness of the current study. All data collected from the interviews were coded, categorized and analysed using a constant comparative method.

Findings from both data collection components emphasize the importance of parents' involvement in the transition process and suggest that an effective partnership between the home, the EIBI program and the school is a significant factor to a successful transition. The findings also highlight the need for strategic planning of the transition process that is family-focused and involves an active role of a facilitator, who can offer practical guidance and support to children and their families.

Practical implications and recommendations for future research are discussed.

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CHAPTER I

OVERVIEW OF STUDY

Introduction

Autism is a lifelong developmental disability that affects an individual in various ways (Wall, 2010). Autism conditions are a spectrum disorder, which means that symptoms can be present in a variety of combinations, and each combination can range from mild to severe. Autism Spectrum Disorders (ASDs) are characterized by challenges in communication, social interaction and learning, stereotyped patterns of behaviour, interests and activities (American Psychiatric Association, 2000). Without effective treatment, the prognosis for children with autism is poor. The majority of these children require some degree of ongoing care, support and supervision, therefore, a wide variety of treatment programs, therapies and techniques are available (Green, 1996). Autism affects almost every aspect of family life and needs to be treated within a holistic framework, instead of a problem of the individual.

Applied Behavior Analysis (ABA) is considered by many researchers and clinicians to be the most effective evidence-based therapeutic approach demonstrated thus far for children with autism (Autism Canada Foundation, 2013). Studies have shown that ABA programming can result in dramatic improvements for children with autism; including many with successful integration into mainstream schools and even some obtain complete normal functioning (Green, 1996). ABA employs methods based on scientific principles of behaviour to build socially useful repertoires and reduce problematic ones. ABA programs are geared specifically to ameliorate the skill deficit of children with ASD. These programs are highly structured, intense and utilise behavioural techniques, and need to be provided by specially trained therapists. Intensive Behavioural

Intervention (IBI) programs are substantially different from most programs offered in the school system. Studies show that children diagnosed with ASDs frequently experience difficulty during transitions (Earles, Carlson, & Bock, 1998) that may cause increased stress levels, somatic and psychological symptoms. This is related to the issues surrounding changing environments, social situations, and challenging academic environments (Pianta & Kraft-Sayre, 2003). Transitions may also cause additional anxiety and stress in the family (Kemp, 2003; Newsome, 2001). One of the concerns expressed by the parents of children transitioning to school is a feeling of being disconnected from their child's schooling and a lack of communication which is usually constrained and driven by the school (Pianta & Kraft-Sayre, 2003). Parents do not always feel that the school has the proper programs, training or resources necessary to meet their children's needs. The differences between the two environments, as well as the students' social deficit, affect the success of the transition and inclusion of children with ASD into the school system.

Significance of Study

The issue of transition is extremely important. *The Guidelines for Early Childhood Transition to School for Children with Special Needs* in Manitoba articulates effective transition planning as a necessary component (Healthy Child Manitoba, 2002). The Guidelines are based on the belief that those who know the children with special needs well, such as their families, preschool service providers and support agencies, are the most effective people to work with school personnel to ensure a successful transition into the school system.

Successful transition into school has been recognized as an important goal of early

intervention (Kemp, 2003), but there has been little research done examining the specific types of support families require during the transition. Policy makers, ABA staff, school professionals, and most importantly, families with children with ASD, can benefit from research about transitions to school. A better understanding of families' experiences during a transitional period is necessary for professionals to help families cope with the situational stress, as well as in meeting the needs of the family in raising a child with autism. Professionals and service providers should be able to anticipate specific challenges to families that are likely to occur during transition periods and consider targeted types of services. With more knowledge, effective transition strategies, supports and interventions can be later developed to help ease the transition to schools.

Purpose of Study

The overall objective of this study was to conduct a qualitative study examining the experiences of parents of children with autism during the transition from preschool to school within Early Intensive Behavioural Intervention (EIBI) program in the city of Winnipeg. The purpose of the presented thesis was to gain a better understanding about parents' perceptions on the social supports they received during the transition period, specifically focusing on the perceived benefits and challenges of these supports.

The specific population of families explored in this study were those with children who have completed the preschool Early Intensive Behavioural Intervention program at the St.Amant Centre within six to twelve months prior to the study. St.Amant is not-for-profit organization for residents of Manitoba that provides services to individuals with developmental disabilities and autism. The St.Amant Early Learning Program offers up to three years of Early Intensive Behavioural Intervention to preschool children diagnosed

with autism, autistic disorder, autistic spectrum disorder, pervasive development disorder, and not otherwise specified (PDD-NOS) or Asperger's Syndrome (St.Amant, 2013).

This study was completed as the thesis component required for completing a Masters degree in Social Work at the University of Manitoba. I had previously worked as a social worker with families who have children with autism in Early Intervention Program at Children's Rehabilitation Centre in Lviv (Ukraine). This experience helped me to realize there are a number of levels of stress that are experienced by these families during every new transition in their child's life. My personal interest in the current study was to discover which social supports provided by social workers were beneficial to the families. This study was designed to further deepen my knowledge in many areas, particularly through researching children with autism and their families. It provided me with the opportunity to review the literature and conduct a study to answer specific research questions.

Research Questions

The research questions addressed in the study were:

1. How do parents of children with ASD describe their experiences related to the transition of their child from preschool to school within EIBI program?

2. What are the parents' perceptions about the factors that appear to facilitate, or prevent, a successful transition of their children with ASD?

3. What roles do formal/informal types of support play in facilitating the transition?

4. What roles do social workers and other professionals play in facilitating the transition?

A review of the relevant literature is presented in Chapter II. To begin, a definition of

autism, the ABA program and prevalence of autism is provided, followed by an explanation of ABA program intervention. This review is continued with a discussion of the influence of autism on individuals with ASD; review of the literature regarding the effects on family is presented as well. Overview of social support is presented to assist the reader in understanding its significance during the transition period. A theoretical explanation of transitions concludes the first chapter.

Chapter III outlines the research methods that were utilized in the study. The methodology followed the grounded theory approach based on a social constructionist framework. This chapter presents research design, the sampling procedures, data collection methods, site of population selection, details of recruitment process and a description of data analysis. The study consisted of qualitative interviews conducted with families whose children with ASD transitioned to school. The chapter is concluded with the discussion of the design issues of validity and reliability, objective of metasynthesis component and ethical considerations.

Descriptive results from data analysis are presented in Chapter IV. This includes results from the interviews conducted with the families as well as findings of metasynthesis analysis. The first part of the chapter provides an overview of data collection methods, settings of the study, instruments and procedures that were applied. Demographic variables are presented as grouped data to protect confidentiality of the participants. The descriptive results of open, axial and selective coding are discussed in the second part of the chapter. A detailed description of four main categories and their connection with the core category are presented, using multiple participants' quotes taken from the interviews. The last part of this chapter describes metasynthesis of five qualitative studies chosen to be analyzed and strengthen the finding of this study. The

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interpretation of the meaning of themes and subthemes are illustrated in the end of this chapter.

The discussion of the findings from both data collection components is presented in the next chapter. The connections and differences between the findings of this study and existing policies and research in the field are discussed. A discussion of the limitations of the present study concludes the chapter.

Chapter six offers the conclusion of the study, considers some of its limitations that include potential research bias and finally discusses recommendations for future research.

CHAPTER II

LITERATURE REVIEW

Introduction

One of the biggest changes in the field of developmental disabilities in the last 25 years has been the emergence of autism spectrum disorder (ASD) as the most common disabling condition for children. ASD was considered a low prevalence disorder only two decades ago. Nowadays numerous studies demonstrate that there has been an astonishing growth in the diagnoses of ASD around the world.

Autism has a tremendous influence on the family and causes parental stress because of the unique issues families encounter at various vulnerable transitions along the child's developmental pathway. The transition into school is considered to be a challenging and anxiety-ridden time for most children and their parents, especially those raising a child with autism. McIntyre, Blacher, and Baker (2006) state that "this shift brings increased responsibility, expectations and opportunities for success and failure for children and their families" (p.349). These children have deficits in cognitive and adaptive functioning that affect their academic and social skills. Despite the obvious difficulty for these children and the importance of this time, the transition into schools has been a relatively under-researched topic in Canada.

Increasing the number of resources available to families with children with autism may not be sufficient as one needs to know which resources are beneficial and which are lacking in order to direct efforts towards bettering the existing ones. This study aims to determine the experience of families when transitioning from preschool to school within EIBI program and to explore their perspectives on the social supports available during this period.

This literature review provides a framework about the issues faced by the families raising a child with ASD, characteristics of the transitions and the significance of social support required by families. The first section of the literature review presents information on the definition of autism, its prevalence and a description of the ABA Intervention program. The second, focuses on the impact autism has on the individuals with autism, and their families. It is followed by a discussion of theoretical approaches to social support and transitions. The summary section of this chapter identifies the gaps in the literature and the research questions that guide this study.

Definition of Autism

Autism is the most common neurological disorder affecting children and one of the most common developmental disabilities affecting Canadians in general (Autism Society Canada, 2010). The term "autism" is often used to refer specifically to Autistic Disorder and it is also used more generally to refer to all Autism Spectrum Disorders (ASDs) which are commonly equated with pervasive developmental disorders (PDDs). The subcategories of ASDs (alias, PDDs) and their boundaries may be disputed but the autism has always been considered as central to the PDDs (Oller & Oller, 2010). Criteria for the clinical diagnosis or classification of autism are outlined in American Psychiatric Association's Diagnostic and Statistical Manual for Classification of Mental Disorders - IV Text Revision (American Psychiatric Association, 2000). Autism Spectrum Disorder is a neurological disorder resulting in developmental disability. The term "spectrum" refers to a continuum of severity or developmental impairment. Children and adults with ASDs usually have particular communication and social characteristics in common, but the conditions cover a wide spectrum, with individual differences in: number and

particular kinds of symptoms, severity, levels of functioning, and challenges with social interactions. There are five Pervasive Developmental Disorders (PDD) that appear in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) of the American Psychiatric Association: 1) Childhood Disintegrative Disorder (CDD); 2) Rett's Disorder (RD); 3) Autistic Disorder (AD); 4) Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), and 5) Asperger's Syndrome (AS). When speaking of ASDs, most people are referring to the last three of the PDDs.

Oller and Oller (2010) state that there have been numerous debates about what to call autism and which disorders, diseases, and conditions should be included under its scope. The authors apply the term "autism" to the whole of the ASD spectrum thus showing that the term is a very vague and a loose classification. Medical tests cannot be performed to indicate the presence of any form of ASD, therefore the diagnosis is based on the presence or the absence of specific behaviour. The DSM-IV recognizes among the symptoms of autism:

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:

- Marked impairments in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body posture, and gestures to regulate social interaction;

- Failure to develop peer relationships appropriate to developmental level;

- A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people);

- Lack of social or emotional reciprocity.

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(B) Qualitative impairments in communication as manifested by at least one of the following:

- Delay in, or total lack of, the development of spoken language;

- In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;

- Stereotyped and repetitive use of language or idiosyncratic language;

- Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

(C) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

- Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;

- Apparently inflexible adherence to specific, nonfunctional routines or rituals

- Stereotyped and repetitive motor mannerisms (e.g hand or finger flapping or twisting, or complex whole-body movements);

- Persistent preoccupation with parts of objects. (American Psychiatric Association, 2000, p. 71)

Autism affects emotional balance, along with vital aspects of physical well-being and overall health such as the ability to digest and make use of common nutrients (Oller & Oller, 2010). The authors state that there is also ample research evidence that autism involves pervasive metabolic imbalance, immune system disruptions, chronic inflammation of the brain and stomach, as well as electro-chemical imbalances leading to seizures in varying degrees of severity. ASD can co-exist with other medical conditions, including seizures and anomalies of the metabolic, motor control and immune systems.

There is growing evidence that many factors such as genetic, environmental, metabolic and immunological are involved in autism. Most researchers agree that autism is a complex developmental syndrome representing a heterogeneous group of disorders with similar symptoms, but with general biological etiologies (Joshi, Percy, & Brown, 2001). Realizing that autism has a multi-casual nature is important for enhancing an understanding of its etiology, prevention and treatment.

Prevalence

The recent Centre for Disease Control and Prevention (CDC) reports indicate a clear rise in prevalence of ASDs in recent years. News reports and some stakeholder groups have called this an "autism epidemic," with the recent CDC estimates suggesting that 1 in 110 children 8 years of age have an ASD (Center for Disease Control, 2009). Autism is more prevalent in males, with a male to female ratio of 4:1. Autism occurs in 13 children per 10,000, PDD in 60 children per 10,000 and Asperger Syndrome in 3 per 10,000 (Fombonne, 2005). Unfortunately, there was no specific data located on the prevalence rates in Manitoba. Autism Society Canada (2004) indicates there has been a steep rise in the number of school children with the disorder in the three provinces that have been reliably monitoring this increase: Saskatchewan, Quebec and British Columbia. In six years (1998-2004) there has been a 150% increase in the number of reported cases (Autism Society Canada, 2004). A new report from the National Epidemiologic Database for the Study of Autism in Canada found increases in autism diagnoses in Prince Edward Island, Newfoundland and Labrador and Southeastern Ontario (NEDSAC, 2012). NEDSAC researchers compared data between 2003 and 2010 in Prince Edward Island and Southeastern Ontario, and between 2003 and 2008 in

Newfoundland. Among NEDSAC's findings:

- The percent change in prevalence was higher for boys than girls in Newfoundland and Labrador and Prince Edward Island (87% versus 63% and 111% versus 18%, respectively);

- In Southeastern Ontario, the prevalence among the younger age group (2–4 years) appeared to be levelling off in the final years of the study period, and in Newfoundland and Labrador the prevalence decreased between the last two years of the study period for this age group;

- In Newfoundland and Labrador and Prince Edward Island, the prevalence in the final year of the study period for children 5–9 years of age (1 in 93 and 1 in 106, respectively) was higher than the average prevalence reported by the ADDM Network for 8-year-olds in 2006 (1 in 110);

- Roughly half of children with autism were not diagnosed until after their fifth birthday;

- Diagnosing children at an earlier age does not seem to explain the increasing autism rates.

High prevalence rates from recent epidemiological surveys have caused the debate about a possible epidemic of autism. Fombone (2003) lists the following factors that may have contributed to the increase in reported prevalence rates: (1) changes in diagnostic practices, as the diagnostic system used first used in the 1960s and 1970s was different from those used more recently, (2) the broadening of the classification to include pervasive developmental disorder PDD that requires minimum criteria for classification, (3) improved methods for case finding in population surveys, and (4) improved access to services.

Applied Behaviour Analysis Intervention

Interventions based on Applied Behaviour Analysis (ABA) are commonly recommended for children diagnosed with autism spectrum disorder. ABA emphasizes employing instructional technology designed to change behaviour in systematic and measurable ways (Anderson, Taras, & O'Malley Cannon, 1996). These authors state that any specific strategy can fall under the rubric of ABA as long as it is conceptually consistent with the basic principles of child development, described in detail for others to use, and introduced in a systematic manner that allows for accurate measurements of effectiveness. Autism is a syndrome of behavioural deficits and excesses that have a neurological basis and are able to change in response to specific, carefully programmed, constructive interventions with the environment (Green, 1996). The essence of this model of intervention is the implementation of behaviour analytic procedures to teach social and academic skills and eliminate challenging behaviours, initiated as early as possible (e.g., 24 months of age), and implemented intensively (at least 30 hours per week) for a minimum of 2 years (Maurice, Green, & Luce, 1996). The ABA model involves one-to-one teaching conducted by paraprofessional staff (e.g., tutors) and parents, supervised by psychologists with advanced training in ABA. Therapists use reinforcement and other behaviour modification techniques during the sessions to slowly shape a child's behaviour. Specific targets of the interventions are chosen based on the child's individual problems and disorder. The goals are set as the child improves or whenever there is a change in the environment requiring a change in the target behaviours; progress is continuously monitored and evaluated. Treatment is based heavily on functional assessment, information, and family input.

The body of research on the effectiveness of ABA programs shows that the

majority of children greatly benefit from it. Most children show substantial improvements in many adaptive areas and reduction in problematic behaviours, while a small proportion (about 10 % of studied) have been found to make few or no improvements despite intensive efforts (Green, 1996). Improved intellectual functioning, measured by standardized IQ tests or developmental scales, is well documented. Green writes that improvements in language, social skills, play, self-help and problematic behaviour are found to be somewhat less widespread and robust than IQ changes. The author explains that this may be a function of characteristics of the children or the treatment provided in different studies.

Effects on Individuals with Autism

Three key areas of difficulty are experienced by children with autism: social interaction, communication and imagination (Volkmar, 2007; Wall, 2010). These impairments are often combined with repetitive and stereotypical behaviours. Deficits in social interaction, social behaviours, and social skills are the most common hallmarks of autism even though no two children with autism will present the same characteristics to the same degree. These deficits are particularly evident during the preschool years: young children experience great difficulty with "normal" or "appropriate" social interactions; they seldom initiate or maintain social interactions and can have severe deficits in the areas of imitation, play skills and responsiveness to others (Maione & Mirenda, 2006). While some social and communicative deficits may be common, there are differences in levels and profiles of abilities across the range of severity of autistic conditions; these differences affect adaptive behaviour as well as intervention opportunities and outcomes in later life (Prior & Ozonoff, 2007).

Social Interaction

Social impairments are apparent very early in life in the majority of cases. Infants who have autism are reported as not cuddly but rather stiff and resistant to contact, or else passive and floppy (Prior & Ozonoff, 2007). Some are described as exceptionally "good" babies, while others are difficult to manage, and their needs are difficult to identify and babies are difficult to comfort. Their self-isolation and lack of communication sometimes might be interpreted as a sign of deafness even though they might show an unpredictable reaction to particular sounds. Some children are so socially impaired that they appear almost completely unaware of others (Sturme & Fitzer, 2007).

Social interaction is normally developed through eye contact, but children with autism usually avoid this as they do not wish to interact and may not understand the verbal interactions that follows (Wall, 2010). Due to the lack of need for social interaction, the child with autism may resist physical contact with others. Individuals with autism might also experience great difficulty forming peer relationships as they cannot master the skills necessary for true reciprocity of social communication. Even high-functioning individuals with Asperger's syndrome who are seeking to make contact with others suffer from lack of insight into the thoughts, emotions, feelings, plans, and wishes of others (Prior & Ozonoff, 2007).

Many of the children who have autism are difficult to manage and to socialize. Besides the absence of appropriate social skills there is also presence of much unacceptable deviant and socially embarrassing behaviour (Prior & Ozonoff, 2007). These behaviours include stereotypes such as rocking, hand banging, head-punching, screaming and temper tantrums in public places, aggressive and hyperactive behaviour as well socially embarrassing eating, toileting, and sometimes verbal behaviours. Prior and

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Ozonoff (2007) state that social functioning in children with autism improves after about the age of five years although normalcy, even in high-functioning cases, is very rarely achieved. It is common for young people to experience continued isolation and preoccupation with their own interests and have difficulty sustaining relationships in any reciprocal way.

Social Communication

Children with autism show a range of deficits in communication, which constitutes one of the core symptoms of autism spectrum disorders. The term "communication" is broad and refers to all forms of sending and receiving messages, not only with language, but in other ways, such as with gestures, body language and others (Prior & Ozonoff, 2007). One of the earliest signs of autism is failure to show social preferences and responsiveness in the first years of life (Prior & Ozonoff, 2007). Many parents report that their children as babies do not always respond to voices or their names, do not spend much time looking at faces and usually are less eager to be engaged into social games that involve smiling and vocalization.

In most children with autism, impairment in language and communication is apparent by the second year of life. Children who have autism may exhibit some communication by that age, but their actions are usually for the purpose of getting others to do or not to do things than for the purpose of sharing and social interaction that characterizes the majority of communicative acts of typical toddlers (Wetherby et al., 2004). Even when they do communicate, they are less likely to engage people visually or direct their acts to the communication partners with eye contact. Around half of the population of children with autism do not develop communicative language and it is rare

to gain language if they have not done so by the age of about six years. The impairment in communication that affects verbal and nonverbal skills varies from failure to develop language at all, to a range of language abnormalities, including echolalia, odd intonation patterns, confusion with pronoun distinctions, and poor comprehension (Lord & Paul, 1997). Some children may be able to master a signing system to be used in place of speech initially, while others may not. Some develop limited speech and language skills, and some may not develop useful speech at all but remain mute (Wall, 2010). Children with autism who have difficulties interpreting and making sense of spoken language may easily be confused if a person directs conversation towards them. Some children may react by resorting to behaviours such as hand-flapping or covering their eyes and ears, or simply removing themselves from the situation to avoid potential difficulty (Wall, 2010).

Although many speakers with autism develop more or less developmentally appropriate forms and meanings for words and sentences, deficits in the use of language for social purposes seems a common issue in this population. These deficits might be major impediments to successful social adaptation and acceptance, even for very intelligent people on the spectrum who demonstrate large vocabularies and age appropriate school achievements in many areas. Intensive instruction and early intervention focused on communication and social skills is needed to help these individuals with limited language development.

Imagination

Children with autism experience difficulties around imagination in addition to the characteristics described above. An impairment in imagination extends to every area of their thinking, language and behaviour. Children with autism are dependent on routines as

a way of understanding the world. Routines are particularly supportive as children become able to rely on the safety of the known programme of events. Difficulties and chaos may arise when routines are changed. Such problems can become overly demanding for the family and create many difficulties in school settings. A child with autism may have the ability to see a picture or object with an unusual aspect that many people would not notice. This is usually linked to a special liking of particular set of toys. Another area of difficulty linked to lack of imaginative skills is the ability of children with autism to appreciate the perspectives of other people. They may consider people as largely irrelevant so they do not try to understand their views and perspectives. This is also connected to the need of sameness, security and routine as persons with autism can only deal with aspects of life that make sense to them. It is easier for them to be unconcerned with the perspectives of others than be threatened by someone's uncertain actions.

The Theory of Mind became prominent in autism research in the 1980s and 1990s and has made a major contribution in bringing together much of what was known about the social, cognitive, and communication problems of children with autism across the developmental period for the purpose of explaining the psychological characteristics of disorder (Prior & Ozonoff, 2007). The Theory of Mind (Baron-Cohen, Leslie & Frith, 1985) explains it in a way that children with autism are unable to perceive and comprehend the thoughts and feeling of others. They do not apprehend the fact that individuals have beliefs, thoughts, plans and intentions and that have to be taken into account as in social transactions as guides to reciprocal behaviours. For example, children with autism often find it hard to understand complex social emotions such as guilt, pride, embarrassment, empathy, loneliness and surprise and do not usually understand implicit social norms and rules (Bauminger, 2002).Their inability to understand and predict

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behaviour of others is shown in their characteristic social deficits and reflects the absence

of such knowledge (Prior & Ozonoff, 2007).

Effects on the Family

The presence of a child with autism can have a tremendous psychological impact

on family dynamics. Parents of children with autism are more likely to experience stress

and are more susceptible to negative outcomes than parents of children with other

disabilities (Bromley et al., 2004; Dunn, Burnibe, Bowers, & Tantleff-Dunn, 2001). The

unique combination of impairment associated with autism may place family members at a

higher risk for difficulties with psychological adjustment (Glasberg, Martins, & Harris,

2006; Siegel, 1997). Due to the great variety and the severity of symptoms experienced

by children with autism, their families must learn how to process and cope with many

complex experiences and challenges.

One of the definitions of stress proposed by Perry (2004) involves "the concept of

a "resource imbalance" between the demands of a situation (stressors) and a person's

resources or coping ability" (p. 3). In the case of families with autism, stress is not simply

a function of child characteristics (stressors), and it is more than a single or series of

stressful events. To a large extent, the level of stress experienced depends on the parents'

coping abilities, the resources in the family and supports received from others (Perry,

2004).

Turnbull, Turnbull, Erwin and Soodak (2006) state that the family system must be

understood as a whole entity and understanding its components (subsystems) is necessary

for understanding a child with disability and vice versa. The authors define four major

subsystems: (a) the marital subsystem that includes interactions between husband and

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wife (or same sex partners), (b) the parental subsystem that includes interactions among parents and their children, (c) the sibling subsystem that includes interactions among the children in a family, and (d) the extended family subsystem that includes interactions among members of the nuclear family, relatives, and others who are regarded as relatives (p.30).

Marital Subsystem

Research pertaining to the impact of having a child with autism on the marital relationship is limited. Findings of some studies show that having a child with a disability has a negative influence on marriages, while other studies do not find any difference between families with or without a child with a disability. Higgings, Bailey, and Pearce (2005) found that mothers and fathers of children with autism showed lower levels of marital happiness, family adaptability, and family cohesion than normative data would suggest. Perry, Harris, and Minnes (2004) argue that parents of children with autism have the lowest level of family harmony when compared to parents of children with other developmental disabilities (i.e., Rett's syndrome, and Fragile X). The study also found that family harmony was lower among families of children with autism and developmental disorders where the cause of the child's disability was unknown.

Dyson (1997) states that mothers and fathers with a school-aged child with a disability experience high child-related stress but this stress related to family functioning does not differ from families with normally developed children. A study that examined the well-being of parents of preschoolers with and without developmental delay found that there were no differences in depression or marital adjustment, however child behaviour problems were strongly related to scores on those two measures (Baker,

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Blacher, & Olsson, 2005).

Parental Subsystem

Sharpley, Bitsika and Efremidis (1997) identify three most stressful factors associated with parenting a child with autism as: (a) concern over the permanency of the condition; (b) poor acceptance of autistic behaviours by society and by other members of the family; and (c) the very low levels of social support received by parents.

Parental stress is renegotiated at different periods of development in the child's life, but the duration and timings of these periods are underesearched. Getting a diagnosis may be very stressful for the parents of children with autism. Dale, Jahoda, and Knott (2006) state that these stressors include the comparatively late diagnosis, especially for children with more subtle difficulties, the delay between parent's first concern and the final diagnosis, and the lack of clarity over the diagnosis. One of the challenges for parents is the lack of unified or generally accepted best practices (Glasberg, Martins, & Harris, 2006). ABA has significant empirical support but even within it there is a variety of decisions to make in creating an appropriate program for an individual child. It leaves families with a number of conflicting recommendations as to what is the best for their child, which in return leaves more doubt about which approaches should be incorporated by families for use in the home. Most commonly, parents experience stress when a child with autism encounters a new environment or situation. The transition to a school can be met by a child with a variety of feelings and behaviours that create stress for both the parents and the child (Newsome, 2001). Parents are concerned about the future for their child, specifically the problems that may arise when their child reaches adulthood.

Research has found that mothers of children with autism are primarily responsible

for caregiving. They appear to be the most adversely affected by the stress-related factors that result from rearing a child with a disability (Boyd, 2002). According to Sanders and Morgan (1997) mothers of children with autism reported higher levels of stress when compared to mothers of children with other developmental disabilities. Hastings (2003) indicates that child behaviour problems intensify the experience of stress among mothers of children with disabilities, but not among fathers, whose stress was found to be associated mostly with partners' depression (Hastings et al., 2005). When fathers of children with autism experience stress it is a result of actual physical care of the child and the behavioural characteristics of autism that might make it more difficult (Sanders & Morgan, 1997).

The qualitative research presented by Jones and Passey (2005) explore the relative impact of the level of coping resources, strategies, and perceptions on the stress experienced by parents of children with developmental disabilities and behaviour problems. The findings of this study indicate that the strongest predictors of parental stress were family coping style and parental internal locus of control. Parents who felt effective in their parenting role believing that their lives were not controlled by their child with a disability, and who coped by focussing on family integration and co-operation, and were optimistic showed lower level of stress. Dunn et al. (2001) assessed the relationship between stressors, social support, locus of control, coping styles and negative outcomes (depression, social isolation, spousal relationship problems) among parents of children with autism. It was found that stressors were not a direct predictor of negative outcomes, but their influence was moderated by social support and coping styles. The data indicated that it would be beneficial to discourage parents from using escape and avoidance as a coping style. Utilizing more appropriate coping methods and receiving social support

should benefit the parents in buffering the effects of stressors and reducing negative

outcomes (Dunn et al., 2001).

Sibling Subsystem

Sibling interactions are viewed as powerful components of socialization that help

to develop instrumental and effective relationship skills (Rodrigue, Geffken, & Morgan,

1993). Findings regarding the impact of having a sibling with autism have been

inconsistent. Some studies show that siblings who have a brother or sister with autism

reported admiration of them and were satisfied with their relationship (Rivers & Stoneman,

2003). In other studies, siblings experienced less closeness, had a decreased number of

interactions, and viewed a brother or sister with autism as a burden (Bägenholm & Gillberg,

1991). Sibling reporting more adverse reactions felt they were expected to take on more

caretaking responsibilities at home, and had difficulties coping with the feeling of rejection

they experienced for their siblings with disability (Bägenholm & Gillberg).

A number of studies show that the social support available to families of children

with disabilities may well affect sibling adjustment. It was found that variables conceptually

related to social support, such as parental satisfaction with the marital relationship and the

quality of family life, are associated with sibling adjustment (Hannah & Midlarsky, 1999).

Furthermore, social support as perceived by parents has been found to be associated with

sibling adjustment in families of children with developmental and other disabilities (Benson,

Gross, & Kellum, 1999). A study that analysed the behavioural adjustment of siblings of

children with autism engaged in ABA early intervention program revealed that social support

functioned as a moderator of the impact of autism severity on sibling adjustment rather than a

mediator or compensatory variable (Hastings, 2003). Siblings in families with less severely

autistic children had fewer adjustment problems when more formal social support was

available to the family.

Extended Family Subsystem

      Autism of a child can be a source of substantial stress for grandparents and other

extended members in the family. Grandparents are concerned for the child and for the

parents who must deal with the demands created by a child's autism, and they feel a sense

of loss and concern for themselves as well. As well, their expectations related to

spending time with the grandchild can be seriously challenged by the behaviour of the

child (Glasberg, Martins, & Harris, 2006). Grandmothers show greater understanding of

the experience of their adult child, and the most empathetic response comes from

maternal grandmothers, while the least empathy was expressed by fathers of the children

with autism and their own fathers (Glasberg, Martins, & Harris, 2006).

Social Support

      Armstrong, Birnie-Lefcovitch, and Ungar (2005) emphasize that social support is

transactional and there are a number of characteristics that influence how social supports

function. Some of these characteristics may include the nature of stressors, the types and

sources of available supports, and the personality characteristics and other attributes of

the recipient of the social supports.

      In analyzing the linkage between theory and research related to social support,

Hupcey (1998) states that "social support is a multi-faceted concept that has been difficult

to conceptualise, define and measure" (p.1232). The concept of social support has been

used in research across different disciplines and in numerous contexts, and even though it

has been extensively studied there is little agreement among theoreticians and researchers

as to its theoretical and operational definition. Hupcey (1998) states that the complexity of the concept has been consistently ignored and research has measured the variables in a simplistic manner.

Supportive actions are used to enhance coping performance and reduce the effect of the stressor, as long as the form of support matches the demands of the stressor. According to this view, each stressful circumstance places specific demands on the affected individual. Studies that use this perspective focus on measures of received support in which respondents report the frequency of the support they receive during a specific period of time in response to stressful events. Cohen and Lakey (2000) define three hypothesized mediators that can be measured in studies on social support: a) coping efforts and styles: this perspective predicts that supportive actions promote health and well-being by promoting coping; b) stress: according to this perspective, received support promotes well-being by protecting people from stress, and c) mediation: to examine the hypothesis that receipt of support influences one's health, as according to this perspective, support protects people from stress by improving their coping performance.

Cohen and Lakey (2000) state that perception of available support leads to appraising potentially threatening situations as less stressful. Authors describe two hypothesized mediators that can be measured in studies on perceived support: a) appraisal: according to this model, beneficial effects of perceived support operate by influencing appraisal, and b) life measures as buffering effects should be tested, and furthermore, measures of appraisal should be included and mediational analysis conducted.

Dunst, Trivette, and Cross (1986) defined social support as multidimensional construct that includes physical and instrumental assistance, attitude transmission,

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resource and information sharing, and emotional and physical support. According to Thompson (1995), "social support consists of social relationships that provide or can potentially provide material and interpersonal resources that are of value to the recipient, such as counselling, access to information and services, sharing of tasks and responsibilities, and skill acquisition" (p. 43). Among various definitions, this particular account of social support seems most suitable for the context of families who have children with ASD.

One of the approaches in differentiating among potential measures of social support is to distinguish between structural characteristics of the support network and functional aspects of support which reflect different characteristics and often operate orthogonally to each other (Cohen & Syme, 1985). Structural measures of support have their origins in social network analysis and reflect the degree to which an individual or family is embedded in social context (Krahn, 1993). Structural characteristics quantify the relationships of the support network and their interconnectedness within it. Krahn (1993) describes the following structural dimensions that are usually used to assess embeddedness: (a) size of the network that describes the number of people who are regarded as supportive (such categories as family, friends, professionals); (b) density of the network that shows the extent to which members of the network have relationships with each other independent of the respondent; (c) multiplexity is a measure of the number of the kinds of aid (emotional, material, informational) that characterize certain relationships; and (d) symmetry or reciprocity which refers to the degree to which relationships are balanced.

Functional characteristics describe the nature of the relationships and relate to availability and content of support. Kahn (1993) concludes that there is a "distinction

between perceiving that support is available if needed (perceived support) and actually gaining access to support (enacted support)" (p.4). The author argues that the distinction between perceived and enacted support is critical when examining the mechanism of how social support works.

The content of support has been recognized as multidimensional, although many writers have agreed with its main categories: a) instrumental support (material aid, services, physical assistance); b) emotional support (appraisal, someone to talk with about problems, help with personal problems, self-esteem); c) informational support (cognitive guidance and advice, informational help); d) belonging (social companionship, people one can do things with); and e) social regulation (appraisal support, information that helps evaluate personal performance) (Krahn, 1993).

Most of the research on families with children with developmental disabilities have focused on parental level of stress. According to Boyd (2002), stress and depression are two of the main factors that lead mothers of children with autism to obtain social support. Research addressing the effects of social support on family stress has focused on two categories: informal support and formal support (Boyd, 2002).

Informal social support is emotional sustenance and/or tangible help actually received and/or perceived to be available from extended family, friends, neighbours, social organizations, and religious communities (Perry, 2004). In this regard, families are reported to be one of the most frequent sources of support for parents of children with ASDs (Jones & Passey, 2005). Bromley, Hare, Davison, and Emerson (2004) examined the impact of a range of factors on the psychological wellbeing of 68 mothers of children with ASDs to explore aspects of social support, mental health status and satisfaction with services. The results showed that "over half of the mothers screened positive for

significant psychological distress and that this was associated with low levels of family support and with bringing a child with higher levels of challenging behaviour" (Bromley, Hare, Davison, & Emerson, 2004, p.409). Mothers were more likely to report lower levels of support if they were a single parent, living in poor housing, or were the mothers of a boy with ADS. The results suggested a need for specific, ongoing post-diagnostic support and counselling for mothers, the provision of respite care and adequate social interventions.

Another similar research study described by Boyd (2002) showed that mothers in the low-stress group reported greater perceived support, and the most important sources of support for them were their spouses and relatives. Herman and Thompson (year) interviewed 415 families enrolled in the Cash Subsidy Program in Michigan for children with developmental disabilities to analyse the factors related to families' perceptions of "internal resources" in rearing a child with a developmental disability. The findings showed that both mothers and fathers considered their partner as the most helpful in providing social support, and more than half of the participating families reported that social support from more formal sources (parent groups, day care centres) was unavailable (Boyd, 2002).

The results of a study that investigated the factors related to positive perceptions in mothers of children with intellectual disabilities showed that support that families receive during the period of transition may be crucial to their adaptation. The study indicated that mothers used social support as a coping strategy to maintain a positive perspective and develop a sense of personal growth and maturity (Hastings, Allen, McDermott, & Still, 2002).

Formal supports and services consist of professional or paraprofessional

interventions, including education/treatment programs for the child with developmental disability and family interventions such as individual, marital, or family counselling, respite care, behaviour management training, parent support groups, and parents' organizations (Perry, 2004). Following regression analyses researchers have concluded that the perceived helpfulness of formal support (i.e., professional services and social organizations) predicted mobilizing the family to acquire and accept help in the community, which in turn predicted strength and family closeness (Greer, Grey, & McClean, 2006).

Schwichtenberg and Poehlmann (2007) found that mothers of children with ASD reported fewer depressive symptoms when children were in programs that had more ABA hours per week. The study also showed that mothers who spent more hours per week involved in their child's ABA program reported more feelings of personal strain.

Boyd (2002) concluded that the most beneficial form of formal support for families is the parent support group that has been shown to mediate the negative effects of perceived stress for parents of children with intellectual disability. Family support services aim to enhance the use of cognitive coping strategies to the extent that they reduce stress in families in order to engage them to a reflection. Summers, Behr, and Turnbull (1988) talk about two types of family support services that may directly influence the use of cognitive coping strategies: social support groups and family education and information services. The authors conclude that relationships between the professionals and the family serving a child with a disability as one of the most important aspects of family support.

Transitions

      Transitions are a fact of life for families, children and the professionals who provide services for them. The transition from an early intervention program to school has been identified as an important and vulnerable time for children with disabilities and their families as they anticipate and adjust to a new system that typically differs from that to which they have become accustomed relative to personnel, structure, and support (Kemp, 2003; Hanson et al., 2000). Studies have shown that some children may experience increased stress levels, as well as somatic and psychological symptoms during the transition to school (Levy & Perry, 2008). Rice and O'Brien (1990) define transitions as "points of change in services and personnel who coordinate and provide services" (p. 2). There is no consensus of opinion regarding the beginning and end of a transition period (Kemp, 2003). It is recognized that the transition period consists of three elements: 1) planning or preparation, 2) the point of change from one service to the next, and 3) the period immediately following the change (Lazzari & Kilgo, 1989). Among researches there is no agreement about terms required for time of the planning and follow-up periods. Usually planning for the entry to school begins up to a year before school starts, and follow-up may last a few months, if it occurs at all (Kemp, 2003).

      Stoner, Angell, House, Jones, and Bock (2007) recognize two types of transitions: vertical and horizontal. Vertical transitions are described as the ones that are predictable, developmental, and experienced by all students and they include transitions from early intervention programs to preschool, yearly grade changes, and the major transition from school to adult life. Stoner et. al. (2007) write that planning for vertical transitions is imperative since ineffective or unsuccessful transition planning can result in negative effects on both the social and academic progress of students. Horizontal transitions are

not as predictable as vertical; they are more individualized and usually take place when students move from one situation to another (Stoner et. al., 2007). Examples of horizontal transitions include transitions from home to school, between activities or classes or from familiar to unfamiliar settings. Horizontal transitions can be especially challenging for children with ASD because of stereotypical or aggressive behaviours; therefore authors suggest that planning and devising strategies for horizontal transitions are critical (Stoner et. al., 2007). Understanding and planning horizontal transitions for students can benefit not only students but also their families and the education professionals who work with them. Communication with parents and incorporating their suggestions and experiences into the educational program is essential, especially when managing transition issues. Collaboration between parents and professionals has historically been an area of weakness for many programs that serve students with ASD. Research studies have shown that parents have repeatedly identified communication and access to services as areas of concern (Stoner et. al., 2007).

Summary

There is increasing evidence that many family members of children with ASD experience high levels of stress. These families face real day-to-day problems, such as the care of child, disrupted daily routines, an inability to engage in social activities, and difficulties during transition periods. The absence of formal or informal support contributes to the situations in which the families themselves are dealing with the child's special needs utilizing only their strained internal resources.

Literature on the transition of children with autism is sparse and demonstrates that it has been a relatively under-researched topic in Canada. Little to no empirical work has

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been conducted on the transition of children with autism from preschool to school within EIBI programming. At the same time, surveys of parents and teachers of children with intellectual disabilities entering school, have found that appropriate support is considered an important component for successful transitions (Kemp, 2003). Hasting (2003) states that not enough attention in recent studies has been given to the role of psychological factors, such as coping strategies and social support for families with autism during this transition period. Kausar, Jevne, and Sobsey (2003) also state that more research is required to determine the ways to increase positive and hopeful interactions between parents of children with disabilities and the professionals they rely upon for support.

According to Newsome (2000) the problem with existing research is that too little is yet known about the role social workers play in serving families who have children with autism, or how well social workers are meeting the needs of the parents. The profession of social work needs to develop a better understanding of the issues and concerns faced by the individuals they serve. Newsome (2000) argues that social workers need to understand the perspectives of parents so as to not treat all people with developmental disabilities as if they are members of the homogeneous class when providing support services. Understanding the perceptions held by parents is vitally important to practitioners and future research in social work for the advancement of practice within autism (Newsome, 2000). Qualitative assessments of parents' experiences and perspectives are essential in helping to understand the family matrix in which the child's social development occurs.

The majority of the research reviewed for this study used parental self-reports to measure stress and parents' perception, and/or actual use, of social support. Boyd (2002) states that more research is needed to examine what types of social support would be

beneficial to parents in order to provide more effective intervention services without increasing parent stress. The continuum of support services to families must be provided and professionals must understand how both formal and informal supports can be used to alleviate the consistent stress associated with parenting a child with autism.

Research Purpose and Questions

Parents' involvement in their children's education is one of the key factors in students' achievement. For parents of children with autism, involvement is essential to the development of effective transition strategies. The purpose of this study was to explore and understand families' experiences of the transition from preschool to school within EIBI program and to hear parents' perspectives on the social support they received during this transition time.

The following research questions were addressed:

1. How do parents of children with ASD describe their experiences related to the transition of their children from preschool to school within EIBI program?

2. What are the perceptions of parents about the factors that appear to facilitate, or prevent, a successful transition of their children with ASD?

3. What roles do formal/informal types of support play in facilitating a transition?

4. What roles do social workers and other professionals play in facilitating the transition?

CHAPTER III

METHODOLOGY

Introduction

This chapter outlines the research design and methodology of the study. It begins

with an overview of grounded theory methodology, its relevance, and a rationale for

utilization of this approach in the study. The latter part of the chapter presents a

description of data collection and analysis procedures. This includes sampling procedures,

recruitment of the participants, data gathering methods, and the approach to analysis of

the data. As well, the issues of reliability and validity are discussed, including the reason

for including metasynthesis component to this study. Ethical considerations are presented

at the end of the chapter.

The methodology for this study involved qualitative research within grounded

theory approach. Qualitative research facilitates a mode of empirical inquiry that explores

and describes naturally occurring social phenomena in an in-depth fashion. This type of

methodology allows researchers to record the inner experience of participants, to

determine how meanings are formed through and in culture, and to discover rather than

test variables (Corbin & Strauss, 2008). A qualitative method was chosen for this study to

achieve a greater understanding of the experiences of families with children with ASD

that transition from preschool to school within an Early Intensive Behavioural

Intervention (EIBI) program in the city of Winnipeg. Qualitative methods helped in

gaining insight into the perceptions of parents and the meaning they assign to behaviours

and experiences. The grounded theory approach was chosen for this study as it

emphasizes the experiences, social processes, and conscious constructions of meaning

made by individuals involved in a specific social phenomenon (Wilson & Hutchinson,

1991). The current study focused on social supports that families receive during the transition period to school. The procedures of grounded theory are designed to develop a well integrated set of concepts that provide a thorough theoretical explanation of social phenomena under study (Corbin & Strauss, 1990). Little empirical research available on transition experiences of children with ASD; therefore it was another reason for using grounded methodology as it makes the greatest contributions in areas where little research has been previously conducted (Chenitz & Swanson, 1986). Grounded theory is based on the premise that the meanings people give to events in their lives are very important in understanding their reaction to events. It is primarily based on symbolic interactionism, which emphasizes that people construct their own meanings from events based, in part, on their interactions with others (Chenitz & Swanson, 1986). Social constructionism provided the broad framework for this study, whereas qualitative methods reflected the approach to design and data collection.

Research Design

Patton (2002) states that qualitative inquiry looks at the subjective side of research, and it sacrifices some objectivity, generalizability, and scientific accuracy to obtain a deeper level of understanding on each individual case. A qualitative study is an inquiry into understanding a social or human problem, based on building a complex, holistic picture that reports detailed views of informants in a natural setting (Cresswell, 1998). In this particular study qualitative research methods allowed the researcher to explore and understand families' experiences during the transitions from preschool to school after completing EIBI preschool program at St.Amant. More specifically this study provided an in-depth understanding of parents' views on required formal/informal social

supports and existing facilitators/barriers in the transition process of their children with ASD. In order to better understand the previously mentioned phenomenon from a social work viewpoint one of the research questions of this study was to identify the roles that social workers play in facilitating the transition process.

With little information regarding the transition experiences of children with ASD into the public schools, an inductive method of inquiry was chosen. Researchers using an inductive approach to theory development do not organize data into a pre-chosen framework; rather, the theories from qualitative studies are developed from collected data. The recommendations are driven by the actual experiences of the families involved in these transitions, rather than by the professionals without the same life experiences. As this was an exploratory research it also generated certain propositions that could be further tested in larger sample studies.

Guided by social constructivist tradition, this study captured parents' perspectives in order to understand their experience of the process of transition. Constructivism values multiple realities and implies that each individual creates their own perception of reality as a result of interactions with others in their own social and cultural ways (Patton, 2002). A main premise of social constructionism is that "beliefs, values, institutions, customs, labels, divisions and labour, and the like that make up our social realities are constructed by the member of a culture as they interact with one another" (Freedman & Combs, 1996, p.16). Social constructionism focuses on meaning and interpretation (Pare, 1995), and places an important emphasis on the ways in which people collectively perceive, interpret, and construct their experience in order to make meaning of it, and thereby shape their worlds. Pare (1995) argues that social constructionism is primarily concerned with the process whereby meaning is arrived at communally and focuses on knowledge as a

function of communal textual interpretation. Knowledge becomes a matter of the meanings that are assigned to experience and negotiated in interaction with others, in relationships, and in social and cultural worlds of meaning (Laird, 1995). Realities are not experienced directly (Laird, 1995) as they are "socially constructed, constituted through language and organized and maintained through narrative" (Freedman & Combs, 1996, p.22). Therefore, realities are organised and maintained through stories that represent how people know themselves and their worlds. In this study, the stories of parents with children with ASD represented their experiences of the transition time to school.

The Grounded Theory Approach

Grounded theory is an "inductive qualitative methodology that allows the researcher to identify the main concern of a group of subjects and the behaviours they use to restore their main concern" (Artinian, 2009, p.3). The understanding of social and psychological phenomenon by the researcher is further expressed in an explanatory theory that captures the subjects' experience (Artinian, 2009; Chenitz & Swanson, 1986). According to Patton (2002) grounded theory "focuses on the process of generating theory rather than a particular theoretical content" (p.125). This method has been used extensively across a variety of social science disciplines and has it roots in the symbolic interaction tradition of social psychology and sociology. A symbolic interaction perspective in grounded theory helps to study human behaviour and interaction. People construct their realities from the symbols around them through interaction, where they are active participants of creating meaning in a situation (Cutcliffe, 2000). Symbolic interaction focuses on the meaning of events to people as they interact with each other, on how they define them and act in relation to their beliefs (Chenitz & Swanson, 1986).

Chenitz and Swanson (1986) define three main implications of this approach for research activity. First, in order to understand human behaviour it must be examined in interaction. All the social forces, the setting and events that affect behaviour are analysed to understand self and shared meanings held by people in interaction. Secondly, the researcher needs to understand the world from the participants' perspective by learning their interpretation of self in the interaction and share their definitions. Lastly, the meaning derived from the research must be understood by others and translated into the language of the research discipline.

In order to explain "basic social processes", grounded theory uses the constant comparative method of analysis, a systematic process that facilitates the identification of codes, categories, contexts, and conditions, and generates substantive-level theory (Creswell, 1998; Dey, 1999). Through the comparative process, conceptual categories are generated as a result of evidence found within the data.

Conceptual categories are of a general nature, while the properties of the categories are more specific. According to Dey (1999) categories are conceptual: "they are creative constructs, which express relations of similarity and difference but can also be connected theoretically through identifying substantive (causal) connections between them" (p.63). While categories are the concepts that are recognized to be the elements of a theory (Dey, 1999), the properties form the basis for making relationships between categories and subcategories. Therefore, the researcher has to recognize the nature of the properties in order to understand all the analytic procedures for developing a grounded theory (Strauss & Corbin, 1999). During data collection and analysis, the researcher identifies a core category that becomes the main theme around which all other categories revolve. Grounded theory requires these identified categories to be verified through

continued data collection and analysis. This process continues until a concept or category becomes "saturated". Strauss and Corbin (1990) suggest that the general rule in grounded theory research is to sample until "theoretical saturation" is achieved. The term "theoretical saturation" refers to collecting data up to the point where no new or relevant data emerges in the area of research, and that the data collected is consistent enough to substantiate a theory. Sampling can be terminated when no new information is forthcoming from new sampled units.

During a comparison of the cases that are being studied, the researcher develops hypotheses about the relationships between concepts. As hypotheses develop, they are also verified through further data collection and analysis. The end result is interrelated concepts that "form an integrated central theoretical framework - the core of the emerging theory" (Glaser & Strauss, 1967, p. 40).

Grounded theory was chosen as the appropriate methodological approach for this study due to its usefulness in exploratory and descriptive research. There are limited number of qualitative studies done in Canada that describe the transition experience of families within EIBI program. As well, the EIBI using the ABA model is a relatively new approach in working with children with autism in Canada, and the legislative provision varies based on the province. Grounded theory makes the greatest contributions in areas where little research has previously been conducted and will help to create a new perspective on the transition issues to school of those children with ASD. In addition to providing a deeper understanding, social workers may have a broader view of the social supports that are crucial to the success of these transitions.

Sampling and Data Collection

Grounded theory has specific procedures for data collection and analysis, although there is flexibility and latitude within its limits (Corbin & Strauss, 1990). As in other qualitative approaches, the data for a grounded theory can come from various sources: interviews, observations, government documents, newspapers, books - anything that can help the researcher to get better understanding of the studied subject (Corbin & Strauss, 1990). Interviews play a central role in grounded theory research as a means of data collection (Creswell, 1998; Corbin & Strauss, 1990). In this study it was most appropriate to collect data through in-depth interviews with parents.

The ultimate purpose of the interviewing is to allow readers to enter into the other person's perspective (Patton, 2002), and to collect enough data for understanding the phenomenon being studied. The qualitative researcher's skills and sensibilities are crucial in interviewing. Patton (2002) states that "the quality of the information obtained during an interview is largely dependent on the interviewer" (p.341). The interviewer should posses "superb listening skills and be skilful in personal interaction, question framing and gentle probing for elaboration" (Marshall & Rossman, 2011, p.145). The richness of the interviews heavily depends on the abilities of the interviewer in asking follow-up and elaborating questions and establishing a conversational style that will the focus on the particular predetermined subject.

Sampling procedures within most research studies depend on the notion of representativeness. In grounded theory research the sample is not selected from the population based on certain variables identified prior to the study. Instead, the researcher chooses participants based on their ability to contribute to an evolving theory (Creswell, 1998). This sampling strategy is known as theoretical sampling, which refers to gathering

sufficient data to develop the properties of categories until no new properties are apparent. According to Glaser (1987) theoretical sampling provides the impetus for directing data collection and analysis (Artinian, 2009). The researcher collects, codes, and analyzes data and decides the appropriate data to collect next in order to develop an emerging theory. Decisions regarding appropriate data collection can assist in theory development as they are based on the data that is being collected and coded during the interviewing process. Further sampling is done to verify the validity of categories and to test their relationships and interrelations. Theoretical sampling is achieved through the constant comparative process.

Site of Population Selection

The potential participants for this study were the families who went through the transition with their child from preschool to school within EIBI within the last six to twelve months prior to the commencement of the research. Theoretical sampling dictated the need to interview parents with varying characteristics and differing experiences. For practical reasons, the families who reside in Winnipeg and rural Manitoba, and whose children completed the EIBI program at St.Amant were contacted. It was required to interview parents or the children's primary caregivers – fathers and mothers. There was no specific requirement regarding the age of the children as it may vary from seven years old and older, depending on the level of autism affecting them and on the time completing the EIBI program.

Recruitment Process and Barriers to Recruitment

After screening potential families for recruitment it was determined that twenty

four families met the research criteria of the study. With the approval and assistance of the staff from the EIBI St.Amant Early Learning Program, a recruitment package was sent to the families whose children had completed the program from six up to twelve months prior to recruitment. Initially, it was aniticipated that a minimum of ten to twelve families should be interviewed to meet the requirement of the study. The recruitment letter (Appendix A) was sent out in March 2012, and four families responded and were interviewed by the end of April. In June 2012 an amendment approval that was received from the Research Ethics Board of the University of Manitoba contained new recruitment approaches and expanded the research criteria. This expansion allowed the recruitment of families who had completed the program within the previous two years, instead of the originally proposed six to twelve months. It also permitted the contact of families through South Central ASD Family Support group (Morden, Manitoba) and the Autism Portage support group for parents of children with autism (Portage la Prairie, Manitoba). Seventeen recruitment packages were sent out to the families residing in and outside of Winnipeg and several emails were sent to the above mentioned support groups. As a result, two more families were interviewed after all the recruitment procedures were applied.

In the fall of 2012 a new amendment was received to allow for the recruitment of families who joined the school-age program in August 2012. The recruitment was delivered to all eligible families and an advertisement about the study was published in the newsletter. The final recruitment did not bring new participants.

One key challenge to finding families willing to participate in the study was a small number of families completing EIBI program each year. This is the only program in Manitoba and due to he number of long term studies focused on children with autism,

most of the families from EIBI were already participating in and were recruited to

numerous previous studies. The overwhelming number of requests from other

researchers, as well as busy family schedules, were probably the most potential obstacle

to participation in the study. The sensitivity and confidentiality of the topics discussed

could have been another reason for recruitment difficulties. The timing of the requests

(Easter and beginning of summer) to participate may have also been a deterrent.

Data Collection

After obtaining written consent from the potential participants, the primary form

of data collection for this study was based on in-depth, face-to-face interviews with the

participants. The interviews were used to gather descriptive data in the parents' own

words about how they interpret their experiences of transitions to the schools with their

children and what kind of social support is the most important to them during this time.

The interviews were audio-taped with prior consent of the study participants (Appendix

B). Each interview lasted approximately one to two hours in length. The interview guide

was used by the researcher as a framework for the data collection within the grounded

theory perspective (Appendix C). The questions were asked in an open-ended format in

order to develop a dialogue with parents to better explore their experiences and

perceptions. Semi-structured interviews consisted of five primary questions to answer the

research questions of the study. The questions changed as the researcher moved into more

interviews during the process of data analysis, using the constant comparative method.

Data Analysis

The central purpose of analysis in qualitative studies is to sort and organize the

masses of information acquired during data collection in such a way that the categories

and interpretations that emerge from the process address the original research questions of the study. In grounded theory the analysis begins as soon as the first data is collected and used by the researcher to direct the next interview and observations (Corbin & Strauss, 1990). Glaser (1998) outlines three-level conceptual perspective analysis: a) the first level is data; 2) the second level is the conceptualization of the data into categories and their properties (sublevels exist within this level), and 3) the third level is the overall integration of data into a theory through data sorting (p.136).

The researcher starts reviewing the data by examining interview transcripts and identifying themes and codes. Categories are identified and developed in terms of their properties and dimensions through the generation of basic categories and constant comparison between cases, instances and categories (Backman & Kyngas, 1999). The connection between the theory and the categories has to be confirmed by continuous comparative analysis, which is done by the researcher during the entire interview process. First the researcher compares the substantive codes and their properties, later the categories and their contents, and finally the discovered theory with other theories (Backman & Kyngas, 1999).

In this study the interviews were tape recorded and transcribed verbatim. Transcription took place as soon as possible after the termination of each interview. Coding of the data began after the transcripts were validated through repetitive listening to the audio tapes.

There are several levels of coding that were utilized during the data analysis. Throughout the coding process the researcher constantly compared the properties, incidents and/or characteristics of different coded units to decide the categories or subcategories that best fit with each unit. Within a category, sub-categories can be

established to demonstrate the variations within it. Grounded theory uses set procedures

for analysis that consists of open, axial, and selective coding (Creswell, 1998). *Open*

coding refers to "the process of breaking down, examining, comparing, conceptualizing,

and categorizing data" (Corbin & Strauss, 1990, p.61). Its purpose is to give the

researcher "new insights by breaking through standard ways of thinking about or

interpreting phenomena reflected in the data" (Corbin & Strauss, 1990, p.12). Once the

categories and their properties are distinguished, the researcher receives the basis for

sampling on theoretical grounds. *Axial coding* puts the data back together in a way that

shows connections between a category and its subcategories (Corbin & Strauss, 1990).

Relationships between properties begin to emerge and new hypothesis to be verified must

be indicated by the data over and over again in order "to seek systematically the full range

of variation in the phenomena under scrutiny" (Corbin & Strauss, 1990, p.13). *Selective*

coding refers to the process of selecting the core category by integrating the developed

categories to form the initial theoretical framework. The core category focuses on the

basic problem addressed by the theory, providing an integrative framework around which

the analysis develops (Dey, 1999).

Design Issues: Validity and Reliability

In qualitative research, the term "credibility" stands as measure of reliability and

validity, which are usually used in quantitative research. Most of the qualitative research

in recent years has moved toward preferring such terminology as "trustworthiness" and

"authenticity" proposed by Lincoln and Guba (1985). Patton (2002) notes that credibility

of a qualitative report depends on the use of rigorous methods of fieldwork, on the

credibility of the researcher and on the fit between the philosophical research paradigm

and the research in question. For Lincoln and Guba (1985) the credibility/validity of the study must be established through the processes of prolonged engagement, member checks, triangulation of data collection and peer debriefing. Marshall and Rossman (2011) state that the goal of credibility in qualitative research is to "demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was appropriately identified and described" (p.251). The authors continue that in order to prove the credibility/validity of qualitative study the researcher should present an in-depth description of the complexities of processes and interactions. These descriptions are embedded within the data that are part of the naturalistic setting. Therefore, within the parameters of that setting and population, the research will be valid (Marshall & Rossman, 2011).

Reliability refers to the ability of other researchers to replicate a study. The lack of replicability in grounded theory has been a major critique of this method. Since the grounded theory method is dependent on the "researcher's skill, creativity, time, resources, and analytic ability", it is difficult to exactly replicate a grounded theory study (Chenitz & Swanson, 1986, p. 13). Authors identified that the application of the theory to similar situations and settings over time is of more importance to reliability than whether or not the research can be replicated exactly.

There were a few criteria used to determine the trustworthiness of the current study. A detailed description of data collection and data analysis is presented stating the parameters of the population and placing boundaries around the study to ensure validity. Another strategy that was used to increase reliability was to explore emerging themes by critically evaluating them and verifying them by the new data. In order to ensure the accuracy of coding (inter-reliability), three of the transcripts were shown to an independent evaluator (advisor) to read and evaluate.

In qualitative research validity refers to the extent in which research results represent reality (Field & Morse, 1985). It focuses on the question of whether or not the theory is relevant to the group being studied. Validity in any study can be increased as the researcher maintains an awareness of his/her own biases and assumptions and how those might affect the research process and findings. According to Hall and Callery (2001) theoretical sensitivity and reflexivity enhance the rigor of grounded theory and provide criteria that make the process of creating data more transparent. Theoretical sensitivity reflects the investigator's ability to use their personal and professional experiences to view the collected research from a broadened perspective. This broadened perspective of the data in the research may then be used to create the developing theory (Strauss & Corbin, 1990). Theoretical sensitivity is used to maximize analytic procedures so that the researchers' bias are accounted for and the hypotheses are revised. This sensitivity also assists the researcher in manipulating the data to best reflect the reality of what is being studied. Patton (2002) defines three sets of questions involved in triangulated reflexive inquiry: self reflexivity, reflexivity about the studies, and the audience. Reflexivity emphasizes "the importance of self-awareness, political/cultural consciousness, and ownership of one's perspective" (Patton, 2002), which is crucial during analysis and reporting of the study. The researcher's experience in the studied topic is advantageous as it can bring a depth of understanding of the studied phenomenon and facilitate access to the field of study (Cutcliffe, 2000). Such awareness can also increase theoretical sensitivity and be an asset in theoretical coding. The researcher in the current study previously worked with families who have children with autism. The influence of the researcher's knowledge experience is discussed in the final chapter of the study to show how it affected the interview process and development of the themes. Making constant

comparisons of the concepts assisted the researcher in guarding his/her personal bias, and breaking through subjectivity. In order to increase the validity and reliability of the study, the data collection protocol was outlined and conducted in a rigorous manner. The researcher kept detailed field notes and personal journaling throughout the research process that allowed her to identify potential threats to validity.

An important way to strengthen a qualitative research design is through the use of triangulation. Triangulation requires researchers to make use of multiple and different sources, methods, investigators, and theories to provide corroborating evidence (Creswell, 1998). In this study triangulation was limited to the use of different sources of information. More specific data from the limited number of interviews was triangulated with metasynthesis analysis of relevant qualitative studies that focused on the transition experiences of families with children with ASD. Metasynthesis is used "to synthesize a group of studies on a related topic into an enhanced understanding of the topic of study wherein the position of each individual study is changed from an individual pocket of knowledge of a phenomenon into part of a web of knowledge about the topic where a synergy among the studies creates a new, deeper and broader understanding" (Aguirre & Bolton, 2013, p. 5). Synthesizing is a methodology that increases the credibility and trustworthiness of qualitative research by data triangulation (Meadows-Oliver, 2003). As such, it is a valuable tool for generating theory about the phenomenon and producing new and integrative interpretation of findings about the constructs that emerge.

Metasynthesis Component: Objective and Method

A review of the literature on the transition experiences of the families with children with autism from preschool to school within an Early Intensive Behavioural Intervention program revealed no published metasynthesis. There are numerous studies

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conducted related to stressors and supports for families of children with autism spectrum disorder (ASD) primarily using quantitative research methods. No previous reviews have sought specifically to synthesize the findings from existing qualitative findings in this area. The main objective of current metasynthesis was to present an integrated description of qualitative findings on the transition experiences of families with children with ASD. The secondary aim is to compare the findings with direct results obtained from the current small sample study conducted with a group of families from the St.Amant EIBI program.

This metasynthesis was guided by the writings of Sandelowski and Barroso (2007), who define metasynthesis as "an interpretive integration of qualitative findings in primary research reports that are in the form of interpretive syntheses of data: either conceptual/thematic descriptions or interpretive explanations" (p.199). The method offers "an integrated description or explanation of a target event or experience" (p. 18), that is, the families' experiences of the transitions of their children with ASD from Intensive Behavioural program into school.

The process of metasynthesis started with the setting of the parameters for the literature search, which was followed by individual and comparative appraisals of each selected report and then across reports. All of the themes that emerged were grouped, interpreted and then presented in a synthesis of findings. A more detailed outline of these procedures are provided in Chapter IV where the results from this component of the study are presented.

Ethical Considerations

Several ethical considerations exist with the research. As subjects committed themselves to participate in the study, several procedures were necessary to ensure that

confidentiality was protected and measures were taken to ensure the rights of the participants during all phases of the research process. These measures included informed consent, ensuring the physical and emotional comfort of participants, and the development of procedures to help the participants make informed choices. Informed consent in written form was obtained from the parents prior to their participation in the study (Appendix C).

The information contained in the forms including the purpose, usefulness, and methods was discussed with all the participants. The participants were also informed of their right to refuse to participate, or withdraw from the study at any time. Participants were also informed of their right to ask questions about the study, and discuss them with the researcher. Confidentiality was outlined explaining that any potentially identifying information would be changed through the use of non-identifying quotations. This included names, occupations, family information, geographic information, etc. Forms were reviewed with the study participants to make sure they were understood, and offered to answer any questions they had of same. This time of reviewing the forms with the participants ensured some comfort with the researcher. Near the end of the interview, there was a debriefing session that occurred between the participnat and researcher. This provided the researcher an opportunity to address any final questions related to the research. Overall, the participants had very few questions in regards to the consent procedure and their rights. Participants were also informed that the staff of St.Amant would not know who participated in the study and that participation in the study would not affect any services they receive from the program.

One of the concerns I had before starting this study was that the research may create challenges in terms of my previous experiences and biases. I have experience of

working with the families with children with ASD. It was considered that this may pose a problem as I have personal knowledge and preconceived notions about what it is like for these families going through the transition and what formal supports they usually receive. Coming from a social work background and due to the fact that the interviews could become emotional, I felt this may cause me fall into the social worker role during the interviews. However, I completed each interview ethically while staying focused on the goals of the study and tried to remain objective within my research. As a researcher, I strived to keep an open mind in order to let empirical knowledge, not my own preferences, form the basis for any conclusion drawn from the research.

In order to preserve confidentiality and anonymity, a coded number on the data accumulated from the interview identified the participants. The staff of St.Amant did not have access to the information regarding who participated in the research study. The information and raw data compiled for the study was only viewed and consulted by the researcher and her thesis advisor. All transcribed interview data and the audio tapes were secured in a locked cabinet, accessible only by the researcher. Upon completion and approval of the thesis, the data will be destroyed. The information the subjects provided will remain confidential, meaning that participants will not be identified as to what they specifically said. Names of the participants will be identified. The information that participants provided from the interviews was presented in the format of quotes from specific answers they had provided.

CHAPTER IV

DESCRIPTIVE RESULTS FROM DATA ANALYSIS

Introduction

The primary purpose of this study was to examine the experience of parents of children with autism during the transition from preschool to school within the Early Intensive Behavioural Intervention[1] program at St.Amant. Semi-structured interviews were conducted with six families to capture their experiences during the transition. Emphasis was placed on the formal and informal social supports received during that period, as well as perceived benefits and challenges. Metasynthesis of qualitative studies about transition experience of families with children with autism was added as additional component to data collection in order to strengthen the results of the current study; its integrated descriptive findings are presented at the end of this chapter.

The first section of the chapter provides an overview of the data collection methods used in this study. This section outlines the setting of the study, and instruments and procedures that were applied. Demographic variables are presented as aggregated data due to a small sample size and in order to protect confidentiality of the families.

The second section of the chapter presents the descriptive results from data analysis utilizing the grounded theory approach. The open coding results which is the initial analysis of the raw data is discussed, including the way in which the data was coded and categorized. The main categories, their properties and descriptions are presented in Table 1. After discussing the open coding results, the second phase of this

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[1] The Early Intensive Behavioural Intervention program at St.Amant was called the Applied Behaviour Analysis program until spring 2013. During the interviews parents referred to it as "ABA program".

analysis- axial coding is discussed. Through this process, the initial categories were refined eventually leading to the development of four categories and their subcategories. Through axial coding the interrelationships amongst the categories and their subcategories are discovered. At the final stage of the analysis, selective coding, the categories are refined and the development of theoretical schemes are presented explaining how the categories relate to each other. All four categories (themes) and their subcategories are organized around central phenomenon. A detailed description of the categories and their connection with the core category are presented, using multiple participants' quotes taken from the interviews.

The third section of this chapter presents the metasynthesis component. A brief description of the research method, procedure and criteria are outlined. This is followed by the table illustrating the key features of research reports selected for synthesis. Each study was analysed individually and the interpreted meaning of five emerged themes is illustrated.

A summary of the findings is presented in the conclusion of the chapter.

Interviews

Within two weeks, commencing April 22, 2012, three mothers and one couple were interviewed. In August 2012, two additional families were interviewed. All of the families participated in in-depth, one-on-one interviews, which were about one hour long and audio taped. Five interviews were conducted in the homes of the participants. One of the last families interviewed resides in Brandon, therefore, it was agreed to complete the interview via telephone.

The qualitative research was based on Patton's (2002) directions which utilized a

semi-structured interview framework allowing participants to feel comfortable responding

to the interview questions, thus enabling the parents to respond accurately and freely

speak about the transition experiences of their families from preschool to school within

the Early Intensive Behavioural Intervention program. At the outset of the interviews, the

participants were given a few minutes to read and sign the consent form (Appendix B)

and have any questions answered at that time. Participants were advised that they could

withdraw from the study at any point and refuse to answer any questions. They also were

assured that their confidentiality would be protected. Each parent was also asked to fill

out a demographic sheet that is kept for the final data analysis. All of the participants

indicated their interest in viewing findings after the study is complete. An interview guide

with a list of open-ended questions was prepared to ensure that the same basic

information was obtained from the families by discussing the same material. By being

mindful of the purpose and research questions of the study, the goal was to get detailed

information to better understand parents' experiences during the transition of their

children to school.

One of the interviews was not audio taped, due to a full memory card in the

recorder that was not noticed until the completion of the interview. Detailed notes,

observations and summaries were made immediately following this interview. Each

interview was transcribed immediately at the end of each interview. All interviews were

transcribed by the researcher, allowing the researcher to become thoroughly acquainted

with the content of the interviews, and providing an opportunity to review and engage

with the data. This transcription involved carefully listening to each tape recorded

interview and converting each word on to paper verbatim. Although transcription is time

consuming it allowed for new questions to be formulated, and the transformation of

opinions and collective information into meaningful data. It was found after the fourth interview that most of the information obtained was quite similar.

Demographic Variables

The present study was conducted with parents of children who completed the preschool Early Intensive Behavioural Intervention program through St.Amant. These children were also currently attending public schools in Manitoba, while continuing to participate in the school component of the EIBI program. These families went through the transition within the last six to twelve months prior the interview, and as earlier noted, all of the interviewed families resided in Winnipeg with the exception of one family from Brandon.

With the approval and assistance of the staff from the EIBI program at the St.Amant Centre, a recruitment package was sent to the families whose children had recently completed the program. The research sample specified in the proposal was to include twelve families and only four responded, and were interviewed, after the first recruitment. In order to involve more participants new recruitment approaches were applied and the research criteria was expanded which allowed two more families to be interviewed. In total, six families were interviewed which was half of the sample indicated in the proposal. The final sample consisted of seven parents of children with autism from six different families: five mothers and one family in which both parents participated in the study. All of the research samples consisted of Canadian born families and all individuals were married. The ages of the participants ranged from approximately 32 years to 47 years of age. Two of the participants were stay-at-home mothers, three work part-time, and two work full time.

Six of the children whose parents were interviewed were male. The majority of the children were diagnosed with PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified) or ASD (Autism Spectrum Disorder) between the ages of two and three and a half years old. Four of the families participating in the study had their children starting EIBI at the age of three and the last two families started when their children were three and a half and four years old. Two of the children were making the transition from nursery school and one from kindergarten where they received their last year of EIBI programming. The rest of the three children participated in the EIBI program for the entirety of the three years in their homes. All of the children made the transition to all inclusive education programs in public schools. Parents of five of the children indicated that their children had a moderately severe level of autism on a scale of five from "not severe" (1) to "extremely severe" (5), and one parent described her son's level of autism as extremely severe. All of the participating families had at least two children living at home.

Interpretation/ Analysis

Grounded theory was chosen as the appropriate methodological approach for data analysis in this study. In keeping with the grounded theory approach analysis began with data collected from the first interview and these results were used by the researcher to direct the next interview and observations. Main categories that were identified in the beginning of the analysis had to be verified through continued data collection and analysis. The central purpose of analysis in qualitative studies is to sift, sort and organize the masses of information acquired during data collection in such a way that the categories and interpretations that emerge from the process address the original research problem. Discussion of the analysis continued using the main paths of the grounded

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theory methodology: open, axial, and selective coding to the selection of a core category around which the analysis will be organized.

Open Coding

Open coding involves breaking data down into discrete parts that are later put together again through theoretical connection. It refers to that part of analysis that deals with the labelling and categorizing of phenomena as indicated by the data. The product of labelling and categorizing are concepts which are the basic building blocks in grounded theory construction (Corbin & Strauss, 1990). Conceptualizing is the process of grouping similar items according to some defined properties and giving the items a name that stands for that common link. The conceptualizing stage helps to reduce a large amount of data to smaller, more manageable pieces of information. Open coding requires the application of what is referred to as the comparative method - the asking of questions and the making of comparisons. Data is initially broken down by asking simple questions such as what, where, how, when, etc. Subsequently, data is then compared and similar information is grouped together and given the same conceptual label. The process of grouping concepts at a higher, more abstract level is called categorizing. Once some categories were determined, their properties were specified. These concepts (categories) also vary dimensionally along these properties. Through specification patterns began to emerge, such as development of a child with ADS while participating in EIBI program, and collaboration of parents with ABA tutors and school professionals. Thus the foundation and beginning structure for theory building began.

Within this study the transcribed data was examined line-by-line. This form of coding involves a close examination of data, phrase-by-phrase and sometimes word-by-

word. Doing line-by-line coding is especially important in the beginning of a study because it enables the analyst to generate categories quickly and develop those categories through further sampling along the dimensions of a category's general properties. As noted earlier, this sampling approach is called theoretical sampling (Corbin & Strauss, 1998). This process began by going through the transcripts and identifying information from the words, sentences and paragraphs that best answered the questions from the interviews. By assigning each category a different colour, categories were established and assigned a code. While the paragraphs were being coded the question was posed: "What is the major idea brought out in this sentence or paragraph?" Then after giving the category a name, a more detailed analysis of that concept can be completed. This approach to coding can be used at any time, but is especially useful when the researcher already has several categories and wants to code specifically in relation to the existing categories. The codes in this study varied in size from words or phrases, to sentences or complete paragraphs.

After every new interview more information became available, and some codes changed to better reflect the data. In this study, open coding consisted of going back into the text of the transcripts and finding phrases, sentences or paragraphs describing issues connected to the research questions. For example, through the open coding in this study, specific words, phrases and sentences were repeated by parents about their transition experiences, and this pattern suggested that a careful examination of these phenomena was necessary.

Identification of major categories emerged and was documented on index cards. The transcripts were individually reviewed and key quotes were placed on index cards that were significant to the particular topic. All of the interview data was not placed on

index cards as the volume of the data was significant. Therefore, notes were made on the transcripts to identify key issues. From the transcription of interviews and line-by-line coding of the data (Appendix D) key issues and eventually categories of interests emerged. The headings of these categories are listed in Table 1 that also includes examples of how the data was incorporated into the categories. Efforts were made to distinguish between generalizing from categorized data and the uniqueness of individual experiences.

Table 1. Open Coding Categories

Category	Properties	Description
Autism (descriptive data about child's ASD)	Diagnosis/symptoms of autism	Parents shared when they first noticed that their child showed symptoms of autism; how and when they received the diagnosis
	Child's behaviour	Description of behaviours child experienced before starting the ABA program and after
	Social skills	Description of the social skills a child had before starting the ABA program and how some of them changed overtime
	Learning skills	Description of the learning skills a child had before starting the ABA program; description of the learning skills acquired after participating in a program; skills that still need to be acquired
	Parents' feelings	Parents' descriptions of their feelings and emotions when they found out about the child's diagnosis
	Child progress in development	Parents' description of the child's general progress in development as a result of enrolment in the ABA program
	Parents' education about autism	Parents shared their ways of learning about ASD, resources available, ABA techniques, etc.
	Interaction with the parents	Parents' perspectives of the effects of the child's disability on the interaction with them; changes of patterns in interaction before and after starting preschool ABA program
Effects of autism	Interaction with the siblings	Parents' perspectives of the effects of the child's disability on the interaction with their siblings; changes of patterns in interaction before and after starting preschool ABA program

Category	Properties	Description
Effects of autism (understanding the impact of the child's ASD on the interactions with others)	Interaction with others	Parents' perspectives of the effects of the child's disability on the interaction with tutors, peers, extended family; description of the changes of the interaction
	Parenting style	Parents described changes in their parenting style
	Effects on family life overall	Parents' perspectives on the effects of the child's disability on the lifestyle of the family overall
Transition (description of families' experiences with the transition to school)	Parents' expectations	Parents shared their expectations prior to their children starting the transition to school
	Preparation/planning	Four children of the interviewed families went to kindergarten within the ABA preschool program. Parents talked about the ABA tutors role in preparing themselves, their children, and new staff to the changes in schedule, settings, etc.
	Challenges/barriers	Parents discussed the challenges and barriers their families experienced in the transition process
	Partnership with the school	Parents shared stories of successful collaboration between ABA tutors, new teachers and themselves
	Parents' feelings	Parents' common feelings during the process of transition
Support (description of the families' support systems during the transition)	Formal support that was received	Description of families' formal support received during the transition
	Informal support that was received	Description of families' informal support received during the transition
	Formal support that was not available	Parents named formal supports that they thought would be helpful to receive but were not available to them at that time
	Informal support that was not available	Parents named informal supports that they thought would be helpful to receive but were not available to them at that time
ABA	Assessment	Parents shared how their children were assessed before starting ABA program
	Programming	Parents descriptions of ABA programming: its intensity, approaches, principles, goals
	Tutors	Parents shared a lot about ABA tutors; their involvement in planning with the transition; their support during and after transition
	Knowledge and use of the ABA techniques	Parents' perspectives on the importance of using ABA techniques in everyday life of a child with ASD; description of the ABA techniques

Category	Properties	Description
ABA (the descriptive data about the interventions based on Applied Behaviour Analysis)	Gaps	Parents commented on things that were missing in the ABA program
	St.Amant	Parents talked about collaborating with St.Amant, how St.Amant staff accommodated their needs, and how they were involved in their families' lives
Social workers (descriptive data on the role of social workers in the process of transition)	Involvement of social workers in the planning of the transition	Parents discussed involvement of social workers in the transition planning; if social workers were not involved then parents indicated what social services would be helpful to receive from social workers
	Contacts with social workers	Families shared the times they were contacted by the social service worker; they talked about the type and frequency of these contacts
	Information provided by the social workers	Description of the information social workers provided to the families overall and specifically during the transition

Axial Coding

In grounded theory methodology axial coding follows open coding. Whereas open coding fractures the data into concepts and categories, axial coding puts those data back together in new ways by developing main categories and making connections between a category and its subcategories. Procedurally, axial coding is the act of relating categories to subcategories along the lines of their properties and dimensions (Corbin & Strauss, 1998). Corbin and Strauss state that subcategories are also considered categories and rather than standing for the phenomenon itself, subcategories answer questions about the phenomenon such as when, why, how, who and with what consequences, thus giving the concept greater explanatory power. Early in the analysis those concepts which were considered categories and subcategories were identified. Through axial coding, interrelationships amongst the categories are also discovered in order to build a

proposition explaining these relationships.

Each one of the six interviews was considered a separate data source. This supported the focus on key categories that emerged from the data, enabled a detailed analysis of each family's experiences and helped to examine the similarities and differences between each experience. Throughout the analysis, constant comparisons across interviews facilitated category development and saturation. Constant comparison is key to the grounded theory method. Cross case analysis occurred by examining the answers of each question across cases to understand the shared themes and dissimilarities. Similarities and differences between the categories were identified in an attempt to detect relationships. The categories were then themselves compared and contrasted in order to discover the relationships between them. This process is necessary in order to examine the emerging themes and patterns effectively, as the researcher can then carefully consider each aspect of the data and how it fits on into the study as a whole during the transcription process.

Four categories appeared to encompass the general ideas uncovered from the initial coding process. The remaining categories are referred to as sub-categories of these concepts that are included in the ideas for the key concept of that main category. The sub-categories include data related to the category and may provide more of description or explanation of the main category.

The four categories are listed below along with their sub-categories.

1. ABA intervention

❯ Effect of ABA program on child's development

❯ Use of ABA techniques or effect of ABA on a family life

2. Process of transition from ABA preschool into school

- ➢ Parents' concerns before going through transition

- ➢ Parents' educational role

- ➢ Factors that facilitated successful transition

- ➢ Barriers to successful transition

3. Social Supports

- ➢ Informal support resources

- ➢ Formal support resources

4. Involvement of social workers in the transition process

- ➢ Services received

- ➢ Services that would be helpful to receive

Selective Coding

The final stage in the coding process is the integration and refining of categories. The primary goal of this step is to develop a theoretical scheme explaining how each of the categories related to each other. In integration, categories are organized around a central explanatory concept. Integration occurs over time, beginning with the first steps in analysis and often not ending until the final writing (Corbin & Strauss, 1998). Once a commitment is made to a central idea, major categories are related to it through explanatory statements of relationships. The core category (the central idea) is defined as the phenomenon. Other categories are then related to this core category according to the schema.

Data analysis during axial coding included grouping statements or ideas into categories/subcategories according to similarities. Each similar group was given a category name. Examples of earlier categories included: ABA intervention; Process of

transition from ABA preschool to school; Social supports; and Involvement of Social Workers in the transition process. As data analysis continued, categories changed and developed. They were combined in order to more accurately reflect families' experiences while data collection and analysis proceeded. For example, the researcher noticed that there was a lot of information shared by parents about factors that facilitated the process and with further analysis it formed a separate category while barriers became a part of it. Another example of a change was when category *Involvement of social worker in the transition process* became a part of subcategory *Formal support*. There was not enough information shared about the role of social workers during the transitions in order to develop a category, therefore it became a part of the subtheme labelled *Support*. Parents shared about their active involvement in the transition process that it formed as a separate subtheme of *The process of transition* showing that it was a significant a factor during the transition process. As analysis proceeded it became evident that the core category was *Transition experience of the families with children with ASD from preschool to school after within EIBI*. Grouping similar themes and connecting them to the core category led to an understanding of the families' experiences, which is necessary to formulate relevant conclusions to the study.

Core category: ***Transition experience of the families with children with ASD from preschool to school after EIBI***

The transition process is the core category of the emergent theoretical model. The core category is the centre piece of the model, an abstraction that represents the main theme of the research (Strauss & Corbin, 1997). It brings together understanding of the data. In this study the core category was determined after examining all four categories and their subcategories. Questions were posed such as "What is the central phenomenon

of this study? What factors influence families' transition experience? What is common/different in all the transition processes? "

The following four categories and their subcategories emerged from the data analysis:

1. Participation in the ABA program

    1.1. Diagnosis/symptoms of autism

    1.2. Effects of the ABA program on child development

    1.3 Effects of the ABA program on family life

2. The process of transitioning from the ABA program to school

    2.1. Parents' concerns before the child's transition to school

    2.2. The planning and preparation stage

    2.3. Parents' role in self-education and advocacy

3. Supports received during the transition process

    3.1. Formal supports

    3.2 Informal supports

4. Factors that facilitated the transition

A detailed description of each category and its subcategories is presented below and supported by quotes taken from the interviews.

1. Participation in the ABA program

1.1. Diagnosis/Symptoms of Autism

    In demographic questionnaires distributed before the interviews, parents were asked to rate the level of severity of their child's autism on a scale from one (not severe) to five (extremely severe). Five out of six parents indicated a moderate to severe level of autism in their child, and one parent stated that the level of their child's autism was extremely severe.

All participants indicated that they began to notice a lack of normal development in their child after he turned approximately eighteen months. Parents recognized that their child was not meeting fundamental developmental milestones, which included underdeveloped language, losing previously developed language, as well as other communication or social difficulties. Such behaviours as fixation on certain stimulation, lack of eye contact, arm-flapping, and breathing difficulties caused parents to become concerned. Children were diagnosed with autism between ages two and a half to four years old. One of the parents talked about their experience:

> I think like a lot of people, we really started to notice the signs when he was about 18 months. He wasn't really speaking much, he really didn't attend and show interest. He was all over the map that way and (pause) just not showing an interest in many things, not playing with other children, not showing enough interest in his peers, barely speaking really. You know, I remember taking him to have his hearing tested, 'cause this often is the first course (of action) to have his hearing tested and see (if) maybe that's the issue and that's why he is not speaking, 'cause he is not actually hearing what you are saying (Family #2).

Similarly, another parent shared:

> …It was only couple months before he (son) turned three and she (doctor) said: "No, you know what, I need you to come back in six months, let me see", 'cause she's like: "it could've been a developmental delay". So then I came back in six months, and she did it to me again and said "Come back in 6 months", and the second time, I guess it would be the third time already, and she said "Oh yeah, this (autism) is what you are dealing with". So that's when he was diagnosed (Family # 5).

Another mother spoke about her experience in the following way:

> We had seen signs a long (time) before that (diagnosis). So he..like I said, he is the third child so it wasn't you know..I had had other children and I kind of knew what milestones he should've been hitting and he wasn't. We had at that time an extremely good pediatrician who was very good, who had kind of already seen things beforehand (Family # 6).

Parents talked about the shock and disturbing thoughts they had after receiving the diagnosis of autism, even though all of them suspected there was something abnormal

about the development of their child. One mother described her reaction to her son's

diagnosis:

> I think, like, a lot of parents when you first get the diagnosis, you grieve. Which is
> pretty common…you grieve all the potential loses. What this child's life will be
> like? What kind of choices will he have? What will his life look like? Will he be
> able to finish school? What will his life look like after school? Will he ever be able
> to marry, have children? … So yeah, it was quite shocking, even (though) we knew
> to expect it, you still, when you get that diagnosis, when its been confirmed, it is a
> loss all over again, right?....hmm...and yeah, it was. I remember not speaking for a
> few days, just really being quite depressed and being worried, worried for my son
> (Family #2).

Parents expressed that in addition to the feelings of shock and grief they also felt a sense

of relief that they finally had an explanation for their child's behaviours. One mother

stated to her experience of relief:

> ...And as far as my feelings after he was diagnosed, I remember coming out of that
> with almost a sense of relief like, finally, I know what I am dealing with. I thought I
> had this strong willed child who had temper tantrums all the time, and I thought: "I
> don't know how to control this child". I felt like a failure parent because I couldn't
> connect with him, I couldn't get him to do anything, so that was almost like a sense
> of relief. I remember that feeling getting into the car, it was like, now I know what it
> is, right? And then, of course, there was a huge sense of grieving that came
> afterwards, but my initial feeling was a relief that I finally knew (Family #5).

Another parent shared:

> When they actually diagnosed him at two and a half it wasn't a surprise it was more
> like, "Okay, that's fine, now what do we do?", like, you know what I mean?
> (Family #3).

Prior to participating in the ABA program three families had their child enrolled in

the "Let's Get Started" program run by the Child Development Clinic, which is a part of

the Health Sciences Centre in Winnipeg. All families participating in the program felt that

their child required a more intensive program, and therefore all put their child on the wait

list for ABA services. Families waited for at least one to three months to start ABA

program. The assessment of the child started after the first initial meeting with the family

and lasted about three to four weeks on average. One of the mothers shared:

> I remember the assessments with ABA – he couldn't even sit in a chair, even like, for a few seconds, and he couldn't even complete his first assessments with ABA, he really showed, like, no level of skills, because he wouldn't do things when you asked him to do (them). He would say a word, he had (no) more than few words at that time, but he could never say a word when I wanted him to say it, he would just say it kind of "out of the blue thing" and I couldn't get him to say it again, or whatever and its like, random words (Family # 5).

1.2. Effect of ABA on Child Development

Parents shared that before starting the program, their child did not use many words and had minimum interactions with others, including parents and siblings. Parents indicated that they did not know how to control their child's extreme temper tantrums and frequent meltdowns, thus, behavioural problems were the biggest concern. Parents felt they could not connect with their child and did not have enough knowledge on how to engage him/her in different activities.

All parents reported that their child benefited from participating in the ABA program. Children with moderate forms of autism started speaking in full sentences, and communicating and interacting with family members. Their temper tantrums occurred less often and their social skills improved.

> My son really took to the program, like, he is the poster child for this, like, the change in him from being in the preschool (program) to the end was different than other people I know... The ABA program has been amazing for him. He is one of the kids who is really taken off. So now he speaks, reads, he does everything (Family #3).

Three out of six families stated their child improved their functioning in many aspects after completing the ABA program. Motor skills and behaviour improved but they were still not able to speak in full sentences and required a lot of assistance and directions. One of the parents described her son's skills in this way:

> His receptive language skills are quite good, not age appropriate necessarily, but quite good, but his expressive language skills are still quite delayed... He's made

tremendous gains, you know there are still some areas where he hasn't got a lot of gains or just slower because of the way in which autism affects him (Family #2).

Four parents noted that upon completion of the ABA program their child could better handle daily transitions with the use of various aids. Children used visual schedules at home and school, "to do" or "self check" lists and other reminders that help them to focus on task completion.

> He is pretty good with transitions for the most part…changing from one activity to another. If he doesn't expect something and it upsets him then, yes, he can become quite distressed, but for the most part if something was explained to him, he doesn't experience any difficulties (Family # 3).

1.3. Effect of ABA Program on Family Life

Parents reported that their child with ASD needed significant attention, supervision and direction before starting the ABA program. Parents felt that time spent with their child was intense and emotionally draining. The tendency of their child with ASD to have outbursts or tantrums when routines were altered, required continual planning. ABA techniques helped parents to follow through with consistency, as well as maintain set routines effectively:

> With the ABA (program) I just realized how important it is every time, to pay attention to little details and follow through on what you are saying, not to let things slide. Whereas before ABA, I was probably letting things slide....but ABA kind of helped me to realize: constantly following through might be tough at the beginning, but that's what's gonna give you reward in the end (Family # 4).

Although parents found that having their child enrolled in the ABA program was time consuming and required a lot of work and commitment it let them obtain new parenting skills, and gave them a lot of confidence and support. These reactions are illustrated below:

> My philosophy didn't change because I realized, like: "hey, this is kind of the way I think", but yet it took me further and kind of gave me confidence....It's really hard

work; I felt like I became a much better parent for sure, but it sort of, I didn't feel like it was going against, like, I didn't have to have my mindset changed. It just reinforced where I was, kind of, already. Yeah, and it took me even further, right? It just gave me a sense of relief, a lot more confidence, and support that I didn't have (Family # 4).

I learned a lot of good parenting skills from the ABA program and we really don't, we are not "wishy-washy" with our kids (Family #3).

One mother shared how the whole family learned how to live and deal with child's autism; they accepted it and it became a part of their family life:

He is seven now so I think the worst is pretty much over. Now its just a part of our life. It just how the things are done in our household. I know how to pick my battles now. … We just kinda go with the flow…We try to keep him as calmly as possible around here (Family #6).

Most of the participants noted that their child with ASD started interacting and communicating with their siblings more after participating in the ABA program. They do not always play together or get alone well with their siblings, but do take part in the same activities or work on the same task together. One mother talked about her son's relations with his sister in the following way:

Before we started ABA there was really nothing. There wasn't a lot interactions. I remember when they first fought and I was like, "they are fighting, they are fighting", that means they are interacting. Like, before he pretty much ignored her and then I thought I would never thought I would be so happy to hear kids fighting (laughing) and I still remind myself of that sometimes, right? .... So, but now, like, she (sister), has been so good for him. She was an extremely verbal kid. She learns so fast, and (is) so good for him. She is interacting with him and he loves her, she is a friend to him and they do play (Family #6).

Summary

Parents shared in their interviews that raising a child with autism had a considerable impact on their family life and discussed the challenges their families encountered in day-to-day activities. They talked about their feelings of stress and grief when they received their child's diagnosis. Parenting a child with autism poses additional

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stressors related to the child's challenges in communication, difficult behaviours, social

isolation, and difficulties in self-care. Families talked about their experiences of being a

part of the ABA program, and its benefits and challenges. Parents were pleased with their

child's development progress and reported vast improvements with their child's language,

social skills, behaviour, potty training and academic knowledge.

2. The Process of Transitioning from the ABA Program to School

2.1. Parents Concerns before the Child's Transition to School

All parents participating in this study talked about their concerns before their child's

transition from the ABA program to school. Three parents felt a gap in services when the

ABA program was completed and school had not yet started. One of the mothers

described the discontinuity she felt during the transition:

> I don't like when it's just, like, "Okay here you are" after ABA- that's it. Can we
> maybe shorten the time until we get to school? St.Amant just gives you a day, when
> your ABA is done, and then it's kinda the responsibility of the school and they
> (ABA) kinda get their hands off it. So that's not good. Because they leave you
> hanging, right? Or for a little bit, until the school starts (Family #5).

A majority of the parents were concerned whether they could keep the same open

communication with the school professionals as they did with the ABA consultants. One

of the mothers was worried that her son might be lost in the school system and his

developmental progress would not be tracked as it has been in the ABA program:

> It was scary, really scary, because all that time he was in my house. I could see him.
> Even though other people are working with him I could hear and see him, and I was
> involved. He would communicate with me. So, sort of letting him go to school,
> where I didn't have the same, I couldn't actually see what was going on- was scary
> to me. And I had talked to some parents, and it was like they really didn't know
> what was going on. The school wasn't good at communicating with them, so that
> was probably my biggest concern. I didn't want him to get lost in a school system, I
> wanted to ensure that he was constantly learning, but to me I was scared that there
> would (not) be the same way of tracking his progress as ABA does
> (Family # 6).

Families felt anxious not knowing how their child would develop and adjust to the new school environment and if the school had enough resources to meet their child's needs. All parents wanted to know who the educational assistant (EA) was going to be, if he/she had knowledge of ABA techniques, and if she/he had previously worked with other children with ASD. One of the parents stated:

> …School is just so different than having tutors here at home. And you don't even know what's to be expected, you don't know who the teacher is going to be; has she ever had training? Who is your EA is going to be? You don't know all this, and the school doesn't even know until the first day of school who the EA is going to be. How are they going to work with your child? You know your child is so already used to work with his tutor. And they know him, you know? Everything is new on the same day and they (are) expected to go to school on the first day so that's not good (Family #5).

Parents were worried that their consultants from ABA were changing, and were not able work with their children in the school ABA program. One of the parents said:

> Our biggest concern was that our consultant was changing. My team, as I thought: "These are the people that know him. The huge transition to school, like how its going to work, and he will get a brand new consultant as well". It was a whole new ABA team that doesn't know him, doesn't know his history and how far he's come - that was my biggest concern
> (Family #5).

2.2. The Planning and Preparation Stage

Planning and preparation for the child's transition to school was different for all families. Two families had their child transition from the nursery school where he had completed the final year of the ABA programming and one of the children transitioned from the kindergarten setting. The last two families had all three years of the ABA program at home before their child started school.

Four of the families reflected that the overall transition of their child was smooth and successful. Parents said they were "on top of everything", working collaboratively

with both the ABA program and school teams to make sure that all the needs of their

child were met. All four of these families shared that prior planning had occurred before

transitioning to school. This meant that parents met with the ABA consultants from

St.Amant and the teachers from school. They exchanged the information about the child's

developmental progress and discussed existing challenges and goals.

One of the couples interviewed reflected on their preparation experience:

> *Father:* We met with ABA, like, St.Amant, us, and the school all met to explain what was going to happen.
> *Mother:* It was probably in March before he started.
> *Father:* And our school is very understanding. They are very like, "Yeah, let's do what best for the kid".
> *Mother:* And then we met personally with principal and resource teacher sometime in August just to find out who (son's) EA was going to be (Family #3).

Another mother commented that planning was crucial in the preparation for her child's

transition to school:

> ...Knowing what to anticipate, going through the motions... You know, we had meeting at the school, he actually went to kindergarten classroom a few times and met the teacher, so on and so forth. As much as we could do before hand (Family #2).

Parents whose child had their last year of ABA programming in nursery school

found this structure to be very helpful in their child's transition to school. Working with

the ABA consultant in the nursery school helped the child to prepare to work in more

structured settings and develop social skills by interacting with other children:

> It might have been a year and a half his tutor in the afternoon would take him to nursery school, so again, that was just to prepare him for school. So, yeah, we had three years full time of ABA at home, but as it got closer to when he was going transition into school the last year, (the first half of a year), which was two times week and then for the last year, like, we prepared him to school he had five afternoons a week to try to get him ready for school and that whole full structure, the setting, and so that was a huge help…Like, I mean, we had to have him potty trained, and then that first half a year was, like, to give him some social stuff and opportunity to practice some of that social stuff, and then last year we wanted to put him for the five afternoons a week to prepare him for school and to all that structure where we had more of a control in the situation, where we could help him with

circle time, you know, sitting all of that stuff… He used to have a lot of temper tantrums at that time, or meltdowns, I should call them. So the nursery school was really good at working with us, and allowing us to try to being more consistent (Family #5).

Two parents shared that going to nursery school created challenges and was not easy for their child, requiring much adjustment from the ABA tutors and teachers. One of the mothers commented:

Nursery was a bit difficult and the tutors went through a bit of a rough time with him. He had behaviour spikes where (there) would be, like, a lot of screaming and aggression. I mean aggression for him is pretty mild. He is not a rough kid and he is not that often that he gets angry, usually he flops, and he threatens like he is going to hit you, and in fact he never makes contact. But, I knew my son well enough to know these things can be difficult for him, but he is very capable, and I knew that he would be able to do it, you know, I knew they weren't going to take him out of nursery school (Family #2).

All of the children with ASD going to school were eligible to receive level three funding and have a fulltime Education Assistant (EA) working with them in school. Parents made sure to meet the EA before school started, as well as the principal and resource teacher, to get familiar with the school and spend some time in their classroom. One of the parents noted:

It was a big thing to know who he was going to work with, that I didn't know and I had to trust my baby to them (laughing) and I couldn't watch them, right?...They allowed us to come, they made arrangements to come into school in August just to have the meeting with (son) and I, so we got to go and meet her (resource teacher) and she got to meet my son (Family #5).

Another mother spoke about her experience introducing her son to the new teacher and school:

Only because I asked for it, and again, I know people at the school, so it was done. At the beginning they just knew that (child) was coming in. I had gone to speak with the principal and the resource teacher. They have asked for the last report which we were given. They kind of want to know how he was, what he has asked for. They actually went to the preschool and visited him at the preschool which was so nice, because that doesn't get done too. So they actually got to see him and how interacted with other children at that time (Family #6).

Two families whose child had three years of ABA programming at home and did not go to the nursery school as part of the ABA program experienced difficulties transitioning to school. Both senior consultants (part of the ABA staff working with a child) of those two families had to leave after the ABA program was completed. Therefore, families started working with a different senior tutor and consultant. Parents said that new consultants did not know their children well and parents felt that they lost the constant support they had with the ABA team that worked with their child for the last three years. The schools to which both the families sent their child to were not supportive of the ABA program; therefore, both of the families felt as though they were the only ones advocating for their child.

> We didn't get any support from the principal and the resource teacher and it seems like they never worked with the children from the ABA program before and didn't try a bit to accommodate our needs. The EA had changed twice since (child) started going there. We could see how exhausted he was coming back from school. It was very frustrating for all of us, was frustrating to see how much struggle he had at that school (Family #1).

2.3. Parents' Educational Role during the Transition

Parents in this study reported the importance of obtaining knowledge about autism. All of the participants had little previous knowledge of autism, or were unaware of what it was when their child was diagnosed. Many stated that part of the challenge of learning to live with autism was a lack of understanding about the disability and the many ways it would impact their lives. In order to better understand and manage the disability, parents started learning and researching on their own, continuously educating their families and friends.

Parents said that the more time that passed after their child received the diagnosis the greater were their feelings of self-efficacy. Parents considered their knowledge

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instrumental to advocate for their child's rights and the capacity to be proactive during the transitions.

> I have my hands on, I don't read a lot of stuff that is scientific, but I've read a lot of accounts. ….There are numerous accounts. I watch DVDs, I watch movies, read magazines, you know, like, whatever is.. the only thing I don't read is scientific research (Family #2).

Parents said that for them as parents to a child with ASD, it was important not only to know the facts and information regarding their child's condition, but also to be educated on the provincial laws, resources, services, and processes within the school system. The resources that parents sought included the opinions of professionals within the community, as well as online sources and literature.

One of the families lived in a different province when they found out their child had autism. The mother spoke about her experience searching for resources:

> So, we got the diagnosis and it was a little piece of paper that the doctors' secretary had printed off about what autism is, you know, "good luck", pretty much. So there wasn't anything. And I think simply because of our attitude, we went looking at our own expense and our own time. We went looking for resources that were available at that time and just asking people that we knew. We eventually found out that there were some resources available (Family #6).

All parents said that it was easy to find out about the St.Amant ABA program in the community: families were either referred to the program, or found out about it on their own. Families reported that they were happy to obtain services from St.Amant as this is the only fully funded program in the province that provides intense behavioural intervention for children with ASD.

When talking about facilitators of the transition process, parents said that most of the time they were initiating the meetings with the ABA program and school representatives. One of the mothers talking about her and her husband's involvement in the transition process of their son:

We were really proactive about making appointments at the school, contacting them. (Husband) and the principal were emailing back and forth quite a bit, like, I think we were not afraid to be like, not annoying, but you know what I mean, on top of everything. I am already wondering about next year: is (child) gonna have the same EA? Like I wanna know now. I don't know if they can tell me now, you know, its like I wanna think about it because if that not gonna happen, and then I just need, like, to prepare him and prepare myself. It's like I can't imagine they would change, but you never know, right? (Family #3)

Summary

Parents felt anxiety before their child's transition to school. Primarily, they were worried if the school would have enough resources to meet their child's needs and to maintain their progress and development. Preparation and planning was identified as an important stage to having a successful transition. Four families were satisfied with their transition experience and reported it was due to the two strong teams they had from the ABA program and the school, and the partnerships they had established between them. Two families that experienced difficulties during the transition stated it was because they had new consultants from the ABA program who had not worked with their children before and the schools were not ready to collaborate and make adjustments to accommodate the needs of their children. Parents also shared that having a child with autism caused them to educate themselves on available resources in the community, learn and use ABA techniques in everyday life, advocate for their child.

3. Supports Received during the Transition Process

3.1. Formal Supports

A majority of the families participating in this study received their child's diagnosis from their paediatrician, and in most cases it was from a doctor from the Children's Clinic (Health Sciences Centre in Winnipeg). Families felt relieved to find out that there were services and resources in the community offered to families with children

with ASD. Three mothers shared that right after their child was diagnosed they had been

contacted and received a visit from a worker from Society for Manitobans with

Disabilities, as well as a family service worker from Children's disAbility Services. These

three families had their child enrolled in a program called "Let's get started".

> I do remember fairly quickly somebody came out and talked to us. It was
> somebody from the Autism Society who came out and met with us and then, (pause)
> I think it was out first initial person who connected with us, and then we got a
> family services worker which fairly quickly, I do remember, because I was thinking
> "Oh my goodness, there is all this support out here that I wasn't getting before he
> was diagnosed". Before he was diagnosed, I was just trying to work with him and
> trying to figure things out all on our own. And then quickly, we got him going right
> away on a program through Child Development hospital this place called "Let's get
> started" (Family #4).

One of the families participated in social programming offered through Health Sciences

Centre. A mother shared:

> At that time Health Sciences Centre was offering what they called, social
> programming, which is separate from what St.Amant did. But we didn't feel that
> was going to be, not necessarily inappropriate, but going to be enough" (Family #2).

All parents responded that once they started the ABA program with St.Amant it became

their primary support and source for information:

> St.Amant bends over backwards to accommodate parents, I can't thank (them)
> enough. We've been so pleased with what they have offered and what they
> accomplished with (son's name) because I would never be able to do that on my
> own (Family #2).

Three parents named ABA and school as the two main formal supports received during

the transition time. One of the parents commented:

> Again it would be ABA and the school. We met with the school, like, even in June,
> and probably even before that. Like, in March I went to the school to know where
> he was coming, and we sort of started the process there and I know by the end of
> June I had gone and met with them. So it was the school he went to as well as the
> ABA (Family #6).

All of the parents interviewed were satisfied with receiving constant support from the

respite care givers. One mother in particular, did not have her family around and felt well

supported by the respite professionals:

> We are all here by ourselves. So we left all of our family, all of our resources –
> everything is back home. So we (are) here by ourselves. So you know respite is
> awesome, because I don't have respite from anybody else (Family #5).

Two families mentioned that their child was receiving services from speech and

occupational therapists, in addition to ABA services:

> Well, when (son's name) was in preschool we also had supports through Society for
> Manitobans with Disabilities because that's were the speech services came through,
> and an OT (occupational therapist) (Family #2).

Only one parent participating in the study was a member of the "MFEAT" *(*Manitoba

Families for Effective Autism Treatment*)* parents support group run by the Society of the

Manitobans with Disabilities. This mother commented that it helped her to connect with

other families with children with ASD and share the information about autism and

resources in the community.

A mixed reaction towards the involvement of social workers in the families'

transition process was found in the descriptions provided by the parents. Three of the

interviewed families gave very positive feedback on the support the social service worker

provided their family before, and during, the transition to school. Parents shared that did

not see their service worker on regular basis but knew they could contact and get

assistance when needed. One of the parents discussed her interaction with the social

service worker in the following way:

> We have a family services worker. I don't if she is an actual social worker, but we
> have a lady who what's now called Children's disAbility Services… She would
> forward things to me if there is workshops, seminars, possibilities for training, let's
> say. She attends IEP meeting at the school, and its Individualized Education Plan,
> and every child with identified special needs, one sort or another, receives one -
> specific goals that are being worked on for that child. So, she attends those kind of
> meetings, she attended meeting at St Amant. I've done equipment loans through her,
> for example. You know, if we have more needs she might help with planning,

behaviour plan, you know whatever might be needed in the house, to keep the house running… She has been available for the vast majority of time, and she is very good, she is somebody I can always turn to (Family # 2).

Another mother talked about their service worker in the following manner:

My family services worker has been great. She is just, like, someone looking for (son's name) best interest, she is like, what's the word? A biased opinion. Right? She is not with the school division, she is not an ABA (laughing). She is unbiased person (Family # 4).

Two of the parents did not receive any support from a family service worker. They did not ask for assistance as everything they needed was provided by the St.Amant ABA program. The family service worker contacted them to check on the child's progress but was never involved in the transition process:

She (family service worker) didn't really contact us in the process of transition, or in the middle of the process… She actually never met (son's name) because I think she had a fairly large case load and because we just sort of sent out our paper work, and she probably never felt she needed to contact us. She hasn't come to any meetings that we had, so that's a little disappointing. I don't know..she just probably has too many kids… *Later in the interview the mother said:* I'm sure it comes to the fact that we just don't have much needs, but yes, if there is someone contacting you every once in a while checking and making sure if I have any questions that would be helpful (Family #3).

One of the mothers said that it would be very helpful to have a social service worker working with their family:

Well, I have never been offered a social worker. I never had a social worker on our team. In my case I think it would've helped. My husband does a lot of travelling as well, and I am left alone pretty much to deal with what goes on in the home. I think for my own sanity (laughing) you know somebody at least to talk to, would've been helpful. Just because - my sister isn't here, my mother isn't here, like, I don't have any of that - that would've been helpful, or just another set of eyes in the family. I have another child, my nine year old, who also is special needs. So I have two children who require a lot of attention. They both are on medication, and I work as well. It's just a lot of stress especially if your spouse is not around to help (Family #5).

Another mother reflected on the possible role of a social worker:

And if there is someone who knows the right school, provincial services would be

really helpful, especially if you are...who knows, maybe you are a single parent, you
are just trying to get by (Family #3).

3.2. Informal Supports

Four of the mothers participating in the study received support from their
extended family and friends.

As far as informal supports, I have a pretty good network: my extended family, I
have several siblings, but I have two that live out of a province and one lives out the
country. So they are not a support network in the same way…My dad is probably
my best form of support (laughing). My closest form of support. Shortly after the
diagnosis, before the respite support kicked in, he was here quite a bit looking after
who was left at home. Yeah, my dad's been quite a Godsend (Family #2).

Another mother sharing about support received from her friends said:

I've not had anyone in my life who hasn't been, you know, good support to me in
one way or another. You know, some people its just a phone call once a week, a
chat. And I have a few friends I am trying to see on a monthly basis, but no, I feel I
have a good support system (Family #3).

One of the families that moved to Manitoba from a different province said they do

not have any relatives or close friends here. Another family residing in Winnipeg said

they refused to admit to their family and friends that their son had autism, therefore they

never received any help or support from them.

Two families indicated their church communities as big sources of support. One of

the mothers spoke of this support in the following way:

Our church is very good. When we are at church they pretty much take care of him
(their son), so you know, that's awesome for us. At least we are able to hear the
service (Family # 5).

Summary

Overall, families were satisfied with the formal supports they received before and

after the transition. The ABA program was named as the most important support. Prior to

the involvement with the ABA program families received services from Children's

Special Services (Children's disAbility Services) and Society for Manitobans with

Disabilities. All of the families used respite services from Children's disAbility Services. Families shared about the contact they had with the service social worker involved, their role in the transition process and involvement in their lives overall. As for informal supports, parents named their families, friends and church communities as the most important support.

4. Factors that Facilitated Transition

Parents reported that having a child with autism put extra stress on a family when transitioning to school. Four of the interviewed families were satisfied with their transition experiences. These families stated the transitions went smooth for the family overall, and was successful for the child. One of the mothers shared her experience:

> You know what it was the best thing that could've happen for us. It was so hard staying home for three years of ABA, so that was really tough. I didn't know what to do with our free time (laughing). That was nice. It was good that he (son) was able to interact with other kids of his own age. And just be out, socialize and get to meet other people. But again, everything that had happened before hand knowing some of the people, helped a lot, I think (Family # 6).

Parents believed that having their child do the third year of the ABA program in the nursery school or kindergarten prepared their child to work in a structured setting and made them progress in their social interaction. They stated that having the same ABA consultants work with the child during the transition was key to a successful transition. The following responses illustrate this theme:

> We have managed to keep all the good tutors we had through St.Amant. We managed to hang on to them and do our school age hours, they babysat or respite. It was very important to us (Family # 4).

Another mother commented:

> I think that for us, well, first of all, we had very good luck with our tutors, our senior consultants. So we actually were, we were motivating parents, because the

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program really worked for us, so we were really sort of on top of what was going on. So, the transition phase was fine, but I think it mostly was because we were motivated and the people we were working with were excellent. If you had a poor trained consultant or you didn't have a good relationship with your senior tutor it would be like, "What do I do now?" (Family #3)

Some parents were in control of the situation and were proactive when it came to making decisions and arranging appointments with the professionals involved in the transition. Parents believed that the readiness of the school staff to work with the child with ASD and willingness to meet the needs of the child and family was a facilitating factor during the transition. One of the mothers shared that the most important factor for her while choosing a school for her son, was school's ability to work as a team. She said:

> Because to me it takes a village to raise children with autism and you have to work together, so that's important to me. I specifically chose that school because I felt they were a team working (Family #4).

After visiting the first school, to which her son was assigned to go, she was not given a positive impression from the resource teacher. After consulting with other parents, this mother went to a different school that was not located in their neighbourhood. She had heard positive feedback about it from other parents of children with ASD who were completing preschool ABA. This mother commented:

> Well I really believe in team work. Building a team work and having to work together. Like I have gone to school and some parents that I talked to they are not allowed communication back and forth… that kind of things and they are pretty secretive of what is going on in the school. I couldn't do that (Family #4).

She continued later:

> The fact that I got to go to the second school did give me a sense of relief so my anxiety wasn't as strong, because I had heard different things about this school in the community ….and about working with the kids with the disabilities. And in fact when I went for interview the resource teacher is like, "Well, who is your consultant?" I told them and they were like, "Oh, we worked with that consultant already in the school". So they were so familiar with her…That relationship that was already built was hugely helpful in the transition (Family #4).

Having an experienced ABA consultant and supporting school staff was a significant factor in a successful transition to school and this response was reiterated by another parent who said:

> I thought it would've been a lot harder, but my two teams: my ABA team and school team were fabulous and I think that played a big role and things being okay…Our ABA consultant is basically the one who runs everything, other than that I don't really have anything else to do with St.Amant. Everything is done through my ABA consultant. And she is fabulous. It was fine (Family #5).

Parents shared that a relationship with the school, and meeting with the child's EA was very important. It gave them a sense of relief to know who their child was going to work with. As voiced by one parent:

> We already knew actually the resource teacher at our sons school, so that was huge for us. He already knew him, we knew him. And he would call during the summer. They didn't know who EA was going to be, and then they finally found out. We got meet him a week before school started. We went to look up at the classroom, he already had his desk and his chair. That was great, but I know it doesn't happen at the norm. So we were just very fortunate, you know. At least we knew somebody at the school. The principal, you know, turned over backwards...so we've been very, very fortunate to be involved with such school, but yeah, this is not the norm (Family #5).

Two families who experienced difficulties going through the transition process identified two main reasons: the inability of the school to accommodate the needs of their child, and a change in the ABA consultant. One parent explained it this way:

> We didn't have our tutors with us. The whole team had changed, and our new senior consultant had never worked with (son's name) before… Teachers at school weren't understanding and it was very stressful for us to work with them (Family #1).

Three out of six parents in this study did not have any information on who their child's EA was going to be and they did not have any contact with them until school started. One of the parents commented on this issue:

> The only barrier that I would say we experienced was at the school board level and we went through this again this past summer. It is not knowing who the EA was going to be, and they throwing you EA with your child on a first day of school. At

our school we know who the new teacher is going to be in June, so at least the teacher gets to send a little note home and we make an appointment to pop by her classroom by the end of the school year, so its not a foreign thing but at the school level- if they don't know how much funding they are going to get, or how many EAs are there allowed or be hired – then it just drags on and on and on (Family #6).

Summary

Families believed that their transitions were successful because proper support was received from both the ABA program and the school teams. The willingness of the schools to work together with the ABA professionals and accommodate the children's need was very beneficial during the transitions. Families whose children did their last year of ABA programming in the nursery school setting had smoother transitions to school. Parents who were actively involved and advocated for their child's needs were also indicated as important factors in facilitating a successful transition.

Summary of the Findings from the Interviews

Information gained from semi-structured interviews with the families that went through the transition provided an initial understanding of the categories identified from the data. Results from open coding allowed for categories to emerge, describing their properties. Using the results of axial coding, main categories and their subcategories appeared, showing the interrelationship between them. Selective coding defined the central phenomenon of this study: *Transition experience of the families with children with ASD from preschool to school after EIBI*. The central category impacted and affected all four main categories that emerged in this process: participation in the ABA program; the process of transitioning from the ABA program to school; supports received during the transition process; and factors that facilitated transition.

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Parents described their feelings and emotions after their child was diagnosed with autism, and talked about their experiences of looking for the support in the community. All the families talked about the development of their child after participating in the ABA program. Parents described themselves as the key facilitators during the transition process, even the families who received strong support from both the ABA program and school professionals. After families received their child's diagnosis they educated themselves regulary, used ABA techniques, initiated meetings with the professionals, networked with other families, and advocated for their children.

Results from Metasynthesis: Procedures Used in Selecting Studies

As noted before metasynthesis was chosen as additional method for data collection to reflect on the processes and perspectives of a body of research to determine what is known about the process of the transition from preschool to school within an EIBI program. The process of metasynthesis begun after the parameters for the literature search were set. Initially, a broad search strategy was used to retrieve articles from Health, Social and Psychology journals and online databases. Keywords used in the search included a combination of topic, and method terms as outlined below:

- *Topic:* children, autism spectrum disorder (autism or ASD), ABA (Applied Behaviour Analysis), parents (perceptions/perspectives), families experiences, transition to school, transition process, social support.
- *Method:* qualitative study/research, case study, constant comparison analysis, grounded theory, descriptive study, focus group, interviews, phenomenology, narrative analysis.

In addition, specific searches were conducted of the following journals:

Qualitative Health Research; Child: Care, Health and Development; Council for Exceptional Children, Journal of Intellectual Disability Research; Exceptional Children; Health and Social Care in Canada; Journal for Specialists in Pediatric Nursing; Journal of Early Intervention, Early Child Development and Care; Autism; Journal of Autism Development Disorder; Journal of Developmental and Physical Disabilities, and *Journal of Family Social Work.* The electronic databases searched included: *Academic Search Elite, PsychInfo, Social Science Citation Index, Social Work Abstract;* and *Digital Dissertations.*

Criteria for Inclusion

The initial search returned about 42 studies which included five unpublished works (two Doctoral dissertations and three Master's theses), but after a first screening of the titles and the abstracts, 26 articles were identified as false positive and excluded due to irrelevant citations. While identifying the qualitative studies within the subset of the 14 articles and two Master's thesis, it became obvious that the abstract and keywords varied considerably in their content, with some failing to state the research method used. After obtaining the articles' full text versions, they were manually screened and only 9 articles and 2 unpublished works matched the criteria for inclusion and were used for further examination. Based on the guidelines provided by Sandelowski and Barroso (2007) for conducting metasythesis studies, the criteria for inclusion were refined and the 11 studies were sorted according to four main criteria as identified in Table 2. Specifying and applying the inclusion/exclusion criteria is considered as being central importance since the validity of a synthesis depends on the quality the primary studies on which it is based. Following these predetermined criteria, six studies were excluded (see Table 2) and

another five met the inclusion criteria and were ultimately incorporated in the

metasynthesis.

Table 2. Inclusion/Exclusion Criteria

Criteria	Rationale	Studies Excluded and Reason
1. Did the study collect and report qualitative data?	This criterion was used to narrow the metasynthesis to articles relying on qualitative studies. This included interviews, observations, and focus groups that provided written or transcribed descriptions, quotations or responses. Studies that combined qualitative and quantitative data (such as questionnaires with open-ended questions) were included if findings based on qualitative data could be separated and examined independently from the quantitative data. Studies primary relying on quantitative data were excluded.	Mixed method used but did not provide enough descriptive data to be used for metasynthesis (Levy, 2006).
2. Did the study focus on children with autism of preschool and school age who completed ABA program?	This criterion was used to include only studies focused on children with ASD who completed ABA program as they receive support from the program and experience specific challenges during the transition due to their disability.	This study was excluded as focused on the transition of children with intellectual disabilities in general and not necessarily those completing ABA program (Kemp, 2003).
3. Did the study illuminate the perspectives or/and families' experiences during the transition period?	This included perspectives of the parents/service providers/teachers on factors and/or barriers to successful transition of the families with children with ASD.	These studies were excluded as it did not contain information about the transition experience (Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; Siklos & Kerns, 2006; Bromley, Hare, Davison, & Emerson, 2004)

Criteria	Rationale	Studies Excluded and Reason
4. Did the authors study an aspect of the social supports families need during the transition?	This criterion was used to explore social supports that were available and/or needed to the families going through the transition with their children with ASD	This study did not contain perspective on social support and transition period (Spann, Kohler, & Soenksen, 2003)

The time limit of 13 years (2000-2013) was deliberately chosen to get recent information and compare it with general issues explored in current study. No age restrictions or location (country) where study was conducted were used in the identification of eligible studies. A deliberate decision was made to include studies that used various qualitative methodologies, as well as mixed methods, because there was insufficient number of studies located using only one specific method of qualitative research. Five studies were included in the final synthesis. Of these, one was a Master's thesis and four were articles published in journals.

Once the primary research reports were selected a table was constructed that listed the significant aspects of studies (see Table 3). This table was created by reading each primary study to identify the methods, use of theory, and findings that contributed to metasynthesis.

Metasynthesis Component: Analysis

At the beginning of the analysis all five articles were read individually. Themes, subthemes and concepts from each author's interpretations were identified and these are summarized below.

Study 1: Stoner, J.B., Angell, M.E., House, J.J., & Jones Bock, S., (2007). Transitions: Perspectives from parents of young children with autism spectrum disorder (ASD).

Table 3. Key features of primary research reports

STUDY	SAMPLING METHOD	SAMPLE CHARACTER.	DATA COLLECTION	DATA ANALYSIS	BRIEF SUMMARY
Grindle, C.F., Kovshoff, H., Hastings, R. P., Remington, B. (2009)	Families were recruited through a university program and through advertisement posted on several ABA websites	53 parents (32 mothers and 21 fathers) of children with autism who had received 2 years of ABA	Semi-structured interviews	Content analysis; Also used a matched-groups design to examine data from the 21 couples who participated (each husband-wife pair)	Data provides insight into the perceptions of parents who use home-based intensive behavioural intervention (EIBI), including its general effect on family life and support systems, their experiences with practical program related issues, and the personal and emotional impact of running the program at home. No information about transition experience was provided.
Hanson, M.J., Beckman, P.J., Horn, E., Marquart, J, Sandall, S.R., Greig, D., et.al. (2000).	Participant were recruited through service providers and service coordinators in local communities	A sample of 22 families was followed as they entered, participated in, and exited the transition process	Structured interviews, participant observation in transition meetings, and document analysis	Qualitative cross-site approach	The purpose of the study was to provide a qualitative description of this transition process and the families' choices and participation in decision making when their children were entering preschool services
Stoner, J.B., Angell, M.E., House, J.J., & Jones Bock, S., (2007).	Recruitment through a parent support group	Four cases each composed of a married couple, resulted in8 individual participants for this study	Multiple interviews, observations, and documentation	Cross-case analysis method	The purpose of the study was to investigate the perspectives and concerns of parents of children with ASD related to transitions

STUDY	SAMPLING METHOD	SAMPLE CHARACTER.	DATA COLLECTION	DATA ANALYSIS	BRIEF SUMMARY
Fontil, L. (2011).	Participants were recruited through private program that provides services for children (aged 16 mos. to seven years old) and integration preschool program for children between 3.5- 6 years old	A purposeful sample of ten children, their parents and their educators/teachers	Semi-structural interviews (3 different times), the Impact on Family Scale and Measure of processes of Care	Quantitative and qualitative data collection	This study explored the experiences of families with children with ASD making the transition to elementary school. Nine of the children were making the transition from full-time specialized care to full time elementary program, with one exception
Sperry, L.A., Whaley, K.T., Shaw, E., Brame, K. (1999)	The participants in the focus group were the result of the self-selection process. Focus groups were conducted as part of the two national forums on issues in the field of early intervention and preschool services organized by NECTAS (National Early Childhood Technical Assistance System) with the approval of US Department of Education, Office of Special Education Program (OSEP).	30 parents (28 women and 2 men) and 22 service providers (1 male and 21 female participants)	Focus groups with parents and service providers	Content analysis, qualitative study	This study explored the perspectives of service providers and parents of children with ASD regarding service systems. A comparison of parent and provider focus groups transcripts yielded points of convergence in the areas of collaboration, family support, financial issues, equity, early identification, advocacy, training and inclusion.

➢ Child-centered paradigm- parents put their children at the centre of all transition concerns. This paradigm encompasses all the concerns, fears, hopes and beliefs of the parents. Knowledge about their children to be used in transition strategies.

➢ Communication- the vital link to successful transitions**:**

  ▪ Strong cooperation and consistent cooperation between home and school

  ▪ *Child Profile* form contains information about the child; completed each year by the teachers and parents and given to the subsequent teacher. Child Profile- a communication facilitator and a planning tool for facilitating vertical transitions

➢ Preparation stage: Use of *identify-observe-explore* strategy in horizontal and vertical transitions:

  ▪ Identify-observe-explore strategy is three-step process: a) initial identification of potential difficult transitions; b) allowing the child to observe the transition setting at a time of low stress; c) allowing the child to explore the setting before the transition actually occurred.

  ▪ This strategy can be used on daily basis for frequent situational changes (horizontal transitions) or each year at the beginning of classes or before entering a new school environment (vertical transitions);

  ▪ Benefits to the child: recognizing child's anxiety and attempting to reduce it by giving the child an opportunity to get to used to the new environment/situation. Benefits to the parents and school: an opportunity to establish a connection before the actual transition, work on a strategy

together using both their expertises and experiences, as well initiate the vital communication chain.

➢ Barriers to successful transition:

- Lack of communication between the children and educational professionals;
- Lack of recognition of transitional strategies; and
- Lack of preparation on the part of the education professionals.

Study 2: Fontil, L. (2011). Parents' and teachers' perceptions of the transitions to school experiences of children with autism spectrum disorder.

➢ Factors contributing to successful transition:

- Establishing of caring partnerships between home and teachers;
- Continued collaboration and open communication (bidirectional) between professionals and families;
- Support and resources to meet the needs of the child and the needs of the family as a unit;
- Services provided by a psycho-educator or a social worker;

➢ Barriers/challenges to effective partnership and successful transition:

- Tenuous home-school relationship: parents needed to strike balance to advocate for their children's needs and be understanding of the teachers role and expectations. Whereas teachers needed to demonstrate understanding of family values and beliefs in order to establish meaningful partnership;
- Lack of teachers knowledge and experience;
- Lack of physical classroom resources;

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- Administration issues;

- Divergent belief systems;

- Children's needs not met by the education system;

➢ Children's experiences:

- Child's development during transition

➢ Family struggles: guilt and judgment from their communities, negative experiences with the school system;

➢ Support systems: familial, educational, community support.

Study 3: Grindle, C.F., Kovshoff, H., Hastings, R. P., Remington, B. (2009). Parents' experiences of Home-based Applied Behavioural Analysis programs for young children with autism.

➢ Benefits of being enrolled in the EIBI (early intensive behavioural intervention) program:

- For children: improved language and communication skills; improved social skills; better play skills; became more used to being with people;

- For the parents: additional support at home; more free time when child in therapy; social socialization opportunities (support and advice from other families); use of effective behaviour management techniques used in ABA;

- For the siblings: involvement in ABA therapy sessions and opportunity to learn more about autism and ABA techniques;

➢ Practical difficulties for the families for being involved in EIBI:

- Difficulties with the Education Authority: families had problems obtaining funding for EIBI program; authorities held outdated and incorrect views about EIBI;

- Difficulties with the therapists: recruitment of new therapists; unreliability; high therapists turnover; problems with therapists being present in the home; administrative difficulties;

- Difficulties for the siblings: received less attention that the child with autism; had to stay out of the way when child with autism was in therapy; fewer holidays/trips;

- Difficulties for the child with autism: child missed socialization opportunities with peers;

➢ Impact of EIBI on family relationships: parent-child relationship improved; sibling-child relationship improved; parent-sibling relationship improved; parent-sibling relationship deteriorated; parents relationship deteriorated;

➢ Emotional impact of EIBI: expectations for the child; level of stress and motivation throughout the program;

➢ Overall evaluation of EIBI.

Study 4: Hanson, M.J., Beckman, P.J., Horn, E., Marquart, J, Sandall, S.R., Greig, D., et.al. (2000). Entering preschool: Family and professional experiences in this transition process.

➢ Transition is an event (or formality) not a process;

➢ Transition as shift from one family-centered services (early intervention) to child and school-centered services;

- Importance of information exchange and communication between families and professionals;
- Availability of preschool service options in the school district after finishing early intervention program;
- Child characteristics and readiness for transition;
- Facilitators in transition process:
  - Viewing transition as a process and starting preparation early;
  - Information exchange between parents and professionals;
  - Participation of a key person or a guide (teacher, service coordinator);
  - Parent-to-parent buddy system: parents who went through transition act as mentors for other families;
  - Continuity of settings or services was helpful in easing the process;
  - "Bring the child to the process" helps parents and professions to not get lost in the logistics and keep in mind who is the program being developed for;

Study 5: Sperry, L.A., Whaley, K.T., Shaw, E., Brame, K. (1999). Services for young children with autism spectrum disorder: Voices of parents and providers.
- Areas of convergence: parents and service providers:
  - Family support: family-centered services that meet the eclectic needs of families and children with ASD;
  - Early identification of children with ASD and utilization of required services;

- Financial resources for the families to provide services for children with ASD;

- Constant training to elucidate the syndrome of autism and to inform best practices;

- Collaboration: partnership between parents and professionals and among professionals from different agencies;

- Advocacy: the ability to foster a sense of empowerment so parents and providers can advocate effectively for children with ASD;

- Inclusion: represents not only the physical presence of the child with autism in an inclusive setting, but also the quality of those experiences within those settings;

- Equity: for parents it meant to be able to participate in the decisions that impacted their children and themselves; and providers viewed equity as families having equal opportunities and access to services.

➢ Areas of Divergence: Parents

- Access: parents viewed access as the mechanisms through which to secure services, and the obstacles encountered obtaining those services

- Home-based programming: interventions programs pursued by families

- Law: statements that reflect the policies and educational laws regarding the rights of children with special needs

➢ Areas of Divergence: Providers

- Quality programs/ Best practices: necessity of setting quality programming standards and delineating what constitutes best practices

- Transitions: changes in service delivery systems that occur as the child moves from one system to another

After all the themes, subthemes and main concepts from the chosen studies were documented then their comparison across the studies began. All five studies focused on different aspects of the experiences of families and their children transitioning from intensive behavioural programs into school. Some of the parents' experiences were described in one study only and could not be compared with others. Therefore, Grindle, et al. (2009) describes parents' experiences of home-based ABA programs for children with ASD focusing on such topics as benefits and difficulties of being enrolled in the EIBI program, and its impact on a child, family members and their relationships. Other studies chosen for this metasynthesis did not focus on families' experiences with ABA program specifically but covered other aspects of the transition process. Such themes as factors and/or barriers contributing to successful transitions or the concept of partnership between families and professionals were compared across four out of five studies and summarized. Finally, these experiences and concepts were synthesized, clustered into a new structure of meanings, and given a name, that way, new themes and their subthemes were created. The next step described each theme and their connection with other themes and subthemes giving a new understanding to the topic.

Metasynthesis Findings

Metasynthesis findings from five published studies are presented through the following themes: transition as a process; the impact of the ABA program on family life and support systems; preparation to the transition; factors contributing to successful transition; and barriers to successful transition.

Transition as a Process: Using the Child-Oriented Paradigm

Families go through various transitions throughout their children's lives. As stated by one of the parents: "The bigger transition, the bigger concern" (Stoner, et al., 2007, p.31). The whole family has to adjust to a transition whether it the one that occurs daily or on frequent basis.

The transition from early intervention services to school have been defined as changes from one service to another (Hanson, et al., 2000; Stoner, et al., 2007). For families this transition often meant a shift from family focused services to child and school-centered services (Hanson, et al., 2000). Families and professionals who participated in the Hanson study viewed transition as a formality or a discrete event or task to be completed, rather than a mutual process for the child and the family. Before the transitions started, the families were informed of the transition steps, meetings, and the documents required. It was also found that families viewed this transition as a marker event because they knew that major decisions would be made about their children's placements and the nature of children's services. Families, however, expressed that even though they knew the transition was occurring they lacked specific knowledge of the tasks or components of the process. The uncertainty of transition requirements left many parents worried: "I'm not sure exactly what is gonna happen. I feel a little nervous. You know, it's a big change…That's kind of scary because I have never done it before. That is very stressful."(Hanson, et al., 2000, p.285). Professionals also view transitions as a formality stating that meeting legal requirements required a lot of paperwork that did not leave time for planning, due to large caseloads.

Many families expressed anxiety moving from one system to another as this meant a shift to new rules, regulations, types of services and different values on service

delivery (Hanson et al., 2000). One parent described the transition as shifting from "a person to a system": "They [early interventionists] don't question your motives like the school system would. They'll tell you things that you don't even know.. The school system won't do that… You have to find out on your own". (Hanson et al., 2000, p.285).

Parents' perspectives regarding transitions were complex and were usually viewed through the needs and characteristics of their children, which means parents put their children at the centre of all the transition concerns (Stoner et al., 2007). A child-centered paradigm includes the children's characteristics, their strengths, weaknesses, as well as the parents' beliefs, concerns and hopes. Parents said they want educational professionals to understand their children, gain knowledge of their child's issues and use that knowledge to implement transition strategies (Stoner et al., 2007).

ABA: The Impact of the ABA Program on Family Life and Support Systems

Research has documented that home-based early intensive behavioural interventions (EIBI) founded on the principles of applied behaviour analysis (ABA) have many benefits and dramatic improvements for young children with autism (Grindle, 2009). The vast majority of parents reported their child's progress in language and communication skills, as well as social and play skills. Parents viewed EIBI as additional support in the home as therapists helped parents with children's behaviour problems, feeding, etc.; having a therapist at home also gave parents time to complete work around the house or participate in recreation. Parents also learned how to use effective behaviour management techniques through observing therapists working with their children. One parent said: "You being there [at home], you see things, you pick things up and you know the kinds of things that the team are working on. And they can provide input, "have you

thought about it this way?" Maybe this will work." (Grindle, 2009, p.46). Involvement in the program let parents acquire a much wider social network where they could receive positive support or advice.

Home-based early intensive programs have had a positive impact on family relationships. Parents shared that their relationship with the child, as well as sibling-child relationship improved (Grindle, 2009). The most common reason named was improved communication and social skills of the child. The majority of the parents reported that their relationships with the sibling had improved as they were able to spend more time together when the child was in a therapy, however some noted that they had fewer opportunities to spend quality time with the sibling. Almost a third of the parents interviewed reported that their relationship with a partner deteriorated as they did not spend enough time together, or wished their partner had been more involved in the program.

One third of the interviewed parents reported that their stress level declined over the course of the program. Positive progress reduced parents' feelings of stress unless there were problems with the program (Grindle, 2009). One parent commented: "I am stressed now that it is coming to the end and he is going to school in September, but also when he wasn't getting the hours he should have been I was very stressed about it, constantly had to chase people up…it has been very stressful" (Grindle, 2009, p. 51).

Preparation Stage

Parents shared that before going into transition they used a three-step preparation process which involved: a) initial identification of potential difficult transitions; b) allowing the child to observe the transition setting at a time of low stress, and c) allowing

the child to explore the setting before the transition actually occurred (Stoner et al., 2007).

Parents perceived the identify-observe-explore strategy as useful during horizontal and vertical transitions. Parents recognized that their children's anxiety was a significant factor during the transitions. Using the identify-observe-explore strategy professionals and families focused on getting to know the child's needs and abilities, recognizing the child's anxiety and attempting to reduce that anxiety. Implying this strategy required effective and established communication between home and school or other professionals involved in the transition. Parents also expressed that this strategy had the additional benefit of building the child's trust: "Because you know any new situation for a kid who is overwhelmed and who doesn't communicate real well it has to be- well- his anxiety level has to be very, very high… And once you build that trust, then well this part is okay, and this part is okay, then okay, I am going to be able to get through this, and it is similar to the teaching process" (Stoner et al., 2007, p.33).

Most commonly, the identify-observe-explore strategy was used in vertical transitions before starting a new school year and it was usually initiated by the parents or teachers: "You know that was one of our biggest concerns, this year, because it was going to be a new school, a new aide, a new principal, a new building, a new everything. And actually he did very well. The new teacher actually came to see Ned a couple of times or we went over there. We did both. And then took him over there. He got to go and see his building" (Stoner et al., 2007, p.34). Allowing the child to explore the new classroom was beneficial to everyone: the child got used to a new physical environment, and this also helped the parents and teachers to establish a connection before the actual transition.

Factors Contributing to Successful Transition

Collaboration between Families and Professionals

Establishing home and school relationships that are characterized by empathy, caring and understanding were described as contributing factors to a successful transition (Fontil, 2011). Information exchange and caring relationships with the families, prior to and after the transition were named as important aspect of the home-school dynamic (Fontil, 2011).

Parents expressed a need for a bi-directional relationship with professionals (Sperry, 1999). One study showed that partnership between parents and professionals had a positive impact on their child's outcome: "We all felt that we were working together and that he [child] was benefiting" (Sperry, 1999, p.25). Most parents expressed a desire to participate and be heard, they deemed the need for information exchange to be crucial. Parents shared that usually decisions surrounding the transitions were driven and dominated by the "system", and over half of the interviewed felt they had no choice in terms of their children's preschool placements and indicated the professionals were the primary decision makers in the transition (Hanson et al., 2000).

The most frequent form of communication between home and school described in Fontil study (2011) was the use of a communication book which teachers used to inform parents of their children's progress. The concept of comprehensive communication planning was discussed in the Stoner et al. (2007) study. *Child Profile* is a form that was used by the families and professionals to share the information about the child; his/her likes and dislikes, strengths and weaknesses, and other additional information relevant to the child's development. Child Profile facilitated communication among parents and educational professionals, but also laid the groundwork for trust between parents and

teachers by acknowledging parent input, recognizing the teacher's experience with the child, and offering both parties the opportunity to engage in meaningful communication concerning transition issues (Stoner et al., 2007).

Social supports and resources

Family support can be provided in a variety of forms. In these studies, family support focused on assisting the family in meeting the needs of the child, enhancing the family's knowledge about the disability, but also supporting a family as a whole. As noted by one of the service providers regarding family support: "There are two kinds of categories of issues here. One is focus on individual child…And second is the business of relieving the stress. I think one of the things that can be taken from the data is good outcome of relieving family stress" (Sperry, 1999, p.26). Parents shared that the team model employed in early intervention and the support they received was central to their experiences: "The communication that I had with the teacher and her affiliates- the eye lady, the speech lady- they were there. They were available. They made the time… And I always felt reassured always through the whole process" (Hanson et al., 2000, p. 286).

Another important factor contributing to successful transition was the participation of a key person or a guide. It could be a teacher from a program where the child is participating, a service coordinator, an acquaintance or another parent. One of the systems described in a study talked about parent-to-parent buddy system: "...having a buddy system so that when we have parents who've just transitioned into preschool and have gotten adjusted that they can serve as mentors to parents that are coming in. and even if possible to be a mentor to a family" (Hanson et al., 2000, p.289). The continuity of settings or services is helpful in a transition process. Support from the early

intervention teachers was instrumental in facilitating the transitions. They talked to the families early on about the transitions, informed them about the options available in the community, and helped families to understand the legal and school system (Hanson et al., 2000).

Parents found respite and parent-to-parent support helpful (Sperry, 1999). They also expressed the need for providers to recognize the potential of their children rather than approaching services from a deficit-based perspective.

Barriers to successful transition

Parents identified a lack of recognition of transition strategies and lack of preparation on the part of the education professionals involved in the transition (Stoner, 2007). Parents expressed that viewing transition as a process and starting preparation to it early would be helpful in facilitating the transition process. Parents wanted educational professionals to have the flexibility to give their children time to make transitions, and expertise to implement strategies that aid transitions. Other challenges shared by the parents were a lack of communication between the children and educational professionals, as well as lack of teachers' knowledge about the child's disability. One of the parents shared that the school where her child transitioned to had no experience working with the children with special needs: "They've had only four [children] at the school. I get the impression they don't know a lot about this" (Fontil, 2011, p.69). Another barrier named by the parents was the administration issues leading to the lack of physical support in the classroom that made the transition experience more challenging for the child.

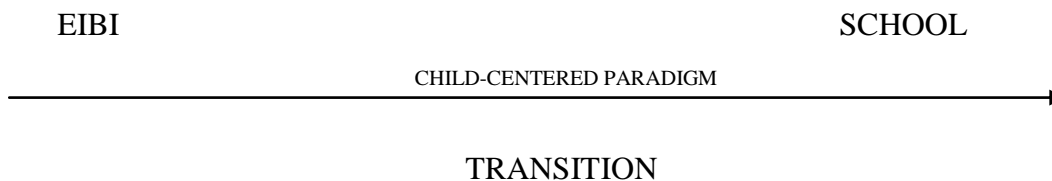Divergent belief systems between home and school was viewed as one of the

major barriers to successful transitions: "… I think its not just that school, I just think society, a lot of society hasn't realized the value of teaching some of these kids… there are people that believe in them but I think some of them its really that is what they expect from this clientele you know what I mean" (Fontil, 2011, p.70).

Partnerships established between the preschool and home appear to be more positive than those established during elementary school (Fontil, 2011). Such barriers as lack of communication between parents and professionals, administration problems, lack of teachers knowledge about the disability, divergent belief systems about children's competence contribute to challenging transitioning experiences for some children and families.

Conclusion to Metasynthesis Component

Parents' perspectives and experiences of transitions with their children from ABA program to school are complex and usually filtered through child-centered paradigm (see Figure 1).

Figure 1. View of the Transition Process

EIBI   SCHOOL

                          CHILD-CENTERED PARADIGM
$\longrightarrow$

TRANSITION

This metasynthesis study showed that transition can be viewed not as an event rather a seamless process of moving from one service to another. There is a number of factors influencing the nature of the transition experiences: impact of enrolment in the

Early Intensive Behavioural Intervention program (ABA); the nature of the preparation stage; communication and partnership between families and professionals; parents` involvement in the transition process; and availability of social supports. Empathetic, caring relationships, open dialogue, and available resources characterized effective partnerships and successful transition (Fontil, 2011). When communication between parents and professionals was consistent it brought strong cooperation between home and school and led to successful transition. The identify-observe-explore strategy was effective during the transitions from ABA to school as it is child-centered and based on the understanding of the child's individual needs. The process of preparing for transitions involves developing an understanding of the child's reactions to transitions in general, and then applying that knowledge to transition situations. The transition to school is a difficult adjustment for children with autism, but it can also be a challenging experience for their families (Fontil, 2011). The most common barriers named were a lack of preparation for the transition, lack of communication between parents and professionals, lack of teachers experience and knowledge about the child, divergent belief systems, and administration problems. Support systems for these families can help buffer some of these negative and challenging experiences. A variety of resources such as, such as familial, educational, and community support, can help families go through difficulties.
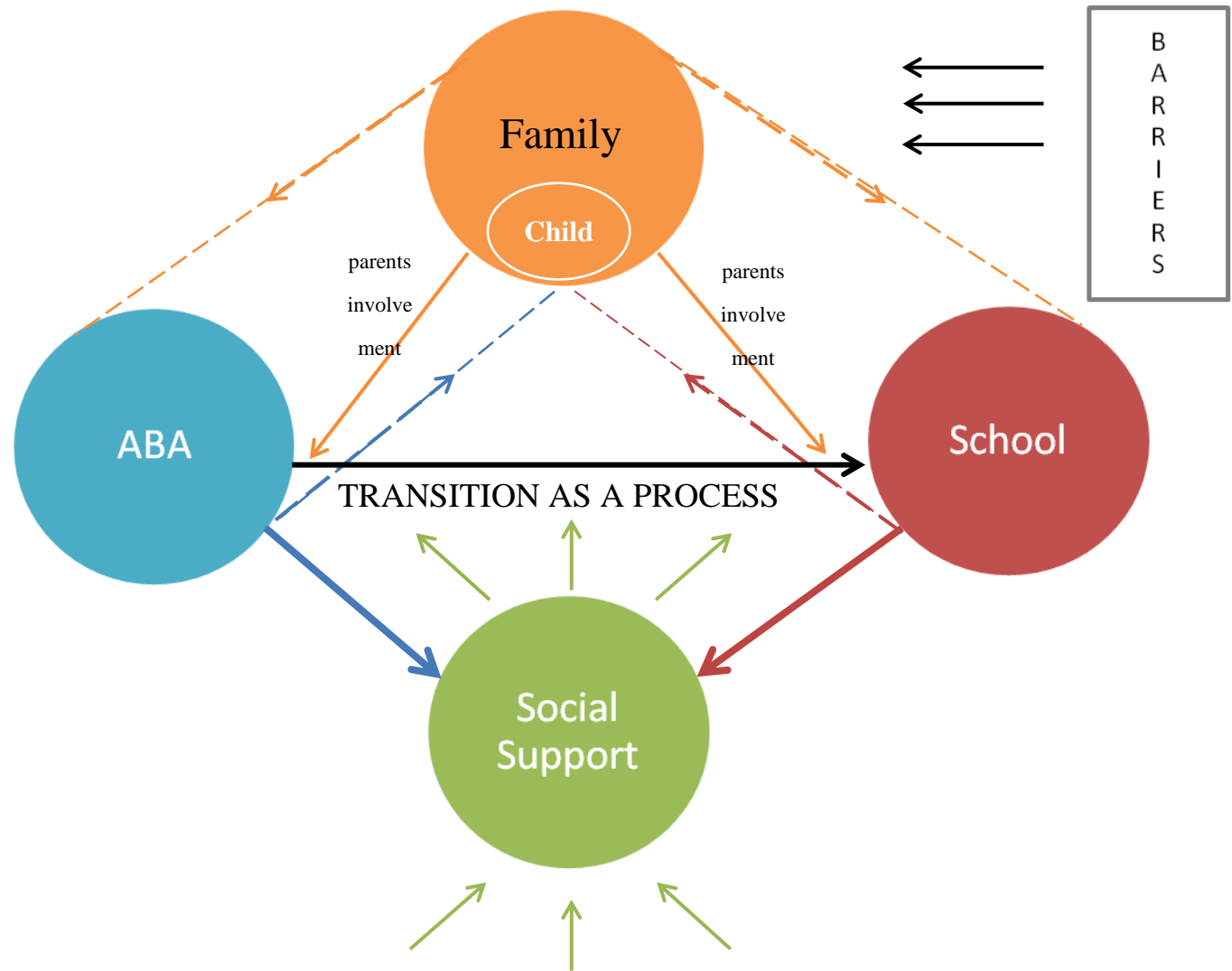
CHAPTER V

DISCUSSION

Introduction

The purpose of this study was to explore the experiences of families with children with ASD (autism spectrum disorder) transitioning from preschool to school within the EIBI program. This study attempted to gain an understanding of parents' perspectives on their transition experiences, social supports and factors facilitating successful transitions. Additionally, the role of the professionals facilitating the transition process was researched.

The results from the interviews conducted for this study were strengthened by the metasynthesis component in order to compare the research findings and obtain a broader perspective on the families' experiences. The discussion of the findings from both studies and their themes are presented in this chapter in relation to supporting research. A discussion of the limitations of the present study concludes the chapter.

Transition as a Process

Findings from the interviews with the parents whose children with ASD transitioned from preschool into school within the ABA program at St.Amant showed that this transition should be studied as a process of moving from one system to another. Figure 2 shows that a broad range of variables should be taken into consideration while investigating the transition process. Based on a grounded theory approach the *Families Transition Experiences* emerged as a central phenomenon or a core category of the study. Figure 2 depicts the transition process from the parents' perspective based on the construct of their own experiences.

Figure 2. Transition from ABA Program to School.

Findings of the metasynthesis shows that transitions from early intervention programs to schools are viewed as changes from one service to another (Hanson et al., 2000; Stoner et al., 2007) or as a shift from family-focused services to child and school-centered services (Hanson et al., 2000). There was no policy or strategic planning used by the families from Manitoba, and they viewed the transition as a change in services from focusing on the child's development to services focused on the child's academic growth. Families participating in Hanson's et al. study (2000) viewed transition as a formality or a marker event that required major decisions for a child's services. Parents participating in Hanson et al. study (2000) stated that decisions surrounding the transition were driven and dominated by "the system", and professionals were primary decision makers in the transition process. All families interviewed for this study had emotional challenges and concerns about the uncertainty of the transition process. The same experiences were reported in the studies used for metasynthesis. Parents from Manitoba were mostly concerned about their child's adaptation to the school environment, possible delays in development, or lack of support and resources from the school. In Hanson's et al. study (2000) parents expressed anxiety about the transition as for them it also meant a shift to new rules, regulations, and different methods of service delivery.

The transition from the EIBI program to the school system is complicated by the differences between these two programs. ABA utilizes one-on-one intervention, special staff training and knowledge, as well as the structure of the programming is focused on specific child needs. ABA therapists work with children individually and are trained in behavioural interventions, whereas teachers in integrated classes do not always receive special education or training specific to each child, and have to work with at least twenty other students in the classroom. Also, the ABA program utilizes high levels of

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reinforcement and praise whereas schools often use low levels of reinforcement.

In a recommendation for practice, Hanson et al. (2000) suggest it is important to conceptualize transition process as containing two components: a) an emotional component that accounts for the differences among families in terms of child and family backgrounds, experiences, needs, and responses to service delivery; and b) a procedural or task component that addresses regulations, paperwork, meetings, information exchange etc. Findings from this study suggest that the match between family preferences, child needs and education services enhance parent involvement in the transition process and influence in the decision making process.

Factors Facilitating the Transition Process

Research has emphasized that transition planning is critical for families with children with ASD (Levy & Perry, 2008; Stoner & House, 2007). Viewing transitions as a process and starting the preparation early was identified as a facilitating factor in the transition process (Hanson, 2000). Parents interviewed for this study also believed that planning and early preparation are essential for smooth transition. In Manitoba parents are required to enrol their children in public schools a minimum of five months prior to the start of the school year. Parents interviewed for this study started looking for a school for their child six months to a year before school started. It is only after a child is registered that the school board can begin preparation for the transition. However, all the parents stated that they themselves initiated preparation work or meetings with the principal or resource teacher. When asked about the relationship built with ABA and school professionals, families described their relationship with ABA staff as very supportive and accommodating, whereas with the school parents did not always feel supported. Three of

the interviewed families did not feel the school was supportive or willing to meet their child's needs. One of those families registered their child with another school where they felt support and understanding from the school staff. A mother commented that a major reason this school was so supportive was due to having worked with children from the ABA program and a partnership relationship was already established between the school and ABA teams. When asked for suggestions for improvements all the families stated it would be helpful to meet with the Education Assistant (EA) that is going to work with their child prior to the start of school. Families said that it is hard to prepare a child to transition without a previous connection with the EA.

In general, families shared the value of caring and understanding partnerships with schools, and an understanding of the importance of frequent communication and collaboration. Parents shared that having professionals on their team who genuinely cared about their child's progress was essential to establishing relationships between the home and school. Adams and Christenson (2000) found that home-school communication is a primary contributing factor to establishing trust between the home and school. The quality of this interaction is a better predictor of trust than the quantity. Findings of the metasynthesis confirm the importance of this partnership and bi-directional relationship between the home and the professionals as a contributing factor to successful transitions (Sperry, 1999). Findings from several studies in the metasynthesis report that communication is a vital link in a successful transition process. A communication book (Fontil, 2011) and/or a *Child Profile* form discussed in Stoner et al. study (2007) are the tools used for home-school communication. Such tools not only provide the information exchange between the home and school regarding the child's development, but also lay a framework of trust, acknowledging input from both sides. The study conducted by Levy

and Perry (2008) showed that IBI (Intensive Behavioural Intervention) staff believed significantly more strongly than school staff in the importance of collaboration and cooperation between two systems. Both sides agreed that communication is an important factor to successful transitions, however, the IBI staff endorsed the participation of a wider range of both IBI and school staff in planning. The study concluded that because school staff reported a IBI staff to have a more limited role in planning, some resistance to include IBI staff into the transition planning may exist, as well as a lack of understanding of IBI roles on the part of school staff.

Transitions that parents considered to be effective were child-centered (Stoner & House, 2007). The identify-observe-explore strategy described in Stoner study (2007) was used by the families and professionals in order to get to know the child's needs and abilities, recognize the child's anxiety and prepare the child for the transition. Both school and IBI staff participating in an Ontario study believed in the importance of individualizing the transition process to the needs and abilities of the child (Levy & Perry, 2008). In order to do so, the child's protocol, and self-help routines should be adjusted to match the school environment and ensure continuity of programming goals. Literature on transitions emphasizes the importance of identifying and teaching skills and behaviours that are critical for the child's success in the school setting (Pianta & Kraft-Sayre, 2003). The results from Levy and Perry study (2008) indicated that IBI staff strongly believed in the importance of teaching these skills. Three out of six families interviewed for this study believed that having the third year of ABA program, run half time in the nursery setting, was an important factor which helped their child to adjust to a more rigid school setting. Successful transitions to school in this study were characterized by bi-directional collaboration between ABA staff, parents and school professionals.

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In a study done by Hanson et al. (2000) it was found that the professionals were the primary decision makers in the transitions, and families' choices were driven and dominated by "the system". Other studies have shown that parents perceived their relationships with professionals as being adversarial, which added to the stress they were experiencing (Kazak, Reber, & Carter, 1988). Perhaps the most remarkable finding of this study is that parents' involvement in their child's education was a significant factor that was essential to the child's successful transition to school. Most of the parents indicated an eagerness to be involved in decision making and choices during the transition to school. This aspect was not the focus of my study but it emerged as an important theme showing the influence of parent involvement in the transition process. This study shows that parents who became actively involved in their child's learning right after they were diagnosed with ASD, played an important role in advocating for their child's rights and facilitating the transition process. According to the *Guidelines for Early Childhood Transition to School for Children with Special Needs* (Manitoba Education and Youth, 2002) parents of children with special needs are one of "the most effective people to work with school personnel to ensure a successful transition into the school system" (p.2). Parents are supposed to take an active role in the meeting regarding the development of the Transition Action plan for their child. Only two out of six families interviewed for this study spoke to participating in these meetings with representatives of the ABA and school teams for the development of the IEP (Individual education plan) for their children. None of the families mentioned the Transition Action plan taking place during the transition period.

Roles of the Formal and Informal Supports

Interviews with the parents revealed similar findings to the metasynthesis results regarding families' perceptions of social support available during the transition period. Parents shared that raising a child with autism caused stress and required a great deal of their input and commitment for their child's development. Parents reported that having a child with autism has affected and defined life of their family. When asked about formal supports all of the families said once they started the ABA program it became the main formal support they were receiving. Similarly, findings from Siklos and Kerns study (2006) show that parents of children with ASD reported that professionals who provided services to them were more important than informal supports.

Parents interviewed for this study were very positive about the ABA services, its benefits to them and their child. Parents' satisfaction has been viewed as an indicator for the effectiveness of intervention program; many studies include parental satisfaction as an outcome measure in intervention studies (Rently & Roeyers, 2005). The research findings show that home-based early intensive behavioural intervention founded on the basis of applied behaviour analysis produce effective improvements for children with autism (Grindle et al., 2009). One of the most significant elements of the effect is intensity that includes a rich ratio of teacher to student attention and maximizing learning opportunities. Parents in this study reported major improvements in their children's development: better control of challenging behaviour, development of language and social skills.

Findings of the studies on the overall functioning of the families enrolled in ABA program show that parents of children with autism engaged in Early Intensive Behavioural Intervention (EIBI) programs are not at increased risk of stress nor do they report lower levels of stress than comparable families (Grindle et al., 2009). Hastings and

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Johnson (2001) studied families participating in home-based behavioural interventions and found that program-related variables did not predict parental stress, but other factors such as adaptive coping strategies, informal social supports, and beliefs in the efficacy of the interventions were associated with lower reported stress. Results from Woodgate, Ateah and Secco study (2008) showed that parents with children with ASD experienced feelings of being in their own world and going it alone to the point that it became the essence of their experience. Fourteen out of sixteen families in that study had their children enrolled in ABA program and from the parents' perspectives their sense of isolation was found to be mainly the result of external sources (e.g., society's lack of understanding). Parents explained that although feeling isolated from many external sources, they had the support from other families of children with autism and have been encouraged to be advocates for their child. A study conducted by Schwichtenberg and Poehlmann (2007) also concluded that mothers participating in ABA experienced elevated depressive symptoms similar to any other family raising a child with ASD. Findings also showed that ABA was intensity related to maternal depression and personal strain. This suggests a potential area for family support interventions. Families who experienced difficulties during the transitions said that a change in consultants was one of the reasons their transition was challenging. Johnson and Hastings (2002) found that some of the potentially stressful aspects of running a program include maintaining a suitable team of therapists, the financial burden and disruption of family routines.

When discussing parents' views on social support received during the transition, three families named school as another source of support. Parents stated that it is fundamental that professionals really understand their child with his or her special needs. Comprehensive knowledge of ASD was seen as an indispensable basis for understanding

the child's unique needs.

Respite care is another form of support that was used by all families participating in this study. Parents stated that having respite care allowed them to spend more time with their spouses, other children, engaged in different activities, or have time for personal development. Respite has been associated with reducing the burden of families caring for a child with disability at home by: relieving familial stress; improving parental attitudes towards their child; improving family functioning; and reducing social isolation (Botuck & Winsberg, 1991).

The literature on formal supports examined support groups for parents with children with ASD and found that these groups enable contact with other families and may help reduce social isolation, stress and increase access to information about appropriate and available services. Only one mother interviewed for this study was involved in a parent support group run by the Society of Manitobans with Disabilities. Other families reported that because of lack of time they were not able to participate in parent support groups.

Four families shared that they constantly received support from friends, families and their church communities. One of the families moved to Manitoba from a different province and did not have any close friends or relatives around to support; another family did not share about their son's autism with anyone and refused to get help from anyone else but ABA. Benson (2006) found that informal parents support decreased depression among parents of children with ASD. Meadan, Halle and Ebata (2010) summarized that parental informal networks play an important role to aid in effective coping skills and reduce negative effects of stress.

Roles of the Social Workers and Other Professionals in Facilitating the Transition Process

All families were assigned a family service worker from Children's disAbility services right after their children were diagnosed with autism. Families were referred there by a physician or by the Child Development Clinic. A family services worker is assigned to each family to discuss families' needs, goals and priorities. The worker informs families about the supports that may be available through children's special services as well as other services available in the community.

Three of the interviewed families reported family service worker involvement in the transition process. Two of them knew how transition was happening and provided advice on available services. Another family service worker attended meeting with parents, ABA and school teams to discuss the child's needs and resources required for transition. Another three families did not receive any help from the family service worker during the transition; he contacted families to check on the child's progress but never was involved in transition planning.

Families reported that no other professionals were involved in facilitating the transition process. The study by Hanson et al. (2000) shows that a major factor in facilitating the transition process is having a key person or guide to facilitate the process. It could be an early intervention teacher, service coordinator, another parent or acquaintance. The main role of a facilitator would be to inform parents of the options in the community, help families to gather information, understand the law and school system, and facilitate the transition process.

Limitations in the Current Study

The major limitation of the current study related to the sample included the inability to recruit enough participants for the study. There were only six families interviewed instead of 10 or 12 as was approved in the original proposal to the study. Such a small sample prevents generalization of the findings, however this study was designed to explore the phenomenon of transition and not intended to produce findings that need to be generalized. Metasysnthesis of similar qualitative studies was conducted to strengthen the trustworthiness of limited interview results. Participants in this study were self-selected; initial response to the letter was a result of individual initiation on the part of participant. Research has shown that participants who volunteer for research studies have a specific set of characteristics and as such the participants in this study may be more representative of those individuals who respond to invitations for research participation. The reason for low participation might have been due to parents' feelings that they did not have the time and/or emotional energy to take part in the study or parents may have wanted to keep their experiences private. Another reason voiced by the coordinator of the EIBI program could be the large number of recruitment requests from other scholars to participate in long term studies.

Another limitation related to the sample was that a specific group of caregivers were interviewed-families who completed the same EIBI program. Results indicated that most families experienced positive transitions to school, and one possible reason, was that the EIBI program appropriately prepared them for the transition. Individuals receiving support may be better adjusted than those dealing with autism without supports. It would be also important to interview families from diverse early education programs as well as geographical residences and compare families' experiences of transitions to schools. The

issue of data saturation may have been a limitation in this study; due to ethical considerations the researcher was not able to choose participants herself to check categories that appeared. Decisions regarding appropriate data collection can assist researcher in theory development as they are based on the data that is being collected and coded during the interviewing process.

Although the results of this study cannot be generalized it allowed for an in depth analysis of families' experiences. Using the narratives from this study future qualitative research may develop models that can gain a clearer understanding of the variables related to transition of children with ASD to school. More specifically, future studies could attempt to determine possible differences between successful and challenging transitions and examine which factors contribute more directly to children's successful transitions and how they impact children's school outcomes. With a larger sample size future studies could research what social skills determine successful transition for children with autism. Depth analysis of factors that influence successful transition to school may help specify variables related to specific outcomes. It would be also important to study ABA and school professionals' perceptions of transitions.

Potential Researcher Bias

Qualitative research involves a good deal of subjective interpretation during analysis on the part of researcher. As both the interviewer and analyst, the researcher brings his/her own standpoint to the research experience. This could enhance reflexivity in the research analysis; some researchers may see this as increasing the likelihood of bias. The researcher discussed the emerging categories with her advisors to ensure that they made sense and this gave her the opportunity re-examine her thinking during the

process of her analysis. The researcher's previous experience, values and opinions may affect the final interpretation of the results or may influence the type of questions that were posed. Qualitative research is not primarily concerned with eliminating variance between researchers in the values and expectations they bring to the study, but with the understanding how a particular researcher's values influence the conduct and conclusions of the study.

CHAPTER VI

CONCLUSION AND IMPLICATIONS

The transition of children with autism into the school system is a complex process. Available literature articulates the importance of effective transition planning and the supports available to families. However, very few qualitative studies have examined how children with autism make their transition to school and what social supports facilitate the process. Despite its limitations, this study provided insight into parents' perceptions of the transitions of their child with autism from the EIBI program into the school system in Manitoba. Findings of the current study suggest that an effective partnership between the home, the ABA program and the school is a significant factor to a successful transition. *Guidelines for Early Childhood Transition to School for Children with Special Needs in Manitoba* (Healthy Child Manitoba, 2002) recommend collaboration between parents, professionals, school personnel, etc., including the establishment of a long-range plan for the supports and services required to meet the needs of the students with special needs. These guidelines outline the roles and responsibilities of each partner in the transition process: the preschool sending agencies/organizations, the school division, the school, and the parents. This recognises the direct influence of social supports and the important role different systems have on children during their transition to school.

Findings from the present study suggest that transitions should be viewed as a process and should reflect an ecological perspective that recognises the interrelationships between individual and different systems. Findings also potentially highlight areas to be examined in improving outcomes in transitions. The researcher's view of the transition process corroborates with Rimm-Kaufman and Pianta's (2000) understanding of the transitions to kindergarten. This model is applicable to the current study as the

kindergarten and school environments are similar in their settings and learning goals. The transition model developed by these authors suggests a "dynamic, ecologically informed approach to conceptualizing and studying the transition to formal schooling" (Rimm-Kaufman & Pianta, 2000, p.491). The authors argue that the environment of the kindergarten classroom is different from the one in the preschool and suggest to use the *Ecological and Dynamic Model of Transition* to analyse factors and their relationships that influence children's transition to school both directly and indirectly. This model defines the transition to school in terms of the dynamic qualities of the transition ecology; the interconnectedness of relationships among the child's characteristics, peers, family, school, and neighbourhood contexts. The central distinction of this model is its emphasis on the development and change of relationships over time. Interactions among the child, school, classroom, and family, change and form patterns and relationships that can be described not only as influences on the child's development, but also as outcomes in their own right. Research informed by the *Ecological and Dynamic Model of Transition* reflects an emphasis, not only on the relationships among contexts, but how these connections form patterns that develop to affect transition outcomes. If the relationships within the transition ecology are characterized by frequent contact, agreed goals, and a focus on supporting the child and the child's development of skills, the authors suggest these factors contribute to positive transition outcomes (Rimm-Kaufman & Pianta, 2000). However, if the relationships lack these attributes, then they contribute to the risk of negative transition outcomes. Families interviewed for this study stated that the active involvement of ABA consultants as well as support received from the school staff (EA, teacher, resource teacher, principal) were crucial for the successful transition of their children to school. Families that experienced difficulties during the transition said it was

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due to limited informal support available, changes of the ABA consultants and limited to no collaboration with school staff. Such transitions were stressful for the child and for the rest of the family. This demonstrated that if some context for whatever reason is missing from the transition process then formal supports should play more proactive role during the change between two different systems.

As noted before, this study highlighted the importance of collaboration between the EIBI program, school and home, emphasizing the importance of parents' involvement in the transition process. Meaningful partnerships are created when everyone participating in the transition is aware of family goals and values and has a good understanding of the way that parents are involved with their child. Parents of children with autism emphasize the need for Early Intervention Services to be family-centered and make systems structures compatible with the diverse family needs (Sperry et al., 1999; Wehman, 1998).

Defining and understanding the explicit roles of staff, within both the school and ABA setting is imperative for effective collaboration. On a system level, it is important to provide a clear title and job description for various positions (i.e., transition coordinator, resource teacher, etc) so that both systems and families are aware of the roles and responsibilities of staff participating in the transition process. It is also important to define the roles and responsibilities of participating staff at the individual level as it might need to be customized for each child and family situation.

The Family-Centered Preschool Model is a family support model for center-based preschool programs that was implemented for five years in an urban school district (Kaczmarek et al., 2004). An evaluation of this model resulted in recommendations about the role of family consultants in facilitating formal and informal supports provided to the families, in addition to the support provided by classroom staff. Family consultants where

chosen from experienced parents of children with disabilities, and served as paraprofessional members of the early intervention staff assigned to specific classroom providing support to the families in the program, while maintaining a close liaison role with the classroom staff. These individuals represented the parents from both within and outside the agency. Studies show that participation of a key person, or guide, in the transition process is an important factor influencing the families' participation in the transition and providing needed social supports to families (Hanson, 2000; Newsome, 2001). A number of suggestions and recommendations were made by the participants in this study regarding a more active role for family service workers during the transition. Social workers assigned to work with the families that go through transitions should employ strategies that help to decrease the stress perceived and experienced by parents during transitions (Newsome, 2001). In order to provide effective services, they should work collaboratively with the EIBI program providers and link families with the resources that will specifically address the needs of the child and family. Family service workers should be in a position to identify potential and existing problems and assist with appropriate interventions. Determining access to informal and formal social supports and examining coping strategies of parents of children with ASD will assist service workers in better understanding and meeting families' needs in order to facilitate effective transitions. Social workers could operate as case managers, or a link between the ABA specialists, school, medical specialists and parents in order to find an optional approach to successful transition. All parents participating in this study emphasized the importance of family knowledge about their child's disability. Where required social workers could conduct parents' support group work to enhance their knowledge on their child's disability as well as educate parents on the resources available in the community. In

addition, family service workers must advocate for policy changes that would incorporate the benefits of the home-based ABA techniques into the classroom settings. There are many families with children with ASD that do not participate in the ABA program therefore social workers need to enhance parents' involvement in their child's education and teach parents to be equal experts and advocates for their children.

In conclusion, the findings highlight the need for strategic planning of the transition process for families with children with ASD that are family-focused and involve an active role of the facilitator, who can offer practical guidance and support to children and their parents.

Future Research Implications

Several interesting findings emerged from the current study that warrants future investigation. In general, the results of this study suggest a need to recognise the variability of transition experiences of children with ASD and their families as it showed a number of variables can affect the transition period. The focus on individual differences in children and level of parents' involvement should continue to be emphasized in future research.

Previous studies examining predictors of successful transition into school have reported that the role of the teacher and the support she/he provides can be important for predicting child's successful transition into school. Examining teacher variables, such as emotional and physical support or their experiences of working with children who completed ABA would be useful in future research. Future research might show a number of other variables related to the teacher's attitudes and behaviours that impact the transition into school.

It was difficult to interpret some of the findings of this study without comparative data from the families whose children did not receive EIBI services or had not participated in any other home-based early intervention programs. With further research on this population, it may become possible to study the differences in the transition process between families who completed the EIBI program and those who have not been involved in early intervention programs. It would also be useful to investigate if there is a difference in adaptation to school between these two groups of children, and examine the role of exposure (i.e., to classroom routine and structure) as compared to skill attainment. Furthermore, it may be valuable to evaluate the effect or influence of a variety of early intervention programs, including preschool and specialized services, to determine how any of these components relate to successful transition to school.

The transition time in this study was identified as a process or shift from one service to another, and is generally thought to include the periods before and after the change. It would be useful to conduct the interviews with the families before and after the transition to examine pre-post measures of change.

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APPENDIX A: Research Participant Recruitment Letter

Faculty of Social Work

521 Tier Building

Winnipeg, Manitoba

Canada R3T 2N2

Fax (204) 474-7594

Dear Parent,

My name is Yulia Khanas and I am a Master's student in the Faculty of Social Work at the University of Manitoba. Currently, I am conducting a thesis study examining the experiences of parents of children with autism during the transition from preschool into schools within the St.Amant Autism programs. The results of this study will provide a better understanding of families' experiences during this transition period, specifically focusing on the perceived benefits and challenges of social supports received from informal networks and formal practitioners.

Mothers and/or fathers, or legal guardians, whose children completed the St.Amant Autism Early Learning Program in August 2012 and are currently going to school, are asked to volunteer for an interview that will take approximately one hour. Questions will be asked about your experiences in this program. The interviews will be scheduled at a mutually agreed time and location where confidentiality can be assured. With your consent, the interview will be audiotaped and later transcribed. All interviews will be kept confidential and identifying information will not be used in any way in reporting results. Once the data is analysed and presented, a summary of the research findings will be sent to you. If, at any time during the research process you decide to withdraw, all data collected from you will be returned to you. Accepting or declining to participate in this study will not affect any services you may be receiving from St.Amant or will be receiving in the future.

The results of the study will be shared with the St.Amant Autism Early Learning Program and other stakeholders that may be used to influence services currently provided during the transition period from preschool to school. Your input is valuable and essential to the successful completion of this project. If you have any questions, or would like to schedule an interview time, please contact Yulia at (204) 292-8971 or via email: yuliakhanas@hotmail.com by February 23, 2013.

Thank you for your consideration of this request.

Sincerely,

Yulia Khanas, B.S.W, Social Work Graduate Student

Dr. Brad McKenzie, Ph.D, Professor, Research Supervisor

APPENDIX B: Consent Form for Parents

UNIVERSITY OF **MANITOBA**

Faculty of Social Work

521 Tier Building

Winnipeg, Manitoba

Canada R3T 2N2

Fax (204) 474-7594

CONSENT FORM FOR RESEARCH STUDY

Research Project Title: **Parental Perspectives on Social Support needed during the transition from Preschool to School within the Applied Behaviour Analysis Program**

Principal Investigator: Yulia Khanas, B.S.W, ph: (204) 292-8971,

email: yuliakhanas@hotmail.com

Research Supervisor: Dr. Brad McKenzie, Ph.D, Professor; phone: (204) 474-8767,

email: mcknzie@cc.umanitoba.ca

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I understand that the purpose of this research project is to conduct a study examining the experiences of parents of children with autism during the transition from preschool to school in the city of Winnipeg within the St.Amant Applied Behavioural Analysis program (ABA).

I, _____, agree to participate in the research study conducted by Yulia Khanas, who is a student in the Faculty of Social Work at the

University of Manitoba. I am aware that results from this research study will be used to fulfill Yulia Khanas' thesis requirements for a Master's degree in Social Work. The primary purpose of this study is to gain a better understanding about parents' perceptions on the social supports they need and have received during the transition period, specifically focusing on the perceived benefits and challenges of these supports.

I understand that this interview will last approximately an hour or an hour a half in length, and that the interview will be audio-taped for the purpose of analysis. If I do not consent to be audio-recorded, the interviewer will take detailed notes. After the interview I may need to be contacted for further information or clarification which would only involve brief conversations over email or telephone. I understand that this contact will be optional and I will be asked separately for my consent to do so. All identifying information about my family will be removed from Ms. Khanas final report. I am also aware that Child and Family Services Act in Manitoba requires Ms. Khanas to report any instances of suspected abuse or neglect.

My responses in this study will remain confidential. I have been assured that my personal information and the audiotapes will not be shared with any person and will be stored in a locked cabinet in room 417 B Tier Building at the University of Manitoba. Once this information is analyzed, all identifying information will be destroyed after the thesis has been successfully defended. Interview transcripts will be deleted and/or destroyed in five years (May 2017).

I am aware that immediately following the interview, the interviewer will be available in the event that any questions or concerns arise as a result of the interview. If desired, I can receive written summary of this research from the principal researcher at the end of the project (June, 2012).

My participation in this study is completely voluntary and I have the option to decline answer any question, take a brief break or continue the interview at another time. I have the right to choose to discontinue the interview at any time by simply indicating this to the researcher. Should I decline to participate in the research study at any point throughout the process, I have been informed that all data collected from me will be returned and it will not affect any services I may be receiving from St.Amant or will be receiving in the future. I am aware that there is a possibility that emotional distress can occur when personal matters are being discussed. If this happens during the interview, I

will be able to discuss it with the researcher if I wish or I can be referred to other helping services for follow-up. If required a list of appropriate resources will be provided to me in the end of the interview.

Furthermore, I am aware that this research project has received approval from the Psychology/Sociology Research Ethics Board at the University of Manitoba. If I have any questions or concerns about this study I may contact Yulia Khanas, Dr. Brad McKenzie or the Human Ethics Secretariat at 474-7122, or email margaret_bowman@umanitoba.ca.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in this research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, thus you are encouraged to ask for clarification or new information throughout your participation if required.

The University of Manitoba Research Ethics Board(s) and a representative(s) of the University of Manitoba Research Quality Management / Assurance office may also require access to your research records for safety and quality assurance purposes.

This research has been approved by the Psychology/Sociology REB. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Participant's signature:_____
Date:_____

Researcher's
signature:_____Date:_____

Do you agree to have the interview audio-recorded?   _____ Yes   _____No

Do you wish to receive a summary the study findings: _____ Yes _____ No

Do you agree to be contacted by phone or e-mail if further information is required after the interview?

_____Yes   _____No

I would like to receive the summary of results by:
_____mail (please provide complete mailing address):

_____

email (please provide email address):
_____

A) Introduction:

- Explanation of who I am and what the study is about

"My name is Yulia Khanas and I am a Master's student in the Faculty of Social Work at the University of Manitoba. Currently, I am working on completing my thesis. I had previously worked as a social worker with families who have children with autism in Early Intervention Program at Children's Rehabilitation Centre in Lviv (Ukraine). This experience helped me to realize there are a number of levels of stress which are experienced by the families during every new transition in their child's life. The purpose of the study is to explore the experiences of parents of children with autism during the transition from home to school within the Applied Behavioural Analysis program. Once the research is completed, specific recommendations will be made to the Pre-School ABA Program to improve services currently provided during the transition period from home to school. My personal interest in the current study is to discover which social supports provided by social workers were the most beneficial to the families and what was challenging during this time.

- Questions or comments before commencing
- Review and signing of the Consent Form

B) Formal interview will begin

1. The first set of questions will inquire about the child who participated in Pre-School ABA program.

What is the name of your child who participated in ABA program? How old is he/she?

Where is your child on the autism spectrum disorder? What ehaviours does the child experience?

How have these behaviours affected your family and your life?

How did you feel when you first found out about your child's disability?

Can you tell me how parenting (name of child) has changed since that time?

2. The next set of questions will be about the transition from home to school within ABA program.

- *I would like to talk about your experiences during the transition from home to public school while your child was still a part of the ABA program.* As a parent,

how did you feel going through this transition with your son or daughter?

- What were your concerns during this transition?
- When you were preparing for your child's change to public school, how did you think this transition was going to affect you?
- What impact has his/her transition had on your family?
- *In any transition certain things can help or facilitate this process and certain things pose barriers.* What would you identify as facilitators of the transition process?
- What would you identify as barriers of the transition process?

3. The third set of questions is about the types of support families received during transition.

- What types of formal social supports did you receive during transition?
- What professionals were involved and contacted you during this transition?
- Did you find your contact with these professionals helpful? Could you please provide some examples?
- Did you find any professionals were not that helpful and did not provide you with all the necessary resources? Could you provide some examples please.
- How could professionals become more supportive for you and your family?
- Have you been pleased with the amount of support professionals have given you during your son or daughter's transition? Can you tell me more about that?
- What supports might have provided that weren't? By whom?
- *Informal supports are defined as the help received and/or perceived to be available from extended family, friends, neighbours, social organizations, and religious communities.* What types of informal supports did you receive during the transition? Who, or what, was the most helpful and why?

4. The last set of questions will ask about input of contributions of social workers in services provided.

- During the transition process did you receive some services from social workers?
- What suggestions would you make to social workers working with families facilitating this transition?
- What can be done by social workers to lessen the stress one feels during the

transitional phase?

- What are your suggestions for social workers and parents who work collaboratively in the area of autism?

5. Allow for other questions and comments about anything you may have missed or they want to tell you about their experiences.

C) Debriefing and thank parents.

Script for the debriefing

Do you have any questions or comments about the interview process itself or any concerns that it might have caused you in talking about those things?

If there is no questions than I will say:

I would like to express my appreciation. Thank you for taking your time to meet with me and participate in this research project. I will provide you with a summary as soon as it will be available.

If some concern arise later and you might be interested in talking to a professional if stress continuous, I want to give you a list of resources that are available in Winnipeg and you should be free to contact them.

Open Coding

1. **Autism (A)**
   - A: Diagnosis and symptoms of autism   A-DIAG-SYM
   - A: Childs' behaviour   A-BEH-CH
   - A: Social skills   A-SOC-SK
   - A: Learning skills   A-LEAR-SK
   - A: Parents` feelings (after diagnosis was received)   A-PAR-FEEL
   - A: Child progress in development   A-CH-FEEL
   - A: Parents' education about autism   A-PAR-ED

2. **Effects of Autism (EA)**
   - EA: Interaction with parents   EA-INT-PAR
   - EA: Interaction with siblings   EA-INT-SIB
   - EA: Interaction with others   EA-INT-OTH
   - EA: Parenting style   EA-PAR-ST
   - EA: Effects on family life   EA-EFF-FAM

3. **Transition into School (T)**
   - T: Parents expectations   T-EXP-PAR
   - T: Preparation/Planning   T-PREP
   - T: Challenges/barriers   T-CHAL
   - T: Parents' concerns before transition   T-PAR-CON
   - T: Partnership with school   T-PARTN-S
   - T: Choice of school   T-CH-S
   - T: Parents' feelings   T-PAR-FEEL

4. **Support (S)**
   - S: Formal support that was received   FS-REC
   - S: Informal support that was received   IS-REC
   - S: Formal support that wasn't available   FS-NA
   - S: Informal support that wasn't available   IS-NA

5. **Applied Behaviour Analysis Program (ABA)**
   - ABA: Child   ABA-CH
   - ABA: Family   ABA-FAM
   - ABA: Assessment   ABA-ASS
   - ABA: Programming   ABA-PROG
   - ABA: Tutors   ABA-TUT
   - ABA: Knowledge of ABA techniques   ABA-KNOW
   - ABA: Drawbacks of the program   ABA-DRAW
   - ABA: St.Amant   ABA-ST-AM

- ABA: Techniques   ABA-TECH

6. Social Workers (SW)
- SW: Involvement in planning the transition   SW-INV-T
- SW: Contact with social workers   SW-CONT
- SW: Information provided by the social workers   SW-INFO