

Running head: AUTISM AND PROGRAMING

Parents and Teachers Perceptions of the Program  
Planning Process for Children with Autism in  
one Newfoundland and Labrador School District

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### **Abstract**

The number of children being diagnosed with autism, a pervasive developmental disorder, has risen dramatically in recent years (Kendall & Comer, 2010). Children with Autism Spectrum Disorder typically attend public schools in Newfoundland and Labrador (NL) and individual program plans are developed to meet their needs. The program planning process involves collaboration among school personnel, medical and developmental specialists, and the child's family (Government of Newfoundland and Labrador, Department of Education, 2007). The purpose of this study was to investigate parents' and teachers' perceptions of the program planning and implementation process when working with children with autism in one geographic area of NL. Results indicated that teachers and parents shared similar perceptions on several points such as when describing autism. Both parents and teachers mentioned that autism was associated with social and communication deficits. They also noted the importance of working with children with autism to improve their social skills and general behavior. However, participants had different perspectives in some areas, especially regarding the program planning process around issues of involvement, program implementation, and providing needed services. Results suggested that the shared perspectives of parents and teachers on some issues would be a good starting point for continued dialogue to ensure that children with autism are receiving needed services and optimal programming.

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## Chapter 1

### Introduction

Over the past two decades, the number of children being diagnosed with autism, a pervasive developmental disorder, has risen dramatically. According to *Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition, Text Revision*, the prevalence of autism can vary from 2 to 20 per 10,000 people (American Psychiatric Association, 2000). While the actual cause of autism is still unknown, there is increasing knowledge regarding how autism affects children, impacting their language, cognitive, behavioural, and social development. (The DSM-V had not been published when this thesis project began and data had been collected.)

Parents and school professionals work closely to develop curriculum and strategies to be used in mainstream classes, which place higher demands on where teachers are expected to accommodate the learning styles, sensory needs, and social skills of children with autism and other special needs. Whitaker (2007) noted that families expressed a need for increased supervision and interaction for their children with autism. Such collaboration requires on-going, quality communication between school and home, an area parents cited as needing improvement. Friedlander (2009) stated parents' felt valued when school professionals listened to their concerns and asked for their advice. When parents trust school professionals, a positive relationship exists, which has an impact on the child's academic and social performance (Lilly, Reed, & Wheeler, 2003).

Results of a recent study by Murray, Ruble, Willis, and Molloy (2009) comparing parents' and teachers' ratings of the importance of social skills when programming for

children with autism indicated that parents and teachers did not rate social skills in the same manner. Parents rated selected social skills higher while teachers rated the same skill lower. For example, when rating comforting others, parents rated this skill higher for older children while the teachers rated the same skill higher for younger children. Parents and teachers need to work as a team and build rapport and trust to ensure children with autism reach their highest potential. Both sides should feel safe to express their concerns and ask questions. Therefore, the present study will focus on the perceptions of teachers and parents regarding programming for children diagnosed with autism and attending public school.

### **Rationale**

While results of recent studies demonstrate that parents have been pleased with program planning, many parents felt teachers had failed to listen to their concerns and that there was a lack of communication between home and school. However, few, if any, of these studies have addressed how parents perceive or are involved in the program planning process, especially in Canadian communities. The current research will investigate whether similar perceptions exist among educators and parents of children with autism in Newfoundland. In addition, will address the roles of parents and educators in developing and implementing programs for children with autism.

Results will be important in identifying information regarding parents' and teachers' perceptions of successes, concerns and areas that need improvement. Based on previous research, results could indicate a need for improved communication among team members, clarification about roles and responsibilities, changes to service delivery, or expansion of service availability. Identification of issues unique to this context of the

study, could lead to recommendations to address parents' and teachers' concerns. For example, rapport building strategies may be an effective intervention to address concerns to improve collaboration. If parents' and school professionals work together as team members, efforts can focus on program development and implementation to ultimately benefit education for children with autism. Therefore, the current study will provide important information regarding perception of program development, involvement, and programming to maximize the potential of children with autism.

## Chapter 2

### Literature Review

This chapter will include an introduction to autism and a discussion of the characteristics typically associated with diagnoses of autism. A discussion of causes of autism and interventions used with children with autism is also presented.

#### Introduction

Autism is a neurological disorder which affects individuals differently, to varying degrees, throughout their personal life (Rose & Anketell, 2009). The *Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text Revised* (DSM-IV-TR), states that a child diagnosed with autism must show deficits in three main areas: impairments in social interactions, impairments in communication, and restricted repetitive and stereotyped patterns of behaviour, interests, and activities (American Psychiatric Association, 2000). Autism is a sub-category of Pervasive Developmental Disorder (PDD) and for a diagnosis of Autistic Disorder one must ensure a child's impairment does not better fit one of the other PDD disorders noted in the DSM-IV-TR (American Psychiatric Association, 2000), such as Rett's Disorder or Childhood Disintegrative Disorder.

#### Characteristics of Autism

Impairment in social interactions The first major characteristic associated with autism is an impairment in social interactions. A child diagnosed with autism must have shown at least two of the following: marked impairments in using nonverbal behaviours, failure to develop peer relationships, lack of spontaneous sharing of enjoyment or interest



with others, and lack of social or emotional reciprocity (American Psychiatric Association, 2000).

Children who lack nonverbal communicative behaviours may avoid eye contact while other people talk to them or try to engage them. Typically, young children use their gaze to indicate an item of interest or need, and wait for an adult to bring the object to them. Such behaviour is not often exhibited by a child with autism. Similarly, children request items by pointing or pulling a person to the object with or without making eye contact (Jefferson & University of Arkansas for Medical Science, 1999; Kendall & Comer, 2010). A high-functioning child with autism may point or bring someone to an object, but many children with autism do not communicate their needs effectively. In fact, if someone else comes into the room, the child with autism may not even acknowledge them. Children with autism also tend to lack facial expressions and tend not to reciprocate non-verbal forms of expression. For example, they may not return another person's smile. Other nonverbal behaviours such as body postures and gestures, may not be evident in children with autism and this may interfere during interactions with others (Jefferson & University of Arkansas for Medical Science, 1999; American Psychiatric Association, 2000). A child with autism often has trouble with joint attention, such as showing enjoyment to other people with whom they may be playing, and looking them in the eye to share this enjoyment (Frankel et al., 2010). These children may also have impairments in affective interactions, they may smile inappropriately or laugh when other people are sad (Jefferson & University of Arkansas for Medical Science, 1999; Mong, 2001). Family members may notice that a child does not want to be touched or cuddled and would rather be left alone (Kendall & Comer, 2010).

Children with autism may have difficulty developing peer relationships that are developmentally age-appropriate (American Psychiatric Association, 2000; Friedlander, 2009). They seem unaware of how to engage another child in play (Kendall & Comer, 2010). Frankel et al. (2010) also note that these children have difficulty initiating social interaction. On the other hand, children with autism who do try to interact with other children may assume everyone shares the same interests and may not understand why others are not interested in playing with them (Mong, 2001).

A child who has autism might not display social or emotional reciprocity (American Psychiatric Association, 2000; Frankel et al., 2010; Friedlander, 2009). If a child is hurt and crying, a child with autism may walk past the hurt child and not acknowledge the obvious distress. They often will not observe other people in the room or notice other people's needs. As mentioned before, children with autism may not return a parent's smile. Frankel et al. (2010) found that children diagnosed with autism often have difficulty joining a group of children who are already at play. These children usually do want to make friends but their attempts to interact are usually clumsy and unsuccessful.

Social interactions are difficult for children with autism because they may not understand or use non-verbal behaviours. In addition, many children with autism have some form of communication impairment, which complicates social interactions by making it difficult for others to understand their wants and needs.

Impairment in communication The second major characteristic associated with autism is impairment in communication (American Psychiatric Association, 2000). A child diagnosed with autism must have shown at least one of the following: delay in or

lack of speech, impairments in starting or maintaining a conversation, stereotyped or repetitive language use, and lack of make-believe or social imitative play based on their developmental level (American Psychiatric Association, 2000).

Autism is often characterized by a “delay in, or total lack of, the development of spoken language which means an individual does not try to communicate using any other form of communication, as in pointing or pulling a person toward an item they desire ” (American Psychiatric Association, 2000, p.75). Often parents state that their child spoke a few words and then lost speech as he/she grew older (Towbin, Mauk, & Batshaw, 2002). A child with autism may develop speech later in life or the child could remain non-verbal (Towbin et al., 2002). However, an estimated “25-30 %” of children with autism never develop spoken language (Jefferson & University of Arkansas for Medical Science, 1999, p. 46). Before a child is labeled as autistic, the developmental age of the child should be considered and an assessment completed to ensure there are no other developmental issues causing the lack of communication (Mong, 2001).

A number of children with autism do have speech, however, their speech is typically impaired (American Psychiatric Association, 2000). Children with autism have been noted to have a flat, mono-tone voice that can be boring to listeners (Jefferson & University of Arkansas for Medical Science, 1999). Others may have trouble starting to speak, as in the initial act of saying the first word, but when the first word is spoken they may be able to complete a sentence (Mong, 2001). Also, children with autism may exhibit inappropriate conversation skills in either word use or conversation style. For example, they may ask personal questions, make comments that are off topic, or talk about an inappropriate topic. Frankel et al. (2010) stated that children with autism may

have an egocentric conversation style, talking about topics they find interesting and not considering the interests of others.

Another possible impairment of communication can be “stereotyped and repetitive use of language” (American Psychiatric Association, 2000). Some children with autism recite sentences from a favourite movie or television show or repeat back what another person has said to them. This behaviour is known as echolalia (Kendall & Comer, 2010; Towbin et al., 2002; Mong, 2001). Another example of echolalia is when children spontaneously repeat a sentence from their favourite show at a later point in the day, with no prompt. Children with autism who do develop appropriate language skills may also talk in a high-pitched voice or in a way that sounds as if they are singing. Others confuse pronouns and use them inappropriately, as when they call themselves “you” (Towbin et al., 2002). These children can speak, but often it is not functional language or communication.

In addition, children with autism might not imitate others. For example, when others clap their hands during the song “if you’re happy and you know it,” they might not participate. Also, children with autism rarely engage in make-believe play or symbolic play (using one object to represent another). However, it is important to consider the child’s developmental age when these symptoms are being considered, as imaginary and symbolic play are advance skills for very young children (American Psychiatric Association, 2000).

As noted, impairments in communication can include lack of non-verbal communication, delays in spoken words, repetitive communication, and lack of make-

believe or social imitation play. Along with communication impairments, children with autism tend to display inappropriate, atypical behaviours.

Restricted repetitive behaviors, interest and activities The final major characteristic of autism is “restricted repetitive stereotyped patterns of behaviour, interest, and activities” (American Psychiatric Association, 2000, p.75). A child diagnosed with autism must have demonstrated at least one of the following: preoccupation with stereotyped and/or restricted patterns of interest that is abnormal in intensity or focus, inflexible adherence to non-functional routines or rituals, repetitive motor mannerisms, or preoccupation with parts of an object (American Psychiatric Association, 2000). A child with autism may develop a high “intensity or focus” for a particular object or action (Mong, 2001, p.18). For instance, a child may become attached to a sandwich bag and want to carry it everywhere. They may want to put random items in and out of the baggie and can do this over and over, never losing interest. Other children may have an extremely good memory for certain facts or figures, such as the names of airplanes and their engines (Mong, 2001), yet this skill might not be used in meaningful situations.

Children with autism may seem fixated on certain rituals and routines. For example, when a family that regularly takes one route to a grandparent’s house takes a detour one day, the child with autism may have a tantrum. The child may not like change and cannot understand why a different route must be taken, even if the destination is still the same. Other children with autism may be upset if someone moves a piece of furniture in a room and try to move it back to its original position. Some children with autism like their day and environment to follow a rigid routine (Jefferson & University of Arkansas for Medical Science, 1999; Kendall & Comer, 2010). They may repeat an action

whenever they walk past a certain object, such as having to close every door they walk past, and never vary the pattern.

A child who has autism may have “stereotyped and repetitive motor mannerisms” (American Psychiatric Association, 2000, p. 75). These behaviours are known to stimulate the sensory system and can take many forms, such as toe-walking, hand-flapping, rocking, and/or self-injurious acts like head-banging or biting (Jefferson & University of Arkansas for Medical Science, 1999). Some mannerisms can be extremely dangerous to a child, including banging their heads off a hard surface, pulling their hair out, and biting themselves or others (Kendall & Comer, 2010). Often children might enjoy a certain object (such as a lid off a bottle) and want to touch the object to see how it feels or drop the object to hear the sound it makes when it hits the floor. It has been noted that some children with autism have pica, causing them to eat items that are not edible, such as paper.

A child with autism may become fixated on parts of an object (American Psychiatric Association, 2000), such as turning a door knob over and over or spinning the wheels of a toy car, instead of pushing the car around. These fixations could also involve children mouthing or smelling everything. Each aspect of the diagnostic criteria should be applied carefully to the behaviour typically expected of a child at a similar age, since mouthing an object is typical at certain ages.

In summary, autism can affect children’s focus, how they process information, and how they integrate into their environment (Kendall & Comer, 2010). Children diagnosed with autism sometimes display every symptom mentioned in the DSM, while others may exhibit the minimal number of characteristics from each criteria to be

diagnosed with autism. Autism affects children differently, and this creates challenges in diagnosis and in determining interventions to teach life skills (Friedlander, 2009).

### **Prevalence**

Estimates by the Centers for Disease Control and Prevention suggest that 1 in 68 people are diagnosed with Autism Spectrum Disorder (2014). According to *Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition, Text Revision* (American Psychiatric Association, 2000) the prevalence of autism can vary from 2 to 20 per 10,000 people. The statistics have risen since 1980, when the prevalence was 0.4 to 0.5 per 1,000 children being diagnosed with autism (Boucher, 2009). In fact, Friedlander (2009) estimates that 1 child in 166 is now diagnosed with autism in the United States.

Bishop, Maybery, Wong, Maley, and Hallmayer (2006) find there is a 2 % to 6 % chance of more than one sibling being diagnosed with autism, suggesting some link to genetics. This percentage rises with twins, as there is about a 50 % chance for identical twins to have autism. These percentages strengthen the genetic link, yet demonstrate that autism is not fully accounted for by genetics (Jefferson & University of Arkansas for Medical Science, 1999). In addition, researchers have noticed a gender difference with males being three or four times more likely to be diagnosed with Autism Spectrum Disorder than females (Jefferson & University of Arkansas for Medical Science, 1999; Kendall & Comer, 2010).

Since Autism Spectrum Disorder was first diagnosed, the definition and characteristics have been changing. Incidences of autism have increased over time and this could be due to researchers developing the definition of autism (Lilly, Reed, &

Wheeler, 2003). With refining the definition of autism, researchers have also been developing theories of what could be possible causes of autism.

### **Causes of Autism**

Suggested causes of autism have ranged from detached mothers to vaccines to genetics and environmental factors. Some of these factors are still being debated, even though there is limited evidence linking them to autism. In trying to determine a cause for autism, researchers have focused on twin and family studies (Freitag, 2007), as well as environmental concerns and vaccines (Boucher, 2009). Despite extensive investigation, no clear cause of autism has been found.

Initially, psychoanalysts and psychotherapists blamed mothers when children exhibited features of autism, thinking it was due to mothers' being emotionally cold and providing less warmth and love to their children. Psychoanalysts speculated this caused autistic behaviours to develop (Boucher, 2009; Kendall & Comer, 2010). However, in the 1970s, this theory was disproved. Results of a study comparing mothers and how they treated their children indicated that mothers of children with and without autism had similar relationships with their children and that mothers of children with autism were neither cold nor indifferent to their children (Boucher, 2009).

Autism seems to have a genetic basis, although this does not appear to be the only cause (Jefferson & University of Arkansas for Medical Science, 1999; Kendall & Comer, 2010). Studies of identical and fraternal twins have investigated the possibility of a genetic basis for autism and the likelihood of both twins having autism. Identical twins share the same genetic makeup; therefore if one twin has autism, so should the other. This is not always the case. For example, Jefferson and University of Arkansas for



Medical Science (1999) stated there is a 50% chance for both identical twins to have autism. Towbin et al. (2002) note a 70% to 90% chance for both identical twins to have autism, and other researchers quote percentages that fall somewhere in between (Boucher, 2009; Freitag, 2007; Mong, 2001). In addition, when both identical twins have autism, the disorder sometimes affects each one differently (Boucher, 2009). Freitag (2007) found when both identical twins have autism, they usually have communication and social impairments, yet other characteristics, such as repetitive behaviours, are not exhibited in both children. There is a 10% chance for both fraternal twins to have diagnoses of autism (Boucher, 2009). If autism were based entirely on genetics then there would be a 100% chance that both identical twins would have autism. Since this is not the case, other areas must be considered (Boucher, 2009).

Siblings of children who have autism have also been researched to help shed light on environmental and genetic factors causing autism. In the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text Revised* (American Psychiatric Association, 2000) it is noted that families who have a child with autism, have a 5% chance of a sibling being diagnosed with autism. Others have suggested the percentage of multiple siblings having autism is higher, between 5% and 7% (Freitag, 2007; Towbin et al., 2002). Boucher (2009) and Freitag (2007) have investigated other extended family members to determine possible links to autism. Freitag (2007) found a correlation between children's stereotyped behaviours and parents having obsessive-compulsive disorder or anxiety disorders. Several of these parents whose child with autism was cognitively lower functioning, were also diagnosed with psychiatric disorders.

Researchers have been investigating the genetic make-up of people who have been diagnosed with autism to see if one or more chromosomes could be discovered as a cause for autism. Again, the research is inconclusive and a specific gene has not been found (Boucher, 2009; Freitag, 2007; Towbin et al., 2002). However, there are about 4 to 10 genes which may be related to autism (Towbin et al., 2002). For instance, about 40% of people with autism have a defect in chromosome seven (Towbin et al., 2002). Freitag (2007) looked at other disabilities, especially if they have been linked to autism, such as Fragile X syndrome. It has been suggested that chromosomes 2, 3, 6, 10, and 17 could be linked to autism, but again the research has had mixed results (Freitag, 2007). Each of these chromosomes is important to human development and is linked to various areas of impairment in people who have autism. For instance, chromosomes 2 and 7 are related to the development of speech and language, which are often impaired in children with autism (Boucher, 2009)

Since autism is diagnosed at a higher rate in males than females, researchers have also been exploring the chromosome pair 23, which determines a person's gender (Boucher, 2009; American Psychiatric Association, 2000; Freitag, 2007). Females have two X chromosomes; if one X chromosome has a defect, the healthy X chromosome may be able to compensate for the defective one. However, males have only one X chromosome, and since there is not another chromosome to compensate, researchers have been seeking a link to autism on the X chromosome. Thus far, no sex-related gene has been found to cause autism (Boucher, 2009; Freitag, 2007). More research into genetics is needed to deepen our understanding of autism. Since the cause of autism is not solely

based on genetics, then maybe autism could be due to the interaction of genetic and environmental factors.

Numerous environmental factors have been considered as possible causes of autism. Several of these factors have been proven to have damaging effects on a child. One theory that has met with mixed reviews involves the herpes virus. Boucher (2009) stated that if a mother is infected while carrying her baby, this could cause abnormal development, which may lead to autism. It has also been speculated that stress might be a factor. Stress causes certain chemicals to be released into our bodies. Researchers have questioned whether these chemicals can affect fetal development during the first trimester, which could result in autism (Boucher, 2009; Towbin et al., 2002). Additional factors suggested include smoking, alcohol, and higher-than-normal levels of testosterone in the mother (Boucher, 2009). Some medical factors that have been considered include viral infections, immune system abnormalities, and complications during birth (Boucher, 2009; Towbin et al., 2002).

Vaccines were proposed as a possible cause of autism. While no link between autism and vaccines has been found, people seem to still place blame on them, especially the measles-mumps-and-rubella vaccine (Boucher, 2009; Kendall & Comer, 2010; Miller & Reynolds, 2009). The measles part of the vaccine has been investigated, since the vaccine causes chemicals to be sent to the brain to develop antibodies to fight measles, and this could affect brain development (Boucher, 2009). One of the ingredients that preserve the vaccine, thimerosal, came under close scrutiny. Thimerosal is about “50 % mercury” and it has been found that some people with autism have higher amounts of mercury in their body (Miller & Reynolds, 2009, p.170). Miller and Reynolds (2009)

reviewed several journal articles, and concluded that there was no association between vaccines having thimerosal and the development of autism. Today mercury has been removed from the vaccines children are receiving, yet there is no decline in the reported incidence of autism (Boucher, 2009). However, some people still seem to think this vaccine is part of the cause of autism, even though no relationship has been demonstrated (Boucher, 2009; Freitag, 2007; Towbin et al., 2002).

Serotonin is a neurotransmitter that has been associated with autism. Towbin et al. (2002) state that “30% of individuals with autistic disorder have elevated blood serotonin levels” (p. 372). Serotonin has many functions related to “sleep, eating, mood, and arousal” (Boucher, 2009, p.135). Boucher (2009) mentions another neurotransmitter, dopamine, which is related to motor function and is associated with our reward system, attention and learning, yet again there is no definitive connection between dopamine and autism. Boucher (2009) further notes that brain size is abnormal in people with autism. Kendall and Comer (2010) concur and state that the brains of people with autism are “larger and heavier” (p.176). The brain regions which seem to be most affected in people with autism are those that develop in the early stages of pregnancy (Boucher, 2009). Jefferson and University of Arkansas for Medical Science (1999) further notes that autism also seems to affect areas of the brain that are associated with our emotional systems.

In summary, researchers are still trying to determine the cause(s) of autism. Numerous environmental and genetic factors have been proposed but no conclusion has been reached. Vaccines have been ruled out as causing autism symptoms (Miller & Reynolds, 2002). Researchers have found some connections to autism by studying

chromosomes and various brain regions from people diagnosed with autism (Boucher, 2009; Freitag, 2007; Kendall & Comer, 2010; Towbin et al., 2002). Perhaps this will bring researchers closer to solving the mystery of what causes autism. Determining the cause of autism could lead to prevention of autism and enhanced interventions to improve the lives of children with autism and their families.

### **Interventions**

Since the 1960s, with the development of social learning theories, numerous interventions have been developed to help children with autism (Koegel, Koegel, & McNerney, 2001). Interventions can be categorized as educational (such as Applied Behavioural Analysis, ABA) or medical (such as vitamin therapy). Empirical evidence supports the positive effects of several interventions, such as ABA (Ingersoll, 2010), while other interventions, such as seclusion, lack empirical evidence (Golnik & Ireland, 2009). It is important to note that these studies often have small sample sizes or are based on a few case studies. This makes it difficult to generalize the results to the population of children with autism.

Each child with autism is an individual and one style of intervention is unlikely to work for every child (Boucher, 2009). Parents and professionals should research multiple interventions to understand each approach and determine which intervention best suits a particular child. There are many interventions and therapies claiming to help children with autism which have been seen on television, the internet, and in books (Senel, 2010). Little or no empirical evidence exists to support the benefits of some therapies, for instance, the holding therapy, which is used when a child behaves inappropriately and involves forced contact until the child stops struggling (Boucher, 2009).

Towbin et al. (2002) outline the common objectives among various interventions used to help a child with autism. These objectives include increasing a child's development and creating and providing learning opportunities. In addition, interventionists want to decrease stereotyped or maladaptive behaviours often seen in children diagnosed with autism. Finally, interventions aim to decrease the stress that family members feel when they are raising a child with autism. Researchers agree that interventions have the best results when they are started early in a child's life (Ingersoll, 2010; Towbin et al., 2002). Furthermore, interventions need to be stimulating, structured, planned, and predictable (Horner, 2009).

Specific interventions use structure to help provide improvements in the life of children with autism, such as, educational interventions (Boucher, 2009). Medical therapies seek to change naturally-occurring biological processes by prescribing medication, changing a child's diet or even stimulating the brain in the hope of improving the lives of children with autism and their families (Boucher, 2009). Other therapies, such as sensory integration therapy, use touch and stimulation. However, these interventions are often not researched sufficiently to determine their effectiveness. In addition, they are often used in combination with other interventions, making it difficult to isolate the impact on individual interventions (Boucher, 2009).

Applied Behavioral Analysis (ABA) is the most researched and supported intervention for children with autism (Babel, Martin, Fazzio, Arnal, & Thomson, 2008; Callahan, Shukla-Mehta, Magee, & Wie, 2010; Hayward, Eikeseth, Gale, & Morgan, 2009; Matson & Dempsey, 2008). Renna (2004) states it is essential for ABA to be incorporated into any therapy used for a child with autism. ABA is a home-based therapy

designed to help children obtain skills through discrete trials, which include repeating a task until a child has mastered that specific skill (Schreibman, 2005). The concept of discrete trial is derived from the Lovass method, which involves introducing a skill, prompting to help the child learn the skill, and reinforcing a child's attempts or correct responses (Towbin et al., 2002).

Hayward et al. (2009) assessed the effects of ABA on children with autism through a one-year follow up study of two groups of children with autism. In one group, children received intensive clinical-based therapy by professionals, while the other group, received intensive therapy by parents. It was found that children in both groups showed significant improvements in their IQ, social skills, and adaptive behaviour. In addition, their visual spatial IQ, language comprehension, and expressive language improved. Results of the study suggest that ABA therapy improves impairments in social skills, communication, and behaviours associated with autism.

ABA is based on positive reinforcement for behaviours and skills that are desired and ignoring or redirecting aggressive and disruptive behaviours in the hope that these behaviours will decrease or be eliminated (Horner, 2009). Hayward et al. (2009) also stated that children improve more when they receive ABA training alone rather than in combination with other programs. The authors argue that for best results, professionals and parents need to be applying ABA techniques within all aspects of the child's life and within various environments to ensure skills are learned and generalized. Ingersoll (2010) cites ABA as the most effective empirically-based intervention for children with autism. A further study by Vismara and Rogers (2008) supports ABA by saying that this therapy improves intellectual and communicative skills.

Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) is another well-known and established intervention for children diagnosed with autism (Callahan et al., 2010). TEACCH was developed in 1996 (Ozonoff & Cathcart, 1998). Its founders believe that families benefit from being involved in therapy and families carry out therapy with their child in their home. The family is trained to teach their child in areas pertaining to cognitive, academic, and pre-vocational skills to increase school success. TEACCH incorporates behavioural strategies to reinforce communication and social skills (Towbin et al., 2002).

Ozonoff and Cathcart (1998) studied the impact of TEACCH on children with autism. A control group and a treatment group, each having nine males and two females aged two to six, were set up. While all the children were involved in day programs, only those in the treatment group received the TEACCH therapy. The study investigated the strengths and weaknesses of the program, the functions of TEACCH, and possible improvements in developmental areas. A baseline assessment on all participants was obtained before the study started and the children were re-evaluated at the end of the program and again four months later. Results demonstrated that the group who received TEACCH therapy showed significant improvements over the control group on various tests (Ozonoff & Cathcart, 1998). TEACCH therapy was effective in improving cognitive and developmental skills. The results also confirmed that children who scored higher at the baseline showed the most improvements. However, when other standardized tests were used, the TEACCH group showed improvements but the results were not significantly different from those of the control group. Even though improvements were noted in cognitive and developmental skills, it is unclear whether



there were improvements in other areas such as social or communication skills or changes in repetitive behaviours.

Tsang, Shek, Lam, Tang, and Cheung (2007) also investigated the use of the TEACCH intervention with children with autism in Hong Kong. The experimental group had 17 males and one female and the control group included 12 males and four females. There was a significant drop rate for participants in the control group, leaving two subjects at the end of the study. The subjects were observed prior to the study to obtain a baseline, then again at six months and once more 12 months later. The experimental group was exposed to TEACCH therapy approximately seven hours a day, while the control group received various interventions neither of which were TEACCH therapy. After six months the group receiving TEACCH therapy showed significant improvements over the control group in “Perception, Fine Motor, and Gross Motor subtests on the CPEP-R Developmental scale” (Tsang et al., 2007, p. 392). The participants were still showing improvements at the 12-month check-up. However, the retention rate of participants in the control group would make it impossible to make any comparisons.

Both of these studies show that TEACCH was effective in helping children with autism learn, however each study had limitations. Each study had a small sample size and participants were not randomly assigned, which makes it difficult to generalize results to the entire population of children with autism. Researchers (Tsang et al., 2007) knew to which group participants had been assigned, which could result in bias.

Callahan et al. (2010) compared ABA therapy techniques with TEACCH therapy methods. Both methods use discrete trials and structure. The researchers found each method worked equally well in teaching children with autism social rules along with

other developmental skills. In addition, both parents and professionals achieved success when treatment guidelines were followed.

The SonRise program, another educational intervention, is a home-based therapy that follows the lead of a child instead of a parent or professional (Boucher, 2009; Williams & Wishart, 2003). The family is responsible for selecting and training volunteers to work with their child. Families, who are interested in providing this therapy in their home, attend a training session. They can also receive follow-up training or contact professionals to ask further questions. The SonRise therapy involves a volunteer/caregiver following a child around their environment performing the same actions and sounds the child is doing. Once the child is focused on the adult, they would expand on the current activity in an attempt to increase the child's social and communication skills. "Throughout the interaction, the adult tries to maintain an accepting and non-judgmental attitude," which is key to the SonRise program (Williams & Wishart, 2003, p. 292). Rewards are provided to a child when they perform a desired action or behaviour.

Williams and Wishart (2003) stated that six months after families received training for SonRise therapy children were receiving, on average, 19 hours of therapy per week with one parent providing about 11 hours and another family member or volunteers doing the remaining 8 hours. Some families made adaptations to enhance the programs efficiency for them and noted that the SonRise program was time-consuming. Families felt pressures/stress when providing SonRise therapy to their child, often feeling they were losing time with other family members (Williams & Wishart, 2003).

Williams (2006) extended the previous study to determine what additional treatments children were receiving with SonRise therapy. It was found that 58.7% of children were participating in other therapies. Twelve participants followed special diets such as the gluten-free/casein-free diet, eight children received vitamin supplements, six participants were receiving TEACCH therapy, four were in music therapy, and four were in speech and language therapy (Williams, 2006). Some children were involved in several therapies at a time. When children received more than one intervention, it was difficult to determine which intervention created the effects researchers were seeing. Senel (2010) acknowledged that applying one or more interventions or switching from one to another makes it hard to determine side effects and benefits.

SonRise is intended to improve a child's social and communication skills, yet the two studies cited above do not address improvements in the three major characteristics associated with autism. Instead the studies focused on the number of hours families were dedicating to SonRise therapy and other therapies the families were using.

Another intervention, Early Start Denver Model (ESDM), is designed to work with infants and toddlers who show signs of autism (Dawson et al., 2009). This model uses ABA techniques and focuses on "developmental and relationship based approaches" (Dawson et al., 2009, p. 18). ESDM is highly structured and is implemented by parents or professionals in the child's home. Vismara and Rogers (2008) asserted that the Denver Model provided an environment that encouraged building relationship between a child and other individuals. This model was developed for children who show signs of autism early in life without having a diagnosis of autism. For instance, children may lose their babbling skills or stop responding to their name. Through this model, parents are

taught ways to interact with their child and how to teach their child appropriate interactions with others.

The results of a case study applying ESDM therapy showed improvements in the child's speech, developmental capacities, and play and imitation skills (Vismara & Rogers, 2008). However, this child was never diagnosed with autism. Questions have been raised concerning this model: do ESDM practices catch and correct behaviours associated with autism, or would the child have matured and obtained developmental skills without the intervention? Nevertheless, the authors state that the Denver Model could be helpful for parents and their infants and toddlers.

A study by Dawson et al. (2009) compared two groups of children with autism; one received ESDM and the other received a community-based intervention. The subjects in the ESDM group had an increase in IQ of just under one standard deviation, and the children were still improving after two years. The ESDM group's receptive and expressive language improved compared to the results of the community-based intervention. In addition, children's daily living and motor skills improved and seven children (30 %) had a change in their diagnoses, from autism to PDD-NOS (Pervasive Developmental Disorder, Not Otherwise Specified) (Dawson et al., 2009). The Denver Model seems to have no effect on repetitive behaviours, yet the authors suggest it can be an effective intervention if parents follow the guidelines. The ESDM model teaches children with autism social and communication skills.

One final educational intervention, Pivotal Response Training (PRT), is based on ABA techniques in that it creates positive outcomes through "reinforcements, consequences and extinction" by focusing on pivotal areas of social language and play

(Baker-Ericzen, Stahmer, Burns, 2007, p. 52). A child is given a choice of activities and he/she chooses one to play; then the worker uses clear instructions throughout therapy to guide appropriate behaviour (Bryson et al., 2007). The aim of Pivotal Response intervention is to increase a child's motivation, self-management, initiations and responsiveness to multiple cues and environments (Baker-Ericzen et al., 2007; Bryson et al., 2007). This intervention is also child-directed, and therapy is provided in a natural environment rather than a highly structured environment (Baker-Ericzen et al., 2007; Bryson et al., 2007). Pierce and Schreibman (1997) noted that the provision of this intervention in a naturalistic way could increase chances of generalizability.

Baker-Ericzen et al. (2007) researched PRT by selecting children who had a diagnosis of autism and no other underlying disability, which made the sample size small. The participants involved were Hispanic and the intervention guidelines were easily adapted for Hispanics by translating the training books. The greatest improvements found in this study came from children who started PRT at the age of three or younger, a finding that supports early intervention. Pierce and Schreibman (1997) described PRT as effective in producing change in social behaviours and the number of social initiations made by children with autism increased. This method helped improve social skills, but did not appear to address communication or repetitive behaviour issues. In this study, peers from participants' classroom were also trained in PRT strategies, which could help increase socialization and generalization of skills. Another article by Bryson et al. (2007) found that PRT helped facilitate social communication, which allowed play and other social skills to develop. The authors noted that the province of Nova Scotia applies PRT strategies in home, community, and day care settings and outlines the reasons for

choosing PRT for Nova Scotia. The authors point out the importance of maintaining skills children have learned by integrating mastered skills with new skills, which increases learning and generalization.

Families use additional therapies along with educational intervention(s) that may focus on self-help, language skills, and/or sensory issues. Interventions build social and pragmatic language skills by rewarding a child's efforts (Jefferson & University of Arkansas for Medical Science, 1999; Towbin et al., 2002). Interventions can also include therapies to strengthen fine and gross motor skills. In addition, the authors mention PECS (Picture Exchanged Communication System) and art and music therapy to help increase nonverbal communication skills. Interventions often focus on acquiring social skills by teaching eye contact, appropriate behaviours, and rules regarding social interactions, as well as helping children understand their feelings and those of others (Jefferson & University of Arkansas for Medical Science, 1999).

PECS is mainly used by children who are nonverbal to increase communication (Jurgens, Anderson, & Moore, 2009). There are several steps to teaching a child how to use PECS. First, they need to learn how to pass a picture to another person in exchange for a highly reinforcing reward. Eventually, the child will be able to discriminate between pictures and ultimately be able to build a sentence to give to another individual, usually to request an item. The authors found improvements in verbal language, joint attention, and increased self-initiation play, along with a decrease in inappropriate behaviour, with the use of PECS. In Jurgens et al. (2009) case study they found the number of spoken words increased when a child was using PECS. The authors also note

low generalizability to other environments in the child's life and mention that for a child to use PECS, the pictures must be present and accessible to the child at all times.

Sulzer-Azaroff, Hoffman, Horton, Bondy and Frost (2009) reviewed 34 studies to determine the effectiveness and benefits of using PECS. It was found that PECS improved communication, and some children did generalize the use of PECS to individuals other than the trainer. The majority of children used PECS to request an item or food, while some children learned to use pictures to help them describe things in their life. Furthermore, it has been noted that PECS decreased inappropriate behaviours, a decrease which could be caused by reducing a child's frustration with communication. Finally, the authors stated that if children are provided with ample opportunities, continue their training, and maintain the skills learned through PECS, they may develop a means of functional communication.

There are other interventions known as medical therapies; however, these therapies often are not researched using a controlled group (Golnik & Ireland, 2009). It is important to note that none of the medications mentioned below "affects the core features" of autism (Towbin et al., 2002, p. 380). Family members should be aware of and understand side effects related to medical therapies and consider these therapies as a last resort, unless the person has symptoms which are severe and is difficult to manage. If a child's behaviour affects their safety or causes them stress, then medication may be needed (Towbin et al., 2002). Children receiving any form of medical therapy should be monitored by a professional for health and safety reasons (Towbin et al., 2002).

Prescription drugs that work for particular disabilities associated with autism have also been used to help treat children diagnosed with autism. For instance, prescriptions

used to relieve effects of Attention Deficit Hyperactive Disorder (ADHD) may be used for children with autism to reduce their hyperactivity (Hollander et al., 2005). Blacher (2003) researched a drug called risperidone, an antipsychotic agent, with 101 subjects ranging from 5 to 17 years old. The main focus of the study was to test the safety and effectiveness of risperidone. The results indicate that the participants in the risperidone group showed significant improvements over the control group in “irritability, tantrums, aggression, self-injurious behaviours, stereotypic behaviour, hyperactivity and, marginally social withdrawal” (Blacher, 2003, p. 73). The results are similar to those observed in a study by West, Brunssen, and Waldrop (2009), who found risperidone to be effective in decreasing irritability, aggression and self stimulating behaviours. Blacher (2003) stated that 69% of the treatment group showed more positive responses, as compared to 12% for the control group. Kendall and Comer (2010) also studied effects of risperidone and found that it reduced self-injurious behaviours often seen with children who have autism. However, some participants in the risperidone group experienced side effects which included “weight gain, dizziness, drooling, tremors and fatigue” (Blacher, 2003, p. 74). After a few weeks of participants not taking the drug, the negative side effects disappeared. Matson and Dempsey (2008) stated participants continue to show improvements once they stopped taking risperidone. It is unknown if participants outgrew particular behaviours or learned a replacement behaviour. Thirty individuals who showed improvements continued to take the drug and six months later, 23 participants were still showing improvements. The study was relatively short, so the long-term effects of risperidone are unknown. However, this study supports the theory



that risperidone helps decrease negative behaviours associated with autism (Blacher, 2003).

Scott and Dhillon (2008) also researched risperidone and its effect on people who have autism. The authors stated that risperidone has been proven to reduce irritability in youth from 5 to 16 years old. When taken orally, risperidone was found to improve stereotypic behaviours and hyperactivity when compared to the participants' baseline. The authors also noted side effects of weight gain, along with increased appetite, dry mouth, and somnolence, and comment that long-term effects of risperidone are still unknown.

Another study, by Aman, Lam, and Collier-Crespin (2003), used surveys to determine the number of people taking medications to control behaviours associated with autism. A total of 417 people responded to the survey, with an average age of 13.24 for participants (ranging from 2 - 46 years old). Several participants were using a variety of antidepressants: Prozac (8.6%), Zoloft (3.8%), and fluvoxamine (2.6%). Participants report using several antipsychotics, which included risperidone (10.3%), Zyprexa (1.9%), and thioridazine (1.9%). Anticonvulsants were also used by participants: valproic (4.3%), Tegretol (3.8%), and Lamictal (0.7%). In addition, some people used stimulants such as Ritalin (9.1%), Dexedrine (1.4%), and Adderall (0.7%). Many participants report using psychotropic drugs and some subjects took more than one medication. As seen in these percentages, many people are using medication to help improve various aspects of autism, and families need to know whether these drugs are helping their children and what the side effects are. Aman et al. (2003) concluded that as subjects grew older, the use of psychotropic drugs increased by about 7 % and people took medication if

symptoms of autism were severe. Several limitations to this study include the researchers not knowing if the respondent to the survey was a professional or a family member; in addition, there were no questions asking why participants were taking each medication.

A similar article discussed which medications would assist in targeting particular aspects of autism. Towbin et al. (2002) say risperidone, clozapine and olanzapine are used for “aggression, agitation and self-injurious behaviours” (p. 381). Anticonvulsants and mood stabilizers, such as Tegretol, valproic acid, and lithium could also help manage aggressive behaviours. Other aspects of autism, such as rituals, problems with transitions, and anxiety have been managed by Prozac, Paxil, and Zoloft. Finally, Ritalin has been used to manage hyperactivity associated with autism, yet it has been found to increase stereotypic behaviours. An antihypertensive drug called clonidine calms hyperactivity and helps with problems associated with sleep, although this drug does not help maintain attention. However, the positive results are often noticeable only for a short period of time.

Research on the brains of people with autism has determined that certain areas of the brain have altered serotonin (5-HT) levels, which could be related to repetitive behaviours associated with autism (Hollander et al., 2005). This may mean that a low dose of Selective Serotonin Reuptake Inhibitors (SSRI), such as a liquid form of fluoxetine, could help people with autism to decrease their repetitive behaviours. Hollander et al. (2005) studied the effects of fluoxetine. In this study, 19 subjects received fluoxetine followed by a placebo, and 20 subjects had a placebo first followed by fluoxetine. Each group had an eight-week session and then a four week wash-out phase before switching drug type, and then another eight-week session.

The subjects who received fluoxetine were less likely to report insomnia, anxiety, and urinary incontinence, and more likely to report sedation, agitation, diarrhea, and anorexia (Hollander et al., 2005). One statistically significant finding was liquid fluoxetine did decrease repetitive behaviours over the placebo group. However, this study was only 20 weeks long and the four-week wash-out time may not have been long enough to remove the entire drug from participants' bodies, which could affect the results.

West et al. (2009) reviewed evidence for using SSRIs in treating autism and note SSRIs are not an effective treatment for the three major impairments of autism. Serotonin influences people's sensory perception, motor coordination, memory and sleep, yet the actual relationship between serotonin and autism is unknown. The results of the study show that SSRIs can be effective, but they can cause hyperactivity, agitation, and suicidal ideation. Therefore, the side effects could outweigh any positive effects the drug may have (West et al., 2009). Other drugs, such as fluvoxamine and fluoxetine, have been tested using controlled studies, with mixed results. Without clear evidence for these drugs they are still being prescribed to people with autism. A problem with medical treatment research is the lack of randomized controlled studies, which makes it difficult to determine the drugs' effectiveness and safety (Boucher, 2009; Matson & Dempsey, 2008; West et al., 2009).

Another medical therapy families have tried is a gluten-free/casein free (GFCF) diet. This diet is being used in about 25% - 50% of families and has shown some improvements in children's behaviour (Golnik & Ireland, 2009). Senel (2010) stated that 70 % of participants in one study were on special diets or supplements that were often

considered helpful by family members and other people associated with the participant. People with autism have been recognized at times to have more or fewer proteins than normal, such as toxic peptides (Page, 2000). Special diets have been found to reduce the toxic peptide which develops from too much protein. In addition, the diet is said to decrease negative behaviours. The GFCF diet avoids foods that contain gluten, such as wheat products, oats, barley, and rye, and items that contain milk products (Elder et al., 2006; Irvin, 2006). Most of the studies on diets assess information provided by family members and teachers, which includes information based on notable changes in a child's behaviour.

Elder et al. (2006) studied 12 males and three females ranging from 2 to 16 years old to determine if the GFCF diet had any effect on the symptoms of autism by investigating urinary peptide levels. Participants were randomly assigned to having either the special diet first or regular diet and after six weeks the diets were switched. No differences were found between the groups based on the Childhood Autism Rating Scale, and there were no differences in the subjects' behaviours or the group data for urinary peptides levels of gluten and casein (Elder et al., 2006). The families were asked if they could tell which group their child was in at the beginning of the study; five families guessed correctly, two did not know, and six were wrong (Elder et al., 2006). However, review of individual data revealed changes in individual subjects. Seven families reported seeing changes in their child's language skills and a decrease in hyperactive behaviours and tantrums, with nine families continuing the diet after the study was completed. This conclusion shows GFCF diet may not affect participants' behaviour substantially. The lack of significant results could be due to the small sample size; also,

the children could have eaten foods that were not included in the special diet, which would affect the results.

Irvin (2006) completed a case study on a 12-year-old boy who was removed from his home and placed in a 24-hour residential treatment program. This boy had behavioural issues, such as self-injurious behaviours, aggression, and destruction of property. The participant was placed on a GFCF diet in an effort to decrease these behaviours. The individual refused food from the special diet: therefore he ate less. The diet phase lasted for a little over a year and the researchers conducted a follow-up study on the participant 30 months later, when he was back to his regular diet. In this case, the diet had no effect on his behaviour, however it is important to remember that only one participant was involved in this study.

Many families (22% - 43%) provided nutrient and vitamin supplements to their child, which are considered a medical intervention (Golnik & Ireland, 2009). Page (2000) found positive effects in some cases when a vitamin deficiency was corrected. The vitamin pyridoxine has been given to children with autism and was found to help improve social behaviours, language, and interest in surroundings, and to reduce aggression (Page, 2000). In addition, children who were given high doses of calcium showed improvements in language, eye contact, and coordination.

Adams, George, and Audhya (2006) studied B<sub>6</sub> levels in children with autism. The authors pooled their data with previous studies and found significant differences in vitamin B<sub>6</sub> levels in the autism group as compared to the control group. The study found vitamin B<sub>6</sub> should be given as pyridoxal HCl or pyridoxine HCl, since pyridoxal 5 phosphate (PLP) may have side effects affecting mental functioning. Curtis and Patel

(2008) found children taking vitamin B<sub>6</sub> showed significant improvements in social interactions, communication and increased their intellectual functioning. However, in similar work, Golnik and Ireland (2009) found mixed results. Curtis and Patel (2008) review nutritional approaches in treating autism. They found multivitamins and mineral supplements significantly helpful in reducing sleep problems and gastrointestinal symptoms. However, these did not significantly improve a child's behaviour or receptive language skills. An article by Senel (2010) reviewed parents' point of view on alternative treatments of vitamins and diets and found parents felt optimistic about vitamin therapy. Parents found either great improvements or fewer improvements with the use of vitamins. At the same time, parents reported less satisfaction with alternative treatments when it came to improving sleep or eating habits.

Overall, it is complicated to study autism since the spectrum is extremely large and every child on the spectrum is different, which makes it exceptionally hard to match groups based on age, gender, behaviour, and severity of the disorder. Even though autism has core symptoms, it manifests in every child differently. Since every child is unique, a therapy may work for one child and have no effect on another child (Lilly et al., 2003). However, one therapy is not necessarily better than another; the intervention needs to match how a child learns and responds (Towbin et al., 2002). Also, more boys are diagnosed than girls, so every study includes a greater percentage of males (Jefferson & University of Arkansas for Medical Science, 1999), which creates complexity in measuring gender differences. A therapy may work for a group of individuals, yet if the group includes only one or two females, can the results be generalized to say the therapy will work for females too?

Ethics increase the difficulty of studying benefits of a particular therapy. A researcher cannot stop a family from trying every intervention possible to help their child. Researchers are left with the question of which therapy caused the differences noticed in a child or group of children. If participants involved in a study receive more than one therapy, it is difficult to determine which therapy had positive or negative effects on a child. If families wish to try a new intervention along with the intervention they previously using, they should add one intervention at a time and allow a few months to observe any changes in their child's skill level.

When families are researching interventions to undertake with their child, they need to be aware of the research and evidence and understand information provided in articles (Senel, 2010). If family members do not understand the evidence in a research article, they should seek professional help in order to make an informed decision. Families should be realistic about the options that are available to them and consider factors related to time, expense, and effort that are involved in some of the interventions mentioned above (Senel, 2010).

### **Parents' and Educators' Perceptions of Programming for Children with Autism**

Rose and Anketell (2009) completed a study with 31 participants assigned to one of four groups, based on age and cognitive skills. The groups consist of: mainstream education (ages 7 -11), special education (ages 7 – 11), mainstream education (ages 12 – 18), and special education (ages 12- 18). The researchers evaluated social skills of participants at the beginning of the study. They determined the severity of deficits in social skills as 4% mild, 30% moderate and 59% severe. The researchers also considered communication difficulties and concluded communication skills were mild in 19% of

participants, moderate in 48%, and severe in 22%. In comparing pre- and post-testing results, many parents felt their child stayed consistent in areas of mood, social skills, and communication. Several parents noticed improvements in social skills and communication, and a decrease in withdrawal behaviour. When evaluating during post-testing some parents found a decrease in their child's skills. The same mixed reviews were found concerning starting conversations, understanding other people's facial expressions, and interacting with peers. Many families at the end of the study stated that their child had made new friends but there was a need for ongoing support. In addition, families found it difficult to attend all sessions and felt the homework was not necessary, since several children lacked writing abilities.

Another study, by Murray et al. (2009), investigated teachers' and parents' perceptions of social skills in children with autism. The children involved were referred to a clinic for social skills training and ranged in age from 5 – 14 years old. The children were divided into two groups, the younger group (5 – 9 years old) and the older group (10 - 14 years old). Parents and teachers answered questionnaires regarding social skills. There was lack of agreement between parents' and teachers' answers to questions. Parents rated the younger group higher on initiation skills while teachers rated maintaining and responding skills higher. Teachers' ratings showed the younger group offered comfort to their peers, yet parents rated the older group as offering more comfort. Again, there was a lack of agreement between parents' and teachers' reports on rating skills pertaining to responses to invitations, responses to questions, initiating interactions, and maintaining and responding to interactions, as well as on participants' social skills. The conflicting results could reflect how children may act in different environments.



However, parents and teachers did have the same perception concerning children's affective understanding. Several limits of this study consist of small sample size, missing data, and the fact that data concerning children with Asperger Syndrome is not generalizable to all populations of autism.

Children with autism learn differently than their typically-developing peers, and school professionals must develop teaching strategies that help children with autism learn (Whitaker, 2007). Children with special needs are now included in mainstream classes, which places demands on teachers to consider special needs in arranging their classrooms and daily schedules. Teachers must consider how children with autism react to social interactions, sensory overload, and change in routines. The teacher should communicate with a family to learn about the child prior to starting school, which could help with the transition to school and improve the following school year (Friedlander, 2009). Families can ask for permission to bring children into the school to become familiar with the surroundings and meet teachers (Friedlander, 2009).

Whitaker (2007) questioned parents about their perceptions and experiences with the school their child attends. When parents were asked if they felt staff understood their child, the responses showed over two-thirds were satisfied, agreed, or strongly agreed while three-quarters were dissatisfied, disagreed or strongly disagreed. Several concerns were expressed by parents: teachers understanding of social skills and happiness, how well staff understands their child, and if teachers can manage their child's behaviours and needs. Parents claimed they do not expect teachers to be experts, but some parents expressed concerns that the curriculum was not modified appropriately. Parents also felt that social skills should be taught to their child directly, along with the rest of the

curriculum. Whitaker (2007) found when parents feel the school is not meeting their child's needs, this can cause considerable stress for families. Overall, families felt teachers were effective but may not understand other difficulties parents may be facing, such as behavioural issues.

Parents mentioned that schools could provide more supervision and protection which could be a concern resulting from children being bullied, not developing gross motor skills, or from children lacking fear and failing to understand the consequences of their actions (Whitaker, 2007). Several parents voiced that schools should try to help peers understand and accept children with autism. Forty-one percent of parents were dissatisfied with the relationship they had with their child's school and the main concern parents had was the quality of communication between school and family. Parents felt valued if they felt the school listened and took their concerns seriously and preferred staff that was willing to ask them for advice (Friedlander, 2009).

Friedlander (2009) mentioned several ideas teachers can use to help make the school year run smoothly. One suggestion is the use of social stories, which can explain appropriate behaviours and/or actions to be used in certain situations. For instance, if a child is having difficulty sharing toys, a social story can be developed explaining why we share, how it makes others sad if we take a toy and how we wait for our turn. Pictures accompany the words of the story to increase understanding and the story should be read to a child as often as needed. Another idea for teachers to consider is the use of fidget toys or a cushion on a child's seat to help increase focus on school work. In addition, children may be on a sensory diet (developed by an occupational therapist) which parents and teachers should follow in order to provide the correct amount of sensory input, which

will help increase focus. Teachers should incorporate visual schedules, model appropriate social skills, and try to use fewer words when explaining concepts to a child with autism.

When parents trust school professionals, it increases cooperation and often creates a positive correlation with school performance (Lilly et al., 2003). Parents want school professionals to listen to their thoughts and concerns and be willing to help them with their child. On the other side, parents need to acknowledge their child's capabilities, since school professionals cannot make their child become someone they are not (Lilly et al., 2003). An Individualized Education Plan (IEP) for children helps parents and professionals come together to develop goals and needs which are specific for each individual. When professionals meet with parents they should ensure their language is understood by family members, and professionals need to acknowledge that family members are experts on their child's abilities (Fish, 2006).

Most of the studies mentioned have been conducted in the United States, and the Canadian studies were not from Newfoundland. The current study will focus on parents' and teachers' perceptions of programming in schools for children with autism. The results will be compared to previous studies to determine whether participants from Newfoundland have the same perceptions as participants outside Newfoundland. The object of this study is to reveal families' and teacher's perceptions of programming in school for children diagnosed with autism. The study will consider how families and teachers feel about program development, their involvement, and the implementation of programs. In addition, there will be questions concerning programs, supports, and services for children with autism and how children can be included in the classroom.

## **Chapter 3**

### **Methods**

This chapter contains an introduction to qualitative research methods and an overview of the research process for this study. It includes a description of the data collection process, potential participants, and measures. Data collection and analysis procedures and ethical considerations are also noted.

#### **Qualitative Research**

Qualitative research provides an in-depth understanding of the perspectives of participants involved through a variety of approaches (Denzin & Lincoln, 1994; Jeanfreau & Jack, 2010; Thomas & Magilvy, 2011). This research method can include grounded theory, phenomenology, ethnography, narrative inquiry and case studies (Nolen & Talbert, 2011). A qualitative researcher develops a set of beliefs which influences how he/she thinks and views social phenomena's. This development of beliefs is known as ontology (Nolen & Talbert, 2011; Denzin & Lincoln, 1994). These views affect the way a researcher investigates social phenomena. The researcher determines the best method to use when exploring social issues. This step of qualitative research is called epistemology. This type of research does not believe in one particular truth since each participant will have their own point of view and experiences.

Qualitative research provides descriptions of participant's life experiences concerning the area being studied. This method is more interactive than quantitative data collection. It provides greater insight into participants' life experiences (Jeanfreau & Jack, 2010), as social phenomena is explored through dialogue and observation, rather than numbers (Nolen & Talbert, 2011). Qualitative research is participant focused and

gives participants a chance to voice their point of view concerning the particular topic being studied (Thomas & Magilvy, 2011).

Qualitative researchers provide an environment, whether through case studies or interviews, where participants can inform others of their experience. This helps readers to understand and connect to participants' life experiences. Interviewing a small group of participants can help identify issues and/or concerns within a particular population (Jeanfreau & Jack, 2010). Interviews can be structured or semi-structures with open-ended questions (Madill & Gough, 2008). A semi-structured interview offers opportunities for a researcher to listen to participants' answers and ask questions related to their answers to receive more information regarding the topic of the study. If researchers select a semi-structure style, they need to be aware and cautious with follow up questions (Hallberg, 2008). For example, a researcher may ask a follow up question that reflects his/her preconceptions of the issue being studied and based on personal views rather than one that builds on the participants dialogue (Nolen & Talbert, 2011). This could affect the results and outcome of the study. Regardless of interview style, the researcher must develop a trusting relationship with participants so they feel comfortable in sharing their life experiences (Hallberg, 2008).

After the data is collected and transcribed, the researcher begins the process of analyzing the data to find emerging themes through a process called coding (Jeanfreau & Jack, 2010). The researcher initially reviews transcripts, noting participants' responses. She then looks for similar ideas that appear several times in response to questions and throughout the interview which captures the core of the social phenomenon being studied (Madill & Gough, 2008). An interview will be coded to distinguish re-occurring themes

connected throughout the interview and then compared to other interviews to determine if the same themes appear in order to determine interconnectedness (Nolen & Talbert, 2011). Themes are also compared to previous literature to establish whether the themes are consistent with previous findings (Nolen & Talbert, 2011). The interviews and themes will continue to be coded and collapsed until no new themes appear (Fitzgerald 1994).

Reliability and validity may be difficult to establish in qualitative research. Collecting additional data that confirms the initial themes helps improve the validity of the original findings (Hallberg, 2008; Thomas & Magilvy, 2011). Reviewing transcripts and having others complete blind reviews to determine similarities and to calculate inter-rater reliability also helps create credibility in the research results (Thomas & Magilvy, 2011). Researchers can also allow participants to read their transcripts, memos and coding to ensure researchers interpretations of the interview is correct, which helps increase readers' trust in the research (Bogdan & Biklen, 1998). Researchers must be cautious and not enter the research process with preconceived assumptions and expectations (Hallberg, 2008). Therefore, researchers must code and analysis data with an open mind to make certain they do not interpret results in a manner that reflects their point of view.

Ethical considerations, which guarantee the rights of participants, must be included with all research, but especially with qualitative research. These considerations include respecting participants, treating participants with dignity, confidentiality, and ensuring no harm comes to participants (Hallberg, 2008).

Overall, qualitative research provides an overview of the experience an individual had at some point in his/her life. Qualitative research usually involves small sample size yet the research still provides valuable information that cannot be gain using other research methods.

### **Participants**

Data was collected from two participant groups. The groups are as follows:

- 1) Three elementary school teachers employed by the Eastern School District of Newfoundland who are currently teaching children with autism or have taught children with autism within the last two years; and
- 2) Four parents who have a child with autism who attends one of the elementary schools within the Eastern School District of Newfoundland.

The Eastern School District has been divided into four regions because of its geographic size. All participants were from one region, the Avalon East Region, of the district. This region has over 20 elementary schools.

### **Measures**

Two measures were employed in this study.

1. Demographic survey - Both parents and teachers were asked to complete a demographic survey. Information was sought on participant's gender, education, and experience. This information helped situate the data and provide comparisons among groups. (Appendix A).
2. Interview Schedule - The researcher developed a set of questions based on her own experience and a comprehensive review of the literature. The questions were open ended and sought participants perceptions on the programs and services

available to children with autism and their families. For example, participants were asked questions focusing on programming for children with autism, support services, and inclusion of children with autism in the community. (Appendix B).

## **Procedure**

The researcher applied for ethics approval from University Research Ethics Board at Mount Saint Vincent University. Once ethics approval from the University was obtained, the research proposal was presented to the Ethics Board of the Eastern School District for approval. When the proposal was approved, the Eastern School District selected schools that the researcher could contact. The researcher initially contacted each school by phone. During the phone conversation with the principal, the researcher provided an overview of the purpose of the study, reviewed what was expected of school personnel and the researcher, and asked if they were willing to participate. If they agreed to participate, additional details such as number of potential parent and teacher participants was obtained. A follow-up letter summarizing information presented during the phone conversation was sent to the school principal (Appendix C).

Participating schools were sent the recommended number of research packages. Each research package contained a self-addressed, stamped envelope; a letter explaining the purpose of the research (Appendix D) and detailing participant's rights; the appropriate demographic survey; and a consent form (Appendix E). Principals distributed packages to teachers and families who meet the criteria for the current research. If teachers and families choose to participate in the study, they can return the demographic survey and consent form to the researcher in the envelope provided. The researcher contacted individuals who have returned the completed demographic survey



and consent form, to arrange a time and place for the interview. As few individuals responded, all were selected.

Interviews took place at a time and location convenient for participants. Every effort was made to ensure participants were comfortable. Prior to beginning the interview, participants were reminded of their rights. Once the interview began, participants were encouraged to speak freely and provide as much detail as possible. Non-directive prompts such as “tell me more” were given. All interviews were audio-taped. Tapes were coded and no identifying information appeared on tapes or transcripts.

### **Data Analysis**

Once the interviews are transcribed, verbatim, the researcher started coding and analyzing each interview. The analysis was undertaken with the assistance of a second coder, using a cross-comparative approach to the discovery of themes, patterns, and conceptual links within the data. Such shared and constant comparisons of data contribute to the “trustworthiness” of the interpretations (Bogdan & Biklen, 1998)

Transcripts were first analyzed through *in vivo* coding that captures “important attitudes, perceptions, feelings, and processes contained in the participant’s experiences, as well as the context in which they occurred” (Fitzgerald, 1994, p. 467). Extracting participants’ key words and phrases related to topics of discussion within the individual interviews was an initial step in the analysis process. With ongoing cross-comparison of the data, initial codes were clustered, collapsed, and thematically conceptualized. Subsequent second and third level coding was undertaken until the data was organized into major categories that explain the data for purposes of discussion.

**Ethical Considerations**

Participation is voluntary. In addition, participants will receive an Informed Consent form outlining their rights that must be signed prior to their interview. The possibility of harm in this study is considered low. However, all participants will be informed that they do not have to answer any question which makes them feel uncomfortable. As well, the confidentiality of participants is paramount. Transcripts and the final thesis document will contain no names of participants or schools.

Since the researcher works with Intervention Services with Eastern Health and she has requested that she not be assigned any clients on her caseload who have been diagnosed with autism and are attending one of the schools in the data collection region. This will eliminate potential conflict of interest issues. Participants will also be informed that this research is not associated with Eastern Health or the services they may receive nor will it influence their status with Eastern Health or the school board.

**Research Questions**

1. How did participants define autism?
2. How did participants describe their experiences working with children with autism?
3. What were participants' perceptions of the program planning process?
4. What were participants' perceptions of the program implementation process?
5. What were participants' perceptions of the programs/supports/services currently available for children with autism?
6. How did participants feel children with autism could be included in the school?

## **Chapter 4**

### **Results**

This chapter contains the results of the qualitative analysis of the one-to-one interview data. Interviews were audio-taped and transcribed verbatim, but removing any identifying information. Each transcript underwent several layers of review to extract common themes. The main themes arising from the data are presented along with description of the participants.

#### **Participants**

Seven female participants were involved in this study, four parents and three teachers. The parent's ages ranged between 26 to great than 46 years old. Regarding education, two parents had Bachelor degrees, another parent had high school with some university courses, and one parent completed a two year program at community college and three years of a four year university degree. The parents' occupations included manager, home-maker, and youth care worker. One parent did not list her occupation. Participants had children attending Kindergarten, grade 1, grade 6 and grade 8. All parents attend workshops including Geneva Center Conference, Eating on the Spectrum, Autism and the Education System, Applied Behavioral Analysis – Regional Autism Services, a conference with Temple Grandin, and a communication seminar with Speech Language Pathologists from Eastern Health.

The teachers involved were between the ages of 26 – 35 years old with two teachers being homeroom teachers and one teacher a special education teacher. The education of teachers included one with a Masters degree, one with a Bachelor degree and the last one with a Bachelor degree and a special education degree. Their experience

ranged from six to eleven years of teaching and they taught between two to seven children diagnosed with autism. At the time of the interview, the teachers were teaching Kindergarten, grade 1 and high-school. As well as parents, teachers completed workshops including professional development on Autism Spectrum Disorder (ASD), special education courses, classroom strategies for ASD, visual schedules and Behavior Management Plan.

## **Emerging Themes**

### **Defining Autism**

Parents were asked to define and/or describe autism in their own words. Two main themes emerged from their responses communication and social concerns. Parents noted that children with autism have difficulties with communication. While some children did have speech, engaging in typical communication with others was an issue. As well, parents pointed out that children with autism have social concerns as evidenced by their difficulties adjusting to and interacting in social situations. Parents noted that the overlap between communication and socialization was obvious, especially as it pertained to understanding body language and interrupting other people's body language. One parent noted that autism was a neurological disorder and another mentioned that it is associated with learning problems. Comments by parents include:

“It’s a neurological disorder that has resulted in my daughter having difficulty communicating with others through spoken language and she has difficulty with social interactions and understanding body language.”

“social I think is more of it than anything else, but it’s also in how they learn. It’s a learning problem as well.”

“She didn’t have language but she had speech. She was very echolalic.”

“We have a lot of anxiety and emotions are completely overwhelming. She understands them too well and she is very empathetic.”

“His difficulties are more social and communication difficulties”

“I would describe it as a life-altering situation for every member of the family, but in lots of ways not necessarily in a bad way.”

Similar to parents, teachers also noted the communication and social concerns associated with autism. However, teachers, but not parents, also pointed out the behavioural issues associated with autism and that autism was a spectrum disorder. Teachers found that children with autism were anxious and had communication difficulties, especially with expressing their emotions. Social concerns were generally in line with those noted by parents. Teachers also found that these children often demonstrated inappropriate and/or unusual behaviors, such as aggression or verbally blurting out things during class. Teachers focused on the fact that autism is a pervasive developmental disorder that presents differently in every child. Several other descriptors, some divergent, were noted by teachers when defining autism. For example, teachers found that some children with autism can be academically strong and/or self-centered while others lack common sense. Another teacher noted that her student was kind and loving. Examples of descriptors given by teachers include:

“Autism is a pervasive developmental disorder. So there is a whole spectrum. They have deficits in social abilities, communication, sometimes like fine motor skills.”

“Children who have social issues, they don’t communicate well with their peers and they have issues communicating with their friends and expressing themselves to others.”

“every single child has been completely different. So, what I can say is similar is that there are usually behaviors that need to be worked on. Many have had social issues. I would have said up until this year that a child with autism would have difficulties expressing emotions.”

“Usually there are sensory needs, though, in all these children and but the way the need and the way it is dealt with is different with every child.”

“I find that a lot of children on the spectrum they are very self-centered and think everything is about them, and this child in particular does.”

### **Experiences with Children with Autism**

When parents were asked to share their perceptions on parenting a child with autism, three themes emerged. Parents expressed that the experience could be rewarding, challenging, and time consuming. Parents stated that looking after their children with autism took a lot of time. Even simple community outings had to be planned, the child had to be prepared for the transition, the site checked out, they had to explain where they would be going to the child and inform him/her what to expect, and getting their child dress and ready to leave could be a challenge. Raising a child with autism, parents stated, was a lot of extra work along with increased anxiety. Parents felt they were split in many directions. They were parents, teachers, and researchers. They taught their children social rules, carried out therapies, parented, and keep up-to-date on recent research to help them understand autism and learn new strategies and techniques that had worked for other families who had a child with autism. Families struggled with judgements from other people and worried about their lack of understanding and knowledge of autism. However, parents were also extremely happy when their child learned a skill they have been working on for some time. One parent stated that learning skills that families with typically developing children take for grants was a huge deal for families who had a child with autism. Comments by parents included:

“it’s different from parenting normal children. She doesn’t understand things like tone of voice when you’re angry. She’s much more literal than the others.”

“very trying at times, but very rewarding as well, because when you work hard with the child and you see the strides that she makes, it makes you feel great.”

“parenting a children with autism, there is a lot of anxiety and a lot of fear for your child”

“when your child is taller than you and they’re having a meltdown in a public place, or they can’t keep it together, or whatever is happening, it really makes it difficult for the parent because you’re trying to focus on the needs of the child in front of you but you’ve got everybody around you looking, and you know the judgement is coming at you.”

“things that wouldn’t necessarily be a big deal for other children are a huge deal for these children.”

When teachers were asked about their perception working with families who have a child with autism the main theme that emerged was the relationship they developed with families. The teachers mentioned working closely with families to form a supportive relationship. They stated that families were very knowledgeable, understanding, and helpful in providing information to staff regarding things they tried at home and which ideas worked or did not work. One teacher stated that through a team approach they are able to keep a consistent routine for the child at home and in school. Another teacher said the relationship depends on the willingness of families, while a different teacher mentioned that socioeconomics circumstances may be a barrier when working with families. Sample quotes from teachers include:

“you have to work really closely with the families but it depends what the family is like and how willing they are”

“The families that I’ve worked with, they are very supportive. They understand. They are very real. They know what’s going on”

“For the most part, they are really good at helping and giving us information on what we can do.”

“Most of the children that I’ve taught, I’ve had a really good relationship with the families. That’s imperative.”

“I have taught a couple of children whose parents unfortunately don’t know a whole lot themselves and are lower socioeconomic families and it can be really difficult.”

### **Expectations for Children with Autism**

Parents felt social and communication skills were the most important tools that children with autism needed to acquire for the future. Parents’ concerns surrounding communication were focused on their children’s lack of conversation skills. They noted their children’s misunderstanding of idioms and phrasing. Difficulty with understanding body language and picking up on social cues were also a concern of parents. Social skills, as one parent stated, are necessary in order for my child to function in the real world. Children with autism are faced with social situations on a daily basis and understanding verbal and non-verbal cues ensures acceptance. Another parent mentioned the importance of her child having self control and being able to deal with anything going on around him or involving him appropriately. Comments by parents included:

“She needs to learn skills with communicating. She wants to have friends but she’s really awkward and unsure and she doesn’t interpret their physical expressions properly all the time.”

“she doesn’t pick up on social cues. And she doesn’t know how to carry a conversation.”

“Finding a way to help them effectively deal with what’s going on around them, because that’s very hard for them.”

“Social skills definitely because that’s the hardest thing and it’s the thing that triggers the most anxiety when it doesn’t go well. And it’s the thing that’s going to allow him to be out in the world”

“But he has little ability to empathize or sympathize or realize his actions affect others”



Teachers, as well, expressed that they considered social skills to be the most important skill for a child with autism to learn. Similar to parents, teachers considered appropriate social skills to be helpful in everyday life and especially essential for sustaining relationships and independence. If children are able to learn appropriate social skills, then they can communicate and express themselves which in turn will help them form relationships with others. Two teachers noted the importance of children with autism learning to be independent so that they could work and live in the community. Another teacher mentioned the importance of children learning to be attuned to their sensory needs so that they can relax and regulate sensory input and express these needs appropriately to another person. Below are comments by teachers:

“Independent living skills”

“Finding their sensory outlet, finding what they need to do to make them comfortable; especially when they have a moment of outbursts or they’re unhappy or the anxiety heightens.”

“being able to communicate and express their feelings to others appropriately and to form good friendships and relationships with peers”

“some independence in their life at some point they have to learn some social cues that are really important and some skills that are really important in order for them to be able to function independently”

### **Individual Program Planning Meetings**

Families stated the guidance counsellor allocated to their school was responsible for organizing and chairing the program planning meetings. A parent stated that when her child was younger, they had more program planning meetings. However, she never mentioned who called the original meetings, but did state extra meetings could be called by the classroom teacher or herself. Another parent said she was responsible for organizing. Quotes from parents included:

“I do that”

“I called the meeting or the teacher called the meeting”

“Usually that’s the guidance counselor.”

“The guidance counsellor”

Teachers, like parents, also remarked that program planning meetings were normally scheduled by the guidance counsellors. However, parents or classroom teachers can also call a meeting when needed. One special education teacher stated she was the Individual Support Service Plan (ISSP) manager and she would call the meetings, but the guidance counsellor would attend. Responses from teachers are as followed:

“Well me, I am because I am his ISSP manager.”

“Usually the guidance counselor in school and the parents will start up the meetings”

“Our guidance counsellor. Now however, the guidance counselor, she is very hands-on but often parents, they absolutely can call a meeting.”

There are a wide variety of school professionals and family members who attend the program planning meetings. According to parents, the school professionals usually involve the principal and/or vice principal, the guidance counsellor, teachers, and sometimes the educational psychologist and/or speech language pathologist. Family members usually involve both parents and one parent stated her child attended one meeting. Several families have other professionals working with their child, if possible, they attend the meeting or they may have consults with school professionals. Other professionals who have been involved included occupational therapists, a private therapist, psychiatrists, and counsellors. Professionals from Eastern Health Applied

Behaviour Analysis program including a senior therapist and a home therapist also attended. Comments by parents included:

“Usually the school seems to contribute quite a few staff. They have the principal, sometimes the vice principal comes. They have their speech language pathologist. The guidance counselor, from the school. If they have a resource teacher, she’s there. From our side, it’s usually our senior therapist for ABA; sometimes our home therapist for ABA; and occupational therapist and the parents”

“it would be myself, if my husband was home a lot of times the principal or the vice principal would be there, the guidance counsellor, the teacher, and a couple of times there was the speech therapist, and a few times there was Ed. Psych from the school board.”

“Myself, her father, and then the guidance counselor and as many teachers who are working with her as can be there. She is seeing a psychiatrist and our counselor and an adolescent medicine specialist, but for them to get to meetings is not usually. If they need to provide a letter or a phone call, they are quite willing to do so.”

“Myself and my husband and our therapist were involved, along with the classroom teacher and their guidance counselor. The second time (child) came in as well. Actually, the board educational psychologist was there for the second meeting as well.”

Similar to parents, teachers cited a wide range of professionals who may attend the program planning meetings. These individuals were either school professionals, parents or other service providers. Every teacher stated parents and guidance counselor attended the meetings. Other school professionals involved included special education teachers, speech language pathologists, school representatives, student assistants, administrative staff, educational psychologists, and if requested, the autism itinerant consultant. Professionals who provided services outside of school and attended the planning meetings included social workers, private therapists, occupational therapists, and professionals from the Janeway Children’s Hospital. One teacher stated a child with

autism had attended once while another teacher stated child may attend but it depends on cognitive functioning. Below are statements from teachers:

“Well, me, I am because I am his ISSP manager. I’d have the guidance counselor, if there was a social worker involved, and of course parents or guardians.”

“So, for example, for the child that I have this year, last year in May/June we met with the parents, and any other organization that’s involved. So the OT, anybody from the Janeway, any school representative, sometimes speech is involved, pediatrician”

“The guidance counselor; usually there is someone on administration there; parents; educational psychologist; classroom teacher; any IRTs that are involved with direct programming with the child; student assistance don’t have to be but we have phenomenal student assistants and they always attend meetings.”

Parents stated that there were typically two meetings a year. Two parents said they could call additional meetings if there is an issue, and the school would accommodate another meeting. Another parent stated there were two program planning meetings last year but this year they had only one so far. However, the team did re-group to discuss an issue but no formal changes were made to the written document. The following comments were made by parents:

“So far we’ve only met once. We have to schedule another one coming up for the spring. So, presumably twice a year”

“usually the beginning of the year, and then towards the end of the year, say, sometimes April, May, June to get a plan put in place for the following year. Then usually we don’t have another meeting unless there is some other issue that comes up.”

“We met twice last year.”

A variety of answers were provided by teachers regarding how many meetings they have for children with autism; however each teacher said at least once during the school year. The number of meetings ranged from 1 to 3 meeting(s) per school year. All

teachers stated that additional meetings regarding program planning or any other concern could be arranged when needed. Comments provided by teachers:

“Well, you should meet like three times. At the beginning, like where you want to go, halfway, how it’s going, and at the end like talk, the end of the school year talk about where you’re going for next year.”

“Depends on the child. For the most part, it is usually just once; every May.”

“Usually there is one in the fall and then there is usually one around May/June.”

Parents and teacher all agreed that program planning meetings were always held at the school the child attended.

“Yeah, it is here at the school”

“At the school”

### **Involvement in Individual program planning Meetings**

Parents were always involved in the program planning meetings. Parents felt there main roles at these meetings was providing information and supporting their child. The parents who said they were involved usually provided information regarding home life and how situations were handled, which helps guide program planning in the school system. Parents also remarked that they assumed the role of child advocate and demanded services from the school system to help their child attend classes. One parent said she discussed the needs of her child regarding self help skills since her child is not toilet trained. The parent who stated she was not involved in program planning stated it was due to changes in the school system from pathways to inclusion. This parent expressed concern regarding now her child must follow the curriculum. Some explanations made by parents are below:

“Pretty much I specify what her needs are, what we think she needs help with in order to succeed in the school, in the classroom, and we talk about how her schooling is affecting her behavior at home.”

“We all talked together and I would give them what I thought would help her, and almost always they put in place what I asked.”

“So as far as the planning of the programming, no, we don’t have much input. She either does what they set out in the regular curriculum or she goes and does nothing”

“As his advocate probably, would be the best way to describe it. And I also bring the information from the programming that we do ourselves outside of school to the school setting, and that informs what we do at school, to a great deal, actually.”

All teachers stated they were involved in the program planning meetings as a contributing team member. The teachers explained that they had discussions with team members regarding strengths and needs, and reviewed the accomplishments achieved by the child. The team discussed goals everyone would be working towards, which would help the child function at school and home. Sample comments by teacher were:

“So with students who are on a functional curriculum, we have four domains that we follow. So specifically I can go through and pick things from each domain and each strand that I want.”

“I contribute to the strengths and needs of the child. So what we do is I would also suggest things to them and they would agree or disagree and we would all as a team. So it is more of a team effort but we all get to contribute to it.”

“I have been involved full on with that process because we look at it as the special services delivery team but I am part of the team. So I’m involved from beginning to end basically.”

Prior to a program planning meeting, there are numerous conversations reported by parents. Every parent stated they had daily communication with the classroom teacher and one parent spoke daily to the guidance counsellor. Before and during the meetings, parents discussed what could or could not work for their child, how the school could

support their child and how parents would provide suggestions to the school professionals who attend the meetings. There were also discussions about making changes to the child's plan. One parent asked school professionals about the curriculum so the parents could prepare and learn the material to help their child with homework or provide extra teaching on a topic in which the child might struggle. Another parent mentioned she and her husband would review and discuss concerns and topics before the meeting to help them prepare for the meeting. Another parent stated a few days before school started she was able to bring her child into the school for him to see his classroom and meet his teachers which helped with his transition to a new school. Comments by parents included:

"I've had conversations with her classroom teacher through e-mail and through the parent-teacher meeting in talking about what helps (child) work better and what doesn't help"

"I'm very, very involved on a daily basis. Not so much now but kindergarten to grade four absolutely. I was in the school every day and constant back and forth with the teachers"

"Well, myself and my husband will figure out, okay, what things do we want to cover, what issues do we want to make sure, and we bring that to the meeting."

"we try to make it as support for her as possible. So make sure she stays with her friends that are going to be a support for her and not put her in class where she doesn't know, because making new friends is very, very difficult."

"I have communication almost every day with the guidance counselor and with the teacher."

"typically if we need a meeting –which, like I said, we have several times throughout the year – it will be because we have been discussing particular issue or set of issues over a couple of weeks and then we will decide, all right, we need to change something now."

When teachers were asked if there were any discussions prior to programming meetings their comments were not as consistent as those provided by parents. Two

teachers stated there were always discussions prior to meetings while the other teacher said sometimes, but not always, they had discussions. The discussions could be informing members what would be discussed during the meeting or reviewing the program plan. There could also be documents to review before the meeting or as one teacher noted, the documents could be provided during the meeting. One teacher mentioned during the meeting there could be discussions surrounding planning for next year. For example, she noted that the child with autism in her class enjoys going to the bathroom for a sensory break but next year there is no bathroom attached to the classroom. Therefore the team must plan where and when sensory breaks will occur for the coming year. Teachers made the following statements:

“No, there is a lot of times I will talk about what’s going to happen beforehand, so that everyone is aware. If it is just a general ISSP at the beginning, there probably wouldn’t be. But I send home, I don’t know if you see the ISSPs, like there is the strengths and the needs. So I will send that home from the previous meeting so they can have a look at it first.”

“There is always, yes. Like, at the beginning of the year he had a tent because this is something that worked at home. But what we found is here in school he didn’t like that. He enjoyed going in the bathroom.”

“No, it depends. Like sometimes, when I went into the big fall meeting, this first fall meeting, there were documents forwarded to everyone involved, based on any kind of testing results that had been done. But it has been different per child. But usually there is something to read beforehand but I had gone into meetings before where documents from the parents had been passed over then.”

Every parent stated the guidance counselor summarized and produced the written program plan that was developed from the meeting. However, one parent noted that the Instructional Resource Teacher (IRT) teacher may sometimes produce the plan. When parents were asked how participants indicated their agreement with the plan, three parents stated everyone signed their name and this



was done by passing a sheet around to all participants. One parent said through discussion the team formed the plan together. Several comments by parents are:

“The guidance counsellor”

“Guidance counsellor. Or the IRT”

“We have to sign a form”

“You have to sign it”

Similar to parents, teachers also stated their guidance counsellor summarized the written reports from the meeting. One IRT teacher mentioned she would be responsible for the written report and another teacher said it could be either the guidance counselor or the IRT teacher. Along with parents, teachers also said items are discussed verbally and agreement is indicated by signing a sheet at the end of the meeting. Teacher comments are included:

“Usually it is the guidance counselor or the IRT teacher.”

“Our Guidance Counselor”

“There is signed sheets. After every meeting everybody signs off on what’s been done and what’s agreed upon.”

“Usually it is verbally and we sign. Everybody signs off.”

“So at the end, we’ll go over the goals. And then it will summarize all the strengths and the needs and then there is a page where everyone signs. Everyone who’s at the meeting.”

### **Implementing Programs and Services**

Every parent mentioned that the services their children needed were discussed at the Individualized Education Plan (IEP) meeting, but how these services were implemented varied for each parent. All parents mentioned their child availed of a student assistant. However, one parent stated that while her child was eligible for a

student assistance, they have never had one and were still on the wait list. The level of student assistance also varied for each student, with one parent noting her child had a full time student assistant, while another parent expressed frustration that her child's student assistant was only there for physical needs and not to help her child stay focused in the classroom. Parents mentioned that some accommodations were made to help their children meet their goals/outcomes. One parent stated the school accommodated her child during tests to either give her extra time or another area to write the test to help her maintain focus. Another parent said the school allowed her and her child go into the school to become familiar with the classroom and school surroundings prior to the start of the school year. Two parents also mentioned extra programs developed for their children to focus on specific needs. A parent stated the school implemented a communication log book which was filled out, but often not reviewed with her child. Therefore, when the child came home from school she was still unable to communicate about activities she had completed that day. This parent did say the school was using visuals in the classroom which helped support her child. Another parent worked with the school to develop a sensory room for her child and others to use when needed. However, a parent expressed frustration with lack of speech language pathology services provided by the school. Numerous remarks by parents included:

“We’ve made suggestions to use visual schedules, use an actual timer for tasks because these things help her focus on what she needs to do and how long she has to do it. And some of those have been implemented but the communication from the classroom back and forth on a daily basis, because the child doesn’t say, she comes home from school and you say what did you do today, you’re not going to get an answer from her.”

“they said at the beginning of the year she was approved for individual assistance but she’s not getting it”

“it depends on what was needed at the time, because it always changed. Student assistance was always a huge problem. Speech therapy in school was basically nonexistent. But anything that was a program specifically for (child), then they tried their hardest to put it in.”

“Well, (child) doesn’t really have a lot. They are put in place. For her, it’s not things like student assistance. There is – she’s still on the list to avail of one, if necessary. Things like extra time for test taking, maybe an alternate setting, that kind of stuff. It’s always been put in place.”

“He has full-time TA. He gets three IRT units, which are two hours each week; one for his social issues, one for anxiety; the other one for fine motor.”

Teachers’ responses to how needed services are put in place were more unified, unlike parent’s responses. Each teacher stated that needed services were discussed during the program planning meeting along with discussions on how to implement plans to best suit the child. A teacher stated that she works on life skills, and the skill is broken down into smaller steps for the student to learn the skill and achieve the goals set for him. Another teacher mentioned special subjects are created to help children learn skills, such as self regulation, with the Instructional Resource Teacher (IRT) teaching the skills. The guidance counselor would complete forms to apply for services based at the school level as in student assistance or special transportation. Below are comments from teachers:

“Anything that they can do on their own, like my main goal with my student right now is to get him to do as much as he possibly can on his own; even if it is just heating up his lunch. Like that was one of our big things for this year, being able to go over to the microwave and pres the buttons, that’s what we do.”

“Yes. He received services within the school. So like this year he’s doing self-regulation and sensory. So the IRT teacher would come in and do some things with him.”

“We’ve decided that the child in my class needs a calming room. So I passed that on to guidance and said I think this is what’s happening. She sent off an e-mail to the private therapist and educational psychologist, who both came in and observed, and then we all met and discussed, including with mom, and discussed what we thought everything was a go and the room has now been set up.”

When parents were asked who ensures the program plan is being implemented, all parents said they did. A parent mentioned she was in the classroom every day for the first 5 years; therefore she was able to see if the plan was being implemented. The importance of a team approach in implementing the program was emphasised by another parent. Below are some comments made by parents:

“I guess I had to make sure it was.”

“I was in the classroom every morning because at one point I had to be in the classroom every morning to help her get ready. So it wasn’t until late grade four or grade five that I finally got myself out of the classroom. So I knew.”

“I guess me. But I have to say, we haven’t had a lot of big problems so it is not something that I can really answer”

“I think the whole team would take part in that, because we review it with each report period.”

Teachers’ responses to who ensures the program plan is being implemented were not consistent with parents’ views. All the teachers agreed school professionals ensured the plan was implemented. The IRT teacher said she ensures the program is implemented since she is the Individual Support Services Plan (ISSP) manager. Another teacher said either the guidance counsellor or IRT teacher, since they are the professionals who will stay consistent over the school years. Another teacher said everybody works together to ensure the program plan is implemented and working. Everybody includes the teacher, family, guidance counsellor and student assistant. Statements provided by teacher are:

“I do, as well, yes; his teacher.”

“The guidance counsellor, the IRT, because they are usually the ones that will be working with him next year in the classroom teacher.”

“Everybody.”

When asked how closely the program plan was followed, parents agreed it was followed fairly closely with adjustments made, on times, to the plan. However, the type of adjustments varied. A parent said she informed the school her child was not toilet trained before entering school and the school placed her child in the kindergarten classroom with no bathroom. When her child had to use the bathroom another peer would escort her to the bathroom. A student assistant was provided after the mother voiced her concern. Another parent mentioned in her child's plan, the child was to write her test in another room due to test anxiety, but this process was not followed consistently. Two other parents stated in the beginning of the school year the plan was not followed very well but, as the year went on, implementing the plan improved. Parents stated:

"At the beginning of the school year it was not followed very well. Like, it was explained that she is not toilet trained. So, they put her in a classroom, the only classroom in the school without a bathroom, complicates the issue. So they were sending her to the bathroom with one of her classmates. A five-year-old being responsible for a child with autism, who's not really verbal. Bad Plan. So, they didn't change that until I brought up the issue of liability."

"It was pretty good at times. Every single year, yeah, September to November it was absolutely horrendous. Once everybody got settled and things like that, I did find it went pretty good."

"Fairly closely. She doesn't always automatically go out, if there's a test, to an alternate setting which has happened in the past and then of course she melts down. She has extreme test anxiety. So sometimes it's more reactive than proactive."

"As closely as possible is what I would say, because of course, especially this year (child) is in grade one, but this was his first year in school, so we had a lot of things that sort of we had to adjust along the way."

Teachers stated that the program plan was followed closely or as closely as possible. A teacher mentioned she reviews the plan every few weeks to determine goals

that have been achieved and to prepare for the upcoming months. Teachers also agreed there were adjustments, yet as one teacher noted, the plan is followed closely because structure is need but she also commented that she is flexible when needed. Some comments from teachers are:

“Pretty close, because what I will do is every month or so or every few weeks I will go into his program and say, okay, what outcomes have we already achieved or where do I need to start focusing in on.”

“My experience is it is usually followed through as closely as you can with adjustments according to the student’s behavior and what’s happening at that time.”

“Have to, closely. Now that doesn’t mean I’m not flexible but structure is needed at times.”

When parents were asked if they felt the program plan was used to guide intervention, three of the four families said yes, while one family said no. The family who said no had concerns about their child being in a classroom with no bathroom and being directed by another peer. However, this family did state visuals were being used in the classroom for daily activities and safety. Another parent mentioned, in the past, the school had things put in place for safety of their child. Parents discussed the support they receive, their concerns and student assistants. Two children had safety concerns regarding running, which was addressed by visuals being implemented in the classroom. Another parent felt the plan was followed due to her consent communication and friendly reminders to school professionals. A few comments made by parents are:

“No. No”

“Yes. Well, there would be, like they would have a student assistance even watched her at recess time and lunchtime to make sure she didn’t run.”

“Yeah, but that’ with close communication.”

“Yes. If his anxiety gets to high, he will run away. And so we programmed around that.”

Teachers noted that the program plans guided intervention, but there were always adjustments made to best fit the child. For example, one teacher mentioned implementing a plan with one student to keep his hands and feet to himself while walking in the hallway. If he did this for the allotted amount of times he would get a reward. As mentioned previously, one teacher said she reviews the plan every couple of weeks to determine where the plan needs to be focused, especially if goals have been achieved. Another teacher referred to the process as trial and error, especially in determining when a child needs a sensory break. She mentioned the student’s plan has scheduled sensory breaks but, once you start to know the child, you notice when they need a break, and therefore some breaks are unplanned. An example a teacher provided for adjusting the plan was that when the student came to school, he was unable to stay the full day. The team adjusted his plan and the student came to school for 30 minutes and when they felt the student was ready to increase the length of his day at school, the team added another 30 minutes. Another teacher mentioned that the previous plan may or may not be relevant, especially when the plan is prepared in May or June for the upcoming September. Children can change a lot in a few months and may begin to display unexpected positive or negative behaviours. Therefore the plan would need to be adjusted to incorporate unforeseen circumstance. Statements provide by teachers were:

“We have visual PECS over here put up. So we have a lot of things put in place for him so then he knows the routine.”

“We have scheduled breaks. So like with the calming room, for example, there is three scheduled times a day.”

“At the beginning of the year he had a tent because this is something that worked at home. When he needed his sensory outlet he would go inside the tent and use like swishy balls or he’d have a box full of stuff. But what we found is here in school he didn’t like that. He enjoyed going to the bathroom.”

“Now, what we had happen this year is half day of kindergarten but the student that we have just couldn’t cope with the two and a half hours. So he started, so we readjusted and we started, he came for a half hour. So then as he got more comfortable and more comfortable, it took long time, so then probably by October/November he was here all day.”

There were mixed reviews from families regarding implementation of the plan developed for their children. Two parents voiced their concerns about implementation and follow through of the plan. Finally, a parent stated they had a very open line of communication with their school in which both side could discuss their concerns and changes made to the plan. Through their communication they were able to target concerns quickly, with some actions being proactive while other times, reactive. The following are statements from parents:

“There’s suppose to be. Yeah, we’re struggling with that now. We’re hoping to address more of these issues in the next month.”

“I had to push for everything. Like, if you have a child with a disability in a school, if you don’t push for everything, you will get nothing.”

“We have a really good line of communication with our guidance counsellor, which has been the most valuable thing. Sometimes the changes were reactive and sometimes they were proactive.”

Teachers indicated that families were involved in implementing the program plan. Teachers’ responses noted that family members contributed to skill transfer. A teacher mentioned she informs the family of the programs she is working on so the family can also work on that skill in the home. These programs can be reviewed during report card time or verbally discussed with the students’ family. Another teacher stated the fact that mothers provide a lot of information and resources to the school. Another teacher



mentioned that the family she works with is amazing and willing to work together to help the child develop his strengths and succeed. Below are quotes from teachers:

“All that needs to be transfer over to home. So they’re aware, I show them the report. It goes home. Their programs go home, so the parent can follow through.”

“The family, the mother and father, they’ll help contribute to the plan during the meetings. They also at home following through with what they have to do at home because sometimes the plan includes things at home.”

“This particular case, this is her second child that has autism and the youngest. So she has a lot of strategies in her belt, right.”

“Now most of these families I have found amazing, because they just as much want some kind of structure and some type of success as well.”

## **Evaluation**

Three of the four parents explained that evaluation of the plan occurred during meetings with the school staff. The plan was reviewed during the meetings and, if a goal was achieved, it is removed. The parents’ view of the evaluation process was the plan was ongoing and changes can be made when needed. A parent mentioned these meeting could be a full ISSP or a smaller meeting with the teacher and guidance counsellor during report card meetings. Another parent felt there was no real evaluation process other than school personal reacting to complaints. Below are comments made by parents:

“As far as I know, they don’t seem to have one. They don’t really evaluate how the plan is working. They basically react to complaints from parents.”

“We would go [over] everything during our meetings. If we had a goal and it was achieved, well, then, we could take that out. So it was an ongoing thing.”

“Well we just kind of discuss it at the meeting and see if anything needs to be tweaked.”

“Then the plan is developed and then it’s reviewed at report card time as a matter of process.”

The teachers' responses to program evaluation revealed they say it is both an ongoing process and as future planning. A teacher said she evaluated the plan at every report card period, which occurs four times in the year while another teacher said twice a year (spring and fall). Another teacher also mentioned the evaluation process was ongoing but the major review is during the program planning meeting where they review the strength and needs from the previous plan. It was also made clear by a teacher that a meeting can be called at any point by any team member. During the evaluation process many items can be discussed, as the plan for next year, changes that need to be made, or new goals to be added. One teacher said they had several meetings with minor changes to the program plan. Below are teachers' responses to this question:

"Well, again, you would evaluate it during each reporting period. So we have a reporting period in November, in January and April, and then again in June. So that's pretty much, like with the new functional curriculum you list all of the outcomes that you're working on and whether it's achieved and what's going on with it."

"Yeah, it is ongoing, like I said. Again, when you get up into that meeting that's when you do major review of everything. You go over all of his strengths that we had set for him last year. We'll say okay, he's doing great on this. This is still a strength but he may need a little bit more work on this now because when you take him from an at-home setting bring him into a school setting, it could be a bit different."

"And again, throughout the whole year you're always kind of looking at what he's doing and trying to change things so that when you do get to that meeting you can go in with your information and help support and change things and make things better for next year."

"At the end of the school year...everything laid out, what worked, what he achieved what he didn't achieve, and where you going to go into the next school year."

"The way it's done, the way it's supposed to be done through our government or board or whatever it is, is the fall and then the spring. There is times, like I said, with this child in particular we have had a lot of meetings, but there hasn't been a whole lot that has changed so much during the year. Things have been tweaked."

Every parent said they were involved in discussing changes to their child's plan. Four parents said the discussion and agreements were mutual and often the school professionals provided input. A parent said it was she and a senior therapist who made suggestions for changes in the plan. This parent stated she would bring her concerns to the homeroom teacher. In addition, one parent mentioned, after the second report card, that the team had made changes to the written program plan. However, throughout the school year several informal changes were made through mutual agreement and these changes were noted in the communication log book. Three of the parents said the team was involved in making changes but one parent said she decided if a change was needed. Some comments from parents included:

“Mostly myself, her senior therapist. We talk about what is needing to be done. So far that's, we're the only ones who's been deciding when it's time to change something.”

“That was a bit of everybody, yeah.”

“We would decide it together. We did make an actual programming change that was sort of physically made in the actual hard copy of the plan after the second report card period. But we've changed it more informally. I guess the other thing that plays into that is there is a communication log that is kept every day by the teaching assistants who are with him, as well as the guidance counselor, and we have access to that log, too. So that is a less formal means of documenting it but things are documented through that as well.”

“Well, we have to bring it up with her homeroom teacher first and try to discuss.”

Teachers were in agreement saying the entire team was involved in making any changes to the program planning. They also were in agreement with parents by saying the changes were made through discussion. A teacher mentioned the team would ask questions why something may not be working and what can be changed to better help the

student. Teachers also mentioned working through agreements or disagreements with focus on how to move forward. Comments by teachers included:

“That would be the whole ISSP team.”

“The whole Team.”

“I guess if there’s something that’s not working then we need to sit down and why isn’t it working, what can we do, like what needs to be done in his plan to move forward.”

“Through discussion. Usually if something is suggested it would be either all agreed upon or disagreed.”

“We all are. We all meet. We work through it.”

### **Perceptions of the Program Planning Process**

Mixed emotions were expressed by parents when they were asked about their overall perception of program planning. Three main themes emerged: communication, cooperation and parent involvement. Parents expressed the plan worked well when there was open communication and one parent said the day-to-day communication was more important than the program planning itself. A parent said at the beginning of the year there was a lack of organization and it could take a few months before improvements were seen. The program plan also seemed more effective when parents felt there was a good working relationship between parents and school professionals. Parents expressed that there was a lot of parent involvement in the program planning process but one parent stated she had to fight for every resource she felt her child should have. Three of the families felt the program planning was realistic or effective or meaningful. A parent said the school was supportive and invested since they wanted the best for her child too. Another parent said the process works for them and school is as realistic as possible. However, one parent found the program planning process very frustrating. She expressed

frustration that her child's needs which she discussed were not part of the plan. This parent felt the program planning was unrealistic and not helpful. Several comments provided by parents:

"It's not realistic at all. It seems like it's going to be a good thing. You discuss the issues and what needs to be addressed and what would be most helpful and what would make her more comfortable and help her get the best out of it. And they all smile and nod, and everyone signs stuff, and you go home and find out that nothing has been implemented."

"It's frustrating."

"It's lacking."

"But you had to put, you has to be extremely involved in order to make sure that things were done. And if you didn't, it wasn't happening."

"It is helpful. I mean she's getting her needs met. Like I said, nothing is perfect."

"I think it's a good process, generally. It has worked very well for us."

"Yes, but not as meaningful as the day-to-day communication."

"They want what's best for her. We feel that they're, well, I can't say just as invested as us but they're very invested her doing well."

"Very grateful for the relationship with her teachers. So, in that respect, for me, personally, the plan is effective because I have that communication very open communication with everybody who's working with (child)."

"They've been cooperative as far as organizing and planning and they are very good at listening to what our concerns are and meeting those concerns. I have to say, I am very pleased with the support we've gotten from the school, for the most part. Nothing is perfect."

Teachers also expressed some concerns regarding the overall program planning process. Teachers' discussions developed three different themes, which were teacher involvement, struggles within the system, and the need for process. A teacher mentioned it was difficult for her, when she first started, in trying to understand the process as well as getting to know the child. This teacher also felt there needed to be more

communication between past teachers and present teachers. There were two teachers who stated school professionals working close to the child must be involved in developing the plan, as well as knowing the plan and develop a relationship with the student. Getting to know a child and developing a relationship could take some time. Teachers were in agreement that the plan was realistic/meaningful/helpful, with some teachers stating all three, with a teacher adding it's good to have a process to help guide teachers, while another added if there is no commitment, the process could fail. Another teacher mentioned it depends on the school and the team adding her team is phenomenal.

Statements made by teachers:

“Yeah, it is hard. So I think there needs to be more planning or more meetings with, if I'm in high school level, with the junior high teachers.”

“Everyone needs a guide and everyone should be using something consistently. I do believe that for sure.”

“I think the process works. If you don't have the commitment, it can fall. For example, there is a lot on the classroom teacher in sense that you have to ensure that you know what the plan is. When September comes around you need to know what your plan is.”

“I think it would depend on the school you were with and team you were working with. This team happens to be phenomenal.”

Parents indicated that their level of communication with their schools, other than program planning was good. Parents reported they have at least weekly contact with school personal, either with a teacher or guidance counsellor. E-mails were the most common form of communication along with face to face communication. Three of the parents stated they have used or are using communication log books and one parent is trying to implement a communication log book. Texting was another form of

communication a parent used to be in contact with school professionals. Another parent stated notes get sent home. Listed below are parents' responses to contact with school:

"Oh, at least once a week."

"E-mails usually, yeah. Or occasionally there's a note sent home in their little mailbag. "

"Well, I would imagine twice a week with the teacher; even now."

"We used to have an agenda that we would send back and forth. It was just, it was like a communication log between me and the teacher."

"E-mails, phone calls. We don't have a communication book. We did in the past when she was younger but now we don't."

"This year it's been a little bit more than last year. Her anxiety seems to be more. So, probably once a week I'm e-mailing somebody, one of the teachers or the guidance counselor or somebody."

"Daily. Yes, absolutely. And from several points of contact for us, from the guidance counselor and the classroom teacher, and the teacher assistant, too."

Similar to parents, teachers stated they had contact with families at least weekly using either face-to-face dialogue, communication log books, or through technology. Every teacher mentioned face to face communication along with communication books. Other forms of communication were completed by e-mails and phone calls. A teacher mentioned texts as a form of communication she used regularly. This teacher would text the family reminders if she was on duty in the morning, if she was not able to make work, and who was the substitute to help prepare the child for his day. In addition this teacher would text whether the child was having a good or bad day and sometimes would send a picture of the student engaging in an activity. Another teacher said there is strong communication between home and school life. Statements provided by teachers are:

"I have a communication book."

“Well, definitely I talk to her weekly”

“There is always a strong communication between home and school.”

“We contact through e-mails, like if he’s sick or something. We have a communication book. So she comes in with him every day so we get the chance to talk or dad is there so we get the chance to talk.”

“Numerous times a day. E-mails, text, phone, yeah, everything.”

“Yes, we do have a communication logbook and the student assistants pass that to each other because they fill each other in on breaks and they’ve gotten to read that real quick. It doesn’t go home.”

Parents listed a variety of services their school provided. The services could be broken down to include school professionals and special programs/areas. The two most common school professionals available were speech therapist and student assistants. One parent said they were unsure of the services provided but did mention the school had special transportation. However, her application for this service for her child was rejected. Another parent said she did not avail of many services but stated their school has student assistants and a special needs room. Other services mentioned were time in resource room, a sensory room, guidance counsellor, calming room, smart board/IPAD programs and modified programs. Below are comments made by parents:

“I don’t really know a whole lot. I know that they have their own speech therapist and I have to sign a release so that she could work with our daughter”

“I forgot to add about the special transportation. But, the application was rejected with no explanation, and so we applied again with an even more detailed explanation from a developmental pediatrician and from the senior therapist, and it was rejected again.”

“Well, they have student assistance; they have the IRTs; they have a sensory room; they have guidance counselors, and I don’t know if they got one or two now. They used to have two; and there is a speech therapist but it is only once a month.”



“Our situation is a little unique, so I can’t answer. I know they do have a special needs room there.”

“We have a calming room which we do use for our child, not all the kids in the program there do. We have a room for sensory breaks which is more movement breaks.”

“They have a Smart Board and iPad base programming that they use with some of the kids; particularly the nonverbal kids, which is great. (Child) has a full-time teaching assistant. He has modified programming for fine motor difficulties.”

Two main areas surfaced when teachers were asked about the services their school provided which were school professionals and modified programs for children. Similar to parents, teachers mentioned speech language pathology, guidance counselors, IRT’s and student assistants. However, teachers also mentioned an autism itinerant and administrative staff. One teacher said the administrative staff supports her in completing professional courses and other teachers allow her time in the gym and fitness room with her student and some peers. Teachers also said there is funding which could be used for anything from iPads to dollar store items, or items for the sensory room. Regarding modified programs, one teacher said the programs are developed around the students needs. These programs are based on the need of the child which could involve going to a sensory room, gym, or delivering the newspaper to participating classrooms. Several other supports or services mentioned by teachers were visuals for routines, social stories, behaviour management traffic light system, fidgets, and Class Dojo. Statements by teachers were:

“We have an autism itinerant. So she’s come in a few times and helped me set up. Also, there is a speech language pathologist.”

“The office, like our administration is really supportive of any professional development I want to do.”

“So, teachers signed up who wants a newspaper delivered to the classroom and that’s really great because they come out and talk to him and he’s learned to say thank you or you’re welcome, which is really big for him.”

“I don’t know if there is any particular program. If there are speech issues, that’s available. Usually they develop the program around the child’s needs and they try and get what each student needs.”

“Well, obviously we’ve a guidance counselor and she is not a full-time guidance. Then he has a full-time student assistant. Then, well this child in particular has two student assistants so there is always coverage. Anything at the school that costs money that we need, we can get it.

“we have a lot of things put in place for him so then he knows the routine.”

“We have social stories incorporated, actually, most of these children have social stories incorporated around different challenges that they may be having.”

“I’ve decided to use the Class Dojo, which is a free online behaviour management system and you just sign up as a teacher online.”

## **Inclusion**

Parents had mixed perceptions of whether the services at their schools supported inclusion. A parent said no while another parent said yes. Another parent said the services supported inclusion if the parents pushed for inclusion. While another parent said yes and then said she was unsure. Parent’s responses were:

“Absolutely”

“Oh yeah. Well, hm (Child) is very inclusive but she is able to be. Some children who are not so able to be in the inclusive system, I’m not sure. ”

“An inclusive setting is not always what kids with autism needs.”

“They can, if you push it. So there is two ways of looking at it. One, yes, your child is in the classroom. That has its pros but it also has cons, too, because a lot of children with autism do way better one on one.”

“No. They like to call it inclusion on the service but just because her body is there in the classroom doesn’t mean she’s being included.”

Teachers, however, universally agreed that the supports/programs at their schools supported inclusion. A teacher said they are trying to involve the student as much as possible. There were two teachers who stated their students were in the classroom with peers all day, with one teacher aiding the student, giving a fidget toy to help him/her stay in the classroom. Several responses from teachers:

“Definitely, yeah. Like inclusion isn’t it him going to a regular classroom it is him being with his peers that also has special needs.”

“Yes. This child is in the classroom with his peers all day.”

“Oh yeah. If I give, if I give him this [fidget], he can stay in my classroom all morning.”

There were a wide variety of answers from parents when asked what additional services they would like to have at their child’s school. Occupational Therapy was a service mentioned by two parents to help support a child through melt downs and inappropriate responses. The parents’ stated that the schools have a speech language pathologist, but families felt their children needed greater access to this service. Shorter lesson periods with an increase in movement breaks were also suggested. Another parent discussed training and greater education for teachers regarding Autism since the numbers are increasing in the classroom. This parent felt education would help teachers understand how a child with autism learns. Some comments by parents are:

“Well, I think it’s true for a lot of autistic children, they have physical need for shorter lesson times, more frequent movement activities to help regulate their nervous system.”

“Language, I don’t know what she’s doing. They have the speech therapist there and we’ve had no interaction with her at all”

“I think the biggest thing is to have more teachers really know about autism. So autism is prevalent now, that they should have more training in it.”

“It would be nice if there was some more sensory services.”

“But if the sensory and the speech could be upped in the school, I think that would be beneficial”

“It would be a great thing to have speech therapy available at the school or an OT available through school”

Each teacher had a different response to what additional services, supports, and/or programs they would like to see in their school. A teacher was interested in trying to initiate a music therapy program at her school since her student was very interested in music. Another teacher expressed interest in yoga or meditation which could help regulate and calm some children. This teacher also mentioned that more guidance time would be beneficial. One teacher mentioned she could not think of any programs and that programs need to be individualized to suit each child’s needs. Responses by teachers:

“I would like to have some sort of music therapy program for him.”

“None that I know of. I know everything is very individual, so it all depends on that child and what they need.”

“Well, there’s lots of things I would like. I would like to have more guidance time. I would love to have some type of yoga program.”

Parents’ opinions on whether inclusion was the best option varied, with some positive and negative views and some feeling inclusion should be individually based. A parent expressed concern that a classroom full of children may not always be the setting for a child with autism to maximize learning. Another parent felt they lost supports through inclusion and stated the supports are not as accessible anymore. A parent mentioned the idea of inclusion for social skills development but felt the system of inclusion needed improvements. While a parent mentioned inclusion was a good idea as

long as the supports are in place to allow the child to be included. In addition, a parent said it was the best option and felt the social aspect of having a homeroom and peer support was excellent. Every parent mentioned individualizing the amount of inclusion because they know of other children who may or may not be able to handle staying in a classroom for the full day. Comments made by parents follow below:

“I think if there’s someone there, if the supports are put in place for each child as they are needed for each child, I think it’s a great idea.”

“I think it’s an individual thing for each child. You need to decide whether it’s the best.”

“Like I said, it has its pros and cons. So it absolutely depends on the child.”

“Depends on the child. I couldn’t say it is or it isn’t because I think individually it has to be assessed to that.”

“I like the idea of inclusion, for the social needs of the kids. It can be very, very helpful.”

“I think the program needs to be reworked a little. (Child) used to have a criteria teacher that was there and if she has issues, that she could go to. We’ve lost that because the criterias are gone. And so she would go out with this teacher so many times during the week to deal with her anxiety. So now that that’s gone, because everything now is inclusion, she doesn’t have that. And that’s a big, a big, loss for us because where she was so high functioning.”

“I think it is the right thing to do, as far as they are capable of doing it.”

“They have a homeroom, they have a social support system in their classroom and that, to me, is extremely important”

Each teacher stated inclusion was the best option for children with autism.

Teachers elaborated and went on to state the level of inclusion needed is child specific.

Teachers noted the importance of a child with autism being around their peers and involved, again mentioning that this depended on how much the student could tolerate being in the classroom. A teacher said her student is not attending the regular classroom,

however, the student is engaged with several peers throughout the day that are at his developmental level. A teacher said it is important to have inclusion but it can be difficult when a student does not want to participate. Several teacher commented:

“Yes. Yeah. Definitely. I think it is just really specific about the child, like what they are capable of in their day. Like with my student he’s too active. He’s loud and he can’t sit down for long periods of time. It doesn’t make sense for him to go in a classroom.”

“I think inclusion for all kids is important. I think they need to be around their peers and they need to be involved in everything that’s going on. Sometimes it can be difficult if the child is not wanting to participate.”

“I think inclusion is realistic but depends on the child. It is not realistic to expect for, number one, a student assistant to be able to deal with [aggressive behaviours] in a way that doesn’t distract anyone else. It is not realistic for that child not to be distracting the learning of someone else.”

## **Chapter 5**

### **Discussion**

The purpose of this study was to investigate parents' and teachers' perceptions of the program planning and implementation process when working with children with autism. Results indicated that teachers and parents shared similar perceptions on several points such as when describing autism. Both parents and teachers mentioned that autism was associated with social and communication deficits. They also noted the importance of working with children with autism to improve their social skills and general behavior. However, participants had different perspectives in some areas, especially regarding the program planning process around issues of involvement, program implementation, and providing needed services. This chapter will highlight some of the common themes expressed by parents and teachers as well as discuss areas where divergent perspectives were presented.

### **Program Planning**

Participants agreed on several points regarding program planning meetings. Both parents and teachers noted a wide range of professionals attended program planning meetings, including several school personal and external professionals and specialists. Program planning meetings were always held at the child's school and both parents and teachers participated and provided information, discussing needed services and contributing as team members. There were always conversations before program planning meetings and all but one participant agreed their guidance counselor organized meetings and summarized the written report. All teachers and three parents felt the program plan helped guide intervention, with teachers adding the plan was consistently

being adjusted to better fit the needs of children. Participants were in agreement that any changes made to the program plan were discussed, agreed upon and then signed to finalize the document. The Individual Support Services Plan (ISSP) process seemed to follow suggested practices as outlined by an article located on the Government of Newfoundland and Labrador website titled *Focusing on Students: A report of the ISSP and Pathways commission* (Government of Newfoundland and Labrador, 2007).

There were many questions regarding program planning to which participants provided different responses. According to families, there were at least two program planning meetings held during the school year. However, teachers stated there were between 1 to 3 meetings. Parents felt their role when involved in program planning meetings was to be the child's advocate and to demand services they felt their child should receive. Teachers stated their involvement was to discuss the child's goals and needs for a successful school year.

Program plans are developed to address children's specific goals that are agreed upon as a team, which involved all service providers working with a specific child. During the program planning meetings many ideas were discussed to help a student succeed in school, such as timers, visuals, and scheduled breaks. However, parents were often unsure if strategies were implemented. Families should take ownership and question school professionals to ensure strategies are being implemented. Participants stated their guidance counselor was helpful in organizing the program planning meetings and encouraging families to participate and provide information they feel would benefit their child for the school year ahead. Many families felt their guidance counselor understood and addressed their concerns. Families feel valued when professionals



wanted to hear their concerns, opinions and advice. Friedlander (2009) concurs and suggests that during Individualized Education Plan (IEP) meetings parents should be given the opportunity to participate fully in all aspects of the program planning process. Perceptions of the overall program plan varied between both participant groups. Teachers perceived there are struggles within the program plan. They saw a need for greater teacher involvement. While they acknowledged the importance of the IEP process and policy surrounding it, they found operating within the guidelines could be difficult. Parents stated they wanted more communication and cooperation among all team members.

When a school is not meeting children's needs, this causes stress on families (Whitaker, 2007). A parent expressed frustration regarding developing program plans that were not always implemented. For example, a communication log book was discussed to help her child gather her thoughts, so when she got home she would be able to communicate the events of the day to her family. The parent reported that the book was not always completed or reviewed because the teacher said she did not have the time to do it. If a parent's goal is to work on developing communication skills and that need is not being met, a parent should call a program planning meeting to discuss another way to develop communication skills that the team will be able to implement. However, one teacher reported implementing a communication log book but the family failed to write updates to the classroom teacher regarding sleep, how their morning was, or other important information. If the team is deciding to implement a plan or strategy to help a student, all team members need to be involved and complete what is expected of each member. Developing attainable and measurable goals for children with autism and

ensuring follow through and implementation to reach agreed up on goals is extremely important (Odom, Cox, Brock, and National Professional Development Center on ASD, 2013; Prizant, Wetherby, Rubin, and Laurent, 2003).

Participants provided a wide range of answers on how the program planning meetings were evaluated. The Government of Newfoundland and Labrador Department of Education (2007), in their document *Focusing on Students: A report of the ISSP and Pathways Commission*, stated Individual Support Services Plan (ISSP) meetings are to be held at least twice a year but there can be more meetings if needed. They found that meetings were not always taking place twice a year and “teachers reported considerable stress in having to attend countless meetings that are of little help to them” (p.47). The article also discussed struggles and concerns noted by teachers and parents. If meetings were occurring once a year, this may be insufficient to decide if the developed plan was working or if goals had been achieved. When a team is meeting only once a year to assess a plan, this leaves the question of whether sufficient information is collected and passed on to future teachers. In addition, if program meetings are being held in the month of May for preparation of the following year, then there are no adjustments/tweaks to the plan to help with success throughout the current year. Strengths and needs for children with autism most likely could change within a year, along with their behavior. One parent mentioned that when her child was doing well in school their program planning meeting would come after other children with higher needs. The parent stated she understood but again her child’s progress in school was important to her. Another parent mentioned the team had several mini meetings throughout the year which were not classified as program planning meetings. However, during these meetings there were

changes to the student's daily programming but no written changes to the formal document. If the team called those meetings a program planning meeting then they could possibly meet policy requirements for evaluation of the plan. It is important for team members to remember they can call a meeting any time during the school year. It is also imperative that the forms are completed during each program planning meeting and document any changes to the original plan (Government of Newfoundland and Labrador, 2007).

It can be frustrating for parents when they are expressing the needs of their child and feeling these needs are not being met. A teacher explained to the school that her child was not independently using the washroom. It upset the mother to learn that her child was placed in the only kindergarten class without a washroom. Later, the mother learned that her child was being escorted to the washroom by another classmate. The reason why the school professionals placed the child in a classroom without a bathroom and allowed another student to guide her to the washroom was unknown. If the school was unable to place this child in the classroom with a washroom, to help ease a parent's mind it may have been best to have a student assistant bring the child to the washroom. In Whitaker's (2007) study it was stated parents would like to have increased supervision for children in the school system. Having a parent be concerned about her child's safety affects the relationship between parents and school professionals and also may break trust. A parent could question if the school is listening to their needs and if the school professionals have their child's best interest in mind. When trust is broken people can become defensive and it may take a long time for school professionals to gain trust again.

Participants disagreed on who ensures the program plan is being implemented with school professionals claiming they ensure it is implemented while families stated they ensured the plan was being followed. All participants agreed that the program plan was followed as closely as possible. Follow through once a plan has been implemented can be difficult for everyone involved. Through team discussion it was agreed upon, according to one parent, that her child would be able to write a test in another room due to test anxiety. However, the parent reported there was a lack of consistent removal to another room to write tests. The mother was concerned that her child could have an emotional breakdown and how this would impact her relationship with her peers. This parent often reminded teachers that her child was anxious prior to upcoming test and asked for her to be removed from the classroom to write the test. If a neutral space was agreed upon by the team, school professionals should remember the plan. If school professionals were proactive rather than reactive, the worry and stress would decrease for this child and her family. The Government of Newfoundland and Labrador Department of Education (2007) also noted that parents are reminding teachers of accommodations which were agreed upon. Teachers agreed with parents, adding there are several students they teach who have program plans based on their needs and teacher's stated there was a lot of information to remember.

### **Services**

All participants mentioned that their schools provided services such as speech language pathologist, guidance counsellors, Instructional Resource Teacher (IRT) and student assistants. However, parents also mentioned additional services such as special transportation, special needs room, sensory room, calming room, smart boards, iPads and

modified programs while teachers also included autism itinerant and administrative staff. Teachers agreed these services supported inclusion while parents had mixed reviews whether these programs supported inclusions. Teachers felt inclusion was the best option with the level of inclusion being based on individual children. Parents reported positive and negative feelings towards whether inclusion being the best option for their child. Parents had positive attitudes toward the classroom teachers were, recognizing that teachers were working with possibly 25 other children so their attention was divided. Parents felt their teachers tried to get services or funding that would be beneficial to their children but understood these services were not guaranteed to be approved.

Teachers and parents provided several suggestions of services or needs they felt their school could benefit from like increased communication between current teachers and future teachers. Sometimes both teachers are unable to attend the May or June program planning meeting. Arrangements should be made for teachers to have a face-to-face discussion on behaviours, strategies and goals rather than reading a report. The issue of building rapport with a child was mentioned a few times. It would be valuable to have the student and teacher meet several times to help with the transition period and building rapport.

Participants' wish list included increased time for speech language and occupational therapy, shorter lesson plans with increase movement breaks, more education for teachers regarding autism, music therapy, yoga, meditation and increased time with the guidance counsellor. Schools are assigned a speech language pathologist. However, this person is assigned to a family of schools. Even when specialists are available, there is no guarantee that the student will receive the service. For example, one

parent signed consent for her child to access speech language pathologist services, however the parent reported her child had not received any speech services. A different participant disclosed speech therapy was never made available for her child, while another parent stated her child did receive services from a speech language pathologist but would have liked to access more of this service. Children with autism may benefit from ongoing speech language therapy since a characteristic of autism is impairments in communication skills (American Psychiatric Association, 2000). Children with autism should be able to access this service to help them maneuver through their life.

Unfortunately, speech language pathology services appears to be allocated to children with higher needs, especially if there are many students in the school who are in need of this service. Even if a child with autism is talking, he/she may need help developing social communication skills like understanding non verbal language cues. All participants agreed that children with autism needed help learning social skills. Children with autism may need additional help in learning basic social communication skills as they apply social rules in the classroom.

Even though all participants mentioned student assistant services were available at their school, many were not satisfied with this service. The demand for this service was a repeated concern for both parents and teachers. Participants expressed concerns regarding the lack of assistants and several teachers seemed concerned with how their time was allocated. According to the Government of Newfoundland and Labrador (2014) website, a student assistant is approved based on individual needs. Student assistant time is allotted based on three characteristics: the number of students approved, severity of needs, and the school's special education teacher allocation. Teachers or guidance

counselors apply for student assistants for students who need the service and then schools are awarded a set number of student assistant hours which have to be divided amongst approved students. Therefore, some students are losing or not receiving services as some children have high needs and require almost full time help. One teacher stated that there was not enough student assistant coverage and the guidance counsellor covered in the morning and afternoon. The guidance counsellors have their own roles and responsibilities and covering for a student assistant removes them from their duties. If a student has a full time student assistant in kindergarten, which is half day of school, when the student moves to grade one he/she will need a student assistant for a full day. If this child has higher needs than another student, the school may need to take the student assistant time away from another student. Parents expressed frustration when told their child's student assistant time had been decreased

There appears to be confusion regarding the role of a student assistant. A student assistant, according to the frequently asked question on the Government of Newfoundland and Labrador Department of Education (2014) is approved to help a student with physical needs, personal care needs and behavior management of students. One parent was frustrated that a student assistant was not available for her child to keep her focused and to ensure her child completed her school work. She feared her child would fall behind without support. Government of Newfoundland and Labrador Department of Education (2007) also sought parents and teachers thoughts regarding student assistants. They found professionals and families expressed a desire to enhance the role of student assistants to help with academics. This would entail a change of job title to teacher assistants. This document stated Newfoundland was the only province

which did not have teacher assistants in the classroom. This article did state that the Commission has recommended redefining student assistant roles and responsibilities to better fit a teacher assistant model and develop a pilot study to determine its effectiveness.

### **Struggles**

One parent mentioned the struggle at the beginning of every school year, even though they prepared the year before. When her child began the new school year, the parent stated the school would not have services in place to help support her child. The student was able to avail of a student assistant, but the person who provided this service could change several times in the first few months. Many children with autism are uncomfortable with changes (Towbin et al., 2002), therefore student assistants assigned to children should be consistent to create a smooth transition. When student assistants get assigned a new student, they need to build rapport, a trusting relationship, learn their behaviours, and strategies that work with this student, which will take time. Even though there are plans and meetings to help a child transition into the new grade, both teachers and parents expressed feelings of rough transitions, noting it usually took everyone a few months to settle in. This caused stress and anxiety for parents.

Many parents have anxiety when their child enters school, especially if their child can be aggressive or have physical outburst. A parent reported that there was no plan developed for possible behaviors their child exhibited, which caused stress. However, schools should have techniques and procedures in place to ensure the safety of the children in their care. Professionals should inform families of these techniques and



policies prior to a physical outburst so that everyone understands these procedures.

Families can also share methods and ways they have successfully used with their child.

### **Communication**

Participants were in agreement that there was daily communication between the school and family, either face-to-face, e-mails or phone calls. Dillenburger, Keenan, Doherty, Byrne and Gallagher (2010) determined that “effective communication and collaboration between parents and teachers and other professionals is increasingly viewed as an important factor in the education and treatment of children diagnosed with ASD” (p.19). School professionals and families in this study seem to have built an open line of communication. Participants stated having open communication is very valuable and helps lower their stress levels. Having open communication ensures that important information from home and school life on all aspects of the child’s development is shared.

Communication creates trust which increases cooperation which in turn can promote a positive change in school performance (Lilly et al., 2003). For example, teachers can inform parents if they will be off and if they know who will be substituting for that day, which in turn will help parents prepare their child for the changes he/she will be facing. Parents can provide knowledge regarding strategies to handle variety of situations and behaviors. The majority of participants felt that communication between home and school was great. Parents seemed more relaxed if school personnel were providing daily updates regarding their children. The open communication makes a connection between parents and teachers which seems to enhance team work to obtain

future goals for the child. Whitaker (2007) also mentioned there needs to be improvements in communication between school professionals and families.

### **Limitations and Recommendations**

#### **Future Research**

1. Initially, the researcher had hoped to interview six teachers and six parents of children with ASD. However, it was difficult getting in touch with principals due to their busy schedules and some did not respond to messages. While the small number of participants means that the results cannot be generalized, the information obtained did provide insight of the programming planning process for children with autism in this area.
2. The researcher did not address where on the autism spectrum the children fell. Future research could query the views of parents and teachers to ascertain whether their perceptions of program planning and inclusion varied according to the degree of involvement the child with autism exhibited.
3. Some participants did not answer all the questions. Two participants left a question on the demographic survey blank and during the interview process this researcher did not get an answer from a parent regarding how many program planning meetings they had in a school year. Perhaps having participants answer demographic questions with the interviewer may be a more effective method to gain complete information.
4. Future research could include the perspectives of substitute teachers, teacher assistants, and school principals to determine their knowledge of and perceptions of the program planning process. Since guidance counselors were the main

people who organized and chaired meetings, they could be questioned regarding effectiveness and policy of program planning meetings.

### Program Planning

1. Guidance counsellors appeared to play a major role in the program planning process, arranging and chairing meetings and managing cases. Perhaps they should have been the point of contact to determine if their school would participate in program planning research. In addition, their perceptions of the program planning process could have been sought. They would have a unique perspective in their roles as manager and participant that would add to the viewpoints of the other stakeholder groups.
2. Both parents and teachers appear to be unsure of the policy for evaluating program planning meetings. Maybe the Newfoundland and Labrador English School District (formally known as Eastern School District) could develop a generic information sheet to be provided to all families involved in program planning meetings outlining evaluation process, implementation, the responsibilities of program planning manager and the process of a program planning meeting.
3. The program planning manager should ensure that new team members are forwarded past team meeting notes to review. This will eliminate families having to repeat issues they are currently being addressed or behavior concerns. Several participants mentioned modified programs were developed to work on increasing skill development, dealing with anxiety, or fine motor movement. To help

generalize these skills to home life, teachers could send home information for parents to teach the skill in the same manner and to use consistent language.

4. One teacher explained how she used the traffic light system for behaviour and once a child reached the red light, the student is sent to the office. Likewise parents may have effective methods for dealing with behavioral concerns that they could share with the schools. During program planning meetings families and schools can discuss techniques and procedures that have proven effective so everyone can implement the same techniques and use the same language. Such consistency will help students understand and use appropriate social skills and language at home and at school. Sharing information can only enhance communication between home and school life, which in turn, may develop trusting relationships.

### Struggles

1. According to Dillenburger et al. (2010) families who have a child diagnosed with autism experience more stress than families who have children with other special needs or disorders. If there is a way to reduce some levels of stress felt by these families, as professionals we should feel obligated to do so.
2. Participants also noted that the first few months of school caused stress due to lack of organization. Everyone needs to be aware of the dates to apply for a student assistant and other services. If this information was known, parents could inform the school well in advance if their child has a disability so the school can plan for the necessary services. If approvals can be completed and positions filled before September this may help decrease stress at the start of a new year.

## Communication

1. School professionals could provide information packages explaining services their school provides along with sample application forms, to help families understand information required for approval process. This may help parents further understand why their child may not be able to obtain certain services, for example a student assistant or special transportation.
2. Professionals should ensure families understand the language used during program planning meetings or any other meetings (Fish, 2006). Several parents could benefit from having a sheet of acronyms, listing what the acronyms stand for and a short description explaining the service and/or role. Even some teachers were uncertain of several job titles due to title changes, for instance Instructional Resource Teachers (IRT's) were referred to by a teacher as itinerant research teacher.
3. School personnel should explain the role of the student assistant during the IEP meeting. However, some parents may be overwhelmed by all the information they receive during a meeting, therefore, maybe the guidance counsellor could provide parents with a pamphlet for them to read later to enhance their understanding of the roles and responsibilities of student assistant support.
4. Friedlander (2009) stated teachers should learn about the child before they come to school to help with transitions and to improve quality of the upcoming school year. Teachers can try to build a relationship before the student enters the class. Parents can also help by making a 'get to know me book', which also would be helpful for substitute teachers. In the book, parents can include information about

favourite toys, relaxation tips, things that over stimulate the child, possible stressors or any other topics of interest. Teachers will then have information regarding their favorite objects or topic along with stressors to keep an eye on. Some of these ideas would be discussed during the program plan meeting, but as mentioned previously, interests or stressors can change over time and the book can provide valuable information to parents of any changes. School professionals can provide pictures of inside the school for families to develop a social story to help prepare their child for school.

### Services

1. Parents would like to have more speech language pathology services available at their children schools. Increasing speech language pathology services in the school system would mean hiring more speech language pathologist and finding qualified people to fill those jobs. The school board could look into this issue to determine if such a need exists and whether adding additional speech language pathologist would benefit the children with ASD.
2. All participants seemed frustrated with student assistant time allotment and roles. Children with autism learn differently (Whitaker, 2007) which can affect their focus (Kendall & Comer, 2010) which could help defend the need of a teacher assistant rather than a student assistant. A parent expressed having to re-teach her child material taught in school to ensure she understood it and was keeping up with the curriculum. This increased stress on family members and decreased time spent as a family. If there was a teacher assistant in her child's grade, this family may not need to re-teach curriculum at home.

3. Many teachers did mention services from the Janeway Children's Hospital yet many children in the younger grades may be involved in the Eastern Health Applied Behavioral Analysis program. The relationship between the school and community supports should be examined to determine the role each institutions plays in the child's intervention.

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## Appendix A

**Demographic Surveys for Parents/Guardians and Teachers****Demographic Survey for Teachers**

**Please complete the following. You do not have to answer any question which causes you discomfort.**

- 1) Gender:      ☐ Male      ☐ Female
- 2) Age:               $\leq 25$  ☐      26-35 ☐      36-45 ☐       $\geq 46$  ☐
- 3) What is the highest level of education you have obtained?
  - ☐ Bachelor Degree
  - ☐ Masters Degree
  - ☐ Other \_\_\_\_\_
- 4) Are you a homeroom (HR) teacher or Special Education (SE) teacher?
  - ☐ HR ☐ SE
- 5) What grade do you teach? \_\_\_\_\_
- 6) Are you currently teaching child(ren) with autism?    ☐ Yes      ☐ No
- 7) How many years of teaching experience do you have? \_\_\_\_\_
- 8) Have you previously taught child (ren) with autism? ☐ Yes ☐ No
 

If yes, how many? \_\_\_\_\_
- 9) Have you completed courses or attended professional development sessions related to autism? ☐ Yes      ☐ No

If yes, please note:

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### Demographic Survey for Parents/Guardians

**Please complete the following. You do not have to answer any question which causes you discomfort.**

1) Gender:    ☐ Male            ☐ Female

2) Age:             $\leq 25$  ☐            26-35 ☐            36-45 ☐             $\geq 46$  ☐

3) Current occupation:

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4) What is the highest level of education you have obtained?

☐ High School

☐ Community College:   ☐ 1 year   ☐ 2 year or   ☐ 3 year program

☐ Bachelor Degree

☐ Masters Degree

☐ Other 

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5) How old is your child(ren) with autism?

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6) What grade is your child(ren) with autism in?

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6. Have you completed courses or attended workshops related to autism?   ☐ Yes

☐ No

If yes, please note:

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## Appendix B

### Interview Schedule for Parents/Guardians and Teachers

#### Teachers Interview Questions

- 1) Based on your experiences, how would you define/describe autism?
- 2) Please share your perceptions regarding working with children with autism and their families.
- 3) As a teacher, what do you feel are the most important skills a child with autism needs to learn?
- 4) Children with autism typically required individual program plans. Please tell me about your involvement in this program planning process.
  - a. Who is responsible for organizing and chairing the meetings?
  - b. Who is involved in this process? How often do you meet, when and where?
  - c. Are you always involved in programming planning? If yes, in what capacity?
  - d. What is discussed prior to and during the planning meetings?
  - e. Are needed services discussed? If yes, how are they put in place?
  - f. Who summarizes the information and produces the actual written plan?
  - g. How do participants indicate their agreement with the plan?
- 5) Once a program plan has been developed for an individual child, who ensures that it was implemented? (In necessary, prompt team, one teacher, teacher and family, etc)
  - a. How closely do you adhere to the program plan?
  - b. Is the plan used to guide intervention? How?
  - c. How is the family involved in implementing the plan?
- 6) Developing and implementing the plan are important aspects of the program planning process. However, plans must also be evaluated?
  - a. Tell me about the evaluation process of the program plan (cue on-going, regular set times, if needed).
  - b. Who decides whether changes need to be made to the plan? How are changes in the plan considered/ made?
- 7) Please share with me your overall perceptions on the program planning process? Is it helpful? Meaningful? Realistic? Elaborate.
- 8) Tell me about your contact with parents who have a child with autism apart from the program planning process. How often are you in contact? How do you communicate with them?

- 9) Tell me about the types of programs/supports/services that are available at your school to support a child with autism? Do these programs, supports, and services support inclusion? Are there any other programs/services/supports you would like to have in place at your school?
- 10) What are your thoughts on inclusion of children with Autism Spectrum Disorder in school? Do you feel inclusion is the best option?
- 11) Is there anything else you would like to share today?

### **Parent/Guardian Interview Questions**

- 1) Based on your experiences, how would you define/describe autism?
- 2) Please share your perceptions of parenting a child(ren) with autism?
- 3) As a parent, what do you feel are the most important skills your child(ren) with autism needs to learn?
- 4) Children with autism typically required individual program plans. Please tell me about your involvement in the program planning process.
  - a. Who is responsible for organizing and chairing the meetings?
  - b. Who is involved in this process? How often do you meet, when and where?
  - c. Are you always involved in programming planning? If yes, in what capacity?
  - d. What is discussed prior to and during the planning meetings?
  - e. Are needed services discussed? If yes, how are they put in place?
  - f. Who summarizes the information and produces the actual written plan?
  - g. How do participants indicate their agreement with the plan?
- 5) Once a program plan was developed for your child, who ensured that it was implemented? (In necessary, prompt team, one teacher, teacher and family, etc)
  - a. How closely was the program plan followed?
  - b. Was the plan used to guide intervention? How?
  - c. How were you, the family, involved in implementing the plan?
- 6) Developing and implementing the plan are important aspects of the program planning process. However, plans must also be evaluated?
  - a. Tell me about your school's evaluation process for program plans (cue on-going, regular set times, if needed).
  - b. Who decides whether changes need to be made in the plan? How are changes in the plan considered/ made?
- 7) Please share with me your overall perceptions of the program planning process? Is it helpful? Meaningful? Realistic? Elaborate.
- 8) Tell me about your contact with your child's school apart from the program planning process. How often are you in contact with your school? How do you communicate with school professionals?

- 9) Tell me about the types of programs/supports/services that are available at your Child's school to support a child with autism. Do these programs, supports, and services support inclusion. Are there any other programs/services/supports you would like to have in place at your Child's school?
- 10) What are your thoughts on inclusion of children with Autism Spectrum Disorder? Do you feel inclusion is the best option?
- 11) Is there anything else you would like to share today?

## Appendix C

**Follow-up Letter to School Principal****(Letterhead)****Follow-up Letter to School Principal**

Dear \_\_\_\_\_,

My name is Nancy Etheridge and I am a student in the Master of Arts (Child and Youth Study) program at Mount Saint Vincent University. I am writing to you as a follow-up to our recent phone conversation regarding my research study on program planning for children with autism in the public school system. The purpose of this research is to gain a deeper insight into parents' and teachers' perceptions of the program planning process. Information gained from this study should increase our understanding of how programs for children with autism are developed and implemented and help identify a set of best practices guidelines to ensure that all children with autism are included.

In order to conduct this research, I am asking you to distribute the enclosed packages to parents and teachers who are or who have taught children with autism in the past two years. Each package contains, a) a letter explaining the purpose of this study, responsibilities of participants and researchers, and outlining participants' rights; b) a demographic survey seeking information such as participants' genders, age range, education, experience and current position; c) an informed consent form to sign if they are willing to participate in an interview; and d) a self addressed, stamped return envelope. The interview should take approximately 30 minutes, will be audio-taped and take place at a mutually convenient time and place. If more parents and teachers consent to an interview than are needed for this research, six to eight will be randomly selected, from each group, to participate. Those not selected will be contacted and thanked for their willingness to participate and their demographic survey destroyed.

As we discussed, participation in this research is completely voluntary. Participants may skip or decline to respond to any questions that they are uncomfortable answering. All information obtained in this study will be kept strictly confidential. Once the transcriptions are completed, participants will be contacted, via the information they provided, and given the opportunity to review the transcript of their interview to determine if it reflects their perceptions and to suggest changes if necessary. The surveys and interviews will be numerically coded to ensure participants' anonymity. Surveys and transcripts will be shredded after they have been coded and audio files destroyed. Only my supervisor and I will have access to the data. Data and quotes from the interviews will be used in the thesis, however, no names or identifying information will be reported in

the thesis or in future presentations or articles. All paper data will be stored in a locked file cabinet in the research supervisor's office for five years and electronic files on the researcher's computer will be password protected. Following completion of the thesis, a summary of the findings will be sent to individual participants at the address they provide.

If you have any further questions or concerns regarding this study or your involvement, please contact me at [REDACTED] or by email at [REDACTED] or you may contact my thesis supervisor, [REDACTED] at [REDACTED] or [REDACTED]. If you have any questions and would like to speak to someone who is not directly involved in the study, you may contact the chair of the University Research Ethics Board c/o MSVU Research and International Office at (902) 457-6350 or through email at [research@msvu.ca](mailto:research@msvu.ca)

Thank you for considering this research project

Sincerely,

Nancy Etheridge  
Master of Arts (CYS) Student  
Mount Saint Vincent University

Appendix D

**Letter for Parent/Teacher Participants**

**(Letterhead)**

**Letter for Parent/Teacher Participants**

Dear Teacher/Parents (appropriate noun will be used for each group)

My name is Nancy Etheridge and I am a student in the Master of Arts (Child and Youth Study) program at Mount Saint Vincent University. I am writing to you regarding my research study on program planning for children with autism in the public school system. The purpose of this research is to gain a deeper insight into parents' and teachers' perceptions of the program planning process. Information gained from this study should increase our understanding of how programs for children with autism are developed and implemented and help identify a set of best practices guidelines to ensure that all children with autism are included.

If you are willing to participate in an individual interview on program planning, please complete the demographic survey, sign the Consent Form, and return both in the enclosed stamped and addressed envelope. The interview should take approximately 30 minutes and will be digitally recorded. If you consent to an interview, you will be contacted to arrange a mutually convenient time and private place for the interview. If more teacher/parents (appropriate noun will be used for each group) consent to an interview than are needed for research, six to eight will be randomly selected to participate. Those not selected will be contacted and thanked for their willingness to participate and their demographic survey destroyed.

Please understand that participation in this research is completely voluntary. You may skip or decline to respond to any questions that you are uncomfortable answering. All information obtained in this study will be kept strictly confidential. The surveys and interviews will be numerically coded to ensure participants' anonymity. Once your audio file has been transcribed, you will be contacted, using the information you provide on the consent form, and given the opportunity to review the transcript of your interview to determine if it reflects your perceptions and to suggest changes if necessary. Surveys and transcripts will be shredded after they have been coded and audio files destroyed. Only my supervisor and I will have access to the data. Quotes from interviews will be used in the thesis, however, no names or identifying information will be reported in the thesis or in future presentations or articles. All paper data will be stored in a locked file cabinet in the researcher supervisor's office for five years and electronic files on the researcher's computer will be password protected. Following completion of the thesis, a summary of the findings will be sent to the address you provide.



If you have any further questions or concerns regarding this study or your involvement, please contact me at [REDACTED] or by e-mail at [REDACTED] or you may contact my thesis supervisor, [REDACTED] at [REDACTED] or at [REDACTED]. If you have any questions and would like to speak to someone who is not directly involved in the study, you may contact the chair of the University Research Ethics Board c/o MSVU Research and International Office at (902) 457-6350 or through email at [research@msvu.ca](mailto:research@msvu.ca)

Thank you for considering this research project.

Sincerely,

Nancy Etheridge  
Master of Arts (CYS) Student  
Mount Saint Vincent University

Appendix E

**Free and Informed Consent**

**FREE AND INFORMED CONSENT**

**(Letterhead)**

**Thesis Title:** Parents' and Teachers' Perceptions of the Program Planning Process for Children with Autism in the Public school System

**Thesis Student:** Nancy Etheridge

I, \_\_\_\_\_, am willing to participate in a one-on-one interview as part of a research study being conducted by Nancy Etheridge as part of her Master of Arts thesis in the Department of Child and Youth Study at Mount Saint Vincent University. The aim of this research is to gain a deeper insight into parents' and teachers' perceptions of the program planning process. Information gained from this study should increase our understanding of how programs for children with autism are developed and implemented and help identify a set of best practices guidelines to ensure that all children are included.

I have been informed that my time commitment for the individual interview will be approximately 30 minutes. I am aware that the interview will be audio-taped and that once the interview has been transcribed I will be contacted (via information provided below) and given the opportunity to review my transcript and suggest modifications. I understand that the transcripts will be kept in a locked file cabinet in the thesis supervisor's office for five years and that electronic files on the researcher's computer will be password protected.

I understand that my participation in this research is entirely voluntary and that I can withdraw at anytime without consequence. I know I can skip or decline to respond to any questions that I am uncomfortable answering. I understand that all information obtained in this study is confidential and that no participant will be identified

I am aware that all tapes, transcripts and surveys will have numerical codes to maintain confidentiality. I also understand that quotes from interviews will be used in a future publication of the thesis to illustrate themes arising from the data. No identifying information will be reported and my identity will not be revealed in anyway. However, I

am also aware that the researcher is legally obligated to report any information that is shared with her which may indicate that a child is being abused or harmed in any way. I

am aware that I can have a summary of the research findings if I wish, when the thesis is completed.

I understand that this research has been approved by the Child and Youth Studies Department and the Research Ethics Board of Mount Saint Vincent University, Halifax, Nova Scotia. If I have any questions, I may freely contact me at [REDACTED] or by e-mail at [REDACTED] or [REDACTED] at [REDACTED] or at [REDACTED]. If I have questions about how this study is being conducted and wish to speak to someone who is not directly involved in the study, I may contact the chair of the University Research Ethics Board c/o MSVU Research and International Office, or by phone at (902)-457-6350 or by email at [Reserach@msvu.ca](mailto:Reserach@msvu.ca)

I have read the information provided above. I understand that by signing below that I am agreeing to participate in this research study.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

I agree to the interview being audio-taped: \_\_\_\_\_

Phone Numbers I can be reached at: \_\_\_\_\_

**and/or**

E-mail Address \_\_\_\_\_

\_Times I may be reached at: \_\_\_\_\_

Researchers Signature: \_\_\_\_\_

Postal address or email where a summary of the results may be sent:

## Appendix F

### Ethics Approval



University Research Ethics Board

#### UNIVERSITY RESEARCH ETHICS BOARD

##### Certificate of Research Ethics Clearance

Title of project: *Parent and Teacher Perceptions of Programming for Children with Autism in Elementary Schools*

Researcher(s): Nancy Etheridge  
Supervisor (if applicable): [REDACTED]  
Co-Investigators: n/a

File #: 2012-004

The University Research Ethics Board (UREB) has reviewed the above named proposal and confirms that it respects the *Tri-Council Policy Statement* as outlined in the *MSVU Policies and Procedures: Ethics Review of Research Involving Humans* regarding the ethics of research involving human participants.

This certificate of approval is valid one year from the date of issue. Renewals are available for up to four years in addition to the initial year and are contingent upon an annual submission to the UREB of a written request for renewal accompanied by a satisfactory annual ethics report thirty days prior to the expiry date as listed below. A final report is due on or before the expiry date. Researchers are reminded that any changes to approved protocol must be reviewed and approved by the UREB prior to their implementation.

[REDACTED] University Research Ethics Board (UREB)	<u>July 19, 2012</u> Effective Date  <u>[Expires: June 18, 2013]</u>
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