

A Parental Perspective on Progress in a Child with Autism.

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Abstract

This thesis examines the life story of a family's triumphs and struggles raising a child with autism. The aim of the study was to understand the experience of one family, their perceptions of success/progress, and the factors that may be involved in that process.

In conducting the research, the researcher recognizes that all children are different and unique. This study will not reveal the most effective way to approach or treat autism, but discuss a number of factors, such as risk and opportunity factors that may be influencing this child's development. The purpose in exploring these findings is to suggest that there are numerous approaches to achieve positive outcomes for a young child with autism, and to expand on the discussion of possible factors promoting such progress or success.

One family was selected in order to create an accurate picture of the family's experiences raising an autistic child. The parents were interviewed using semi-open ended questions and the interview focused on their experiences with the following: signs of autism, the diagnosis, experiences following the diagnosis and treatment, understanding of diagnosis and how it has changed, entrance to the school system, parents view on their child's progress, and views about what the future holds. The parents also completed questionnaires to confirm responses from the interview and create a clearer understanding of the various risk and opportunity factors involved in their child's development. The child's teachers and principal were also interviewed to gain a better understanding of the child in the school system and the teacher's competence in the area of autism. The child was also observed in a number of settings and administered

cognitive and ability tests to examine her ability. Additionally, previous psychological reports and childhood videos were also examined for additional insight into the family's life and to create a biographical sketch of the child's life.

The responses and information were analyzed using qualitative techniques such as coding, meaning condensation, and meaning categorization. Further analysis of the data lead to the emergence of common themes and issues, which include: acceptance of the diagnosis, frustration with the school and health system, a sense of family values and expectations, perceived progress as real, and a sense of urgency for the family's experiences to be heard.

The findings of this study indicate that the parent's perceived progress is likely real, based on the perceptions of the parents, teachers, professionals involved with the child, and the researcher's observations. The family believes that the progress can be attributed to the early implementation of early intervention, speech language pathology, occupational therapy, and the family's undying support.

This thesis attempts to make visible the need for research in the area of progress in autistic children and the struggles that families endure along their lengthy path to success. It allows one family the opportunity to share their experiences, attitudes, and perceptions about the progress witnessed in their autistic child and what it took to get there.

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List of Abbreviations

ASD	Autism Spectrum Disorder
CILC	The Child Improvement Locus of Control Scale
CISS	Coping Inventory for Stressful Situations
DAS	Differential Ability Scale
DSM IV	Diagnostic Statistical Manual (4 th Ed.)
EPA	Educational Program Assistant
IEP	Individualized Education Program
IWK	Isaac Walton William Health Canter
OT	Occupational Therapy
PDD	Pervasive Developmental Disorder
RLE	Recent Life Events
SLP	Speech Language Pathologist
WIAT-II	The Wechsler Individual Achievement Test (2 nd Edition)
WISC-IV	The Wechsler Intelligence Scale for Children (4 th Edition)
VABS	Vineland Adaptive Behavior Scale

Chapter I: Introduction

When an individual thinks of autism a variety of responses are possible. One may picture a mute child rocking in the corner, flapping his or her hands. Another may envision a child with wonderful artistic abilities or a child who does not interact with others. Growing up I too knew a young boy that fit the previous description of a child sitting in the corner flapping his hands. However, a few years ago I had the opportunity to witness a child with autism, unlike the descriptions above. This child appeared very intelligent and highly verbal, very unlike my typical experience. As my experience made me aware, which is consistent with literature (Furieux, 1977; Video, 1989; Cohen, 1998) autism may vary from child to child. As a normally developing child, each child with autism also has his or her own unique characteristics that set him or her apart from other children. Wahlberg, Obiakor, Burkhardt, & Rotatori (2001) reiterate this point by stating that there is no 'typical autistic child.'

There are various factors involved in why some children with autism do better than others. Some factors are related to the characteristics of the child and some factors are independent of the child (Cohen, 1998). Most families with children presenting with disabilities, such as autism, experience high levels of stress. Research suggests that some families do better because they cope more effectively with the situation, avoiding mental illness (Cohen, 1998; Neil, 2002; Allen, 2004). Families also seem to fare better when they have an extroverted personality, feel more competent, and have close supports, such as family or friends to rely on (Cohen, 1998; Chehrazi, 2002).

Society has begun to fight for the rights of families with children possessing autism. Many groups of parents have launched Charter challenges and human rights complaints in attempt to raise awareness of the needs of their children and the hefty cost attached to obtaining those needs. Fortunately, some provinces (such as Ontario) have begun to acknowledge the burden that rests on families with children possessing autism and announced that they will increase their funding for autism initiatives and early intervention.

Research suggests that intense early intervention and various treatments can produce significant positive outcomes for young children with autism (Arick, Young, Falco, Loos, Krug, Gense, & Johnson, 2003). These positive outcomes include acceleration of developmental rates, increased language ability, improved social behavior, and decreased symptoms of autism (Arick, et al., 2003). The best predictors of progress or positive outcomes, thus far, are intelligence quotients and speech ability (DeMyer, Barton, DeMyer, Norton, Allen, & Steele, 1973).

An important aspect in the exploration of why some children experience more progress than others may be how parents define success. Success may be defined in terms of meaningful actions, such as improvements in the quality of the life of the child and his or her family, and the ability of the child to gain a greater sense of self-esteem and accomplishment (Wetherby & Prizant, 2000). Furneaux (1977) has a somewhat different outlook on success. She defined success as the child's ability to deal with autism, which helps a child with autism cope as in adult. Furneaux (1977) further added that success may also pertain to the parent's ability to cope with their child throughout the treatment process.

The Nature of Autism

Since Leo Kanner described Autism in 1943 (Rutter & Schopler, 1978) our understanding of the disorder has expanded substantially. Autism is seen as a part of a spectrum of disorders, known as Autism Spectrum Disorder. The disorders are located under Pervasive Developmental Disorders (PDD) in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000). Other diagnostic categories included under this umbrella, in the DSM-IV-TR, are Rett's Disorder, Childhood Disintegrative Disorder, Asperger Disorder, and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS).

Pervasive Developmental Disorders are characterized by severe impairments in various areas of development. There are no biological measures for the diagnosis of autism, such as a blood test or brain scan, even though it is a neurological disorder (Grandin, 1995). The diagnosis is based on behavioral symptoms and developmental milestones (Webster, Knostantareas, Oxman, & Mack, 1980). In addition, autism must begin its onset before the age of three years, and professionals are now able to diagnose autism in children as young as two years of age, at least in retrospect (Hermelin & O'Connor, 1970; Baron-Cohen, Cox, Baird, Swettenham, Nightingale, Morgan, Drew, & Charman, 1996; Cohen, 1998; Baranek, 1999). Research by Hermelin and O'Connor (1970) suggests that an onset prior to two years of age or even from birth is representative of a "genuine autistic child."

Diagnosis

A diagnosis of autism must include impairment in social abilities, deficits in communication skills, and the presence of pervasive repetitive or restricted, and stereotyped behaviors in activities or interests (DSM-IV-TR; American Psychiatric Association, 2000). It is difficult to get clinical agreement on symptomatology in children with autism, although, the previously identified characteristics are the most agreed upon behavioral manifestations of the disorder (Hermelin & O'Connor, 1970; American Psychiatric Association, 2000). It appears to be the absence of normal development, not the presence of atypical development that raises the red flag.

The impairment in social abilities appears to be the core defining area, which sets a child with autism apart from a normally developing child (Schuler & Wolfberg, 2000). A deficit in social abilities is thought to prevent a child from interacting normally with others. He or she may not have the ability to imitate another individual, understand another's emotions, or share a focus of attention with other individuals, as a normally developing child (Klinger, Dawson, & Renner, 2003). This failure to create typical connections with others takes different forms. A child with autism may have difficulty with interpersonal relationships, may not grasp social rules, and may desperately wish to interact or communicate, but not possess the knowledge of how to do so or may have an impairment in understanding (Smith, 2004). If social exclusion persists, it may lead to further social deficits (Schuler & Wolfberg, 2000).

Given the deficits in social abilities of a child with autism, it is not surprising that communication difficulties would also affect both verbal and non-verbal skills (American Psychiatric Association, 2000). Language impairments range from failure to develop any

functional speech, to the development of functional and idiosyncratic use of spontaneous language (Wetherby, Prizant, & Schuler, 2000). Findings by Rutter and Schopler (1978) revealed that, historically, approximately 50 percent of individuals with autism remained without speech throughout the entirety of their lives. This estimate appears to be decreasing with early diagnosis and intense intervention (Klinger et al., 2003). However, the acquisition of language and communication still tends to be an enormous challenge not only for the child, but also for the family, as the impairment of communication may be one of the greatest sources of stress (Klinger et al., 2003).

Those individuals who do learn to speak often have immediate or delayed echolalia (e.g., word for word repetition of previously heard words) and pronoun reversals (e.g., replacement of 'you' instead of 'I' when referring to self) (Cantwell, Baker, Rutter, & Mawhood, 1989; Klinger et al., 2003). Additionally, when language is acquired, the pitch, rate, rhythm, or intonation may be irregular (American Psychiatric Association, 2000). Often conversations include irrelevant details, such as dates when discussing an event or spontaneous information (Tager-Flusberg, 1999). Many children with adequate verbal abilities may lack the behavior of attempting to communicate with others, thus have reciprocal communication difficulties.

Additionally, children with autism frequently have difficulty with the semantics of language. They follow the same progression of grammatical development as typically developing children, but how effectively they employ the language skills and follow social rules of conversation is impaired (Wetherby, et al., 2000; Klinger et al., 2003). Tager-Flusberg (1999) reported that children did not appear to use the vocabulary that they had learned, nor did they use their language to elicit further conversation, through

“wh-” questions. Persons with autism are also found to be very literal and concrete individuals (Cohen, 1998; Klinger et al., 2003). Even when many children begin to fit in, many still continue to be quite literal. This is often upsetting to the child, as he or she may truly wish to be humorous or understand humor, but not grasp the characteristics necessary to do so (Cohen, 1998).

Many children with autism frequently engage in receptive, ritualistic behaviors.

These repetitive behaviors fall into two distinct categories, which include:

“lower-level behaviors, which are characterized by repetitive motor movements, and higher-level or more complex behaviors, which are characterized by insistence on following elaborate routines and circumscribed interests” (Klinger et al., 2003, p. 416).

They often adhere to strict routines and even the slightest variation from their normal routine can cause dramatic distress (Bristol, McIlvane, & Alexander, 1998; Cohen, 1998; American Psychiatric Association, 2000). Often the repetitive movements occur in younger, lower-functioning children with autism. The movements often include toe walking, rocking, and arm, hand, or finger flapping (American Psychiatric Association, 2000; Klinger et al., 2003). The more complex behaviors, involving elaborate routines, are frequently observed in higher-functioning children with autism (Klinger et al., 2003). These routines include such behaviors as the ordering of toys and strict sequencing of events during activities. Klinger and colleagues (2003) reported findings of a recent study of 40 high-functioning children with autism and asperger syndrome, which revealed a decrease in these routines and stereotyped movements over time.

Other behavioral symptoms often attached to autism include self-injurious behaviors, sleep difficulties, eating disturbances, abnormal fears, such as a lack of fear in situations where danger may be a reality to excessive fear in situations that pose no harm,

and peculiar responses to sensory stimuli (American Psychiatric Association, 2000; Klinger et al., 2003). Sensory problems can range from not being able to enjoy a hug, as the sensation may be too overwhelming due to the stimulation, to auditory occurrences such as noise, which may be distracting, or odors, which may elicit exaggerated reactions (American Psychiatric Association, 2000; Grandin, 1995; Williams, 1992).

Autism and Cognitive Ability

The symptoms previously discussed often cause differences in the way the brain processes information and thus affects a child's ability to think or learn as a typically developing child (Wetherby & Prizant, 2000). These thinking and learning differences may cause intense confusion, frustration, and anxiety, which may be expressed in a variety of methods, including withdrawal, repetitive behaviors, or aggression and self-injury (Wetherby & Prizant, 2000).

More than half of all children with autism are mentally challenged (Cohen, 1998), a diagnosis which can range from mild to severe (American Psychiatric Association, 2000). Regardless of the general level of intelligence, which can be impacted by communication difficulties, thereby rendering invalid typical measures of intellectual ability, cognitive skills are often uneven in children with autism (American Psychiatric Association, 2000; Mayes & Calhoun, 2003a; Mayes & Calhoun, 2003b). Some children have high vocabularies but often do not comprehend, while others have areas of competence in mathematics or other skills (Cohen, 1998). Some of these skills have been regarded as "splinter skills" and thus the true nature of cognitive differences

and cognitive impairments continues to challenge researchers (Cohen, 1998; Wetherby & Prizant, 2000).

Strengths of autistic children that appear to remain consistent are an excellent rote memory for auditory and especially visual information (Williams, 1992; Grandin, 1995; Wetherby & Prizant, 2000; Mayes & Calhoun, 2003a; Mayes & Calhoun, 2003b), and an outstanding performance on tasks requiring visuospatial judgment and pattern recognition (Williams, 1992; Grandin, 1995; Wetherby & Prizant, 2000). These skills enhance memorization, recognition, the reproduction of a series of facts or lists, and the construction of visuospatial designs from samples (e.g., designs with blocks) and puzzles. Williams (1992) reveals that the strong ability of a rote memory allowed her to learn rules for dealing with situations, although she did not understand the meaning or significance of such rules.

Apparent cognitive weaknesses of children with autism include difficulty with coding tasks, the categorization of sequential information, and social reasoning (Mayes, & Calhoun, 2003a; Mayes, & Calhoun, 2003b). Many children will also equally recall meaningful and non-meaningful information unlike a normally developing child, who appears to perform significantly better when presented with meaningful information (Wetherby & Prizant, 2000).

Children with autism tend to have a higher performance of non-verbal tasks as opposed to verbal tasks on the Wechsler Intelligence Scale for Children (*WISC-IV*; Wechsler, 2002) (Mayes, & Calhoun, 2003a; Mayes, & Calhoun, 2003b). The lowest non-verbal subtest is frequently Coding and the lowest verbal subtest is often Comprehension. The highest non-verbal subtest is often Block Design, and the highest

verbal subtests are commonly Similarities and Digit Span (Mayes, & Calhoun, 2003a).

Research by Mayes and Calhoun (2003a) revealed that IQ scores were also proportionate to academic test scores.

High-functioning children with autism tend to have more severe graphomotor problems, thus perform significantly lower on visual-motor integration tasks than their IQ predicts (Mayes, & Calhoun, 2003a). Perez and Sevilla (1993) reported that many children with autism have more serious problems with visual-motor tasks than mentally challenged children.

Children that received an IQ score of 80 or above performed well on the reading decoding, math, spelling, and reading comprehension subtests of the Wechsler Individual Achievement Test (WAIIT; The Psychological Corporation, 2002) and had difficulty on the Written Expression subtest.

Cohen (1998), and Wetherby and Prizant (2000) noted that a performance IQ of 70, combined with functional language by the age of 5, seems to predict a better developmental course for the individual with autism. These factors appear to be good indicators of subsequent IQ scores, academic achievement, and adaptive skills in later years. Thus, standardized testing is frequently a part of interpreting the functioning and progress for children with autism (Koegel, Koegel, & Smith, 1997)

Additionally, children with autism tend to show a unique pattern of adaptive behavior, with significant deficits in socialization, relative strengths in daily living skills, and average scores in communication (Carter, Volkmar, Sparrow, Wang, Lord, Dawson, Fombonne, Loveland, Mesibov, & Schopler, 1998; Fenton, D'ardia, Valente, Vecchio, Fabrizi, & Bernabei, 2003). Even high-functioning children, those who have adequate

cognitive skills, often display deficits in adaptive behavior, but their profiles are less scattered than low-functioning individuals (Carter, et al., 1998; Liss, Harel, Fein, Allen, Dunn, Feinstein, Morris, Waterhouse, & Rapin, 2003). The adaptive functioning measure can shed light on an individual's adaptive functioning, strengths, and weaknesses, which serve to ascertain how well the individual may function in his or her environment and in addition monitor the individual's progress over time (Carter, et al., 1998; Liss, et al., 2003).

Causes/Etiology

There are a variety of factors that may play a role in the development of autism. Genetic factors play a significant role in the development of autism and other pervasive developmental disorders (Schopler, Van Bourgondien, & Bristol, 1993; Szatmari, Jones, Zwaigenbaum, & Maclean, 1998). A study conducted by Szatmari (1999) found that the frequency of autism in siblings of autistic children is estimated at 2.2 percent to 4.5 percent. This is 15 to 30 times greater than the occurrence of autism in the general population. There is no solitary gene that can account for autism and a combination of genes appear to place an individual at risk for autism (Klinger et al., 2003).

There appears to be a connection between prenatal complications and the development of autism (Klinger et al., 2003). Although findings by Filipek, Accardo, Baranek, Cook, Dawson, Gordon, Gravel, Johnson, Kallen, Levy, Minshew, Prizant, Rapin, Rogers, Stone, Teplin, Tuchman, and Volkmar (1999) suggest that mild obstetrical complications have been ruled out as factors causing autism. It has been proposed that various biochemicals are involved in the onset of autism, however, inconsistent findings make it difficult to accurately declare which are involved and how.

Another proposed hypothesis raised is the idea that autism is connected to immunizations and pollutants, especially in cases where regression is witnessed. Research suggests immunizations, more specifically vaccines for rubella, mumps, and measles, may be causing agents because typically children receive their MMR vaccination between 12 to 18 months, which is often around the time autism is diagnosed (Boyes, 2003). Current research has not warranted any truth to this assumption (Boyes, 2003; Klinger et al., 2003).

A further proposed causal factor and/or indicator of autism may be the hypothesis that the head of a child with autism is significantly smaller at birth, than average, but proceeds through a phase of explosive growth during the child's first year of life (Boyes, 2003; Cowley, 2003; Treffert, 2003). Neuroanatomical studies suggest that the brain is enlarged in some areas and reduced in size in others, thus leaving portions of the brain with too many neurons and others with too few (Boyes, 2003; Klinger et al., 2003; Treffert, 2003). Research reveals that abnormalities may arise in the cerebellum, cerebral cortex, limbic system, and corpus callosum (Treffert, 2003). However, the precise cause of autism still remain largely unknown, and thus no core treatments exist.

Prevalence

Sadly the prevalence of autism is increasing significantly, with approximately 1 in 200 children born developing autism (Boyes, 2003; Smith, 2004). Cohen (1998), Szatmari and colleagues (1998), and Klinger and colleagues (2003) suggest that even higher rates of occurrence may be possible, reaching rates as high as 10-16 cases per 10,000. Prevalence rates from 1970 reveal much lower rates of approximately 4 cases per 10,000 (Hermelin & O'Connor, 1970).

Researchers are unsure whether a true rise in prevalence has taken place or if the higher reported rates are due to increased knowledge of the condition and better identification (Cohen, 1998; Smith, 2004), or modifications to the diagnostic criteria and differences in methodology (American Psychiatric Association, 2000).

Autism is largely a male disorder, as approximately 4 or 5 males are affected to 1 female (Hermelin & O'Connor, 1970; Cohen, 1998; American Psychiatric Association, 2000; Smith, 2004). It has been noted that girls diagnosed are more severely impaired and tend to have lower IQ's (Cohen, 1998). However, high-functioning females tend to reveal less severe forms of autism compared to high-functioning males (Cohen, 1998; Klinger et al., 2003). There is no explanation for this tendency, but Cohen (1998) reports that it may reflect genetic mechanisms.

Past studies performed by Kanner (1943), consisted of samples from wealthy families. Thus, clinicians initially assumed that autism was caused by rejecting and cold parents (Furieux 1977; Klinger et al., 2003). It is believed that the increased rates of autism in wealthy families surfaced because these families were more able to afford treatment for their children (Klinger et al., 2003). Socioeconomic status (SES) does not appear to influence the prevalence of autism (Bristol et al., 1998) However, the fact remains unknown whether SES influences the prognosis or outcome. Autism is now known to affect individuals throughout the world, with reports of symptomatology, intellectual abilities, gender differences, and socioeconomic status remaining highly consistent (Bristol, et al., 1998; Klinger et al., 2003).

Prognosis

The onset of autism occurs prior to the age of three years and two patterns of symptom development seem to arise (American Psychiatric Association, 2000). First, a lack of skills development rather than the development of unusual behaviors in infancy appears. Secondly, a period of regression of skills during the first three years of a child's life may arise. The specific behaviors and course depend on the child's age and developmental level (Webster, et al., 1980). Autism strikes each child differently. Each child has his or her own special abilities and not all diagnosed children display the same symptoms, or all of the symptoms (Webster, et al., 1980).

The ultimate prognosis for an individual with autism is often poor, with respect to academic achievement and independent living (Klinger et al., 2003). Prognosis, however, depends on several factors, such as the presence of communicative language and overall intellectual ability (American Psychiatric Association, 2000). In about one third of cases, at least partial independence is possible, although even the highest-functioning individuals with autism continue to show some problems with social interaction and communication (American Psychiatric Association, 2000). A study conducted by Kobayashi, Murata, and Yoshinaga (1992) of 197 young adults with autism, who had received treatment, 27 percent achieved social independence and the remaining 73 percent required supervision. Kobayashi and colleagues (1992) also reported that approximately 43 percent of the parents of these children reported remarkable improvements in adolescence.

There is evidence to suggest that long-term outcome can be dramatically improved following the implementation of any intervention program (Howlin, 1997). The

fact that children may be able to attend a normal school or later find jobs does not mean that they are cured (Bristol, et al., 1998), nor that the chosen treatment has been responsible for their progress (Howlin, 1997), although, implementing earlier interventions may lead to a better prognosis for individuals with autism.

Early Diagnosis & Intervention

The timing of the intervention is important. The average age of a child diagnosed with autism is four years, although, autism may be diagnosed in children as young as two years of age (Klinger et al., 2003). Early detection means earlier access to intervention during sensitive periods of brain development, which may have a significant effect on the child's nervous system and ultimately reduce the symptoms of autism (Dawson, Ashmore, & Carver, 2001).

An early diagnosis provides a label, which occasionally considered negative, can also be a blessing, as it allows a family to gain control of the problem and obtain aid (Schopler et al., 1993). The clear diagnosis permits the ability to plan an effective intervention, which is critical for future success (Schopler, et al., 1993; Szatmari, 1995; Moore & Goodson, 2003).

The autism early intervention program is coordinated by the provincial autism committee, which includes parents, staff of regional health authorities, department of health and social services, mental health, school boards, the department of education, and community-based organizations. The program offers clinics, information and resources, home-based early intervention, and support.

Various types of early intervention programs offer educational and therapeutic services to children ages two-to-six years, twelve months a year. Interventions include

those in specialized settings, community settings, behavior management, and speech and language therapy (Szatmari, 1995). Specialized settings consist of specialized early intervention that is highly intensive, consisting of approximately 40 hours per week. The therapy is also highly structured and focused on strict behavioral management principles. The results at school entry indicate gains in IQ and a marked reduction in behaviors characteristic of autism (Szatmari, 1995).

Community settings integrate children with autism with normally developing children, which often results in progress in social and communication skills (Szatmari, 1995). The program aims to help children develop the skills necessary to survive in other mainstream settings.

Behavior management adheres to the notion that problems do arise in both the preschool setting and in the home. The goal is to replace the problem behavior with a more appropriate and socially acceptable behavior. It is assumed that by surrounding the child with the communication of others and with social interactions, he or she will be exposed to developmentally appropriate behaviors, and thus will be able to model them.

The ultimate goal of speech and language therapy is to encourage the use of language to socialize and build on developmentally appropriate communication skills. Any form of communication is encouraged at this stage and situations may be created to elicit communicative functions (Szatmari, 1995).

Those who do not receive treatment often do not outgrow their symptoms, but those who do receive early and intense treatment often make significant improvements (Schopler et al., 1993). The early intervention process also often helps the child move into the public school system (Szatmari, 1995). Research suggests that the earlier the

intervention is introduced, the better the chance that the child will develop functional language and be placed in a regular classroom (Klinger et al., 2003).

Solutions are not obvious and thus all families deal with autism in their own way (Williams, 1992). Many treatment studies have failed to consider all the issues and thus which early treatment approach is most effective is largely unknown (Gresham & MacMillan, 1997).

Intervention Approaches

A long list of treatment options for children with autism has developed. The main interventions include, Applied Behavior Analysis and discrete-learning trials (ABA; Lovaas, 1987), Educational Interventions, Treatment and Evaluation of Autistic and Related Communication-Handicapped Children (TEACCH; Schopler & Reichler, 1971), Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP; Hoyson, Jamieson, & Strain, 1984), and 'Alternative treatments', such as Auditory Integration Training (AIT; Zollweg, Palm, & Vance, 1997), dietary treatment (Whitey, Rodgers, Savery, & Shattock, 1999), and Sensory Integration Therapy (SIT; Ayres, 1979).

Applied Behavior Analysis (ABA) refers to a process of systematically observing and recoding an individual's behavior, with the collected information being used to shape instruction and formulate effective interventions (Cohen, 1998). ABA is based on discrete-trials, whereby complex skills are broken down into smaller specific skills, which are repeated and mastered before progressing onto the next skill in sequence (Cohen, 1998; Yazbak, 2002). The small steps are positively reinforced, which allows for behavioral, cognitive, and language skills to be modeled (Yazbak, 2002). Prompts are

also used initially, and then faded out as the child masters the skills and learns to generalize the skills to other areas. The treatment is very intensive, with approximately thirty to forty hours of one-on-one behavioral intervention necessary (Cohen, 1998).

ABA has become widely accepted as an effective treatment and often enables a child with autism to enter a mainstream education classroom (Cohen, 1998; Ollendick & King, 2000; Dunlap, Kern, & Worcester, 2001; Yazbak, 2002). Research suggests that the treatment with the most support for its efficacy is the behavioral program founded by Lovaas (Ollendick & King, 2000; Dunlap et al., 2001). However, the question remains whether the children also received other services, which may have enhanced their gains as well (Ollendick & King, 2000).

Educational treatments appear to benefit many children with autism and there is virtually no disagreement of its value (Cohen, 1998). It has been suggested that many families try to embrace different forms of treatment and less focus is put into educational treatment, which is thought to be a shame (Cohen, 1998). Educational treatment must be intensive to produce a significant improvement in functioning and narrow the gap in IQ and language, between a normal developing child and a child with autism (Cohen, 1998). The educational school system and its involvement will be discussed more in depth in a following section.

TEACCH, which stands for Treatment and Education of Autistic and Related Communication-Handicapped Children, is an intervention that provides services to children with autism and their families (Cohen, 1998; Schopler, et al., 1993). The primary educational goal of TEACCH is to increase the child's level of skill and the child is provided with an environment designed to accommodate his or her autistic characteristics

(Schopler, et al., 1993). The intervention makes use of visual cues, as visual processing is often a strength for children with autism (Schopler, et al., 1993). Past studies revealed that parents were satisfied with the services provided to their children, however, very little is known about the amount of progress a child makes using this form of intervention (Schopler, et al., 1993).

LEAP, which stands for Learning Experiences: An Alternative Program for Preschoolers and Parents, is a model for the integration of children with autism with typically developing children, developed in Pittsburgh. Activities, such as incidental teaching, play, and direct instruction with reinforcement and modeling, are designed to facilitate language, adaptive behaviors, and social interaction (Schopler, et al., 1993). Research suggests that a child participating in the LEAP program, which is directed by highly trained professionals for two years, generally shows a reduction in autistic symptoms (Schopler, et al., 1993).

Auditory Integration Training (AIT) is based on the premise that some characteristics of the child with autism are a result of a sensory dysfunction. This may involve hypersensitivity to various frequencies, thus making many sounds painful to the child (Schopler, et al., 1993). The procedure involves the individual listening to modulated music, with certain frequencies filtered out, through headphones for approximately two half-hour periods a day, over ten days. It has been suggested that AIT appears to reduce sound sensitivity and decrease problem behaviors, but no controlled studies have been performed to confirm these results (Schopler, et al., 1993).

Sensory integration therapy focuses on other types of sensory input. The therapy is based on the sensory integration theory, which proposes dysfunction in the

proprioceptive, vestibular, and tactile systems of the body. The proprioceptive system receives sensory information from the body, while the vestibular system is responsible for gravity and movements. When the information from these systems is not integrated, the outcome will result in developmental problems. This therapy addresses the dysfunction caused by sensory stimulation and produces an adaptive behavior (Schopler, et al., 1993).

Researchers are skeptical of the therapy's effectiveness and suggest many weaknesses in the design of studies producing positive results (Schopler, et al., 1993). Well-controlled studies found that sensory integration therapy was ineffective or no more effective than other treatments, and thus the therapy is often integrated into other treatment programs and services, and rarely used unaccompanied (Schopler, et al., 1993).

Dietary interventions are based on the idea that food allergies cause symptoms of autism, and an insufficiency of a specific vitamin or mineral may disrupt the central nervous system and cause problems associated with autistic symptoms (Whiteley, Rodgers, Savery, & Shattock, 1999). The removal of gluten and/or casein from the diet of those with autism has proven to be related to improvements in behaviors tailored to autism (Whiteley, et al., 1999). Gluten is a casein-like substance that is found in the seeds of various cereal plants, such as wheat, oat, rye, or barley. Casein is the principal protein in milk.

Whiteley and colleagues (1999) suggest that there may be other factors, such as educational strategies, environmental influences, and developmental issues, influencing the significant improvement. It is further suggested by Whiteley and colleagues (1999)

that the variability in the success of the diet may be reflective of different biological mechanisms associated with those individuals possessing autism.

Researchers Cohen (1998), and Schopler and colleagues (1993) suggest that there is no standard treatment for autism and no single treatment possesses all of the answers, nor ensures progress or success. Cohen (1998) further notes that some children produce very good results, while others don't. Most forms of treatment for autism are thought to improve functioning, but not eliminate the core characteristics of autism (Cohen, 1998; Schopler, et al., 1993).

The categories of establishing treatment efficacy include, well-established treatments, which include those better than the placebo or other treatments in at least two trials, those probably efficacious, which include those better than no treatment and a waiting list, and experimental treatments, which are those treatments not yet showing efficacy (Ollendick & King, 2000). The intensive behavioral program developed by Lovaas holds empirical support, although the study possesses weaknesses within the methodology. Thus, no well-established or probably efficacious treatments for autism exist at the current time (Ollendick & King, 2000). With all the possible interventions available and no definite cure, choice of treatment and the progress that a child makes may ultimately depend on the family, their characteristics, personality, and lifestyle.

Risk & Opportunity Factors

There are a multitude of risk and opportunity factors present in all families, such as parent education, income, job stability, number of siblings, parental mental health, parental self-esteem, parental personality, coping strategies employed, parenting style,

etc... (Wolery & Garfinkle, 2002; Dunst, 1993) (See Table 1 for a complete list of risk and opportunity factors). These factors have been found to influence a family and a child's functioning and development (Wolery & Garfinkle, 2002).

Risk factors include both intrafamily and extrafamily influences that undermine a family's ability to nurture a child's development (Dunst, 1993). Opportunity factors are the same influences that are assisting and thereby supporting the families' ability to promote a child's progress and success (Dunst, 1993).

The absence of a risk or opportunity factor does not result in a guaranteed delay or improvement in the progress of a child's development (Dunst, 1993). However, a strong argument has been made that the prevention of poor outcomes or risk factors and existence of opportunity factors may result in enhanced positive functioning (Wolery & Garfinkle, 2002). Researchers Dunst and Trivette (1992) suggest that the more opportunity factors present in a family, the more advanced the child's development. Alternatively, the presence of several risk factors has been associated with the increased possibility of poor outcomes and surprisingly even one risk factor can negatively influence the child's outcome and development (Wolery & Garfinkle, 2002).

Self-efficacy. Higher levels of self-esteem make a person more resilient in the face of stressful events (Lovejoy & Steuerwald, 1997). Control over an event or behaviour makes a person feel as though they can modify or reduce some aspects of a stressful situation, therefore making coping easier (Aspinwall & Taylor, 1992).

Self-efficacy theory proposes that all forms of psychotherapy and behavioural change stem from a common mechanism: the change in one's expectations of success and personal mastery (Sherer, Maddux, Mercandante, Prentice-Dunn, Jacobs, &

Table 1

List of Risk and Opportunity Factors Influencing Child Learning and Development

<u>Variable</u>	<u>Risk Factors</u>	<u>Opportunity Factors</u>
Mother's Age	Younger/older than normal childbearing age	Within optimal childbearing years
Parent Education	Low educational attainment	High educational attainment
Income	Inadequate Income	Adequate Income
Occupational Status	Low occupational status	High occupational status
Socioeconomic status (SES)	Low SES	High SES
Job stability	Repeated job changes or unemployment	Stable job
Pregnancy	Unplanned	Planned
Number of siblings	More than four	One or two children
Residential stability	Repeated relocations	None or few relocations
Marital status	Absence of spouse/partner	Supportive spouse or parent
Marital relationship	High levels of conflict	Harmonious
Marital stability	Repeated changes in conjugal relationship	Stable conjugal relationship
Child temperament	Avoidant, difficult	Warm, responsive
Infant separation	Prolonged separation in first year	Limited separation in first year
Parental health	Poor physical health	Excellent physical health
Parental mental health	Repeated occurrences of mental health problems	Stable emotional well-being
Parental self-esteem	Low self-esteem	High self-esteem
Parental locus of control	External	Internal
Parental social skills	Poor	Good
Coping strategies	Reactive	Proactive
Quality of primary caregiver	Controlling and emotionally unavailable	Stimulating and warm
Parenting style	Authoritarian and directive	Responsive and facilitative
Toxic substances	High exposure	No exposure
Nutritional intake	Inadequate	Adequate
Accidents	Frequent	Infrequent
Infections and illnesses	Frequent	Infrequent
Alternative caregivers	None	One or more
Presence of extended family	None or few relative	Many and supportive
Extra-family support	Poor and unsupportive	Good and supportive
Life events	Negative	Positive

Taken from: Dunst, C. (1993). Implications of risk and opportunity factors for assessment and intervention practices. *Topics in Early Childhood Special Education*, 13, 143-153.

Rogers, 1982). Fisher (1984) proposed, “the tendency to perceive whether control is or is not possible is a personality disposition that varies between individuals.” He also believes that attitudes about control might affect ideological beliefs and the nature of experiences.

Bandura (1982) describes self-efficacy as one’s perception of how one must deal with one’s environment. Self-efficacy is a positive perception of one’s capabilities to organize and execute a course of action required to produce given attainments and goal setting behaviour (Bandura, 1977). More specifically, self-efficacy is the personal beliefs about the ability to control one’s environment and life’s challenges (Maciejewski, Prigerson, & Mazure, 2000).

The uncertainty of autism leaves many parents feeling frustrated and unsure of what they can do for their child (Sofronoff & Farbotko, 2002). Many parents feel unable to care for their child and question their parental competence, which refers to how confident parents feel in their ability to handle their child’s problems. Mothers are found to suffer from a lack of parental confidence more frequently than fathers (Sofronoff & Farbotko, 2002).

Poor self-efficacy often leads to poor persistence and depression (Sofronoff & Farbotko, 2002), thus parents may not persist in advocating for better outcomes for their child. They may feel as though they are unable to provide for their child and help him or her succeed. Sofronoff and Farbotko (2002) further suggest that parents of children with autism often feel less competent, than parents of normally developing children. If this is the case, the opposite may also hold true and thus believing that one has the ability to care for one’s child and produce positive outcomes may cause families to strive for progress and ultimately succeed.

Depression and Life Events. Symptoms of depression include: feeling of sadness, difficulty concentrating, changes in appetite and sleeping habits, fatigue, loss of interest in normal daily activities, and thoughts of death (Musil, Haug, & Warner, 1998).

Depressive symptoms have been found to be correlated with a wide range of difficulties, including anxiety, irrational beliefs, negative cognition, negative attribution style and perceived lack of control over environment, and lessened ability to self-monitor, self-evaluate, self-reinforce behavior, and deal with negative life events (Hops, Lewinsohn, & Andrews, 1990).

Life events may be quick to occur, but they may have enduring consequences. They can be distinguished from more chronic difficulties, such as poverty (Brugha, Bebbington, Tennant, & Murray, 1985). The events may also affect families differently (Brugha et al., 1985), depending on the supports that the family has in place or coping mechanisms employed. Such negative life events may be a move to a new neighborhood, a change of schools, the death of a loved one, a serious accident or family illness, a violent family environment, parental conflict, or the diagnosis of a lifelong disorder, such as autism.

Depression may, additionally, contribute to poor social functioning and an overall poor quality of life (Musil et al., 1998). These negative life events may occur alone or in combination with other risk factors, such as lack of social support. Research indicates that higher rates of depression are reported in parents of children with autism, particularly in mothers (Brereton, Tonge, & Kiomall, n.d.). Depression affects the way individuals function and their overall quality of life. It can be assumed that a parent may develop depression when his or her child is diagnosed with a life altering disorder and that the

mental illness will likely influence the parent's ability to cope and deal adequately with the disorder.

Dunst (1993) identifies parental mental health and life events as either a risk or opportunity factor for positive outcomes in dealing with children with developmental disorders. He proposed that repeated occurrences of mental health related problems and negative life events act as a risk factor, which negatively influences a child's development. Positive life events and a stable emotional well-being were indicative of opportunity factors influencing a child's development.

Coping. Efforts to understand the concept of coping have a long history. Coping was initially discussed by Freud, as a "defense mechanism" (Endler & Parker, 1999). Various defenses, such as repression, projection, and rationalization, were thought by Freud to be unconscious processes to cope with stress. These defenses were not problem- or task-focused types of coping, but instead a form of avoidance- or emotion-focused coping mechanisms. One would not be dealing actively with one's problem with these types of defense mechanisms, but instead pushing the problem aside, pretending it didn't exist, or putting the problem onto another person.

In the literature, "coping style" is used to indicate a person's characteristic or typical manner of confronting a stressful situation and dealing with it (Folkman & Lazarus, 1980; 1985). Coping must be distinguished, however, from automatized adaptive behavior. Coping implies effort, whereas automatized adaptive behaviors do not (Lauzarus & Folkman, 1984).

Multiple coping mechanisms may be employed when dealing with a single stressful event. Three main forms of coping are discussed most often in the current

literature: problem-focused, emotion-focused, and avoidance-oriented coping (Endler & Parker, 1999). Problem-oriented coping is aimed at solving the problem or doing something to alter the source of stress. It is, in addition, identified as task-oriented coping, as the individual is attempting to address the problem (Endler & Parker, 1999). Emotion-oriented coping is aimed at reducing or managing the emotional distress that is associated with the situation (Carver, Scheier, & Weintraub, 1989), by trying to eliminate the negative emotional consequences of the situation. Emotion-oriented, or palliative coping is considered to be a person-oriented coping style (Endler, Vitelli, & Parker, 1989). For example, emotion-focused forms of coping include detaching oneself from the situation or wishing the problem would go away (Lesar, 1998). Avoidance-oriented coping is aimed at avoiding or repressing a stressful situation. When a stressful event has been encountered the individual employing avoidance coping will not attempt to solve the problem. They may not even acknowledge that there is a problem.

Families use a variety of coping strategies that may influence the functioning of their families (Judge, 1998). These families may have preferred coping styles, or patterns they typically use to respond to different stressful events and these may vary among individuals (Endler & Parker, 1999). An individual's choice of coping may produce very different results within the family and influence family functioning (Lesar, 1998).

Research suggests that coping with a situation beyond one's control is very stressful and often requires a coping strategy that changes the self to fit the situation, as opposed to changing the situation (Tunali & Power, 2002). Lesar (1998) suggests that problem-solving is the preferred mechanism of coping with 'disability-related problems.' This would apply to parents of a child with autism. They must cope by accepting the

diagnosis, redefine what constitutes fulfillment and develop alternative means of achieving it. If parents are able to achieve a balance between meeting the special needs of their child and maintaining their 'unrelated personal interests', then stress is reduced (Schuntermann, 2002). If parents choose to employ emotion-focused coping by denying the situation or avoiding it, then depression or mental illness may occur (Lesar, 1998).

Dunst (1993) identifies parental coping strategies as either a risk or opportunity factor for positive outcomes in dealing with children with developmental disorders. If parents cope adequately, in a problem-solving manner, and engage in the continuous process of adaptation, then coping may be seen as an opportunity factor (Schuntermann, 2002). Coping strategies can strengthen the family and protect them from stressful encounters (Judge, 1998; Lesar, 1998; Gabriels, Hill, Pierce, Rogers, & Wehner, 2001), especially if a family is able to cope with the many uncertainties that accompany autism (Tunali & Power, 2002). However, if parents employ an emotion-focused method of coping, this is seen as a risk factor in a child with a developmental delay, such as autism (Dunst, 1993; Tunali & Power, 2002). The child and parent's successful coping are also important goals of family interventions (Schuntermann, 2002).

Coping may be difficult, especially since children with autism tend to have uneven patterns of development (Schuntermann, 2002). Likely when parents have finally begun to cope adequately, the child's behavior may change. Thus, parental stress, coping and self-efficacy may fluctuate with the child's progress (Schuntermann, 2002). If the parents are unable to deal with the situation and are exerting unnecessary energy denying the truth, then coping may be viewed as a risk factor. The more time the parents spend

focusing on the unchangeable, the less time they are working on producing the best outcomes they can for their child.

Personality Type. The field of personality is among the most confusing areas of psychology. It has been characterized as "...one thousand theories in search of a fact" (Endler, 1982). Different theorists have attempted to explain the development of personality throughout the years.

Personality can be viewed as a person's logical or coherent manner of interacting with one's self and one's environment (Endler, 1982). The interaction model of personality proposes that behavior is a function of the interaction between persons and their situations (Edwards, Vitelli, & Parker, 1989). Particular events and situations are difficult for some types of people, and not for others. Moreover, personal characteristics may interact with event characteristics in accounting for response outcome, yielding this personality-interaction model (Blaney, 2000). This helps explain individual differences in how people respond to the same event. Thus, one family with a child with autism may manage the situation differently than another family, thereby possibly producing different outcomes for the child. Patrick (2004) further suggests that a family member's personality may also play a part in the early intervention experience. Just as the environment can shape an individual's personality, personality factors also influence individuals' environments. (Neale, Davison, & Haaga, 1996). Some parents are persistent and tenacious and fight for services for their child, while others are timid and unable to handle confrontation well (Patrick, 2004). Furthermore, Patrick (2004) revealed that passive families do not receive proper services for their child, as they do not possess

the personality characteristics to fight for the rights of their child. At the same time, other families are persistent and go to great lengths to obtain the needed services.

The types of personalities include: Extraversion, Neuroticism, Frustration, Rigidity, Isolation Tendencies, and Esoteric Tendencies, as assessed by the MPT. A person portraying the extraversion personality trait is outgoing, gracious, assertive, and sociable. They like people and prefer large groups and gatherings to small isolated groups (McGrae & Costa, 1986). Extroverts are talkative, active, cheerful, and like excitement and stimulation. They are also thought to be upbeat, optimistic, and very energetic. Parents of children with autism who possess this type of personality tend to have more healthy adaptation patterns and are more prone to deal adequately with many of the stressors associated with raising a child with autism (Chehrazi, 2002).

The most persistent of the personality traits to be seen is Neuroticism (McGrae & Costa, 1986). Individuals high in neurotic characteristics are prone to experience anxiety, anger, disgust, sadness, embarrassment, and other negative emotions (McGrae & Costa, 1986). Individuals high in neuroticism appear to cope less effectively with stress, have an inability to control urges, have a dependency on emotional attention and hold unrealistic ideas (Sakado, Sato, Uehara, Sato, & Sakado, 1997). A study by Dor-Shav and Horowitz (1984) proposed that mothers of children with autism tend to be significantly more neurotic than mothers of normally developing children. Parents who are neurotic are often socially isolated and have poor adaptation patterns (Chehrazi, 2002). The cause of this personality trait in mothers of children with autism is largely unknown.

Another personality trait to be examined is frustration tolerance. Frustration tolerance reflects traits like emotional stability and ego strength. A frustrated individual

will be aggravated and irritated easily. They will be annoyed by relatively minor events and situations. The rigidity trait describes an individual who is strict and stringent. They are firm and inflexible in how they respond to events occurring in their lives. A rigid person represents a kind of “obsessionality,” such as having a need for orderliness (Sakado et al., 1997). Isolation tendency illustrates those individuals who are segregated, separated, and secluded. They are very often lonely and keep to themselves. Without much interaction with other human beings they cannot develop a supportive social network. Individuals possessing this type of personality are often passive and thus frequently do not get their needs met (Patrick, 2004).

Finally, esoteric tendency personality implies a mysterious and obscure persona. These individuals are cryptic, mystifying, and difficult to understand. One probably would find them difficult to befriend or interact with.

Locus of Control. Locus of control refers to “the perceived sense of control one has over one’s behavior” (Smith, Oliver, & Boyce, 2000; Mandlco, Olsen, Dyches, & Marshall, 2003). Individuals may possess an internal locus of control or an external locus of control. An individual with the aptitude to take responsibility for one’s actions and feel as though one has control over one’s behaviors and experiences is displaying an internal locus of control. Individuals who tend to attribute their failures or successes to external influences have an external locus of control (Smith, et al., 2000; Mandlco, et al., 2003).

Dunst (2003) lists locus of control as a possible risk or opportunity factor for predicting positive outcomes in dealing with children with developmental delays. An internal locus of control is seen as an opportunity factor, while an external locus of control is viewed as a risk factor (Dunst, 1993; Wolery & Garfinkle, 2003). Parents of

children with developmental disorders, such as autism, who embrace an internal locus of control generally believe that they are in control of the outcomes of their life events and hardships. They believe that they are able to take an active role in managing the stressful life events and producing positive outcomes for their child and family (Mandleco, et al., 2003). Research reveals that if parents have an internal locus of control and believe that their child's condition is controllable, then the child is more likely to receive more professional treatment and parent involvement in aiding the child (Smith, et al., 2000). The opposite can be said for parents that believe they have no control over their child's destiny. This type of family often believes that any improvement made by their child is likely due to fate, and thus they are more likely to receive less professional help and involve themselves less in their child's life (Smith, et al., 2000).

Parenting Style. Parenting style is defined as many behaviors that can work individually or together to influence a child's outcome (Baumrind, 1991). Baumrind (1991) suggests that parenting style is used to capture variations in parent's attempts to socialize their children. There are two important elements of parenting, which include parental responsiveness and parental demandingness (Maccoby & Martin, 1983). Parental responsiveness refers to those parents who foster individuality, self-regulation, and self-assertion, by offering support and being tuned into their child's needs (Baumrind, 1991). Parents who are demanding often demand maturity, supervision, and are willing to confront the child who disobeys (Baumrind, 1991).

Maccoby and Martin (1983) reveal four parenting styles, which include indulgent, authoritarian, authoritative, and uninvolved styles. Indulgent parents are also referred to as nondirective and permissive. They are more responsive than they are demanding.

Authoritarian parents are highly demanding and directive, but not responsive. These parents are well-ordered and structured. Authoritative parents are both demanding and highly responsive. They do provide discipline, however, in a supportive manner. Finally, uninvolved parents are neither responsive nor demanding. They are thought to be somewhat neglectful.

Dunst (1993) identifies parenting style as either a risk or opportunity factor for positive outcomes in dealing with children with developmental delays. He proposes that parents who are authoritarian and directive pose a threat to their child's outcome and parents who are responsive and facilitative offer a more positive outcome. Baumrind (1991) and, Weiss and Schwarz (1996) further state that children with parents who are authoritative and responsive are more socially competent. The researchers also suggest that children from authoritarian families tend to perform adequately in academics, but have poorer self-esteem, social skills, and increased depression.

Reaction to Autism Diagnosis. Parents' reaction to the diagnosis of autism varies, but mainly the reaction is one of shock, denial, anger, and grief (Cameron, Snowdown, & Orr, 1992; Nissenbaum, Tollefson, & Reese, 2002). Many parents often go through a grieving process after hearing the diagnosis due to the loss of an anticipated normal child (Cameron, et al., 1992). These stages can be categorized as the following: Confronting, which consists of shock, denial, guilt, and blame; Adjusting, which entails depression, anger, loneliness, and bargaining; and Adapting, which includes acceptance, change of lifestyle, altered expectations, and realistic planning (Powers, 1993).

Research by Nissenbaum and colleagues (2002) suggests that parents' failure to accept a diagnosis of autism is often due to either incorrect or negative perceptions of autism or due to characteristics of the family and concern about the reaction of the extended family. Thus, many families often deny the diagnosis. Cameron and colleagues (1992) and Milo (1997) suggest that after grief is resolved families culminate in a final stage of acceptance. Not all families are fortunate enough to reach this stage, but some families are able (Cameron, et al., 1992). It has been concluded that the age of the child at the time of diagnosis is also related to the acceptance of the family (Nissenbaum, et al., 2002). For example, if a child is still very young, the parents frequently have not had time to realize that the child's behaviors are abnormal and they still "envision the perfect child" (Nissenbaum, et al., 2002). For example, "families describe this as letting go of a normal child" (Cameron, et al., 1992). Also, very difficult for families to face is the suspicion of another disability other than autism, as the families preconceived notion of the reasons for the child's behaviors are shattered (Nissenbaum, et al., 2002).

The process of the grief cycle may endure weeks, months, or even years before parents fully accept and come to terms with their loss (Bristor, 1984). Some parents and families will go through more than one stage at once, or oscillate between stages (Dale, 1997). The notion that parents go through these stages sequentially, or that they all reach the final stage of acceptance is unlikely. Researchers believe that the adjustment process is a complex one which differs between individuals and families (Blacher, 1984).

Research proposes that parents who believe they have entered a stage of acceptance often feel more satisfied with their ability to parent their autistic child (Cameron, et al, 1992). In the acceptance stage the family has completely accepted the

child and the disability into their family (Milo, 1997). Some parents even go beyond this stage and bypass the grief stage and proceed straight into the problem solving stage.

These parents begin defining the experiences in their lives and find meaning or value in parenting a child with a disability (Milo, 1997).

Research by Bailey, Blasco, and Simeonsson (1992) suggests that parents have expressed the need for support, information about the diagnosis, child care, and professional help and support in order to progress through the stages of the grief cycle and finally reach the acceptance stage. However, they do conclude that “..the expression of family needs cannot be predicted on the basis of broad child or family categories but, rather, is unique to individual families” (Bailey et al., p. 9). Other researchers propose that families require empowerment and a sense of self-efficacy to move forward, as they take control and gain access to their needs (Turnbull & Turnbull, 1997).

Parental Involvement. Parental involvement has emerged as a major factor in treatment success and is often referred to as a ‘cornerstone’ in treatment programs (Ozonoff & Cathcart, 1998; Moes, 2000). Parents work with teachers and therapists to identify the behaviors to be changed and the skills to be taught (Cohen, 1998). Recognizing that parents are the child's earliest teachers, more programs are beginning to train parents to continue the therapy at home. The at-home therapy and parental involvement increases parent’s feelings of competence and success and also decreases prior feelings of stress and depression (Ozonoff & Cathcart, 1998).

Some parents are still concerned that professionals are not always sensitive to their needs nor support their involvement in the treatment process (Patrick, 2004).

Professionals do not deny this claim. They express doubts about whether families have

the skills necessary to participate in the intervention process (Patrick, 2004).

Professionals also feel that considerably more time and resources are required to implement family interventions (Patrick, 2004).

Parents often assume multiple roles. They seek out cures and or at least effective treatments. In addition, they are advocates for their child, fighting for services and rights to give their child a chance at better outcomes (Cohen, 1998). Many parents had to search for interventions for their child, ones that were effective, and they still continue to search for new treatments and knowledge.

Public School System. The public education of children with autism has drastically changed over the past 30 years (Schopler, et al., 1993). Traditionally, children with autism were hospitalized and quite possibly mute, uncomprehending the world in which they live and making no improvements. Then such children were placed in segregated classrooms with children possessing various mental disorders, often outside their communities (Bryson, Rogers, Fombonne, 2003). Approximately 15 percent of children with autism had entered normal classrooms and made fair social adjustments before the 1980's (Hermelin & O'Connor, 1970). Since the 1980's, policies have changed dramatically to one of inclusion (Schopler, et al., 1993; Robertson, Chamberlain, & Kasari, 2003). Now many children with autism are integrated into the regular classroom, either on a part-time or full-time basis, and most within their own community.

It has been suggested by Harrower and Dunlap (2001) that the proximity of a child to typical peers may be tremendously beneficial. Researchers have found that students with autism who are fully included in the classroom display higher levels of social interaction, offer and receive higher levels of social support, have larger friendship

networks, and have developed more advanced education plan goals, than those children in segregated classrooms (Harrower & Dunlap, 2001). Wahlberg and colleagues (2001) suggested that high-functioning children with autism should be included in classrooms with age level peers, so that they are able to model classmates' appropriate behavior.

However, including children with autism in the regular classroom poses many challenges, including training school personnel in teaching and behavioral management practices, but more importantly is the child's education (Bryson, et al., 2003).

Researchers make a good point stating that children with autism are "first and foremost" students (Dunlap & Fox, 1999) and they should be treated this way. Wahlberg and colleagues (2001) state that "teaching is a necessity, not a privilege to be left to chance" and thus teachers must have the necessary knowledge of how to teach children with autism, as they are becoming more involved in and responsible for their education (Robertson, et al., 2003).

There are many factors that are thought to influence the learning of a student with autism and his or her outcomes, such as the teacher's attitude, expectations, and competence (Furneaux, 1977; Wahlberg, et al., 2001; Simpson, de Boer-Ott, & Smith-Myles, 2003). Schools must discover what children are able to do, what they know, and how they think, and match these variables to the needs of the child to obtain optimal results.

Wahlberg and colleagues (2001), additionally, state that the most important variable accounting for gains made by persons with autism are the skills held by education personnel, such as their competence in the areas specific to children with autism. 'Good teachers' sense when children are ready to learn and seize those moments

to teach children with autism (Wahlberg, et al., 2001). They help motivate children when they are discouraged and challenge those children who are bored (Wahlberg, et al., 2001). They know how to discover the source of the problem in a child's learning and identify his or her strengths to build on. These teachers must go beyond the norm while teaching children with autism and be particularly resourceful (Wahlberg, et al., 2001). They must also be aware of effective instruction strategies and have the time to plan for these strategies (Simpson, et al., 2003).

There have been a number of strategies outlined, by Harrower and Dunlap (2001), for including students with autism in the classroom and promoting success. Antecedent procedures include priming, prompt delivery, and picture scheduling. Priming, commonly referred to as a prepractice, consists of previewing the activity that a child is likely to have difficulty with before the child engages in the activity. This method has shown to be an effective classroom intervention, especially in improving social interactions. Prompt delivery is used to elicit an appropriate response to a targeted activity. The use of prompts can be reduced over time as the child begins to make transitions independently. Lastly, picture schedules are used as an alternative to written and verbal instruction to increase predictability. These schedules are often used as cues to alert the child of an upcoming change in activity, in hopes of easing transitioning.

Delayed Contingencies may also be used to facilitate the generalization of behavior in the absence of supervision. Additionally, self-management strategies include discriminating between appropriate and inappropriate behaviors, evaluating one's own behavior, and monitoring the behavior over time. These strategies allow the child to become actively involved in the intervention process, improve social skills, and reduce

inappropriate behavior. Finally, peer-mediated interventions, such as peer tutoring and cooperative learning have been advocated as useful approaches, as the child has the opportunity to actively work with another child, thus social interaction takes place.

Multiple strategies may also be combined to fit the child's needs.

Many additional factors exist in promoting development for a child with autism. The school should be relatively close to the child's home environment, so that the child can experience how to live within the community and deal with its demands (Furneau, 1977). A larger school also has advantages as the staff is ultimately larger, thus the child interacts with more people and additional people may discuss the child's development. Also, the child may progress from grade to grade within the school. Thus, a transition to another school is not required as often. Reduced class size is important for a student's academic achievement and social development, as teachers with fewer students are able to individualize directions more easily (Simpson et al., 2003). The school also must encourage parents' participation within the school. Furneau (1977) believes that the child is part of his or her family and that the problems the child experiences are also the problems of the family, thus why treat a child apart from his or her family. He further believes that the teacher and school must try to understand the additional stressors experienced by the family.

Research, additionally, suggests that a teacher's personality is as important as his or her professional ability (Furneau, 1977; Simpson, et al., 2003). The teacher must be "kind, warm and accepting and have the ability to project a stable and calm personality" (Furneau, 1977, p.58). He or she must be consistent with the child, but also flexible when dealing with other children. A number of different personalities may deal

successfully with children with autism and the different personalities may even be needed at different stages of the child's development. Closely connected to the teacher's personality is his or her confidence and belief in the child and also himself or herself which often dictates the amount of success a child makes (Furieux, 1977; Simpson, et al., 2003). In addition, a child who has a close relationship with his or her teachers are considered better adjusted and likely to develop better relationships with others (Robertson, et al., 2003).

Parental Expectations. Some children with autism make significant progress during early childhood (Mayes & Calhoun, 2003a) and many go on to enjoy an essentially normal life (Cohen, 1998). Progress usually manifests itself more clearly in adolescence (Perez & Sevilla, 1993). Research with high-functioning children with autism revealed that half of the children demonstrated favorable outcomes (Perez & Sevilla, 1993). Favorable outcomes can be defined as near-normal academic and social functioning. Parents attach the greatest significance to advances in verbal communication, daily living skills, and socialization (Clare & Garnier, 2000; Schuntermann, 2002).

In regard to progress, many parents focus on what the child cannot do and forget about what he or she can do and the progress being made (Wetherby & Prizant, 2000). Sometimes parents develop the worst case scenario and expect the worst in development for their child, so that if the child makes more progress than expected, they see this in a positive light (Schopler, et al., 1993; Schuntermann, 2002). Others may be blinded by their child's strengths and focus on what the child is unable to do. Many of these parents jump over the child's present abilities and into the future voicing concerns about their child as an adult. They worry about their child's future, instead of tracking their child's

progress over time (Clare & Garnier, 2000; Schuntermann, 2002). Many families feel discouraged, as they work very hard for sometimes limited progress. Others experience a rush of hope when their child begins to develop a new skill, but disappointment when the progress comes to a standstill. For other parents, the strengths of a high-functioning child often hide their deficits in social understanding and language comprehension (Wetherby & Prizant, 2000). Thus, when a child is unable to perform, explanations often omit the child's neurological compromises, characterizing the child as deliberately noncomplying. Other parents see a balance of progress and difficulties yet to overcome (Schuntermann, 2002). Thus, how one family views progress may not be equivalent to another family's outlook.

A family's view on progress may also vary as parents have very different goals for their child. Research suggests that this variation in goals produces extremely different outcomes (Clare & Garnier, 2000). Clare and Garnier (2000) further suggest that parents may adjust these goals to meet their child's characteristics and that the child's characteristics contribute to shaping his or her interactions with both caregivers and teachers. It has been suggested that the parents who align their child's goals with a normally developing child's goals tend to function better and have a higher IQ (Clare & Garnier). These parents of higher-functioning children frequently normalize their children. Similarly their children show signs of overcoming many of their delays as they mature and of catching up to normally developing peers. This study may shed light on factors contributing to great outcomes for children with autism.

Rationale

A plethora of research has been conducted on autism over the past decade, however, very little is known about the progress made by a child with autism (Howlin, 1997). Today, there is evidence that children with autism have improved beyond human expectation, despite the small increase in resources (Bryson, Rogers, Fombonne, 2003). Many children who began in the severest autistic states have made excellent academic and social improvements. It is bewildering to imagine that some children with autism go on to obtain university degrees, while other make slow limited progress, even with intensive treatment (Cohen, 1998).

There is controversy surrounding the agreement of which treatment method produces the best outcome for children with autism. The use of traditional evaluation methodologies may fail to account for the elaborate set of components that can have differential effects on student outcomes (Gresham & MacMillan, 1997; Cohen, 1998).

Since it is difficult to address this specific question, investigating what appears to work for an individual child with his or her unique qualities may be a step in the right direction. Since each child is different and possesses each his or her own unique characteristics, it does not appear effective to group all children with autism together and assume that one specific treatment approach works for every child. There are too many factors to consider, such as a child's ability, achievement, personality, family involvement, coping mechanisms, treatment approaches, among other risk and opportunity factors.

The study will document, describe, and analyze the cognitive, behavioral, and social changes that occurred in a child diagnosed with autism. A single case study was appropriate for the present study as it allowed the single child to be the unit of analysis (Schwartz & Sandall, 1998). Using all the information gathered a comprehensive examination of the types of progress that the child achieved thus far will be conducted, along with a biographical sketch of the child's life.

The purpose in exploring these findings is to suggest that there are numerous approaches to achieve positive outcomes for a young child with autism, and to expand on the discussion of possible factors promoting such progress or success.

This study will not reveal the most effective way to approach or treat autism, but simply follow and describe the experience of one family and their perceptions of success/progress. Neither researchers nor parents can predict the success of a child with autism by any treatment or teaching method (Furneaux, 1977); however, progress made by a child can be examined to explore what may be helping the child. Cohen (1998) makes the statement that "it's time to tease apart the head smashers." This is an intense statement that seems to make the need for answers into why some children make substantial progress and what appears to work for many. It may be time to take a closer look at a family's triumphs and struggles and examine what is working for their child making apparent progress.

An important question in the exploration of how a child makes progress may be how parents define progress or success. What constitutes progress or success to the parent? Why do they believe that their child is excelling? Is the child meeting outcome goals? What risk and opportunity factors have the family and child experienced? What

treatment methods and supports have been in place for the child? Were other services rendered, such as community services? What events have taken place in the child's life? What is the parent's perception of the prognosis of their child? How do the parents feel that their child will fare in the future? And, do they feel that they can have an influence on their child's future?

Chapter II: Methodology

Participants

A case study method was employed with a single child diagnosed with Autism Spectrum Disorder (ASD). The female child was eight years of age. She was the only participant involved in the study in hopes of obtaining an exclusive insight into her life, upbringing, family lifestyle, and treatment approaches. The Early Interventionist in an area of Nova Scotia (see Appendix A) was approached for parent volunteers who have a child, preferably female, aged seven to nine years, who was diagnosed with autism and experiencing success. Once the proposal was approved, contact with a family open to participation was made. Had the family declined or decided to stop participating in the study, another volunteer would have been selected from the list of willing volunteers provided by the Early Interventionist.

Parental consent was obtained to gather the necessary information and conduct semi-formal interviews (see Appendix B). As well consent was obtained to access the school information, such as the child's cumulative record file, classroom observation, and teacher interviews; approval was required from the School Board (see Appendices C, D, & E). Information, with parental consent, also was gathered from multiple sources, such as medical sources, school resources, and family information.

Procedures

First, an in-depth interview was conducted with the parents concerning the child's birth, developmental, and medical history, along with the family's medical history.

Information concerning obstetrical complications and immediate concerns were obtained. Mild complications have been ruled out as correlated factors of autism (Filepeck, et al., 1999), however, authors suggest the importance of obtaining information concerning pregnancy (Klin, 2000; Volmar, 1999). Additional information pertaining to any significant events in the developmental history of the child was also noted.

The medical history of the child and family was explored. Questions inquired about any significant medical problems experienced. Parents were asked additional questions into their child's present functional behavior, how they define progress or successes, whether they feel their child has progressed, and why they feel their child has performed so well (see Appendix F). The questionnaires were adapted from prior research to meet the needs of the present study.

Important information was gathered from the examination of the reports conducted by the Autism Team at the Center from the time of diagnosis. More specifically, information pertaining to the problems leading up to the diagnosis of autism and their criteria for diagnoses was insightful. The diagnosis made by the autism team was also reviewed.

Parents were given the chance to talk freely about their child and steps they feel were in the right direction for her. Interviews with the parents were audiotaped to insure that no pertinent information was missed in the transcribing of the responses.

Parents were asked to complete five questionnaires. The Coping Inventory for Stressful Situation (CISS; Endler & Parker, 1999), The Recent Life Events Questionnaire (Brugha et al., 1985), The Child Improvement Locus of Control Scale (DeVellis, DeVellis, Revicki, Lurie, Runyan, & Bristol, 1985), the Parental Self-efficacy in the

management of aspergers syndrome questionnaire (Sofronoff & Farbotko, 2002), and Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984) .

Coping Measure - CISS. The Coping Inventory for Stressful Situations (Endler & Parker, 1999) is a self-report paper-and-pencil measure of three different coping styles, which takes approximately 10 minutes. Validity and reliability has been tested extensively on many populations. Alpha coefficients ranged from .81 to .91 for the three main coping styles. Moderate to high test-retest reliabilities have also been found, ranging from .54 to .73 (Endler & Parker, 1999). This test was used to assess how often the individual engaged in Task-Oriented, Emotion-Oriented, and Avoidance-Oriented coping, when faced with stressful events.

1. Task-Oriented Coping describes purposeful task-oriented efforts aimed at solving the problem (thinking about how to solve the problem), cognitively restructuring the problem (trying to understand the problem), or attempting to alter the problem (changing lifestyle or environment).
2. Emotion-Oriented Coping describes emotional reactions that are self-oriented with the intent to reduce stress. Reactions include emotional responses (e.g., blame myself or blame someone else), and self-preoccupation (e.g., daydreaming or fantasizing).
3. Avoidance-Oriented Coping describes activities and cognitive efforts aimed at avoiding the stressful situation. This can occur via distraction with other events (e.g., going to a movie) or tasks or via social diversion (e.g., visiting a friend). Different subscales can be used to distinguish social from non-social avoidance tendencies.

The CISS contains 48 items, associated with three main factors defined above, each of which contains 16 items. The avoidance scale contains two subscales: distraction (8 items), and social diversion (5 items). The three remaining items for the avoidance scale are not scored in these two subscales. Subjects were asked to rate each item on a five point Likert scale ranging from (1) "Not at all" to (5) "Very much," to indicate how often they generally engage in these types of activities when they encounter a difficult or stressful situation. Individual coping responses were assessed using the ratings of each statement from each category. Any missing responses were to be given a neutral score of three. This scale provides insight into the coping style of the child's parents. Research suggests that specific coping strategies are related to opportunity and risks factors for children with developmental delays (Dunst, 1993).

Life Events Measure – RLE. The Recent Life Events Questionnaire (Brugha et al., 1985) addresses recent life events occurring in the last 12 months (see Appendix G). It, additionally, inquires whether the respondents feel that the events have a continuing influence on their lives, as life events affect individuals in different ways. Thus, it is important to explore how the events influenced the family. The test can also be used to evaluate events and impact over a longer period. The questionnaire takes approximately 15 minutes to complete, but discussion about whether or how the life event affected the family often takes additional time. The scale provides insight into the life events experienced by the family and the effect of the events on the family and child.

Locus of Control Measure – CILC. The Child Improvement Locus of Control Scale (DeVellis, et al., 1985) assesses parent's beliefs about a child's ability to improve (see Appendix H). It further assesses the degree to which a parent or caregiver attributes

change in a child's condition to professionals, divine influence, the parent (self), the child, and chance. These items are measured with a Likert-type scale ranging from 1 to 6, with a higher score indicating a greater endorsement for the item. The CILC demonstrates acceptable reliability and validity. The scale documents parental beliefs about whom or what influences their child's outcomes.

Parental Self-efficacy Measure. The Parental Self-efficacy in the Management of Aspergers Syndrome Questionnaire (Sofronoff & Farbotko, 2002) lists the most common behaviors displayed by a child with aspergers (high-functioning children with autism). It asks parents to indicate 'yes' or 'no' to whether their child has displayed any of the listed behaviors, in the past month. For each item that parents answer yes to, they also rate their confidence in managing the behavior on a six-point scale ranging from 'no confidence' (0) to 'complete confidence' (6) (see Appendix I). This scale was used to get a better understanding of how confident the parents feel dealing with their child and the disorder.

Adaptive Behaviour Measure – VABS. The VABS was administered to the mother of the child (as it is to be administered to the primary care giver of the child) to examine the performance of daily activities required for personal and social sufficiently (VABS; Sparrow, Balla, & Cicchetti, 1984). The Interview Edition, Survey form consists of 297 questions directed at the parent or primary caregiver of an individual, aged birth to 18 years of age. The test taps into three domains, which include: Communication (e.g., Receptive, expressive, and written), Daily Living Skills (e.g., personal, domestic, and community), and Socialization (e.g., interpersonal relationships, play time, and coping skills). The VABS offers good reliability and validity, with an internal consistency of .83-.94 and test-retest scores of .81-.86.

Recent achievement and ability testing was not performed, thus the child was administered such tests. The current test results were compared to previous results to examine if the child has made progress in any of these domains.

The Wechsler Intelligence Scale for Children Fourth Edition (*WISC-IV*) (Wechsler, 2002) was administered to examine the child's cognitive abilities. The WISC-IV is an individually administered clinical instrument for assessing the cognitive abilities of children, aged 6 years to 16 years and 11 months. It is comprised of 15 subtests that assess general intelligence, scholastic aptitude, and readiness to master the school curriculum. This updated version provides subtest and composite scores that reflect intellectual functioning in particular domains. The WISC-IV can be used to identify intellectual giftedness, cognitive strengths and weaknesses, and is excellent for research purposes. The evaluation of cognitive abilities in those children with autism may provide more insight into how children acquire knowledge and demonstrate intellectual abilities. The WISC-IV offers evidence of reliability ranging from .98 to .99 and excellent validity scores.

The Wechsler Individual Achievement Test (WIAT-II; The Psychological Corporation, 2002) was administered to the child to identify if she was achieving to her full potential. The WAIT-II is a comprehensive measure of academic achievement, also used to evaluate specific deficits that may account for low academic achievement and to predict future academic success. This individually administered test is used for children ages 4 through to adulthood.

Important information was also gathered in the school setting. A review of the cumulative record file was conducted, which tapped into particular areas (see Appendix

J). Secondly, interviews were conducted with the child's current teacher and two of the three previous classroom teachers. The interviews addressed the child's behavior, academic functioning, general ability, motor skills, self-help abilities, social skills, and peer relationships. Questions pertaining to desired outcomes for the child and whether they were attained were also addressed, including what strategies were employed and help rendered in the classroom to attain the set outcomes (see Appendix K).

Further information was obtained from the school principal, who has been at the school since the child was in grade one. He was asked questions pertaining to the school's involvement in aiding the child, such as what services are available for children with autism and which the child has or is currently benefiting from (see Appendix L).

An important addition to the information collected at the child's school was systematic observations of the child's behavior in the classroom, on the playground, and in the home setting. By making observations in a variety of settings, the examiner can gain a better understanding of the child's communicative and social skills (Wahlberg, et al., 2001). The classroom observation first addressed how the class is physically organized, the number of assistants in the class, where the child sits, and the daily routine (see Appendix M). The playground and home observation also addressed her behaviors in the settings (see Appendix N).

Data Analysis

Data analysis is described as the process of arranging interview transcripts, notes, and other materials that one accumulates to increase his or her understanding of the research and enables he or she to present what one has discovered to others (Bogdan & Biklen, 1998).

Given the purpose of the present study, which was to develop a greater understanding of progress in children with autism and to examine a family's struggles and progress with their child, qualitative research was selected as the most appropriate method to acquire the desired data. An examination of self-accounts and described experiences, observations, questionnaires, and past reports and videos lead to an ethnographic understanding of what lead this family to believe that their child with autism was making progress, what factors may be contributing to this progress or success, and what struggles they had along the way. The conceptions that are formed about the child's life are based on the common themes that emerged from the above sources of data.

Observations, interviewing, and questionnaires gave the researcher a sense of specific issues and concerns that the family had. In-class, playground, and home observations, and questionnaires enabled the researcher to clarify and verify the occurrence of issues raised in the interviews and served as a method of supporting the parents' responses.

The data from all sources was transcribed onto computer, saved on both a hard drive and a floppy disk, and printed in order to obtain complete and accurate data prior to beginning the analysis (Patton, 1990). The researcher then went over the transcripts and noted any outstanding comments. She also eliminated any non-essential detail from the responses; such as comments about the environment not related to the study, which Kvale (1996) refers to as 'clarification of material'. The transcripts were then given back to the family so that they could comment on the accuracy of the transcription of the interview. This provided the family with the opportunity to add any additional comments or delete

comments that they felt were incorrect or inaccurate. The family made little change to their original interview transcript.

The transcripts were then analysed by the method of a coding system that involved discovering and naming the categories (Strauss, 1987). To do this the process of meaning condensation was utilized (Kvale, 1996, p.192). Keeping in mind the rationale of the study and possible questions to be addressed as a guide, each response in the transcripts were condensed and abbreviated next to the corresponding answer. This brought together many similar ideas, concepts, and themes (Rubin & Rubin, 1995) and allowed the researcher to capture “important attitudes, perceptions, feelings, and processes contained in the participant’s experience...” (Fitzgerald, 1994, p.467).

In addition to this the researcher categorized the participants responses based on Kvale’s (1996) principle called ‘meaning categorization’, as either positive (+), negative (-), or partially positive and negative (=). These codes were marked in the margin of the transcript next to the responses. The responses were not all positive, negative, or partially positive and negative, but a number of research questions could be coded in this manner. A positive response was considered to be one in which the participant answered the question posed to him or her in a positive manner and offered optimistic experiences, attitudes, or perceptions. For example, when the parents were asked about the school system, a positive response would reflect positive feelings toward the school, one where the parents were happy with the schools performance in dealing with their autistic child. A negative response to the same question would be one in which the parents indicated that they had a negative or poor perception of the school and or their experience with the school. A partially positive and negative response to this question would be one in which

the parents were divided in their opinion about the school. They may have been able to find a number of positives and negatives about the topic. These codes were used to collect a clearer picture of the themes and examine whether the family possessed attitudes and perceptions concerning the theme that were positive or negative.

Further analysis of the data involved searching for common themes in the data, in order to develop theoretical concepts. After themes emerged the researcher went back to the transcripts and underlined quotes that supported the themes. In the final stages, the themes and interview comments were used to complete a picture of the child's life, opportunities and risk factors experienced, and provide implications for the research.

Chapter III: Findings

Family Background

A female child named Sarah¹ was born to a mother and father in July 1996. The pregnancy was non-eventful and Sarah was born naturally, weighing nine pounds and five ounces. Sarah's mother was 35 years old at the time of birth. She is a trained CNA and worked in the field prior to having children. She then opted to remain in the home to manage the household and care for the children. Sarah's mother was adopted at six months of age. Her adopted mother passed away a few years ago, as she had severe diabetes and eventually passed of a stroke. Her father lives upstairs and is a great support for the family. She had a loving upbringing and a stable childhood. She also has an adopted brother, who she has a good relationship with, but he is also very busy with his life. She has made previous contact with her birth family, but had little contact with them. She views the adoption as a positive occurrence as her biological family deals with mental illness and alcoholism.

Sarah's father was 53 years old at the time of her birth and is best described as being "addicted to his children." He adores them and will do anything to see them happy. He is self-employed in a financially secure boat building business. He works long hours and is in good health. He is one of ten children with a close-knit family.

This mother and father also have two other boys, aged six and four, at the time of the birth of their daughter.

¹ *The name of the child has been changed to ensure the family's confidentiality and compose a more personal picture of the child's life.*

First Signs of Concern

Mom and dad stated that they thought life was progressing “great”. They had three apparently healthy children, whom they loved dearly. There had been nothing unusual about Sarah’s birth or the early months. Sarah stood at six months and met many developmental milestones. They noticed that although Sarah preferred to be alone and play with her toys, she did smile at family members occasionally. The parents felt truly lucky that their child was so good and quiet and tried to excuse her solitary habits.

As Sarah grew older other puzzling, disturbing behaviors changed her parents’ vague concern into outright worry. They then began questioning their daughter’s development at 16 months of age and decided to bring Sarah to the doctor. Mom was concerned that something may be wrong with Sarah and that she did not seem to be developing as her first two children had. Mom commented:

“She was different than the boys had been and I knew something was wrong...She said a few things around the appropriate age and then it all stopped...all advances disappeared...Emotionally, she did not develop normally. When she cried she screamed. For example, if I’d stop the car she’d scream and I’d have to go back and forth in a parking spot so that she’d stop...”

Mom and dad were also concerned that their daughter had begun to stare off. They were worried that something serious was happening to their child and that this type of staring or zoning out was not normal. This frightened the parents terribly. Mom stated:

“She was a child with big eyes that didn’t even blink or look our way, regardless of the amount of stimulation. We could tickle her or move her around and it never resulted in anything but staring.”

The doctor responded that of course she would be different, “why wouldn’t she be, she is a girl.” The parents also commented to friends and family that they felt something was different with this child and received the response that those were “her

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quirks.” The family accepted the doctor’s response and thought that she may be correct, because as she had said, they did only have boys to compare her to. Shortly after this, Mom brought Sarah back to the doctor with the same concerns. This time the doctor said that Sarah had shutters and that was normal. Mom did not agree with the Doctors response. She was sure that something was wrong with Sarah and was getting frustrated. As any mother, she wanted to help her daughter and make her feel better. Mom’s response to this was:

“I knew this was not normal. It was like someone had stuck a pin in her. I took her back to the doctor and said that something had to be done.”

In March of 1998, mom became concerned yet again. Their 20 month old had begun to wake from a deep sleep vomiting relentlessly for hours. Mom indicated that the vomiting occurred with no sign of fever or any other flu symptoms and each time the vomit was dark brown and did not have any foul odor. At this point in time, the staring episodes were more frequent and Sarah would startle easily. Mom had become very frightened by Sarah’s vomiting episodes and she had decided that it was time to bring Sarah back to the doctor and find out what was wrong with her. Mom stated:

“It wasn’t until the grand mal when she fell and lost all bodily functions...she woke from the staring she didn’t know who I was...I couldn’t have that anymore...I wrote tons of letter to the doctors explaining the problem...She went from having normal naps to napping five hours a day...and be up an hour and sleep again...and have seizures (which we now know) and throw up.”

Dad stated the following:

“ We kept telling the doctor that for no reason she would throw up...we could detect no fever or anything abnormal...she’d just throw up and then sometimes be normal and sometimes happy out of the blue. The she was exhausted...It didn’t make sense to us.”

¹ *The name of the child has been changed to ensure the family’s confidentiality and compose a more personal picture of the child’s life.*

The child was immediately referred to a neurologist and underwent several EEG's. The results indicated myoclonic seizures. She had been having these absence seizures for months, sometimes 20 to 100 per day. The child was prescribed Depakene, which controlled the seizures and the family was told to come back if a difference in the child's staring off was not seen within three months.

The parents believed that everything would be well now and didn't think that they'd be revisiting the doctor. They figured that their problem had been solved and that at last their almost two year old little girl would feel better and begin to interact normally.

Mom stated:

"I thought that she's take the meds and be fine and she was in a sense...we took her outside and she was so fascinated by the sky, the birds, and the noises...she did respond because she wasn't absorbed by the seizures...She had begun, for the first time, to rediscover the world that she didn't know was there because she was so controlled by the seizures and her brain couldn't process or develop...and then it stopped...She didn't do another thing. This was as far as her progression went."

Looking back Mom felt that the doctor knew better and that there may have been more to the seizure diagnosis. She feels that he may have known that something further was wrong with Sarah. She indicates:

"The doctor knew that something else wasn't right with this child at the time. I think he knew all along that we'd be back...and why. ...he said (to us) 'if it's just the seizures she'll wake up and be a new born all over and rediscover her world'..."

Signs of Autism

If the doctor did indeed feel that something else was wrong with Sarah, he was correct. Only three months later Sarah began to display new very concerning behaviors.

Mom commented:

¹ *The name of the child has been changed to ensure the family's confidentiality and compose a more personal picture of the child's life.*

“By this time she was toe walking, hand flapping, and climbing over people and never making eye contact. She used people as objects to get to things. In the doctor’s office, he put a toy on the shelf and she climbed over him, as if he were an object to get it... We had even begun to pull her in a wagon, as she couldn’t tolerate the physical contact of being carried... She watched TV and rocked. She made very few sounds and didn’t speak.”

Sarah’s mom and dad allowed the researcher to watch videos of Sarah as an infant and a child. Examination of the videos was astounding. The researcher began watching videos of Sarah from as early as nine months of age. At only nine months, Sarah sat in a corner and stared at a wall. She was very content playing on her own and had no interest in her surroundings. Her failure to develop normal social skills was probably the most noticeable. She didn’t interact with children the way most children do (Powers, 2000). She preferred to be alone. She appeared uninterested in others and appeared to “look through people.”

As she began to walk she frequently flapped her hands. She attempted to move one foot forward then began to flap her hands again. She cried often, as if she is so preoccupied with the hand flapping that she was unable to walk, but appeared to want to. As people attempted to hold this sweet child, she squirmed to get away. At a year and a half, she was toe walking. Her enjoyment now consisted of walking back and forth down a hall for hours, while flapping her hands. Even when her parents spoke to her she does not stop to acknowledge them or interact with them.

A video from approximately two years of age reveals Sarah standing and staring at an orange shampoo bottle. She walks a step and then continues to stare. She then shakes her head, as if to shake out of a trance and then refocuses her eyes on the bottle. She has also begun to touch pages of books for long periods of time. When mom and dad

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were asked about this behavior, they commented that this was her “downtime” and it relaxed or calmed her. As a part of her sensory problems, she was fascinated with the surfaces of books. She would rub the pages of books for hours.

The family was unaware of all the concerning behaviors and is only now able to distinguish that they were not normal behaviors of a typically developing child. Mom commented:

“Looking back the doctor’s reports and videos, they do not connect with the baby books. I was a happy mother writing about what I wanted to see and was basically blind to the features of autism.”

The Diagnosis

The doctor immediately referred Sarah for a neurological assessment at Tertiary referral center for children for a suspected autistic spectrum disorder in conjunction with a history of myoclonic seizures. At two years and six months of age, after a three month wait, she was seen for a multidisciplinary assessment by the PDD Assessment Team, while an inpatient on the care by parent unit at the Center. She met the criteria for a diagnosis of autistic disorder, based on clinical observation and the profile derived from the Autism Diagnostic Interview (ADI-R). The diagnosis was based on many concerning behaviors, which included her severe impairment to use nonverbal behaviors, such as lack of eye contact and gestures to regulate social interaction, a lack of seeking to share enjoyment or interests with others, a delay in the development of spoken language, and preoccupation with restricted patterns of interest that is abnormal in intensity or focus. She was also diagnosed with a seizure disorder.

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Steps Taken Following the Diagnosis and Treatment

The child began Speech Language Therapy and Occupational Therapy while waiting for the assessment at the Center. They continued with the therapy following the diagnosis and waited for admittance into the Early Intervention Program. The family was admitted into the Southwest Early Intervention Program in February, 1999. The family and reports from the Early Interventionist reveal that home visits occurred on a biweekly basis. The early interventionist served 19 families, 20 children, and 9 children were waiting for entrance into the program.

The early intervention program used assessment tools to assess the child's developmental skills in all domains of development, and guide the development of the Individualized Family Service Plan. The tools used included The Assessment, Evaluation, and Programming System for Infants and Children (AEPS) and The Carolina Curriculum for Preschoolers with Special Needs (CCPSN). The assessment included observation, direct testing, and parental report. From this assessment and priorities expressed by the family developmental goals were established and recommendations suggested.

The program goals were tailored to various domains, such as cognition, communication, social adaptation, and gross and fine motor skills. The cognition area included such goals as remembering incidental information, identifying objects as hard or soft, demonstrating an understanding of prepositions, demonstrating an understanding that different activities occur at different times of the day, grouping objects by two characteristics, selecting two and three objects upon request, demonstrating an understanding of "none" and "not any", understanding the concept of tall and short,

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assuming different roles when engaging in pretend play, and describing simple absurdities seen in pictures or in real life. The communication goals included following two-step direction involving sequence, naming objects by function, and using irregular past tense verb forms correctly. The social adaptation domain set forth goals to avoid common dangers related to safety, to identify what basic body parts are used for, to interact and play with children, eat using a fork, pour liquids, and dress and undress with minimal assistance. The gross motor skills to be worked on were demonstrating a hand preference and cutting a straight line with scissors. The fine motor skills to attain were hopping on one foot, jumping two inches off the ground, jumping down from low structures, balancing on one foot, kicking and throwing a ball, and pedaling a tricycle.

The family was taught a number of activities to perform with the child at home. These activities included practicing the movements of drawing on paper and trying to get Sarah to copy the actions, extensive hand-over-hand work as she was unaware of pressure and her sensory functioning was inaccurate, and practicing to get her to roll play dough without flattening it. They further worked on coordination, doing button and snaps, banging shapes into holes, and playing on a mat to perform movements with her body. These activities were practiced on a daily basis.

The family also practiced what Sarah was learning in speech therapy. From the way mom spoke, the researcher assumed that this was a difficult process. The Speech pathologist began teaching Sarah very basic sounds and progressed from there. Mom explained the process:

“We had her listen to various sounds on tape, showed her how to make them with our mouths, and then would get her to mimic them. After this was accomplished, we moved onto words. This was a long process.”

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It was determined that regular occupational and speech language therapy appointments were no longer required in 2001. Sarah was reassessed on an ongoing basis to determine if regular services were required in the future. To this date they have not been required.

When mom and dad were asked why this avenue of treatment was followed, mom and dad expressed their need to help their daughter succeed. This family would try any recommendation presented to them by the doctors. Mom explained:

“This is what was suggested by the hospital and we would do what ever possible to help her. The only interventions we were aware of were the OT, SLP, and Early Intervention through the IWK.”

When questioned about the types of intervention currently employed, mom indicated that none were at the present time. Sarah no longer required speech language or occupational therapy. Mom seemed pretty happy that Sarah no longer required the therapy; however she sounded fairly annoyed and frustrated that Sarah no longer had the support of an EPA within the classroom. Mom responded to the question of supports currently in place:

“There are none, no aids at school or anything, just our home support. We do role playing with her and discuss situations and conflicts to help her understand...”

Understanding of the Diagnosis and how it's changed

The parents reported that finally after ten months of chasing back and forth to the doctor and fearing something was wrong with Sarah, they had an answer. Their daughter was not developing as a typically developing child and there was at last an explanation to why. They had seen the doctor several times only to hear that nothing was wrong with

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their daughter and now to hear that she had autism was shattering. The Sarah's parents were shocked by the diagnosis.

The sequence of emotions experienced following a diagnosis of autism often begins with shock, proceeds to helplessness, then guilt, anger, grief, and resentment (Powers, 2000). This family felt many of these same feelings. They were shocked by the prognosis and numb. Once this feeling of disbelief wore off they began to feel helpless, unsure of what steps to take, and finally searching for answers. At this time they also worried about being responsible for this outcome, angry that their child had autism, and then worried about the child's future. The family realized that they must move forward and there was no time to look back. They did the only thing that they knew to do and that was gathering as much information as they could. By doing so they would no longer fear the unknown and they would begin to understand the diagnosis and what they should do.

Mom described her experience:

“We were prepared for her to be mentally challenged or have a learning disability or even brain damage, but not for the word ‘autism’... I had babysat a child with autism who flapped his hands and head smashed. So, hearing the diagnosis was not even in my realm of thinking. Kids like that were sent away and my reaction was shock and denial.”

She further noted:

“We are more aware of autism and more increasing aware and learning more. We have read lots and mostly learned through her. As the problems arise we read and learn to see what to do or how the behavior is connected to autism.”

Dad further commented:

“We overload ourselves with information trying to learn as much as we can to help her.”

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This family appears to have accepted the diagnosis of autism and begun to take action in helping their child. As Copley and Bodensteiner (1987) suggest, some parents are able to move on to the phase of acceptance. Instead of doing nothing following the diagnosis of autism, they followed the recommendations outlined by the doctors and began to research on their own. We will see this acceptance emerge throughout the story of Sarah's life.

Pre-school

The child attended preschool, as recommended by the PDD Team at the time of her diagnosis of autism, to provide her with "additional opportunities to interact with and model the activities of other children, and to expose her to a more structured learning environment." Research suggests that children with autism can benefit from attending preschool with normally developing peers (Domingue & Goldberg, 1998). The research documents social and educational benefits, as the child models the behaviors of other and learns spontaneously.

Sarah attended one morning per week in the fall of 1999 and attended three mornings per week beginning in January of 2000. Preschool reports initially revealed a quiet little girl who kept to herself. Sarah was a child who sat and played alone. She also ate the play dough, as she was unaware of what to do with the foreign material, mom revealed. But after watching what the other children did with the material she began to do the same.

The pre-school report indicated that as the year progressed Sarah made many gains. She began to play along side of other children and paid additional attention to the

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teacher. Her first end of the year report stated “as per many conversations, we are thrilled with Sarah’s on-going successes!” Her second year at the preschool proved even more successful, comments included “Sarah learned how to count to ten and had been taught her ABC’s.” These were accomplishments that her parents never thought were attainable. Her final preschool report indicated:

“Thanks to a great family, Sarah’s program has been remarkable! All areas of her growth and development have improved this term. We will continue to support the effort.”

This family was impressed with the progress experienced in preschool. They were excited by how much she had learned and the difference in her behavior. They felt that Sarah had benefited greatly from socializing with typically developing children and believe that most children with autism would benefit from the highly structured learning environment and daily routine that the preschool provided. Research by Forest, Horner, Lewis-Palmer, and Todd (2004) also suggests that children who receive services such as early intervention and who attend preschool are often better prepared to face academic challenges and continue to grow socially and cognitively.

Preparation for the Public School System and the Transition from Preschool

The family never thought Sarah would begin school at the age of five like other children. However, Sarah did begin school with the rest of her peers at the age of five. When Sarah was able to begin school with her peers the parents reactions were divided. On one hand they were happy that their child had developed sufficiently to attend school, but on the other hand they were worried about Sarah being away from them in the somewhat unmonitored school atmosphere.

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Sarah was required to attend her local school, which was only minutes from the family's home. Furneaux (1977) suggests that it is important for a child to attend a school reasonably close to their normal living environment, as it provides the child with the experience of how to live within one's community and cope with its demands.

The school was not capable of offering a specialized program for an autistic child, nor was some of the more common instructional approaches for children with autism used, such as TEACCH (Treatment and Education of Autistic and Communication Related Handicapped Children) and ABA (Applied Behavioral Analysis). However, it was a larger school, which does have some organizational advantages (Furneaux, 1977). First of all the child remains in the same school for a longer period of time, thus the transitioning to another school happens less frequently. Secondly, a larger school often means a larger staff. Furneaux (1977) suggests that the larger staff accustoms the child to interacting with more people.

The parents began preparing Sarah for school even though they had suspected that she would not begin school with her peers. When asked what was done to prepare her for school, mom stated:

“She attended preschool in order to engage with other children and prepare her. I also had a friend who was an early interventionist and as a friend she helped us to prepare her. She also had a shared EPA entering primary.”

The child had already taken part in OT, SLP, and early intervention, and had successfully completed those programs prior to beginning school. Mom and dad seemed to understand the importance of the transition between preschool and primary. They made the visits with her to the school and explained what would happen.

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The family was also involved in the program planning process for the child before she began primary. Together with the school, the parents discussed the areas of concern they had with their daughter. These areas included her difficulty with going to the washroom (as she is only comfortable with the washroom in her own home), eating was a difficulty as she may consume food pieces too large if not cut in a certain manner, and she should not be left unattended due to concerns of her running into the street or wandering off. The parents also indicated that they were more concerned with their daughter's social growth rather than academic progress in the initial stages of beginning school. The school put in place transition support to ease the stress of the school year, offered assistance with certain aspects with toileting due to her phobia (via picture cues and the use of social stories), met her at the bus in the morning and watched her at recess and noon to ensure that she did not wander off, helped her with personal care, such as removing her coat and changing her footwear, and kept her focused within the classroom.

Entering the Public School System and the School Years

Sarah began school in a regular classroom with typically developing peers (See Table 2 for her yearly placement and specialized instruction). The benefits of being included in a fully inclusive classroom are outlined by Mesibov and Shea (1998). They believe that by placing the child in an inclusive classroom the teacher's expectations of the child are increased. It is thought that the child models the behaviors of typically developing children, there is less isolation on the part of the child and more acceptance from peers, and often the child develops higher self-esteem.

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Table 2

Learning Environment Placement

	Grade Primary	Grade One	Grade Two	Grade Three
Regular Classroom	YES	YES	YES	YES
EPA Support	YES	PARTIAL	PARTIAL	NO
Resource Time	NO	NO	NO	YES

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Grade Primary. In Sarah's regular grade primary classroom, an Educational Program Assistant (EPA) was shared between her and another boy with Down Syndrome. She did not receive additional instruction and/or scheduled resource support during her first year of school. Mom indicated that she had learned how to count and recite her alphabet in preschool, so the academic aspect was not a challenge for her in primary, although she did not interact with her peers. A revised IEP indicated that by the end of grade primary there was no longer concern that Sarah would wander from the playground and toileting encouragement via a picture cue was in place, but she had begun to tell an adult when she had to go to the washroom.

Sarah's grade primary teacher indicated that her classroom was highly structured with set routines to be followed. Sarah's teacher was asked about her academic functioning, self-help skills, motor skills, and general ability. Her teacher felt that she was a "capable" student academically. She found it difficult to judge her general ability as Sarah did not speak much. Sarah's teacher felt that Sarah may have had some difficulty with motor development. For example, Sarah had some trouble holding a pencil properly and printing. She also thought that Sarah may have been lacking a number of self-help skills, however, her help from home and her aid often compensated for this difficulty.

When Sarah's primary teacher was asked about Sarah's social skills, her words were "they were non-existent." She further noted:

"She did not interact with other children ever. She interacted with nobody, except her family probably."

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Her primary school teacher indicated that Sarah was somewhat resistant to change and loud noises especially bothered her. Sarah displayed no aggressive behaviors and no obsessive or repetitive behaviors. Her teacher felt that Sarah did present with poor communication, in the sense that she did not speak much, and she was distracted and “spacey,” not by others but by herself.

Grade One. A review of Sarah IEP upon entering grade one, indicated that she required reminders to get ready and to stay focused and on-task. It specified that her printing was improving, that she was now able to get to the bus on her own, and she had less fear of the bathroom. She still did not interact with her peers, but would now follow. The neurologist noted that there was no need for her to interact with others. The IEP further indicated that she was a capable grade primary/one student.

In grade one, Sarah continued in the regular grade one classroom and participated in the regular classroom activities. She developed difficulties with mathematics and class program support was offered twice a six day cycle, as necessary. Her term one and two of her report card indicated that she was developing both socially and academically. It noted that her reading skills were great, but math was developing more slowly. Her final term in grade one indicated that she had made “great progress.” It further noted her persistence in dealing with issues causing her great anxiety and difficulty.

Grade Two. Sarah’s grade two classroom environment was highly structured, with the freedom to explore and learn. Her grade two teacher had high expectations of his students and encouraged learning. He offered cooperative learning, peer-tutoring, and heterogeneous groups within his classroom. He taught the core curriculum and after

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outcomes were met, the students worked in groups in their lab. This particular teacher believed strongly in and engaged in differentiated teaching methods for his students.

During her grade two year, Sarah was not assigned an EPA. An EPA circulated the classroom helping those in need. Initially, the EPA helped Sarah with bathroom issues, but as the year progressed these issues were worked through. Sarah's teacher felt that she was a very bright student, with reading being a particular strength and math a weakness. He believed that Sarah possessed a wealth of general knowledge, but this was difficult to assess as she was particularly quiet. He also felt that her self-help skills were weak and her motor abilities presented no problems.

When asked about Sarah social skills, her grade two teacher commented that initially she did not interact with her peers at all, inside the classroom or on the playground. However, close to the end of the year, she began interacting with a peer on the playground. He noted that in the classroom she remained very quiet and her interaction within her group was limited.

Sarah's grade two teacher indicated that Sarah presented with no aggressive, obsessive or repetitive behaviors. He felt that she was somewhat resistant to change and had some difficulty remained focused. For example, she would zone out and focus on herself or a high interest activity such as reading. He further noted that her communication was alright and if posed a question she would answer, but she did not initiate conversation or ask for help, if needed.

The IEP for grade two indicated that Sarah had more confidence and was now able to mix with other children on the playground. New long-term goals entailed helping her communicate her needs and wants verbally and answering questions posed to her.

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Regular contact with the family was made via a daily notebook and social stories were used to help her understand people and things that triggered fear and anxiety. Language development was another goal aimed at encouraging her to describe things that made her anxious and respond to questions in class.

Grade Three. The learning environment in Sarah's grade three classroom was unstructured, but routines were in place. Sarah did not have an EPA, nor was one in the classroom. Sarah's grade three teacher commented that Sarah would benefit from an EPA to keep her on task and to ensure she that understands what is being asked of her.

Sarah's teacher indicated that she is a strong student in language arts, but presents with significant difficulties in math. Sarah received resource support ten times per cycle for thirty minutes, along with home support to reduce her fear of mathematics. Her teacher was impressed with her motor abilities and indicated that she is very artistic. She noted that Sarah had some difficulty with organization and her desk was often cluttered. Her grade three teacher further noted that Sarah has a small group of friends and one particular child is very clingy to her. A number of adaptations were put in place for Sarah for the school year.

Teacher's Views on Changes Witnessed and Progress

Of the three teachers interviewed, all three felt that Sarah had made significant progress. The most progress was noted in her grade two and three year. Her grade two teacher noted progress in all areas. He commented that she was more involved in class activities and she began to make eye contact as the year progressed. Her grade three teacher felt that Sarah was more expressive and has begun to express her feelings in the

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daily writing of her journal. Her grade three teacher noted that Sarah had begun writing about when friends had upset her and how this made her feel. Other areas of progress noted by her teacher were her social skills and peer interaction and lesser degree of anxiousness. Sarah's grade three teacher commented that she has begun to interact with kids on the playground and she also interacted with her peers in small groups. Her teacher further indicated:

“She has made constant progress and change in all areas... She is no longer upset by change and is able to change with the rest of the class... She also responds easily to questions and comments when asked.”

Sarah's grade primary teacher felt that some progress was noted. She felt that Sarah communicated better as the year progressed and wasn't as resistant to change as she was beginning the school year. Her teacher added:

“I see her around the school and she has come along way. She now seems to interact with her peers and I even hear her talking. I think she has made gains socially and academically.”

Teacher's Views on their Competence in Working with a Child with Autism

Of the three teachers interviewed regarding their self-perceptions of their competence in working with a child with autism the results were fairly consistent (See Table 3). The three teachers felt that they had average ability in dealing with behavior management and social interaction enhancement techniques for students with autism. Two teachers felt they had slightly below average competence in the area of speech and language and nonverbal communication techniques for students with autism and one teacher felt that she had average ability. All three teachers felt that they had average ability in developing curricula for students with autism. In the area of evaluation and

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Table 3

Teacher's Self-Perceptions of their Competence in Working with Children with Autism

	Grade Primary Teacher	Grade Two Teacher	Grade Three Teacher
Behavior management and social interaction enhancement techniques	Average	Average	Average
Speech and language techniques	Average	Below Average	Below Average
Nonverbal communication techniques	Average	Below Average	Below Average
Ability to develop curricula	Average	Average	Average
Evaluation and assessment techniques	Average	Below Average	Average
Expressive therapy (e.g. art/music)	Average	Below Average	Below Average
Daily living programming	Average	Average	Average
Self-care skill programming	Average	Average	Average
Working with parents and families	Above Average	Average	Average

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assessment techniques for students with autism, two teachers felt that they had average knowledge in the area, and one teacher felt she was slightly below average. When asked about their competence in expressive therapy, two teachers felt they were slightly below average in this area and one teacher felt she was average. In the area of daily living and self-care skill programming for students with autism, all three teachers felt they had average competence. Finally, two teachers felt that they were average in working with parents and families of student with autism, and one teacher felt she was above average in this area.

Upon asking these questions the researcher offered each teacher a chance to add any further comments. One particular teacher felt quite strongly that he could use further professional development (PD) in the area of autism. This teacher's comments were:

“I feel that I, and likely many others, could use further professional development in the area of autism and teaching children with autism. Whenever a teacher knows that he/she will be teaching a child with autism, an expert on the topic should provide a PD day and the teacher should be required to attend.”

Teacher Qualities

All of the teachers interviewed seemed to be warm and easy to speak to during the interviews. They were extremely willing to take time out of their busy day and meet with the researcher to discuss Sarah. They spoke highly of Sarah and all of her accomplishments.

It appears that Sarah's teachers had elements of effective teachers, such as their warmth, high expectations of Sarah, and positive attitude. Sarah's teachers had high expectations of their students and expected the same of her. Research suggests that the

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types of expectations a teacher holds for a student can significantly impact the learner's outcome (Wahlberg, et al., 2001) and most likely it did. Her teachers also appeared to have a positive attitude about her, which is also critical in a child's learning environment, suggests Wahlberg and others (2001). Furneaux (1977) also points out the importance of a warm and accepting teacher who can project a stable personality, as such a teacher is often consistent in his or her approach but flexible in dealing with the child.

Academic Ability and Achievement

A psychological assessment was conducted shortly after Sarah's diagnosis of autism in August of 2000. Sarah was administered the *Differential Ability Scale (DAS)* in order to assess her overall cognitive development. Her General Conceptual Ability score fell in the Below Average range, above 6 percent of her peers. Sarah's performance on the Verbal scale of the DAS placed her in the Low Average range at the 12th percentile. Her performance on the Nonverbal scale of the DAS was in the Below Average range at the 5th percentile.

Sarah's ability and achievement was recently examined to observe how she is performing compared to her peers and her previous cognitive assessment. Sarah's cognitive abilities were evaluated using the *Wechsler Intelligence Scale for Children Fourth Edition (WISC-IV)*. Her general cognitive ability fell within the Average range of intellectual functioning. Sarah's overall thinking and reasoning abilities exceed those of 45% of children her age.

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Sarah's verbal reasoning abilities (her ability to think and reason with words) as measured by the Verbal Comprehension Index (VCI) fell in the Average range and above 55% of her peers. The VCI is designed to measure word knowledge, the ability to identify commonalities in objects and concepts presented verbally, and social judgment. Sarah's performances on all subtests, which contribute to the VCI, were in the Average range, suggesting that her abilities in this domain are equally developed. She appears to be successful at verbally expressing similarities between stimuli, defining words, and answering general knowledge questions.

Sarah's nonverbal reasoning abilities (her ability to think and reason without words) as measured by the Perceptual Reasoning Index (PRI) fell also in the Average range and above 32% of her peers. The PRI is designed to measure her ability to think and manipulate visual images and her ability to reason without words. Sarah's performances on the subtests that make up the PRI were not equally developed. She performed in the Average range on tasks that required her to compare familiar objects or concepts presented visually and visually process unfamiliar information and reason abstractly to complete designs and patterns. She performed in the Below Average range when asked to analyze part-whole relationships to recreate block designs. This required her to problem solve using visual information with a model.

Sarah's working memory abilities as measured by the Working Memory Index (WMI) fell in the Average range and above 34% of her peers. This scale examines her ability to sustain attention, concentrate, and exert memory control.

Her speed of processing, as measured by the Processing Speed Index (PSI), appeared in the Average range, above 66% of her peers. Processing speed indicates the

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rapidity with which Sarah can copy and process rote, visual information without making errors.

Sarah's overall cognitive development has increased slightly from the Below Average range to the Average range of functioning. Sarah performed slightly better on the verbal tasks of the WISC, than the nonverbal tasks, although both were in the Average range. This is consistent with research by Mayes and Calhoun (2003& 2003b), which suggests that a child with high-functioning autism frequently performs better on verbal tasks. This was also consistent with her past performance on the DAS in August of 2000. The lowest verbal subtest was Comprehension which reflects the research by Mayes and Calhoun, however, the lowest non-verbal subtest was block design, which does not correspond with their findings. Research by Mayes and Calhoun (2003a) also revealed that IQ scores were proportionate to academic test scores, which was the case for Sarah.

Sarah's academic performance was evaluated using the *Wechsler Individual Achievement Test Second Edition (WIAT-II)*. Her performance on the Reading Composite fell in the Average range. On a subtest examining her ability to read single words without the benefit of context, she performed in the Average range and above 66% of her peers. Sarah read words quickly and automatically. She used her finger to break apart unfamiliar words. When required to read short passages and answer questions, Sarah performed in the Average range and above 43% of her peers. She read aloud and at times searched for answers in the passage. When asked to read a list of nonsense words to which she was to apply phonetic decoding skills, Sarah performed within the Superior range and above

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94% of her peers. Sarah sounded out the syllables silently and then put them together to form the nonsense word.

Sarah's performance on the Oral Language Composite was in the Average range. On a subtest requiring her to match words and sentences to pictures, and generate words, she performed in the Low Average range. She performed better than 32% of her peers. On a subtest where she was asked to express herself orally, she performed in the Low Average range and above 12% of her peers

Sarah's performance on the Mathematics Composite fell in the Borderline range. On a test of mathematical reasoning where questions were read orally, she performed in the Extremely Low range and above only 2% of her peers. She performed at a late grade one level in this area. On a test of computational math, she performed in the Borderline range and above only 8% of her peers. Sarah used her fingers and the provided scrap paper as strategies to solve problems. She appeared to have a firm grasp of addition and subtraction basic facts. She, however, exhibited difficulties in renaming and regrouping. Sarah took a considerable amount of time completing the problems. She also made some errors due to inattention to signs of operation.

Sarah's performance on the Written Language Composite could not be evaluated, as the written expression portion of the subtest was not fully completed. Sarah found it difficult to write about her favorite game as she indicated that she had too many favorite games. She also had some difficulty combining sentences and did not combine the sentences but instead changed words in each sentence. She did not appear to understand the instructions of the task. On a subtest that required Sarah to spell single words, presented verbally in context, she performed in the High Average range and above 88%

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of her peers. Sarah wrote very neatly and quickly. Her errors were often made when she spelled words phonetically, when they were not phonetic in configuration.

Sarah does have an IQ higher than 80 and performed well on the reading, decoding, spelling, and reading comprehension subtests of the WAIT, and had difficulty on the Written Expression subtest. She, however, also had significant difficulty in the area of mathematics, which is supported by both her parents and school teachers. Since Sarah also does have Average intelligence and had acquired functional language before the age of five, a better developmental course can be predicted for her (Wetherby & Prizant, 2000).

Adaptive Profile

A past psychological report conducted at the time of Sarah's diagnosis of autism administered the Vineland Adaptive Behavior Scales (Interview Edition)-Survey Form (VABS) in order to obtain a standardized measure of her skills at home. Sarah's skills were in the low average range compared to her peers. In the Communication domain, her scores were in the low average range. Her receptive skills were slightly higher than her expressive skills. Sarah's skills in the Daily Living Skills domain were also in the low average range. Her Personal Care Skills were low, while her Domestic and Community Skills were only moderately low in comparison to her peers. In terms of Sarah's Socialization skills, her scores placed her in the low average range. Her scores in the Motor domain were in the moderately low range in comparison to her peers.

A recent administration of the VABS to Sarah's mother indicated that Sarah's skills were in the Low Average range. Within the Communication domain, her scores fell

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in the Low Average range. Her receptive and written skills were adequate and her expressive skills were low. Her Daily Living Skills remained in the Low Average range. Her Socialization skills have improved, placing her in the adequate range. Sarah's coping skills scores placed her in the Low Average range.

Sarah continues to exhibit difficulties performing daily personal and social activities sufficiently. There are a number of actions that mom must remind her of, such as using the washroom, getting ready and how to dress appropriately for the weather, and she still requires explanation of many topics and emotions. Sarah has continued to learn and grow over the years and has not slipped behind in these skills. She is progressing but the skills have not been developed to the level of a typically developing child.

Parents Thoughts on Child's School

When asked about the child's school, mom began by explaining how frustrated she and her husband were with the school system. Even though she felt that the school system had helped with Sarah's development, the first words to come out of her mouth were ones of anger and resentment towards the school. Mom felt that because Sarah was high functioning, the school did not realize that she had some difficulties and required support at times. Mom did not like to use the label "autism" and agreed with the statement "only as a special as necessary." However, she would do as needed to obtain support for her child. Mom stated:

"This is the most frustrating part for me with a high functioning autistic child. It's trying to get it through their heads that this child has some exceptions and I get so upset with the school system... Do I have to go to the school and put a label on her forehead to get it through to the teachers?... I have been taught from day one not to label her and I don't want her to be autistic, but I know she is and I don't

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have a problem with that, but I don't want her to walk around with the crutch word 'autism'."

Mom explained that she was upset that the teachers do not check in to see if Sarah understands, or make eye contact with her to ensure she's listening, or explain things to her one-on-one or in step-by-step directions. She was quite frustrated that they assumed that Sarah understands what is asked of her, because she is not a bother and is very quiet.

All of the accommodations and concerns voiced by mom have been outlined in an official accommodations form, which was signed by both mom and dad. Mom was very upset that the forms are not followed and felt that they were a waste of time. She stated:

"They make you sign forms and nobody follows through on them (about accommodations)...they are non-existent and not followed.... I don't know what else to do.... We have tons of meetings to help her, but nothing is ever done on behalf of the teacher...I don't even think I will sign them this year."

Discussion then turned to other supports received by the child within the school system. The child previously had the shared support of an EPA in grade primary and the family was happy with the support offered from the EPA. In grade one, they were happy that support was also offered, however, the EPA changed frequently. The family felt frustrated with this and decided that it was better to have no support at all than to confuse her with the frequent change. As a result, mom began spending her days at Sarah's school and the teacher took over the EPA's role. Mom and dad were impressed by her grade one teacher and indicated that if permitted they would have retained her in this classroom. When asked why they would have kept her in grade one, the parents commented that they liked the parent-teacher collaboration of this teacher and they also liked the way she treated Sarah. She was also kind and understanding, and soft spoken. By grade two the

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EPA was only on screen if a problem arose, which was mainly for math or bathroom issues. Again the family felt that Sarah enjoyed this classroom experience. Her grade two teacher was very eager to help her and the other students learn. He allowed for differentiated instruction and got the students involved in the activities.

Finally, this year in grade three, no EPA was present within the classroom. The family and teacher do feel that having an EPA in the classroom to check in with Sarah would be of benefit to her; however, no support is available to her.

Progress in Parents Eyes

The researcher opened up the question session asking about the parents' views of progress and success. This was surprisingly a difficult question for the parents to answer. They had never truly sat and thought about what they felt was progress. Dad felt that any change in behavior in the 'proper direction' was progress or success. He stated:

“Related to Sarah?...umm...that’s an interesting one...this shouldn’t be tough...progress...I guess noticeable changes in the proper direction...”

Mom went on to give examples of their child’s successes without providing a definition of the term. She stated that Sarah had made progress in a number of areas, such as her self-confidence and her learning ability.

The parents used the terms progress and success interchangeably. They explained that the prognosis given at the time of her diagnosis was grim and anything she is able to accomplish was positive or a success to them. Mom didn’t feel as though Sarah would be able to do any of the things she is able to do now.

When asked whether they felt that their child had made progress, both parents immediately declared “definitely” simultaneously and went on to explain the changes in

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their child. Mom added that on a progress scale of one to ten, with ten being the most progress, their child was a definite ten. They were thrilled and amazed with the amount of progress she has made. Dad stated:

“We have seen progress in all aspects of her life, from accomplishments to self-confidence and esteem, to making new friends and trying new things.”

He went on to add that even her language and academic ability and interpersonal skills have improved. Mom agreed with dad’s comments, but felt the need to not be overly optimistic. She added:

“The social aspects are progressing, although there is still a long road and a distance to travel, but it is starting to emerge.”

When asked about Sarah’s changes in behavior and progress made, mom and dad both commented that they were unsure of where to start, as there was so much ground to cover. He felt that she had made progress in all areas and was shocked at how Sarah has managed to overcome many of the concerning behaviors. Dad stated:

“There have been so many years of progress that its hard to know what you are leaving out...we can go way back to infancy or early childhood where she would sit in the van and trace the steering wheel with her hands for hours and scream if you removed her...or look at all the fears she’s overcome, like the fear of the washroom, mouthwash, bugs, and animal faces. These things made her miserable, but she has overcome all these things one-by-one.”

Mom found it very upsetting to think about Sarah’s progress, as that meant going back and remembering all of the troubling behaviors. She’d rather focus her energy on the present and on making Sarah progress further and succeed. Again it appears that mom has moved past the grieving stage and into the acceptance stage (Copley & Bodensteiner, 1987). She refuses to dwell on the past and instead accepts the diagnosis and focuses on the present and future. Mom is unable to spend unnecessary time and energy reliving the

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past and is more concerned with effective problem solving. For example, mom feels the need to work with Sarah on the current difficulties and leaves the past concerning behaviors buried in the past. Mom did note that she was blind to a lot of progress made and that it had to be pointed out to her. Research suggests that this is common for many parents (Clare & Garnier, 2000; Schuntermann, 2002), as they wish so hard for certain accomplishments and overlook the small deeds. Mom commented:

“I was discussing this with Sarah today, that we start off with baby steps and then we move on to the next step. She has made leaps and bounds, and I had been overlooking a lot of her accomplishments or progress, as I thought that it was normal to progress in such a way (since the boys had). The neurologist had to point out to me the trillion other successes that she has made and now they are daily occurrences. It was like I wanted those big occurrences so badly that I didn’t even see the small accomplishments. I wanted to see the progression so bad...and then I was made to realize that I had to slow down and take it a step at a time and go through all the little things to get to the bigger steps.”

The family felt that they will continue to go through many changes with their daughter. They believe that Sarah will likely overcome her issues, but she may develop new issues. As may other parents, this family sees a balance of progress and difficulties yet to overcome, which is supported by research by Schuntermann (2002).

Self-help Skills. When asked what the family felt Sarah’s most significant advancement was, mom exclaimed that it was feeding herself, as she never thought that it would occur. Mom explained that at the time of Sarah’s diagnosis she was unable to feed herself or even hold a fork and barely a spoon. Sarah’s ability to feed herself seems to be one of her first accomplishments and perhaps that is why this accomplishment jumped so rapidly into mom’s mind. Also, since it was one of the first signs of progress, it may have aroused the most excitement. Mom responded:

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“If we go back to childhood it’d be feeding herself...to me I didn’t know if she’d ever be able to feed herself...She is now able to get her own cereal and pour her own drinks, so her self- help skills have improved.”

Emotions and Feelings. Dad had a different view on Sarah’s biggest advancement. He felt that her progress emotionally was the most significant. Dad explained how it felt to have a child that showed no emotions towards his or her parents, with a sense of desperation in his eyes and a sense of seriousness in his voice. He talked as if Sarah’s inability to express emotion and show love towards him and his wife was horrifying and quite upsetting. He stated:

“I wondered if she’d ever be able to feel or want a hug from her parents. It was the physical contact and those emotional feelings that just weren’t there. We were living with a robot in a sense and now ...wow...she gets upset and cries when a friend had hurt her and it’s almost a relief because it’s normal and we never thought that we would see this.”

Mom agreed with dad’s views and added that she felt that those areas had progressed but felt that Sarah’s sense of empathy was just beginning to emerge. Mom believes that progress is evident in this area; however has not yet fully emerged. She noted:

“Empathy has just started to progress...she is still slowly progressing and it’s still so new yet. There’s not a lot happening, but it’s coming...There are not a lot of examples but they are there....For example, people crying don’t really bother her, but now it makes her nervous. At one point someone could cry their head off and she wouldn’t say ‘what’s wrong’ or do anything...she may tell someone else ‘she’s crying’ and that would be it.”

Dad is happy that at least if someone upsets Sarah she responds properly, which wasn’t the case in the past, but she still has difficulty understanding the emotions of others and reading them. Dad added:

“The difference is now that if someone has upset her directly she responds properly...so if she’s involved she can respond, but she can’t understand others very well.”

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Socially. Both mom and dad felt that the social aspect of Sarah's progression was the slowest. They felt that she has become more comfortable around people and has even begun to use the telephone. Mom said that up until recently she was frightened by the telephone and did not understand its purpose. Sarah didn't see the point in calling someone that you couldn't see and was unsure how one knew that they were really there. Sarah didn't even answer the phone and just lately she has begun to call friends. When asked how this came about, the parents explained:

“One day she wanted to call a friend to come play (which was also not a usual occurrence) and we told her to pick up and phone and dial her number. We basically went through the steps she should take and encouraged her to do it.”

Mom basically gave Sarah the confidence to face her fear of the telephone. She worked through the fear with Sarah, until Sarah was able to confront the fear and control it.

In school Sarah also has begun to be more confident socially. She still will not approach a teacher, but she is less fearful. Sarah will often tell her mom of her needs or requests concerning school and mom will either call or write a note to the teacher to ensure that her needs are met. Mom stated that until recently this was even non-existent, that Sarah would not voice her concerns at all. Sarah would come home upset and the parents would not know why. It appears that Sarah will explain what is bothering her and seems to understand that if she tells her parents they will be able to solve the problem together.

Another progressive social aspect is her relationship with peers. At one point Sarah would not interact with others, especially her peers. Dad stated:

“At recess and noon this child would be seen sitting in the corner by the school, not playing with anyone.”

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This has changed dramatically. During my observations at the school, Sarah was observed going to lunch with her peers and interacting with them. Following lunch, she even engaged in play with two other friends. They ran and played together on the playground. Mom supported this observation when she made the comment:

“She has gone from sitting in the corner to making friends and even asking if they can come over to play. This has all changed this year. Until this year she was alone.”

Parents Views on Why Progress was Achieved

When the family was asked about why they believe some of these changes have occurred in Sarah a number of reasons surfaced. Mom believed that Sarah had really begun to trust them and believe that they are there to support her. Dad agreed with mom but put a lot of faith in early intervention, themselves and Sarah’s two brothers. Dad felt adamant that having early intervention applied at an early age was especially important and large differences could be witnessed as a result of this. Both mom and dad felt that Sarah’s brothers taught her a lot as well. They also watched out for Sarah and helped her through her difficulties. The family also felt that speech therapy had a large impact on their child’s successes, as they did not know if she’d ever speak. Dad commented:

“...I’d say that the greatest thing that happened was early intervention. I have seen it applied early and late and the result is so different. The intervention applied at the right time makes such a difference in progress.”

Dad based his thoughts on having witnessed early intervention applied early with his daughter and having it seen applied too late with his nephew. His nephew experienced very little progress and Sarah has undergone remarkable change. Mom believes that she can sense how Sarah’s feeling and will often ask her about her day and then they will

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discuss and work through the issue. Mom feels that by being patient and open to discussion Sarah begins to understand the situation and believes that any situation may be worked through.

Mom and dad both agree that because of the past supports put in place for Sarah, such as early intervention, speech therapy, occupational therapy, etc... and their ongoing support, Sarah is able to make progress.

New Goals for Child

When asked whether goals were set for Sarah, mom and dad were quick to answer 'no'. Dad stated "we are letting her become her...we've been surprised every month." Mom further added "whatever her potential she will obtain." The family is not putting pressure on Sarah and instead they are supporting her accomplishments and simply encouraging further progression to emerge. Sarah is able to set her own goals in a sense and achieve them as she is ready.

Even though the family had not set goals for their child, there were accomplishments that they would like for their child to achieve in the next year. The family is not rigid about the goals they set for Sarah. They do not set time limits for goals or put unnecessary pressure on her. However, they feel that Sarah has not finished her progression and that there are indeed areas that require further progress. First and foremost, the child's parents would like for her to learn how to deal with friends. She has friends that are manipulative and controlling and her parents and teacher would like for her to have the ability to handle and confront such friends. Mom stated:

"We are having a hard time explaining friendships to her...She has friends and they are very controlling and manipulative. I explained to one of these children

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that Sarah has issues on her level hoping that she'd be more understanding and tolerant and be more patient and it got worse. It's like she now has ammunition. She bosses her around and threatens to tell the teacher if she doesn't listen to her...it's so frustrating...."

Sarah's dad added:

"She can't read people yet and judge what will happen next."

Mom further adds:

"She waits for help and until she learns the rules then she's lost."

The family has begun to help Sarah deal with her friends. Mom has attended a conference put on by the Autism Society which addresses how to deal with social skills and teach parents how to deal with these issues and help their child. Mom has also begun role playing common situation with Sarah and her brothers. The role playing is concentrated on showing her new ways to join a group of peers, how to deal with conflict between peers, and basic social skills. Mom feels that by showing her different ways to handle various situations she may take one of the examples and use it as her own, once placed in such a situation. Dad also believes that by teaching her coping skills she may begin dealing with life's challenges.

Mom and dad felt that Sarah had many challenges yet to overcome. Dad felt that one of Sarah's greatest challenges thus far is her inability to distinguish reality from pretend. The family feels that Sarah is very literal and is unable to comprehend abstract situations or concepts. Mom feels that so many things still confuse her in life. Dad stated:

"One of her next greatest challenges with her is helping her distinguish between reality and pretend or cartoons because they have a human voice...we talk about this a lot."

Mom added:

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“...So many things are still confusing her. She’s intelligent but still so immature in her thinking...She’s so black and white and it’s there or not. I don’t always think that she understands the concept (or what’s being told to her) but she just learns to do it...like the phone for example, she likely doesn’t understand how it works and how someone can be on the line and not be seen, but now she can use it.”

Views on Future

The researcher asked the family about what they see in Sarah’s future and what, if any, special accomplishment they’d like for her to achieve. Mom felt that she’d like to see Sarah “continue to make friends and grow.” She would also like to see her marry, have a career, and have children of her own. Mom feared that her daughter would be lonely and only wanted her to feel supported and be able to face challenges that she is faced with. Dad was unsure of what she’d achieve and is curious and excited about what the future holds. He hopes that Sarah is able to achieve and be what she wants, which is a ballet dancer or a writer and illustrator.

Mom and dad joked that Sarah would still be living home at 20 years old and maybe older. Dad teased mom that she’d be unable to let her go and grow up, as many parents find it difficult to allow their children to leave home and begin their own lives. They had difficulty predicting what the future held for their daughter and imagining so far in advance. They believe that she may live at home, but could attend college to take a trade. They do not see her attending university as she has significant difficulty with mathematics. Mom could only hope that she would have her own place someday, but couldn’t begin to predict what the future held. She hopes that her daughter will marry so that she has someone to help and support her. Mom feels that if Sarah had someone to

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explain confusing situations to her that she'd feel more secure about letting her go and experience life. Mom stated:

“I hope that one day she will have her own place, but I don't know. She has so much more that she has to develop before...that's why I need her to get married so that someone else can help care for her. I know it is wrong to think this way but that would make me more comfortable to let her go. It's just so hard to imagine so far in advance...If she had the street smarts she could do so much more, but I don't think that she'll ever develop that hard shell around her to survive this sometimes cruel world alone. I think she'll survive some situations and have the proper coping skills but not all...”

Risk & Opportunity Factors within the Family

The risk and opportunity factors outlined by Dunst (1993), which were thought to influence a child and family's functioning and development were investigated to examine which were present within the family. Of the factors outlined by Dunst (1993), all were opportunity factors for this family and child based on the results from the questionnaires, interviews, and observations (See table 4).

Self-Efficacy. Based on the results of the Parental Self-Efficacy questionnaire, a number of the challenging behaviors had occurred in the past month for the mother. Of those behaviors that have arisen, mom indicated that she felt moderately to mostly competent in dealing with the behavior. The father had only dealt with one of the challenging behaviors in the past month and he felt somewhat confident in dealing with the behavior. Dad works a lot and likely is not present when many of the challenging behaviors occur, this may account for why he did not reveal as many challenging behaviors as mom. It is suggested that mothers are often the primary caregivers, thus are more likely to manage the child's behaviors, and thereby have greater opportunity to practice managing the child's behavior (Sofronoff & Farbotko, 2002). Based on the fact that mom and dad feel

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Table 4

List of Risk and Opportunity Factors Influencing Sarah's Learning and Development

Variable	Risk Factors	Opportunity Factors
Mother's Age	no	yes
Parent Education	no	yes
Income	no	yes
Occupational Status	no	yes
Socioeconomic status (SES)	no	yes
Job stability	no	yes
Pregnancy	no	yes
Number of siblings	no	yes
Residential stability	no	yes
Marital status	no	yes
Marital relationship	no	yes
Marital stability	no	yes
Child temperament	no	yes
Infant separation	no	yes
Parental health	no	yes
Parental mental health	no	yes
Parental self-esteem	no	yes
Parental locus of control	no	yes
Parental social skills	no	yes
Coping strategies	no	yes
Quality of primary caregiver	no	yes
Parenting style	no	yes
Toxic substances	no	yes
Nutritional intake	no	yes
Accidents	no	yes
Infections and illnesses	no	yes
Alternative caregivers	no	yes
Presence of extended family	no	yes
Extra-family support	no	yes
Life events	no	yes

Taken from: Dunst, C. (1993). Implications of risk and opportunity factors for assessment and intervention practices. *Topics in Early Childhood Special Education*, 13, 143-153

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somewhat to mostly confident in dealing with their child's behavior it can be assumed that they have relatively average or high self-efficacy and self-esteem.

Research by Sofronoff and Farbotko (2002) suggests that mothers are more likely to suffer from a lack of self-efficacy in dealing with a child with autism. This is the not case for this family. Mom feels quite capable of dealing with the child's behaviours and dad feels somewhat capable, which results in an opportunity factor for the family. Since mom and dad believe that they have the ability to care for their child and produce positive outcomes, this may make the family strive for progress and ultimately succeed.

Depression and Life-events. The results of the Recent Life Event questionnaire indicates whether a number of events have happened to the family in the past year and whether it still affects them. If an event took place a score of one was awarded and a score of zero was awarded if the event had not occurred. The number of life events that the respondents experienced and those that were still affecting them were summed up. This number was compared to the average of life events most people experience those still affecting them (Brugha et al., 1985). The amount of negative life events that have affected the family are within the average range and thus not thought to be influencing the family.

The mother has only experienced two negative life events outlined in the questionnaire and has indicated that neither influence her currently. The father experienced three negative life events and only one of them still affects him. Thus, the family has likely not experienced any severe stress and depression due to negative life events, which results in an opportunity factor for the family.

Coping. The types of coping mechanisms employed by the parents were summed and scored. The results of the CISS reveal that both the mother and father employ task-

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oriented or problem-focused coping mechanisms. This form of coping is proactive and thus allows the family to actively deal with problems and situations that arise in their lives (Endler & Parker, 1999). As Leasr (1998) suggests problem-solving coping is the preferred mechanism of coping with 'disability-related' problems and thus produces the best outcome. It is further noted that parents that employ a more effective and proactive form of coping reduce the strain on the family system and meet the needs of their child. Since the family (both the mother and father) employs a proactive form of coping, this is thought to be an opportunity factor influencing the child's development positively.

Locus of Control. The items were summed to examine who or what the parents attributed their child's improvement to. Results of the CICL questionnaire revealed that the family feels that both they and the doctors or professionals were involved in Sarah's improvement. The mother felt that she and her husband were most responsible for their child's improvement. She believed that the doctors or professionals involved with their daughter were the next most responsible for their child's improvement and the child was the third source involved. The mother felt that she and her husband were the main advocates for their daughter and they helped her progress most, but she also believed that the professionals involved with their daughter and also their daughter had a hand in the progress made.

The father attributed the improvement made by their daughter to the doctors and professionals mainly. He felt that he and his wife also played a role in this improvement and that their daughter also had a role in her own development.

Since the parents believe that they have control over their child's improvement, they will take an active role in producing positive outcomes for their child (Mandleco, et

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al., 2003). They are more likely to believe in the effects of treatment, thus seek proper treatment and be more involved in helping their child (Smith, et al., 2000). These parents have an internal locus of control, which is an opportunity factor for the family and child's development.

Parental Involvement & Parenting Style. Both parents were highly involved in Sarah's upbringing and development. As discussed previously mom was highly involved in the early intervention, occupational therapy, and speech language therapy processes. She also worked with Sarah on many of the exercises at home. Mom and dad were also very involved with the school. They made many visits to the school to discuss Sarah's needs and advocated for her. Mom also went to the school whenever Sarah needed her presence. Many teachers felt that the family was very supportive. One particular teacher commented:

“Mom met with me as needed. The family is very supportive and helpful.”

Another teacher commented:

“We have had several regulated visits and lots of in-depth meetings...there is lots of home support and you can always count on them.”

The family appears to have taken on an authoritative parenting style, which is outlined by Dunst (1993) as an opportunity factor for positive outcomes in dealing with children with developmental delays. The family feels that Sarah is able to progress and is helping her do so. Through their guidance and Sarah's trust in them, they are helping Sarah achieve. These parents' foster individuality and self-assertion, by offering support and being tuned into Sarah's needs (Baumrind, 1991).

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Sarah Today

Sarah can be described as a bright young child, based not only on her cognitive ability but also on the observations of her. She loves to dance and has enjoyed doing so from a very young age, states her mother. Past videos of Sarah, show a young child dancing to her own music. Mom indicated that Sarah now actively takes part in Ballet School and would love to become a prima ballerina. Sarah also takes pride in her drawing. She indicated to the researcher that this was her favorite pastime. She filled pages with bright and colorful artwork on a daily basis and drew several for the researcher.

Sarah reported that she also enjoys her summers camping with her family. She commented that she takes pleasure in riding her bike around the park and swimming with the other children camping in the park.

Sarah will begin another year of school in a grade four classroom in September of 2006 and she stated that she is looking forward to the new school year.

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Chapter IV: Summary of Themes

Several major themes emerged following the qualitative analysis of the family and teacher transcripts. The transcripts, interviews, and questionnaires gave the researcher insight into the issues experienced by the family. The researcher felt that this family had an important story to tell, which may help other families promote progress in their own children.

Some of the major themes that emerged by the method of a coding system that involved discovering and naming categories (Strauss, 1987) and the process of meaning condensation (Kvale, 1996) were the importance of accepting the diagnosis, strong parental expectations and involvement, powerful family beliefs, values and philosophy, the progress perceived by the parents as real, a sense of frustration with the school and health system, and a sense of urgency to tell their story.

Accepting the Diagnosis

One theme that emerged very quickly within the interview was the parents' ability to grieve and move on to accepting the ASD diagnosis quickly. They did not focus their energy on the diagnosis and the grim outlook; instead they looked to the future. The parents accepted the shocking diagnosis and immediately began seeking intervention for their child. They knew very little about autism and feared the worst possible outcome. Instead of sitting idle and doing nothing, this family took action and began problem solving, which most parents are unable to do (Milo, 1997). Since they knew very little about autism, they began researching the disorder and answering their own questions,

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instead of waiting to be answered by the doctors. When a problem arose they sought out answers and dealt as effectively as they could with the issue. The family became very involved in their daughter's development and became confident in their ability to parent a child with exceptionalities. Research suggests that families that reach the stage of acceptance are better able to parent their child with autism (Cameron, et al., 1992).

These parents also became advocates for their daughter. They fought for services for their child, so that she had a chance for better outcomes. The family began their fight for early intervention, and this fight continued with the school system. They fought for an EPA each year and extra support as needed to help Sarah have a better school experience.

Frustration with the School and Health Systems

Another theme that emerged during the interview with the parents was the frustration they felt towards the school and health system in their area. The parents felt that there was a lack of support and guidance from the school staff regarding how to best care for their child. The family was also annoyed and angered by the amount of time it took for the doctors to finally realize that something was wrong with their child. The family felt as though they had spent precious time making unproductive visits to their doctor. After Sarah had been diagnosed with an Autism Spectrum Disorder, the parents felt like they were on their own to deal with the implications of the diagnosis. The family followed the recommendations of the doctors and then was left to their own devices to educate themselves about their child's disorder. The family also felt that there was a lack of empathy on behalf of the school personnel, especially the teachers. Research suggests that teachers are not as empathic in their views towards autism as mental health

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professionals (Helps, Newsom-Davis, & Callias, 1999). The parents felt that the school staff did not understand the severity of the autistic disorder and thus did not care for the child as she required. There are also studies to support this parents feeling, as teachers often do not see the severity of the disorder and frequently over estimate the abilities of the child (Helps, et al., 1999). The parents also felt that the school was wasting precious time writing up specialized accommodation or adaptations for children as they were rarely followed. This left the parents feeling helpless, unimportant, and unheard in their local school. Sarah's mom described her experience in these words:

“That is the most frustrating part for me...is to get it through some people's heads that this child does have some exceptions and I get so upset with the school system...I feel like it's a battle to make sure they're hearing me...They make you sign forms and nobody follows through on them (about accommodations)...but it's nonexistent and isn't followed...I don't know what else to. We have tons of meetings to help her but nothing is ever done on behalf of the teacher.”

Family Beliefs, Values, & Expectations

Another theme that emerged relates to the philosophy of a family. This family appears to allow their children to become themselves. They seem to provide a loving and stable environment in which their children are able to create themselves within their family structure. The parents appear to have the belief that each child is able to be different and unique. The parents do not put pressure on their child or expect her to make miracles or become “a preconceived notion” of what a child should be. Instead their child is able to take comfort in knowing that she will be loved regardless of what she does. Research concludes that a child's development is influenced by parental judgments and the expectations of parents' influence the child's self-perceptions and achievement (Ivey,

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2004). This family is supporting their child's accomplishments and encouraging further growth and success. Dad summarized his feelings about what goals he has set for Sarah: "I'm letting her become her. We have been surprised by her every month." Mom added to his statement "whatever her potential she will obtain."

As parents they also take a positive outlook on what their daughter has achieved, as opposed to focusing on what she has yet to achieve. For example, this family is able to finally see the small accomplishments and work through them to achieve the larger steps.

Perceived Progress as Real

A major theme within the research was the issue of progress. The family felt confident that Sarah has made evident progress and is still continuing to progress. The parents very easily offered examples of change in Sarah's development and ability. Based on the experiences and stories outlined by this family, Sarah has made advancements in her self-help skills, has developed appropriate emotions and feelings, has progressed socially, and developmentally.

Others involved with Sarah had similar views on Sarah's progress. Her principal, who has known Sarah since Grade one, felt that she had made "great strides and huge progress." Past psychological and speech language reports commented on Sarah's significant gains and progress. Her teachers also felt that she had made significant gains.

One teacher commented:

"She makes constant progress in all areas...she is not upset by change now, is able to change with the class, and responds easily to questions and comments when needed."

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Progress was also evident in the videos watched by the researcher. In the early years very concerning behaviors were witnessed, however as the years passed the behaviors began to disappear. Sarah also began to learn social rules and began interacting with others. One very evident example of this was witnessed. Every year since Sarah was a very young child her dad video recorded Christmas morning and every year before he turned off the video recorder, dad said to her “Merry Christmas Sarah” and every year Sarah ignored him. She would continue what she was doing and sometimes look at him blankly, until one year she finally looked at him and said “Merry Christmas daddy.” This may be such a small step, but yet an exhilarating example of progress to the family.

Sarah’s cognitive ability has also progressed, which is in the average range. She is performing extremely well in the areas of reading, spelling and word attack skills. She has significant difficulty with mathematics and written expression. She also still does struggle with some daily living skills, but is making progress.

A Sense of Urgency

The last theme that emerged from the research relates to the eagerness showed by the family towards participating in the study. The researcher thought that it may be difficult to find a family to commit to volunteering to such a timely study, but one particular family was eager to take part. This family was eager to share their experiences and had many stories to tell. It felt as though the family was relieved that someone was actually looking into the issue of progress for children with autism and this family desperately wanted to voice their opinion and successes. This family seemed thrilled that a study was actually focusing on the positive aspects of a child with autism and showing

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families that there was hope for progress. The parents also commented that they were very discouraged initially about how their daughter would develop, as much of the research out there was grim and discouraging.

This family willingly disclosed their life story, the triumphs and complexity of raising a child with autism. They allowed the researcher to enter their lives and recreate their story. They were open and direct about their concerns and how the medical and education systems made them feel and feared no repercussions for doing so, as they wished to convey their true feelings and experiences to date.

In summary

Sarah has unquestionably made progress in all areas of development. Researchers suggest that reducing the symptoms that led to the diagnosis in the first place should be considered progress (Powers, 2000). Symptoms may also decrease to the point that they are no longer visible and no longer meet the criteria for a diagnosis of autism (Powers, 2000). Powers (2000) indicates that this is not considered a “cure” or “recovery”, but “habilitation.” “Habilitation is the process of learning to adapt, accommodate, and cope with one’s strengths and limitations” (Powers, 2000). With the hard work of the parents, professionals, and the child, this process is possible. Sarah has not yet reached the Habilitation stage, as she still exhibits symptoms associated with autism, however, she has decreased many of the symptoms, is learning to adapt, and thus has made considerable progress.

Why Sarah has made such gains is uncertain, but what cannot be disputed is the fact that Sarah has made significant progress. Her parents feel that early intervention may

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have played a significant role, along with their parental support and trust, and the love and support of her two older brothers. This family accepted the diagnosis and began researching how to produce the best outcomes, which research suggests produces significant progress (Dominique & Goldberg, 1998). Research also suggests that children are born with autism, but the symptoms associated with autism vary and may change for the better with appropriate teaching and time (Powers, 2000). Sarah was taught many of the skills she was lacking beginning from a very young age. Her parents began teaching her immediately following the diagnosis, along with the early interventionist, speech language pathologist, occupational therapist, and preschool and education system teachers who also had a hand in her teaching and development.

Sarah and her family also possess a number of opportunity factors, which may have also produced such remarkable progress. The family did all they could for Sarah, which has ultimately paid off.

What the future holds for Sarah, the family cannot say for certain. However, they are sure that she will continue to “surprise them” and “become herself” and that’s all they could ever hope for.

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Chapter V: Implications, Limitations, Future Research, & Conclusion

Implications

The Need for an Accurate and Quick Diagnosis of Autism

The findings of the research have several important implications. The first is the need of the medical system to be aware of the concerns of parents. These parents went through a long, stressful year of being concerned for their child. They wasted valuable time that could have been spent obtaining services, such as early intervention for their child. Research suggests that early intervention applied early proves more successful and better outcomes (Charman & Baird, 2002).

Family practitioners should be more educated in diagnosing disorders such as autism, so that families do not experience the same unnecessary stress and worry of this family. If doctors are more aware of the signs and symptoms of the onset of autism, which warrant further investigation, children may be diagnosed more rapidly. Fortunately, there has been recognition of the early signs of autism due to more media and public interest, which is leading to earlier referrals for diagnosis (Charman & Baird, 2002).

In providing a diagnosis of autism, the doctor or professional providing the diagnosis should also be supportive in rendering the results. They should nurture the family into the acceptance of the diagnosis and not attempt to make the family take on their point of view. Instead they should direct the family to peer reviewed research so that the family is able to make their own decisions regarding the diagnosis and the prognosis.

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The Need for Proper Training and Understanding among School Staff

Another implication from the research is the need for further professional development among school staff. Research has delineated this lack of training among school staff, especially teachers, as teachers frequently have significantly less training about autism (Helps, et al., 1999). Many teachers feel as though they are somewhat to moderately prepared and versed in areas concerning children with autism. However, teachers, educational program assistants, special educators, and administrators would all benefit from further professional development in the area of programming and working with children with autism and also effective collaboration with the parents of children with autism. Starr, Foy, and Cramer (2001) state the importance of teachers acquiring the necessary knowledge about specific disabilities in their classroom in order to ensure the best outcomes for the child and so not to further add to the child's difficulties. This is a difficult issue as many teachers feel frustrated and overwhelmed by the diverse needs of their students, however, research suggests that having the proper training and knowledge of the area would reduce the stress and frustration experienced by many school personnel (Helps, et al., 1999; Starr, et al., 2001).

Until the school team is well versed in the area of autism and the development of programs and the delivery for instruction for autistic students, parents can only hope that the teacher will seek out the necessary information needed to teach and provide adequate programming and support for their autistic child. The family's concern that their child is not receiving adequate support is a legitimate concern on their behalf, as they send their child to school to receive the best possible teaching and expect programs establishing for their child to be adhered to.

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On the other hand, the lack of knowledge on behalf of the teachers is not always their own fault. If school boards do not offer courses in the area or professional development time, the teachers may not have the opportunity to obtain such information. Parents of children with autism sometimes find it difficult to realize that some teachers do not have adequate time to review current information on such disabilities. Teachers should be made aware of what types of exceptionalities they will encounter for the following year. This suggestion was made on behalf of a teacher who felt that he too could profit from further education regarding autism. He suggested that an expert in the area of autism offer a workshop to teachers who will be teaching children with autism.

The researcher feels that as time elapses and the need for a greater understanding of autism surfaces in schools, there will be an increase in professional development in the area. This will possibly result in better programming for children with autism and better home-school collaboration. Once school personnel fully understand the realm of autism they may be better equipped and better able to recognize the parents concerns. Also, school staff may begin to understand the need for the programming required by the child and begin to abide by the program put in place for him or her.

Many school boards are beginning to offer more professional development and specialized training in the area, however, it seems as though only the larger boards have the funding necessary for such programs thus far. One can be optimistic that in time other boards will see the need for such training and acquire the means to offer needed professional development.

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EPA Support

It is hard to imagine that only children that cause disturbances in the classroom are provided with an EPA. There are so many children diagnosed with disabilities and disorders that could benefit from the support, but do not receive one, as they are not causing any problems within the classroom.

Many children that require support are left on their own as educators assume that they understand and are able to comply with directions without support, as they are quiet and do not request help. However, these children may not be aware of how to gain help and thus their success is limited because they are not given the essential support. Funding arrangements may need to be scrutinized to maximize the number of students who receive support.

A Need for Collaboration

It is essential that all professionals who work with children with autism, such as doctors, therapists, or teachers, adopt a collaborative approach when working together and with families. For a child to excel and inclusion to be successful within a school system, collaboration is essential (Myles & Simpson, 1993; Starr, et al., 2001). Star and colleagues (2001) discuss the effects of effective collaboration. They propose that collaboration between parents and professionals may offer greater stability for families of autistic children, which would in turn create a better functioning family. A collaborative relationship may allow both parties to come together to develop an ideal program for the child, one which is adhered to and one that would allow the child to function more productively within the classroom.

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The Need for Community Support

Moroz (1989) suggested that collaboration and required support can only happen when families have access to community-based support services and educational services for their children with autism. This family may have benefited from the support of the community, as they sought out any sources of supports available to them. However, few community services are available in small rural communities. The family may have attended local meetings and prospered from the wealth of information shared and perhaps other families would have profited from the information this family had to offer, had they had access to the support.

Establishing local groups and support services in rural communities for families of children with developmental disabilities, such as autism would provide an additional support for families when they are unsure of which direction to turn and require guidance. Such groups may alleviate the isolation many parents feel when they attempt to provide adequate treatment and programming for their child.

The Need for Parents to Advocate and Be Involved

A key implication that has surfaced from the research is the importance of family involvement. Research has recognized the importance of families being involved in treatment programs (Ozonoff & Cathcart, 1998; Moes, 2000). It is important for parents to follow the recommendations suggested by the professionals, but it also is important for the family to advocate for these rights.

This family took the child to the doctor repeatedly until they had a diagnosis. They then actively took part in the treatment process and continue to be involved to date.

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The researcher believes that this family found peace and acceptance by advocating for their daughter. Searching for research and answers to their questions may have kept the family focused on what was important and led them to their success. Taking an active role in their child's treatment and "recovery" may have given them the strength to move on and the confidence to parent effectively.

Limitations

As in any study, limitations are inevitable. The first limitation is that the child was not chosen from a random sample. The child was chosen from a group of children whose parents were willing to participate and believed that their child had made "progress."

Secondly, there is no way to identify for certain that "progress" or "success" had occurred. The study solely examined the perceived progress over the course of the study, without identifying if the progress was real or perceived. Thirdly, the study does not offer any definite conclusions to what works or ensures progress. It simply presented the results to provide readers with added knowledge and understanding of another case of autism, with perceived progress or success. No previous studies of this kind have been conducted, thus there is no set protocol to follow in studying or presenting the data to readers.

Fourthly, the majority of the data was from a retrospective standpoint, thus neither the behaviors nor the progress made was witnessed by the researcher. The researcher had to rely on the data collected from other parties in examining the child's progress. Finally,

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some methodological limitations may exist, as data was also collected by self-report measures and interviews, which may lead to cognitive distortions.

Future Research

In conducting future research it would be beneficial to interview a number of families with children experiencing perceived progress and specifically examine what they feel may be influencing the progress. The findings of such research would illustrate whether or not the parents hold similar views and perceptions about what factors aided progress as those in the current study. A number of different themes and implications may also arise from other families, as they may have had very diverse experiences and experienced different risk and opportunity factors as a family.

It may also be interesting to conduct a study with families who have children who are not experiencing success and examine their life stories. It would be interesting to examine whether the child is truly not making progress or whether the family is focused on other problematic matters, preventing a focus on the successes. It would also be interesting to compare the lives of the children making progress to the children not making progress and examine the differences in the lives of the children.

Lastly, it may also be valuable to conduct a study that examines the concept of acceptance in relation to the outcomes for families with a child with autism. It may have been interesting to discuss with the family the issue of acceptance and ask when they believe they had finally accepted the diagnosis and whether they still grieve it. It may also be beneficial to ask how they feel they surpassed the grieving stage and progressed into the acceptance stage.

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Conclusion

In conclusion, this family of a child with autism believes in progress and feels that their child has made progress in all areas. They think progress is only possible with the support of early intervention, speech pathology, occupational therapy and the aid of a supportive family. The parents do also see the importance of a proper early diagnosis and support within the school system.

This study was not to investigate the best method of producing progress but only to provide the reader with what the family felt worked for them and how they dealt with a child with autism. The study does reveal that progress is real for some children with autism and that autism is not an impenetrable wall. The study supports research by Dominique and Goldberg (1998) that significant progress can occur when a family accepts the diagnosis of autism and continuously seeks out a greater understanding of what the diagnosis is and how it's treated. As the researcher, the conversation with the family brought alive the need to keep in mind that the characteristics of autism spectrum disorder can change over time within the individual. As previously noted, as a practitioner in the field, I need to be aware of these changing characteristics. Furthermore, all of us need to be aware of the nature of autism spectrum disorder, how to diagnose it, and how to intervene. With regard to intervention, one of the more striking matters for me was how each child is unique and as such requires a highly individualized intervention approach. Thus, those of us who work in the field must be conscious of a variety of interventions that may aid children with unique needs. As I learned from this family, who are "letting her become her", which within its context of professional practice is guided by an ecological family centered approach.

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Appendix A: Early Interventionist Letter

Appendix A

Early Interventionist Letter

Dear Madame/Sir:

My name is Krista Doucette and I am a graduate student in the Master of Arts in School Psychology Program at Mount Saint Vincent University. As part of a thesis requirement, I am conducting a study examining what events have taken place for a child with autism to make progress under the supervision of my thesis supervisor Dr. Fred French.

Today, many children diagnosed with autism have made academic and social progress, but little is known about what factors have been involved in this process. It is my hope to identify what contributes to a family's belief that their child has made progress and to create a biographical sketch of the child's life.

I am contacting you in the hope that you may be aware of families with children possessing autism that are experiencing success or making progress. I was hoping that perhaps you may be willing to compose a list of parent volunteers who have a child, preferably female, aged seven to nine years, who has been diagnosed with autism and experiencing success, and who might be willing to be contacted by me to discuss the study. From this list a family could be randomly selected for contact. The family contacted is not obliged to participate, but upon hearing about the study and its requirements may then decide whether they choose to take part. As well, I am wondering if you could send the attached letter requesting their participation. It can be returned to you in the confidential self addressed envelope for pick up by me should they agree.

The procedure of this study will consist of the completion of a set of paper-and-pencil questionnaires. The questionnaires will be given to the parents in their home. They will be answering questions about the way that they cope with stress, about self-efficacy, and life events. Additionally, they will be interviewed about their child's adaptive functioning, and developmental and medical history. Also, if they have a copy of the child's medical file from the Autism Team, the examination of its contents may provide some insight into their child's diagnosis. The child will be interviewed and assessed in areas of academic achievement and intellectual ability in their home setting. The child will also be observed three times in both their home and in the school setting (classroom and playground), for approximately fifty minutes on each occasion. As well, with the permission of the parents and the school board, their child's current and previous teachers and principal will be interviewed and a review of her cumulative file will be conducted at the school. Approximately ten hours of the family's time will be required, if they choose to participate in the study.

No known or foreseen risks are expected with the proposed research. By taking part in the study, the child is not likely to experience any distress. The activities are constructed to be somewhat appealing to children. However, during the completion of the questionnaires, the parents may be asked about stressful situations. If the parents find the study upsetting or wish to stop at any time, they may choose not to answer any of the questions or stop participating in the study at any point in time.

The University Research Board at Mount Saint Vincent University has reviewed and approved the ethical component of this study.

I would like to take the opportunity to thank you for your consideration of this request. If you have any questions and/or concerns regarding the research, please contact me, Krista Doucette, (902) 445-7119 or my thesis supervisor Dr. Fred French (902)457-6186. If you wish to speak to someone not directly involved in this project you are invited to contact Dr. Davis, Acting Chair of the University Research Ethics Board at (902)457-6296.

Sincerely,

Krista Doucette
Graduate Student, School Psychology
Mount Saint Vincent University

Dr. Fred French
Thesis Supervisor/Associate Chair
Faculty of graduate Education
Mount Saint Vincent University

Appendix B: Parent Consent and Debriefing Form

Appendix B

Consent/Debriefing Form
Mount Saint Vincent University
Department of Graduate Education
Progress in Children with Autism: A Case Study

Participation for Parents and Child:

My name is Krista Doucette and I am a graduate student in the Master of Arts in School Psychology Program at Mount Saint Vincent University. As part of a thesis requirement, I am conducting a study examining what events have taken place for a child with autism to make progress. Both you and your child are invited to take part in this research study. Your participation in this study is completely voluntary. Although participation may not benefit you, the results may be helpful to others in the future. You may withdraw from the study at any time and may refuse to answer any questions you choose. You may also opt out of any of the individual measures of your child's abilities, without penalty.

Purpose of the study:

The main objective of this study is to examine what life events have taken place for your child, who has been diagnosed with autism, to make progress. Today, many children diagnosed with autism have made academic and social progress, but little is known about what factors have been involved in this process. It is my hope to identify what contributes to your belief that your child has made progress and to create a biographical sketch of your child's life.

Description of Research:

The procedure used in this study will consist of the completion of a set of paper-and-pencil questionnaires. The questionnaires will be given to you in your home. You will be answering questions about the way that you cope with stress, about self-efficacy, and life events. Additionally, you will be interviewed about your child's adaptive functioning, and developmental and medical history. Also, if you have a copy of the child's medical file from the Autism Team, I would like to review it as it may provide additional insight into your child's diagnosis. Additionally, past written work or childhood videos may be insightful. Your child will be interviewed and assessed in areas of academic achievement and intellectual ability in your home setting. This will take approximately three hours, and will involve asking her to manipulate blocks, answer questions pertaining to her general knowledge, and respond to questions in the area of academic subjects. Your child will also be observed three times in both your home and in the school setting (classroom and playground) for approximately fifty minutes on each occasion. As well, with your permission and the permission of the school board, your child's current and previous teachers and principal will be interviewed and a review of her cumulative record file will be conducted at the school. Approximately ten hours of your time will be required, if you choose to participate in the study.

Potential Risk:

No known or foreseen risks are expected with the proposed research. By taking part in the study, your child is not likely to experience any distress. The activities are constructed to be somewhat appealing to children. During the completion of the questionnaires you may be asked about stressful situations. If you or your child finds the study upsetting, you may choose not to answer any of the questions or stop participating in the study at any point in time.

Potential Benefits:

The findings of the study will contribute to our understanding of the complex relations of autism and what appears to promote progress.

Confidentiality:

You and your child's anonymity will be maintained throughout the course of the study. Upon completion of the project, files will be shredded and all data will be deleted. The final report of the research will contain no identifying information, as names will not be reported. Also, measures will be taken to ensure confidentiality and restricted sharing of information. All information collected will be kept in a locked filing cabinet and data access will be limited to myself, Dr. French, and my thesis committee members, Dr. Foley and Ms. Lusk. Results will be disclosed in a thesis with all identifying data having been removed.

Questions or Problems:

If you have any questions about the study, please feel free to contact: Krista Doucette – Phone: (902) 445-7119 or Dr. Fred French – Phone: (902) 457-6186, or Dr. Davis, Acting Chair of the University Research Ethics Board at (902) 457-6296, who is not directly involved in the project.

CONSENT:

I have read the study's description and my questions have been answered to my satisfaction. I hereby give consent that my daughter may take part in this study, and I will also take part.

_____ Signature of Parent/Guardian	_____ Date Signed
_____ Signature of Parent/Guardian	_____ Date Signed
_____ Signature of Researcher	_____ Date Signed

Thank you for your support!

Appendix C: Superintendent Letter

Appendix C

Superintendent Letter

Dear Sir:

My name is Krista Doucette and I am a graduate student in the Master of Arts in School Psychology Program at Mount Saint Vincent University. As part of a thesis requirement, I am conducting a study under the supervision of Dr. Fred French examining what events have taken place for a child with autism to make progress. The child taking part in the study is attending a school in your district.

I am requesting permission to obtain information about the particular student, whose parents have given prior consent. (A copy of the parents signed consent form has been appended.) The study involves conducting twenty to thirty minute semi-formal interviews with the student's current and past teachers, and a brief ten minute semi-formal interview with the school principal, if they are willing. Teachers will be able to conduct the interview at a time that is convenient for them, either during a free period or after school hours. The study also includes conducting three, fifty minute observations of the child in the classroom and on the playground, and examining the child's cumulative record file.

The principal and teachers of the school will receive a letter explaining the study along with a copy of the questions that will be asked. The researcher will then make contact with the teachers, and if they are willing to participate, set up a time convenient for them. The interview may take place in person or via telephone.

The University Research Board at Mount Saint Vincent University has reviewed and approved the ethical component of this study.

I would like to take the opportunity to thank you for your consideration of this request. If you have any questions and/or concerns regarding the research or interviews, please contact my thesis supervisor Dr. Fred French (902)457-6186. If you wish to speak to someone not directly involved in this project you are invited to contact Dr. Davis, Acting Chair of the University Research Ethics Board at (902)457-6296.

Sincerely,

Krista Doucette
Graduate Student, School Psychology
Mount Saint Vincent University

Dr. Fred French
Thesis Supervisor/Associate Chair
Faculty of graduate Education
Mount Saint Vincent University

Appendix D: Principal Letter/Consent Form

Appendix D

Principal Letter/Consent Form

Dear Sir:

My name is Krista Doucette and I am a graduate student in the Master of Arts in School Psychology Program at Mount Saint Vincent University. As part of a thesis requirement, I am conducting a study under the supervision of Dr. Fred French, examining what events have taken place for a child with autism to make progress.

The superintendent of the district has given his permission to contact you regarding this study. I am requesting your permission to obtain information about the particular student, whose parents have given prior consent. (A copy of the parents signed consent form has been appended.) The study involves conducting twenty to thirty minute semi-formal interviews with the student's current and past teachers, and a brief ten minute semi-formal interview with you, if you and they are willing. You and the teachers will be asked to conduct the interview at a time convenient for you, either during a non-teaching period or after school hours. The study also involves conducting three fifty minute observations of the child in the classroom and on the playground and a review of the child's cumulative record file.

The University Research Board at Mount Saint Vincent University has reviewed and approved the ethical component of this study.

I would like to take the opportunity to thank you for your consideration of this request. If you have any questions and/or concerns regarding the research or interviews, please contact my thesis supervisor Dr. Fred French (902)457-6186. If you wish to speak to someone not directly involved in this project you are invited to contact Dr. Davis, Acting Chair of the University Research Ethics Board at (902)457-6296.

Sincerely,

Krista Doucette
Graduate Student, School Psychology
Mount Saint Vincent University

Dr. Fred French
Thesis Supervisor/Associate Chair
Faculty of graduate Education
Mount Saint Vincent University

CONSENT:

I have read the study's description and my questions have been answered to my satisfaction. I hereby give consent that I will take part in this study.

Signature of Principal

Date Signed

Appendix E: Teacher's Letter/Consent Form

Appendix E

Teacher Letter/Consent Form

Dear Madame/Sir:

My name is Krista Doucette and I am a graduate student in the Master of Arts in School Psychology Program at Mount Saint Vincent University. As part of a thesis requirement, I am conducting a study under the supervision of Dr. Fred French, examining what events have taken place for a child with autism to make progress.

The superintendent of the district and your principal have given his permission to contact you regarding this study. I am requesting your permission to obtain information about the particular student, whose parents have given prior consent. (A copy of the parents signed consent form has been appended.) The study involves conducting twenty to thirty minute semi-formal interviews with the student's current and past teachers, if you are willing. You will be asked to conduct the interview at a time convenient for you, either during a non-teaching period or after school hours. The study also involves conducting three fifty minute observations of the child in the classroom and on the playground and a review of the child's cumulative record file.

The University Research Board at Mount Saint Vincent University has reviewed and approved the ethical component of this study.

I would like to take the opportunity to thank you for your consideration of this request. If you have any questions and/or concerns regarding the research or interviews, please contact my thesis supervisor Dr. Fred French (902)457-6186. If you wish to speak to someone not directly involved in this project you are invited to contact Dr. Davis, Acting Chair of the University Research Ethics Board at (902)457-6296.

Sincerely,

Krista Doucette
Graduate Student, School Psychology
Mount Saint Vincent University

Dr. Fred French
Thesis Supervisor/Associate Chair
Faculty of graduate Education
Mount Saint Vincent University

CONSENT:

I have read the study's description and my questions have been answered to my satisfaction. I hereby give consent that I will take part in this study.

Signature of Teacher

Date Signed

Appendix F: Parent Interview

Appendix F
Parent Interview

Progress

Could you please tell me how you define progress or success? _____

Do you use the term interchangeably or define the terms differently?

Do you feel that your child has made progress? _____

If yes, in what ways do you feel she has progressed? _____

Could you describe any changes in your child's behaviors or abilities? _____

Could you tell me about your child's most significant advances? _____

Could you tell me a bit about what you think helped her perform so well and make this progress? _____

Are there any special goals that you have set for your child? If so, have your goals changed for your child over the years? _____

As you look back over the past 6 months, what were the most exciting developmental steps accomplished by your child? _____

I'm interested in knowing what developmental steps you'd like your child to accomplish in the next 12 months? _____

Has your child acquired skills that have given you a sense of pleasure and anticipation of things to come? _____

Are there any special accomplishments that you would like your child to achieve?

Do you believe that these accomplishments are achievable? _____

Are there certain strengths that you feel your child has that may be used as assets in her future? _____

I'd be interested to know what you see in your child's future as an adult. What are your thoughts about what lies ahead? _____

Is there anything else that you would like to tell me about your child's progress?

Family Background

Could you tell me a bit about your education, work/employment, and lifestyle/home life?

Developmental History

Could you please tell me about any events during or after pregnancy that you believe were significant? _____

Are there any significant birth or developmental factors that caused you any concern or that you'd like to share today? _____

How would you describe your child's temperament and would you say that it has changed over time? _____

Is there any additional information pertaining to your child's development that you would like to share? _____

Family Medical History

Could you please tell me about any pertinent medical, learning, or emotional problems experienced by yourself or your children? _____

Is there any additional medical information that you would like to add?

Events Surrounding the Diagnosis

Would you mind telling me about when you began to realize that your child showed responses or behaviors that concerned you? _____

Could you tell me about when you learned of your child's diagnosis? (What were you told? How old was she?) _____

Has your understanding of the diagnosis changed over the years? If so, could you please tell me how? _____

Reflections of Changes over Time

Could you please tell me about your child's interactions with peers?

Do you believe that there have been changes in your child's interactions with peers? If so, could you please tell me about these changes?

Could you please tell me about your child's language abilities/communication and whether you believe that a change has taken place in your child's communication?

Could you please tell me a little about your relationship with your child? Would you say that this relationship has remained the same or changed over time?

Can you think of any past emerging behaviors that may now have begun to work for your child? (Ex. interaction with adults to interaction with children, babbling to talking)

Could you tell me about what you feel are your child's areas of strength, skills, and interests? _____

Would you mind telling me about her dislikes? _____

Could you please tell me about what you feel are your child's challenges and areas of greatest difficulty? _____

With regards to your child's likes and dislikes, could you please tell me what, if any, changes have taken place? _____

Could you please describe any challenging behaviors faced with your child and how these behaviors are responded to? _____

How would you say that you react to the child's positive behaviors?

Could you please tell me about your child's learning style and whether you feel that this has changed over time? _____

Are there times where you feel frustrated with how your child is progressing? If so, could you please tell me about those times? _____

Are there times when you ever feel disappointed in your child's behavior? If so, could you tell me about these times? _____

Supports

Could you please tell me about any supports in your life (such as family or friends)?

Would you mind telling me about whether the diagnosis of ASD impacted your family and the impact it had, if indeed it had one? _____

Treatment

Could you please tell me about when treatment was commenced?

Would you please tell me what types of interventions were used with your child?

Was there any particular reason that that method of treatment/intervention was used?

How aware were you of the interventions available for ASD? _____

Could you tell me about any treatments or services that your child is currently receiving?

Would you mind telling me what about your views on the successfulness of the treatments? _____

How much time was/is invested in treatment interventions (hours per week)?

School history

Could you please tell about what types of things were done to prepare your child for entering school? _____

Would you mind telling me about your child's school? _____

Could you please tell me about what types of supports the school has or had in place for your child? _____

Could you please tell me about your child's academic abilities and challenges, and whether you have witnessed any changes in either of these?

Is there anything else that you would like to discuss with me today?

Appendix G: Recent Life Events Questionnaire (RLE)

Appendix G
Recent Life Events Questionnaire

Listed below are a number of life events. Please read each item carefully and indicate whether or not each event has happened to you in the past year. Please check the yes box if the event has occurred. Check the still affects me box, if the event is still having an effect on your life.

Event	Yes	Still affects me
Have you had a serious illness or been seriously injured?		
Has one of your immediate family members been seriously ill or injured?		
Have any of your close friends or other relatives been seriously ill or injured?		
Has any of your immediate family died?		
Have any of your close relatives or close friends died?		
Have you separated from your partner (not including death)?		
Have you had any serious problems with a close friend, neighbor, or relative?		
Have you or an immediate family member been subject to serious racial abuse, attacks, or threats?		
Have you or an immediate family member been subject to any abuse, attack, or threat, perhaps due to you or someone close to you having a disability of any kind (mental health, learning disability)?		
Have you or an immediate family member been subject to any other form of serious abuse, attack, or threat?		
Have you or your partner been unemployed or seeking work for more than one month?		
Have you or your partner been fired from your job or made redundant?		
Have you had any major financial difficulties?		
Have you or an immediate family member had any police contact or been in a court appearance?		
Have you or an immediate family member been burgled or mugged?		
Have you or another individual who lives with you given birth?		
Have you or another individual who lives with you suffered from a miscarriage or had a stillbirth?		
Have you moved house (through choice)?		
Have you moved house (not through choice)?		
Have you had any housing difficulties?		
Have you had any other significant events take place? Please Specify:		

Appendix H: The Child Improvement Locus of Control Scale (CICL)

Appendix H

CICL

Please rate whether you agree or disagree with the following statements, which tap into beliefs about your child's improvement.

If my child decided to get better, he/she will.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My child's well-being is beyond anybody's control.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

Professionals keep my child from getting worse.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My efforts at working with my child will probably result in him/her getting better.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

If it is meant to be, my child will get better.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

Where my child is concerned, the professional experts know what is best.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

No one can change my child's destiny.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

If my child decided to, he/she could be doing a lot better.

1	2	3	4	5	6
Strongly	Disagree	Somewhat	Somewhat	Agree	Strongly

Disagree		Disagree	Agree		Agree
When I work harder at helping my child, he/she seems to do better.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

God will decide what will happen to my child.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My child's progress depends mostly on what he/she does.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

It takes professional knowledge and skill to help children like mine.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My child's well-being depends on me.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

In order to get well, my child has to make up his/her own mind about getting well.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My child's well-being cannot be influenced by anyone.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

If my child gets proper professional care, he/she is more likely to get better.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

Only God can help my child.					
1	2	3	4	5	6

Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
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The things I do at home with my child are an important part of his/her recovery.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

No one's effort can change my child.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My child's progress depends on what experts can do.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My child's efforts to improve will eventually help him/her.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My child's well-being is in God's hands.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

The things I do for my child can make all the difference in his/her improvement.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My child is the master of his/her own destiny.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

Whether my child gets better or worse is just a matter of fate.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

My efforts are the most important things in helping my child get well.

1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

Without professional help, my child probably would not get better.					
1	2	3	4	5	6
Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree

Appendix I: The Parental Self-efficacy in the Management of Aspergers Syndrome
Questionnaire

Appendix I

Parental Self Efficacy

Please rate the amount of confidence you have had in dealing with the following behaviors that have occurred during the past month.

How much confidence do you have?

0 **1** **2** **3** **4** **5**
None Slight Some Moderate Mostly Completely
Confident

Behavior	Occurred in the past month? (Yes/No)	Rate confidence in ability to manage behavior (0-5)
When you have become agitated or distressed by certain sounds		
When your child follows routines rigidly		
When your child insists things be done her way		
When she misinterprets the motives of others		
When she can only see one way to do things		
When she does not make or maintain eye contact		
When your child lacks empathy		
When she does not take turns in conversation		
When she finds criticism or losing at a game intensely distressing		
When your child interrupt conversations		
When she talks excessively about a particular topic		
When she makes stereotypical movements when excited or distressed, e.g. rocking, flapping, facial movements		
When she engages in routines/rituals, e.g. lining things up		
When your child spends an excessive amount of time engaged in a particular interest or activity		

Appendix J: Review of Cumulative Record File Form

Appendix J

Review of Cumulative Record File

Did the child have any assessments or specific interventions prior to beginning school?

Review of school history and yearly anecdotal records

Grade Primary: Dates: _____ Days Absent: _____

Grade One: Dates: _____ Days Absent: _____

Grade Two: Dates: _____ Days Absent: _____

Grade Three: Dates: _____ Days Absent: _____

Did the child repeat any grades? _____

Is the child in an inclusive classroom? _____

Are the reports consistent across years? _____

Are there any new concerns? _____

Is there a history of particular difficulties or strengths? _____

Assessment and Intervention Reports on File:

Primary: _____

Grade One: _____

Grade Two: _____

Grade Three: _____

Appendix K: Teacher Interview Questionnaire

Appendix K

Teacher Interview

Academic Placement Review:

Grade the teacher taught the child: _____

Could you tell me how long you have known the child and in what capacity?

How much contact have you had with the child's family? _____

Could you tell me about your classroom structure: (highly structured or flexible, assigned or flexible seating, in rows or groups, where did the child seat, number of students)

Assistants:

Were any assistants available for your classroom: _____

Was the child designated an assistant? If so, what type and how frequently?

Child's Abilities and Skills Assessment:

Could you tell me about the child's academic functioning?

Could you tell me about the child's general ability (general knowledge about the world)?

Could you tell me about the child's self-help skills (ex. tying shoe laces)?

Would you please tell me about the child's motor skills (fine and motor)?

Could you please tell me about the child's social skills/peer relationships?

Would you say that any changes were witnessed in the previously discussed abilities?

Teaching Approaches:

Could you tell me about the teaching approaches used with the child?

Have you worked closely with many children with autism? _____

Were any of the following behaviors witnessed when working with the child?

- A resistance to change? _____
- Aggressive behaviors? _____
- Poor communication? _____
- Obsessive or repetitive behaviors? _____
- Poor attention abilities? _____

Did any changes occur in the previously discussed behaviors?

Did you observe any challenging behaviors displayed by the child? If so, what were these behaviors and how were they dealt with? _____

Were any changes in the challenging behaviors witnessed?

Appendix L: Principal Interview Questionnaire

Appendix L

Principal Interview

How long have you known this child and in what capacity?

Could you please tell me a bit about the child?

Could you tell me about the interventions in place for children with autism and which the child is currently or has previously benefited from?

Are you aware of outcome goals for this particular child?

Would you say that she has met the outcome goals?

Appendix M: Classroom Observation Form

Appendix N: Playground/Home Observation Form

