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Stress and Coping in Families of Children with Autism Spectrum Disorders

By

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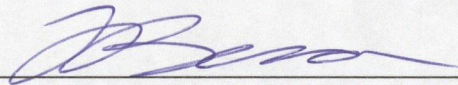
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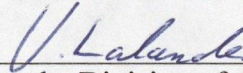
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Stress and Coping in Families of Children with Autism Spectrum Disorders" submitted by Susan G. Hendrickson in partial fulfillment of the requirements for the degree of Master of Science.



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ABSTRACT

The current study examined perceptions of stress and coping in parents of children with Autism Spectrum Disorders. A total of 36 families completed questionnaires about child behaviours, parenting stress, overall stress and coping behaviours prior to a period of intervention involving either a half or full day program. Eighteen families completed the same checklists following an average of nine months of programming. ANOVAs were completed to determine group differences at pre and post-test. No significant differences were noted initially; post-test results indicated a significant difference with respect to parenting stress, $F(1,18) = 5.462, p < .05$. Specifically, parenting stress decreased in parents of children accessing half-day programs, and increased in parents of children attending full-day intervention programs. Additionally, when correlation analyses were performed on differences in parenting stress and child behaviour scores over time, a moderate correlation ($r = .40, p < .1$) was noted when the combined groups were examined. These results suggest that parents of children with ASD accessing the full-day intervention program are not reporting the reductions in parenting stress expected. Also, although a correlation was found between a decrease in child behaviours and a decrease in parenting stress, this result is not significant within sub-groups of parents examined. More research into the specific sources of parenting stress within the groups involved is recommended to better inform intervention efforts.

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CHAPTER ONE

INTRODUCTION

Autism and the spectrum of disorders encompassing it (ASD) are Pervasive Developmental Disorders, affecting 2-6 out of 1000 individuals (Centers for Disease Control and Prevention, 2006). Diagnostic criteria for ASD focus on the existence of significant social and communication impairments, accompanied by restricted or repetitive patterns of interest and behaviours, all occurring in the first few years of life. Qualitative impairments indicative of an ASD diagnosis exist relative to the individual's developmental level, meaning that they are not better explained by an overall cognitive delay.

More specifically, social impairments include delays in the development of peer relationships and the ability to engage in reciprocal interactions. In addition, people with ASD tend not to engage in spontaneous sharing with others through actions such as showing, bringing, or pointing out objects of interest. Communication deficits include a delay or total absence in the acquisition of spoken language, with little to no supplemental communicative behaviour such as gesturing. Rather, they tend to use stereotyped or repetitive phrases. Challenges with the reciprocal nature of communication (e.g., conversation) are common. In addition, individuals with ASD tend to have difficulty with the symbolic nature of language and spontaneous pretend play. In addition to the impairments noted, certain restricted, repetitive patterns of behaviour and interests tend to be present. These refer to characteristics such as being preoccupied by interests that are abnormal in intensity or focus (e.g., table legs), adhering strictly to non-functional routines,

engaging in odd motor mannerisms such as hand flapping, or demonstrating a persistent interest in parts of objects (e.g., car wheels).

Additional characteristics such as difficulties with eating, sleeping, anxiety, aggression, self-injurious behaviours, seizure disorder and cognitive impairments are frequently present in individuals with ASD (American Psychiatric Association, 2000). Given the complexity of these behaviours, assessment of an ASD involves a multidisciplinary team providing input across multiple areas of development, relying on observation, parent feedback and standardized assessment.

Historically, our perception of the etiology of ASD has changed considerably. It was originally viewed as having a biological basis. Views then shifted to poor parenting as an explanation. Subsequently, it reverted to being considered a biological disorder with neurological impairment as a hallmark feature. Recent research has resulted in the discovery of some neurological differences between the autistic brain and the non-autistic brain. Current conceptualization of ASD is that it is a multi-causal disorder, where heredity and environment together determine the developmental pathway (Newsom, 1998).

With estimates of prevalence rates of ASD at about 2-6 out of 1000 (CDC, 2006), this cluster of disorders has become a rising concern for individuals involved in diagnosis, intervention, education, medicine and social supports. Medical health professionals are having to acquaint themselves with the disorders, how to best assess them, rule out alternative diagnoses, and look for comorbid medical and psychological conditions such as seizure disorder or depression. Agencies involved in providing supports to parents of children with disabilities are now expected to be knowledgeable regarding the specific

needs of these children and families dealing with ASD. Even popular media have been dealing with the increasing issue, with movies such as *Rainman*, *Mercury Rising*, *Mozart and the Whale*, and *Snow Cake* portraying the lives of individuals with ASD. A look at real life experiences with respect to the stresses of parenting a child with ASD was provided at Sundance Film Festival through the short film *Autism Every Day*. Books, such as *An Anthropologist on Mars* and *The Curious Incident of the Dog in the Night-Time*, attempt to describe the experience of this disorder. Well-known magazines such as *Time* have spotlighted ASD stories, and presented information on intervention approaches. In addition, popular talk shows such as *Oprah*, *Larry King* and *The View* have all dedicated entire shows to discussing ASD. Actors have recently disclosed their personal stories of raising a child with ASD (e.g., Jenny McCarthy, Holly Robinson). Through these popular media sources, public awareness of ASD has become more widespread.

With increased reported rates of ASD also comes the need for adequate educational placements. Educators are expected to be knowledgeable about a wide variety of special needs as integration into regular education classrooms has become common practice over the last couple of decades (Corsello, 2005). However, given the unique and diverse needs of children with ASD, many parents are demanding placements that are specialized. A variety of treatment programs exist for intervention with this population of individuals, typically focusing on early intervention (before the age of 5 years; Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris & Handleman, 2000; Harris & Weiss, 1998; National Research Council, 2001; Sheinkopf & Seigel, 1998). Interventions can be comprehensive, following a set curriculum plan, or eclectic incorporating a variety of

approaches. Research into program evaluation concludes that no one program is superior to another. Studies, rather, focus on common qualities across programs that appear to contribute to best possible outcomes (Corsello, 2005; Dawson & Osterling, 1997; Stahmer, 2007).

These commonalities in best practice for intervention include: early intervention; intensive treatment (upwards of 20 hours per week); regular assessment procedures; generalization of acquired skills; structured learning environments; intensive intervention training for program staff; focus on sustained interactions with the child; program goals which match a child's needs profile; clear lesson content focusing on areas impacted by ASD; and parent involvement (Dawson & Osterling, 1997; Mash & Barkley, 1998; National Research Council, 2001; Stahmer, 2006). In order to access programs encompassing these quality indicators, parents must be aware of their children's needs, the realm of possible programs, which would best match their children's and family's needs, and how to access funding. There are agencies which can assist parents in program selection, but ultimately, choosing a service provider is the parents' responsibility.

Raising children with typically developing needs brings certain stresses. Worrying about the well-being of children and dealing with the many everyday "hassles" that raising a child brings with it can build into significant levels of overall stress (Crnic & Booth, 1991; Crnic & Greenberg, 1990). Parents tend to consider their ability to parent competently, particularly in light of changing parenting practices over the years as traditional strategies such as spanking or relying on punishment are no longer considered acceptable disciplinary practice in many countries (Gracia & Herrero, 2008). Parents also

tend to think about how to protect their children from environmental influences such as peer pressure, drug use, sexual abuse or disease (Hines & Paulson, 2006). In addition to child-specific stresses, parents must juggle the responsibilities of a job, a spouse, and the financial and practical management of a household (Webster-Stratton, 1990). Because of our mobile society, parents are often not geographically close to their extended family to rely on them for support (Webber & Boromeo, 2005).

Raising a child with an ASD has been shown to be more stressful than raising a typically developing child (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Bouma & Schweitzer, 1990; McCubbin, Cauble, & Patterson, 1982; Tomanik, Harris, & Hawkins, 2004). If we define overall stress as something that occurs when perceived threat is high and perception of ability to cope is low (Lazarus & Folkman, 1984), we can see how parents of children with ASD would experience high levels of overall stress. Their children's special needs represent the "threat" and many parents feel ill-equipped to cope with those special needs. In fact, research suggests that two-thirds of mothers of children with developmental delays experience overall stress levels in the clinically significant range (Baker-Ericzen et al., 2005; Tomanik et al., 2004). Activities considered routine and simple by some families such as going to a restaurant for dinner can be stressful for a family with a child with ASD. Challenges can include behavioural outbursts as the noise and activity level of the restaurant may over-stimulate the child with ASD; inability to order something the child can eat, as children with ASD typically have significantly limited food options; anxiety on the part of the child having to deal with a novel setting, people and expectations.

Parenting a child with ASD has also been deemed more stressful than parenting a child with any other developmental disability (Bouma & Schweitzer, 1990; Fisman, Wolf, Ellison, & Freeman, 2000; Gray, 2006; Holroyd & McArthur, 1976; Homes & Carr, 1991; Siklos & Kerns, 2006). Characteristics inherent to the diagnosis itself (e.g., uneven cognitive profiles, lack of adaptability and responsiveness, disruptive behaviours and long-term needs) have been shown to contribute to these increased stress levels (Donenberg & Baker, 1993; Koegel, Koegel, & Surratt 1992; Moes, 1995; Tomanik et al., 2004). Additional factors such as public perception of ASD, the complexity of the diagnosis and additional life stresses such as increased marital discord also contribute to increased parenting stress (Koegel et al., 1992; Moes, Koegel, Schreibman, & Loos, 1992; Rivers & Stoneman, 2003; Rodrigue, Morgan, & Geffken, 1990; Schwichtenberg & Poehlmann, 2007). Many parents report the uncertainty of their children's prognosis as a stress producer (McCubbin et al., 1982), as a diagnosis on the autism spectrum does not necessarily predict their children's functioning as an adult. Factors such as IQ, expressive language skills and adaptive functioning are more helpful in predicting outcomes for children with ASD, but as diagnoses are made with younger and younger children, assessment of those skill sets are not always accurate or stable over time.

Program selection can also be stressful for parents as they worry whether or not they have made the right decision. This can be particularly stressful in light of the importance placed on early intervention, creating a sense of a time limit for the greatest impact. Intensive home-based programs have been implicated in reduced parenting stress, although the effect is mitigated by initial stress levels prior to intervention and the

expectations of the program itself (Newsom, 1998; Schwichtenberg & Poehlmann, 2006). Decreased parent stress can also increase intervention efficacy (Robbins, Dunlap, & Plenis, 1991), demonstrating the importance of considering parenting stress levels and coping abilities both in the selection of a program, and in program evaluation.

Coping behaviours or strategies refer to the ways in which people attempt to manage stress (Lazarus & Folkman, 1984). Coping behaviours that tend to reduce the experience of stress, such as turning to social supports, or engaging in physical fitness activities (Curlette, Aycock, Matheny, Pugh, & Taylor, 2006) are referred to as effective strategies. Ineffective approaches are seen as those that lead to further exacerbation of the stress response, for example, alcohol or drug use, or risk taking behaviours (Bieliauskas, 1982; Curlette et al., 2006). Just as parents of children with ASD differ from parents of non-ASD children in their experience of stress, overall differences appear to exist between the coping strategies of parents of children with ASD and parents of non-ASD children. Primarily, it appears that parents of children with ASD tend to use less constructive behaviours such as escape and distancing more frequently than parents of non-ASD children (Sivberg, 2002).

Access to appropriate levels of social support is thought to reduce the experience of stress and increase the ability to cope in parents of children with ASD (Siklos & Kerns, 2006; Wolf, Noh, Fisman, & Speechley 1989). This is a highly important coping resource for these parents as many of the more traditional methods of stress reduction such as spending time alone with a spouse or friend, exercising, or meditating are not always available to parents of children with ASD due to difficulty accessing adequate respite care, time constraints and financial concerns. Although parents of children with ASD report

increased access to agencies among their coping strategies, many factors can offset the positive results. Factors such as the number of agencies involved in service provision, and the quality and flexibility of those supports can affect the outcome of the coping strategy (Brinker, Seifer, & Sameroff, 1994; Bristol, 1984; Konstantareas & Homatidis, 1989).

Purpose of the Study

The purpose of this study is to evaluate the effect of two distinct types of early intervention programs provided in Calgary on parents' perceptions of stress and coping. Parents' experiences of general stress, parenting stress, and coping patterns are evaluated in two groups of parents accessing half or full-day intervention programs. Comparisons are made to determine any initial differences between the groups, to ensure that any post test differences are not due to pre-existing group differences. Stress and coping levels are again evaluated following a period of intervention. Finally, the relationship between parenting stress and child behaviours was determined to see whether the reduction of child behaviours was correlated to a reduction in parenting stress.

Overview of Thesis

Chapter two will provide a review of research relevant to understanding ASD and prevalent intervention programs. Differences in parenting stress and coping between parents of children with ASD and parents of non-ASD children are presented, in addition to how those differences affect intervention efficacy. In Chapter three, the participants, specific intervention programs and measures used are fully described. Chapter four reviews the results from the statistical analyses used in the study, and chapter five presents

a discussion of those results, along with implications for practice, and limitations of the study.

CHAPTER TWO

LITERATURE REVIEW

This chapter begins with an overview of Autism Spectrum Disorders including diagnostic criteria, prevalence, etiology and assessment. Current literature on interventions for children with ASD is discussed next, followed by guidelines for best practice for intervention. Next, research into stress and parenting a child with ASD is presented, along with a discussion about parenting stress and treatment programs. Coping strategies in general, and then those specific to parents of children with ASD are presented. The chapter concludes with an outline of specific research questions examined within this study.

Autism Spectrum Disorders

Pervasive Developmental Disorders encompass a group of diagnostic categories characterized by a range of qualitative impairments primarily in the areas of social interaction, communication and symbolic play skills, as well as the presence of stereotyped behaviours and repetitive or restricted patterns of behaviour and interest (APA, 2000; New York State Department of Health, 1999; Newsom & Hovanitz, 1997). These categories include Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, Rett's Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). All are dependent on the presence of characteristics in early childhood, occurring across all environments, and persisting across the lifespan of the individual. More recently, the term Autism Spectrum Disorders or ASD (Wing, 1988) has come into regular usage to refer to this cluster of disorders, as behaviours and characteristics are seen as occurring along a

continuum or spectrum of severity or intensity. The term ASD will be used throughout this paper to indicate a diagnosis on the spectrum.

Severe social impairment can refer to a multitude of observed characteristics. Children with ASD seldom supplement or modulate social interactions with nonverbal behaviours such as eye contact, gestures or directed facial expression, particularly in an integrated fashion (APA, 2000; Newson & Hovanitz, 1997). Social interactions initiated by children with a diagnosis on the spectrum are more likely to involve having their needs met (e.g., to request an item), than to occur solely for a social purpose. Frequently, interactions lack social reciprocity and look rather one-sided. A lack of initiation of, or response to, joint attention has also been identified as an early characteristic seen in the ASD population (Mundy, 1995). In addition, peer relationships are not developed to the level expected by the child's cognitive abilities (APA).

With respect to communication impairments, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR; APA, 2000) outlines the following characteristics: delay or lack of spoken language, as well as supplemental communicative intent, difficulty in initiating and sustaining a conversation, the use of stereotyped, idiosyncratic or repetitive phrases or language (e.g., using a phrase from a movie in a rote manner to mean something other than what the words themselves imply), and a lack of spontaneous pretend play.

The third area of impairment includes behaviours such as intense preoccupation with certain interests (such as trains), carrying out non-functional rituals (such as having to open and close all cabinet doors upon entering the kitchen), stereotyped motor movements (such

as hand flapping or body posturing), and a persistent interest in parts of toys or objects (such as repetitively spinning the wheels on a toy car).

In addition to the diagnostic criteria laid out in the DSM-IV-TR manual (2000), characteristics such as unusual responses to sensory stimuli, difficulties with eating, sleeping, anxiety, aggression, self-injurious behaviours, seizure disorder and cognitive impairments as measured by traditional standardized assessments exist in conjunction with the disorders, all contributing to the challenges of raising and intervening with individuals with ASD. Indeed, the breadth and depth of areas of impairment (socialization, communication and play skills), behavioural challenges and associated features, are likely to exert significant stress on parents of children with ASD.

In general, 4 to 5 times more boys than girls are affected by ASD, with girls being more likely to display significant cognitive deficits. This significant gender difference likely reflects a sex-linked inheritance pattern, although the specific genetic pathway remains unclear (Newsom & Hovanitz, 1997). Some studies from the United States have indicated that increased risk for the development of ASD was associated with being male, having multiple births, being born to black mothers and increased maternal age and education (Croen, Grether, & Selvin, 2002; Croen, Grether, Hoogstrate, & Selvin, 2002; Hillman, Kanafani, Takahashi, & Miles, 2000). Other studies indicate no significant differences in prevalence rates based on race (Yeargin-Allsop et al., 2003; Powell et al., 2000).

Prevalence

There has been considerable discussion in the literature and in popular media regarding the possible rise in prevalence rates of ASD, often referred to as the “autism epidemic”. Rates for Autistic Disorder are reported in the DSM IV-TR as 5 per 10, 000 people (APA, 2000), and rates for ASD overall as 2-20 per 10, 000 (APA). However, the Centers for Disease Control and Prevention recently released a statement indicating ASD rates of 2-6 out of 1000 (2006), which reflects a higher prevalence. According to a document released by the Canadian Parliamentary Information and Research Service, rates of 1 in 147 were found in a study conducted at Montreal Children’s Hospital (Norris, Pare, & Starky, 2006). The United States Government Accountability Office indicated that the number of children with an ASD diagnosis served under the Individuals with Disabilities Education Act increased by more than 500% between 1992 and 2002. Canadian data also reflect a sharp increase in the number of school-aged children with ASD (Statistics Canada, 2003). There is considerable debate as to whether the prevalence of ASD is actually on the rise, or if increased awareness, more specific diagnostic tools or over-diagnosis could explain the changes. Inflated rates could also be explained by “diagnosis shifting”, where ASD is being more accurately distinguished from alternate diagnoses such as Mental Retardation. Whatever the reason, measured prevalence rates of ASD appear to have increased (Chakrabarti & Fombonne, 2001; Fombonne, 2002; Stahmer 2007), highlighting the need for adequate supports to individuals, families, communities and educational settings.

Etiology and History of ASD

Our understanding of ASD and its etiological underpinnings has alternated between nature and nurture explanations, settling currently on a multi-causal theory. Kanner (1943) was the first to use the phrase “early infantile autism” to describe a group of 11 young patients who presented with self isolation, insistence on sameness, little to no language or persistent echolalia, idiosyncratic speech, and literal thinking patterns. Kanner saw the syndrome as arising from an innate deficit in the ability to form and sustain social relationships, and spent most of his time with his patients studying their presentation, rather than on intervention efforts. Asperger (in Frith, 1991) published a paper describing children born with what he referred to as “autistic psychopathy”; these children were similar to Kanner’s sample, but lacked the significant cognitive and language delays. Asperger noted difficulty with empathy, social interactions, reciprocal conversation, fixations with specific topics, and clumsy movements. His work was largely unrecognized in English speaking circles until British researcher Lorna Wing published a paper referring to children with “Asperger’s Syndrome” (1981), a diagnostic category that was added to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, in 1994. Upon introduction of this disorder into the diagnostic manual, conceptualization of ASD shifted to include those with higher functioning skill sets, focusing more on social impairments as the core deficit area.

Conceptualization shifted from this initial biological model to viewing ASD as arising from poor parenting (Bettelheim’s study as cited in Newson, 1998), where “refrigerator mothers” who were cold and unloving caused their children to “retreat” into their own world. As a result of this re-conceptualization, intervention efforts began drawing

from psychodynamic theory, using strategies such as removing children from their parents, using play therapy to attempt to work through the psychological “damage”, and ongoing psychotherapy for both children and parents. Residual echoes from this poor nurturing paradigm appear to still exist, as parents of children with ASD report increased guilt in regards to their child’s diagnosis (Newsom), possibly contributing to levels of elevated stress.

ASD began to be viewed as a disorder with a biological and neurological basis again following Rimland’s (1964) extensive review of research published on individuals with an Autism diagnosis. As this belief gained credence, interventionists began to focus their efforts not on “curing” the underlying cause of Autism, or changing the parent-child dynamic, but on mitigating the behavioural presentations demonstrated by these individuals. Further, pursuant to the conceptualization of ASD as a behavioural disorder, Lovaas (1987), a clinical psychologist, used the basic principles of behaviour modification (prompting, shaping, reinforcing and punishing) to reduce maladaptive behaviours such as self stimulatory or aggressive behaviours and teach socially appropriate behaviours such as eye contact and answering questions, through applied behaviour analysis (ABA) programming.

The conceptualization of ASD as primarily an organic disorder persists to this day, with the DSM IV-TR reporting a genetic component (2000). The chance of having a second child with Autism is 5% if a first child has Autism, and the chance of having a second child with characteristics of Autism (e.g., social or communication deficits) is 25%. Twin studies have revealed that there is a 60% risk for the development of Autism in identical twins, a

12% risk for PDD-NOS, and a 16% risk for social or cognitive problems. This indicates that although there is a hereditary component, there are additional factors leading to the development of the disorder.

Some findings suggest ASD is a neurological impairment. Autopsy studies of the brains of individuals with ASD have indicated some differences from the typical population (Courchesne, Carper, & Akshoomoff, 2003; Courchesne, Redcay, & Kennedy, 2004; Palmen, Van Engeland, Hof, & Schmitz, 2004; Penn, 2006). Brain structures believed to be implicated in the development of the disorder include the limbic system (social and communication deficits), the hippocampus (memory), the amygdala (emotional processing), basal ganglia, forebrain or prefrontal cortex (executive functioning including working memory, planning, inhibition, and attention, as well as affecting theory of mind), the cerebellum (balance and motor coordination and planning), cerebral cortex, the corpus callosum, and the brain stem (Courchesne et al., 2004; Penn). In addition, brain weight studies have indicated differences in brain size and growth patterns in that of the autistic brain as compared to the brains of typically developing children (Courchesne et al., 2003). Neuropeptides and neurotransmitters have also been implicated in the neurology of the disorder (Palmen). Although these differences have been reported in the research, it is important to note that they exist as between group differences and are not clear markers for the disorder. This means that the brains of people with ASD as a whole show significant differences from the brains of people without ASD; however, not all differences exist in all ASD brains examined during autopsy studies. These findings, in conjunction with the heritability patterns, point toward an underlying neurological basis for the disorder.

The 60% genetic correlation between identical twins developing ASD indicates that some other factor is operating to either protect from or contribute to the development of the disorder. Alternative theories (so labeled due to their lack of both empirical support and acceptance in mainstream ASD research) hypothesize that ASD could be a result of exposure to specific toxins, such as thimerosal in Measles, Mumps and Rubella (MMR) vaccinations (Doja, 2006). Currently, researchers refer to ASD as having a multi-causal pathway, where different genetic predispositions and unique experiences contribute to the single outcome of ASD (Newsom, 1998). Overall, there appears to be no consensus on an underlying cause of ASD, although we do know that neurological differences have been found in autopsy studies of individuals with ASD; that there is a heritability factor; and that environmental factors may contribute.

Assessment

Because ASD cannot be detected through genetic markers, specific neurological differences or other biological means, assessment relies on observation of the behavioural characteristics or deficits outlined above. Best practice for assessment requires a multi-disciplinary team of professionals experienced in the area of ASD, observation of the child in multiple settings, and an accurate history from the parents (New York State Department of Health, 1999; Newsom & Hovanitz, 1997). Tools such as the Modified Checklist for Autism in Toddlers (M-CHAT) exist to assist professionals screen children who may need referral for further evaluation (Eaves, Wingert, & Ho, 2006). Formal assessment by the multi-disciplinary team should include medical consultation, to rule out medical reasons for the presentation of symptoms; cognitive or developmental evaluation to rule out Mental

Retardation or any other developmental disorder as a more accurate diagnosis; adaptive functioning testing to complement the cognitive profile; and the use of specific diagnostic instruments designed to look at core criteria for ASD (Newsom & Hovanitz). Current research suggests that the use of two such diagnostic tools, the Autism Diagnostic Interview – Revised and the Autism Diagnostic Observation Schedule, produce greater diagnostic sensitivity and specificity when used in combination than on their own (Risi et al., 2006). Diagnosing a child as having an ASD is a complex process, relying on information from multiple sources and a variety of assessment tools examining multiple areas of development.

Interventions and Children with ASD

Intervention models for children with ASD are diverse, and differ according to their theory of the underlying cause of ASD. A primary distinction is made in the literature between early as compared to later childhood interventions (i.e., before or after age 5 years). Research into adolescent and adult interventions is limited, likely because early intervention has been empirically shown to produce greater gains on outcome measures for children with ASD (Fenske et al., 1985; Harris & Handleman, 2000; Harris & Weiss, 1998; National Research Council, 2001; Sheinkopf & Seigel, 1998).

Common categories for interventions include traditional behavioural (such as Lovaas, Princeton and Verbal Behavior programs); naturalistic behavioural (such as pivotal response, incidental teaching, and positive behaviour support models); and developmental (such as the Denver model, Greenspan's DIR model, SCERTS, Hanen and TEACCH models). Currently, no one approach is deemed superior to others (Corsello, 2005;

Simpson, 2005; Stahmer, 2007). In addition to these categories are those referred to as eclectic approaches (drawing upon strategies from a variety of more comprehensive programs), and “alternative” interventions (such as gluten and dairy free diets, secretin injections and facilitated communication). Programs can also reflect the population being targeted, as with peer-mediated interventions and parent training. The diversity of available programs stems from the diversity of theories explaining ASD, and each has its own strengths and weaknesses. These program characteristics are discussed next.

Traditional Behavioural

Traditional behavioural models tend to consist of applied behaviour analysis (ABA) programs, relying on principles of operant conditioning and behavioural learning theory. Operant conditioning refers to the process of changing behaviours using shaping, chaining, discrimination training, where behaviours approximating those desired are reinforced, steps are taught in sequence then chained together, and children learn to distinguish between different verbal or visual cues. Behavioural learning theory refers to the idea that the frequency of a behaviour can be increased or decreased through either reinforcement or punishment immediately following the behaviour. These programs also employ discrete trial methodology where skills to be learned are broken down into component steps and taught one at a time, often in conjunction with mass trial methodology so that there are repeated experiences to learn the skill. Programs tend to be one on one, intensive (Maurice, 1996), and occur primarily in home, although they can be implemented in any setting.

Many strengths have been identified with traditional behavioural approaches. Children often make gains quite rapidly initially, as the connection among antecedents,

behaviours and consequences are emphasized for the child (Maurice, 1996). The discrete trial component can assist in making abstract behavioural and social skills more concrete. For example, a non verbal child receiving positive feedback or reinforcement after completing eight behavioural actions in a row may not intuitively understand which behaviour specifically earned access to the reinforcement, whereas with discrete trial methodology, reinforcement would occur immediately following the desired behaviour. This pattern would be repeated until the child understood clearly what the expected behaviour was. ABA programs follow a clear curriculum with a goal sequence and developmental skill hierarchy, and are, therefore, considered easy to implement. ABA programs recognize that parent participation is critical to constant intervention, and typically include parents as interventionists. In addition, a large body of research has been devoted to this area of intervention, thus providing more information than is available for many other programs.

There are many criticisms to traditional behavioural interventions. They can be very expensive for families depending on the region they live in, and for governments who may be involved in cost sharing. In Canada most provincial governments pay a portion of the associated costs for home based programs (Norris et al., 2006), but parents are responsible for the balance. Due to the intensity inherent in the programs, they are highly time consuming for families to implement, particularly while maintaining additional family and employment obligations. Given that behaviours are taught in discrete steps it becomes a daunting task to teach the full range of individual missing skills. Another criticism is that children may be learning rote skills in a matter more suited to animal training than to the

human socialization process. That is, they are given a direction, compliance is ensured, and then reinforcement is provided. Additionally, because skills tend to be taught in isolation of a corresponding social context, they do not always translate to new environments, and generalization must be targeted separately. For example, learning to say, “hi, my name is Susan” is functional, but only when taught to be used appropriately, in the context it is needed, with typical intonation, accompanied by the socially acceptable non-verbal skills. Finally, in traditional behavioural models it is typically the interventionist, not the child, who initiates the lesson, thus creating a respondent pattern of behaviour as opposed to a more natural reciprocal pattern. More contemporary behavioural intervention programs have evolved as a result of these criticisms.

Ferster (1961) conducted seminal research using behavioural principles with children with ASD, based on the belief that parents of children with ASD provided little to no attention and social praise resulting in the children failing to link parental attention with social praise. Lovaas’ landmark longitudinal study (1987) reported that 47% of participants in his program had “recovered”; and an additional 42% had demonstrated significant gains. This paper led to the idea of a “cure” or recovery as a possibility for a significant percentage of children with ASD (although Smith and Lovaas later wrote a retraction for using the term “recovered” in the original study; 1997). Although pursuant research has indicated gains associated with ABA interventions, similar levels of recovery and clinically significant gains have not been replicated (Smith, Groen, & Wynn, 2000; Shea, 2004; Smith & Lovaas), and further studies are recommended in order for original claims to be substantiated (McGahan, 2001).

Naturalistic or Contemporary Behavioural

Naturalistic or contemporary behavioural models emerged from growing criticisms of the more traditional applied behaviour analysis programs. Approaches such as pivotal response training are used in these models, where the belief is that teaching core behaviours or skills will affect change indirectly in other areas of development. For example, if a variety of social skills are missing from a child's repertoire, pivotal response training programming would require going back through developmental sequences and arriving at an early "pivotal" skill such as joint attention to teach. Incidental teaching is also utilized, whereby skills are taught as opportunities arise. Another approach incorporated into these models is the use of positive behaviour supports, where the emphasis is placed on proactively supporting the development of adaptive skills rather than on modifying maladaptive ones. Intrinsic to these programs is the idea of teaching in natural settings, embedding reinforcement into activities, and allowing for child initiation, all of which constitute strengths to this approach (Corsello, 2005). This differs from the more traditional behavioural models where teaching would likely occur in a separate room, with controlled access to toys and materials, and where behaviours deemed inappropriate would be actively extinguished through the provision of consequences or punishments. Criticisms of the naturalistic behavioural model target the fact that certain skills are difficult to teach using single methods of instruction, and that improvement in areas such as joint attention and symbolic representation in this manner have been limited (Corsello). Some positive outcomes have been noted in response to teaching vocabulary development, commenting, answering and asking questions and overall functional communication aimed at reducing

maladaptive behaviours (Horner et al., 1990; Koegel et al., 1992; McGee, Morrier, & Daly, 1999).

Developmental

Developmental interventions are based on cognitive developmental models of learning, whereby children learn through interaction with their environment and proceed through distinct stages of cognitive growth. Developmental models tend to view ASD as an organic disorder, whereby innate individual differences interfere in a child's ability to learn from the environment. These differences include sensory processing difficulties or impairments in executive functioning (Greenspan & Wieder, 1997; Newsom, 1998). Approaches include modifying the environment to accommodate a child's individual needs, following the child's lead to ensure that activities are motivating and meaningful for the child, learning through play and integrating lessons into affective-based social interactions. Strengths of the developmental models include recognition of individual differences in children with ASD, motivation and reinforcement are built into activities so that external reinforcement becomes less necessary, lessons are taught within context reducing the need for generalization lessons, and parents are typically actively involved in program delivery. A typical session may involve the interventionist in the child's home or community setting, watching the parent interacting with the child and providing immediate feedback with respect to what the parent could try in order to extend the length and quality of their interactions. Criticisms of developmental interventions include the level of skill necessary on the part of the interventionist to effectively embed learning trials into play, and the difficulty in balancing following the child's lead with teaching a wide variety of skills

(Corsello, 2005). Research has indicated some support for the use of developmental approaches (Greenspan & Wieder; Ozonoff & Cathcart, 1998), although, as with most approaches, further research is recommended to determine specific factors of the program that are most predictive of positive outcomes.

Eclectic

Eclectic interventions draw on approaches from a variety of programs, but do not follow one complete comprehensive program philosophy. For example, a program could incorporate aspects of both behavioural and developmental models, while also incorporating peer mediation as a mode of treatment delivery (Erba, 2000). Programs may implement approaches from general educational models such as providing an enriched learning environment and capitalizing on teachable moments, and from developmental disabilities research. For example, many operate in integrated classroom settings, use visual supports, adapt the environment and incorporate developmentally appropriate practice. In addition, many eclectic programs draw on strategies designed for use with children with ASD, such as the Picture Exchange Communication System (Bondy & Frost, 1994) or social stories (Gray & Gatand, 1993). Strengths of these approaches are that they are designed to meet the individual needs of the child, and that strategies can be implemented in home, school and community settings. However, due to the fact that interventionists have to be well schooled in a variety of techniques rather than just one, finding well trained professionals can be challenging. Because eclectic models do not follow a set curriculum, they often rely solely on the experience and expertise of the professionals involved, meaning that programs for different children may look very different. This has

ramifications for measuring program outcomes as there is no one overriding treatment paradigm being followed. Two studies reported significant differences between children involved in eclectic models and controls, suggesting some evidence for the use of this approach (Ozonoff & Cathcart, 1998; Panerai, Ferrante, & Zingale, 2002).

“Alternative” Interventions

Alternative interventions are those not supported by empirical evidence, or that have been proven ineffective in repeated studies, and they are not unique to the ASD population (Simpson, 2005). An example of such an approach geared for non-verbal people with ASD is facilitated communication. In facilitated communication, the individual is provided with a typing device, and a facilitator uses touch prompts or light guidance to help the person initiate the motor actions necessary for typing. The premise of facilitated communication is that by assisting the individual with motor planning deficits in typing one could “tap into” the hidden talents and thoughts of non-verbal people with ASD (Umbarger, 2007).

Criticisms shortly arose that the facilitator, not the person with the disability, was guiding the typing of messages (Newsom, 1998). Auditory integration training is another intervention deemed to have no empirical support. In fact, the American Speech-Language-Hearing Association has recommended against using facilitated communication and auditory integration (Umbarger). Randomized control trials found no evidence of efficacy for the use of secretin injections for remediation of ASD symptomology (Esch & Carr, 2004; Sturmey, 2005), or for dietary interventions (Elder et al., 2006). Chelation is a recognized medical intervention for people suffering from heavy metal poisoning involving the extraction of the heavy metals from the body. It has also been proposed as a treatment

for ASD on the basis that exposure to thimerosal, a mercury-based preservative found in MMR vaccinations, is a root cause of ASD. However, the process is considered potentially dangerous, and became controversial following at least one death (Children's Hospital of Philadelphia, 2005). Time, cost, amount of effort and potential risks should be considered when beginning any intervention, but particularly with alternative interventions lacking empirical support.

Although these interventions have failed to demonstrate any proof of efficacy, the argument has been made that within-group differences may exist, pointing to the possibility that for a very small percentage of individuals, a significant outcome such as reduction of aggression or self-stimulatory behaviours may occur. For example, Esch and Carr (2004) suggested that secretin injections might positively impact outcomes for children with ASD who also experience gastrointestinal problems. These types of possibilities appear promising to parents who continue to seek out alternative interventions despite overall evidence to the contrary. Within-group differences speak to the need for research designed to evaluate program efficacy in conjunction with more homogeneous research samples. Diverse groups of children are often compared in treatment samples, rather than controlling for factors such as age, gender or specific diagnoses. For example, children with Asperger's syndrome can differ quite significantly from those with Autistic Disorder with respect to intellectual functioning and level of language skills. In addition, completing research with children with specific clusters of skill deficits or similar co-morbid disorders or medical conditions may provide better input into selecting an appropriate intervention, rather than

trying to find a “one size fits all” approach for a heterogeneous group (Newsom & Hovanitz, 1997).

Peer-Mediated Programs

Peer-mediated interventions are based on the theory that ASD is a social deficit disorder, and that peers, as a critical socialization group for typically developing children should be involved in supporting and teaching children with ASD to develop peer relations. Examples of this type of program include LEAP (Erba, 2000), and Integrated Play Groups (Wolfberg, 2003). Although peer programs may utilize approaches from varying treatment paradigms, all are similar in that peers are involved as mediators. Peers are coached on how to interact with children with ASD; essentially how to “read” their behaviours and respond in ways that facilitate continued interaction. Peer mediated programs can readily be facilitated in inclusionary educational systems, skills are targeted in the situation they are required in, and functional skills such as interactive play are targeted (Erba; Newsom, 1998). However, peer mediation on its own does not address the in-home situation, and requires frequent “booster” sessions for typically developing peers. Studies have demonstrated some effectiveness as defined by an increase in regular educational placements for children with ASD (Dawson & Osterling, 1997; Strain, Kohler, & Goldstein, 1996).

Parent Training

In addition to models that target skill development in children, parent-training programs have been developed to assist parents with a range of issues specific to raising a child with ASD. Family involvement has been identified as one of the key components in

effective early intervention programs (Hurth, Shaw, Izeman, Whaley, & Rogers, 1999). Parent involvement refers to regular participation in training sessions and support groups, making use of consultation from professionals, and being actively involved in goal development (Hurth et al., 1999). Most training programs for parents are available through the child's primary service provider, and include such services as increasing awareness of ASD, coaching and modeling of how to manage challenging behaviours, and how to advocate for services. Levels of parent commitment differ based on programs and on the ability of the family to be involved. For example, the DIR model relies on the parents completing a certain number of parent/child sessions throughout the day. School-based interventions require less involvement as teachers and aides fill the role of primary interventionist. Research has supported the idea that parent training is beneficial to intervention programs for children with ASD (Newsom, 1998; Schreibman, 2000; Tonge et al., 2006). Parent provision of intervention strategies increases skill maintenance and generalization (Koegel, Schreibman, Britten, Burke, & O'Neill, 1982). Parents who have participated in parent training also report increased feelings of confidence regarding their ability to interact with their child (Koegel et al., 1982). Overall, parent training and involvement is considered critical to positive program outcomes (Dawson & Osterling, 1997; Newsom, 1998; National Research Council, 2001).

Although identified as a core component for early intervention for children with ASD, parent training programs are not always offered or implemented. One barrier to the provision of programs is that comprehensive parent training models are not readily available to mainstream educators and service providers (Ingersoll & Dvortcsak, 2006).

Even in agencies where a program has been developed, child interventionists often double as program facilitators, lacking the knowledge and experience of how to effectively teach adults (Mahoney et al., 1999). In addition, in order to be effective, parent training must be provided individually to families, preferably in the home, several times per month for an extended length of time (Koegel, Bimbela, & Schreibman, 1996; Mahoney, 2004). For many intervention programs, funding is not available for this level of service, particularly for programs whose primary funding mandate is provision of services to the child. An additional obstacle to effective parent training is voluntary parent participation (Ingersoll & Dvortcsak, 2006). Parents themselves report significant change in their child's development as a result of training (Hume, Bellini, & Pratt, 2005), but feel that they are not always able to access it. Parents report difficulties in being able to attend parent training sessions, and in implementing recommended strategies due to competing time constraints such as work, housework, or care of siblings (Drew et al., 2002). Overall, there appear to be considerable advantages to parent training and involvement in child directed programs; however, there are many barriers for parents participating in these types of programs.

Intervention Evaluation

The shift in public policy to supporting only evidence-based interventions, as outlined by the United States Elementary and Secondary Education Act of 2001, the Individuals with Disabilities Education Act of 2004, and Alberta's Family Supports for Children with Disabilities Act of 2004, has increased the need for critical program evaluation. The Council for Exceptional Children (2006) has specified the following categories for evaluating interventions: Research-based, Promising Practices, and Emerging

Practices. Each category is determined based on the number of quality studies completed by different researchers in a variety of geographical areas. Randomized control trials are considered the gold standard for assessment; however, this seems to be a model of research not often completed in research with children with ASD due to problems with limited samples, heterogeneous programs being evaluated and the need to match research design with the specific research question (Simpson, 2005). The need for evidence based, scientifically-validated programs have affected researchers as they work to design studies deemed high quality. It has also affected private service delivery for children with disabilities as parents may be turned down for publicly funded programs not deemed evidence-based.

Criticisms of Outcome Research

Research into treatment evaluation for ASD has often focused on comparing the efficacy of one program against another in an attempt to determine which program best reduces challenging behaviours and most increases prosocial behaviours. Criticisms of this body of research include treatment fidelity whereby programs are not consistently implemented as intended. This process of evaluation is often ignored in evaluation studies (Gresham, Gansle, & Noell, 1993; Simpson, 2005; Wheeler, Baggett, Fox, & Blevins, 2006). Families of children with ASD often access services such as private speech-language therapy involvement or social skills groups in addition to core comprehensive programs. Research does not always control for additional services accessed (Stahmer, 2007), possibly resulting in the core program receiving credit for all findings. Also, common outcome measures such as IQ and school placement are problematic in several

ways. IQ measures are not considered indicative of overall functioning in children with ASD due to associated language deficits, motivation concerns, and uneven cognitive profiles making interpretation difficult (APA, 2000; Prizant, 2008). Adaptive measures are a less commonly used although perhaps more valid form of assessment (Prizant). Also, placement in a typical educational setting may not be a valid indicator of positive outcome as there has been a move toward full inclusion for all children with disabilities in the public school system (Division of Early Childhood, 1993) regardless of their developmental level. Rather than using IQ and school placement as outcome measures, research has suggested examining “quality of life” factors such as satisfaction with self, social connections, jobs and living situations (Simpson).

Recent research in the area of treatment evaluation has focused on commonalities that successful intervention programs share, highlighting approaches and program qualities that are critical for successful interventions as opposed to focusing on the philosophy of the program itself (Corsello, 2005; Dawson & Osterling, 1997; Stahmer, 2007). To date, some of the characteristics deemed common to effective practice are: (1) early intervention; (2) intensive treatment (upwards of 20 hours per week); (3) regular assessment procedures designed to assist in ongoing goal development; (4) built in opportunities for generalization of acquired skills; (5) structured learning environments; (6) program staff highly trained in the intervention modality; (7) focus on sustained interactions with the child; (8) program goals which match a child’s needs profile; (9) clear lesson content focusing on areas impacted by the ASD (social interaction, communication, cognitive development, adaptive skills and behavioural functioning); and (10) parent involvement (Dawson & Osterling,

1997; Newsom, 1998; National Research Council, 2001; Stahmer, 2007). As one comprehensive treatment program has not stood out as significantly more efficacious than others, it will be important to increase awareness and implementation of these elements in clinical practice, and to focus research efforts on determining with more specificity how the factors combine to predict best possible outcomes for children with ASD and their families.

Stress

Selye, considered by many to be the father of modern stress theory (Wagenaar & LaForge, 1994), observed that investigators have found it challenging to define the concept of stress (Selye, 1983). Selye and Rahe initially discussed stress in terms of life events (Abidin, 1995). Lazarus and Folkman (1984) referred to stress as the reaction that occurs within the individual when perceived threat is high and perception of ability to cope is low. Elliot and Eisdorfer's (1982) view of stress looks at the duration and course of the stress, where stressors are broken down into one of five categories: (1) acute time-limited stressors (e.g., public speaking); (2) brief naturalistic stressors (e.g., thesis defence); (3) stressful event sequences (e.g., death of a loved one); (4) chronic stressors (e.g., injury leading to ongoing physical disability); and (5) distant stressors (e.g., having experienced abuse as a child). Stress can be seen as residing within circumstances (e.g., financial worries) or occurring within the individual's response to the situation (e.g., Johnny perceived his financial concerns as stressful; Segerstrom & Miller, 2004; Wagenaar & LaForge). Stress can affect people's physical and mental health, attention, concentration, processing speed, and behaviour (Curlette et al., 2006). Overall, conceptualizations of stress involve an

interaction between the event and the complex psychological schema the individual brings to that event (Cassel, 1974; Mason, 1975).

Stress and Having a Child with ASD

Children with special needs present with a variety of characteristics requiring considerable attention and care from their families, and resources to assist parents are not always available (thus possible perceived increased demand without perceived resources necessary). Abidin (1995) stated that the general stress experienced by parents would be the result of child-related characteristics, such as adaptability, demandingness and hyperactivity, and parent-related characteristics such as perceived competence in the parenting role, their own emotional availability, and feeling of attachment to parenting. In addition, building on the work of Selye and Rahe, Abidin recognized the impact of situational life stressors such as death of a family member, loss of a job, or divorce, on the ability to parent and on perceptions of overall stress. Models of stress, such as Abidin's, can be applied to parents raising children with developmental disabilities, including ASD, and reflect the increased needs of these children, the corresponding perception of general stress and associated life stressors.

Parents of children with developmental disabilities, including ASD, may also experience higher levels of parental stress than do parents of children with typically developing needs (Baker-Ericzen et al., 2005; Bouma & Schweitzer, 1990; McCubbin, Cauble, & Patterson, 1982; Tomanik, Harris, & Hawkins, 2004). Estimates have been put forth suggesting that two-thirds of mothers of children with developmental delays experience stress levels in the clinically significant range (Baker-Ericzen et al.; Tomanik et

al., 2004). McCubbin et al. (1982) indicated eight categories contributing to increased stress in parents of children with developmental disorders as compared to parents of typically developing children: finances; strained emotional relationships between family members; changes in family and leisure activities; social isolation and the perception of social rejection; time constraints with respect to involvement in intervention programs; adaptations to housing to accommodate the child with special needs; challenges with the educational system; and grief on the part of the parents as they deal with their child's diagnosis and accept a new reality for parenting. These may be just a few of the multiple factors responsible for increased levels of stress reported in parents of children with special needs.

In addition to exhibiting higher levels of stress than parents of typically developing children, studies suggest that parents of children with ASD experience even higher stress levels than parents of children with other special needs (Bouma & Schweitzer, 1990, Fisman, Wolf, Ellison, & Freeman, 2000; Gray, 2006; Holmes & Carr, 1991; Holroyd & McArthur, 1976; Siklos & Kerns, 2006). In order to examine these differences, researchers focused on characteristics seen as unique to the ASD diagnosis. Donenberg and Baker (1993) indicated that children's lack of responsiveness (i.e., how they communicate and their affective response to caregivers), their temperament, and the amount of repetitive or self-stimulatory behaviours contributed to these higher stress levels. Children with ASD tend to present with uneven cognitive profiles (i.e., having significantly scattered skills on subscales of standardized cognitive assessments), disruptive behaviours, and long-term care needs that have also contributed to increased parental stress (Koegel et al., 1992; Moes,

1995). Tomanik et al. (2004) reported the following child characteristics related to maternal stress: irritability, withdrawal, non-compliance, hyperactivity, low self-care skills, and severe social communication impairments. Noh, Dumas, Wolf, and Fisman (1989) focused on lack of adaptability in the child (i.e., rigidity), acceptability (i.e., parents seeing the child as less able), and the child's demandingness as key contributing factors. All of the constructs that were paired with higher levels of parenting stress are related to core features of ASD, thus contributing to reported increases in parenting stress within this population.

Additional demands on parents may exacerbate their stress. For example, research indicates that parents' concern regarding their child's level of dependency, their uncertain prognosis, and limited opportunities as a family due to the difficulty of taking the child with ASD out into public areas has impacted their perceptions of stress (Koegel et al., 1992; Moes et al., 1992). This concern over public perception (and judgment) of both their children and their parenting can cause parents to avoid such typical family events as going to the pool, grocery store or restaurant. Public acceptance of children with disabilities appears to have changed significantly over the years, with certain disabilities (e.g., physical handicaps, Down syndrome) being more accepted than others (e.g., Fetal Alcohol Syndrome). Disabilities that people can "see" (e.g., with physical markers) seem to be accepted more readily, and children with ASD look quite typical, leading to the expectation that they are in fact typical. Perhaps over time, as society becomes more exposed to individuals with ASD, parents will feel more comfortable taking their children on community outings, and be less concerned that a behavioural outburst or odd behaviour may occur.

In addition to dealing with features characteristic of ASD, parents are expected by many professionals to understand the complex nature of their child's diagnosis. There is pressure to learn distinctly new ways to parent as traditional methods may not be successful, become conversant with a variety of possible treatments, secure funding for intervention programs, and often maintain a high level of involvement in those programs (Schwichtenberg & Poehlmann, 2007). This differs from the experiences of parents of children with disabilities where appropriate interventions are clearly indicated. Gross (2004) refers to parents' searches for the right intervention as 'frantic', highlighting the stressful nature of the process itself. The uncertainty of knowing which program to access and how to do so can be seen as contributing to increased stress levels.

An additional difference between parents of children with what could be considered an immutable disorder (for example Fragile X or Down syndrome) and parents of children with ASD is that there exists in popular culture the idea of a "cure" for ASD. Countless alternative interventions exist and are promoted as promising recovery from the symptoms of ASD (Umbarger, 2007). When this "cure" does not come about (as it typically does not), parents are often re-immersed into the grieving process, delaying the move toward the development of more functional coping strategies (Guralnick, 2000). This pattern of searching for a cure and subsequent disappointment, may contribute to increased parent stress.

Child and parent related characteristics are only one component of overall perception of stress. Abidin (1995) states that general life stressors contribute as well. Separation and divorce are weighted heavily as life events contributing to increased stress.

Studies suggest that having a child with ASD contributes to increased marital stress and impaired marital relationships (Rivers & Stoneman, 2003; Rodrigue et al., 1990). The National Autism Association is currently collecting data on divorce rates among parents of children with ASD to assess the validity of an 80% rate claimed by various agencies, an increase of 30% from the U. S. national average (National Autism Association, Inc., 2007). Financial worries are also implicated in the perception of stress, and many families report loss of income as one parent stays home to care for their child with a disability. The cost for child care (e.g., respite, aide support for recreation programs) is more for children with disabilities than those without, and parents often report stress over not having enough money to secure the services they want for their child, both in the short term (e.g., early intervention programs) and with respect to the need for possible life-long care (Kelly & Booth, 1999). Additional life stressors as described by Abidin (1995) likely to be relevant to parents given their child's ASD diagnosis might be challenges with teachers and worries over their child attending school. Overall, it appears likely that parents of children with ASD will experience increased general and parenting stress.

It is relevant to note that the majority of research into parental stress and raising a child with ASD tends to rely on maternal reports. This is largely because mothers comprise the majority of primary caregivers for children with ASD (Baker-Ericzen et al., 2005; Wolf et al., 1989). Studies on paternal stress patterns suggest that fathers do report increased levels of stress; however, these results are mixed. Some studies report similar stress levels (Hastings, 2003; Noh et al., 1989) and others indicate that mothers experience higher levels (Moes et al., 1992). Gray (2006) suggests that paternal stress tends to be derived from

stresses experienced by their spouses, rather than from the child with the disability; thus even if differences in actual stress levels are not reported, there may still be core differences in stress profiles of mothers and fathers of children with ASD. This could be due to the differences in roles assumed by parents of children with ASD, where women tend to assume the traditional role of primary caregiver.

Parenting Stress and Implications for Intervention

Research regarding intervention programs and their effects on parenting stress is fairly limited, and much of it is contradictory with respect to results (McConachie, Randle, Hammal, & Le Couteur, 2005; Osborne, McHugh, Saunders, & Reed, 2007). Hastings and Johnson (2001) suggested that parents of children with ASD receiving applied behaviour analysis programs such as those that arose from Lovaas's work might show increased susceptibility to stress. Birnbrauer and Leach (1993) found that mothers of children in ABA style programs exhibited lower levels of stress. Indeed, Newsom (1998) indicated that intensive home-based programs may reduce parental stress and improve family functioning. Schwichtenberg and Poehlmann (2006) found that although mothers of children with ASD involved in ABA programs with more child hours per week showed less depressive symptoms than those with children receiving fewer hours, those spending more hours actively involved in the program (in the role of therapist) reported more feelings of personal strain. Baker-Ericzen et al. (2005) indicated reduced parental stress in response to their child with ASD participating in an inclusive early intervention program, although stress reduction was not a primary target of the intervention. Osborne et al. (2007) report that regardless of the intervention program, efficacy is decreased when parenting stress is high,

particularly as the time input of the program increased. Based on the limited research summarized, it appears that no one intervention approach is correlated with the greatest amelioration of parenting stress. Rather, it appears that distinct factors, such as having a positive belief about the efficacy of the intervention and having a child show decreasing levels of behaviour symptomatic of ASD, are most associated with a decrease in parenting stress (Hastings & Johnson, 2001).

Parent stress is relevant to programming for children with ASD in that it is both affected by, and affects program outcomes. Interventions have been shown to decrease parental stress, even when parent training is not a key component of the intervention (Baker-Ericzen et al., 2005; Feldman & Werner, 2002; Koegel et al., 1996), and decreased parent stress can act to increase intervention efficacy (Osborne et al., 2007; Robbins et al., 1991). Because of the two-way effect between parental stress and program outcomes, Lessenberry and Remfeldt (2004) recommended assessing parental levels of stress as a routine process in intervention programs for children with ASD.

The research outlined above would imply that it would be beneficial to consider parents' level of stress, and to find a program that would match their stress profile as well as the learning profile of the child. For example, low stress parents with adaptive coping patterns may be better suited to ABA or intensive in home programs with a requirement of high parent involvement and consistency, whereas high stress parents, may better benefit from a less intense inclusive education program with low parent requirements, complimented by counseling or intervention services aimed at stress reduction. Since levels of parenting stress may impact the measured success of an intervention, it would make

sense to match the treatment paradigm and service delivery model to the overall profile of the family, considering both child and parent factors.

Coping with Stress

The responses we use to attempt to manage stress are referred to as coping behaviours (Lazarus & Folkman, 1984). Three primary coping behaviours are outlined in the coping literature: problem solving, where the attempts are made to alter the situation; cognitive reappraisal, where if the problem itself cannot be modified then the individual can change how he/she perceives the problem; and relaxation training, where the individual is taught how to reduce emotional and physical responses associated with the stress (Pearlin & Schooler, 1978; Roskies & Lazarus, 1980). Bandura (1982) argued that having a past history of successful coping created confidence in one's ability to cope in the future. Effective coping behaviours are seen as those that tend to reduce the experience of stress, such as turning to social supports, or engaging in physical fitness activities (Curlette et al., 2006); and ineffective approaches are seen as those that lead to further exacerbation of the stress response, for example, alcohol or drug addictions, or engaging in risk taking behaviours (Bieliauskas, 1982; Curlette et al., 2006). Any action that we take in an attempt to reduce experienced stress, whether it results in a positive or negative outcome, is referred to as a coping strategy.

Coping with Stress for Parents of Children with ASD

Research indicates that parents of children with ASD appear to draw on qualitatively different patterns of coping than parents of non-ASD children. Tunali and Power (2002) discuss the use of “primary” coping strategies in response to controllable situations versus

the use of “secondary” strategies necessary in stressful situations that are out of one’s control. If people cannot alter the situation to reduce stress, then they must adjust the way they view or perceive the situation. These secondary strategies include actions such as gaining new perspective, assigning meaning to the situation, accepting the situation knowing that it cannot be changed, reinterpreting the situation into a more favourable light, or managing the situation with humour. Having a child diagnosed with ASD can be perceived as a situation that is out of one’s control, so it would be expected that parents with children with ASD who are coping most successfully would be those who rely on secondary coping strategies. Although we know that mothers of children with ASD report higher stress and overall lower life satisfaction than parents of non-ASD children, Tunali and Power’s research supports the idea that mothers of children with ASD reporting the most life satisfaction were those who redefined their perceptions of relevant concepts such as motherhood, career choices, marital success and leisure pursuits to reflect their own values and choices. For example, they tended to endorse beliefs such as “a good mother is a mother who stays home to take care of her children”, because that is what they did.

Sivberg (2002) also conducted research looking at differences in coping behaviours demonstrated by parents of children with ASD versus parents of non-autistic children. According to the study, the former tended to use coping behaviours of escape and distancing more frequently than more constructive ones such as self-control, social support and problem solving. Implications of those inadequate coping behaviours could be further heightened stress as parents avoid facing the multiple challenges created by the ASD diagnosis. Gray (2006) found that over time, the number of strategies utilized decreased,

and that parents began to use more emotion focused strategies after trying more problem-focused strategies as their children aged. This study showed that parents of children with ASD eventually stopped trying to change the “problem” (i.e., the ASD diagnosis) and began to engage in activities such as praying, talking about their emotions, or withdrawing. Gray’s research suggests that although parents of children with ASD begin by coping with parental stress in qualitatively different ways than parents of non-ASD children, those differences may decrease over time, with parents moving toward more typical coping strategies.

Families that receive social support are thought to cope better with raising a child with an ASD than families that report not receiving much support (Wolf et al., 1989). Social supports can refer to resources that allow us to feel cared for, valued and esteemed, and assist us in facing challenges (Siklos & Kerns, 2006). This can include informal supports such as spousal support, family, friend or church involvement; or more formal supports such as community resources and professional assistance. Young and Roopnarine (1994) indicated that the social networks of parents with children with ASD tend to consist of more health care professionals than do those of the typical population. However, Gray (2006) found that this relationship lessens as children age. Provision of social supports to families with children with ASD is yet another way to assist parents in coping successfully.

Although access to social supports has been demonstrated to decrease stress and increase parents’ perceptions of coping, the degree of influence appears mitigated by various factors. Sivberg (2002) emphasizes “how important it is that parents of a child with an autistic spectrum disorder develop and employ as many well-functioning coping

strategies as possible” (p. 406). Yet Brinker et al. (1994) indicated that involvement with a greater number of agencies for families with children with developmental disabilities actually contributed to increased stress. Involvement with a single program providing services that are more comprehensive was implicated in reduced stress. The quality of social supports offered also positively impacts stress reduction and perceptions of ability to cope with the demands of raising a child with ASD (Konstantareas & Homatidis, 1989). This study indicated that parents of children with ASD, although accessing similar levels of supports to those accessed by parents of non-ASD children, encountered more “aggravations” in conjunction with support agencies, thus offsetting the positive effects of the support. Additionally, parents’ perceptions of the intent of the intervention can influence the actual effect the program has (Bristol, 1984). Parents who believed that the program had their child’s best interests at heart tended to cope better. It appears then that simply increasing the amount of support available to a family is not adequate in facilitating increased perceptions of coping: consideration should be given to the number and quality of supports, and the parents’ perceptions of them.

Parents’ perceptions of their ability to cope is relevant to intervention programs for children with ASD in that the use of more adaptive coping resources leads to the reduction of parental stress (Curlette, et al., 2006), which, in turn, affects program outcomes. Given the increased levels of stress in parenting a child with special needs, particularly one with an ASD, it becomes imperative to look for ways to support families and increase their perception of being able to cope. Activities that might be considered typical outlets for coping with stress for parents of typically developing children (e.g., exercise, socializing,

meditating) may not be reasonable for parents of children with ASD due to the considerable behavioural demands, decreased availability of appropriate childcare, time demands of intensive interventions, time consuming parent advocacy tasks, strapped finances, impaired friendship networks and marital discord. Agencies providing comprehensive services can address some of these barriers to adaptive coping by implementing strategies such as: working on child-specific skills designed to lessen the effect of child behaviours on parent stress; working on empowering families to feel that they can address challenging behaviours successfully; assisting parents in accessing funding for intervention programs; providing opportunities for parent education on ASD; incorporating parent support groups so that parents have the opportunity to connect with their peers; liaising with other community agencies; and assisting with transitions to new programs. By addressing the challenges to accessing effective coping strategies, agencies could in fact facilitate reduced levels of stress in parents of children with ASD.

Summary

Elevated levels of overall stress are reported in parents of children with special needs, particularly those with ASD. This includes stress related to child characteristics such as low responsiveness, high rigidity and significant behavioural challenges; parent-related characteristics such as being accepting of their child's diagnosis; and additional life stressors such as marital discord and financial worries. In addition, parents of children with ASD seem to rely on different coping behaviours than parents of non-ASD children, particularly when their children are young. For example, Sivberg (2002) found that parents of children with ASD tended to use behaviours such as escape and distancing more

frequently than parents of non-ASD children. Research also indicates that access to appropriate social supports increases parents ability to cope, and can serve to reduce overall parenting stress.

Given the information outlined above, one would expect that programs that either directly or indirectly address identified stressors (e.g., by providing fully funded programs, targeting the increase of adaptive behaviours as well as the decrease of maladaptive behaviours, encouraging parent participation, offering opportunities for parents to become more knowledgeable about ASD, and coaching parents on how to handle specific behaviours), would result in a general reduction of parent stress. In addition, programs providing increased social support to parents through direct day-to-day discussion and coaching with a front line worker; through support from a multidisciplinary team of professionals; and through opportunities to network with other parents of children with ASD would be expected to elicit greater coping abilities. Given the different goals and approaches that various interventions have, one would expect to see varying levels of change in different areas related to parenting stress. The present study allows an opportunity to gain information relevant to parents' perceptions of stress and coping, and to evaluate whether or not an intensive, in-home, full-day program impacts family functioning to a greater degree, and in different areas, than an inclusive half-day educational setting alone.

Research Questions

1. *Is there a difference in overall stress, parenting stress, child behaviour and coping between parents who access full-day programs as compared to half-day programs?*

2. *Following a period of intervention, do parents of children in full-day programs show a greater reduction in overall stress and parenting stress, as well as an increase in feelings of coping, than parents of children in half-day programs?*
3. *Do parents of children in either program experience a reduction in parenting stress as their children's behaviours improve?*

CHAPTER THREE

METHODS

Participants

Thirty-six parents of children with an ASD diagnosis enrolled in a private agency's preschool programs were involved in this study. The children ranged in age from 3 to 6 years old. As indicated in certain studies (Baker-Ericzen et al., 2005; Wolf et al., 1989), the majority of primary caregivers and study respondents were mothers (92% mothers and 8% fathers in the initial sample). Four of these families had more than one child with ASD, but each completed only one set of checklists. Sixteen of the children from the participating families attended a half-day preschool program only, and 20 attended the same program, in addition to a half-day Specialized Autism Services (SAS) in-home program.

Interventions

Half-day Program

The half-day program attended by children ages 3 to 6 takes place in an integrated educational setting. Children with a variety of special needs attend a junior or senior kindergarten program, 5 days a week, two and a half hours per day. Round trip bussing is offered to all families for a nominal fee. Each classroom has a teacher and 3-5 Child Development Facilitators (CDFs) depending on the number of children with special needs in the class (typically the ratio is 3-4 children per CDF). The classroom curriculum follows Alberta Education guidelines, with modifications made to programming as necessary for individual children. Individual Program Plans (IPPs) which lay out goals for the child are

created based on input from parents, classroom staff and the therapy team. Children with typically developing needs also attend the program, and often serve as age appropriate models for their classmates. Consultation from a multidisciplinary team is available, with some direct therapy, small groups, or classwide interventions. A home visit coordinator completes monthly home visits with the children with special needs, demonstrating to parents how goals are worked on, and liaising between the parents and the classroom team. Parents are also invited to come to family nights at the school offered once every two months, in addition to two family days occurring at a community location. At these events staff set up a variety of learning centres and support the parents and their children in completing them. Parent-teacher interviews occur three times per year in conjunction with reporting periods. Classrooms also offer opportunities for parents to come to the class and volunteer, or to participate in field trips.

Full-day Program

The full-day program provided to children ages 3 to 6 in this study is designed to provide intensive intervention to families of children with an ASD. The program primarily operates in the child's home, five days a week for two and a half hours per day, in addition to the half-day program described above. Each child receives one to one daily programming from a Child Development Facilitator (CDF), with the support of a multidisciplinary team of professionals (Speech and Language Pathologist, Occupational Therapist, Psychologist, Behaviour Consultant and occasionally a Physical Therapist). Social workers are also available for consultation and for referral. The multidisciplinary team provides both direct therapy to the child and consultation to parents and staff in their home.

The full-day program is an eclectic model. Rather than following one comprehensive curriculum, it draws upon a variety of treatment approaches. Among these approaches are the Developmental Individual-Differences Relationship-based (DIR) model from Dr. Greenspan, positive behaviour supports, various social communication programs designed to stimulate social initiation and interaction, and developmentally appropriate practice (where lessons are geared toward a child's developmental rather than chronological level). Goals are created in the areas of interactive play, functional communication, self help and adaptive functioning, social interaction, play skills and cognitive development. Therapists and CDFs work together to target goals by embedding them in social play activities, balancing following the child's lead with strategically setting up activities designed to maximize learning opportunities. For example, when working on a social goal such as turn taking, the CDF might follow the child's lead to see what materials he/she is drawn towards, watch what the child does with the preferred materials, then begin gently inserting themselves into the play, taking the toy for very brief periods of time (seconds only at first), and prompting the child to request a turn back at the first sign of distress. This would be repeated several times until the child began to show signs of increased independence with requesting a turn, or until there was decreased interest in the activity.

One of the core beliefs of the full-day program is that parents understand their children best, and should be actively involved in their child's intervention through goal planning, monitoring and implementation. Time is spent discussing the ASD diagnosis, how to modify expectations to be realistic for the child with ASD, and how to implement

strategies to deal with the learning and behavioural needs of that child. Parents are encouraged to attend an initial IPP meeting to discuss their child's needs, priorities for programming, and specific goals and strategies. Progress review occurs through ongoing IPP goal monitoring, weekly team planning meetings, bi-monthly progress meetings involving parents, and specific skill assessment as deemed necessary by the professional involved. Parents are also encouraged to attend special events offered on occasional evenings and weekends. For example, sibling nights occur where parents are encouraged to bring all of their children, and typically developing siblings learn how to understand what ASD means and how to better interact with their sibling with ASD. Parent education events are also offered throughout the year.

The full-day program is typically funded through Family Supports for Children with Disabilities (FSCD), a branch of Alberta Children's Services. The FSCD Act came into place in 2004 with the intent of providing information and access to province wide services available to support families during the diagnostic process and in securing supportive interventions once a diagnosis is made. Goals of the Act are to support child and family functioning, facilitate the development of the child, and support community inclusion for the child. Programs include family support services, child-focused services and community based services. The intent behind Specialized Services for Children with Severe Disabilities, as outlined by FSCD, is to ensure that children displaying severe disabilities across multiple areas of development receive coordinated, multidisciplinary services based on effective rehabilitative approaches (Alberta Government, 2004). One of the expectations for parents is committing to involvement in their child's program: participation will vary

based on the family's situation. Once children are approved for specialized services funding, parents must select a service provider from various community agencies.

Procedures

Recruitment initially occurred by sending out a notice to all children with an ASD diagnosis attending any of the agency's five locations, informing parents that the study was to take place, and that a more in depth letter and consent form would follow shortly. The second letter explained exactly what would be expected from participants, and instructed parents to complete and return the attached consent form should they be interested, or to simply not return it should they not want involvement. Upon receipt of the consent form, the researcher phoned all parents and arranged a time to meet either at their child's school, or at their residence. The meetings consisted of reviewing the purpose of the research, explaining the measures being used, staying with the parents while they completed the checklists and being available for questions arising during completion. To increase the sample size participants for pre-test data collection, an additional letter was sent home one month after the first, again indicating that the study was ongoing and that more participants were needed. In addition, members of the agency's psychology department contacted families and indicated that the researcher was continuing to look for more involvement.

For post test data collection, the researcher attempted to contact the 36 participants by phone to arrange meetings. Only 12 participants were contacted in this manner: checklists and a cover letter outlining the process for returning checklists, in addition to contact information for the examiner, were then mailed out to the remaining 24 participants. Of those, two checklists were returned completed. One final phone call was

made to parents who had not returned the checklists, asking if they would be able to do so. Four more packages were returned, for a total of 18 (50% response rate from the initial sample size). Two families dropped out of the study because they had moved to another city, 7 had moved on to a grade one community school, two had switched to different service providers, 3 indicated that they were no longer interested in participating, and 4 could not be reached. The total sample at post was 18 parents. The mean length of time between completion of the first set of checklists and the second was 9 months, with a range of 6 to 12 months.

Measures

Parenting Stress Index

The Parenting Stress Index (PSI), Third Edition is a checklist designed to examine levels of stress within the parent/child system. It is comprised of 120 test items (including 19 optional ones) looking at three domains of stressors: child characteristics, parent characteristics and situational life stresses. Responses are scored on a 5-point Likert scale where “5” indicates a response of “strongly agree” and “1” indicates “strongly disagree”.

Within the Child Domain, the following subscales are included:

Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability. The Distractibility/Hyperactivity subscale examines the presentation of behaviours such as over-activity, restlessness, short attention span, and failure to finish what they started. Adaptability refers to the difficulty displayed by the child in adjusting to change. The Reinforces Parent subscale measures whether parents feel rejected by the child. The Demandingness subscale examines children’s dependency behaviours. Mood

refers to the child's affective expression including happiness. The Acceptability subscale measures whether the parents perceive their child as less physically attractive, intelligent or pleasant than they had initially hoped. Children rated higher in these areas would likely be displaying characteristics that make parenting more challenging.

In the parent domain the subscales are: Competence, Isolation, Attachment, Health, Role Restriction, Depression, and Spouse. The Competence subscale reflects how well parents feel they can handle the job of parenting their child. Isolation refers to the level that parents are feeling supported by their spouses, family and friends, and high scores here suggest considerable stress and the need for intervention supports. The Attachment subscale measures parents' emotional closeness to their children and how well they observe and understand their children's needs. The Health subscale examines health issues and how they can impact parenting abilities. Role Restriction refers to how much the parents see the parenting role as restricting their own actions and aspirations. The Depression subscale examines items related to those found to be indicative of the presence of depression. The Spouse subscale measures how supported parents feel by their spouse, and how they feel about the relationship in general. High scores in this domain would likely indicate that parenting stress is arising from characteristics present within the parent themselves.

These two domain areas comprise a Total Stress score. Total Stress raw scores of 260 or higher indicate a need for referral to professional services. There are also 19 optional Life Stress items recorded separately. The Life Stress items are asked in a yes/no format, and each carries a different score weight depending on how it factors into cumulative stress. Scores are reported in percentiles for the separate domains and Total Stress scores. A

Defensive Responding score is also available with scores below 24 indicating that caution should be used when interpreting the information as these parents may be faking good.

The internal consistency of the PSI was .90 or greater (Abidin, 1995) for the two domains and the Total Stress score. Test-retest reliability coefficients are reported in the manual based on four independent studies, reporting coefficients ranging from .55 to .82 for the Child domain, .69 to .91 for the Parent domain and .65 to .96 for the Total Stress scale, suggesting strong stability over time. The time lapse in the four studies ranged from 3 weeks to 1 year.

Content validity for the PSI was established using factor analyses. A six-factor model used for the Child domain accounted for 41% of the variance. The seven-factor solution for the Parent domain accounted for 44% of the variance. With respect to the Total Stress score, the two-factor solution (Parent and Child domains) accounted for 58% of the variance. Factor loadings reported from these analyses indicate that the 13 subscales are measuring distinct types of stress.

Considerable research has been completed comparing the PSI to other measures such as the Beck Depression Inventory; the Child Behaviour Scale; the Family Adaptability and Cohesion Evaluation Scales; and the Family Impact Questionnaire (Abidin, 1995). Significant correlations were reported between Total Stress scores, domain scores and these other tests suggesting strong construct validity.

Coping Resource Inventory for Stress

The Coping Resources Inventory for Stress (CRIS) was developed primarily to measure resources available to individuals that aid them in reducing the effects of the

stresses in their lives. It is a self-reporting checklist consisting of 280 items requiring true or false responses. Responses are reported on scan sheets that must be scored on a specific computer program, either by the test publisher or through a personal computer program that the user can purchase. Test administrators receive either a brief score report, or a more lengthy interpretive report. The CRIS yields 12 Primary scales (Self-Disclosure, Self-Directedness, Confidence, Acceptance, Social Support, Financial Freedom, Physical Health, Physical Fitness, Stress Monitoring, Tension Control, Structuring and Problem Solving). The Self-Disclosure scale examines how willing individuals are to share their feelings and thoughts with others. The Self-Directedness scale evaluates how well people are willing to behave independently of what other people think of them. The next scale, Confidence, relates peoples faith in their own ability and correlates highest with the overall CRIS score. The Acceptance scale refers to people's beliefs and acceptance of themselves and others. Next is Social Support, which measures what part family and friends play in helping the individual cope with stress. Financial Freedom measures people's perceptions around having enough money to meet their needs. The Physical Health scale assesses overall wellness, and how much a person's ability to cope is impacted by specific health conditions. The Physical Fitness scale examines the health practices subscribed to by the respondent. Next is Stress Monitoring, which evaluates how well people are aware of their own stress and situations that are likely to produce stress. Tension Control refers to the ability to use relaxation exercises and self talk to lower overall arousal. The Structuring scale measures the individual's approach to goal planning. The final primary scale is

Problem Solving, which assesses how well the respondent can generate and act on solutions to problems.

Three Composite scales are also provided for the CRIS: Cognitive Restructuring, Functional Beliefs, and Social Ease. Cognitive Restructuring refers to how well a person is able to identify possible stressful situations, and act to deal with those using cognitive strategies such as clarifying the problem, perspective taking, gathering necessary information, considering alternatives, and practicing relaxation. The Functional Beliefs composite evaluates those beliefs that contribute to preventing or lowering stressful responses. Social Ease measures how comfortable people are with others, sharing information, and feeling that they can speak up for themselves.

The CRIS also yields a global score (the Coping Resource Effectiveness score). Sixteen items related to factors that inhibit wellness such as engaging in high risk behaviours or having health disorders that may exacerbate the effects of stress are measured. Four validity scales are also included: Social Desirability, Infrequency of Response, Omitted Items and Random Response Indicators. Social Desirability examines the tendency of the respondent to answer in such a way as to “look good” to others. The Infrequency of Response Scale is based on 24 items where less than 20% of the normative population answered in the undesirable directions, representing atypical responses. Omitted items reports how many items were not responded to: scales with more than 10% of items omitted should be interpreted with caution. Random Response Indicators attempt to evaluate how frequently a respondent was guessing at items.

Test items are reported as readable at a grade seven level. Scores are available in percentile ranks and T scores. Coefficient alpha reliability for each of the 12 Primary scales is reported as .84 or greater (Curlette et al., 2006). Test-retest reliability was found to be .95, indicating high stability over time (Curlette et al., 2006). Curlette et al. reports a study comparing the CRIS to eight validating tests, with results supporting both convergent and divergent validity for the measure. Test development incorporated group difference studies, factor analysis and item analysis as support for construct validity. In addition, researchers knowledgeable in the field of coping rated items as representative of the scale they contributed to or not: where agreement was made between 3 or more out of 5 such experts, items were taken to be representative. Results from this process indicated that 3 out of 5 experts agreed with the CRIS item placement 90% of the time. In addition, over 50 validity studies have been completed using the CRIS, with scales on the CRIS reported to correlate with health concerns, personality types, life satisfaction and measures of distress (Weinberg, 2008).

CHAPTER FOUR

RESULTS

This chapter presents the results in two sections. The first section contains descriptive information about the participants as well as their responses to the questionnaires. The second section presents the results relating to the research questions posed regarding differences in stress and coping levels between groups and over time.

Descriptive Statistics

Descriptive Summary

Demographic characteristics, namely the gender and ages of the children whose parents were involved in the study are summarized in Table 1. For each of the variables examined in the study, the mean and standard deviation are also presented (Table 1).

Table 1

Demographic Characteristics of the Sample and Descriptive Statistics of the Variables

	<i>Pre-test</i>			<i>Post test</i>		
	Half-day	Full-day	Total	Half-day	Full-day	Total
	(<i>n</i> =16)	(<i>n</i> =20)	(<i>n</i> =36)	(<i>n</i> =8)	(<i>n</i> =10)	(<i>n</i> =18)
Child age						
3	2	2	4	1	0	1
4	5	3	8	3	0	3
5	5	5	10	3	5	8
6	4	10	14	1	5	6
Gender of child						
Male	13	15	28	5	7	12
Female	3	5	8	3	3	6
Gender of parent						
Male	1	2	3	0	1	1
Female	15	18	33	8	9	17
PSI						
Total stress						
Mean	280.25	273.15	276.31	272.50	279.10	276.17
SD	37.43	45.86	41.89	29.02	45.36	38.04
Child						

behaviours						
Mean	140.69	142.55	141.72	136.13	141.10	138.89
SD	21.15	24.51	22.78	11.59	21.32	17.39
Parent stress						
Mean	139.44	130.60	134.53	136.13	138.00	137.17
SD	21.86	27.87	25.42	19.90	28.10	24.12
CRIS – Global coping						
Mean	54.44	51.25	52.67	53.63	55.40	54.61
SD	20.94	25.42	23.26	30.31	26.42	27.36

The sample at pre-test consisted of 28 male and 8 female children. As reflected in the larger population of individuals with ASD, a larger proportion of boys to girls was represented (7:2). Additionally, the majority of respondents (92%) were mothers. In this sample, 10 out of 36 parents reported having attained a high school diploma or less (28%). The majority of parents, 20 out of 36, reported having attended college or vocational school (56%). The remainder (16%) had graduate or professional level training. Parents of children who qualified for full-day services (i.e., had severe needs in two or more developmental areas) were aware of the possibility of accessing the additional program. Those interested would contact local service providers, have their names put on a wait list, and begin programming once a placement came available. Many parents however chose to access

half-day programs only, typically due to the high time commitment required of the full-day services.

At pre-test, 1 out of the 16 parents (6%) in the half-day group received a Defensive Responding score as defined by a raw score of 24 or less on the PSI. This means that caution should be used when interpreting that individual's scores on the PSI. This was not a parent who participated in post test data collection, so the score would not have affected post test data analysis. No Defensive Responding scores were noted on the PSI for parents in the full-day group. On the CRIS, 3 out of 20 parents (15%) in the full-day group received Social Desirability scores at or above the 98th percentile, suggesting that these respondents have answered in such a way as to appear to be coping favourably. One of these scores occurred at pre-test, the other two at post test. Overall, then, the results seem valid.

Pre-test data gained through the administration of two checklists were analyzed using one-way analysis of variance (ANOVA) to determine whether significant differences occurred between the two groups of parents before the intervention started. ANOVAs were completed for four dependent variables including total stress, parent stress, child behaviours and global coping. Following an average time of 9 months, parents were re-administered checklists and data were analyzed using one-way ANCOVAs to determine group differences, with pre-test scores entered as covariates. Additionally, in order to evaluate whether changes in one dependent variable (child behaviours) were related to change in another (parent stress) differences were calculated between scores at both times for those variables, and the differences were then correlated using Pearson's product moment correlations.

Results

Pre-Test Differences Between Half-Day and Full Day Parents

To determine if there was a difference in overall stress and coping between parents who accessed full-day programs as compared to those parents who accessed half-day programs at pre-test, one-way ANOVAs were conducted for each dependent variable. The results are presented in Table 2.

Table 2

Between Subjects Analysis of Variance at Pre-test

	df	F	<i>p</i>	Partial Eta Squared
PSI				
Total stress	1	.250	.620	.007
Child behaviours	1	.058	.811	.002
Parenting stress	1	1.076	.307	.031
CRIS				
Global coping	1	.163	.689	.005

Total stress on the PSI refers to the cumulative effect of child behaviours such as reduced adaptability or increased hyperactivity, and characteristics of the parent such as feelings of parental competence or social isolation. No significant differences were found between parents of children in half-day programs and parents with children in full-day programs at pre-test on measures of overall stress or coping. Additionally, no differences

were noted on the subscales of child behaviours or parenting stress, indicating that the groups were relatively equal at pre-test with respect to the dependent variables being examined.

Post test Differences Between Half-Day and Full-Day Parents

In regards to the second research question about whether or not parents of children in full-day programs showed a greater reduction in overall stress and parenting stress, as well as an increase in feelings of coping, than parents of children in half-day programs, ANCOVAs were completed. In order to ensure that any differences were not related to pre-existing group differences, pre-test levels of stress and coping were entered as covariates. Results for this analysis are presented in Table 3.

Table 3

Analysis of Variance Following Intervention

Source	<i>df</i>	F	<i>p</i>	Partial Eta Squared
PSI				
Total stress	1	3.925	.066	.207
Parenting stress	1	5.462	.034	.267
CRIS				
Global coping	1	.002	.967	.000

Results from the ANCOVA indicate that, following a period of intervention, the change in parenting stress is significant $F(1,18) = 5.462, p < .05$. Examining the change in mean scores on parenting stress over time, it appears that parents of children in the half-day program experienced a reduction in parenting stress (mean difference = -3.3), whereas parents of children in the full-day program appeared to show a slight increase (mean difference = 7.4). Unlike for parenting stress, there is no significant difference between the half-day and full day parents on measures of total stress or coping. However, the differences in total stress experienced approaches significance $F(1,18) = 3.925, p = .07$. Again, parents accessing half-day programs experienced a reduction in total stress (mean difference = -7.25) and parents accessing full-day programs experienced an increase (mean difference = 5.95).

Correlations Between Parenting Stress and Child Behaviour

To address the third research question regarding the relationship between child behaviours or characteristics and parenting stress, a series of correlational analyses was conducted. Differences between scores at pre-test and post test for the full-day intervention group were calculated for parenting stress and child behaviours. These values were then analyzed using Pearson's product-moment correlations to establish how children's behaviours and parenting stress in parents of children receiving full-day services were related. The results are presented in Table 4.

Table 4

Relationship Between Child Behaviour and Parent Stress

<i>Variable</i>	<i>Parent stress</i>	<i>Child behaviour</i>	<i>Parent stress (half-day)</i>	<i>Child behaviour (half-day)</i>	<i>Parent stress (full-day)</i>	<i>Child behaviour (full-day)</i>
Parent stress	-	.40* (n = 18)	1.0 (n=8)	.51 (n=8)	1.0 (n=10)	.40 (n=10)
Child behaviour		-	.51 (n=8)	1.00 (n=8)	.39 (n=10)	1.00 (n=10)
Parent stress (half-day)			-	.51 (n=8)	a (n=0)	a (n=0)
Child behaviour (half-day)				-	a (n=0)	a (n=0)
Parent stress (full-day)					-	.40 (n=10)
Child behaviour (full-day)						-

a. Cannot be computed because at least one of the variables is constant

b. $*p < .1$ (2-tailed)

A positive correlation was found ($r = .40$) between parent stress and child behaviours. This suggests that as children's behaviours decrease, parenting stress decreases.

The correlation was true for both groups combined: no significance was reported within either the half-day or full-day program only.

Summary

According to results from the analyses conducted, parents of children with ASD receiving full-day intervention programs did not differ significantly from parents of children receiving half-day programs at the beginning of this study on measures of stress or coping. Following a period of intervention, a statistically significant difference existed between groups with respect to change in parenting stress, with parents of children in half-day programs showing a decrease, and parents of children in full-day programs exhibiting an increase. A moderate correlation was noted between child behaviours and parenting stress when analyzing the full sample at post test, suggesting that as behaviours improve, parenting stress improves.

CHAPTER FIVE

DISCUSSION

The present study set out to determine differences in parenting stress and coping between two groups of parents of children with ASD accessing two intervention programs. It also examined the relationship between child behaviours and parenting stress in groups of parents accessing programming for their children. The main results of the study indicate that following a period of intervention, a statistically significant difference in parenting stress was found. However, there was no significant improvement in either parent group on measures of general stress or coping. Another significant finding was that the reduction in parenting stress was related to improved children's behaviours. In this chapter, these results will be discussed in terms of how they relate to previous research. The strengths and limitations of the present study are then provided, followed by a discussion of implications for intervention.

Elevated Stress Levels

Research indicates that parents of children with special needs, particularly those with ASD, experience elevated overall stress (Baker-Ericzen et al., 2005; Bouma & Schweitzer, 1990; McCubbin et al., 1982; Tomanik et al., 2004). Indeed, it is estimated that two-thirds of mothers of children with developmental delays experience overall stress levels in the clinically significant range (Baker-Ericzen et al., 2005; Tomanik et al., 2004). The current study was consistent with 70% of parents reporting clinical stress levels, as defined by a total raw score of 260 or greater on the Parenting Stress Index (PSI). These elevated levels

were consistent for parents regardless of whether they attended the half or full-day program, with no significant differences noted at pre-test between groups on measures of overall stress, child behaviours, parenting stress, or coping.

Studies suggest that certain types of intervention programs may be better suited to parents with elevated total stress levels (Baker-Ericzen et al., 2005; Hastings & Johnson, 2001; Schwichtenberg & Poehlmann, 2006). In the present study, we found that the percentage of parents exhibiting total stress in the clinical range changed differently from pre to post test depending on which program their child accessed. Specifically, the percentage of parents in the half-day program experiencing clinical total stress levels changed from 75% at pre-test, to 50% following intervention. For parents of children in full-day programs, clinical total stress levels actually increased, with 65% experiencing clinical levels of overall stress pre-test, and 70% reporting this level of overall stress following intervention. It would appear then that the full-day program actually contributes to increased stress. Reasons for this could include the fact that the program is very time intensive, that it requires consistent parent participation, that it assumes a readiness on the part of the parent to be actively involved as a therapist, and that it has very high expectations regarding parents' ability to carry through on all advised strategies during the times that therapists are not present. It could also be that parents with high stress levels initially were more likely to drop out of the study, leaving a higher percentage of parents with lower levels of stress. While this is possible, it did not seem to occur in the group accessing half-day programs.

Changes in Parenting Stress

Consistent with Baker-Ericzen et al. (2005), parents in this study of children in a half-day school program reported reduced parenting stress following intervention, even though that was not a primary goal of the program. However, treatment evaluation research indicates that involvement with intensive home-based programming results in a reduction in parenting stress (Hurth et al., 1999; Newsom, 1998). That was not the case in the present study as parents of children in the full-day program showed an increase in parenting stress. In order to explain the differences that occurred, characteristics of the programs, the parents and the children involved in the study can be examined.

Location of programming may contribute to the changes noted in parenting stress following intervention. The half-day program, which resulted in a reduction of parenting stress, occurs at one of 15 community preschool classrooms. Children are typically picked up from their homes on an agency bus and driven to their school location where they spend 2.5 hours of the day and then are bussed home. Overall, parents receive the equivalent of at least 10 hours per week of respite time. Many parents report that knowing they have that time to themselves every morning or afternoon helps them cope with the rest of the day, particularly when they know that their children are receiving quality programming at the same time. Children in the full-day program attend the same school program for half their day, and then received in home programming for the other half. Parents of children in the full-day program stated that they felt the pressure to “look good” at all times to the staff members in their house. They may have felt obligated to have a clean presentable house, and to show that they knew how to handle their child’s behaviour. Both groups of parents

received a consistent break from the demands of parenting a child with challenging needs, which may contribute to an overall reduction in parenting stress. However, this effect may be offset for parents of children in full day programs by perceived pressure to present a positive front on a daily basis.

Another difference between the two programs that may contribute to differences in parenting stress over time is that parents of children in the full day program have typically made a commitment to be involved in daily sessions. Schwichtenberg and Poehlmann (2006) reported that expectations of high parental involvement in programming might result in increased parenting strain.

The length of time that programming occurs may also be a factor contributing to differences in parenting stress. Literature on interventions and ASD often refers to the number of hours or intensity of programming as a key program factor, suggesting that more than 20 hours per week is ideal (Dawson & Osterling, 1997; Newsom, 1998; National Research Council, 2001; Stahmer, 2007). The half-day program in this study lasted 10 hours per week, and operated according to a regular school calendar, with extended breaks in winter, spring, and summer. This allowed the family to plan for the same holidays for their child with ASD as for their other children in regular educational settings. Parents of children accessing this half-day program did not appear to express concern regarding the number of hours their child is in programming, and seemed more concerned with the quality of programming. The full-day program, which parents themselves requested for their children, accounted for at least 20 hours per week, and did not provide extensive seasonal breaks. Parents of children in the full-day program often appeared quite concerned

about the number of hours of programming their children received, tending to become quite stressed over missed sessions (i.e., due to illness, professional days, staff absences) feeling that they needed to get as much time in programming as possible. This perception of operating under a “time limit” may also contribute to ongoing elevated stress levels of parents of children in the full day programming.

Parent factors may also be related to differences in parenting stress. Parents of children in full-day programs chose to have the additional intervention. Typically, when an ASD diagnosis is made, the clinician will make recommendations regarding program placement, and full day services are usually explained if the child demonstrates need as per the criteria laid out by the funding source (e.g., severe delays in two or more areas of development). It could be that parents requesting and accessing additional services hold the ideal that their children will recover from ASD. According to Guralnick (2000), failure to accept the situation or the diagnosis, and learn ways to re-interpret or deal with the unchangeable situation can lead to a delay in the acquisition of positive coping behaviours, and increase the length of time experiencing stress.

Child behaviours and parents’ exposure to and involvement in programming likely also affect differences in parenting stress. For children in the half-day program, intervention typically occurred without the parent present. Parents received updates following goal achievement or at report card times, but were not involved in day-to-day implementation of the intervention. In the full-day program, parents were involved and were witness to the successes and setbacks of their child. Many parents in the full day program reported feelings of frustration watching their child with ASD struggle to learn things that their

younger typically developing siblings had already mastered. When behavioural outbursts occurred parents often stated that they did not feel able to handle them appropriately, particularly in front of a staff member. Frequently parents have expressed concern that their child will only “be good” with their Child Development Facilitator (CDF). Although the strategy is to show parents that the development and maintenance of positive behaviours can be supported, many parents seemed to feel that they were not capable of doing this. This may lead to increased stress, as parents feel less competent in comparison to professionals when managing challenging behaviours.

To summarize, a significant difference existed following intervention between parents of children in half-day programs, and parents of children in full-day programs, with respect to parenting stress. Factors of the treatment programs such as location, duration and parental expectations may have contributed to these differences. Parent features such as expectations of program outcome may also have contributed to decreased parenting stress in the half-day group and increased parenting stress in the full-day group. Finally, the proximity of the parent to the behavioural intervention used for dealing with significant child behaviours may also have affected differential parenting stress outcomes.

Changes in Coping

The provision of adequate social supports has been deemed salient to increasing coping abilities in parents of children with special needs (Cohen & Wills, 1985; Konstantareas & Homatidis, 1989; Wolf et al., 1989). Specifically, studies indicate that maximum benefits are gained from involvement with fewer rather than more agencies, perceived access to a wide variety of quality services and the expectations of the

intervention with respect to parent involvement (Brinker et al., 1994; Bristol, 1984; Konstantareas & Homatidis, 1989). In the current study, the agency involved appeared to meet many of those criteria. It was comprehensive in that it provided multiple services including direct child intervention, parent involvement and training, parent support services, assistance with accessing funding, and consultation with professionals involved in the child's education program. The service evaluated in this study was approved following a considerable tendering process to Family Supports for Children with Disabilities, suggesting that the quality of the program was acceptable. Despite this, parents of children attending full-day programs did not demonstrate significant gains in their coping skills as reflected by the measure used. Parents of children accessing half-day programs demonstrated a decrease in parenting stress, but not a corresponding increase in their coping behaviours. As discussed, this could be explained by the fact that the half-day program provides parents with a break from the challenges of raising a child with challenging needs, without teaching parents ways to cope with those challenges. Although parents of children in the full-day program also receive this respite time while their child is in school, this effect may be minimized by the stresses possibly resulting from participation in the full-day program.

The fact that parenting stress is not decreasing and coping skills are not measurably increasing in parents of children in the full-day program may be due to inadequate parent training. If parents are not receiving active coaching on how to implement behavioural strategies, it is likely that their feelings of ability to cope will not increase. In fact, as mentioned, seeing others able to handle their child's behaviour when they themselves

cannot, may actually increase parenting stress, and would explain the lack of an increase in coping behaviours.

Child Behaviours and Parenting Stress

Because of the many supports provided by the full-day program that appear to meet the criteria for best practice for intervention for children with ASD, the initial hypothesis of this study was that parents of children in full-day programs would demonstrate a greater reduction in overall stress than parents of children in half-day programs. Additionally, previous research indicated that a lessening of overall stress was typically a result of a reduction in child behaviours only (Baker-Ericzen et al., 2005). Since the full-day program in the current study attempted to provide parent training on how to handle challenging behaviours, it was questioned whether or not there would be a reduction in parenting stress correlated to changes in child behaviour. A moderate correlation was noted for both groups combined. This correlation suggests that programs can affect change in parenting stress by working to improve child behaviours. However, when examining the group of parents accessing full-day programs, the correlation was not significant. If this is indeed a group of parents expecting greater reduction in overall ASD characteristics and greater improvement in general, then a gradual reduction of acting out behaviours may not be seen as enough change to reduce their parenting stress. It may be worth noting in the future what effect parent expectations have on parenting stress outcomes.

Recommendations and Limitations

Recommendations

The present study provided a comparative analysis between two programs with respect to parenting stress and coping. Although the results require replication with a larger sample size, there are some implications that may inform program delivery for the upcoming year. It is recommended that the half and full-day programs be routinely evaluated regarding parenting stress, and questions about parents' perceptions of confidence in managing their children's behaviours be examined. Information regarding the primary sources of parenting stress would better inform intervention efforts to reduce that stress. Routine assessment of stress and stress related factors as part of program policy would likely reduce the difficulty in gaining information from a larger sample size.

A major strength of this study is the inclusion of measures of both coping and stress. It is important to note whether parenting stress decreases because of greater feelings of coping, or if it is due to external reasons. This is relevant to programming, as it is the goal to foster change within the family itself, not to create a dependence on services and stress relief solely provided by accessing those services.

Limitations

Although the current study provides information relevant to ongoing interventions, several limitations to the results must be considered. Two of the primary limitations to the present study are the small initial sample size and the high attrition rate between pre and post intervention. Small sample sizes inhibit the range of statistical analyses available and the generalization of results. High attrition rates reduce the number of analyses possible as

sample size becomes even smaller, further reducing the reliability of results. Although more participants were desired, repeated efforts of recruitment were unsuccessful. If the clinical stress levels of the parents in this study are representative of the greater population of parents involved in the intervention programs evaluated, one could assume that stress was a factor in choosing not to be involved. Parents experiencing significant stress could have perceived participation as a drain on already limited time and energy. This may also explain the high attrition rate, as responding to examiner phone calls and repeated participation may have felt overwhelming for parents experiencing clinical overall stress levels.

This study also did not include measures of other factors that may affect outcome measures such as age, gender, language skills or IQ, which are considered protective factors for long-term prognosis (APA, 2000). In addition, the specific diagnosis of the child was not provided, allowing for the possibility that there may be differences in the stress and coping levels of parents of children with different diagnoses on the Autism spectrum. For example, perhaps parents of children with a diagnosis of Pervasive Developmental Disorder – Not Otherwise Specified see their children as less “impaired” than children with an Autism diagnosis, and therefore perceive less stress in relation to parenting them. Additionally, time since diagnosis could have impacted outcome, as studies indicate that parenting stress tends to decrease following a period of time to adjust to diagnosis and grieve (Darling, 1991; Dunlap & Fox, 1996).

This study did allow an average of 9 months of intervention between pre-and post tests. However, given the significant behavioural challenges of children with ASD and the

clinical levels of stress experienced by their parents, 9 months may not have been long enough to have affected measurable change. Given that most children are in the full-day program for up to 3 consecutive years, it would be informative to follow families for the full length of time to ascertain whether or not greater change occurs on these constructs over time. In addition, this study did not account for the possibility of initial changes in stress and coping, which may then have attenuated over the nine month intervention period.

Although there is research to suggest that treatment fidelity is critical to meaningful program evaluation, this study did not attempt to account for integrity of instruction. Given that the children had individualized programs, with a variety of multi-disciplinary therapy teams, it is possible that goals, strategies and program implementation varied considerably across families.

With respect to the measures used in this study, it may have been beneficial to have used an additional behavioural measure to capture the range of behaviours seen in children with ASD, in order to determine which factors of child behaviour or functioning most specifically correlate with higher parenting stress. Also, the CRIS is designed to assist in analyzing coping behaviours in the general population, and is not specific to the coping patterns of parents, particularly those with children with special needs.

Implications for Clinical Practice

The majority of parents in this study reported clinical levels of parenting stress (70%). That decreased parenting stress has been correlated with improved program outcomes (Newsom, 1998; Robbins et al., 1991) suggests the importance of evaluating parenting stress as part of a comprehensive intervention program. Additionally, programs

should ensure that they have an action plan for dealing with stress once it is evaluated. This could involve referral to outside agencies, contracting in services, or hiring trained professionals for that purpose. Reduction of challenging child behaviour, often a core goal of intervention programs, appears to reduce parenting stress, and as such one would expect to see some stress reduction simply by virtue of program involvement. Should this not be occurring, it would be beneficial to examine the reasons why. Additionally, assessment of parent factors such as overall stress, perceptions of coping and access to social supports should occur at key points during a child's program (e.g., baseline, after several months of services, and again prior to dismissal). This would allow service providers to be more informed with respect to having realistic expectations of the families they are working with, and to ensure that appropriate referrals to appropriate supports are being made when most needed.

In addition, the full-day program examined is not creating the reduction in parenting stress anticipated by the level of services it provides to parents. Rather than simply looking to provide more services, it would be advantageous to examine how to better provide current services. As mentioned in chapter two, parenting training is a critical element in successful programming for children with ASD; however, there are challenges such as access to a comprehensive training package and parent availability that often hinder the practice. In the full-day program evaluated, parent availability has already been established, but no clear pathway for parent coaching is delineated in the child's program plan. In order to make the move from focusing solely on child learning, as the half-day program does, to affecting change in both child behaviour and parent coping, it is recommended that a more

structured parent training process be put into place, with staff training on how to consistently implement the strategies.

Implications for Future Studies

In order to better evaluate the full-day program and its ability to reduce parental stress, it would be beneficial to repeat a similar process, but coordinate pre-test data collection with program entry, and post test with completion of the program year. This would decrease confounding factors in interpretation such as length of time in programs, and would coincide with typical assessment periods thus possibly reducing stresses associated with evaluation involvement. It would also be helpful to look at increasing the number of measures used. Rather than relying on child related measures within a parenting stress survey, one could add in child focused measures (e.g., behavioural and adaptive) to try and determine which specific child related factors most significantly impact parental stress. This would be beneficial in helping to target skills and behaviours that would have the most impact on stress reduction. Introducing an incentive factor designed to increase research participation would also likely be beneficial in increasing the relevance of the findings to the whole program, and would improve the reliability of the results.

Also of interest is whether parents of children with ASD experienced higher levels of stress than the general population prior to having children. It could be that the increased stress reported in families of children with ASD are a result of parenting a child with ASD, or these may be people who come into the role of parenting with already qualitatively different perceptions of stress and their ability to cope. Interventions focusing on improving child behaviours and how to handle them would likely reduce stress and increase coping in

cases where that is the primary source of the experienced stress. If the source of the stress is not necessarily children and their special needs, then likely broader supports would be required to assist in reducing stress.

SUMMARY

This study set out to determine whether parents of children with ASD attending a full-day program experienced a greater reduction in stress and increase in coping skills than parents of children in a half-day program. Comparisons were made between these groups before they started their programs, and then following an average of nine months of intervention. A majority of parents in both groups reported stress in the clinical range. Contrary to expectations based on previous literature, parents of children in the full-day program did not experience greater reduction in overall or parenting stress than parents of children in half-day programs. Nor did they report a greater increase in coping ability. Rather, they showed a non-significant gain in overall parenting stress. Certain factors such as location, duration, intensity and expectations of parent involvement in programming may have contributed to increased stress. When changes over time with respect to child behaviours and parenting stress were examined for parents of children in full day programs, a moderate positive correlation was discovered. Although the sample size was small, results of the current study indicate the need for increased monitoring of parenting stress, and how that stress affects outcomes for children with ASD accessing intervention programs. Although the goal of the full-day program was to support parents in feeling more confident about their ability to handle their child's challenging behaviours, it appears that parenting stress did not improve, and the relationship between reduction of challenging behaviours

and decreasing parenting stress was not strong within this group of parents. Overall, results from this study suggest the need for greater monitoring of child behaviours, parenting stress and coping behaviours, and examination of variables within programming such as expectation of parent involvement that may be contributing to ongoing clinical stress levels in parents.

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Appendix A

Initial Notice of Intent to Recruit Participants

December 1, 2006

Dear Parents,

My name is Susan Hendrickson. Some of you may know me through my involvement with Renfrew Educational Services. I am also a Master's student at the University of Calgary in the School Psychology program. I am interested in focusing research efforts for my thesis on children with Autism Spectrum Disorders. In summary, I would like to look at levels of stress and perceptions of coping for parents of children with Autism Spectrum Disorders.

Over the next couple of weeks in your child's school mail, you will receive a copy of a consent form, further explaining the proposed research project. If you would like to be involved, you can complete the form and return it to your child's school. If you would like further information, you can contact me at the number below. Should you decide not to become involved, simply do not return the form.

Thank you for your time,

Susan Hendrickson
291-5038, ext 1881

Appendix B

Notice Accompanying Consent Form

January 8, 2007

As I mentioned in the letter that went home with your child last month, enclosed is a consent form outlining my proposed research study. If you are interested in being involved, please read through the information, and return the signed form with your child marked "Attention: Susan Hendrickson".

If you are not interested, simply do not return the form. Should you have any questions, please contact me anytime at 291-5038 extension 1881.

Thank you, and I look forward to meeting with many of you!

Susan Hendrickson

Appendix C
Consent Form

hi

Name of Researcher, Faculty, Department, Telephone & Email:

Susan Hendrickson, Faculty of Applied Psychology, Department of Education
 291-5038 extension 1881
 shendrickson@renfreweducation.org

Supervisor:

Dr. Tanya Beran Faculty of Applied Psychology, Department of Education

Title of Project:

Stress and Coping in Families with Children with Autism Spectrum Disorders

This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this research study.

Purpose of the Study:

The purpose of this study is to look at levels of stress and coping strategies of parents with children with autism spectrum disorders.

What Will I Be Asked To Do?

If you agree to be a part of this study, you'll be asked to complete two checklists. These should take approximately 30 - 45 minutes to complete. The researcher will be available in person to answer any questions that may arise while completing the questionnaires. You have the right to withdraw your permission for your child's participation in the research at any time, and can withdraw from the study at any time with no consequence to your child's activities at school or in their specialized services program. Upon withdrawal, all information collected will be shredded.

What Type of Personal Information Will Be Collected?

Information collected will include your name, age, gender, your child's specific diagnosis and length of time in programs.

Are there Risks or Benefits if I Participate?

The main benefit in participating in this study for you and your child is increased information regarding the impact of programs for children with Autism Spectrum Disorders. Upon completion of the study you will receive a summary of the results. With respect to risks, there is the possibility that your responses to specific questions within the checklists or the overall profile of your responses may indicate significantly high levels or stress, or significantly low perceptions of ability to cope. Should this be the case, a referral to Renfrew Educational Services' Family Support team can be made, and they may contact you in regards to helping you access any appropriate resources to deal with this.

Should any responses indicate potential or existing harm to another individual, the researcher is required to reveal this information to either the police and/or Children's Services.

What Happens to the Information I Provide?

There will be no names on the questionnaires. They will be numbered and matched to a corresponding list that will include your name, your child's age, gender, specific diagnosis and length of time in programs. No one except the researcher and her supervisor will have access to this list. Only group information will be summarized for any presentation or publication of results. All information will be kept in a locked filing cabinet in a locked office and destroyed after 5 years. Identifying information will **not** be included in the final report or subsequent publications.

Signatures (written consent)

Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this research project, and 2) agree to participate as a research subject.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time, and this will not affect the services you and your child receives at Renfrew. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name: (please print) _____

Participant's Signature _____ Date: _____

Researcher's Name: (please print) _____

Researcher's Signature: _____ Date: _____

Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation, please contact:

Ms. Susan Hendrickson
Department of Education/Faculty of Applied Psychology
291-5038, extension 1881
shendrickson@renfreweducation.org
And (Dr. Tanya Beran, Division of Applied Psychology/220-5667/tnaberan@ucalgary.ca)

If you have any concerns about the way you've been treated as a participant, please contact Bonnie Sherrer, Ethics Resource Assistant, Research Services Office, University of Calgary at (403) 220-3782; email blwebber@ucalgary.ca

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.

Appendix D

Notice Accompanying Checklists for 24 Families at Time of Second Data Collection

November 16, 2007

Dear parents/caregivers:

Thank you so much for your participation so far in my research study on stress and families of children with autism spectrum disorders. As it has been difficult to get in touch with all of you, and you have already completed the first round of checklists with me available to answer questions, and are familiar with the process, I am including the second round for you to complete on your own. Also included is a self addressed stamped envelope for you to return your completed checklist to me in, either through the mail, or in your child's backpack to their Renfrew classroom should this be simpler. Each checklist is numbered so I don't need you to complete any identifying information – just your responses to the questions. I really appreciate the time you have taken to provide me with your answers, and will be sure to send out a summary of all the results once the information is analyzed.

Please call me if you would rather that I came out and met with you again while you go over the checklists, or if you have any other questions for me.

Thanks again!

Susan G. Hendrickson
291-5038 extension 1881

Appendix E
Copy of Ethics Approval

CERTIFICATION OF INSTITUTIONAL ETHICS REVIEW

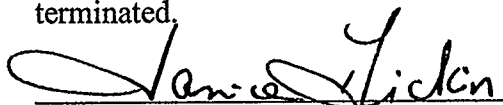
This is to certify that the Conjoint Faculties Research Ethics Board at the University of Calgary has examined the following research proposal and found the proposed research involving human subjects to be in accordance with University of Calgary Guidelines and the Tri-Council Policy Statement on *"Ethical Conduct in Research Using Human Subjects"*. This form and accompanying letter constitute the Certification of Institutional Ethics Review.

File no: 4932
Applicant(s): Susan G. Hendrickson
Department: Applied Psychology, Division of
Project Title: Stress and Coping in Families with Children with Autism
Spectrum Disorders
Sponsor (if applicable):

Restrictions:

This Certification is subject to the following conditions:

1. Approval is granted only for the project and purposes described in the application.
2. Any modifications to the authorized protocol must be submitted to the Chair, Conjoint Faculties Research Ethics Board for approval.
3. A progress report must be submitted 12 months from the date of this Certification, and should provide the expected completion date for the project.
4. Written notification must be sent to the Board when the project is complete or terminated.



Janice Dickin, Ph.D, LLB,

Chair

Conjoint Faculties Research Ethics Board

21 November 2006

Date:

Distribution: (1) Applicant, (2) Supervisor (if applicable), (3) Chair, Department/Faculty Research Ethics Committee, (4) Sponsor, (5) Conjoint Faculties Research Ethics Board (6) Research Services.