Assessing the Diagnostic Experiences and Family Needs of Parents With Autistic Children

by

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ABSTRACT

Though no studies have been conducted in Canada, there are studies suggesting that parents of children with autism experience significant hardships obtaining a diagnosis for their child. Parents were given four questionnaires: a diagnostic survey, providing information on parents' experiences obtaining a diagnosis for their child; the Family Needs Questionnaire, which provided information on what needs parents feel are important, and which of these needs are being met; a questionnaire that assessed autistic symptomatology; and finally, a demographics questionnaire. Results indicate that parents of autistic children experience significant difficulties obtaining a diagnosis for their child, and report greater dissatisfaction with the diagnostic process and services received, as compared to parents of children with Down syndrome. The groups did not differ in the number of perceived important needs nor in the number of needs met. The impact of autistic symptomatology on the diagnostic process and parents self-reported needs is also discussed.

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Dedication

To my wonderful parents, who have given me more love
and support than I ever dreamed possible.
I love you.

Introduction

Autism, which was first described by Leo Kanner (1943) more than half a century ago, is a severe developmental disability affecting approximately 5 out of 10,000 individuals, and is three to four times more common in boys than girls (Diagnostic and Statistical Manual-4th Ed.-Text Revision [DSM-IV-TR]; American Psychiatric Association, 2000). In his original study, Kanner described a group of young children who showed severe language impairments and a failure to develop normal interpersonal relationships, were easily upset by changes in the environment, and who engaged in a pattern of stereotypic and repetitive activities (Kanner, 1943). The DSM-IV-TR (American Psychiatric Association, 2000) now classifies autism as a pervasive developmental disorder (PDD), defined by abnormal development in social interaction, impairments in communication, and a restricted repertoire of interests and activities. The term "autism spectrum disorders (ASD)" (Wing, 1988) will be used throughout this paper, and should be considered interchangeable with the term Pervasive Developmental Disorders used in DSM-IV-TR. It will be used to represent individuals with autistic disorder, Asperger's syndrome, and pervasive developmental disorder-not otherwise specified. Autistic children typically exhibit a range of behavioral deficits in cognition, language, speech, and social functioning (American Psychiatric Association, 2000). These children may also display a range of behavioral symptoms, including hyperactivity, difficulties with attention, impulsivity, aggression, self-injurious behaviors, temper tantrums, strange responses to sensory stimuli, as well as abnormalities in eating, mood, affect, and fear responses (American Psychiatric Association, 2000). Despite the fact that the symptoms of autism can often be detected in a child as young as 12-18 months of age (Howlin & Asgharian, 1999; Osterling & Dawson, 1994), and can be reliably diagnosed by the age of 30 months (Gillberg, Norden, & Ehlers, 1996), on average, the diagnosis does not typically take place until the child is approximately five to six years of age (Howlin & Moore, 1997). Chung, Smith and Vostanis (1995) report that the delay in providing early diagnosis may be due to several factors: 1) the variability in the nature and development of autism in different children; 2) the scarcity of assessment measures suitable for use with preschool age children; 3) a lack of specialized training among professionals dealing with autistic children regarding their ability to recognize the symptoms of autism; and 4) a shortage of specialized services. Still, the early detection and diagnosis of autism in young children is essential for providing services, developing a treatment plan, and for preparing the parents to adapt to a child with a disability (Chung et al., 1995; Konstantareas, 1990; 1989; Siegel, 1996). Early diagnosis is essential to implement early interventions known to have a positive effect on later outcome: early interventions can make the difference between complete dependency and marginal adaptation (Howlin, 1997; Konstantareas, 1990).

Studies have shown that the best indicators for later prognosis in these children include early interventions beginning between the ages of two to four years, the presence of communicative language, and overall intellectual level (American Psychiatric Association, 2000; Howlin, 1998; 1997). Wolf and Goldberg (1986) found that over 50% of the autistic adults in their study required long-term institutional care, confirming that there is a need for life-long planning and assistance for individuals with autism. However, Howlin's (1997) more recent results indicate that over the years there have been improvements in the level of functioning attained by autistic individuals, demonstrated by more people with autism living independently and having jobs, while fewer are spending their lives in hospitals or in other institutional settings.

Obtaining a Diagnosis of Autism

Pfeiffer and Nelson (1992) report that significant changes have occurred in the field of autism in the areas of diagnosis and intervention. These researchers surveyed a sample of experts on autism to discover their views on past progress as well as recent and emerging trends. The professionals surveyed reported substantial progress in basic and applied research as well as increased intervention options in the ten years leading up to the study. However, despite these major advances in the field of autism, Baron-Cohen and colleagues (1996) report that early diagnosis is still relatively rare.

Although a large body of knowledge has been gathered over the last few decades, this information has not been effectively transmitted to some professionals in the fields of general medicine, pediatrics, neurology and even psychiatry and clinical psychology (Konstantareas, 1989). As well, it is important to keep in mind that because of the relatively low incidence of autism[1], many of these clinicians rarely see children with symptoms of autism. This lack of first-hand experience could result in a limited understanding of relevant diagnostic issues. Consequently, many pediatricians and

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[1] Although autism is still a relatively low incidence disorder, there is concern about whether the prevalence of ASD's is rising (Fombonne, 2001). One recent study has shown prevalence rates of 17 per 10,000 for autistic disorder and 46 per 10,000 for other ASD's (Chakrabarti & Fombonne, 2001). Other studies have shown rates as high as 21 to 60 per 10,000 for autistic disorder, and 58 to 121 per 10,000 for all ASD's~~d~~ combined (Arvidsson et al, 1997; Baird et al., 2000; Honda, Shimizu, Misumi, Niimi, Ohashi, 1996; Kadesjo, Gilberg, & Hagberg, 1999).

general practitioners who are first presented with parental concerns regarding their child's poor development of language expression or inconsistent response to sound stimuli often fail to recognize the symptoms of autism and merely refer the child for an otolaryngologic examination to rule out a hearing deficit (Ho, Keller, Berg, Cargan, & Haddad, 1999). Although otolaryngologists are not qualified to make diagnoses of ASD's, they have "a unique opportunity to identify these autistic children and initiate their evaluation and management" (Ho et al., 1999, p. 129). Unfortunately, otolaryngologists also frequently fail to recognize the early presentation of autism. This typically leads to further delay as they are either referred to another specialist or are referred back to their pediatrician or general practitioner who may recommend that the parents "wait and see," despite the potential deleterious effects of putting off treatment (Howlin, 1998).

Several researchers have stressed the necessity for providing an early and accurate diagnosis for the family (Chung et al., 1995; Gillberg, et al., 1996; Howlin, 1998; 1997; Konstantareas, 1990; Siegel, 1996). Receiving an accurate diagnosis has two very important purposes: 1) the diagnosis is a label that can lead to an appropriate treatment plan; and 2) the diagnosis is crucial to receive needed services (Siegel, 1996). A diagnosis of autism provides parents with options to begin treatment for their child. The diagnosis should not just tell the parent what is wrong with their child, but should also provide the parents with answers regarding what to do for their child (Siegel, 1996). Most brain growth, as well as many fundamental aspects of learning, takes place in the first six years of life. Thus intervention prior to the age of six years is crucial (Siegel, 1996). Since the timing of diagnosis has a direct impact on how soon treatment is obtained, early diagnosis can ultimately change the quality of the child's life. The diagnosis of autism also provides the family with access to various resources and services that can help treat the child, as well as providing parents with ways to cope with the often-stressful effect of having a developmentally delayed child in their family (Konstantareas, 1990). The insufficient availability of special programming for individuals with autism in Canada leads to long waiting lists for these services (Konstantareas, 1990). The earlier the child is diagnosed, the earlier they will be able to get on these waiting lists, and the earlier the child will be able to obtain the services needed.

Konstantareas (1989) points out that some clinicians will give a child an ambiguous diagnosis such as "autistic tendencies" rather than a diagnosis of autism. The implications of such an ambiguous diagnosis are that many treatment agencies and school boards (for example, in Ontario) are not able to offer services to a family without a formal diagnosis of autism, and will only treat clients that meet stringent diagnostic criteria mandated by the Ministry for Child and Family Development. Also, school boards cannot provide appropriate placements unless the child has been given an unambiguous diagnosis, and access to community services such as week-end relief homes, child care workers, special summer camps, athletic facilities and other community facilities are not available without an autism diagnosis, leading to adverse implications both for the child and for the family trying to cope with their "special needs" child (Konstantareas, 1989, 1990).

Satisfaction with the Diagnostic Process

Many researchers have reported that a positive experience within the diagnostic process has a significant impact on a parent's initial reaction to the diagnosis of a developmental disability (Cottrell & Summers, 1990; Leff & Walizer, 1992; Quine & Pahl, 1987; Stallard & Lenton, 1992; Woolley, Stein, Forrest, & Baum, 1989). In spite of the importance of a positive diagnostic experience, many parents of children with autism remain dissatisfied with this process (Howlin & Moore, 1997; Smith, Chung, & Vostanis, 1994). Howlin and Moore (1997) recently conducted a survey of over 1200 families belonging to autism support groups in the United Kingdom, in which parents were asked about their experiences in obtaining a diagnosis for their child. They found that: 1) parents who had received an early diagnosis were more satisfied with the diagnostic process than those who had to wait longer; 2) parents who had received a clear-cut diagnosis of autism or Asperger syndrome were more satisfied with the diagnostic process than those receiving a more vague diagnosis of autistic "traits," "features," or "tendencies;" 3) parent satisfaction was unrelated to the current age of the child; 4) abnormalities in communication were the principal initial source of concern for the majority (40%) of parents, and just under 20% were initially anxious about their child's social development; 5) differences in the ages at which children living in different areas received a diagnosis were not clearly associated with the extent of professional expertise available in those areas; and 6) diagnosis was made earlier for the younger children in the survey, suggesting that children are beginning to be diagnosed at younger ages. However, regarding the latter point, years since the diagnosis was made was not controlled for, and therefore it is not possible to conclude that diagnoses are in fact occurring at younger ages. These researchers also found that parents needed to persist to obtain a diagnosis for their child: only eight percent received a formal diagnosis upon their first visit with a professional, only 40 percent received the diagnosis after a referral to see a second professional, and the majority, 63 percent obtained a diagnosis for their child only after their third visit with a professional. Howlin and Moore (1997) reported that 49 percent of the parents surveyed were "not very" or "not at all" satisfied with the diagnostic process indicating that parents' attempts to obtain a diagnosis for their child are laden with delays and frustrations.

Other researchers have also found that dissatisfaction in the diagnostic process was related to the child's age at diagnosis. Parents of children diagnosed when they were younger were more satisfied with the diagnostic process than parents of older children (Quine & Pahl, 1986). It has also been found that *how* the parents were given the diagnosis also affected their satisfaction with the diagnosis, possibly influencing their long-term feelings about professionals (Quine & Pahl, 1986). Researchers have found that parents want to be told as early as possible if there is something wrong with their child; they want to be told in a sympathetic, caring and honest way; and they want to be given full information about their child's condition (Cottrell & Summers, 1990; Quine & Pahl, 1986). Firth (1982) found that, frequently, parents' expectations of support from health care professionals were not met: parents wanted more information and wanted someone to talk to about their child's condition.

Contrary to the literature citing dissatisfaction with how the diagnosis of autism was given, Piper and Howlin (1992) found that two weeks after the initial assessment, 87 percent of parents were "very" or "fairly" satisfied with the way the diagnosis was given.

Interestingly, at a later follow-up, levels of satisfaction were lower than those reported two weeks after the initial assessment. Piper and Howlin (1992) interpreted these lower levels of satisfaction as being due to the fact that parents anticipated ongoing support in a variety of ways, and many felt that they had not received the help they had been promised or that not enough help had been offered. These researchers also report that the parents' expectations were often unrealistic and that identifying families' expectations prior to their appointment may be useful in planning the feedback discussion.

Stallard and Lenton (1992) surveyed parents of pre-school children with a variety of special needs to assess how satisfied these parents were with the services they had received. They found an overall high level of satisfaction amongst this group of parents. However, 29 percent of the parents felt they had not received enough information on their child's condition, 61 percent felt they had not received enough information about their child's future, and 32 percent felt they had not received enough understanding from professionals regarding their concerns. This indicates that although parents were somewhat satisfied with the services they were receiving, they still felt that professionals could offer more support and information.

Patient satisfaction with the medical system has been shown to be an important outcome measure because it increases the predictability of utilization: patients who are satisfied with the medical system are more likely to use medical services in the future when they are needed, whereas patients who are dissatisfied are less likely to use medical services even when they need medical attention (Fitzpatrick, 1991; Roghmann, Hengst, & Zastowny, 1979). This finding suggests that parents' initial satisfaction with the diagnostic process will influence their future decisions to seek professional help for their child. Consequently, dissatisfaction in the initial diagnostic process may have a major impact on subsequent interactions between the parent and the health care provider, as well as on the parents' decision to seek help from the medical community.

Adjusting to the Diagnosis of Autism in One's Child

As previously discussed, early diagnosis is crucial for beginning intervention with the child, as well as to obtain services for the parents. Marcus (1984) points out that early diagnosis is also important in order for parents to begin the process of coming to grips with the "painful reality" of having a disabled child for life. Some investigators have simply listed and/or described common parental reactions to the diagnosis, while others have developed models describing coping reactions of parents. Regardless of the approach taken, most researchers agree that parents experience a wide range of psychological changes and adaptations following the diagnosis of their autistic child.

Several researchers have noted that parents' initial reactions to the diagnosis are similar to the stages of grief that are experienced when a loved one dies or when one experiences an intense crisis: shock, numbness, grief, anger, helplessness, rage, disbelief, blame, guilt, hopelessness and resentment (Bentovim, 1972; Leff & Walizer, 1992; Siegel, 1996). Fear and isolation are also commonly felt by parents following the diagnosis of their child (Leff & Walizer, 1992). Coping with a diagnosis of autism is also felt to be more of a burden than the diagnosis of other handicaps or developmental disorders, because an autistic child is impaired in social interaction and therefore does not provide the parent with positive reinforcement in the same way that a child who engages in social reciprocity (Siegel, 1996).

Many families try to cope with the unsettling news that their child is autistic by denying the problem: these families might believe that the child will grow out of his or her problems or that the differences observed in the child's development are unique expressions of his/her individuality (Siegel, 1996). Parents may also "grasp at straws" by turning to radical unscientific or unproven treatments in the belief that their child can be cured (Siegel, 1996). More healthy coping styles include the gathering of information about their child's disorder, as well as turning to support groups (Leff & Walizer, 1992). These initial contacts with "senior families" with an autistic child can bring great comfort to families just learning about their child's disorder. The support group can answer many of the parents' questions, as well as to listen to, and understand, the families' emotional reactions to the diagnosis.

Coping and Adaptation in Families with an Autistic Child

Stress has been defined as the individual's response to life-strains, demanding events, or crises consisting of a pattern of physiological and psychological reactions that can be both immediate and delayed (Rabkin & Struening, 1976). Responses such as marital problems, parental concerns, family problems, and child symptomatology have all been documented as indicators of stress in parents of autistic children (Bristol, 1984; Bristol, Gallagher, & Schopler, 1988; Donenberg & Baker, 1993; Donovan, 1988; Fisman & Wolf, 1991; Henderson & Vandenberg, 1992; Holroyd & McArthur, 1976; Konstantareas, 1991; Konstantareas & Homatidis, 1989; Liwag, 1989; Milgram & Atzil, 1988; Sanders & Morgan, 1997; Wolf, Noh, Fisman & Speechley, 1989). Coping has been defined as the things people do to avoid being harmed by the stresses in their lives (Pearlin & Schooler, 1978). A great deal of research has been conducted over the last two decades assessing parents coping styles and successful adaptation to having an autistic child (Bristol, 1984, 1987; Bristol et al., 1988; Donovan, 1988; Henderson & Vandenberg, 1992; Konstantareas, 1991; Liwag, 1989; Morgan, 1988; Sanders & Morgan, 1997; Siegel, 1996; Tunali & Power, 1993).

Stress levels in parents of autistic children have been measured and compared to stress levels in parents of children with externalizing behaviors (e.g. hyperactivity, noncompliance, aggression), mental retardation, Down syndrome, other developmental delays, as well as parents of children from outpatient psychiatric clinics, and parents of typically developing children (Donenberg & Baker, 1993; Donovan, 1988; Fisman & Wolf, 1991; Holroyd & McArthur, 1976; Koegel, Schreibman, O'Neill, & Burke, 1983; Konstantareas & Homatidis, 1989; Rodrigue, Morgan, & Geffken, 1992; Sanders & Morgan, 1997; Wolf et al., 1989). Higher levels of stress were found in the autism group using parent self-report measures that assess relative stress within the parent-child system (e.g. Parenting Stress Index [Loyd & Abidin, 1985]), parents' attitudes and feelings (e.g. Questionnaire on Resources and Stress [Holroyd, 1974] and Questionnaire on Resource and Stress-Revised [Friedrich, Greenberg, & Crnci, 1983]), and parental coping and adjustment (e.g. Coping Health Inventory for Parents [McCubbin, McCubbin & Cauble, 1979]). Most of these studies report that parents of autistic children exhibited more stress and poorer coping than parents in the other groups investigated, with a couple of notable exceptions. Donenberg and Baker (1993) found that parents of children with externalizing disorders reported levels of stress as high as those reported by parents of children with autism. Similarly, Rodrigue and colleagues (1992) found no difference in stress levels between fathers of autistic children and fathers of children with Down syndrome. Finally, Koegel and colleagues (1983) found similar levels of general stress in the parents of autistic children as compared to parents of typically developing children. It is important to note, however, that Koegel et al.'s (1983) conclusions are based on measures of marital happiness, parental personality characteristics, and the familial social system. They did not use any direct measures of parental stress levels that would support their conclusions that general stress levels in the parents of autistic children are not higher than those found in the parents of typically developing children.

Researchers have rigorously studied factors predicting stress in parents of autistic children and have found extensive sources of stress (Bentovim, 1972; Bristol, 1984; Holroyd & McArthur, 1976; Konstantareas, 1991; Konstantareas & Homatidis, 1989; Liwag, 1989; Sanders & Morgan, 1997). Contradictory evidence has been posed regarding the impact of the severity of the child's disorder on inducing stress in parents. Bristol et al. (1988) have found that the severity of the child's disorder is a poor predictor of family adaptation, while Henderson and Vandenberg (1992), Konstantareas (1991), and Bristol (1984) have reported that the severity of the child's disorder was a significant factor in family adjustment and was positively correlated with stress.

Bristol (1984) reports ambiguity as a high risk factor for eliciting stress in parents of autistic children. She reports that the child's normal physical appearance can lead to ambiguity regarding whether the child is in fact handicapped. The ambiguity of the handicap causes stress for the parent in terms of accepting the diagnosis as well as with respect to gaining acceptance and understanding from the community when the child appears physically normal but behaviorally acts out. Also, the ambiguity of having a mildly impaired child can make it difficult for parents to gauge what are realistic expectations for their child. In Konstantareas and Homatidis' (1989) investigation of stressful factors for the parents of autistic children, they found that the child's self abuse behaviours were the most stressful for parents, followed by having an older adolescent with autism. These researchers also found that mothers tended to be more stressed than fathers, congruent with the fact that most mothers take on more of the parenting burden. Perhaps this explains the previously mentioned finding that fathers of autistic children did not exhibit more stress than fathers of children with Down syndrome (Rodrigue et al., 1992).

The disabilities associated with autism itself seem to also cause a great deal of concern for most parents (Konstantareas, 1991; Liwag, 1989). Liwag (1989) found that families were most stressed by several of the symptoms of autism such as lack of speech, hyperactivity and tantrum behaviour. Konstantareas (1991) additionally found that behavioural oddities in the form of self-stimulation, such as flapping, mouthing objects, twirling, and finger gazing, were rated as very stressful by parents.

The long-term effects of having a child with autism tend to also create a great deal of stress for many parents (Bentovim, 1972; Liwag, 1989; Sanders & Morgan, 1997). Parents have reported stress dealing with the permanence of their child's condition and the knowledge that their child will never be normal (Liwag, 1989); parents must deal with the disappointments regarding their child's delays in reaching developmental milestones (Bentovim, 1972); and parents report a great deal of stress trying to find the time and energy to make effective use of the little free time they get (Sanders & Morgan, 1997).

In a study comparing reports of stress from mothers of children with autism, mothers of children with Down syndrome, and mothers of children being seen at an outpatient psychiatric clinic, Holroyd and McArthur (1976) found that the mothers of autistic children scored higher on the Questionnaire on Resources and Stress (Holroyd, 1974) than both other groups. Compared to mothers of children with Down syndrome, mothers of autistic children were more upset and disappointed about their child, as well as more concerned about their child's dependency, the effect of their child on the rest of the family, a lack of available activities to keep their child busy, and were more aware of personality problems in their child. This study demonstrates the multitude of concerns and stresses that parents of autistic children must deal with on a day-to-day basis throughout the life of their child.

The Effect of Supports and Services on Family Adjustment

The influence of social support on the family's healthy adaptation has been well documented over the last five decades (Hill, 1949; McCubbin & Patterson, 1983). Social support has been defined as "information leading the person to believe that he is cared for and loved, valued and esteemed, and is important in a network of mutual obligation and communication" (Cobb, 1976). Examples of social support include support from one's spouse, extended family, and friends; the availability of leisure time in which one can engage in recreational activities; as well as support from community programs, professional help, and the availability of services and programs geared towards families with a disabled child. Families that receive these supports exhibit healthier adaptation to having a child with autism (Bristol, 1984, 1987; Donovan, 1988; Fisman & Wolf, 1991;

Henderson & Vandenberg, 1992; Konstantareas & Homatidis, 1989; Milgram & Atzil, 1988; Sanders & Morgan, 1997; Wolf et al., 1989).

Supportive relationships are important for healthy adaptation (Bristol, 1987). Families who have adequate support from spouses, immediate and extended family, as well as other parents from support groups, report happier marriages, are less stressed, and are rated as having better family adaptation (Bristol, 1984, 1987). Displaying a high degree of commitment, and help and support within the family, are all factors that lead to a greater capability in coping with the autistic child. Interestingly, parental life satisfaction has been shown to be unrelated to the autistic child's symptomatic behaviour, but is, however, highly related to the parents' needs from their partners, implying that spousal support is crucial for healthy adjustment in dealing with an autistic child (Milgram & Atzil, 1988).

A second area that affects family adaptation is the availability of leisure time and recreational activities for the parents of autistic children (Bristol, 1984; Sanders & Morgan; Tunali & Power, 1993). Due to the significant amount of time needed to provide autistic children with daily therapy or treatment, both the amount and flexibility of spare time are greatly reduced in these families (Tunali & Power, 1993). Families with autistic children also experience a great deal of stress in trying to find time and energy for even a little leisure activity. Also, parents of autistic children report negative feelings about their child's odd behaviours, placing them at risk for withdrawing from others, into the family and not making effective use of social supports and activities in the community that may help to alleviate their stress (Sanders & Morgan, 1997).

Studies examining the recreational habits of mothers of autistic children have all found that these mothers report less involvement with people, and less participation in recreational and sporting activities outside of their household, as compared to families without a handicapped child (Bristol, 1984; Sanders & Morgan, 1997). Although these activities can greatly reduce stress, mothers of autistic children view them as being less available because they do not have the time or energy to engage in activities outside of the home (Sanders & Morgan, 1997). Parents report that the lack of trained baby-sitters and respite care makes participating in recreational activities very difficult (Bristol, 1984). Sanders and Morgan (1997) conclude that respite care and baby-sitting are very important services that should be provided to parents of autistic children, so that parents have an opportunity to spend time away from the demands of their autistic child, and engage in recreational, cultural and intellectual activities. The activities help reduce stress and give parents a chance to spend time together.

It has been well documented that successful family adaptation depends on adequate educational, recreational, medical and other family supports (Bristol, 1984; Donovan, 1988; Henderson & Vandenberg, 1992). Family support has been defined as "services, resources and other types of assistance that enable individuals with developmental disabilities of any age to live with their families and to be welcomed, contributing members of their communities" (Freedman & Boyer, 2000). These types of supports include respite services, home health care, family education and training, family counseling, and support groups (Freedman & Boyer, 2000).

Studies have found that parents with more activities and services available to them, tend to show low levels of stress as well as having better prospects of independent living for their autistic child (Bristol, 1984). When examining mother's coping styles in particular, mothers have been shown to strongly rely on community resources, professional help, affiliated agencies, and programs outside of the family for successful coping (Donovan, 1988; Henderson & Vandenberg, 1992). The availability of adequate child care and respite arrangements is crucial for the parents' own relationship: being able to invest time in each other leads to a healthy relationship between the parents, which ultimately leads to long-term benefits for the autistic child (Bristol, 1984).

Konstantareas (1991) points out that it is not just the number of supports that should be considered when discussing the influence of supports on healthy adaptation in families with autistic children. In fact, in one study, Konstantareas and Homatidis (1989) found that parents of autistic children received just as much support as parents of normally developing children. The difference was in the quality of the support received by the two groups of parents: the parents of autistic children reported receiving aggravations from more of the same agencies compared to the parents of the developmentally normal children, and also reported receiving a greater degree of aggravation from the individual agencies (Konstantareas & Homatidis, 1989). In a subsequent study, Konstantareas (1991) found that mothers of mentally retarded children reported receiving the same amount of aggravations from these agencies as mothers of developmentally normal children, but that mothers of autistic children reported more aggravations than both of the comparison groups. Konstantareas (1991) noted "it is the net product of supports versus aggravations, not just supports, that has to be considered."

Finally, parents' *beliefs* about receiving adequate social support for themselves and their child have been shown to be very important for successful family adaptation

(Bristol, 1984; Donovan, 1988; Wolf et al., 1989). Bristol (1984) found that the strongest indicator of healthy adaptation and coping in the family was the amount of *perceived* support the mother received from her spouse. In the same study, parents reported that their most important coping strategy was the belief that their child's program had the family's best interests in mind, indicating that the *belief* that their child is receiving appropriate services is vital for parents' to cope with the ongoing stresses related to having a child with autism (Bristol, 1984). Social support, or the *perception* of social support, can also decrease the impact of stress on depression in mothers of autistic children, indicating that social support plays an important role in maintaining the mental health of these parents (Fisman & Wolf, 1991; Wolf et al., 1989).

The overwhelming evidence leads us to conclude that formal services and programs are very important for the successful adaptation of the family of a child with autism. Mothers of autistic children who *perceive* supports to be helpful have been shown to cope more successfully (Donovan, 1988). Consequently, professionals and agencies that provide these specialized services to families of autistic children should be monitoring parents' perceptions of their programs and responding to the needs identified by the families in order to promote healthy adaptation (Donovan, 1988).

In a study examining the most important coping strategies, or needs, in parents of autistic children, Bristol (1984) found the following results: 1) believing that my child's program (Treatment and Education of Autistic and related Communication handicapped Children, [TEACCH]) has my family's best interest in mind; 2) learning more about how I can help my child improve; 3) believing in God; 4) talking over personal feelings and concerns with my spouse; 5) building a closer relationship with my spouse; 6) trying to maintain family stability; 7) developing myself as a person; 8) telling myself that I have many things I should be thankful for; 9) doing things with my children; and 10) believing that my child will get better. This list of coping strategies represents some of the core areas necessary for family adaptation: the belief that their child and family was receiving adequate and appropriate services and education was ranked as most important, followed by family support, and then time to do things for themselves or with their family (recreational support). The fact that adequate educational and professional services were ranked as the most important coping strategy suggests that the service delivery system plays an important role in family adaptation (Henderson & Vandenberg, 1992).

Agosta (1989) discusses three fundamentals that family supports should embody: 1) services should both enable and empower parents to make informed decisions regarding their disabled child; 2) services should be open to the needs of the entire family; and 3) services should be flexible in accommodating to the unique needs of individual families. Unfortunately, many parents feel that the services available to them are not living up to these basic axioms of health service delivery (Freedman & Boyer, 2000). Parents report the service system as being too "crisis-driven." These parents feel that the service system for developmentally delayed children and their families does not pay enough attention to proactively supporting families, nor in engaging in measures designed to prevent maladaptive functioning in these families (Freedman & Boyer, 2000).

Although parents of developmentally delayed children report significant improvements in the flexibility and number of family supports available over the past two decades, various needs have still been unmet by the service delivery system (Freedman &

Boyer, 2000). Parents reported unmet needs in the areas of types of services and supports, socialization and community inclusion opportunities for their child, as well as education and advocacy (Freedman & Boyer, 2000). More specifically, parents reported a need for more consistent behavioral, physical, occupational, and speech therapy for their children; a need for therapies and services to continue through the summer months when there was no school; the need for psychological counseling for parents and siblings of a developmentally delayed child; the need to look at the child as a part of the family unit, rather than as a separate being; the need for social and recreational opportunities for their developmentally delayed child; the need for services to be coordinated across agencies; and finally, the need for public education and advocacy to educate professionals about the needs of the child and the family.

Summary and Hypotheses for the Study

The literature clearly indicates that parents of children with autism experience significant hardships in attempting to obtain a diagnosis for their child. Parents typically are first aware of some problems sometime between their child's first or second birthday, but on average must wait until the child is between five and six years of age to obtain a formal diagnosis. During the long and stressful diagnostic process, parents typically see several professionals, and are often told to "wait and see" whether the child is going through a phase, or is truly developmentally delayed. The implication of delaying treatment for these children has been well documented: the earlier intervention is started, the better the chances for higher functioning in individuals with autism. The early intervention literature clearly spells out the need for early diagnosis of this population. By gathering information regarding the current diagnostic process in British Columbia, problems can be identified and recommendations can be made for the modification of the process to ensure earlier diagnosis for autistic children and less distress for their parents.

Following the diagnosis of autism, many parents typically experience a series of emotions including shock denial, grief, resentment, hopelessness, guilt, and helplessness. However, following these responses to the initial diagnosis of autism, as well as to the realization of the long-term consequences of having a child with autism, several types of supports can be utilized in order to adapt more successfully to having a child with this disorder. Studies have indicated that support from one's spouse, extended family, friends and support groups can lead to healthy adaptation in these parents. Also, community supports such as respite, baby-sitting, recreational programs for the families and the children with autism, and educational programs can provide parents with the time and information they need to successfully adapt to having a child with autism. Although several studies have reported on the types of supports and coping strategies that are effective in adapting to an autistic child, very few studies have examined parents self-reported needs, and only one study has examined the types of needs parents felt were not being met. As well, in spite of the overwhelming evidence regarding the importance of parents *perceptions*, to date no study has examined which needs parents feel are most important and, at the same time, determined which of these needs parents felt were being met.

This study endeavors to evaluate the diagnostic experiences of parents of autistic children, as well as determine which needs parents feel are most important and whether these needs are being met. Another goal of the present study was to develop a new measure of family needs that would be specific to parents of children with autism and

Down syndrome, as well as to develop a new measure that would produce scores for the three domains of autistic symptomatology: communication impairments, social impairments, and behavioral difficulties. The goal was to develop these scales so that they could be analyzed and explored using Rasch analysis, a new method of scale development that allows the investigator to determine whether the items form a unidimensional construct, to calibrate the items on an interval scale, and to measure each participant on the construct in question (Fox & Jones, 1996)

In order to determine how the experiences and needs of parents of autistic children are unique when compared to parents of children with other developmental disorders, parents of children with Down syndrome will be used as a comparison group.

This group of parents was selected based on the similarities and differences with parents of autistic children. Both groups of children represent a severe disability associated with some intellectual handicap, both exhibit life-long delays in functioning, and both autism and Down syndrome tend to have considerable variation in the degree of impairment within each group (Sanders & Morgan, 1997).

It is expected, however, that the dissimilarities between the two syndromes will lead to different diagnostic experiences and needs for the parents. Down syndrome is typically diagnosed in utero or at birth due to physical abnormalities such as unusual facial appearance and lack of muscle tone. The diagnosis can be confirmed through a genetic test that results in an unambiguous diagnosis. Autism, on the other hand, is often diagnosed at a much older age and the normal, and often physically attractive, appearance of the child may lead to doubts and ambiguities regarding the existence of a disorder. Also, the inconsistency of the autistic child's development (behavioural regression, variable cognitive functioning, extreme behavioural disturbances) leads to frustrated parents who are unsure regarding what expectations they can hold for their child's current functioning and later prognosis (Rodrigue et al., 1992). On the other hand, children with Down syndrome typically are delayed in all developmental aspects allowing for clearer parental expectations regarding the child's true abilities and life-long prognosis (Rodrigue et al., 1992). The lack in social reciprocity from children of autism as well as their behavioural disturbances and language deficits, tends to make this disorder more difficult and stressful for parents. Down syndrome children are often more sociable by nature than those with autism and therefore provide the parents with more positive reinforcement and less stress. Finally, early intervention treatment programs are equally important for both groups, in terms of long-term prognosis; however, these programs have tended to be more readily available to children with Down syndrome than for children with autism (Rodrigue et al., 1992).

In summary, the comparison group was selected based on the similarities in intellectual handicaps, developmental delay, as well as life-long dependence on the parents, and because of differences in the way the child is diagnosed, the physical abnormalities in the disorders, the behavioural disturbances, and the social functioning of the two groups. Given the similarities and differences between the autistic group and the Down syndrome group, the predictions for the current study are as follows:

A. Diagnostic Experiences

1. Parents of children with autism will report more difficulties with the diagnostic process than parents of children with Down syndrome. The parents of autistic children will report having seen more professionals in obtaining the

diagnosis, having a greater delay in obtaining a diagnosis following their initial concerns, their child will have been significantly older when the formal diagnosis was obtained, and they will report less satisfaction with the diagnostic process and the support services they have received as compared to parents of children with Down syndrome.

2. Parents of autistic children that were diagnosed more than ten years ago will report more difficulties (e.g. more professionals seen, child diagnosed at an older age) obtaining a diagnosis for their child than the parents of the younger autism group
3. Parents of the younger children with autism will report more satisfaction with the diagnostic process and the services received than the parents of the older children with autism.

B. Self-Reported Needs

1. Parents of autistic children will report similar needs as being important, but will report less of these important needs as having been met, as compared to parents of children with Down syndrome
2. As the time post-diagnosis increases, parents of these older children will report fewer needs as having been met, as compared to parents of children who have more recently been diagnosed with autism.

C. The Relationship Between Diagnostic Experiences and Self-Reported Needs

1. Parents of autistic children who reported dissatisfaction with the diagnostic process will report fewer needs as having been met.

Method

Design

The study used a within-group design for the majority of analyses conducted (parents of autistic children group [AUTISTIC group]). A between-subjects comparison of two groups of participants (AUTISTIC group and parents of children with Down syndrome group [DOWN'S group]) was conducted for select analyses.

Participants

Participants for the AUTISTIC group were recruited through an autism support group in British Columbia (the Autism Society of British Columbia, [ASBC]). Questionnaires were mailed out to community support groups throughout the province of British Columbia and were also distributed at a parent/teacher workshop on autism. Parents with children between the ages of 2 and 18 years were asked to complete the questionnaires and mail them to the University of Victoria. The participants of the DOWN'S group were recruited through the Down Syndrome Research Foundation (DSRF) in Vancouver, British Columbia. Questionnaires were mailed out to the parents on their member list who have children between the ages of 2 and 18 years. To be included in the study, the child either had to have a formal diagnosis of an autism spectrum disorder (including autistic disorder, Asperger's disorder, or PDD-NOS) or Down syndrome, and be between the ages of 2 and 18. Participants were excluded if there was a dual diagnosis of autism and Down syndrome.

Three hundred questionnaire packets were distributed to parents of autism spectrum disorders and 60 were returned (20 percent return rate). One hundred fifty questionnaire packets were distributed to parents of children with Down syndrome and 34 were returned (23 percent return rate). Of the 94 questionnaires returned, six participants were excluded from the study as the respondent's child was older than 18 ($n = 1$; 1 AUTISTIC), no formal diagnosis of an autism spectrum disorder ($n = 3$; 3 AUTISTIC), or having a dual diagnosis of autism and Down syndrome ($n = 2$; 2 DOWN'S).

Eighty-eight total participants met selection criteria (AUTISTIC = 56; DOWN'S = 32). Group means and standard deviations and frequencies for the demographic variables of the participants' families can be seen in Table 1. Independent samples t-tests or chi-square statistics were run to compare these characteristics across the two groups. Group comparisons revealed the following: 1) the current age of the children in the DOWN'S group was significantly greater than those in the AUTISTIC group ($F(1, 86) = 12.21$, $p<.01$); 2) the mothers and fathers in the DOWN'S group were also significantly older ($F(1, 86) = 14.62$, $p<.01$; $F(1, 85) = 6.70$, $p<.01$); 3) there were more girls in the DOWN'S GROUP ($X^2(1) = 9.309$, $p<.01$); 4) the AUTISTIC group was more likely to have other children in the family with developmental disorders ($X^2(1) = 4.145$, $p<.05$), and; 5) the children in the DOWN'S group were more likely to have medical problems ($X^2(1) = 5.969$, $p<.05$). The groups were similar in all other areas measured.

Table 1.
Characteristics of Study Participants

	Group	
Demographic Variable	AUTISTIC (n = 56)	DOWN'S (n = 32)
Current Age of Child (years)**		
M	7.98	11.08
SD	3.36	4.87
Range	3.50 - 18.00	2.17 - 18.00
Time since Diagnosis made (years)**		
M	2.96	11.00
SD	2.35	4.81
Range	-.08 - 9.00	2.17 - 18.75
Mother's Age (years)**		
M	38.54	43.60
SD	5.80	6.26
Range	24.00 - 50.00	33.00 - 55.00
Mother's Years of Education (years)		
M	14.85	14.55
SD	2.26	3.10
Range	11.00 - 20.00	5.00 - 20.00
Number of male children**		
n	39	12
%	69.6	37.5
Number of 2-parent families		
n	48	29
%	85.7	90.7
Number of participants who were mothers		
n	51	31
%	91.1	96.9
Living in Urban Areas		
n	28	19
%	50.0	59.4
Child has Comorbid Psychological Disorders		
n	12	3
%	21.4	9.4
Child has Medical Problems**		
n	20	20
%	35.7	62.5
Other Children in Family with Developmental Disorders*		
n	13	2
%	23.2	6.3

*Significant group difference, $p<.05$. **Significant group difference, $p<.01$.

Table 2 summarizes the different diagnoses of the children in the AUTISTIC group. The majority of the group was diagnosed with Autistic Disorder, with a much smaller percentage being diagnosed with PDD-NOS, Asperger's, or a vague diagnosis such as autism spectrum disorder.

Table 2.
Diagnoses of Children with Autism Spectrum Disorders

Diagnoses	AUTISTIC (n = 56)
Autistic Disorder	
n	48
%	76.2
Asperger's Syndrome	
n	5
%	7.9
Pervasive Developmental Disorder- Not Otherwise Specified	
n	3
%	4.8
Autistic Traits or Features	
n	4
%	6.3
Other	
n	3
%	4.8

Measures

Diagnostic Survey

The Diagnostic Survey (Howlin & Moore, 1997) is a 33-item questionnaire designed to assess the problems faced by parents in obtaining a diagnosis for their children with autism (see Appendix A). The measure provides information about the age at which parents first became concerned about their child's development; the reasons for these concerns; the age at which help was first sought; the professional(s) seen; the number of and ages at subsequent referrals; the final diagnosis obtained; and satisfaction with the diagnostic process and the help received following diagnosis. The original Diagnostic Survey by Howlin and Moore (1997) was modified to be more appropriate to the medical system in Canada, as well as to assess additional information on parent stress levels, and child language and intellectual impairment.

The original questionnaire was reviewed by a group of parents to ensure that it was easily understandable, easy to complete, and comprehensive (Howlin & Moore, 1997). The modified version used for this study was also given to a set of parents (not included in the study), and they reported that the questionnaire took approximately 45 - 60 minutes to complete, was readable and easy to complete.

Family Needs Questionnaire

Kreutzer (1988) developed the Family Needs Questionnaire to assess family needs and how well these needs were being met in parents and family members of *adults* with Traumatic Brain Injury (TBI). Waaland, Burns and Cockrell (1993) modified the Family Needs Questionnaire to make it more pertinent to children with TBI. Since its development, the Family Needs Questionnaire (FNQ) has been shown to have adequate reliability and validity for the assessment of perceived 'family needs' in family members of TBI patients (Kreutzer, Serio & Bergquist, 1994; Serio, Kreutzer & Witol, 1997).

Although the FNQ has only been used in parents of individuals with TBI, many of the cognitive, behavioural, and emotional disturbances in children with TBI are similar to those of individuals with autism: both groups may exhibit disruptive, often embarrassing, behaviours; both groups may show mild to profound intellectual impairments; and both groups may exhibit mild to significant impairments in social functioning. Parents of both autistic children and children with TBI report feelings of helplessness, denial, anger, and guilt when the child is first diagnosed or injured. Both sets of parents fear that their child will never reach independence (Lezak, 1988; Liwag, 1989). Finally, coping with their child's disorder is a long and difficult process for parents of autistic children and parents of children with TBI.

The Family Needs Questionnaire used in this study was modeled around Waaland and colleagues (1993) Child Version of the FNQ (see Appendix B). It was modified in order to obtain information specific to the needs of families of children with autism or Down syndrome. Twenty-three questions were used from Waaland et al.'s (1993) Child Version of the FNQ and thirty-one new questions were added. The new questions were chosen based on a review of the literature, clinical experience working with the families of autistic children, and from discussions with members of some of those families. This modified FNQ is a 51-item questionnaire that provides information regarding the extent to which needs are perceived as important (not important/slightly important/important/very important), as well as how well these needs have been met (yes/no/partly).

Factor analysis of the adult questionnaire has revealed six scales (Serio et al., 1997): 1) health information; 2) emotional support; 3) instrumental support; 4) professional support; 5) community services; and 6) involvement with care. No research has been conducted to address the factor structure of the Child Version of the FNQ, but it is likely that it does not differ significantly from the adult version since the two measures still attempt to measure the same domains.

A Rasch analysis was conducted on the new modified FNQ created for this study to determine its reliability and to determine which participants had greater self-reported 'overall needs' using this new statistical scoring method.

Currently, the method most used in scale development involves administering a group of items that assess the same construct and summing the responses to form a total score (Fox & Jones, 1998). This method involves equally weighted items, and treats items as if they fall on an interval scale (Kindlon, Wright, Raudenbush, & Earls, 1996). However, when items are weighted equally, this suggests that all of the items are of equal importance in assessing the construct in question. Fox and Jones (1998) provide an example to demonstrate this point:

> "For example, items measuring anxiety with respect to mundane events (such as asking a sales clerk for help) are weighted the same as those measuring anxiety in more extreme situations, such as speaking in front of a large crowd. It seems nonsensical to treat endorsement of both of these qualitatively different items as equal contributors to a total anxiety scale (p. 30)."

Kindlon and colleagues (1996) also point out that treating items as equal intervals requires one to assume that the distance between points on the Likert scale (e.g. strongly agree, agree, disagree, and strongly disagree) are equal.

This study aimed to use the Rasch model as an alternative to classical true score theory for developing and analyzing certain constructs. The Rasch model transforms ordinal data to an interval scale and provides an alternative to summing items (Wright & Stone, 1979). Rasch analysis can be used assuming three basic requirements are met: 1) the test items on the questionnaire are unidimensional; 2) the items have local independence; and 3) the items have similar discrimination characteristics.

In the present study, the trait being examined is the need for social support. Therefore, the Rasch model predicted the probability that a person will endorse any item dependent on how "in need" that particular person is, as well as by the degree of need detected by any item on the questionnaire. Using item response theory principles, responses to the FNQ were used to create a scale satisfying the Rasch measurement model. Respondents missing greater than five percent of their data points (i.e. five points or more) were not used in the present study. For participants missing one to four data points, missing data was filled in with the mean response for that item. Therefore, 52 participants were used in the Rasch analyses conducted on the three scales of the CCQ.

Child Characteristics Questionnaire

An 82-item questionnaire was included in the packets distributed to the AUTISTIC group (see Appendix C). This questionnaire was used to assess autistic symptoms or characteristics within the triad of autistic features: Communication, Social, and Behaviour. The Communication scale was composed of 21 items, the Social scale was composed of 28 items, and the Behaviour scale was composed of 33 items. The questions were gathered from the literature (e.g. Filipek et al., 1999), clinical experience, and other questionnaires designed to screen for autistic spectrum disorders such as the Autism Screening Questionnaire (Berument, Rutter, Lord, Pickles, & Bailey, 1999), Autism Spectrum Screening Questionnaire (Ehlers, Gillberg, & Wing, 1999), and the Autism Behavior Checklist (Krug, Arick, & Almond, 1980).

Another goal of the present study was to develop a new measure of the triad of autistic symptoms that would also be subjected to Rasch analysis. Three separate Rasch analyses were conducted measuring the reports of three separate traits: Communication, Social, and Behaviour. Using item response theory principles, responses to the CCC were used to create three scales satisfying the Rasch measurement model.

Demographics Questionnaire

A 15-item demographics questionnaire was also included in the package of questionnaires sent to parents assessing education levels of the parents, number of siblings, other developmental disorders in the family, medical problems of the child, the type of area that the family lives in (e.g. urban vs. rural), and the approximate population of the town in which the family lives (see Appendix D).

Procedure

Questionnaire packages were sent to participating organizations that had agreed to send them to the appropriate families or support groups. Each questionnaire package included an informational letter and the four questionnaires described above. For the DOWN'S group, self-addressed stamped envelopes were also included in the packet. The ASBC had agreed to pay for the return postage of the packages, and therefore envelopes were not provided to this group. In the packages sent to the AUTISTIC group, the informational letter also included a slip for parents to return if they would be interested in participating in a future study which would involve a parent interview surrounding diagnostic and service issues. To ensure anonymity of families living in small communities, questionnaires were returned anonymously. The introduction letter included in the questionnaire packet clearly indicated that by returning the questionnaires parents were providing their consent to participate in the study (Appendix E).

Results

Preliminary Analyses

Prior to testing the major hypotheses set forth in this paper, power analyses were conducted in order to determine whether there was adequate power to detect group differences. The power to detect a large effect size of 0.8 at the p=.05 level was .97 for the current study (Cohen, 1977).

Analysis of Diagnostic Experiences

Unless otherwise specified, the majority of the analyses conducted in this study are within group analyses of the AUTISTIC group. Group comparisons are specifically noted within the text.

Families reported that, on average, they first became concerned about their child at approximately 23 months of age (standard deviation 12 months; range 1 month to 5 years), with 88 percent of parents reporting concerns prior to their child's third birthday. The majority of parents were first concerned about their child's language (20.2%) and social development (20.7%). Other significant concerns were behaviour problems (12.5%), failure to develop normal pretend play (10.3%), or having rituals, obsessions, or object attachments (10.8%).

On average, parents tended to wait 5 to 6 months before consulting with a professional about their concerns. The average age at which parents first sought help was 2 years 4 months (SD 16 months, range 1 month to 8 years 3 months). The first professional parents sought help from was predominantly their family physician (48.6%), although several went straight to a pediatrician (23.7%), and a few went to a mental health professional (9.5%), speech language pathologist (6.6%), or a nurse, social worker, or infant development worker (7.8%). Despite parents' initial concerns, only 7.8 percent received a formal diagnosis at this first visit. Most were referred on to another professional (50.0%), while several were told not to worry (19.7%) or to return if the problems did not improve (13.6%). Of the five participants who received a formal diagnosis at this initial visit, three were diagnosed with Autistic Disorder, and two were diagnosed with PDD-NOS. Another two were given a tentative diagnosis of autistic traits.

For the 51 participants referred on, many saw various combinations of professionals. Many families were referred to a speech language pathologist (25%), an audiologist (17.6%) or clinical psychologist (14.8%). On average, families traveled 60 km (SD 118.4; range 0 to 500 km) for this assessment. Thirty-two percent of participants had to travel outside of their hometown or city to attend the appointment. At this second visit, 44.9 percent of participants were given a diagnosis. Of the diagnoses made, 43.3 percent of the respondents were diagnosed with autistic disorder, while 13.3 percent of respondents were diagnosed with other autism spectrum disorders. Although the majority of participants who received a diagnosis at this visit were diagnosed with autistic disorder or another autism spectrum disorder, 17.9 percent of participants were diagnosed with some sort of disorder not on the spectrum, such as attention deficit hyperactivity disorder or a language disorder. Approximately 5 percent of respondents were diagnosed with a developmental disability. At this stage, 6.1 percent were told to return for a follow-up visit, 4.1 percent were told there was no problem, and 2 percent were told to only return if the problems did not improve. However, 34.7 percent were referred on to yet another professional.

Families were asked about the types of supports they received, if any, following this diagnosis. The most frequent supports received were explanations of the child's disorder or advice (18.6%), speech language pathology (18.6%), contact with other parents or with the Autism Society (17.8%), and help with (pre) school provision (13.9%). Approximately 5 percent of participants reported that they had not been offered any assistance.

A number of families (36) went on to seek a further referral. Of these, the majority visited a pediatrician (29.7%) or a mental health professional such as a psychiatrist or psychologist (26.6%), while a few saw a speech language pathologist (10.9%), child neurologist (6.3%), occupational therapist (7.8%), audiologist (4.7%) or a social worker (4.7%). For the 26 families who reported the distance they traveled to seek professional help, the mean distance traveled was 290 km (SD 665.6; range 3 to 3000 km). Fifteen families reported seeing a professional that was not in their city, while fifteen families specified that they saw a professional within their city. The mean age of the children at this third visit was 4 years 1 month (SD 2 years; range 1 year 6 months to 10 years).

At a third visit with a health care professional, a majority of families were given a diagnosis (63.5%). Twenty-nine families received a formal diagnosis, with the majority receiving a diagnosis of Autistic Disorder (45.5%). A few received a diagnosis of PDD-NOS (9.1%), Asperger's syndrome (6.1%), or a general diagnosis of an autism spectrum disorder (6.1%). However, 19.5 percent were referred once again to another professional, and 10 percent were told to either return for follow-up, return if no improvement was noticed, or not to worry. At this point, 16.5 percent were still not offered any diagnoses to explain their concerns about their child.

Families were questioned about the types of supports or help they received following this third assessment. Similar to the supports they received after their second assessment, families reported receiving advice or explanations (19.6%), contact with parents or with the Autism Society (16.1%), or help with (pre) school provisions (18.5%) as the most useful supports they received. Several families also reported receiving language therapy (10.3%), personal support or counseling (9.2%), or respite care (5.7%). Approximately 5 percent of families reported that no help was offered following this assessment.

Twenty-one families reported needing further referrals before obtaining a diagnosis of an autism spectrum disorder for their child. On average, families saw two more professionals (SD .921; range 1 to 4) before receiving the final diagnosis. Seventeen of these families reported that they had to travel an average of 204 km (SD 409.5; range 0 to 1200 km) to attend this appointment. Approximately 43 percent of families had to travel outside of their city to seek further advice, while 57 percent found assistance from professionals within their own city. The majority of families visited a psychiatrist or psychologist at these subsequent referrals (39.2%), while several saw a pediatrician or general practitioner (17.4%), medical specialist (10.8%) or a multidisciplinary team at a health center (13.0%).

Overall, 76.2 percent of respondents received a diagnosis of Autistic Disorder, while 7.9 percent received a diagnosis of Asperger's syndrome, 4.8 percent received a diagnosis of PDD-NOS, 6.3 percent were diagnosed with autistic traits or features, and

4.8 percent reported comorbid diagnoses of language disorders, mental retardation, or developmental disabilities (see Table 2). On average, the final diagnosis was obtained at 5 years of age (SD 2 years 5 months; range 2 years 1 month to 12 years). Most families received the final diagnosis from a clinical psychologist (30.9%) or a pediatrician or family doctor (30.9%), while several were diagnosed by a child psychiatrist (13.2%) or a multidisciplinary team at a health center (19.1%). Fifty-eight percent of families reported that the professional who made the diagnosis was located in their city, while 42 percent had to travel to another city for the diagnosis.

In total, families saw an average of 4.46 (SD 2.42; range 2 to 14) professionals during the diagnostic process, with 23 percent of parents seeing 2 professionals, 14 percent seeing 3 professionals, 21 percent seeing 4 professionals, and 41 percent seeing more than 5 professionals. Five percent of families needed to see more than 10 professionals before obtaining a final diagnosis of an autism spectrum disorder for their child. Families waited 2 years 8 months (SD 2 years 6 months; range 0 to 10 years 6 months) from when they first sought help to receive the final diagnosis.

When parents were asked if they were satisfied with the diagnostic process, 51 percent were not satisfied, compared to 19 percent of DOWN'S participants ($X^2(2)$, = 8.484 $p<.05$). When asked if they found the diagnostic process stressful, 82 percent of AUTISTIC participants rated the process as stressful. However, 78 percent of the DOWN'S respondents also rated the process as stressful ($X^2(2) = 3.225$ $p>.05$). To try to tease out whether it was the diagnosis itself that parents found stressful, versus the diagnostic process, parents were asked to rate their stress levels surrounding the diagnosis itself (i.e. Down syndrome or ASD). Eighty percent of AUTISTIC respondents rated the diagnosis itself as stressful, while 78 percent of DOWN'S participants rated the diagnosis as stressful ($X^2(2)$, = 1.139 p>.05.

Finally, families were asked to provide information about the most useful supports or services they have received since the time of the diagnosis, and to list who provided those supports. AUTISTIC respondents reported that resources or knowledge was the most useful help they received (25.3%), while learning or behaviour assistance (20%), speech therapy (20%), family support (13%), and childcare (12%) were also very useful. The most useful help provided was often provided by speech therapists (17.2%), school personnel (16.1%), other parents (13.8%), or professionals from a multidisciplinary team (12.6%). DOWN'S participants also reported that resources or knowledge was the most useful help they received (23.9%), while help with general development (17.9%), speech therapy (13%), physical therapy (10.9%), health issues (8.7%) and childcare (8.7%) were also very useful. DOWN'S respondents reported that the most useful help was provided by a multidisciplinary team from a health center (e.g. Infant Development Program; 27.5%), pediatrician or family physician (17.6%), or speech therapist (11.8%). When asked if they were satisfied with the services they have received since the diagnosis, 53 percent of AUTISTIC participants were dissatisfied with the help they have received, whereas only 21 percent of DOWN'S participants were dissatisfied ($X^2(2)$ = 10.054 p<.01).

It was hypothesized that the two groups would differ significantly on variables assessing difficulty with the diagnostic process. Independent t-tests were conducted and the groups differed significantly on the number of professionals seen during the diagnostic process, t(1, 86) = 5.513, p<.001; the delay in receiving a diagnosis following their initial concerns, $t(1, 84) = 6.186$, $p<.001$; and the age at diagnosis, $t(1, 85) = 11.567$, $p<.001$. As previously reported, the AUTISTIC group also reported greater dissatisfaction with the diagnostic process ($p<.05$), and with the services received since the time of the diagnosis ($p<.01$).

Age effects were analyzed in order to first determine whether the age of the child during the diagnostic process was related to difficulty receiving a diagnosis, and also to determine whether the diagnostic process has improved with time (as assessed by child's age). The current age of the child did correlate significantly with the number of professionals seen $r(56) = .284$ $p<.05$, suggesting that older children indeed see a slightly greater number of professionals. There was also a correlation between child's age and the delay in diagnosis following the parent's first attempt to seek professional help about their concerns $r(55) = .748$ $p<.001$, and the age at diagnosis $r(55) = .721$ $p<.001$, indicating that the older children in the sample took longer to get a diagnosis and had to see more professionals.

It was originally thought that children diagnosed more recently would be diagnosed at a younger age, and have less difficulties in the process, suggesting that the diagnostic process is improving with time. To examine whether the previous correlations were mostly a factor of the age of the child, or whether these correlations actually represented improvement of the diagnostic process, a variable representing 'years since the diagnosis was made' was created by subtracting the age of the child at the time of diagnosis from the child's current age. There was no significant relationship between years since the diagnosis and number of professionals seen during the diagnostic process $r(55) = .174$ $p>.05$, delay in diagnosis following first attempts to seek professional help

$r(55) = .206$ $p > .05$, nor age at diagnosis $r(55) = .008$ $p > .05$. These results suggest that it is not that the diagnostic process has improved over the last few years, but that older children going through the diagnostic process have a harder time receiving a diagnosis.

It was also hypothesized that parents of younger children with autism would report more *satisfaction* with the diagnostic process and the services received since the diagnosis, compared to parents who have older children with autism. Correlations were conducted and a significant negative correlation was found between the current age of the child and satisfaction with the diagnostic process $r(55) = -.275$ $p < .05$, indicating that parents with older children are less satisfied than parents with younger children. However, correlations between "years since the diagnosis was made" and satisfaction with the diagnostic process revealed no significant relationship ($r(54) = .059$, $p > .05$), indicating that dissatisfaction was related to the age of the child and not time since the diagnosis was made. No significant relationship was found between current age of the child or "years since the diagnosis was made" and satisfaction with services received since the diagnosis $r(55) = -.088$ $p > .05$ and $r(54) = -.130$ $p > .05$, respectively.

A closer examination of the relationship between various demographic variables and families' diagnostic experiences was conducted for the AUTISTIC group. A significant correlation between mother's years of education, a measure of socioeconomic status (SES), and the number of professionals seen throughout the process was found $r(55) = .276$ $p < .05$, indicating that higher SES families saw more professionals. No significant relationship was found between family SES and delay in diagnosis or age at diagnosis. Father's years of education was significantly negatively correlated with satisfaction with the diagnostic process $r(52) = -.305$ $p < .05$, suggesting that father's with more education are more dissatisfied with the diagnostic process. No relationship was found between parent education level and other measures of stress or satisfaction.

Finally, the child's gender was significantly related to difficulty during the process $r(54) = -.358$ $p<.01$, suggesting that families with a female child seeking a diagnosis of an autism spectrum disorder had a harder time in the diagnostic process, perhaps secondary to the higher prevalence of this disorder in boys. Independent samples t-tests were conducted to determine whether there were significant differences between genders on variables measuring difficulty in the diagnostic process. Females (n=16) waited significantly longer to obtain a final diagnosis following their first visit to a health care professional, $t(1, 52) = 2.839$ $p<.01$, on average waiting 4 years 2 months, while males waited 2 years 2 months. There was also a trend towards females being diagnosed later, $t(1, 52) = 1.969$ $p=.054$. Females were diagnosed at a mean age of 6 years 1 month, while males were diagnosed at 4 years 8 months. Males and females did not differ significantly in the number of professionals seen during the diagnostic process. Interestingly, there were no significant differences in self-reports of satisfaction and stress levels between the families with male or female autistic children ($p>.05$), in spite of the differences in their diagnostic process.

Analysis of Importance Ratings

Based on the methodology of previous literature (e.g. Kreutzer et al., 1994; Witol et al., 1996), responses on the Family Needs Questionnaire were classified as "Important" if respondents circled either "important" or "very important" for an item. Items rated as "not important," or "slightly important" were not counted for this frequency measure. Using this cut-off, AUTISTIC participants rated 40 needs as important, while the

DOWN'S participants rated 39 needs as important (Table 3). Of these items, the following four items fell in the top ten "Important" needs endorsed by both groups: being well-educated about the child's disorder, being shown that the parent's opinions are being used in planning treatments, being actively involved in the child's treatments, and having a teacher's aide who has experience working with children with the same disability.

Table 3.
Means and Standard Deviations of Number of "Important" Needs, "Unmet Important" Needs and "Met Important" Needs

	Group	
Variable	AUTISTIC (n = 56)	DOWN'S (n = 34)
Number of "Important Needs"	40.18 (7.4)	39.13 (7.9)
Number of "Unmet Important" Needs	26.7 (8.9)	24.4 (12.5)
Number of "Met Important" Needs	13.18 (7.5)	12.93 (7.7)

A summary of the top ten ranked important needs for each group, and the proportion of respondents who rated that item as important is provided in Table 4. Chi square analyses of the top items were conducted in order to assess whether there were differences in the proportion of the groups who endorsed each item. The results indicated that there were no significant group differences between the proportions of parents who endorsed any of the 15 top ranked items seen in Table 4.

Table 4

Top Ten Needs Most Frequently Rated as "Important" or "Very Important"

Item endorsed	AUTISTIC %	DOWN'S %
I need…		
to be well-educated about my child's disorder in order to be an effective decision-maker regarding the needs of my child	**100**	**97**
to be shown that my opinions are used in planning my child's treatment, therapies, or education	**100**	**97**
services continuously rather than only in times of crisis	**98**	80
to be actively involved in my child's treatments and therapies	**95**	**97**
to have a professional to turn to for advice or services when my child needs help	**95**	93
to work with professionals who have expertise working with children who have the same developmental disorder as my child	**95**	83
to have information regarding my child's therapeutic or educational progress	**95**	**100**
for the professionals working with my child to understand the needs of my child and my family	**95**	93
to be shown respect by the professionals working with my child	**95**	87
my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child	**95**	**96**
for my child to have friends of his/her own	91	**100**
to have my child's teachers understand his/her problems	93	**100**
information about special programs and services available to my child and my family	89	**100**
to have my questions answered honestly	91	**97**
my child's school to set up a specialized education plan for my child	94	**96**

Note. Bold numbers indicate this item was in top 10 for this group

The total number of items participants rated as "Important" were tallied and averaged across each group, and then compared using an independent samples t-test. It had been hypothesized that the two groups would report similar numbers of needs as important. The results of this analysis confirmed the hypothesis. There was no significant difference between the AUTISTIC group and the DOWN'S group in the number of items ranked as important $t(1, 84) = .607$ $p>.05$.

An analysis was conducted to determine whether the groups differed in their reports of 'child-centred' versus 'parent-centred' needs. That is, the items of the FNQ were separated into items that represented needs for the child (e.g., "That my child get speech therapy") versus needs for the parents themselves ("That my family receive respite care;" See Appendix F). Not all of the items of the FNQ were used in these analyses because many items could not be strictly interpreted as either child- or parent-centred. Total child-centred and parent-centred scores were calculated for each group and independent samples t-tests were conducted. Significant group differences were found on scores of child-centred needs $t(1, 86) = 2.114$ $p<.05$, indicating that the AUTISTIC group endorsed a greater number of child-centred needs as being important. No significant group differences were found on scores of parent-centred needs $t(1, 86) = 1.086$ $p>.05$.

Analysis of Met and Unmet Needs

In order to calculate which needs were met and which were unmet, Kreutzer et al.'s (1994) approach was used. For each respondent, only the responses endorsed as "important" or "very important" were used, as defined above. Needs were rated as "Unmet" if respondents rated an item as either "partly met" or "unmet." Using this method, the AUTISTIC group rated 27 out of 40 "Important" needs as being unmet or partly met (i.e., "Unmet"). The DOWN'S group rated 24 out of 39 "Important" needs as being "Unmet." Table 5 summarizes the items most often rated as "Unmet" across the two groups, and the percentage of participants who rated them as "Unmet." One of the AUTISTIC group's most "Important" needs was rated as "Unmet," as was one of the DOWN'S group's "Important" needs.

Chi-square analysis revealed that the proportion of participants who endorsed these needs as Unmet was significantly different for two of the items listed in Table 5. The Unmet items that were significantly different for the two groups were "I need financial support (e.g. from the government) in order to provide my child with his/her therapies, treatments and care" $X^2(2) = 13.612$ $p<.001$, and "I need for my children's friends to feel comfortable around my child" $X^2(2) = 12.026$ $p<.01$.

Table 5.
Important Needs Most Frequently Rated as "Partly Met" or "Unmet"

Items endorsed as unmet	AUTISTIC %	DOWN'S %
I need…		
financial support (e.g. from the government) in order to provide my child with his/her therapies, treatments and care.***	**93**	63
for my child to have friends of his/her own	**82**	**78**
help dealing with my fears about my child's future	**79**	**72**
services continuously rather than only in times of crisis	**79**	66
for my children's friends to feel comfortable around my child**	**79**	44
weekend and after-school activities for my developmentally delayed child	**77**	**72**
to have my child's therapies continue throughout the summer months and school breaks	**77**	**72**
information about special programs and services available to my child and my family	**75**	**84**
to have consistent behavioural therapy for my child	**73**	69
to have consistent occupational therapy	**73**	56
to get a break from my responsibilities	63	**75**
to have consistent speech therapy for my child	71	**72**
help in remaining hopeful about my child's future	70	**72**
for my developmentally delayed child to have social activities other than with his/her own sibling	64	**72**
to be told why my child acts in ways that are different, difficult, or unusual	59	**72**

Note. Bold numbers indicate this item was in top 10 for this group
Underlined numbers indicate the item also one of the 10 most important needs for this group
*significant difference at p < .05; ** significant difference at p < .01; *** significant difference at p < .001

Both groups were dissatisfied in their need for their child to have friends of his/her own, to have weekend and after-school activities for their child, to have therapies continue through the summer and school breaks and to have information about special programs and services available for the child and family.

Further analysis of Important needs revealed that the AUTISTIC group rated 13 out of 40 Important needs as met. The DOWN'S group rated 13 out of 39 Important needs as met. Table 6 summarizes the items most often endorsed as met, and the percentage of participants who rated these needs as met. Five of the AUTISTIC group's most Important needs were met, while only two of the DOWN'S group's most Important needs were endorsed as met. Chi-square analysis revealed that the proportion of participants who endorsed these needs as met was significantly different for one item listed in Table 6: "for professionals to be discrete when talking about my child while he/she is in the room" $X^2(2) = 6.568$ $p<.05$.

Both groups endorsed the need to be well-educated about their child's disorder, to have professionals speak to them using understandable terms, to be actively involved in their child's treatments, to be shown respect by professionals, to have their spouse and him/her agree on decisions, and for professionals to be discrete when talking about their child in their top ten met needs. In spite of being in the top ten met needs, on some items only 46 percent of parents rated these needs as being met, indicating that even the top ten endorsed met needs are not being overwhelmingly met for many of the parents in this study.

Table 6.
Important Needs Most Frequently Rated as "Met"

Item endorsed	AUTISTIC %	DOWN'S %
I need…		
to be well-educated about my child's disorder in order to be an effective decision-maker regarding the needs of my child	**66**	**59**
to have the professionals working with my child to speak to me in terms I can understand	**64**	**53**
to be actively involved in my child's treatments and therapies	**63**	**72**
my child's school to set up a specialized education plan for my child	**63**	41
to be shown respect by the professionals working with my child	**61**	**53**
to discuss feelings about my child with a parent who has a child with the same disorder	**59**	41
my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child	**55**	34
to have my spouse and me agree on decisions regarding our developmentally delayed child	**54**	**63**
for professionals to be discrete when talking about my child while he/she is in the room*[2]	**48**	**50**
to have information regarding my child's therapeutic or educational progress	**46**	41
to have help from other family members in taking care of my child	41	**56**
respite care for my child	41	**50**
my child's doctor and dentist to have experience working with children with the same disorder as my child	36	**50**
for my children's friends to feel comfortable around my child**	16	**50**

Note. Bold numbers indicate this item was in top 10 for this group
Underlined numbers indicate the item also one of the 10 most important needs for this group
*significant difference at p < .05; ** significant difference at p < .01; *** significant difference at p < .001

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[2] A Chi-square analysis was conducted to determine this difference. The difference on this item was mostly due to the difference in missing responses between the two groups, as well as to the difference in "Unmet" needs, rather than a difference in reports of "Met" needs.

Table 3 summarizes the means and standard deviations of the proportion of Unmet and met needs across groups. Independent samples t-tests were conducted to compare the Unmet and met needs between the two groups. It had been hypothesized that the two groups would show similar numbers of "Important" needs, but that the AUTISTIC group would report more needs as being "Unmet" compared to the DOWN'S group. The results of this analysis showed that there was no significant group difference in the number of Important items rated as Unmet $t(1, 84) = 1.417$ $p>.05$.

Relationship Between Diagnostic Experiences and Self-Reported Needs

Several analyses were conducted in order to determine whether parent experiences during the diagnostic process influenced parent perceptions of important needs and whether these needs were being met.

Correlational analyses revealed that total scores on the FNQ correlated significantly with stress levels surrounding the diagnosis itself $r(56) = .287$ $p<.05$, indicating that families who were more stressed by the diagnosis report more needs as important. However, the total FNQ score did not correlate significantly with measures of satisfaction with the diagnostic process or services received, nor with stress levels surrounding the diagnostic process. It was hypothesized that parents of autistic children who reported dissatisfaction with the diagnostic process would report less needs as having been met. This hypothesis was not supported by the data. Parent reports of Important Unmet needs were uncorrelated with any measures of stress or satisfaction during the diagnostic process.

Analyses of whether having a difficult time during the diagnostic process (e.g. more professionals seen, later age at diagnosis, greater delay in diagnosis following first seeking help) predicted number of important needs or number of important needs that were met again revealed no significant relationships F(3, 51) = 1.680 p>.05, and F(3, 51) = .778 p>.05, respectively.

It was also hypothesized that as the time post-diagnosis increased, parents of the children who were diagnosed with autism longer ago would report fewer needs as having been met, compared to parents of children who have more recently been diagnosed with autism. This hypothesis was not supported. The number of years since the diagnosis was made was significantly correlated with the number of Important met needs r(55) = .266, p=.05, indicating that families who were diagnosed longer ago are in fact having more of their important needs met. There was no significant relationship between years since diagnosis and needs met for the DOWN'S group r(29) = .088 p>.05.

Analysis of Autistic Features

The Child Characteristics Questionnaire (CCQ), a new questionnaire being developed in this study, was used to analyze the relationship between autistic features and families' experiences with the diagnostic process, as well as the relationship between autistic features and family needs. Before analyzing the relationship between the CCQ and the Diagnostic Survey and FNQ, some simple correlations were conducted to determine whether there were any relationships between the CCQ and demographic variables.

Several researchers have reported that the presentation of autistic features seen in very young children (e.g. preschoolers) with autism can be somewhat different from the presentation seen in older children (Charman & Baird, 2002). For example, very young children with autistic spectrum disorders show impairments in adult-initiated joint attention, but by age 5 can follow such gestures. Therefore, correlational analyses were conducted between the three scales of the CCQ and the current age of the child. No significant correlations were found suggesting that total scores on the Communication, Social, and Behaviour scales were not related to the child's current age.

Because a significant relationship was found between gender and delay in obtaining a diagnosis, and a trend was found between gender and age at diagnosis, independent samples t-tests were conducted to determine whether there was a relationship between scores on the CCQ and gender of the child. Again, no significant differences were found between boys and girls on Communication, Social, Behaviour, or Total CCQ scores, indicating that the girls in the study did not have significantly different autistic features compared to the boys.

To determine whether children with autistic disorder (AD) have higher overall scores on the CCQ than children with other autism spectrum disorder (ASD) diagnoses, independent samples t-tests were conducted on each scale comparing children with AD to children with other ASD's. Again, no significant difference was found for the Communication, Social, Behaviour, or Total scores between the two groups, though there was a trend towards a significant difference on the Behaviour score for the two groups $t(1, 54) = 1.80$ p=.077. However, it was the autism spectrum disorder group that had higher Behaviour scores than the autistic disorder group. Several questions on the Behaviour scale were selected from Asperger's syndrome questionnaires, and these items would likely not be endorsed by parents whose child has autistic disorder, but would more likely be endorsed by parents of children with Asperger's.

Relationship Between Autistic Features and Diagnostic Experiences

Simple correlations were conducted to determine whether autistic characteristics of the child were related to parent reports of stress and satisfaction during the diagnostic process. Communication scores on the CCQ were significantly negatively correlated with parent reports of stress surrounding the diagnosis $r(56) = -.290$ $p<.05$, and positively correlated with satisfaction with the diagnostic process $r(55) = .273$ $p<.05$, and with satisfaction with the services received since the diagnosis $r(55) = .304$ $p<.05$. These results suggest that having an autistic child with greater communication difficulties may be linked to being less stressed by the diagnosis, and to having more positive feelings about the diagnostic process and services for these children.

To determine whether the three scales of the CCQ significantly predict difficulty in the diagnostic process, multiple regressions were conducted. There was a marginally significant trend towards Communication, Social, and Behaviour scores predicting difficulty with the diagnostic process $F(3, 51) = 2.740$ $p=.053$, with the Communication scale uniquely accounting for a significant amount of variance above and beyond the other predictors in the model $F(3, 51) = 4.35$, $b = -15.826$, $p<.05$, suggesting that children with greater communication impairments have an easier time in the diagnostic process. The three scales of the CCQ are also significantly related to the number of professionals seen $F(3, 52) = 3.353$ $p<.05$, with the Social scale accounting for unique variance in the model $F(3, 52) = 2.27$ $p=.051$. However, the CCQ scales were not significantly related to the delay in diagnosis $F(3, 51) = .848$ $p>.05$, nor the age at diagnosis $F(3, 51) = 1.866$ $p>.05$.

Multiple regressions were conducted to determine whether the scores on the CCQ significantly predict satisfaction and stress levels surrounding the diagnostic process. Results of these analyses indicate that Communication, Social, and Behaviour scores significantly predict satisfaction with the diagnostic process F(3, 51) = 3.055 p<.05. Closer examination revealed that the Communication and Behaviour scores account for a significant amount of unique variance in the model F(3, 51) = 5.81, b = 3.351, p<.05 and F(3, 51) = 4.74, b = -3.163, p<.05, respectively, indicating that families who have children with greater communication impairments are more satisfied with the diagnostic process, while those with greater behavioural scores are less satisfied with the diagnostic process. Scores on the CCQ do not significantly predict satisfaction with services F(3, 51) = .952 p>.05, nor stress levels surrounding the diagnostic process F(3, 51) = .461 p>.05, or the diagnosis itself F(3, 52) = .454 p>.05.

Relationship Between Autistic Features and Self-Reported Needs

To determine whether the three scales of the CCQ significantly predict parent self-reports of important needs and whether these needs are being met, multiple regressions were conducted. Communication, Social, and Behaviour scores on the CCQ significantly predict number of important needs F(3, 52) = 3.503 p<.05, suggesting that families whose children have more autistic symptomatology may report more needs as important. Behaviour scores on the CCQ account for a significant amount of the unique variance in the model F(3, 52) = 8.49, b = .531, p<.01. Communication, Social, and Behaviour scores on the CCQ, as a group, did not significantly predict the number of important needs rated as met or unmet. There was also a trend towards a relationship between increased social concerns (CCQ) and fewer met needs on the FNQ r(56) = .231

p=.087, indicating that having a child with social impairments may be linked to receiving fewer needed supports.

Family Needs Questionnaire Development and Reliability

One goal of the present study was to develop a new measure of family needs that could be analyzed and explored using Rasch analysis. This study aimed to use the Rasch model as an alternative to classical true score theory for developing and analyzing certain constructs. The Rasch model transforms ordinal data to an interval scale and provides an alternative to summing items (Wright & Stone, 1979). This method of analysis allows the investigator to determine whether the items form a unidimensional construct, to calibrate the items on an interval scale, and to measure each participant on the unidimensional construct (Fox & Jones, 1996).

Initially, separate Rasch analyses were conducted for each group, resulting in a final FNQ with very different items for each group (the top ten endorsed items for each group are shown in Appendix G). Therefore, the two groups were combined in order to create an FNQ that would be applicable to families with children with developmental disabilities in general, rather than specific disorders (i.e. autism or Down syndrome). Consequently, 50 participants from the AUTISTIC group and 26 participants from the DOWN'S group were used, totaling 76 persons for the FNQ Rasch analysis.

The Rasch analysis of the FNQ resulted in six items being removed that had low loadings on the first factor, implying that these items were not loading onto the same derived factor as the remaining 46 items. Further analysis of the FNQ led to 19 respondents being deleted due to an unacceptably high index of misfit to the model, indicating that these participants responded in an unexpected way, such as in a careless or random manner (Fox & Jones, 1998). The final FNQ had a high internal consistency (alpha=.92). Figure 1 shows the item-person map of the final 48-item FNQ. Appendix H shows the final 48-item FNQ, with the items that were removed crossed out with a horizontal line. Appendix I shows the items of the FNQ in order of item difficulty, from easiest (most often endorsed), to hardest (rarely endorsed).

Because the Rasch scores produced in the Rasch analysis correlated so strongly with the total scores on the FNQ ($r(86)= .929$, $p<.001$), simple correlations and multiple regressions between the Rasch scores on the FNQ and variables from the CCQ or the Diagnostic survey were not different from the results using the total scores from the FNQ. However, the item-person maps do provide the reader with a way of visualizing which participants are more in need, and which items are harder to endorse than others. Finally, the item-person map further supports the results of descriptive statistics showing that the two groups do not differ significantly in their self-reported level of need.

Figure 1.
Item-Person Map of the FNQ Following Rasch Analysis

```
                                 PERSONS -MAP- QUESTIONS
                                     <more>|<rare>
    5                                      +
                                           |
                                           |
                                           |
                                           |
                                           |  Q52
    4                                 a18  +
                                           |
                                           |
                                      a36  |
                                           |
                                           |
    3                                      +
                                      d05 T|
                                           |
                                           |
                                           |T
                                  a41 d31  |  Q54
    2                             a19 d15 S+
                          a06 a26 d22 d30  |
                          a03 a40 d08 d28  |  Q22  Q23
              a07 a14 a29 a42 a50 d19 d27  |
                                      a43  |  Q35  Q4
                          a05 a10 a48 d06 M|S Q19
    1                             a22 a28  +  Q27
                  a09 a23 a32 d18 d21 d25  |  Q15  Q39
      a15 a17 a31 a44 a49 a51 a54 a60 d04  |  Q14
                                  d29 d33  |  Q11  Q17  Q36  Q5
                                      a33 S|  Q16  Q26  Q37
                      a04 a21 a34 a55 d24  |  Q12  Q25  Q31
    0                             a53 d11  +M Q24  Q33
                                      a52  |  Q29  Q46  Q7
                                      d26  |  Q30  Q43  Q45  Q49
                                           |  Q34  Q51
                                      a58 T|  Q50
                                           |  Q20  Q28  Q38  Q41  Q42
Q6   Q9
   -1                                      +  Q13
                                           |S Q1   Q18  Q8
                                           |  Q47
                                           |  Q32
                                           |
                                           |  Q48
   -2                                      +
                                           |  Q2
                                           |T
                                           |
                                           |
                                           |
   -3                                      +
                                     <less>|<frequ>
```

Development and Reliability of Child Characteristics Questionnaire

Another goal of the present study was to develop a new measure of autistic features that would also be subjected to Rasch analysis. In the present study, the three traits being examined are known as the triad of autistic symptoms: impairments in reciprocal social interaction, impairment in communication, and behavioural concerns, including restricted, repetitive, and stereotyped behaviours (DSM-IV-TR; APA, 2000). Three separate Rasch analyses were conducted measuring the reports of three separate traits: Communication, Social, and Behaviour. The Rasch analysis of the Communication scale led to 11 items being removed that did not fit the unidimensional construct being measured. Further analysis of the Communication scale resulted in two persons being deleted due to unexpected response styles. The final CCQ Communication scale had a high internal consistency (alpha=.89). Figure 2 shows the item-person map of the final 9-item CCQ Communication scale.

Figure 2.
Item-Person Map of the CCQ Communication Scale Following Rasch Analysis

```
                     PERSONS -MAP- QUESTIONS
                           <more>|<rare>
 2                     a27  a57 T+
                                 |
                                 |
                            a35  |
                                 |
                            a49  |
                                 |T Q1
                        a10  a5  |
 1                               +
                                 |
                            a20 S|
             a19  a44  a6   a60  |S
                            a28  |  Q2   Q6
                            a32  |
                             a8  |  Q3
                        a24  a9  |
 0                          a50  +M
             a34  a42  a51  a54  |  Q7
                       a15  a37  |
                            a55 M|  Q11
   a18  a29  a30  a4   a45  a53  |  Q10
                   a31  a46  a7  |S
                                 |  Q8   Q9
                            a39  |
-1                               +
                            a56  |
                            a23  |T
                  a17  a33  a48  |
                                 |
                       a22  a40 S|
                                 |
                       a14  a26  |
-2                               +
                            a16  |
                                 |
                       a21  a41  |
                                 |
                                 |
                                 |
                            a59 T|
-3                               +
                                 |
                                 |
                                 |
                            a36  |
                                 |
                                 |
                                 |
-4                     a11  a52  +
                           <less>|<frequ>
```

Rasch analysis of the Social scale of the CCQ resulted in18 items being removed, as they did not fit the unidimensional construct being examined. Subsequent analyses resulted in two persons being deleted from the model due to random or careless response styles. The final CCQ Social scale did not meet the required PCA ratio (3:1), indicating that it does not measure a unidimensional trait. However, it had an acceptably high internal consistency (alpha=.80). Figure 3 shows the item-person map of the final 10-item CCQ Social scale.

Figure 3.
Item-Person Map of the CCQ Social Scale Following Rasch Analysis

```
                     PERSONS -MAP- QUESTIONS
                        <more>|<rare>
3                             +
                              |
                              |
                              |
                              |
                              |
                              |
                           a8 |
                              |
                              |
2                             +
                           a3 |
                              |
                             T|
                              |
                              |
                              |
                              |
                              |
                          a17 |
1                             +
              a20 a29 a50 a60 |
                             S|
                          a16 |T
                              |
                  a19 a49 a59 |  Q31
   a10 a26 a35 a40 a44 a53 a9 |  Q38
                              |S
                              |  Q34
                      a23 a46 |  Q32 Q36 Q37
0                             +M Q33
          a11 a15 a28 a33 a45 |
                  a22 a31 a41 M|  Q27
                  a34 a4  a56 |S
```

```
                                      |  Q35
                       a5   a51  a52  |
              a18  a27  a30  a57  a6  |
                            a14  a36  |T Q39
                                      |
                                      |
-1                          a39  a42  +
                                 a55 S|
                                 a32  |
                                      |
                                 a54  |
                                      |
                                 a48  |
                                      |
                                 a37  |
                                 a21  |
-2                                   T+
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Finally, Rasch analysis of the Behaviour scale of the CCQ resulted in 18 items being removed indicating that the original Behaviour scale was not unidimensional. Further analysis of the Behaviour scale resulted in seven persons being deleted due to their response styles. The final CCQ Behaviour scale had a high internal consistency (alpha=.83). Figure 4 shows the item-person map of the final 15-item CCQ Behaviour scale.

Appendix J shows the initial CCQ, with the items that were removed crossed out with a horizontal line. Appendix K shows the final set of 34 items representing unidimensional traits of Communication, Social and Behaviour difficulties. Appendix L shows the items on each scale of the CCQ in order of item difficulty, from easiest (most often endorsed), to hardest (rarely endorsed).

Simple correlations were conducted between the total scores for each of the three scales and its corresponding Rasch scale score (e.g. total Communication with Rasch Communication scores). All Rasch scores correlated highly with their summated scale counterparts ($p<.001$), and consequently further statistical analyses using the Rasch scores were consistent with analyses using the total scores from each scale.

Figure 4.

Item-Person Map of the CCQ Behaviour Scale Following Rasch Analysis

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                              a49  |  Q54  Q60
                               a9  |  Q80
   0                          a39  +M
                         a48  a50  |  Q69
      a14  a29  a32  a6   a60  a7  |
                                   |  Q50
                a16  a28  a4   a8 M|  Q63
                         a31  a59  |
                a33  a42  a44  a5  |S Q56
          a10  a21  a52  a53  a54  |
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Discussion

A review of the literature clearly indicates that parents experience significant difficulties attempting to receive a diagnosis for their autistic child. This finding is of particular concern since an early diagnosis will allow for early interventions and for helping parents adapt to having a child with a chronic disability. The need for early diagnosis of this population is especially important in British Columbia right now, given the substantial funding through the Interim Early Intensive Intervention Program (IEIIP) being provided to parents with children younger than six years of age, diagnosed with an autism spectrum disorder.

The need for early diagnosis is also important for helping parents to begin to deal with their child's diagnosis and to move towards healthy adaptation and coping. In addition to early diagnosis, social supports have been shown to be important for parents' healthy adaptation to having a child with a life-long developmental disability. Given the considerable difficulties these families face and the roles of parents in the children's interventions, supports that are developed and provided based upon parents' self-reported needs may prove especially useful for the child and the family. Previous literature concerning family needs has investigated the self-reported needs of families whose child has experienced a traumatic brain injury (Armstrong, 1999; Waaland et al., 1993), but has not been conducted with families whose child has an autism spectrum disorder. A few studies have examined the important needs of parents of developmentally delayed children (Bristol, 1984), and other studies have assessed which needs have not been met for a similar population of parents (Freedman & Boyer, 2000). However, no studies to date have investigated the needs parents feel are most important, and which of these needs are being met.

A review of the literature indicates that parents of autistic children are significantly more stressed than parents of children with other developmental delays, mental retardation, Down syndrome, or typically developing children. Consequently, parents of children with an ASD were compared to parents of children with Down syndrome to assess whether the groups differed in the number of important needs reported and how many of these needs were met. Group comparisons were also conducted to determine whether the groups differed on measures of stress and satisfaction surrounding the diagnostic process, the diagnosis itself, and services received since the time of the diagnosis.

Before discussing the findings of the study, as well as their implications to the service delivery system, several limitations should be briefly discussed. The number of parents participating in the study was quite limited, representing only one to three percent of parents with autism or Down syndrome within the province of British Columbia. Also, the participants for the study were obtained through community parent support groups, suggesting that these parents are not a random sample of parents with children with autism or Down syndrome, but may in fact share common characteristics. Because these parents are reaching out to community support groups for support, they may be more highly stressed as a result of their child's disorder, and therefore may be reporting less satisfaction and greater stress with the service delivery system. However, because these families have the time to attend support group meetings, they may actually be less stressed or may be more aware of supports available from the social support system.

In addition to the previous limitations, most of the parents with autistic children participating in the study had their children diagnosed within the last five years, and therefore may have very different needs and concerns than parents who may have had a longer amount of time to adapt to a diagnosis of autism. The recency of the diagnoses may also suggest that parents attending community support groups are those that have had their children diagnosed more recently.

Finally, the sample consisted of parents with children between the ages of 2 and 18. This wide range may have masked any age specific trends in parent responses. For example, it may be that parents of adolescents with autism or Down syndrome rate very different needs as important than those of younger children. A more in depth discussion of these limitations can be found at the end of the discussion section.

Diagnostic Experiences

The present study examined the diagnostic experiences of 56 parents of children with a diagnosis of an ASD. The families in this study reported initial concerns about their child at approximately 23 months of age, consistent with previous research (Howlin & Moore, 1997). Initially, the majority of parents were concerned about their child's language and social development and initially sought help from a family physician regarding their concerns. However, despite their concerns, the majority of parents did not receive a diagnosis at this point, but were referred to various child specialists (e.g. pediatrician, speech language pathologist) for further investigation. Unfortunately, one fifth of participants were told not to worry about their child, and a further 14 percent were told to return if the problems did not improve. Therefore, greater than one third of participants in this study were initially told that their concerns were not justified, even though they all later received a diagnosis of an ASD.

Fortunately, 51 participants were referred on to another professional at some point, and almost one half of these families received either a preliminary or formal diagnosis of an autism spectrum disorder for their child at this second visit. The majority were diagnosed with autistic disorder, while several other families received other diagnoses in the autistic spectrum. One fifth of families received diagnoses not in the spectrum, such as ADHD or a language disorder. The vast majority of families received supports such as advice, speech language therapy, contact with other parents or with the Autism Society of British Columbia, or help with school provisions following their consultation with a child specialist. Unfortunately, five percent of families reported being offered no help for their child.

Thirty-six families went on to seek further referrals to developmental specialists, and a majority of these received a diagnosis of an autism spectrum disorder at this visit, while approximately seven families were referred on to yet another specialist. Families received similar supports following this visit, with five percent reporting no help offered.

Almost half of the sample reported that they needed two more referrals before receiving a diagnosis for their child, totaling an average of four referrals before having their child diagnosed with an autism spectrum disorder. Children were diagnosed at approximately five years of age. Boys were diagnosed on average at four years of age, while girls were diagnosed closer to six years of age. This finding indicates that the system may be more efficient for males than females. This may be due to the prevalence rates associated with autism spectrum disorders: approximately four times more boys have autism than girls (APA, 2000). Therefore, health care specialists may not as readily consider autism as a possible diagnosis for girls presenting with social, language, and other developmental delays as they would for boys. Although most children were diagnosed at approximately five years of age, six children were diagnosed after age ten. Although one might predict that these were all cases of Asperger's or PDD-NOS, only three respondents reported these diagnoses (Asperger's syndrome, n=2; PDD-NOS, n=1). Three of the participants indicated that their child had been diagnosed with autistic disorder at an age greater than ten years, suggesting that some children are still being missed despite increased awareness about the importance of the early diagnosis of autism within the health care profession (Charman & Baird, 2002; Ho & Smith, 2001; Kope, Eaves, & Ho, 2001; Smith et al., 1994).

On average, families waited almost three years from when they initially sought help from a professional to receive a diagnosis for their child. However, seven families waited over five years for the diagnosis, and one family waited over ten years to receive a diagnosis of Asperger's syndrome.

Given the findings from the present study, it is not altogether surprising that over half of the participants in the AUTISTIC group were dissatisfied with the diagnostic process, as compared to only nineteen percent of DOWN'S parents, whose children were diagnosed at birth, by one to two professionals. Surprisingly, however, similar proportions of parents from the two groups reported finding the diagnostic process stressful. It was hypothesized that the two groups would differ in the levels of stress reported during the diagnostic process. However, the literature shows that parents of children with Down syndrome also have poor experiences when receiving the diagnosis:

"The most painful experience was the way I was told Ken had Down syndrome. The doctor came into the hospital room with a nurse and blurted flat out, 'Your child has Down's. Do you know what that is?' When I said, 'Yes,' (praying not to cry), he said, 'Okay,' turned on his heels, and left. I had to tell my husband alone and saw this bear of a man shrink in front of my eyes." (Leff & Walizer, 1992, p. 158). Experiences such as these may result in parents of children with Down syndrome reporting significant stress during the diagnostic process. Parents of both groups also reported similar levels of stress surrounding the diagnosis itself, indicating that whether one's child is diagnosed with an ASD or with Down syndrome, both are equally stressful diagnoses for parents to hear. This finding is consistent with the reports that parents whose child is diagnosed with any form of chronic disability often experience a reaction similar to the stages of grief (e.g. shock, grief, anger, helplessness, and guilt) experienced when a loved one dies or when one experiences a serious crisis (Bentovim, 1972; Leff & Walizer, 1992; Siegel, 1996).

When asked whether parents were satisfied with the services they have received since the diagnosis, parents of children with autism were significantly less satisfied with services compared to parents of children with Down syndrome. This finding likely represents the current state of the service delivery system, as well as the literature about prognosis following treatments for the two disorders. Parents of children with Down syndrome are eligible for early interventions (e.g. physical therapy, speech language therapy) through their local Infant Development Program, due to the early age of diagnosis and the knowledge about the types of interventions necessary for this population of children. However, at the time data was collected for this study, parents of autistic children likely had difficulty obtaining needed services for their child. Long waiting lists and specific criteria for eligibility lead to difficulties receiving speech language therapy, respite care, and occupational therapy. Only families with children aged 5 or younger are eligible for the Early Intensive Behavioral Intervention programs, and even this program is set up in only three locations, therefore only being accessible to families in particular geographic regions. Those with diagnoses made after five years of age often have difficulties receiving certain supports, due to the limited services available within the school system. Finally, intensive behavioral treatments have been written about as possible "cures" for autism (Lovaas, 1987; McEachin, Smith, Lovaas, 1993), leading parents of autistic children to cling to the hope that the appropriate behavioral intervention could cure their child. In addition, the ambiguity of the presentation of autism leads to increased stress levels in parents (Bristol, 1984), and often leads to ambiguity regarding whether the child is in fact handicapped (Bristol, 1984). This can lead to difficulty for the parent to gauge what are realistic expectations for their child and their child's future. However, due to the physical features of Down syndrome and the genetic nature of the disorder, these parents do not tend to experience such difficulty gauging expectations for their child. With the knowledge that there are no cures for Down syndrome, these parents may be more likely to accept the services that are available to help their child.

In the last few months the government has instigated a program called the Interim Early Intensive Intervention program, in which parents whose children is diagnosed with an autism spectrum disorder by a multidisciplinary team can receive substantial funding (approximately $1600/month) to pay for speech language therapy, occupational therapy, preschool, and behavioral intervention for their child. It would be interesting to see whether the parents receiving these funds report similar levels of satisfaction with services received since the diagnosis, or whether the new funding initiative would significantly increase their satisfaction with supports received.

It was hypothesized that younger children in the study would experience significantly less difficulty obtaining a diagnosis than the older children in the study, implying that the diagnostic process is getting better with time, due to the increased knowledge distributed throughout the health care system (e.g. Ho & Smith, 2001; Kope et al., 2001). Older autistic children in the study experienced significantly more difficulty, but this was a factor of age and not a factor of the number of years since the diagnosis was made, indicating that older children saw more professionals and waited longer between when they first sought help and when they received the final diagnosis. These older children may have milder forms of autism, such as Asperger's syndrome or PDD-NOS that were not detected earlier or that were misdiagnosed for many years.

These results suggest that the efficiency of the diagnostic process has not improved over the last decade. However, the range, within this sample, of years since the diagnosis was made is quite restricted, as the majority of children were diagnosed within the last five years. It is possible that significant improvement has not occurred in the last five years, or that the specific characteristics of the sample mask any effects of improvement. For example, the families with autistic children participating in the study were all recruited from family support groups throughout the province. The fact that the majority of these families had their child diagnosed in the last five years is likely a characteristic of families participating in support groups. It is likely that parents more recently diagnosed are the ones needing support from other parents, whereas parents who have had their child diagnosed years ago may be less likely to use local support networks and may have successfully adapted to having a child with a developmental disability such as autism. In addition, parents utilizing community support groups may be the parents who have had a harder time getting their child diagnosed, and have experienced more stress in their interactions with the health care delivery system. Consistent with the findings that parents of older autistic children experienced greater difficulty throughout the diagnostic process, parents of older autistic children also reported greater dissatisfaction with the process.

The relationship between autistic features of the child and the diagnostic experiences of the family indicate that parents of children with greater communication impairments were more likely to report decreased stress levels surrounding the diagnosis, increased satisfaction with the diagnostic process, and increased satisfaction with the services received since the diagnosis. These results indicate that a parent whose child either has a language disorder or shows impairments in nonverbal communication may actually experience an easier time adjusting to the diagnosis of autism, and may have an easier time with the diagnostic process and the service delivery system. The first of these findings, that communication scores on the CCQ are significantly correlated with stress levels surrounding the diagnosis itself, suggests that communication impairments are likely to be less ambiguous to parents, and may be a clear indicator that something is significantly wrong with their child (Howlin & Moore, 1997). This is consistent with the finding that parent's initial concerns were often surrounding language development. For these parents, the diagnosis may be more expected and therefore may be a starting point towards getting services, rather than a complete surprise.

The second finding, that communication impairments are linked to increased satisfaction with the diagnostic process, suggests that these parents experience an easier time getting their child diagnosed. It is likely that children who have greater verbal or nonverbal communication difficulties would get picked up quicker by health and educational professionals who have experience with young children. It is also a great deal easier to diagnose communication impairments, since both psychologists and speech language pathologists have standardized tests to measure communication skills in young children, and these deficits are more likely to be visible during an appointment with such a professional. On the other hand, social and behavioral difficulties are not always apparent in all situations, and cannot easily be quantified by any standardized measures. Therefore, communication impairments may be easier to diagnose, and may be the first feature picked up by professionals, leading to further examination of social and behavior issues, finally resulting in a diagnosis of an autism spectrum disorder.

The third finding, that communication impairments are linked to increased satisfaction with services, suggests that these children are likely to receive more services than children with greater social or behavioral features of autism. This finding is consistent with the types of services typically available to these families. Speech language therapy, educational programs, and many behavioral interventions often address communication issues for these children, whereas fewer specific interventions are available to address social and behavioral difficulties. In addition, communication tends to be seen as a fundamental basic skill that is valued and encouraged in all individuals

(Newcombe, 1996). Communication skills aid in social development and often decrease certain behavioral issues seen in many children with language disorders or behavioral difficulties. One of the best indicators for future prognosis in individuals with autism is the "presence of communicative speech," resulting in pressure to teach language to young autistic children (APA, 2000). Therefore, teaching communication skills is often seen as the first priority for many of these children and consequently parents of language impaired children are likely to be more satisfied with services than parents of children with social or behavioral disorders.

Self-Reported Family Needs

Consistent with the proposed hypothesis, the two groups of participants did not differ in the number of important needs reported. However, closer examination of the supports rated as most important provides evidence that the two groups differ with respect to the specific needs rated as most important. By examining the ten most important needs for each group using the mean score for each item (see Table 4), five items were in the top ten "Important" needs for both groups: "to be well-educated about my child's disorder in order to be an effective decision-maker regarding the needs of my child," "to be shown that my opinions are used in planning my child's treatment, therapies, or education," "to be actively involved in my child's treatments and therapies," "to have information regarding my child's therapeutic or education progress," and "my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child." Closer examination of the most "Important" items not shared between the two groups, revealed that parents of children with ASD's are more consistently endorsing needs relating to professionals working with their child and family, whereas the parents of children with Down syndrome endorsed items related to school supports, community programming, and friendship opportunities for their child. However, the groups did not significantly differ in the proportion endorsing any of the top ten items for either group, suggesting that although there may have been subtle differences, similar proportions of participants rated each of these items as important.

Another way to examine the most important needs rated by each group was to examine the items that were most frequently endorsed by each group during separate Rasch analyses. This method allows one to look at unidimensional items that were consistently responded to by each group. However, it should be noted that the separate Rasch analyses for each group resulted in different items fitting the model and therefore direct comparisons of all of the items could not be conducted. It was noted that only two items were in the top ten endorsed items fitting the model for both groups: "I need to have my questions answered honestly," and "I need to have my child's teachers understand his/her problems." Closer examination of the items fitting the Rasch model for the two groups revealed that the parents of children with Down syndrome more consistently endorsed items of personal support for themselves, such as "I need to have time to spend alone with my partner," and "I need for the professionals working with my child to speak to me in terms I can understand," whereas the parents of children with ASD's tended to endorse items relating to supports for their child *as well as* personal supports: "I need my child's school to set up a specialized education plan for my child" and "I need to be shown respect by the professionals working with my child."

Finally, items on the FNQ were separated into child-centred versus parent-centred needs. Group comparisons were conducted to determine whether there were group differences in the endorsement of child-centred versus parent-centred needs. Results of these analyses showed that the autism group rated more child-centred needs as important, but that the groups did not differ with respect to the number of personal needs endorsed. These results suggest that parents of children with autism spectrum disorders may be more focused on the needs of their child than parents of children with other developmental disorders. This may be due to the belief that focusing more on the child's needs may lead to significant recovery or even a possible cure. As previously discussed, parents of autistic children seem to reach out for supports with the hope that enough intensive intervention can lead to a cure or a significant improvement in their child, due to a few studies showing remarkable recovery in a select sample of autistic children (Lovaas, 1987; McEachin et al., 1993).

Another hypothesis was that parents of children with autism spectrum disorders would report fewer "Important" needs as being met, compared to parents of children with Down syndrome. This hypothesis was not supported by the data: the two groups reported the same number of Important needs as being met. Interestingly, only one-third of each group's Important needs were met, indicating that parents of children with developmental disabilities still feel that the service delivery system is not providing adequate social supports. Table 6 shows the Important needs most frequently rated as met for each group. Only five of the most important needs of parents with children with ASD's were endorsed as met, and only 46 to 66 percent of participants rated these items as met needs. This finding indicates that the majority of the group's Important needs are unmet, and the top ten met needs are only being met for one half to two thirds of the sample. Only one of the top Important needs was rated as met by the parents of children with Down syndrome, indicating that even fewer Important needs are being met for these parents than the parents of children with ASD's.

Interestingly, although the two groups of parents reported similar numbers of met needs, the parents of children with autism spectrum disorders reported significantly less satisfaction with the help received since the time of the diagnosis. This suggests some fundamental difference between the two groups of parents regarding their expectations from the service delivery system. It seems that although the parents of children with Down syndrome only rated one third of their Important needs as met, 72 percent of these parents were satisfied with the services they have received. This suggests that these parents do not have as high expectations for receiving services compared to the parents of the autistic children. This may be, once again, due to the belief held by many parents of children with autism that their child can be cured or can make significant gains in their functioning if only they were to have adequate supports and interventions available to them. Parents of children with Down syndrome may be more likely to accept their child's disability and may be less likely to believe that their child can be cured with adequate interventions, leading to greater satisfaction with the services available to their child and family. Parents of children with Down syndrome may also be more satisfied with the progress that their child is making with the supports being offered.

The quality of the supports received by the two groups may also be contributing to the group difference in satisfaction with services. Konstantareas (1991) found that parents of autistic children reported receiving more aggravations from social support agencies than a group of parents of children with mental retardation. Although the present study did not enquire into the quality of the supports received or the types of aggravations parents may experience, it is possible that the group differences in satisfaction with services may have been due to quality of services rather than number of supports received or parent expectations for services.

Table 5 shows the Important needs that were rated as Unmet for both groups. One of the most Important needs of parents with autistic children was rated as Unmet by 79 percent of these parents, while one of the most Important needs of parents of children with Down syndrome was rated as Unmet by 78 percent of these parents. Group comparison's revealed that the group's differed significantly in their responses to two items: "I need financial support in order to provide my child with his/her therapies, treatments and care" and "I need for my children's friends to feel comfortable around my child." An overwhelming 93 percent of parents of autistic children reported that they were not receiving adequate financial support for their child's therapies. However, only 63 percent of parents of children with Down syndrome felt this need was unmet. Although so many parents of children with ASD's rated this need as Unmet, it was not rated as one of their top ten important needs. However, 93 percent of parents *did* rate this need as Important, and consequently this item fell just short of the top ten items, indicating that this need was both Important and overwhelmingly Unmet for most parents of children with autism spectrum disorders. Only 73 percent of parents of children with Down syndrome rated this item as important and it was only Unmet for 63 percent of parents in this group, suggesting that parents of children with ASD's perceive themselves as significantly more in need of financial support for their child's therapies. This is an interesting finding given the current situation within British Columbia, where parents of children with ASD's recently pursued, and won, a well-publicized law suit against the government to force provincial support for early interventions. Consequently, parent responses to this item seem to be very representative of the current view of the government's role in providing financial support to families with autistic children. Due to the lawsuit, the government has instigated a program providing parents with substantial financial support to buy therapies for their child, and it would be interesting to determine whether the proportion of parents reporting this need as Unmet would decrease because of the new funding initiative within British Columbia.

A significantly greater proportion of parents of autistic children reported the need for "my children's friends to feel comfortable around my child" as Unmet compared to parents of children with Down syndrome. This may be due to the fundamental difference between the two groups with respect to social skills. One of the diagnostic criteria for autism is a "qualitative impairment in social interaction" (APA, 2000, p.75), and therefore it is expected that the children with autism spectrum disorders would be less likely to have friends and that their peers may be uncomfortable around them, due to the significant social impairments of the autistic child. On the other hand, children with Down syndrome are often quite sociable children (Rodrigue et al, 1992) and therefore it is intuitive that parents of children with Down syndrome may not have as many concerns surrounding their child's social interactions with peers.

It was hypothesized that parents of autistic children who reported greater dissatisfaction with the diagnostic process would report fewer needs as having been met. This hypothesis was not supported. However, parents who reported greater stress surrounding the diagnosis itself were more likely to report more needs as important. This suggests that it was not the diagnostic process that is related to parents' reports of unmet needs, but rather the stress surrounding the diagnosis itself that was more likely to lead to the need for more supports. This finding is consistent with Bristol's (1984) finding that the least stressed mothers in her study were the ones that reported greater perceived support on a measure of social supports. Therefore, parents who react to a diagnosis of autism with greater stress are more likely to feel in need of more supports from the community and health care delivery system. Consequently, it is important for professionals diagnosing autism to assess the parent's reaction to the diagnosis, and either personally monitor the parent's coping skills over the next few years or ensure that the family has some sort of personal support or counseling available to help them adjust and decrease their stress levels. Ensuring that parents have adequate personal support and counseling could lead to fewer perceived needs and possibly less pressure on an already saturated service delivery system.

Another hypothesis was that as the time post-diagnosis increased, parents of autistic children would report less needs as having been met as compared to parents of children who had been more recently diagnosed. This hypothesis was not supported by the data. In fact, the data suggested that families whose children were diagnosed longer ago were *more* likely to report having their Important needs met. This finding may be because some of the items were more relevant to older autistic children, such as "I need for my developmentally delayed child to have social activities other than with his/her own parents and siblings" or "to have my child's after-school friends to understand his/her problems," and therefore more items would be likely to be met for older children than younger ones. In addition, it is possible that families whose child was diagnosed more recently have not had enough time elapse for these needs to be met, whereas families whose child was diagnosed years ago have had more time to receive various services. Although the hypothesis was not supported, this is an important finding because it suggests that the support system is not only providing services to recently diagnosed families, but is also providing a number of supports to families whose child was diagnosed longer ago. It is also possible that this finding represents the issues with long waitlists for many families with autistic children. One could speculate that the reason families with more recent diagnoses are not reporting more met needs may be because these parents are still on waitlists to receive services, whereas families whose child was diagnosed longer ago may be the ones who are already receiving services. It is important to note once again that the majority of families in the sample were diagnosed within the last five years, and therefore this finding may be a result of the limited range of years since diagnosis.

Finally, the interactions between autistic features of the child and parent self-reported needs were examined. A significant relationship between autistic symptoms and needs rated as important was found, indicating that families whose child was more severely autistic were more likely to report greater need of social supports. Bristol and colleagues (1988) did not find evidence that severity of the child's disorder was predictive of family adaptation. However, several other researchers have found evidence consistent with the present findings, indicating that severity of the child's disorder is likely a significant factor in family adjustment (Bristol, 1984; Henderson & Vandenberg, 1992; Konstantareas, 1991).

To determine whether the child's communication, social or behavioral impairments were more likely to impact parents' self-reported needs, the relationship between each individual scale of the CCQ and parent's reports of family needs was examined and revealed that families whose child had greater behavioral difficulties were more likely to endorse more needs as Important. This finding suggests that stereotypic, ritualized or odd behaviors characteristic of autism may lead to poorer adjustment in parents. One could think of these behaviors as positive symptoms: symptoms that "reflect an excess or distortion of normal functions" (APA, 2000, p. 299). One could also think of the communication and social deficits found in autism as negative symptoms: symptoms that "reflect a diminution or loss of normal functions" (APA, 2000, p. 299). It is likely that these positive symptoms are regarded as odd by both the child's parents and by other individuals in the community, leading to distress and embarrassment for the parent. However, the "negative symptoms" of autism are less likely to be regarded as strange by the community. The negative symptoms may lead the parent to believe their child is somewhat delayed in their development, but not lead others to believe the child is odd or strange. Therefore, these symptoms may not be as stress inducing for the parent. The finding that it is the more "positive symptoms" that lead the parent to experience greater needs from the health service delivery system is consistent with the literature indicating that parents of autistic children tend to experience equivalent levels of stress compared to parents of children with externalizing disorders (Donenberg & Baker, 1993).

There was also a trend towards increased social impairments leading to fewer met needs on the FNQ, indicating that a child with greater social impairments may be receive fewer needed supports. This finding is consistent with the types of supports our service delivery system provides. Services to aid in language development tend to be one of the first types of supports offered to parents of autistic children (e.g. speech language therapy; Howlin & Moore, 1997). Behavioral consultation or intervention is also offered to help parents manage a child with significant behavioral issues. However, there are not many formal supports available to aid in an autistic child's social development. Although speech language pathology, occupational therapy, behavioral intervention, and educational programs often include a social component, this is not usually the focus of the treatment nor is it the reason for referral to such services. Therefore, the finding that families whose child has greater social impairments may report fewer needs as met seems to be quite consistent with our service delivery system.

Rasch Analysis of Family Needs Questionnaire

One of the purposes of the present study was to develop a new measure of family needs that would be specific to parents of children with autism and Down syndrome, and subject the new measure to Rasch analysis. Rasch analysis provides an alternative to classical psychometric theory. It allows one to produce a calibrated interval scale of items that measure a unidimensional construct, and measure each participant on this newly created construct (Fox & Jones, 1998). The analysis of the FNQ revealed that six items did not measure the same underlying construct as the remaining 48 items. Because the final 48-item FNQ did fit the Rasch model, it can be assumed that this set of items measures a single construct of social support within this sample.

Examining the six deleted FNQ items provides some insight into why these particular items did not fit the model. Five out of the six items ("I need services continuously rather than only in times of crisis," "I need to have consistent behavioral therapy for my child," "I need to have consistent speech therapy for my child," "I need to have counseling for my other children," and "I need respite care for my child") dealt with the parent's need for specific services or therapies for their child or other children, and therefore may have all loaded more strongly onto another factor. The sixth item ("I need to take 3-week long family vacations each year") might not have fit the model because it dealt with a very different kind of "need" than other items in the questionnaire and because it was probably very inconsistently responded to. This item was added to a piloted version of the FNQ subjected to Rasch analysis in order to increase the spread of the item-person map. It was expected to be rarely endorsed, and these factors may have led to this item not tapping into the same construct as the other items on the measure.

Because 25 percent of the respondents were deleted due to unexpected response styles, this new FNQ cannot be generalized to all parents of children with ASD or Down syndrome. However, by examining the item-person map in Figure 1, it can be observed that there is a range of items that are rarely endorsed (e.g. Q52, Q54) as well as many items that were frequently endorsed (e.g. Q2, Q48, Q32). The persons do not show as large a range, with the majority having more needs, as opposed to fewer, indicated by the cluster of persons in the upper half of the item-person map. This shows that both of the groups are in need, and the fact that both groups cluster evenly in the same area indicates that neither of the groups have more needs than the other, consistent with the descriptive statistics conducted on the FNQ.

Future studies should be conducted to determine whether this Rasch analysis could discriminate between parents of typically developing children and children with developmental disabilities. In addition, a larger mixed sample of parents with developmentally delayed children should be used in order to better generalize the new 48-item FNQ.

Rasch Analysis of Child Characteristics Questionnaire

Another aim of the present study was to develop a new measure of autistic characteristics that would measure the triad of autistic features (Communication, Social, Behavior) separately. The three scales were subjected to Rasch analysis in order to ensure that each were measuring a unidimensional construct, and to reduce the number of items in each scale resulting in a brief and reliable instrument of autistic features.

The analysis of the Communication scale of the CCQ revealed that 12 of the original 21 items on the Communication scale factored heavily on the second component, indicating that the original Communication scale was not unidimensional but in fact had at least two strong components. The strongest factor included a variety of items representing normal communication development, whereas the second factor included items measuring autistic styles of communication.

Examining the 12 deleted items provides some insight into why these particular items may not have fit the model. All of the deleted items were items representing autistic communication styles, such as "your child appears deaf at times," "your child repeats phrases over and over," and "your child echoes questions or statements made by others." It seems that all of the items that represented "autistic features" loaded onto the second component, whereas items that represent skills normally present, but that parents of autistic children would be less likely to endorse loaded onto the first component. The final 9-item Communication scale was able to differentiate between children with mild communication difficulties (e.g. a11, a52, a36) and those with significant impairments (a27, a57, a 35), far beyond the level that classical test score theory could differentiate between persons on a 9-item scale.

Analysis of the Social scale of the CCQ revealed that 18 items from the original scale did not measure the same unidimensional construct as the remaining ten items, and were deleted. Closer examination of the 18 deleted items provides some insight into why these particular items did not fit the model. All of the deleted items were items representing autistic socialization styles, such as "your child prefers to play alone," "your child tunes you out," and "your child gets thing for him/herself." It seems that all of the items that represented "autistic features" loaded onto the second component, whereas items that represent skills present in normally developing children appeared to load onto the first component. The final 10-item Social scale was able to differentiate between children with mild social skill deficits (e.g. a7, a21, a37) and those with significant impairments (a8, a3, a17), far beyond the level that classical test score theory could differentiate between persons on a 10-item scale.

Rasch analysis of the Behavior scale of the CCQ revealed that the original 33-item scale was not measuring a unidimensional construct, and consequently 18 items were deleted. The final 15-item Behavior scale fit the Rasch model, and therefore it can be assumed that this set of items measured a single construct within this sample. All of the deleted items were items that were probably not relevant to the majority of families. They may have represented less common behaviors that may be present in some children but not others, or may be more relevant to higher functioning autistic children or children with Asperger's syndrome. For example items such as "your child has special abilities," "your child shows common sense," and "your child is self-injurious" were all deleted. The final

15-item Behavior scale was able to differentiate between children with subtle behavioral difficulties (e.g. a24, a45, a11) and those with more significant impairments (a40, a17, a18). However, seven persons did not fit the model indicating that caution should be used when generalizing this scale to autistic individuals compared to the other two scales of the CCQ. The Behavior scale may need further investigation with a larger sample to determine whether it can be generalized to all autistic individuals.

The final 34-item Child Characteristics Questionnaire is a reliable measure of three unidimensional traits characteristic of autism spectrum disorders. Future studies should be conducted with a larger sample to ensure that similar items would hold together on the three scales. A significant strength of this new CCQ is its ability to measure communication, social, and behavioral difficulties separately, providing the clinician or researcher with more specific information about the child's areas of strengths and weaknesses.

Limitations

In drawing conclusions about the meaning of the results presented here, certain limitations must first be addressed. While several of the hypotheses set forth were confirmed, the actual reason for parent difficulties in the diagnostic process and their unmet needs cannot be determined. Without specific knowledge about the exact process parents underwent when obtaining a diagnosis for their child, it remains unclear whether these findings truly reflect a difficult diagnostic process or whether these difficulties were unavoidable given the presentation of the child. There is clear evidence that autism presents itself differently at age two or three, compared to age five, and that it may be difficult to differentiate between a child with a language delay or mental retardation and autism at the preschool age (Charman & Baird, 2002; Gray & Tonge, 2001). In addition, without first-hand knowledge about the resources parents in this study have utilized since the time of diagnosis, it remains unclear whether these results reflect services that are not addressing the needs of the family, or whether these families have not made use of available services. Furthermore, even if these results do represent interactions with professionals who did not pick up on the features of autism early enough, it remains unclear if this is because experienced professionals and appropriate resources are unavailable, or whether the parents are not adequately accessing these professionals in the community. Finally, it remains unclear whether the results surrounding family needs reflect less involvement by the parent with the professional community due to resources being unavailable or the parent not accessing available services from the community.

Future studies, therefore, should endeavor to obtain medical records and reports of these families in order to determine who saw their child at various points prior to the diagnosis and what were the concerns or diagnostic impressions expressed by these professionals. It would be important to determine whether autism was suspected earlier but could not be definitively diagnosed, or whether alternative diagnoses were given to these children that did not adequately represent the child's presentation. It would also be important to determine from the medical records who were the professionals most likely to see these children early on. For example, this study shows that families first sought help from their family physicians regarding their initial concerns, and that the family physician often referred the child to a speech language pathologist. Therefore, it would be important to educate these two types of health care professionals about the early features of autism, in order to ensure that these children were referred to a professional experienced in the diagnosis of autism. Recent articles have been published in the BC Medical Journal to educate family physicians about early detection of autism (e.g. Ho & Smith, 2001; Kope et al., 2001), but it is likely that more education needs to be provided.

Future studies should also endeavor to delineate the reasons why parents of children with autism and Down syndrome are reporting so many unmet needs. It may be that once families are diagnosed they receive services for a short time prior to the child entering the school system, but that once in the school system adequate services are no longer available to these families. On the other hand, it may be that parents are still receiving adequate services from the community years after the diagnosis, but that the services themselves are not meeting the parent's needs. Finally, it may also be possible that while adequate services are available in the community, the families are not utilizing these services, either due to a lack of awareness of what is available, or because these families are so overwhelmed by their developmentally disabled child, that they do not have the time or the effort needed to take advantage of these supports (Armstrong, 1999). A study to delineate these factors should not only assess family needs, but should also investigate the services parents are using, how they obtained these services, their ratings of these supports, and their knowledge about the services available within their community. This information could be used to develop a more efficient support system that would better address the needs of the family.

Sampling limitations should also be considered when drawing conclusions about the results of the present study. Despite mailing out 300 questionnaires to parents of children with autism spectrum disorders, only 60 questionnaires were returned. One hundred fifty questionnaires were mailed out to parents of children with Down syndrome, but only 34 questionnaires were returned. Therefore representativeness of both samples is in question. By using current prevalence rates of the two disorders and the population of children between the age of 2 and 19 within the province of British Columbia, it can be deduced that there are approximately 4,000 children with autistic spectrum disorders (about 1,500 children with autistic disorder, specifically) and approximately 1,200 children with Down syndrome within the province of British Columbia. This indicates that the sample participating in this study represents only one to three percent of the population of children with these developmental disorders. One possibility for such a poor return rate from the autism group is that the families participating in community parent support groups may be highly stressed and may not have the time to participate in a study. Also, it was originally arranged with the Autism Society of British Columbia that the support groups would dedicate one meeting to fill out the questionnaires and then the group leader would send back the group's questionnaires in one packet. Unfortunately, this is not what happened. Parents were sent home with the questionnaires and required to mail them back on their own, needing to purchase an envelope and stamps to return the information. The extra effort required returning this information likely resulted in a poor response rate.

The representativeness of the population of parents of children with Down syndrome is also in question. One possibility for the return rate is reflected by some comments made by those who did respond. Some of these participants noted that the Diagnostic Survey was not relevant to the experiences of these parents, and therefore they were often unsure how to fill it out. Also, many parents from this group who did complete the Diagnostic Survey, related experiences about obtaining medical diagnoses for their child; for example, obtaining a diagnosis about a heart condition. It would have been clearer and more efficient to have had these participants only fill out the summary items on the Diagnostic Survey and the entire Family Needs Questionnaire. The fact that many parents who returned the packets related experiences about medical diagnoses needed for their child indicates that the sample may have had a greater percentage of families whose child has medical complications associated with Down syndrome. This could, in turn, influence families' self-reported needs. If this hypothesis is correct, then the generalizability of the results to families of children with Down syndrome is in question.

It is also important to note that because the sample of parents with autistic children was obtained through community support groups, this may represent a sample of parents who are more highly stressed due to their child's disorder and are reaching out to the community for help. On the other hand, these may be families who are somewhat less stressed, because these parents could actually find the time to attend community support group meetings. It is unclear which hypothesis is true of the group, but leads to the possibility that this is not a random sample of parents but rather a group that shares certain common characteristics. For example, as discussed earlier, most of the families within this group had their child diagnosed within the last five years, which limited some of the analyses conducted to determine the diagnostic experiences and long-term needs of parents whose child had been diagnosed more than ten years ago. Because families utilizing parent support groups are those that were diagnosed more recently, this indicates that those that have successfully adapted to having a child with a chronic disability may eventually stop attending support groups. This is likely not only a weakness for the study, but also for the effectiveness of community support groups who do not have members attending that could provide newly diagnosed families with long-term views and strategies on how to cope with an autistic child.

Finally, sampling limitations may have arisen by including parents of a wide range of ages (2 - 18). Families with adolescents with autism or Down syndrome may have an entirely different set of needs and challenges than those of elementary school aged children. Because the majority of the sample were not adolescents, the specific needs and experiences of families with a developmentally delayed adolescent may have been masked by clumping all of the children into one group. Obtaining a sample with a larger group of adolescents may have made it easier to recognize patterns of needs that may be unique to specific age groups.

Summary, Conclusions and Suggestions for Future Research

Due to the small sample size obtained, the present study must be considered as a pilot. A larger sample of parents with autistic children throughout the province would be needed to confirm the findings reported. A sample should be collected from sources other than parent support groups so that the sample might better represent the range of diagnostic experiences and family needs of families with an autistic child, throughout the province of British Columbia. Furthermore, future studies should examine the availability of resources and experienced professionals in the community, the types of services families have been utilizing, and parent's knowledge about the types of services available to them. This information would be important to determine where changes in the diagnostic and service delivery system may be most useful.

Given the limitations noted above, several conclusions can still be drawn from the present study. Specifically, parents of autistic children report significant hardships trying to get their child diagnosed. Most families wait approximately three years from when they initially sought help from a professional to receive a diagnosis for their child. Despite the knowledge about the importance of early diagnosis for long-term prognosis of the child, the children in this study were not diagnosed until approximately five years of age, with several children diagnosed after age ten. Parents saw an average of four professionals, and report significant dissatisfaction with the diagnostic process and the services received since the time of the diagnosis.

Furthermore, group differences were not found in the number of important needs endorsed, nor in the number of met important needs. However, only one third of families' important needs were endorsed as met, indicating that the service delivery system is failing to adequately address parent needs. Of particular interest was the finding that although both groups reported equivalent numbers of important met needs, the parents of children with autism spectrum disorders were significantly more dissatisfied with the services received since the diagnosis. This finding suggests that parents of autistic children have significantly greater expectations from the service delivery system than parents of children with Down syndrome. Parents of children with autism spectrum disorders likely hold strong beliefs that adequate supports can lead to a cure or significant influence on their child's long-term prognosis, whereas parents of children with Down syndrome are more likely to accept their child's disability and the fact that their child will likely have life-long impairments.

Finally, it is also of importance to recognize the impact of autistic features on parents' experiences with the diagnostic system, as well as on their self-reported needs. Parents of autistic children with greater communication impairments are more likely to report greater satisfaction regarding the diagnostic process and the services received since the diagnosis, as well as to report decreased stress levels surrounding the diagnosis. Parents of children with greater behavioral impairments were more likely to endorse more needs as important, suggesting that the behavioral oddities associated with autism may lead to increased stress levels in these parents. Finally, greater social impairments were linked to fewer met needs, suggesting that our service delivery system may be lacking in programs or interventions aimed specifically at the development of social skills in these children.

The state of the health care and service delivery system within British Columbia is in a state of constant flux, due to changing governments and policies regarding services available to families with an autistic child. Currently, the government has taken more proactive measures to ensure that these families have adequate financial support to buy therapies needed for their autistic child and to decrease waitlists for diagnostic assessments for autism spectrum disorders at local health centres. It is likely that the results of this study are very specific to the current state of the health care system, and that changing policies could change the results of similar future studies.

This study has several clinical implications for those working within the health care delivery system. For example, health care professionals who see very young children with social, behavioral, or language impairments must be aware of the features of autism spectrum disorders and make appropriate referrals to developmental specialists as soon as there is concern about the child's development. Because the literature has shown the positive effects of intensive behavioral interventions, prior to age five, on the long-term prognosis of autistic children, clinicians should be urged to make appropriate referrals early enough for these children to maximally benefit from these interventions. This study suggests that children are still not being diagnosed early enough within the province of British Columbia. Although this may partially be due to long wait lists, parents report having seen an average of four clinicians before obtaining a diagnosis. If parents could be referred straight from a pediatrician or general practitioner to a developmental specialist, this would lead to quicker diagnoses.

Also, the findings from this study suggest that those parents who react to the diagnosis of autism with higher stress levels were more likely to report more needs as important, suggesting that the clinicians who make the diagnosis should be very sensitive to the parents' reactions to the diagnosis. Professionals diagnosing autism should personally monitor the parents' coping skills over the months or years following the diagnosis to ensure healthy adaptation. Parents' receiving a diagnosis of an autism spectrum disorder should be offered counseling or put in touch with community support groups to help them deal with the stressful diagnosis. Helping these parents with their initial reactions may result in decreased pressure on an already saturated service delivery system.

Finally, clinicians working with families of children with autism spectrum disorders should keep in mind the many stresses of having a child with this cluster of problems. These parents do not receive the same kind of "reinforcement" from parenting their child compared to a parent with a child with Down syndrome or a typically developing child. Many of these parents deal with very difficult behaviors, have no way of functionally communicating with their child, and are not able to interact socially with their child. All of these features of autism make it a difficult disorder for parents to adapt to. In addition, the health care delivery system is not usually able to address many of the needs parents report as important. The combination of dealing with a saturated service delivery system and the pressures associated with parenting an autistic child, leads to many parents feeling stressed and in need of social supports. Clinicians who interact with these families need to be sensitive to the needs of these parents and should focus on helping the family cope with their child, and not just on diagnosing and treating the child.

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APPENDIX A: DIAGNOSTIC SURVEY

Child's Date of Birth: ________________

Current Age: ______________________

Male/Female: ______________________

Was the City/Town you were living in at the time you were seeking a diagnosis:
  a. small rural (e.g. 100 Mile House)
  b. medium rural/small urban (e.g. Kamloops)
  c. medium urban (e.g. Victoria)
  d. large urban (e.g. Vancouver)

---

1. How old was your child when you first began to have concerns about his/her development? Please indicate in years and months
   Age: ______years ______months

2. What sort of problems were you worried about? ---Please rank your top 5 choices in the spaces below. Just write **the letter** of the choice you are selecting in each space (There is no need to fill in all 5 spaces)

1.__________ 2.____________ 3.____________4.____________5.__________

  a. Delay in starting to talk
  b. Delay in other milestones such as learning to walk
  c. Social development (failure to relate to people in the normal way)
  d. Rituals/obsessions/dislike of change/object attachments, etc.
  e. Failure to develop normal pretend play
  f. Behaviour problems (hyperactivity/tantrums, etc.)
  g. Schooling
  h. Medical problems (epilepsy etc.)
  i. Hearing problems
  j. Physical abnormalities (Muscle tone, motor coordination, etc.)
  k. Other (please specify)_____________________________
  l. No worries until other professional raised concerns (please give details)____________________________________
  ____

3. How old was your child when you first sought help? Please indicate in years and months.
   Age: _____years _____months

4. Who did you see at this time? Please circle the relevant number.

a. Family Physician	f. Social Worker
b. Pediatrician	g. Teacher
c. Child Psychiatrist	h. Nurse
d. Psychologist	i. Obstetrician/Gynecologist
e. Other (please specify)_______________	

5. What happened then? Please circle the relevant number.

   a. Diagnosis made
   b. Referred to other professional
   c. Told not to worry ("He/she would grow out of it")
   d. Told to return if problems did not improve
   e. Told there is no problem ("Your child is fine")
   f. Other (please specify)__________________

6. If a diagnosis was given, what was this?

7. If you were referred on, whom did you see? (Please circle the relevant number)

   a. Pediatrician
   b. Child Psychiatrist
   c. Clinical Psychologist
   d. School Psychologist
   e. Child Neurologist
   f. Speech Therapist/Pathologist
   g. Audiologist
   h. Otolaryngologist/Hearing Doctor
   i. Occupational Therapist
   j. Social Worker
   k. Educational Specialist (special needs teacher, resource worker, etc.)
   l. Other (please specify)___________
   m. No referral made

8. If you were referred on, how old was your child by the time you saw this new professional? Please indicate in years and months.
   Age: _____years _____months

9. How far did you have to travel to see this person? Indicate in approximate kilometres and indicate whether this person was located in your city.

10. What happened at this referral? Please circle the relevant number.

   a. Diagnosis made
   b. Referred to other professional
   c. Told not to worry (He/she will grow out of it")
   d. Told to return if problems did not improve
   e. Told "There is no problem, your child is fine"
   f. Other (please specify)________________

11. If a diagnosis was given what was this?

12. Did you have problems obtaining this referral? Circle relevant answer.

   YES/NO

   If yes, please provide details:

13. If this referral led to you being offered practical help/support of any kind, what sort of help were you given? Please list the supports you received in the ***order of their usefulness*** (i.e. the support listed in the first space would be the most useful). There is no need to fill in all 5 spaces. Write **the letter** of the choice you are selecting in each space

1.__________ 2.____________ 3.____________ 4.____________ 5.____________

a. Help with pre/school provision
b. An Individual Education Plan (IEP) was set up
c. Help with monetary benefits, etc (e.g. government funding)
d. Help with medical problems
e. Contact with other parents
f. Language therapy
g. Respite care
h. General advice
i. Personal support/counselling treatment
j. Family Therapy
k. Contact with Autism Society/Down Syndrome Foundation
l. Explanation of child's problems
m. Other (please specify)__________________________
n. No help offered

Some families need to try more than once to get the appropriate diagnosis for their child. If this was the case for you please complete Questions 14-22. Otherwise skip to the SUMMARY QUESTIONS after question 22.

14. Why did you find it necessary to seek a further referral? Give details on extra sheets if necessary.

____
____
____
____
____

15. Who did you see at this second referral? Please circle the relevant number(s).

a. Pediatrician
b. Child Psychiatrist
c. Clinical Psychologist
d. School Psychologist
e. Child Neurologist
f. Speech Therapist/Pathologist
g. Audiologist
h. Otolaryngologist/Hearing Doctor)
i. Occupational Therapist
j. Social Worker
k. Educational Specialist (special needs teacher, resource worker, etc.)
l. Other (please specify)__________
m. No referral made

16. How far did you have to travel to see this person? Indicate in approximate kilometres and indicate whether this person was located in your city.

____

17. How old was your child by the time of this next referral? Please indicate in years and months.
Age: _____years _____months

18. What happened at this referral? Please circle the relevant number.

    a. Diagnosis made
    b. Referred to other professional
    c. Told "No problem"
    d. Told not to worry (He/she will grow out of it")
    e. Told to return if problems did not improve
    f. Other (please specify)________________

19. If a diagnosis was given what was this?

____

20. Did you have problems obtaining this referral? Circle relevant answer.

    YES/NO

    If yes, please provide details:

    ____
    ____
    ____
    ____
    ____

21. If this referral led to you being offered practical help/support of any kind, what sort of help were you given? Please list the supports you received in the ***order of their usefulness*** (i.e. the support listed in the first space would be the most useful). There is no need to fill in all 5 spaces. Write **the letter** of the choice you are selecting in each space.

    1.__________ 2.____________ 3.____________ 4.____________ 5.___________

    a. Help with pre/school provision
    b. An Individual Education Plan (IEP) was set up
    c. Help with monetary benefits, etc (e.g. government funding)
    d. Help with medical problems
    e. Contact with other parents
    f. Language therapy
    g. Respite care
    h. General advice
    i. Personal support/counselling treatment
    j. Family Therapy
    k. Contact with Autism Society/Down Syndrome Foundation
    l. Explanation of child's problems
    m. Other (please specify)________________
    n. No help offered

22. If you have needed to seek still more referrals:

    How many? ________________

    How far from your home (in kilometres)?__________________

    In your own city? YES/NO

    What type of professional(s)?___________________________

IN SUMMARY ....

HAVE YOU EVER HAD A DEFINITE DIAGNOSIS OF AUTISM OR DOWN SYNDROME FOR YOUR CHILD? **YES/NO**

At what age? _____years _____months

In your own city? **YES/NO**

How many kilometres away? ____________________

By what type of professional? ____________________

IF **NOT** DIAGNOSED AS AUTISTIC OR DOWN'S, HAS HE/SHE BEEN DIAGNOSED AS HAVING . . . . (check relevant answer)

_____Autistic traits or features

_____Asperger's syndrome

_____Pervasive Developmental Disorder

_____A learning disability

_____A language disorder

_____Mental retardation

_____Developmental Disability

_____Fragile X syndrome

_____Other (please specify):__________________

At what age? _____years _____months

In your own city? **YES/NO**

How many kilometres away?_______________________

By what type of professional?_______________________

Has your child been diagnosed with an intellectual disability? **YES/NO**

If yes, is your child (circle one): MILDLY DISABLED MODERATELY DISABLED SEVERELY DISABLED

Has your child been diagnosed with a language disability? **YES/NO**

If yes, what is your child's level of language ability (average = age-appropriate):

SEVERE DISABILITY	BELOW AVERAGE	SLIGHTLY BELOW AVERAGE	AVERAGE	ABOVE AVERAGE

OVERALL, HOW SATISFIED HAVE YOU BEEN WITH THE DIAGNOSTIC PROCESS?

1	2	3	4	5
Very Satisfied	Quite Satisfied	Neither Satisfied nor Dissatisfied	Not Very Satisfied	Not at all Satisfied

OVERALL, HOW STRESSFUL DID YOU FIND THE DIAGNOSTIC PROCESS?

1	2	3	4	5
Very Stressful	Quite Stressful	Neither Stressful nor Unstressful	Not Very Stressful	Not at all Stressful

HOW STRESSFUL DID YOU FIND THE DIAGNOSIS (i.e. Autism, Down Syndrome, etc) ITSELF?

1	2	3	4	5
Very Stressful	Quite Stressful	Neither Stressful nor Unstressful	Not Very Stressful	Not at all Stressful

OVERALL, HOW SATISFIED HAVE YOU BEEN WITH THE HELP THAT YOU HAVE RECEIVED FOLLOWING THIS?

1	2	3	4	5
Very Satisfied	Quite Satisfied	Neither Satisfied nor Dissatisfied	Not Very Satisfied	Not at all Satisfied

FINALLY, WHAT HAS BEEN THE MOST USEFUL HELP YOU HAVE BEEN OFFERED OVER THE YEARS AND WHO HAS PROVIDED THIS?

____

____

____

____

____

MANY THANKS FOR YOUR HELP – PLEASE FEEL FREE TO PROVIDE ANY MORE INFORMATION YOU WOULD LIKE TO ADD ON A SEPARATE SHEET.

APPENDIX B: FAMILY NEEDS QUESTIONNAIRE

DIRECTIONS: The following statements describe needs that parents of children with developmental disorders sometimes have. Because many of these needs are likely to be important to you, please respond according to how important each need is in relation to your overall needs. Also, these needs normally change over time. We are interested in knowing how important they are to you at the present time and whether they are being met. The information you provide will help us to understand the needs of your family and other families of children with similar problems.

Please show how important you feel these needs are relative to your overall needs, by using the scale below and placing a circle around the number which best describes your answer:

1	2	3	4
Least Important	Slightly Important	Important	Most Important

Use this scale to tell us whether each need is being met by circling: Y (Yes), P (Partly), or N (No):

Y	P	N
Yes	Partly	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?				NEED MET?		
1. to be actively involved in my child's treatments and therapies.	1	2	3	4	Y	P	N
2. to be well-educated about my child's disorder in order to be an effective decision maker regarding the needs of my child.	1	2	3	4	Y	P	N
3. services continuously rather than only in times of crisis.	1	2	3	4	Y	P	N
4. to have consistent physical therapy for my child.	1	2	3	4	Y	P	N
5. for professionals to be discrete when talking about my child while he/she is in the room.	1	2	3	4	Y	P	N
6. for my child to have friends of his/her own.	1	2	3	4	Y	P	N
7. to have different professionals agree on the best way to help my child.	1	2	3	4	Y	P	N
8. to be shown that my opinions are used in planning my child's treatment, therapies, or education.	1	2	3	4	Y	P	N
9. to have a professional to turn to for advice or services when my child needs help.	1	2	3	4	Y	P	N
10. to have consistent behavioural therapy for my child.	1	2	3	4	Y	P	N

1	**2**	**3**	**4**	**Y**	**P**	**N**
Least Important	**Slightly Important**	**Important**	**Most Important**	**Yes**	**Partly**	**No**

I NEED....	**RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?**				**NEED MET?**		
11. to have help from other family members in taking care of my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
12. weekend and after-school activities for my developmentally delayed child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
13. to work with professionals who have expertise working with children who have the same developmental disorder as my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
14. to have consistent occupational therapy for my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
15. to be told why my child acts in ways that are different, difficult or unusual.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
16. to have time to spend alone with my other children.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
17. to be shown what to do when my child is acting unusually or is displaying difficult behaviors.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
18. to have information regarding my child's therapeutic or educational progress.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
19. to have help in deciding how much to let my child do by himself/herself.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
20. for my developmentally delayed child to have social activities other than with his/her own parents and siblings.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
21. to have consistent speech therapy for my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
22. to have help with housework.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
23. to have counseling for myself and my spouse/partner.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
24. to get enough rest or sleep.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
25. to get a break from my responsibilities.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
26. to spend time with my friends.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**

1	2	3	4	Y	P	N
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?				NEED MET?		
27. to be told if I am making good decisions about my child.	1	2	3	4	Y	P	N
28. for the professionals working with my child to understand the needs of my child and my family.	1	2	3	4	Y	P	N
29. for my children's friends to feel comfortable around my child.	1	2	3	4	Y	P	N
30. to have other family members understand my child's problems.	1	2	3	4	Y	P	N
31. to have my child's after-school friends to understand his/her problems.	1	2	3	4	Y	P	N
32. to have my child's teachers understand his/her problems.	1	2	3	4	Y	P	N
33. to discuss feelings about my child with a parent who has a child with the same disorder.	1	2	3	4	Y	P	N
34. to have my child's therapies continue throughout the summer months and school breaks.	1	2	3	4	Y	P	N
35. to be reassured that it is not uncommon to have negative feelings about my child's unusual behaviors.	1	2	3	4	Y	P	N
36. help dealing with my fears about my child's future.	1	2	3	4	Y	P	N
37. help in remaining hopeful about my child's future.	1	2	3	4	Y	P	N
38. to have my questions answered honestly.	1	2	3	4	Y	P	N
39. to be encouraged to ask for help.	1	2	3	4	Y	P	N
40. to have counseling for my other children.	1	2	3	4	Y	P	N
41. information about special programs and services available to my child and my family.	1	2	3	4	Y	P	N

1	2	3	4	Y	P	N
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?	NEED MET?
42. to be shown respect by the professionals working with my child.	1 2 3 4	Y P N
43. financial support (e.g. from the government) in order to provide my child with his/her therapies, treatments, and care.	1 2 3 4	Y P N
44. respite care for my child.	1 2 3 4	Y P N
45. the children in my child's classroom to understand that my child cannot help his/her unusual behaviors and difficulties.	1 2 3 4	Y P N
46. to have time to spend alone with my partner.	1 2 3 4	Y P N
47. my child's school to set up a specialized education plan for my child.	1 2 3 4	Y P N
48. my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child.	1 2 3 4	Y P N
49. to have the professionals working with my child to speak to me in terms I can understand.	1 2 3 4	Y P N
50. to have my spouse and me agree on decisions regarding our developmentally delayed child.	1 2 3 4	Y P N
51. my child's doctor and dentist to have experience working with children with the same disorder as my child.	1 2 3 4	Y P N
52. I need to go out for dinner with my family three times each week.	1 2 3 4	Y P N
53. I need to take 3-week long family vacations each year.	1 2 3 4	Y P N
54. I need to take week-long vacations by myself each year.	1 2 3 4	Y P N

APPENDIX C: CHILD CHARACTERISTICS QUESTIONNAIRE

DIRECTIONS: The following statements describe symptoms or behaviors that autistic children sometimes exhibit. These symptoms often change across the child's lifetime. We are interested in what your child is like right now. The information you provide will help us to understand your child's *current* level of functioning.

Please indicate how often your child exhibits certain behaviors by using the scale below and placing a circle around the number which best describes your answer:

1 ↓	**2** ↓	**3** ↓	**4** ↓	**5** ↓
Never (0% of the time)	**Rarely** (10-30% of the time)	**Sometimes** (30-50% of the time)	**Often** (50-70% of the time)	**Very Often** (70-100% of the time)

Communication Concerns

1. Your child responds to his/her name	1	2	3	4	5
2. Your child can tell you what (s)he wants	1	2	3	4	5
3. Your child follows directions	1	2	3	4	5
4. Your child appears deaf at times	1	2	3	4	5
5. Your child seems to hear sometimes but not others	1	2	3	4	5
6. Your child points or waves bye-bye	1	2	3	4	5
7. Your child points with his/her finger	1	2	3	4	5
8. Your child nods yes	1	2	3	4	5
9. Your child shakes his/her head for no	1	2	3	4	5
10. Your child directs your attention by holding up objects for you to see	1	2	3	4	5
11. Your child shows things to people	1	2	3	4	5
12. Your child will lead an adult by the hand	1	2	3	4	5
13. Your child gives inconsistent responses to commands (e.g. sometimes they seem to understand and do the right thing, and other times they seem to not understand or do the wrong thing)	1	2	3	4	5
14. Your child repeats phrases over and over	1	2	3	4	5
15. Your child echoes questions or statements made by others	1	2	3	4	5
16. Your child asks inappropriate questions	1	2	3	4	5
17. Your child can accumulate facts on certain subject (good rote memory) without really understanding the meaning	1	2	3	4	5
18. Your child has a literal understanding of ambiguous and metaphorical language (your child takes sarcasm or irony literally; e.g. I'm so full I'm going to explode!)	1	2	3	4	5
19. Your child invents idiosyncratic words or expressions (e.g. words or expressions that only have meaning to them or those who know them well, or using odd or strange words to describe something)	1	2	3	4	5
20. Your child has a "different" voice or speech	1	2	3	4	5
21. Your child makes naive and embarrassing remarks	1	2	3	4	5

Social Concerns

22. Your child smiles socially	1	2	3	4	5
23. Your child seems to prefer to play alone	1	2	3	4	5
24. Your child gets things for him/herself	1	2	3	4	5

25. Your child is very independent (e.g. likes to do things by him/herself, such as playing alone)	1	2	3	4	5
26. Your child does things "early" (e.g. learns to get things from the cupboards or refrigerator by him/herself before other kids who are the same age)	1	2	3	4	5
27. Your child has poor eye contact	1	2	3	4	5
28. Your child is in his/her own world	1	2	3	4	5
29. Your child tunes you out	1	2	3	4	5
30. Your child is interested in other children	1	2	3	4	5
31. Your child cuddles like other children	1	2	3	4	5
32. Your child looks at you when you are talking	1	2	3	4	5
33. Your child looks at you when you are playing	1	2	3	4	5
34. Your child smiles in response to a smile from others	1	2	3	4	5
35. Your child engages in reciprocal, back-and-forth play	1	2	3	4	5
36. Your child plays simple imitation games (like pat-a-cake or peek-a-boo)	1	2	3	4	5
37. Your child is responsive to other's facial expressions or feelings	1	2	3	4	5
38. Your child has a social smile	1	2	3	4	5
39. Your child has friends	1	2	3	4	5
40. Your child uses toys appropriately	1	2	3	4	5
41. Your child offers to share	1	2	3	4	5
42. Your child is responsive to other children's approaches	1	2	3	4	5
43. Your child shows a range of facial expressions	1	2	3	4	5
44. Your child is regarded as "odd" by the other children	1	2	3	4	5
45. Your child wishes to be sociable but fails to make relationships with peers	1	2	3	4	5
46. Your child can be with other children, but only on his/her own terms	1	2	3	4	5
47. Your child has a best friend	1	2	3	4	5
48. Your child is poor at games: he/she has no idea of cooperating in a team, scores "own goals"	1	2	3	4	5
49. Your child has unusual facial expressions	1	2	3	4	5

Behavioral Concerns

50. Your child has temper tantrums	1	2	3	4	5
51. Your child is hyperactive/uncooperative or oppositional	1	2	3	4	5
52. Your child gets stuck on things over and over	1	2	3	4	5
53. Your child toe walks	1	2	3	4	5
54. Your child has unusual attachments to toys	1	2	3	4	5
55. Your child lines things ups	1	2	3	4	5
56. Your child is oversensitive to certain textures	1	2	3	4	5
57. Your child is oversensitive to certain sounds	1	2	3	4	5
58. Your child has odd or stereotyped movement patterns	1	2	3	4	5
59. Your child has a narrow range of interests	1	2	3	4	5
60. Your child attends more to parts of objects (e.g. wheels)	1	2	3	4	5
61. Your child has limited or absent pretend play	1	2	3	4	5
62. Your child imitates other people's actions	1	2	3	4	5
63. Your child plays with toys in the same exact way each time	1	2	3	4	5
64. Your child dresses him/herself without frequent help	1	2	3	4	5
65. Your child is oblivious to danger	1	2	3	4	5
66. Your child shows a "startle response" to loud noise	1	2	3	4	5
67. Your child has "special abilities"	1	2	3	4	5
68. Your child gets involved in complicated rituals	1	2	3	4	5
69. Your child flaps his/her hands	1	2	3	4	5

70. Your child whirls him/herself for long periods of time	1	2	3	4	5
71. Your child is very destructive	1	2	3	4	5
72. Your child will feel, smell, taste objects in the environment	1	2	3	4	5
73. Your child hurts others by biting, hitting, kicking, etc.	1	2	3	4	5
74. Your child interrupts	1	2	3	4	5
75. Your child is self-injurious	1	2	3	4	5
76. Your child expresses sounds involuntarily; clears throat, grunts, smacks, cries or screams	1	2	3	4	5
77. Your child shows common sense	1	2	3	4	5
78. Your child has clumsy, uncoordinated, awkward movements or gestures	1	2	3	4	5
79. Your child has involuntary movements or gestures	1	2	3	4	5
80. Your child is able to complete simple daily activities	1	2	3	4	5
81. Your child has special routines: insists on no change	1	2	3	4	5
82. Your child has markedly unusual posture	1	2	3	4	5

Thank you for taking the time to fill out these questionnaires

APPENDIX D: DEMOGRAPHICS QUESTIONNAIRE

1. Who filled out the questionnaires? (relationship to child)____________________
   (If more than one person, specify relationship of both)

2. Who does your child live with (e.g. both parents, parent and stepparent, single parent)?
   ____

3. How many siblings does your child have?_________________________

4. Are there other children in the family with autism, Down syndrome, or any other disorders?________________ if Yes, please specify________________

5. Is your child with autism or Down syndrome the:
   a. youngest child
   b. middle child
   c. oldest child

6. What is the total family income:
   a. Less than $15,000 per year
   b. $16,000 - $30,000 per year
   c. $31,000 - $50,000 per year
   d. $51,000 - $70,000 per year
   e. $71,000 - $100,000 per year
   f. greater than $100,000 per year

7. Who in the family is currently working?_______________________

8. How many years of education does the mother have?______________________

9. How many years of education does the father have?______________________

10. How old is the mother currently?_____________________________

11. How old is the father currently?_____________________________

12. Is the area you currently live in a(n):
    a. urban environment (e.g. Vancouver, B.C.)
    b. rural environment (e.g. Mission, B.C.)

13. What is the approximate population of the town/city you currently live in?________________________

14. Does your child have any other psychological disorders, besides Down syndrome or autism?
    __________ If Yes, please specify______________________

15. Does your child have any medical conditions or problems?_____________
    If Yes, please specify__________________________

Appendix E: Introduction Letter Provided in Questionnaire Packets

Assessing the Diagnostic Experiences and Family Needs of Parents Of Children with Autism and Down Syndrome

Dear Parent:

I am a master's student at the University of Victoria studying child neuropsychology. As a training child neuropsychologist, I have had the opportunity to work with parents of children who are coping with various developmental disorders. These families frequently interact with various professionals during the diagnostic process, as well as on a long-term basis. Throughout my experiences, I have been struck by how many families have expressed some degree of disappointment regarding the availability of professionals for information, educational issues, and simple advice, and how they have had difficulties within systems which are anticipated to provide support. Although there are numerous intervention programs based on what health professionals *believe* may be useful for families, there is limited information about the needs of parents from their own experiences and based on *their* perspectives. Consequently, it is possible that many well-meaning programs or services may not be addressing the actual issues or needs that parents feel are most important or the most useful.

In order to provide more information on the diagnostic process, provide more helpful services, and provide a higher quality of care, it is important to get information from families regarding what has been useful and what needs of their family have and have not been met. Although parents of children with any disorder share many of the same concerns, specific needs are frequently related to the type of disorder that affects their child. Therefore, this study will be aimed at comparing the diagnostic experiences and needs of families of children with different developmental disorders to determine what types of services or changes to the diagnostic process may be helpful based on the child's unique difficulties. This kind of comparison will allow professionals to provide a more individualized service based on the child's disorder and the needs of their families.

I am writing to you today to ask for your participation in this study so that we can better identify the types of experiences families have had with the diagnostic system, as well as to identify the types of needs which may be going unmet in families of children with developmental disorders. The Autism Society of BC or the Down Syndrome Research Foundation helped me to identify you as a possible participant in this study. Data collected as part of this project will be included in a master's thesis being completed at the University of Victoria. The questionnaires found within this package should not take more than 45 – 60 minutes to complete, and can be returned to me in the enclosed return-addressed, stamped envelope. There are no known or anticipated risks to you by participating in this research. Your help in this project will allow professionals to better help future parents to cope with the difficult issues you have already overcome, and those that you still find troublesome. It will also help to better provide families with resources so that they may also learn to cope with their child's difficulties.

In an effort to keep responses completely anonymous, I will not collect any information with you or your child's name on it. For the same reason, please do not write a return address on the questionnaire package when mailing it back to me. **By returning the enclosed questionnaires, this will be considered the same as giving your consent to have data from your family included in this research study.** Once the questionnaires are returned there is no way to identify an individual's questionnaires, and therefore they cannot be removed from the study. In this manner we can assure you that your decision to participate or to not participate will be strictly confidential (***without exception***), and that your decision to participate **will not** affect the quality of care you or your child receives. The completed questionnaires will be destroyed (through shredding) 2 years after the completion of the study.

It is anticipated that the results of this study will be shared with others in the following ways: writing up the results for my master's thesis, sharing them in front of a supervisory committee, publishing the data in a peer-reviewed journal, and presenting the results at a conference. If you are interested in receiving a brief written report detailing the results of this study (once it has been completed) you may notify me of this by mailing in **a separate letter** indicating your interest in this project and including your name and mailing address. **PLEASE DO NOT PROVIDE THIS INFORMATION WITH YOUR QUESTIONNAIRES** so that your responses can be kept anonymous.

All mail should be sent to: Susan Siklos
c/o Dr. Kimberly Kerns
Department of Psychology
University of Victoria
PO Box 3050 STN CSC
Victoria, B.C.
V8W 3P5

If you have any questions regarding this project, please feel free to contact me at (250) 472-4195, or my supervisor, Dr. Kimberly Kerns, at (250) 721-7553. In addition to being able to contact myself and my supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4632).

Thank you again for your help.

Yours truly,

Susan Siklos, B.Sc.
Master's Student in Clinical Neuropsychology
University of Victoria

APPENDIX F: CHILD- VS. PARENT-CENTRED NEEDS

Parent-Centred Needs:

1. I need to be actively involved in my child's treatments and therapies.
2. I need to be well-educated about my child's disorder in order to be an effective decision maker regarding the needs of my child.
8. I need to be shown that my opinions are used in planning my child's treatment, therapies, or education.
9. I need to have a professional to turn to for advice or services when my child needs help.
11. I need to have help from other family members in taking care of my child.
15. I need to be told why my child acts in ways that are different, difficult, or unusual.
16. I need to have time to spend alone with my other children.
17. I need to be shown what to do when my child is acting unusually or is displaying difficult behaviors.
18. I need to have information regarding my child's therapeutic or educational progress.
19. I need to have help in deciding how much to let my child do by himself/herself .
22. I need to have help with housework.
23. I need to have counseling for myself and my spouse/partner.
24. I need to get enough sleep or rest.
25. I need to get a break from my responsibilities.
26. I need to spend time with my friends.
27. I need to be told if I am making good decisions about my child.
33. I need to discuss feelings about my child with a parent who has the same disorder as my child.
35. I need to be reassured that it is not uncommon to have negative feelings about my child's unusual behaviors.
36. I need help dealing with my fears about my child's future.
37. I need help in remaining hopeful about my child's future.
38. I need to have my questions answered honestly.
39. I need to be encouraged to ask for help.
42. I need to be shown respect by the professionals working with my child.
44. I need respite care for my child.
46. I need to have time to spend alone with my partner.
49. I need to have the professionals working with my child to speak to me in terms I can understand.

Child-Centred Needs

3. I need services continuously rather than only in times of crisis.
4. I need to have consistent physical therapy for my child.
5. I need for professionals to be discrete when talking about my child while he/she is in the room.
6. I need for my child to have friends of his/her own.
10. I need to have consistent behavioral therapy for my child.
12. I need weekend and after-school activities for my developmentally delayed child.
13. I need to work with professionals who have expertise working with children who have the same developmental disorder as my child.
14. I need to have consistent occupational therapy for my child.
20. I need for my developmentally delayed child to have social activities other than with his/her own parents and siblings.
21. I need to have consistent speech therapy for my child.
34. I need to have my child's therapies continue throughout the summer months and school breaks.
47. I need my child's school to set up a specialized education plan for my child.
48. I need my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child.

APPENDIX G

Top Ten Endorsed Items that Fit the Rasch Model (Rasch Analysis)

(Autism = 38 persons, 38 items; Down's = 23 persons, 37 items)

Ten Most Frequently Endorsed Items that fit Rasch Model: AUTISM

1. I need to be well-educated about my child's disorder in order to be an effective decision maker regarding the needs of my child
2. I need to be shown that my opinions are used in planning my child's treatment, therapies, or education
3. *I need to have my child's teachers understand his/her problems
4. I need to work with professionals who have expertise working with children who have the same developmental disorder as my child
5. *I need to have my questions answered honestly
6. I need to have consistent behavioural therapy for my child
7. I need to be shown respect by the professionals working my child
8. I need my child's doctor and dentist to have experience working with children with the same disorder as my child
9. I need financial support (e.g. from the government) in order to provide my child with his/her therapies, treatments and care
10. I need my child's school to set up a specialized education plan for my child
11. I need to have a professional to turn to for advice or services when my child needs help

(9, 10, 11 = all have the same logit value)

Ten Most Frequently Endorsed Items that fit Rasch Model: DOWN'S

1. I need information about special programs and services available to my child and my family
2. I need for my child to have friends of his/her own
3. I need for my developmentally delayed child to have social activities other than with his/her own parents and siblings
4. *I need to have my questions answered honestly
5. I need to have my spouse and me agree on decisions regarding our developmentally delayed child
6. I need to have information regarding my child's therapeutic or educational progress
7. *I need to have my child's teachers understand his/her problems
8. I need to have time to spend alone with my partner
9. I need to have the professionals working with my child to speak to me in terms I can understand
10. I need for the professionals working with my child to understand the needs of my child and my family

* = in top ten endorsed for both groups

APPENDIX H: FAMILY NEEDS QUESTIONNAIRE (RASCH DELETIONS)

DIRECTIONS: The following statements describe needs that parents of children with developmental disorders sometimes have. Because many of these needs are likely to be important to you, please respond according to how important each need is in relation to your overall needs. Also, these needs normally change over time. We are interested in knowing how important they are to you at the present time and whether they are being met. The information you provide will help us to understand the needs of your family and other families of children with similar problems.

Please show how important you feel these needs are relative to your overall needs, by using the scale below and placing a circle around the number which best describes your answer:

1	2	3	4
Least Important	Slightly Important	Important	Most Important

Use this scale to tell us whether each need is being met by circling: Y (Yes), P (Partly), or N (No):

Y	P	N
Yes	Partly	No

I NEED....	**RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?**				**NEED MET?**		
1. to be actively involved in my child's treatments and therapies.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
2. to be well-educated about my child's disorder in order to be an effective decision maker regarding the needs of my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
~~3. services continuously rather than only in times of crisis.~~	~~1~~	~~2~~	~~3~~	~~4~~	~~Y~~	~~P~~	~~N~~
4. to have consistent physical therapy for my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
5. for professionals to be discrete when talking about my child while he/she is in the room.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
6. for my child to have friends of his/her own.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
7. to have different professionals agree on the best way to help my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
8. to be shown that my opinions are used in planning my child's treatment, therapies, or education.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
9. to have a professional to turn to for advice or services when my child needs help.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
~~10. to have consistent behavioural therapy for my child.~~	~~1~~	~~2~~	~~3~~	~~4~~	~~Y~~	~~P~~	~~N~~

1	2	3	4	Y	P	N
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?				NEED MET?		
11. to have help from other family members in taking care of my child.	1	2	3	4	Y	P	N
12. weekend and after-school activities for my developmentally delayed child.	1	2	3	4	Y	P	N
13. to work with professionals who have expertise working with children who have the same developmental disorder as my child.	1	2	3	4	Y	P	N
14. to have consistent occupational therapy for my child.	1	2	3	4	Y	P	N
15. to be told why my child acts in ways that are different, difficult or unusual.	1	2	3	4	Y	P	N
16. to have time to spend alone with my other children.	1	2	3	4	Y	P	N
17. to be shown what to do when my child is acting unusually or is displaying difficult behaviors.	1	2	3	4	Y	P	N
18. to have information regarding my child's therapeutic or educational progress.	1	2	3	4	Y	P	N
19. to have help in deciding how much to let my child do by himself/herself.	1	2	3	4	Y	P	N
20. for my developmentally delayed child to have social activities other than with his/her own parents and siblings.	1	2	3	4	Y	P	N
~~21. to have consistent speech therapy for my child.~~	~~1~~	~~2~~	~~3~~	~~4~~	~~Y~~	~~P~~	~~N~~
22. to have help with housework.	1	2	3	4	Y	P	N
23. to have counseling for myself and my spouse/partner.	1	2	3	4	Y	P	N
24. to get enough rest or sleep.	1	2	3	4	Y	P	N
25. to get a break from my responsibilities.	1	2	3	4	Y	P	N
26. to spend time with my friends.	1	2	3	4	Y	P	N

1	2	3	4	Y	P	N
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?				NEED MET?		
27. to be told if I am making good decisions about my child.	1	2	3	4	Y	P	N
28. for the professionals working with my child to understand the needs of my child and my family.	1	2	3	4	Y	P	N
29. for my children's friends to feel comfortable around my child.	1	2	3	4	Y	P	N
30. to have other family members understand my child's problems.	1	2	3	4	Y	P	N
31. to have my child's after-school friends to understand his/her problems.	1	2	3	4	Y	P	N
32. to have my child's teachers understand his/her problems.	1	2	3	4	Y	P	N
33. to discuss feelings about my child with a parent who has a child with the same disorder.	1	2	3	4	Y	P	N
34. to have my child's therapies continue throughout the summer months and school breaks.	1	2	3	4	Y	P	N
35. to be reassured that it is not uncommon to have negative feelings about my child's unusual behaviors.	1	2	3	4	Y	P	N
36. help dealing with my fears about my child's future.	1	2	3	4	Y	P	N
37. help in remaining hopeful about my child's future.	1	2	3	4	Y	P	N
38. to have my questions answered honestly.	1	2	3	4	Y	P	N
39. to be encouraged to ask for help.	1	2	3	4	Y	P	N
~~40. to have counseling for my other children.~~	~~1~~	~~2~~	~~3~~	~~4~~	~~Y~~	~~P~~	~~N~~
41. information about special programs and services available to my child and my family.	1	2	3	4	Y	P	N

1	2	3	4	Y	P	N
Least Important	**Slightly Important**	**Important**	**Most Important**	**Yes**	**Partly**	**No**

I NEED....	**RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?**				**NEED MET?**		
42. to be shown respect by the professionals working with my child.	1	2	3	4	Y	P	N
43. financial support (e.g. from the government) in order to provide my child with his/her therapies, treatments, and care.	1	2	3	4	Y	P	N
~~44. respite care for my child.~~	~~1~~	~~2~~	~~3~~	~~4~~	~~Y~~	~~P~~	~~N~~
45. the children in my child's classroom to understand that my child cannot help his/her unusual behaviors and difficulties.	1	2	3	4	Y	P	N
46. to have time to spend alone with my partner.	1	2	3	4	Y	P	N
47. my child's school to set up a specialized education plan for my child.	1	2	3	4	Y	P	N
48. my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child.	1	2	3	4	Y	P	N
49. to have the professionals working with my child to speak to me in terms I can understand.	1	2	3	4	Y	P	N
50. to have my spouse and me agree on decisions regarding our developmentally delayed child.	1	2	3	4	Y	P	N
51. my child's doctor and dentist to have experience working with children with the same disorder as my child.	1	2	3	4	Y	P	N
52. I need to go out for dinner with my family three times each week.	1	2	3	4	Y	P	N
~~53. I need to take 3-week long family vacations each year.~~	~~1~~	~~2~~	~~3~~	~~4~~	~~Y~~	~~P~~	~~N~~
54. I need to take week-long vacations by myself each year.	1	2	3	4	Y	P	N

APPENDIX I: FAMILY NEEDS QUESTIONNAIRE (MOST TO LEAST ENDORSED ITEMS)

DIRECTIONS: The following statements describe needs that parents of children with developmental disorders sometimes have. Because many of these needs are likely to be important to you, please respond according to how important each need is in relation to your overall needs. Also, these needs normally change over time. We are interested in knowing how important they are to you at the present time and whether they are being met. The information you provide will help us to understand the needs of your family and other families of children with similar problems.

Please show how important you feel these needs are relative to your overall needs, by using the scale below and placing a circle around the number which best describes your answer:

1	2	3	4
Least Important	Slightly Important	Important	Most Important

Use this scale to tell us whether each need is being met by circling: Y (Yes), P (Partly), or N (No):

Y	P	N
Yes	Partly	No

I NEED....	**RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?**				**NEED MET?**		
2. to be well-educated about my child's disorder in order to be an effective decision maker regarding the needs of my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
48. my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
32. to have my child's teachers understand his/her problems.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
47. my child's school to set up a specialized education plan for my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
8. to be shown that my opinions are used in planning my child's treatment, therapies, or education.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
18. to have information regarding my child's therapeutic or educational progress.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
1. to be actively involved in my child's treatments and therapies.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**
13. to work with professionals who have expertise working with children who have the same developmental disorder as my child.	**1**	**2**	**3**	**4**	**Y**	**P**	**N**

1	2	3	4	Y	P	N
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?				NEED MET?		
20. for my developmentally delayed child to have social activities other than with his/her own parents and siblings.	1	2	3	4	Y	P	N
38. to have my questions answered honestly.	1	2	3	4	Y	P	N
28. for the professionals working with my child to understand the needs of my child and my family.	1	2	3	4	Y	P	N
9. to have a professional to turn to for advice or services when my child needs help.	1	2	3	4	Y	P	N
6. for my child to have friends of his/her own.	1	2	3	4	Y	P	N
41. information about special programs and services available to my child and my family.	1	2	3	4	Y	P	N
42. to be shown respect by the professionals working with my child.	1	2	3	4	Y	P	N
50. to have my spouse and me agree on decisions regarding our developmentally delayed child.	1	2	3	4	Y	P	N
34. to have my child's therapies continue throughout the summer months and school breaks.	1	2	3	4	Y	P	N
51. my child's doctor and dentist to have experience working with children with the same disorder as my child.	1	2	3	4	Y	P	N
49. to have the professionals working with my child to speak to me in terms I can understand.	1	2	3	4	Y	P	N
45. the children in my child's classroom to understand that my child cannot help his/her unusual behaviors and difficulties.	1	2	3	4	Y	P	N
30. to have other family members understand my child's problems.	1	2	3	4	Y	P	N
43. financial support (e.g. from the government) in order to provide my child with his/her therapies, treatments, and care.	1	2	3	4	Y	P	N

1	2	3	4	Y	P	N
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?				NEED MET?		
29. for my children's friends to feel comfortable around my child.	1	2	3	4	Y	P	N
46. to have time to spend alone with my partner.	1	2	3	4	Y	P	N
7. to have different professionals agree on the best way to help my child.	1	2	3	4	Y	P	N
24. to get enough rest or sleep.	1	2	3	4	Y	P	N
33. to discuss feelings about my child with a parent who has a child with the same disorder.	1	2	3	4	Y	P	N
12. weekend and after-school activities for my developmentally delayed child.	1	2	3	4	Y	P	N
25. to get a break from my responsibilities.	1	2	3	4	Y	P	N
31. to have my child's after-school friends to understand his/her problems.	1	2	3	4	Y	P	N
26. to spend time with my friends.	1	2	3	4	Y	P	N
16. to have time to spend alone with my other children.	1	2	3	4	Y	P	N
37. help in remaining hopeful about my child's future.	1	2	3	4	Y	P	N
36. help dealing with my fears about my child's future.	1	2	3	4	Y	P	N
11. to have help from other family members in taking care of my child.	1	2	3	4	Y	P	N
5. for professionals to be discrete when talking about my child while he/she is in the room.	1	2	3	4	Y	P	N
17. to be shown what to do when my child is acting unusually or is displaying difficult behaviors.	1	2	3	4	Y	P	N
14. to have consistent occupational therapy for my child.	1	2	3	4	Y	P	N

1	2	3	4	Y	P	N
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT?				NEED MET?		
15. to be told why my child acts in ways that are different, difficult or unusual.	1	2	3	4	Y	P	N
39. to be encouraged to ask for help.	1	2	3	4	Y	P	N
27. to be told if I am making good decisions about my child.	1	2	3	4	Y	P	N
19. to have help in deciding how much to let my child do by himself/herself.	1	2	3	4	Y	P	N
4. to have consistent physical therapy for my child.	1	2	3	4	Y	P	N
35. to be reassured that it is not uncommon to have negative feelings about my child's unusual behaviors.	1	2	3	4	Y	P	N
22. to have help with housework.	1	2	3	4	Y	P	N
23. to have counseling for myself and my spouse/partner.	1	2	3	4	Y	P	N
54. I need to take week-long vacations by myself each year.	1	2	3	4	Y	P	N
52. I need to go out for dinner with my family three times each week.	1	2	3	4	Y	P	N

APPENDIX J: CHILD CHARACTERISTICS QUESTIONNAIRE (RASCH DELETIONS)

DIRECTIONS: The following statements describe symptoms or behaviors that autistic children sometimes exhibit. These symptoms often change across the child's lifetime. We are interested in what your child is like right now. The information you provide will help us to understand your child's *current* level of functioning.

Please indicate how often your child exhibits certain behaviors by using the scale below and placing a circle around the number which best describes your answer:

1	2	3	4	5
↓	↓	↓	↓	↓
Never	**Rarely**	**Sometimes**	**Often**	**Very Often**
(0% of the time)	(10-30% of the time)	(30-50% of the time)	(50-70% of the time)	(70-100% of the time)

Communication Concerns

1. Your child responds to his/her name	1	2	3	4	5
2. Your child can tell you what (s)he wants	1	2	3	4	5
3. Your child follows directions	1	2	3	4	5
4. ~~Your child appears deaf at times~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
5. ~~Your child seems to hear sometimes but not others~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
6. Your child points or waves bye-bye	1	2	3	4	5
7. Your child points with his/her finger	1	2	3	4	5
8. Your child nods yes	1	2	3	4	5
9. Your child shakes his/her head for no	1	2	3	4	5
10. Your child directs your attention by holding up objects for you to see	1	2	3	4	5
11. Your child shows things to people	1	2	3	4	5
~~12. Your child will lead an adult by the hand~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~13. Your child gives inconsistent responses to commands (e.g. [illegible] and [illegible])~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~14. Your child repeats phrases over and over~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~15. Your child [illegible] others.~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~16. Your child asks inappropriate questions~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~17. Your child [illegible] (good rote [illegible] really understanding the meaning~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~18. Your child has a literal understanding of ambiguous and metaphorical language (your child takes sarcasm or irony literally; e.g. I'm so full I'm going to explode!)~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~19. Your child invents idiosyncratic words or expressions (e.g. words [illegible] them or those who know [illegible] strange words to describe something)~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~20. Your child has a "different" voice or speech~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~21. Your child [illegible] and embarrassing remarks~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~

Social Concerns

~~22. Your child smiles socially~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~23. Your child seems to prefer to play alone~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~24. Your child gets things for him/herself~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~

~~25. Your child is overly independent (e.g. likes to do things by him/herself such as playing alone)~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~26. Your child does things "early" (e.g. learns to get things from the cupboards or refrigerator by him/herself before other kids who are the same age)~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
27. Your child has poor eye contact	1	2	3	4	5
~~28. Your child is in his/her own world~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~29. Your child tunes you out~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~30. Your child is interested in other children~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
31. Your child cuddles like other children	1	2	3	4	5
32. Your child looks at you when you are talking	1	2	3	4	5
33. Your child looks at you when you are playing	1	2	3	4	5
34. Your child smiles in response to a smile from others	1	2	3	4	5
35. Your child engages in reciprocal, back-and-forth play	1	2	3	4	5
36. Your child plays simple imitation games (like pat-a-cake or peek-a-boo)	1	2	3	4	5
37. Your child is responsive to other's facial expressions or feelings	1	2	3	4	5
38. Your child has a social smile	1	2	3	4	5
39. Your child has friends	1	2	3	4	5
~~40. Your child uses toys appropriately~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~41. Your child offers to share~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~42. Your child is responsive to other children's approaches~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~43. Your child shows a range of facial expressions~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~44. Your child is regarded as "odd" by the other children~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~45. [illegible] to be sociable but fails to make [illegible]~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~46. Your child can be with other children, but only on his/her own terms~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~47. Your child has a best friend~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~48. Your child is poor at games: he/she has no idea of cooperating in a team, scores "own goals"~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~49. [illegible] facial expressions~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~

Behavioral Concerns

50. Your child has temper tantrums	1	2	3	4	5
~~51. Your child is hyperactive/uncooperative or oppositional~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
52. Your child gets stuck on things over and over	1	2	3	4	5
~~53. Your child toe walks~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
54. Your child has unusual attachments to toys	1	2	3	4	5
55. Your child lines things ups	1	2	3	4	5
56. Your child is oversensitive to certain textures	1	2	3	4	5
57. Your child is oversensitive to certain sounds	1	2	3	4	5
~~58. Your child has odd or stereotyped movement patterns~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~59. Your child has a narrow range of interests~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
60. Your child attends more to parts of objects (e.g. wheels)	1	2	3	4	5
~~61. Your child has limited or absent pretend play~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~62. Your child imitates other people's actions~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
63. Your child plays with toys in the same exact way each time	1	2	3	4	5
~~64. Your child dresses him/herself without frequent help~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
65. Your child is oblivious to danger	1	2	3	4	5
~~66. Your child shows a "startle response" to loud noise~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~67. Your child has "special abilities"~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
68. Your child gets involved in complicated rituals	1	2	3	4	5
69. Your child flaps his/her hands	1	2	3	4	5

70. Your child whirls him/herself for long periods of time	1	2	3	4	5
71. Your child is very destructive	1	2	3	4	5
~~72. Your child will feel, smell, taste objects in the environment~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
73. Your child hurts others by biting, hitting, kicking, etc.	1	2	3	4	5
~~74. Your child interrupts~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~75. Your child is self-injurious~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~76. Your child expresses sounds involuntarily; clears throat, grunts, smacks, cries or screams~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~77. Your child shows common sense~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~78. Your child has clumsy, uncoordinated, awkward movements or gestures~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~79. Your child has involuntary movements or gestures~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
80. Your child is able to complete simple daily activities	1	2	3	4	5
~~81. Your child has special routines; insists on no change~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~
~~82. Your child has markedly unusual posture~~	~~1~~	~~2~~	~~3~~	~~4~~	~~5~~

Thank you for taking the time to fill out these questionnaires!

APPENDIX K: CHILD CHARACTERISTICS QUESTIONNAIRE AFTER RASCH ANALYSIS

DIRECTIONS: The following statements describe symptoms or behaviors that autistic children sometimes exhibit. These symptoms often change across the child's lifetime. We are interested in what your child is like right now. The information you provide will help us to understand your child's *current* level of functioning.

Please indicate how often your child exhibits certain behaviors by using the scale below and placing a circle around the number which best describes your answer:

1	**2**	**3**	**4**	**5**
↓	↓	↓	↓	↓
Never	**Rarely**	**Sometimes**	**Often**	**Very Often**
(0% of the time)	(10-30% of the time)	(30-50% of the time)	(50-70% of the time)	(70-100% of the time)

Communication Concerns

1. Your child responds to his/her name	1	2	3	4	5
2. Your child can tell you what (s)he wants	1	2	3	4	5
3. Your child follows directions	1	2	3	4	5
4. Your child points or waves bye-bye	1	2	3	4	5
5. Your child points with his/her finger	1	2	3	4	5
6. Your child nods yes	1	2	3	4	5
7. Your child shakes his/her head for no	1	2	3	4	5
8. Your child directs your attention by holding up objects for you to see	1	2	3	4	5
9. Your child shows things to people	1	2	3	4	5

Social Concerns

10. Your child has poor eye contact	1	2	3	4	5
11. Your child cuddles like other children	1	2	3	4	5
12. Your child looks at you when you are talking	1	2	3	4	5
13. Your child looks at you when you are playing	1	2	3	4	5
14. Your child smiles in response to a smile from others	1	2	3	4	5
15. Your child engages in reciprocal, back-and-forth play	1	2	3	4	5
16. Your child plays simple imitation games (like pat-a-cake or peek-a-boo)	1	2	3	4	5
17. Your child is responsive to other's facial expressions or feelings	1	2	3	4	5
18. Your child has a social smile	1	2	3	4	5
19. Your child has friends	1	2	3	4	5

Behavioral Concerns

20. Your child has temper tantrums	1	2	3	4	5
21. Your child gets stuck on things over and over	1	2	3	4	5
22. Your child has unusual attachments to toys	1	2	3	4	5
23. Your child lines things ups	1	2	3	4	5
24. Your child is oversensitive to certain textures	1	2	3	4	5
25. Your child is oversensitive to certain sounds	1	2	3	4	5
26. Your child attends more to parts of objects (e.g. wheels)	1	2	3	4	5
27. Your child plays with toys in the same exact way each time	1	2	3	4	5
28. Your child is oblivious to danger	1	2	3	4	5
29. Your child gets involved in complicated rituals	1	2	3	4	5
30. Your child flaps his/her hands	1	2	3	4	5
31. Your child whirls him/herself for long periods of time	1	2	3	4	5

32. Your child is very destructive	1	2	3	4	5
33. Your child hurts others by biting, hitting, kicking, etc.	1	2	3	4	5
34. Your child is able to complete simple daily activities	1	2	3	4	5

APPENDIX L: CHILD CHARACTERISTICS QUESTIONNAIRE
(MOST TO LEAST ENDORSED ITEMS)

DIRECTIONS: The following statements describe symptoms or behaviors that autistic children sometimes exhibit. These symptoms often change across the child's lifetime. We are interested in what your child is like right now. The information you provide will help us to understand your child's *current* level of functioning.

Please indicate how often your child exhibits certain behaviors by using the scale below and placing a circle around the number which best describes your answer:

1	**2**	**3**	**4**	**5**
↓	↓	↓	↓	↓
Never	**Rarely**	**Sometimes**	**Often**	**Very Often**
(0% of the time)	(10-30% of the time)	(30-50% of the time)	(50-70% of the time)	(70-100% of the time)

Communication Concerns

1. Your child shakes his/her head for no	1	2	3	4	5
2. Your child nods yes	1	2	3	4	5
3. Your child directs your attention by holding up objects for you to see	1	2	3	4	5
4. Your child shows things to people	1	2	3	4	5
5. Your child points with his/her finger	1	2	3	4	5
6. Your child follows directions	1	2	3	4	5
7. Your child can tell you what (s)he wants	1	2	3	4	5
8. Your child points or waves bye-bye	1	2	3	4	5
9. Your child responds to his/her name	1	2	3	4	5

Social Concerns

10. Your child has friends	1	2	3	4	5
11. Your child engages in reciprocal, back-and-forth play	1	2	3	4	5
12. Your child has poor eye contact	1	2	3	4	5
13. Your child looks at you when you are playing	1	2	3	4	5
14. Your child looks at you when you are talking	1	2	3	4	5
15. Your child is responsive to other's facial expressions or feelings	1	2	3	4	5
16. Your child plays simple imitation games (like pat-a-cake or peek-a-boo)	1	2	3	4	5
17. Your child smiles in response to a smile from others	1	2	3	4	5
18. Your child has a social smile	1	2	3	4	5
19. Your child cuddles like other children	1	2	3	4	5

Behavioral Concerns

20. Your child is oversensitive to certain sounds	1	2	3	4	5
21. Your child gets stuck on things over and over	1	2	3	4	5
22. Your child is oblivious to danger	1	2	3	4	5
23. Your child is oversensitive to certain textures	1	2	3	4	5
24. Your child plays with toys in the same exact way each time	1	2	3	4	5
25. Your child has temper tantrums	1	2	3	4	5
26. Your child flaps his/her hands	1	2	3	4	5
27. Your child is able to complete simple daily activities	1	2	3	4	5
28. Your child has unusual attachments to toys	1	2	3	4	5
29. Your child attends more to parts of objects (e.g. wheels)	1	2	3	4	5
30. Your child gets involved in complicated rituals	1	2	3	4	5

31. Your child lines things ups	1	2	3	4	5
32. Your child hurts others by biting, hitting, kicking, etc.	1	2	3	4	5
33. Your child is very destructive	1	2	3	4	5
34. Your child whirls him/herself for long periods of time	1	2	3	4	5

Appendix M

challenge minds
change worlds

UNIVERSITY OF VICTORIA - HUMAN RESEARCH ETHICS COMMITTEE

CERTIFICATE OF APPROVAL

PRINCIPAL INVESTIGATOR	DEPARTMENT/SCHOOL	SUPERVISOR
Susan Siklos **Graduate Student**	**PSYC**	**Dr. Kimberly Kerns**

CO-INVESTIGATOR(S):

TITLE: **Assessing the Diagnostic Experiences and Family Needs of Parents of Children with Austism and Down Syndrome**

PROJECT NO.	START DATE	END DATE	APPROVAL
14-02	**12/7/2001**	**12/6/2002**	**2/1/2002**

CERTIFICATION

This is to certify that the University of Victoria Ethics Review Committee on Research and Other Activities Involving Human Subjects has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

J. Howard Brunt,
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions/minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.

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Publications

Siklos, S., Jasper, J. A., Wicks, S. R., & Rankin, C. H., (2000). Interactions between an endogenous oscillator and response to tap in C. elegans. *Psychobiology, 28(4),* 571-580.

Siklos, S., & Kerns, K. (2002). Assessing multitasking in children with ADHD using a modified Six Elements Task [Abstract]. *Journal of the International Neuropsychological Society, 8(2),* 304.

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Siklos, S., & Kerns, K. (2003). Assessing family needs in parents of children with autism and Down syndrome [Abstract]. *Accepted for publication in Journal of the International Neuropsychological Society.*

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Title of Thesis:

Assessing the Diagnostic Experiences and Family Needs of Parents With Autistic Children

Author [redacted]

Susan Siklos

September 30, 2002