EXAMINING THE NEEDS OF FAMILIES OF SCHOOL-AGED CHILDREN
WITH AN AUTISM SPECTRUM DISORDER

by

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Abstract

Background. Children with autism spectrum disorders have complex needs requiring a broad range of supports. High demand for autism services has led to gaps in the provision of care, and there is little research examining whether families of school-aged children receive services reflective of their needs.

Objectives. The objectives of this thesis were to describe unmet needs reported by parents of school-aged children with an autism spectrum disorder and to examine the association between the child’s level of functional independence and the parent’s reported level of unmet need.

Methods. A review of the literature on needs assessments in autism was performed. A cross-sectional study was then conducted among parents of 101 children who (1) had an autism spectrum disorder, (2) were between the ages of 6 and 13 years, and (3) were living in Manitoba, South Eastern Ontario, Prince Edward Island, or Newfoundland and Labrador. Data were collected using a written questionnaire (Family Needs Questionnaire, Impact on Family Scale, demographic questions) and a telephone interview (Scales of Independent Behaviour-Revised, service use questions). Log binomial regression was used to examine the association between the child’s functional independence and the parent’s perceived unmet needs.

Results. The most commonly reported unmet needs were related to social inclusion for the child, information about special programs and services, and continuity of support. Families of children with high functional independence had lower unmet need compared to families of children with moderate functional independence (RR = 0.81, 95% CI = 0.67-0.99). Families of children with high functional independence, and who perceived a
high level of impact of the child’s disability on the family, had greater unmet need (RR = 1.22, 95% CI = 1.03-1.45).

Conclusion. This thesis identifies family needs which have not been met by the service system. Assessments of child and family functioning may provide insight into unmet need that is not revealed simply by knowing a child’s diagnosis on the autism spectrum. Information about the unmet needs of families of children with autism spectrum disorders may help policy makers and service planners to develop resources and services that are responsive to their client group.
Co-Authorship Statement

This thesis presents research conducted by Hilary Brown, under the supervision of Hélène Ouellette-Kuntz, Duncan Hunter, and Elizabeth Kelley. The decision to conduct a study involving primary data collection was the product of a discussion between Hilary Brown and Hélène Ouellette-Kuntz. Hilary Brown designed the protocol for this study with feedback from Hélène Ouellette-Kuntz, Duncan Hunter, and Elizabeth Kelley. Recruitment of families was carried out by Deborah Gorski and Wei Cau (National Epidemiologic Database for the Study of Autism in Canada) and by Melissa Hudson and Raegan Mazurka (Autism Spectrum Disorders – Canadian-American Research Consortium). All implementation of telephone interviews, scoring of written and telephone survey instruments, and entry and double-entry of data were performed by Hilary Brown. Data analyses were performed by Hilary Brown, with guidance from Miu Lam for Manuscript Three. Elizabeth Kelley and Virginie Cobigo provided content advice. All manuscripts were written by Hilary Brown, with feedback from Hélène Ouellette-Kuntz, Elizabeth Kelley, and Duncan Hunter as well as Virginie Cobigo (Manuscripts Two and Three) and Miu Lam (Manuscript Three).
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Chapter 1: General Introduction

General Overview

Autism spectrum disorders (ASD), which include autistic disorder, pervasive developmental disorder-not otherwise specified, and Asperger’s disorder, are a group of neurodevelopmental disorders that are characterized by social and communication impairments as well as repetitive or stereotyped behaviours (American Psychiatric Association, 2000). They affect one in every 150 children (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators, 2007) and are typically associated with intensive support needs (Jarbrink, Fombonne, & Knapp, 2003). It has been acknowledged at both the research (Ruble, Hefflinger, Renfrew, & Saunders, 2005) and policy (Standing Senate Committee on Social Affairs, Science, and Technology, 2007) levels that a substantial increase in the numbers of individuals seeking autism services has resulted in a strain on the service system in terms of the provision of health, social, and educational supports for those with ASD. Moreover, many parents of children with ASD report difficulty finding and accessing services (Kogan et al., 2008). This lack of support seems to be pronounced once children enter school and, in many regions, no longer have access to early intensive behavioural interventions (Madore, 2006). However, despite these observations, little research has focused on identifying unmet needs among families of school-aged children specifically. The purpose of this thesis is to address this limitation by developing and testing a conceptual framework with which to study unmet need among families of children with ASD in this age group.

Several definitions are important to consider when framing the scope of this thesis. These definitions are described in detail in Manuscript One and are explored
empirically in Manuscripts Two and Three. Unmet need is defined as the evaluation of a discrepancy between actual provision of support and what is desired from the perspective of the individual seeking help, i.e., *perceived unmet need* (Dunst, Trivette, & Deal, 1988).

The main burden of care for children with ASD falls on the family (Kohler, 1999). Parents’ perceptions of unmet need provide insight into the efficacy of the service system and may thereby inform policy and practice with respect to the efficient and effective allocation of limited resources.

Several previous studies describing parents’ unmet needs have identified associated parent and child characteristics (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Ellis et al., 2002; Siklos & Kerns, 2006). However, a weakness of the existing literature is that it lacks a conceptual framework with which to organize investigations of characteristics potentially related to parents’ perceptions of unmet need. This thesis proposes a framework which conceptualizes the child’s *functional independence* as the main factor associated with parents’ perceived unmet needs.

Functional independence is determined by a combination of adaptive skills (i.e., self-help, socialization, and communication skills) and challenging behaviours (i.e., aggression, self-injury, and non-compliance). It is predictive of the resource intensity needed to support the individual (Bruininks, Woodcock, Weatherman, & Hill, 1996) and is a practical conceptualization of the types of abilities and problems likely to affect the parent’s perceptions of unmet need. The roles of other factors—including the way in which the child’s disability affects the family (i.e., *impact on family*) (Stein & Jessop, 2003), service use, and several other parent and child demographic characteristics—are also considered.
Empirical Objectives

Given the increased interest in improving autism services in Canada (Standing Senate Committee on Social Affairs, Science, and Technology, 2007) and elsewhere (All-Party Parliamentary Group on Autism, 2007; National Research Council, 2001), it is critical to gain an understanding of the characteristics of subgroups whose needs are largely unmet in order to better plan autism services and policies. The two main objectives of this thesis were:

1. to describe areas of unmet need reported by parents of school-aged children with ASD, and
2. to examine the association between the child’s level of functional independence and the parent’s reported level of unmet need.

The objectives are addressed in three manuscripts which utilize discussions of previous literature as well as the results from a cross-sectional study conducted in four regions of Canada. These manuscripts are as follows:

1. a theoretical paper which presents the background literature review as well as the conceptual framework underlying the thesis (Manuscript One);
2. a descriptive paper which explores the unmet needs reported by families of school-aged children with an autism spectrum disorder, as measured in the cross-sectional study (Manuscript Two); and
3. a paper which analyzes the relationship between the child’s functional independence and the parent’s reported level of unmet need, while accounting for parent and child characteristics, as measured in the cross-sectional study (Manuscript Three).
Thesis Organization

This thesis conforms to the framework provided by the *General Forms of Theses* which is outlined by the School of Graduate Studies at Queen’s University (School of Graduate Studies and Research, 2009). The second chapter of this thesis is Manuscript One. It presents the conceptual framework for the thesis. This manuscript is published in *Research in Autism Spectrum Disorders* (Brown, Ouellette-Kuntz, Hunter, & Kelley, 2010). The third chapter is Manuscript Two and addresses Objective 1. This manuscript has been submitted to the *Journal of Autism and Developmental Disorders*. The fourth chapter is Manuscript Three and addresses Objective 2. This manuscript has also been submitted to the *Journal of Autism and Developmental Disorders*. Additional documentation describing the methods and implementation of this study are found in the Appendices.
References


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Abstract

The assessment of support needs of children with an autism spectrum disorder and their families has been hindered by the ambiguity surrounding the definition of need and the lack of a conceptual framework to guide investigations. This paper examines two major approaches to measuring need and discusses their appropriateness for use in autism. We focus on school-aged children because of the relative lack of research in this area and the challenges of measuring need in children with an autism spectrum disorder in this age group. A conceptual framework, which explores parents’ perceived need, is proposed. We suggest that the child’s adaptive skills and challenging behaviours will be important in predicting the extent of the parent’s perceived unmet need.
Assessing Need in School-Aged Children with an Autism Spectrum Disorder

Autism spectrum disorders (ASD) affect one in every 150 children (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators, 2007), and the prevalence is believed to be increasing (Blaxill, 2004). Although there is controversy around whether this trend is due to an increase in awareness of the disorder, changes in diagnostic practices, or a true increase in affected individuals (Fombonne, 2005), it is clear that greater numbers are seeking services (Grether, 2006; Ruble, Hefflinger, Renfrew, & Saunders, 2005). This increased demand has resulted in a strain on the current service system in terms of the cost, provision, and organization of health, social, and educational supports for children with ASD (Kogan et al., 2008). This problem has gained attention in Canada (Siklos & Kerns, 2006), the United States (Krauss, Gulley, Sciegaj, & Wells, 2003; Liptak et al., 2008), and elsewhere and necessitates an examination of the unmet needs of children with ASD and their families.

Autism spectrum disorders, which include autistic disorder, pervasive developmental disorder-not otherwise specified, and Asperger’s disorder, present a significant burden to both the service system and the family unit. Deficits in adaptive skills (i.e., self-help, socialization, and communication skills) (Saulnier & Klin, 2007; Tomanik, Pearson, Loveland, Lane, & Shaw, 2007), the presence of challenging behaviours (i.e., stereotypies, self-injury, aggression, and non-compliance) (Dawson, Matson, & Cherry, 1998; Tomanik, Harris, & Hawkins, 2004), and the lifelong nature of the disorder (Howlin, Goode, Hutton, & Rutter, 2004) result in the need for intensive resource allocation for many with ASD (Jarbrink, Fombonne, & Knapp, 2003; Leslie &
Moreover, it is common for individuals with ASD to have co-morbid conditions, such as developmental delay, attention deficit/hyperactivity disorder, sleep disorders, and seizure disorders, which require support from several professionals across different service systems (e.g., health, educational, and social) (Boulet, Boyle, & Schieve, 2009; Kielen, Rantala, Timonen, Linna, & Moilanen, 2004; Wiggs & Stores, 2004). Annual costs of caring for a child with ASD are considerably higher than those for a child without ASD (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Liptak, Stuart, & Auinger, 2006).

Parenting a child with ASD is associated with maternal psychological distress, reduced marital happiness, and reduced family adaptability and cohesion (Bromley, Hare, Davison, & Emerson, 2004; Higgins, Bailey, & Pearce, 2005). These outcomes are thought to be due to the physical and emotional demands of dealing with the challenging behaviours and poor social and communication skills associated with ASD (Higgins et al., 2005; Lecavalier, Leone, & Wiltz, 2006; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Research suggests that the stress experienced by parents of a child with ASD is more extreme than that experienced by parents of a child with another developmental disability or special healthcare need (Schieve et al., 2007). This may be due to the unique stressors associated with caring for a child with ASD, resulting from the child’s difficult behaviours and deficits as well as a lack of community understanding of these (Bebko, Konstantareas, & Springer, 1987; Higgins et al., 2005; Schieve et al., 2007). It is clear from this research that the service system must be responsive to the needs of these families so that parents have the resources they require to cope with the demands of caring for their child.
Because of the recognized burden of ASD on the family and on the service system, there has been a move toward expanding service coverage for individuals with ASD. Recently, there has been an acknowledgment of the disparity between policy recommendations and actual service coverage (All-Party Parliamentary Group on Autism, 2007; Standing Senate Committee on Social Affairs, Science, and Technology, 2007). What is needed to address this gap is information on the specific needs of families who have a child with ASD. A focus on school-aged children is particularly warranted. Much of the existing research has focused on young children (for example: McLennan, Huculak, & Sheehan, 2008; Thomas, Morrissey, & McLaurin, 2007) or has included a wide age range (for example: Kogan et al., 2008; Liptak et al., 2008). In many jurisdictions, autism services are significantly cut back after the preschool years (Madore, 2006), and there is little understanding of the needs of older children. Moreover, the development of an understanding of need has been hindered by the ambiguity that surrounds its definition and measurement (Culyer, 1995; McDavid & Hawthorn, 2006). The objective of this paper is therefore to propose a conceptual framework with which to study the needs of school-aged children with ASD. In developing this framework, we describe and discuss: (1) the service use approach to needs assessment and (2) an approach to needs assessment which examines parents’ perceptions of unmet need.

Major Approaches to Needs Assessment in Autism

Service Utilization Studies

Needs assessments identify priorities for allocating programs and services in a resource-limited system (Magi & Allander, 1981) and are intended to be a valid means of planning, tailoring, and measuring the efficiency and effectiveness of services, based on
the available evidence (Stevens, Raftery, Mant, & Simpson, 2004; Wright, Williams, & Wilkinson, 1998). Service utilization data are often used to approximate need (Eyles & Birch, 1993; Morgan, Mays, & Holland, 1987). The assumption behind this definition of need is that inequalities in service use reflect inequalities in access to services. Unmet need is experienced by individuals who do not have the same recommended service use as others who have the same medical condition or disability (Morgan et al., 1987).

Previous Service Utilization Studies in Autism

Historically, there has been limited information on the patterns of service use of children with ASD and their families. However, given the increased demand for services, there has been a recent recognition of the need to understand where pressures exist within the system and the extent of experienced unmet need. A number of studies have therefore examined the breadth and frequency of service use of children with ASD. One American study found that in the past year, of children with ASD aged 3 to 17 years of age, 44.9% saw a medical specialist, 54.8% saw a mental health professional, 60.5% saw a therapist, and 87.1% used special education services (Boulet et al., 2009). Speech/language therapy is usually the most common therapy reported to be used (Green et al., 2006; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007), and other common therapies include occupational therapy and applied behavioural analysis (Green et al., 2006; McLennan et al., 2008; Thomas, Morrissey, et al., 2007).

Differences in service use between children with ASD and those with other disabilities or without disabilities reveal the impact of ASD on the service system. For example, children with ASD are more likely to have seen a mental health professional during the last year compared to children with other developmental disabilities (Boulet et
al., 2009). Furthermore, they visit emergency rooms and physicians; see physical, occupational, and speech/language therapists; and use therapy for emotional, behavioural, or developmental problems more often than children without ASD (Gurney, McPheeters, & Davis, 2006). Children with ASD are also more likely than children without ASD to use psychotherapeutic medications and gastrointestinal agents (Croen et al., 2006).

Frequency of service use among children with ASD is also noteworthy. An American study found that 3- to 9-year old children with ASD used an average of 6.44 services (range 4 to 10) from an average of 7.7 professionals and 4.4 agencies over the past six months (Kohler, 1999). Another American study found that children with ASD under the age of 8 years used an average of 7 services and as many as 24 services at any one time (Thomas, Morrissey, et al., 2007). Similarly, in an Irish study, preschool-aged children with ASD were reported to see an average of 5.9 professionals at one time (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008). These statistics are in comparison to the 1.75 physician and 0.40 other medical professional visits made by children without disabilities per year (Newacheck & Kim, 2005). The high service utilization of children with ASD is associated with the complexity of the disorder (Kohler, 1999) as well as the frequent occurrence of co-morbid conditions (Gillberg & Billstedt, 2000) which require treatment from multiple professionals. It is clear from these studies that children with ASD have intensive support needs.

Factors associated with service utilization. Among families of a child with ASD, there are variations in the types and frequency of service use that can be predicted on the basis of parent and child characteristics. Low service use is related to low parental education (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007) and to minority
ethnicity (Liptak et al., 2008). It is also related to poverty and, in the United States, to type of healthcare insurance plan (Liptak et al., 2008). In the United States, for instance, having a higher family income increases the odds of using a developmental paediatrician (OR = 3.53) or speech/language therapist (OR = 2.49) (Thomas, Ellis, et al., 2007). Rural residence is also related to service use. One study found that families who live in rural areas are less likely to use summer camps and respite care than those in urban areas (Thomas, Ellis, et al., 2007).

Child characteristics are also related to patterns of service use. Greater ASD severity is related to having special education support (White, Scahill, Klin, Koenig, & Volkmar, 2007) and to using more services (Green et al., 2006). The diagnosis that the child has received within the autism spectrum is associated with the number and types of treatments used. For instance, children with Asperger’s disorder use fewer therapies (Green et al., 2006) and are more likely to use medications (Thomas, Ellis, et al., 2007) than those with another ASD. Results have been inconsistent with respect to the relationship between the child’s age and service use. In one study, while school-aged and preschool-aged children used approximately the same number of services, those in school received more hours per week of intervention (Kohler, 1999). In contrast, others found that those in younger age groups used more treatments than those in older age groups (Green et al., 2006). It should be noted, however, that this difference by age group likely reflects the availability of services for older children with ASD.

**Shortcomings of Service Utilization Studies**

While service utilization data provide insight into the demands on different sectors of the service system, needs assessments which employ service utilization data
have several disadvantages which are somewhat amplified when considering ASD. In general, utilization data can be biased by historical patterns of service use (Morgan et al., 1987), the current supply of services (Hunter et al., 2004), the interests of health professionals and other invested individuals (Wright et al., 1998), and political pressure for change (Stevens et al., 2004). As measures of need, needs assessments which employ service use data therefore risk perpetuating pre-existing inequalities in service provision (Eyles & Birch, 1993). Although the above studies provide insight into current trends in service use, they cannot measure the appropriateness of these trends and therefore do not necessarily reflect whether or not the needs of the population are being met.

Furthermore, utilization data are helpful in identifying unmet need only to the extent that less utilization accurately reflects less access. Usually, to determine the presence of an unmet need, utilization rates in a particular population subgroup are compared to an established benchmark (Hunter et al., 2004). However, the lack of a universal standard approach to treatment for ASD, especially among older children, complicates needs assessments and renders utilization data inadequate in establishing an understanding of need. In the preschool years, applied behavioural analysis is the recommended approach to the treatment of symptoms of ASD (Rogers, 1998). However, among older children, these types of therapies are often no longer available (Madore, 2006), and there is no standard or straightforward approach to treatment of ASD symptoms in older children (Simpson, 2005). The myriad of therapeutic options espoused to improve functioning in children with ASD has received international attention, both within the research community and the media. An Autism Organization Worldwide Internet survey of 552 parents of children with ASD from the United States, Canada,
New Zealand, the Philippines, and elsewhere found that 108 of the 111 listed treatments were reported by at least one parent to be used currently or in the past (Green et al., 2006). This study illustrates how the wide range of approaches to treatment of ASD symptoms makes it difficult to establish a benchmark of recommended service use with which to make comparisons.

Moreover, while many medical conditions are linked to unsupported treatment options, ASD has been particularly plagued by controversial and unproven interventions (Simpson, 2005). Although guidelines for good practice have recently been published by several organizations (for example: Le Couteur & the National Initiative for Autism: Screening and Assessment, 2003; Ohio Developmental Disabilities Council, 2009), many commonly used treatments for ASD still have little or no empirical support to demonstrate their effectiveness (Heflin & Simpson, 1998). This trend is perhaps driven by the promise of a “cure” for ASD, fuelled by the fact that ASD is lifelong (Howlin et al., 2004), and its causes remain unclear (Simpson, 2005). Because of the lack of a benchmark for comparison between actual and recommended service use, a direct link between utilization and need is difficult to make.

Finally, whether or not a need is met is not a binary outcome. Utilization studies may mask factors which facilitate or impede the process of accessing care and that are important to families’ experiences of need (Krauss et al., 2003). These factors include waiting lists, referrals, communication and interaction with professionals, coordination of care from multiple service providers, and financial support for therapies. These processes are an integral component of considering the effectiveness and efficiency of a service system. A broader approach is therefore needed that measures process factors in
accessing care as well as the extent to which problems are not addressed by the current provision of services.

Perceived Need Studies

There is a substantial history in the medical field of conducting needs assessments by measuring perceived needs (Magi & Allander, 1981). This approach reflects the growing focus on consumerism in today’s healthcare system (Wright et al., 1998). Dunst et al. define perceived need as “an individual’s judgment of the discrepancy between actual states or conditions and what is normative, desired, or valued from a help seeker’s and not a help giver’s perspective” (Dunst, Trivette, & Deal, 1988, p. 13, authors' emphasis).

The assessment of perceived unmet need offers several advantages over the assessment of service utilization. This perceived need approach removes the requirement for a benchmark for recommended treatment against which trends in service use must be compared. It also allows for an examination of process factors, rather than service use outcomes alone (Krauss et al., 2003). For instance, a family’s difficulty receiving a referral or time spent on a waiting list may provide more insight into their experience of need than whether or not they eventually received the service.

Furthermore, with the current emphasis on community care in autism, the main burden of care falls on the family (Kohler, 1999), making parents’ perceived needs particularly important. Children with ASD require a broad range of services from multiple sectors, often leaving parents overwhelmed while trying to navigate the service system (Trute, Hiebert-Murphy, & Wright, 2008). In response, there has been a move toward family-centred services which promote parents’ emotional well-being by
addressing parent-identified issues (King, King, Rosenbaum, & Goffin, 1999; Sperry, Whaley, Shaw, & Brame, 1999; Trute et al., 2008). While the basic premise of family-centred services is that supports should be tailored toward the specific needs of the family, broader service planning requires information to be available on the needs of the particular client group (Cassidy et al., 2008).

Assessments of perceived need are not without their disadvantages. While they can promote equal access for equal need, the limited ability to assess the appropriateness of requests for services makes it difficult to ensure unequal access for unequal need (Culyer, 1995). Some would argue that because perceptions may lack objectivity, it is difficult to ensure that resources are allocated so that those who need more services receive more (Eyles & Birch, 1993). Because resources are finite, to advocate for an individual group without considering the competing priorities of others would be unrealistic (Stevens & Gillam, 1998). Furthermore, it is difficult to evaluate the perceived unmet need for a program or professional when parents who do not know that it exists will not perceive a need for it.

Previous Studies of Perceived Need in Autism

Despite these drawbacks, assessments of perceived unmet need provide a direct measure of self-assessed need for care and lead to a better understanding of the complexity and efficacy of the service system. Several studies have identified frequently reported unmet needs among families of a child with an ASD. These studies reveal gaps in service provision that cannot be identified using utilization data alone.

Need for information. Parents of children with ASD describe the need for information about services as well as the need for information about how to handle their
child’s difficult behaviours (Ellis et al., 2002; Granlund & Roll-Pettersson, 2001; McLennan et al., 2008). In one study, need for information was the most prominent need, endorsed by 47.1% of parents who had a 3- to 22-year old child with autistic disorder, pervasive developmental disorder, or intellectual disability. These parents reported the need for information about teaching strategies, behaviour management, and the availability of services (Ellis et al., 2002). With the complexity of ASD and the number of treatment options offered, it is clear that parents require guidance when trying to access services.

*Coordination of services.* Parents also identify the need for coordination of multiple services (Cassidy et al., 2008; Kogan et al., 2008; Kohler, 1999). One study found that 89% of parents reported that they were the most common case manager for their child (McLennan et al., 2008), revealing a lack of a centralized key worker for many families. In the same study, 65% of parents reported that repeating the child’s story to different professionals was a problem. This finding demonstrates the need for improved communication among professionals. Coordination of care between doctors and other service providers is an issue for almost three times as many parents of children with ASD as it is for parents of children with other types of special healthcare needs and twice as common as it is for parents of children with an intellectual disability (Krauss et al., 2003).

*Communication with the family.* In addition to coordination among different professionals, collaboration and communication between the professional and the family is also an issue for many parents (Kohler, 1999). In one American study, 60% of parents of 3- to 9-year old children with ASD reported that the agencies that provided services to them failed to communicate adequately with them. Specific problems that parents
identified included the perception that the professional did not listen to the parent or did not keep the parent updated on changes in the child’s needs (Kohler, 1999). This issue reflects the need for a continued and improved emphasis on family-centred care in autism services.

Access to care. Access to care is also a significant concern (Cassidy et al., 2008; Kogan et al., 2008; Kohler, 1999; McConachie & Robinson, 2006). In an American study, despite all groups having similar healthcare plans, one third of children with ASD had difficulty accessing specialty care from a medical doctor compared to one fifth of children with an intellectual disability or other special healthcare need (Krauss et al., 2003). Similarly, in a study from the 2005-2006 U.S. National Survey of Children with Special Healthcare Needs, compared to children with other emotional or behavioural problems, children with ASD were more likely to have unmet needs for specific healthcare services and family support. They were also more likely to experience delays in receiving care than those with other special healthcare needs. Moreover, their parents were less likely to be satisfied with their service receipt. These differences persisted after controlling for sociodemographic characteristics, the child’s functional abilities, and the type of healthcare coverage (Kogan et al., 2008).

In a study conducted in Ireland, when parents of preschool-aged children with ASD were asked how services could be improved, their main response was that access to services should be increased. The most frequently mentioned needed service was speech/language therapy, and parents also raised concern about access to respite care, educational assistance, and occupational therapy (Cassidy et al., 2008). This study was limited to children who had been referred to a specialist clinic (Cassidy et al., 2008) and
leaves undetermined the number of “non-connected” families who may have experienced even greater access difficulties.

Likewise, in a Canadian study of young children with ASD, 50% of parents reported a lack of services as a problem, while 66% of these reported this to be a moderately severe or severe problem. In the same study, 52% of parents reported waiting lists for treatment to be a problem, and 67% of these reported this to be a moderately severe or severe problem (McLennan et al., 2008).

*Family support.* Parents also identify the need for family support. This includes the need for respite care (Sperry et al., 1999) and help with family functioning (Cassidy et al., 2008; Kogan et al., 2008; Kohler, 1999). For instance, in one study’s interviews, many parents of 3- to 9-year old children with ASD reported needing respite services or babysitting (Kohler, 1999). Another study found that 23.2% of parents of 3- to 22-year olds with ASD reported the need for help with family functioning (e.g., learning how to support one another) and 51.1% reported the need for help finding respite care providers (e.g., finding a babysitter willing to care for the child with ASD) (Ellis et al., 2002). These needs reveal the impact of ASD on the entire family and demonstrate that the family as a whole must be supported.

*Financial support.* Financial issues are also a frequently reported concern. Because of limited publicly funded services, many parents turn to private assessments and therapies and report inadequate support for financing these (Kogan et al., 2008; Siklos & Kerns, 2006). For example, one Canadian study of 2- to 18-year olds with ASD found that a staggering 93% of parents reported that they were not receiving adequate financial support for their child’s therapies (Siklos & Kerns, 2006). The authors note that
this was after parents in this Canadian province had won a law suit against the government, forcing the government to provide more funding for autism services. The finding is particularly interesting when contrasted with the comparatively lower 63% of parents of children with Down syndrome who also found governmental financial support to be inadequate (Siklos & Kerns, 2006). This difference may indicate that families of a child with ASD experience financial difficulty that is in excess of that which is experienced by families of a child with other special healthcare needs.

Similarly, an American study found that, compared to children with other special healthcare needs (including other emotional and behavioural problems), children with ASD were more likely to live in families that had large out of pocket expenditures, experienced financial problems, or reported the need for additional income in order to pay for services and therapies for their child with a disability. Differences in measures of financial impact were smaller when the child with ASD had a “medical home”, meaning that the child had a usual place for care, a personal care provider, and family-centred and coordinated care (Kogan et al., 2008).

Factors associated with perceived unmet need. Research is only beginning to identify factors that are associated with perceived unmet need among families who have a child with ASD. Studies have shown that unemployment (Ellis et al., 2002) and minority ethnicity (Kogan et al., 2008) are related to greater perceived unmet need. Child characteristics that are associated with perceived unmet need include language level (Bromley et al., 2004), the severity of the disorder (Siklos & Kerns, 2006), the level of functional ability (Kogan et al., 2008), and the presence of a motor impairment (Granlund & Roll-Pettersson, 2001) or problem behaviour (Bromley et al., 2004; Kogan et al.,
Results have been inconsistent with respect to the relationship between perceived unmet need and the child’s age (Ellis et al., 2002).

Discussion

Proposed Conceptual Framework

Although a number of factors have been identified which are related to perceived unmet need, results have been inconsistent as to which measures are most important in predicting the extent of the experienced need. Furthermore, there has not been a theoretical framework to guide the investigation and conceptualization of these relationships. This paper proposes a framework which incorporates child and parent factors, the impact of the child’s disability on the family, and service use in predicting perceived unmet need. (Refer to Figure 1.) The focus of this framework is on school-aged children with ASD, since this group has been somewhat neglected in research. This framework is currently being tested empirically by the authors.

Figure 1. Conceptual Framework
Among school-aged children with ASD, adaptive skills and challenging behaviours may be particularly important in predicting parents’ perceived unmet needs. Measures of these behaviours have been used to predict the resource intensity needed to support the individual. Examples of such measures are the Adaptive Behaviour Scales: Residential and Community (ABS-RC:2: Nihira, Leland, & Lambert, 1993), the Inventory for Client and Agency Planning (ICAP: Bruininks, Hill, Weatherman, & Woodcock, 1986), and the Scales of Independent Behaviour-Revised (SIB-R: Bruininks, Woodcock, Weatherman, & Hill, 1996). These measures are based on the assumption that the level of overall adaptive behaviour and the presence, frequency, and severity of challenging behaviours substantially determine a person’s level of functional independence (Bruininks et al., 1996).

Adaptive behaviour encompasses the skills one has to function within the everyday environment, including the ability to communicate and interact with others; to take care of health, grooming, and domestic needs; and to participate in group activities (Bruininks et al., 1996; Harrison & Boney, 1995). Adaptive behaviours are situationally specific; they describe the ability to adapt to the requirements of a particular environment. They are also developmentally relevant; as children age, their skills expand with the increasingly complex demands of their surroundings (Harrison & Boney, 1995). Children with ASD show deficits in adaptive skills that are more severe than would be predicted on the basis of their cognitive functioning (Saulnier & Klin, 2007; Tomanik et al., 2007). Moreover, the negative relationship found between adaptive behaviours and age in ASD suggests that the maturation of adaptive skills does not keep pace with chronological development (Klin et al., 2007). Earlier studies have found that children
with autistic disorder have greater deficits in communication and social skills than children with Asperger’s disorder (Szatmari, Archer, Fisman, Streiner, & Wilson, 1995) and Pervasive Developmental Disorder-Not Otherwise Specified (Gillham, Carter, Volkmar, & Sparrow, 2000), although Saulnier and Klin (2007) and Paul et al. (2004) found no such differences.

Challenging behaviours, including self-injurious, aggressive, and disruptive behaviours; repetitive movements; and withdrawal or inattentive behaviours, are commonly displayed by children with ASD (Dawson et al., 1998; Tomanik et al., 2004; Tonge, Brereton, Gray, & Einfeld, 1999). These behaviours are an impediment to self-help, socialization, and learning and have a profound impact on adaptation to the environment (Matson & Nebel-Schwalm, 2007). Children with autistic disorder have more severe challenging behaviours than those with Pervasive Developmental Disorder-Not Otherwise Specified, but differences become non-significant after controlling for mental age (Gillham et al., 2000). Challenging behaviours make it difficult for parents and teachers to gain and keep the child’s attention. They must often compete with these behaviours to teach skills (Tomanik et al., 2004).

Challenging behaviours and adaptive skills in children with ASD have a significant impact on parental mental health (Bromley et al., 2004; Hastings & Brown, 2002; Tomanik et al., 2004). Similarly, it is likely that these behaviours will influence parents’ perceptions of need. When the resources of the health, educational, and social service systems are strained, there are gaps in the provision of care (Kogan et al., 2008). In such situations, it is conceivable that parents of children who are at the extremes of the spectrum of functional independence will report the highest levels of unmet need, but for
different reasons. Children with strong adaptive skills and few or no challenging behaviours (i.e., high functional independence) are likely to be ineligible for many services and therapies or, because of finite resources, may be overlooked in favour of providing support to a child with lower functional independence. Needs that may be important to families of children with high functional independence, such as involvement in recreational activities or acceptance by peers, may be unrecognized by the service system and therefore remain unmet. In contrast, families of children with poor adaptive skills and/or extreme challenging behaviours (i.e., low functional independence) may have tremendous needs that the services provided simply cannot meet. These families may struggle more with long waiting lists for services that are in high demand or may have difficulty coordinating a myriad of supports.

Families cope with disability in different ways and therefore do not require the same amount of support. It is possible that the perceived impact of the child’s disability on the family modifies the relationship between the child’s level of functional independence and the parent’s perceptions of unmet need. Impact is the effect of the child’s disability on the normative behaviours of the family system and the changes that result, such as practical burden or social isolation (McConachie, 1994; Stein & Riessman, 1980). Parents of children with ASD describe restrictions on socializing, not being able to take their child shopping or to others’ homes, and not being able to leave the child with a babysitter (Cassidy et al., 2008). While some parents may not perceive their child’s disability as a burden and may therefore have few needs, others may feel overwhelmed by their child’s disability and may therefore perceive a great number of needs. The parent’s appraisal of the effect of their child’s disability on the family may therefore play
a critical role in describing the association between the child’s level of functional independence and the parent’s perceptions of unmet need, and so is hypothesized to influence this relationship.

In our framework, we conceptualize service use as a mediator in the relationship between functional independence and perceived unmet need. In many jurisdictions, eligibility for services is determined not only by the diagnosis itself but also by the severity of the disorder (Madore, 2006). We also propose that the extent of the child’s dependence on others and the severity of his or her problem behaviours (i.e., the level of functional independence, defined by adaptive and challenging behaviours) will determine the extent to which families seek out and are willing to pay for services. Service use may in turn affect the parent’s perceptions of need. Specifically, those parents whose children receive what they judge to be adequate service provision will most likely perceive fewer unmet needs. We therefore suggest that service use will explain some of the association between the child’s functional independence and the parent’s perceptions of unmet need.

We propose that the child’s level of functional independence, the impact of the child’s disability on the family unit, and service use will be important factors in predicting the extent of parents’ perceived unmet needs. There are several other confounding variables which may affect these relationships. These are depicted in the framework (Figure 1). Child characteristics include age, gender, the presence of co-morbid conditions, time since diagnosis, and use of medication for attention or behaviour problems. Parent characteristics—including level of income, education, and marital status; urban or rural residence; changes made to employment; and having more than one child with a disability—are also likely to play a role. These measures are included
because of their demonstrated (Bromley et al., 2004; Ellis et al., 2002; Kogan et al., 2008) or likely association with perceived unmet need and should be explored as important components of the framework.

Conclusions

Needs assessments in autism are in their infancy and have typically described the service use of children with ASD in relation to children with other developmental disabilities or special healthcare needs (for example: Boulet et al., 2009; Croen et al., 2006). However, the complexity of ASD (Gillberg & Billstedt, 2000) and the lack of a universal approach to treatment, especially among school-aged children (Simpson, 2005), call into question the value of service use data in portraying this population’s needs. Rather than focusing on need as a service use outcome, measures of perceived unmet need address issues associated with the process of accessing care. Potential obstacles during this process, such as long waiting lists, difficulty obtaining referrals, and problems interacting with professionals involved in the child’s care, contribute to perceived needs and are important to consider when trying to determine a family’s unmet needs (Krauss et al., 2003). Information about the perceived unmet needs of families of children with ASD will help policy makers and service providers to rethink eligibility criteria and the process of accessing care and will enable them to develop resources and services that are responsive to the needs of their client group. The framework which we have proposed can be used to identify subsets of families who may benefit from more intensive care. Using this framework, further investigation into the experience of unmet need and the factors associated with it can be carried out so that autism services and policies can be planned effectively.
References


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Abstract

Background. In order to aid decision-making regarding the allocation of limited resources, information is needed on the perceived unmet needs of parents of school-aged children with an autism spectrum disorder. Methods. A cross-sectional survey was conducted of 101 Canadian families of school-aged children with an autism spectrum disorder. Results. Commonly reported unmet needs were for social activities for the child (78.2%), information about services (77.2%), and continuous service provision (74.3%). Conclusions. This study provides insight into needs which have not been met by the service system. Information about the unmet needs of children with an autism spectrum disorder and their families may help policy makers and service providers to develop resources and services that are responsive to their client group.

Recognition of the overburdened nature of autism services has prompted policy recommendations for improved support coverage for individuals with autism spectrum disorders (ASD) which include autistic disorder, pervasive developmental disorder-not otherwise specified, and Asperger’s disorder (All-Party Parliamentary Group on Autism, 2007; National Research Council, 2001; Standing Senate Committee on Social Affairs, Science, and Technology, 2007). In order to effectively and efficiently allocate limited resources, the needs of families of children with ASD must be systematically examined.

There is a considerable history of conducting needs assessments by measuring perceived unmet need (Magi & Allander, 1981). This approach reflects the focus on consumerism in today’s healthcare system (Wright, Williams, & Wilkinson, 1998) as well as the emphasis on family-centred care for children with developmental disabilities including ASD (Kohler, 1999; Sperry, Whaley, Shaw, & Brame, 1999). Dunst et al. (1988) define perceived need as “an individual’s judgment of the discrepancy between actual states or conditions and what is normative, desired, or valued from a help seeker’s and not a help giver’s perspective” (authors’ emphasis, p. 13). While family-centred services are built on the belief that supports should be tailored toward the needs of the family, policy development and service planning require information to be available on the needs of the consumer group as a whole (Cassidy et al., 2008). Parents’ perceptions of unmet need have the potential to highlight areas of the service system which need to be modified or strengthened.

Several studies have described the perceived unmet needs of families with a child with ASD. Parents commonly report the need for information about available services as
well as the need for information about how to handle their child’s difficult behaviours (Ellis et al., 2002; Granlund & Roll-Pettersson, 2001; McLennan, Huculak, & Sheehan, 2008). Parents identify themselves as the most common case manager for their child (McLennan et al., 2008) and report the need for improved coordination of (Cassidy et al., 2008; Kogan et al., 2008; Kohler, 1999; Krauss, Gulley, Sciegaj, & Wells, 2003) and access to services (Cassidy et al., 2008; Kogan et al., 2008; Siklos & Kerns, 2006). In addition, collaboration and communication between professionals and the family are areas of unmet need identified by parents (Kohler, 1999). Parents also report the need for family support (Cassidy et al., 2008; Sperry et al., 1999), respite care (Ellis et al., 2002; Kohler, 1999), and help with family functioning (Ellis et al., 2002).

Most previous research has focused on the needs of very young children (Cassidy et al., 2008; McLennan et al., 2008; Thomas, Morrissey, & McLaurin, 2007) or has included a wide age range (Kogan et al., 2008; Liptak et al., 2008; Siklos & Kerns, 2006), leaving undetermined the needs of families of school-aged children. During the preschool years, applied behavioural analysis is the recommended approach to the treatment of ASD symptoms (Rogers, 1998). However, among older children, these types of therapies are often no longer available (Akshoomoff & Stahmer, 2006; Madore, 2006), and there is no standard approach to treatment (Simpson, 2005). Due to this lack of service structure as well as the unique environment and activities of older children, a focus on this age group is needed to bridge the research gap and to inform service providers and policy makers regarding the needs of families of school-aged children with ASD. The objective of this paper is therefore to describe areas of unmet need reported by families who have a school-aged child with ASD.
Method

Participants

This was a cross-sectional study. A list of potential participants was taken from two databases at Queen’s University in Ontario, Canada: the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) and the Autism Spectrum Disorders – Canadian-American Research Consortium (ASD-CARC). The targeted population included the parent or legal guardian of all children who (1) had a diagnosis of ASD (i.e., autistic disorder, pervasive developmental disorder-not otherwise specified, Asperger’s disorder, or autism spectrum disorder1), (2) were between 6 and 13 years of age, and (3) were living in one of the study regions (Manitoba, South Eastern Ontario, Prince Edward Island, or Newfoundland and Labrador).

NEDSAC (www.nedsac.ca) is a surveillance program for diagnosed cases of ASD among children in various regions of Canada (for more information, see: Ouellette-Kuntz et al., 2009). NEDSAC served as the source for recruitment from South Eastern Ontario, Prince Edward Island, and Newfoundland and Labrador. Potential participants were contacted in two ways. Parents new to NEDSAC, who were recruited through school boards and government agencies, were asked if they would like to receive information about the study when they completed their consent form for inclusion in NEDSAC. Parents currently in NEDSAC, who had previously consented to be contacted yearly, were asked if they would like to receive information about the study when they completed their update call. ASD-CARC (www.asdcarc.com) holds an international

1 Although not included in the Diagnostic and Statistical Manual of Mental Disorders IV-TR (American Psychiatric Association, 2000) definition of autism, “autism spectrum disorder” is a general diagnosis often used by clinicians in Canada.
Research Registry of children and adults with ASD. ASD-CARC served as the source for recruitment from Manitoba. Families in the Research Registry in the other three regions, with whom NEDSAC did not have yearly contact, were also invited. Eligible ASD-CARC families were invited to participate in the study by e-mail.

Overall, 499 families were eligible (i.e., they met the inclusion criteria and had consented to be contacted about studies). Of those, 101 participated (20.2%). Children whose parents participated had a diagnosis of autistic disorder (42.6%), pervasive developmental disorder-not otherwise specified (7.9%), Asperger’s disorder (24.8%), or autism spectrum disorder (24.8%) and were diagnosed an average of 4.92 years ($SD = 2.36$) previously. They had a mean age of 9.49 years ($SD = 2.11$), and 86.1% were male.

**Materials**

For the current analysis, the survey consisted of (1) the Family Needs Questionnaire (Siklos & Kerns, 2006) and (2) several additional questions developed by the research team to collect information on the characteristics of the child and the family.

*Family Needs Questionnaire.* The Family Needs Questionnaire was used previously by Siklos and Kerns (2006) to evaluate the needs of parents of children with ASD or Down syndrome. It was originally developed to describe the needs of family members of adults (Kreutzer, Serio, & Berquist, 1994) and children (Waaland, Burns, & Cockrell, 1993) with traumatic brain injury. Siklos and Kerns (2006) argued that many of the problems experienced by children with traumatic brain injury, such as intellectual impairment, disruptive behaviours, and impairments in social functioning, are similar to those experienced by children with ASD. Both traumatic brain injury and ASD are lifelong conditions, and parents report similar feelings of helplessness and stress.
questionnaire contains themes that are often identified in the ASD literature: the need for information, for professional and community support, and for involvement with care (Cassidy et al., 2008; Ellis et al., 2002; Sperry et al., 1999).

The Family Needs Questionnaire consists of 51 items: 23 adapted from Waaland et al. (1993) and 28 added by Siklos and Kerns (2006). The added questions were chosen based on a review of the literature, clinical experience, and discussions with families of children with ASD (Siklos & Kerns, 2006). Each item is first scored as not important, slightly important, important, or very important. Parents then rate how well each need has been met: met, partly met, or unmet. Similar to Kreutzer et al. (1994) in the original scale, only responses endorsed as important or very important are used when describing unmet needs (= partly met or unmet). Partly met needs are included in the unmet category, given that if a need is not fully met, more can be done to ameliorate it. Siklos and Kerns (2006) reported a Cronbach’s alpha for the internal consistency of the scale of .90.

Additional questions. Survey items were added to describe the sample. Child variables included age, gender, diagnosis, the parent’s perception of the severity of the condition, the presence of comorbidities, time since diagnosis, and whether the child was taking medication for attention or behaviour problems. Parent variables included levels of education and income, changes made to employment as a result of caring for a child with ASD, marital status, and having another child with a disability. Parents were also asked about the child’s use of several professional services. The goal was to describe the use of major services by children in the sample in order to illustrate, in general terms, the pattern of professional support they were receiving and to aid in the interpretation of parents’ perceived needs. The list was developed by reviewing several studies (Kohler,
1999; Krauss et al., 2003; Thomas et al., 2007) and identifying the more common professional services listed. Parents reported whether or not they used these services in the last 12 months. Finally, they were asked an open-ended question in which they were invited to describe their experiences related to accessing services.

Procedure

Parents who indicated an interest in the study were sent both an information and a consent form as well as a survey (Family Needs Questionnaire and demographic questions). Once these were returned, they completed a telephone interview (service use questions and open-ended question). This study received ethics approval from each of the sites from which recruitment occurred: the Research Ethics Boards at Queen’s University (for South Eastern Ontario NEDSAC and for the ASD-CARC Research Registry), at Memorial University (Newfoundland and Labrador NEDSAC), and in Prince Edward Island (for Prince Edward Island NEDSAC).

Analyses

The analyses were primarily descriptive. Cronbach’s alpha was used to determine the internal consistency of the Family Needs Questionnaire. SPSS version 12.0 was used. Responses to open-ended questions were categorized by major themes.

Results

Child and parent characteristics are reported in Table 1. Table 2 presents the services used by the children. Almost all children had an educational assistant (86.8%) and a family physician (94.9%). Most allied health professional services (i.e., occupational, physical, and speech/language therapy) were received in school, and few families had a case manager (33.7%) or respite provider (32.7%).
Table 1. Sample Characteristics (N = 101)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis on the autism spectrum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autistic disorder</td>
<td>43</td>
<td>42.6</td>
</tr>
<tr>
<td>Pervasive developmental disorder-not otherwise specified</td>
<td>8</td>
<td>7.9</td>
</tr>
<tr>
<td>Asperger’s disorder</td>
<td>25</td>
<td>24.8</td>
</tr>
<tr>
<td>Autism spectrum disorder</td>
<td>25</td>
<td>24.8</td>
</tr>
<tr>
<td>Male gender</td>
<td>87</td>
<td>86.1</td>
</tr>
<tr>
<td>Had a comorbid condition</td>
<td>46</td>
<td>45.5</td>
</tr>
<tr>
<td>Taking medication for attention / behaviour problems(^a)</td>
<td>41</td>
<td>40.6</td>
</tr>
<tr>
<td>Parent-reported severity of ASD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>45</td>
<td>44.6</td>
</tr>
<tr>
<td>Moderate</td>
<td>40</td>
<td>39.6</td>
</tr>
<tr>
<td>Severe</td>
<td>16</td>
<td>15.8</td>
</tr>
<tr>
<td><strong>Parent</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respondent’s relationship to child</td>
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<td></td>
</tr>
<tr>
<td>Mother</td>
<td>93</td>
<td>92.1</td>
</tr>
<tr>
<td>Father</td>
<td>7</td>
<td>6.9</td>
</tr>
<tr>
<td>Other(^b)</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Education</td>
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<td></td>
</tr>
<tr>
<td>Less than high school diploma</td>
<td>3</td>
<td>3.0</td>
</tr>
<tr>
<td>High school diploma</td>
<td>23</td>
<td>22.8</td>
</tr>
<tr>
<td>College diploma</td>
<td>38</td>
<td>37.6</td>
</tr>
<tr>
<td>University undergraduate degree</td>
<td>19</td>
<td>18.8</td>
</tr>
<tr>
<td>Graduate or professional degree</td>
<td>18</td>
<td>17.8</td>
</tr>
<tr>
<td>Average yearly household income(^c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $25,000</td>
<td>15</td>
<td>14.9</td>
</tr>
<tr>
<td>$25,000 to less than $45,000</td>
<td>13</td>
<td>12.9</td>
</tr>
<tr>
<td>$45,000 to less than $65,000</td>
<td>23</td>
<td>22.8</td>
</tr>
<tr>
<td>$65,000 to less than $85,000</td>
<td>16</td>
<td>15.8</td>
</tr>
<tr>
<td>$85,000 or more</td>
<td>30</td>
<td>29.7</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or common law</td>
<td>81</td>
<td>80.2</td>
</tr>
<tr>
<td>Divorced</td>
<td>16</td>
<td>15.8</td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Single or never married</td>
<td>3</td>
<td>3.0</td>
</tr>
<tr>
<td>Made changes to employment status to care for child with ASD</td>
<td>66</td>
<td>65.3</td>
</tr>
<tr>
<td>Had at least one other child with a disability</td>
<td>20</td>
<td>19.8</td>
</tr>
</tbody>
</table>

\(^a\) Medication information was missing for 3 individuals due to the inability to reach them for the telephone interview portion of the study.
\(^b\) One respondent was a grandmother who was the legal guardian for the child with ASD.
\(^c\) Values in Canadian currency.
Table 2. Pattern of Service Use of Children with ASD (N = 98)

<table>
<thead>
<tr>
<th>Professional Type</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Services received in school</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational Assistant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Part-Time&lt;sup&gt;a&lt;/sup&gt;</td>
<td>47</td>
<td>48.0</td>
</tr>
<tr>
<td>Full-Time</td>
<td>38</td>
<td>38.8</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>38</td>
<td>38.8</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>6</td>
<td>6.1</td>
</tr>
<tr>
<td>Speech/language Therapist</td>
<td>33</td>
<td>33.7</td>
</tr>
<tr>
<td><strong>Services received outside of school</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>10</td>
<td>10.2</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Speech/language Therapist</td>
<td>10</td>
<td>10.2</td>
</tr>
<tr>
<td>Audiologist</td>
<td>18</td>
<td>18.4</td>
</tr>
<tr>
<td>Family Physician</td>
<td>93</td>
<td>94.9</td>
</tr>
<tr>
<td>Case Manager/Social Worker</td>
<td>33</td>
<td>33.7</td>
</tr>
<tr>
<td>Respite Provider</td>
<td>32</td>
<td>32.7</td>
</tr>
<tr>
<td>Neurologist</td>
<td>7</td>
<td>7.1</td>
</tr>
<tr>
<td>Psychologist</td>
<td>20</td>
<td>20.4</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>12</td>
<td>12.2</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paediatrician</td>
<td>27</td>
<td>27.6</td>
</tr>
<tr>
<td>Developmental Paediatricician</td>
<td>12</td>
<td>12.2</td>
</tr>
<tr>
<td>Applied Behavioural Analysis Therapist</td>
<td>9</td>
<td>9.2</td>
</tr>
</tbody>
</table>

Note: Service use information was missing for 3 individuals due to inability to reach them for the telephone interview portion of the study.

<sup>a</sup> Part-Time educational assistant refers to either the use of an educational assistant one-on-one for less than a full day or the use of an educational assistant that is shared among two or more children in the class.

The internal consistency of the Family Needs Questionnaire was high (Cronbach’s alpha: .92). Parents’ perceived needs are presented in Table 3, where they are ranked first by importance (from most to least important) and then by whether or not they were unmet. Needs which were reported as important by at least 80% of parents and as unmet by at least 70% of parents are discussed (in bold, Table 3). These include unmet needs for information about special programs and services (77.2% unmet), for social activities (78.2% unmet) and friends (74.3% unmet) for the child, for understanding from
the child’s classmates (74.3% unmet) and friends (71.3% unmet), and for continuous service provision rather than service receipt only in times of crisis (74.3% unmet).

Table 3. Family Needs Questionnaire Items Ranked by % Reported as Important and % Reported as Unmet (N = 101)

<table>
<thead>
<tr>
<th>I need…</th>
<th>% rated importanta</th>
<th>% rated unmetb</th>
</tr>
</thead>
<tbody>
<tr>
<td>to have information regarding my child’s therapeutic or educational progress.</td>
<td>99.0</td>
<td>51.5</td>
</tr>
<tr>
<td>to have my questions answered honestly.</td>
<td>99.0</td>
<td>49.5</td>
</tr>
<tr>
<td>to be actively involved in my child’s treatments and therapies.</td>
<td>99.0</td>
<td>33.7</td>
</tr>
<tr>
<td>to have my child’s teachers understand his/her problems.</td>
<td>98.0</td>
<td>64.4</td>
</tr>
<tr>
<td>to be well-educated about my child’s disorder in order to be an effective decision-maker regarding the needs of my child.</td>
<td>98.0</td>
<td>40.6</td>
</tr>
<tr>
<td>to be shown respect by the professionals working with my child.</td>
<td>98.0</td>
<td>36.6</td>
</tr>
<tr>
<td><strong>for my child’s friends to feel comfortable around my child.</strong></td>
<td><strong>97.0</strong></td>
<td><strong>70.3</strong></td>
</tr>
<tr>
<td>to be shown that my opinions are used in planning my child’s treatment, therapies, or education.</td>
<td>97.0</td>
<td>52.4</td>
</tr>
<tr>
<td>to work with professionals who have expertise with children who have the same disorder as my child.</td>
<td>96.0</td>
<td>69.3</td>
</tr>
<tr>
<td>my child’s school to set up a specialized education plan for my child.</td>
<td>96.0</td>
<td>39.6</td>
</tr>
<tr>
<td>for the professionals working with my child to understand the needs of my child and my family.</td>
<td>94.1</td>
<td>67.3</td>
</tr>
<tr>
<td>to have a professional to turn to for advice or services when my child needs help.</td>
<td>94.1</td>
<td>61.4</td>
</tr>
<tr>
<td><strong>information about special programs and services available to my child and my family.</strong></td>
<td><strong>93.1</strong></td>
<td><strong>77.2</strong></td>
</tr>
<tr>
<td>the children in my child’s classroom to understand that my child cannot help his/her unusual behaviours and difficulties.</td>
<td>93.1</td>
<td>74.3</td>
</tr>
<tr>
<td><strong>to have my child to have social activities other than with his/her own parents and siblings.</strong></td>
<td><strong>92.1</strong></td>
<td><strong>78.2</strong></td>
</tr>
<tr>
<td>my child to have a teacher’s aide with him/her at school who has knowledge about, or expertise with, working with children with the same disorder as my child.</td>
<td>92.1</td>
<td>58.4</td>
</tr>
<tr>
<td>to have my spouse and me agree on decisions regarding our child.</td>
<td>92.1</td>
<td>39.6</td>
</tr>
<tr>
<td><strong>for my child to have friends of his/her own.</strong></td>
<td><strong>91.1</strong></td>
<td><strong>74.3</strong></td>
</tr>
<tr>
<td>to have other family members understand my child’s problems.</td>
<td>90.1</td>
<td>63.4</td>
</tr>
<tr>
<td><strong>services continuously rather than only in times of crisis.</strong></td>
<td><strong>89.1</strong></td>
<td><strong>74.3</strong></td>
</tr>
</tbody>
</table>
Table 3 (Continued)

<table>
<thead>
<tr>
<th>I need…</th>
<th>% rated important</th>
<th>% rated unmet</th>
</tr>
</thead>
<tbody>
<tr>
<td>to have different professionals agree on the best way to help my child.</td>
<td>89.1</td>
<td>46.5</td>
</tr>
<tr>
<td>my child’s doctor and dentist to have expertise working with children with the same disorder as my child.</td>
<td>87.1</td>
<td>54.5</td>
</tr>
<tr>
<td><strong>to have my child’s after-school friends understand his/her problems.</strong></td>
<td><strong>84.2</strong></td>
<td><strong>71.3</strong></td>
</tr>
<tr>
<td>financial support (e.g., from government) in order to provide my child with his/her therapies, treatments, and care.</td>
<td>84.2</td>
<td>69.3</td>
</tr>
<tr>
<td>to get enough rest or sleep.</td>
<td>82.2</td>
<td>58.4</td>
</tr>
<tr>
<td>weekend and after-school activities for my child.</td>
<td>79.2</td>
<td>57.4</td>
</tr>
<tr>
<td>to have the professionals working with my child to speak to me in terms I can understand.</td>
<td>79.2</td>
<td>29.7</td>
</tr>
<tr>
<td>to have time to spend alone with my partner.</td>
<td>77.2</td>
<td>64.4</td>
</tr>
<tr>
<td>to have help from other family members in taking care of my child.</td>
<td>76.2</td>
<td>43.6</td>
</tr>
<tr>
<td>to have consistent behavioural therapy for my child.</td>
<td>75.2</td>
<td>62.4</td>
</tr>
<tr>
<td>to have my child’s therapies continue throughout the summer months and school breaks.</td>
<td>73.3</td>
<td>61.4</td>
</tr>
<tr>
<td>help in remaining hopeful about my child’s future.</td>
<td>72.3</td>
<td>61.4</td>
</tr>
<tr>
<td>to be shown what to do when my child is acting unusually or is displaying difficult behaviours.</td>
<td>71.3</td>
<td>48.5</td>
</tr>
<tr>
<td>for professionals to be discrete when talking about my child while he/she is in the room.</td>
<td>70.3</td>
<td>35.6</td>
</tr>
<tr>
<td>help dealing with my fears about my child’s future.</td>
<td>67.3</td>
<td>63.4</td>
</tr>
<tr>
<td>to get a break from my responsibilities.</td>
<td>67.3</td>
<td>54.5</td>
</tr>
<tr>
<td>to have time to spend alone with my other children.</td>
<td>67.3</td>
<td>49.5</td>
</tr>
<tr>
<td>to be told why my child acts in ways that are different, difficult, or unusual.</td>
<td>66.3</td>
<td>33.7</td>
</tr>
<tr>
<td>to discuss feelings about my child with a parent who has a child with the same disorder.</td>
<td>65.3</td>
<td>44.6</td>
</tr>
<tr>
<td>to be told if I am making good decisions about my child.</td>
<td>63.4</td>
<td>51.5</td>
</tr>
<tr>
<td>to have consistent occupational therapy for my child.</td>
<td>63.4</td>
<td>51.5</td>
</tr>
<tr>
<td>to spend time with my friends.</td>
<td>61.4</td>
<td>47.5</td>
</tr>
<tr>
<td>to be reassured that it is not uncommon to have negative feelings about my child’s unusual behaviours.</td>
<td>56.4</td>
<td>39.6</td>
</tr>
<tr>
<td>respite care for my child.</td>
<td>53.5</td>
<td>41.6</td>
</tr>
<tr>
<td>to have consistent speech therapy for my child.</td>
<td>51.5</td>
<td>42.6</td>
</tr>
<tr>
<td>to have help in deciding how much to let my child do by himself/herself.</td>
<td>48.5</td>
<td>30.7</td>
</tr>
<tr>
<td>to be encouraged to ask for help.</td>
<td>46.5</td>
<td>37.6</td>
</tr>
<tr>
<td>to have help with housework.</td>
<td>41.3</td>
<td>35.6</td>
</tr>
<tr>
<td>to have consistent physical therapy for my child.</td>
<td>37.6</td>
<td>32.7</td>
</tr>
<tr>
<td>to have counselling for my other children.</td>
<td>35.6</td>
<td>29.7</td>
</tr>
</tbody>
</table>
Table 3 (Continued)

<table>
<thead>
<tr>
<th>I need…</th>
<th>% rated important&lt;sup&gt;a&lt;/sup&gt;</th>
<th>% rated unmet&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>to have counselling for myself and my spouse/partner.</td>
<td>34.7</td>
<td>29.7</td>
</tr>
</tbody>
</table>

<sup>a</sup> Important = rated as *important* or *very important.*

<sup>b</sup> Unmet = rated as *partly met* or *unmet.* Only those rated first as important are included in this score.

Categories of responses to open-ended questions are presented in Table 4. As with the responses to the Family Needs Questionnaire, major themes included concerns about poor access to, coordination of, and information about services as well as few social or recreational activities for the child.

Table 4. Categories of Open-Ended Responses Provided by Participants (N = 98)

<table>
<thead>
<tr>
<th>Category / Systemic</th>
<th>Formal Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Educational</td>
</tr>
<tr>
<td>Access</td>
<td>-No educational assistant or not enough one-on-one time</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality</td>
<td>-Educational assistant lacking expertise in autism</td>
</tr>
<tr>
<td></td>
<td>-Lack of consistent educational assistant from year to year</td>
</tr>
<tr>
<td></td>
<td>-Teacher lacking expertise in autism</td>
</tr>
<tr>
<td></td>
<td>-Lack of support at school board level</td>
</tr>
<tr>
<td></td>
<td>-Lack of understanding at school board level</td>
</tr>
</tbody>
</table>
Table 4 (Continued)

<table>
<thead>
<tr>
<th>Informal Supports</th>
<th>Extra-Curricular Activities</th>
<th>Family Support</th>
<th>Information &amp; Advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>-Lack of social programs</td>
<td>-Difficulty finding respite care or support groups</td>
<td>-Lack of information about services and funding (availability, eligibility)</td>
</tr>
<tr>
<td></td>
<td>-Lack of availability in rural regions</td>
<td>-Lack of availability in rural areas</td>
<td>-No ‘go-to’ person</td>
</tr>
<tr>
<td>Quality</td>
<td>-Programs focused on behaviours when need social skills training</td>
<td>-Respite worker lacking expertise in autism</td>
<td>-System of service provision is passive rather than active</td>
</tr>
<tr>
<td></td>
<td>-Programs not applicable for ‘high functioning’ children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coordination / systemic</td>
<td>-Discontinuity of services throughout weekends and summer holidays</td>
<td>-Lack of fit with family’s schedule</td>
<td>-Lack of coordination among services -Difficulty getting referrals</td>
</tr>
</tbody>
</table>

Note: Responses were missing for 3 individuals due to inability to reach them for the telephone interview portion of the study.

To determine the representativeness of the group of children in the sample, two comparisons were made, based on the availability of comparative data from NEDSAC. (ASD-CARC contained invitees \(n = 27\) and, of these, participants \(n = 5\) who were not captured by NEDSAC. Due to the unavailability of comparative data for ASD-CARC, these individuals are excluded from this comparison.) Because only NEDSAC participants whose parents had consented to be contacted yearly were invited, invitees \(n = 472\) were first compared to non-invitees \(n = 1,184\) of the same age range and region.

There were significant differences in regional representation \(\chi^2 = 309.44, p < .01\), with Manitoba being under-represented due to recruitment issues. Invitees \((M = 9.73, SD = 2.28)\) were also significantly younger than non-invitees \((M = 10.31, SD = 2.24), t = 6.83,\)
There were no differences in gender ($X^2 = 2.68, p = .10$). Second, within invitees, we compared participants ($n = 96$) and non-participants ($n = 376$). There were no differences in regional representation ($X^2 = 4.54, p = .21$), gender ($X^2 = 0.36, p = .55$), age ($t = 0.20, p = .84$), or ASD diagnostic distribution ($X^2 = 2.54, p = .47$).

**Discussion**

**Summary of Main Findings**

The most common unmet needs identified by parents were for (1) information about services, (2) social inclusion for the child, and (3) services continuously rather than only in times of crisis.

*Information about services.* The majority of parents indicated that their need for information about special programs and services was unmet. Furthermore, in response to the open-ended question, many commented that the service system is passive rather than active: parents had to “dig” for information rather than having it available to them. This finding is in line with previous literature which has consistently found that a top concern identified by parents is difficulty obtaining information to guide them through the process of finding and acquiring supports (Ellis et al., 2002; Granlund & Roll-Pettersson, 2001; McLennan et al., 2008).

*Social inclusion for the child.* Many parents also identified unmet needs for social activities outside the home as well as for friends for their child with ASD. Similarly, many reported an unmet need for understanding and acceptance of their child’s difficulties and behaviours by the child’s classmates and friends. These sentiments were reflected in responses to the open-ended question, in which many parents commented about the lack of social programming or social skills training available to their child.
Similarly, previous studies have reported higher levels of loneliness in school-aged children with ASD compared to their typically developing peers, demonstrating the absence of social activities and the lack of social acceptance experienced by many children with ASD (Bauminger & Kasari, 2000).

Continuity of services. The majority of parents also reported unmet needs for continuous services (rather than receiving services only in a time of crisis). Continuity of support (McLennan et al., 2008) and access to care (Cassidy et al., 2008; Kogan et al., 2008; Kohler, 1999) are issues also identified in the literature. The majority of parents describe themselves as the most common case manager for their child and report having to repeat their child’s story to multiple professionals (McLennan et al., 2008). This is highlighted in the current study which found that only one third of parents had contact with a case manager. Similarly, in response to the open-ended question, parents commented about poor coordination of services and unavailability of services during holidays. Discontinuity may be an issue particularly for families of school-aged children, most of whom no longer have access to time-intensive early intervention services. (Only 9.2% of parents in this study received applied behavioural analysis for their child.)

Methodological Strengths

During the development of the Family Needs Questionnaire, it was argued that the importance rating should be used to validate the unmet rating (Kreutzer et al., 1994; Serio, Kreutzer, & Witol, 1997). This is a significant improvement over earlier perceived needs scales used in populations of children with physical or other special healthcare problems, which only asked whether or not family needs were met (for example: Farmer, Marien, Clark, Sherman, & Selva, 2004; Sloper & Turner, 1992). When faced with
difficult decisions regarding resource allocation, it is important for policy and service planners to be aware not only of the unmet needs of their population, but also of the importance of these needs to them. This understanding of importance will aid in the prioritization of support distribution. It should be noted that the highest unmet needs identified here (for social inclusion, information, and continuous services) also had high ratings of importance (from 84.2% to 97.0%), pointing to the need to address these problems in particular.

Another strength of this study was the opportunity for parents to respond to an open-ended question about their experience accessing services. This question added detail that could not be captured by the Family Needs Questionnaire alone. For example, a portion of parents commented that although their child was receiving services from an allied health professional (e.g., occupational therapist or speech/language therapist), many commented that the child was not receiving enough one-on-one time with the therapist. The open-ended question therefore served to probe further into the reasons why parents felt a need was met or unmet. Moreover, in response to the open-ended question, parents identified unmet needs which were not captured by Family Needs Questionnaire items. For instance, many parents who lived in rural regions noted that travel distance impeded their access to services as well as informal supports such as parent support groups. In addition, several parents noted that their higher functioning children were caught in a service gap where intensive therapeutic supports were not appropriate, but social activities with light supervision were not available. Such comments offer potential for further investigation or consideration for inclusion in future examinations of unmet need.
Limitations

Representativeness of the sample. Several considerations must be made when determining the generalizability of this study’s results, especially given the 20.2% response rate. While response rates in this range are common in this area of research (Siklos & Kerns, 2006), potential sources of sampling bias were evaluated nonetheless. To investigate potential selection bias, children of those who were invited to participate were compared with children of non-invitees. These groups were similar in terms of gender ratio. However, children of invitees were slightly younger than those of non-invitees. This could be due to research fatigue among families of older children and the greater willingness of families of younger children to participate in research studies. In addition, sampling regions were not proportionally represented due to recruitment issues in Manitoba. Because of this, region-specific conclusions cannot be drawn. Potential non-response bias was also explored by comparing, within children of invitees, children of participants and non-participants. There were no differences among the children on the basis of regional representation, gender, age, or diagnosis. However, since it was only possible to compare these groups on basic child demographic and diagnostic

Information for the NEDSAC database in Manitoba is collected by Children’s Special Services staff who review files and complete anonymized data collection forms for all children under the age of 18 with an ASD in the province. For this reason, NEDSAC staff do not have direct contact with families through yearly update calls. (In other NEDSAC study regions, these update calls serve to collect the same demographic information available in the Manitoba charts.) For the purposes of the current study, Children’s Special Services was approached to send information about the study to families in the region. However, their cooperation could not be gained. Therefore, recruitment for the current study did not cover a large number of families in Manitoba, as it did in the other study regions. Instead, an incomplete list was used of families from the region who were invited through their involvement in the ASD-CARC Research Registry.
characteristics, the representativeness of the sample could not be determined on the basis of other characteristics.

For example, results must be interpreted in relation to other sample characteristics. Specifically, parents’ perceptions of the severity of their child’s ASD were low. The types of needs which were unmet may have differed had the parents perceived greater severity (e.g., greater unmet need for respite or behavioural therapy). As well, although there were broad ranges of parental education and income, these were, on average, high, suggesting that this sample may be privileged. In particular, although 69.3% of parents reported unmet need for financial support for funding their child’s therapies, this may be an underestimation. While the wide range of ratings that needs were given (i.e., from 29.7% to 78.2% unmet) suggest that a variety of experiences of unmet need were represented, caution should be used in generalizing these results to the population as a whole. Moreover, future studies should replicate these findings in the context of a larger study sample.

This study was conducted in four regions of Canada. Therefore, some of the needs that parents reported may be unique to the Canadian context. However, the study’s findings are consistent with previous studies conducted in the United States (for example: Krauss et al., 2003; Liptak et al., 2008) and in the United Kingdom (for example: Cassidy et al., 2008). This suggests that, given the increased demand for autism services in many jurisdictions (Grether, 2006; Ruble et al., 2005), the types of needs and experiences reported in this study may be applicable elsewhere.

Limitations of assessments of perceived unmet need. Assessments of perceived need do have disadvantages. Critics argue that because perceptions lack objectivity, such
measures are limited in their ability to assess the appropriateness of requests for supports (Eyles & Birch, 1993). It is therefore difficult to ensure that resources are allocated so that those who truly need more services receive more (Culyer, 1995; Eyles & Birch, 1993). Moreover, because resources are finite, advocating for the needs of a particular group may result in overlooking the competing priorities of other high risk groups (Stevens & Gillam, 1998). However, in a service system as complex as the autism system and where the main burden of care falls on the family (Kohler, 1999), parents’ perceptions of unmet need will at least point to areas of the service system which need to be examined critically and strengthened.

Implications and Recommendations

Despite these acknowledged limitations, this study has important implications for service planning and policy development. The unmet needs identified in the current study support a body of literature which has consistently found unmet needs for information and for continuity of services. The unique contribution of our findings is in the interpretation and implication of these findings in the distinct context of school-aged children who are no longer eligible for early intervention services and whose parents therefore face a new set of challenges in supporting their child.

For instance, the finding of an unmet need for information about services is particularly important, given that children in the sample were diagnosed with ASD, on average, almost five years previously. There are a large number of different therapies for the treatment of ASD symptoms (Green et al., 2006), some with questionable effectiveness (Simpson, 2005). Moreover, because school-aged children with ASD often need a wide variety of supports from the educational, social, and health sectors, it can be
difficult for parents to know where to turn for support. Our finding shows that it is not only families of young, newly diagnosed children who need guidance; difficulties navigating the service system persist well into the school years despite the previous experience of parents with the service system. Two major points of contact with the service system for school-aged children with ASD are the school and the family physician. Work needs to be done to ensure that these service providers have information about programs and supports that they can provide the family.

Social concerns like those expressed in this study may be especially important to families of school-aged children. Unmet needs for social activities for the child suggests the need for school and community programs to focus on facilitating extra-curricular activities and friendship development for school-aged children with ASD. Moreover, they point to a need for fostering understanding and acceptance by the peers of children with ASD; this is especially important for the success of inclusive education. It may be advisable for schools to take on the responsibility for developing these opportunities and improving the social experiences of children with ASD in the classroom.

Parents’ unmet need for continuous services reflects an overburdened and fragmented service system which has difficulty keeping pace with the demands placed upon it. Improving the centralization and coordination of services (e.g., appointing a key worker or case manager to a family) may help to ameliorate this discontinuity, especially after early intensive supports have ended. In turn, this may decrease the stress that parents feel when trying to find their way through the service system. The carry-over of a key worker may act to support families when there are gaps between the cessation of one service and the start of the next. Families experiencing periods of transition in particular
(e.g., from preschool to school or from school to adulthood) may benefit from such continuity.

Conclusion

The school years are marked by the removal of early intensive supports and the onset of new challenges that families face as they navigate a complex service system. This study provides useful information on the unmet needs of families of school-aged children with ASD. Future studies should consider the relationship between these unmet needs and parent and child characteristics.
References


Author Note

We gratefully acknowledge the parents who participated in this study. This work was supported by a trainee stipend with the Canadian Institutes of Health Research/Autism Speaks STIHR Autism Spectrum Interdisciplinary Research (ASPIRE) Training Program (J. J. A. Holden), an Autism Ontario Stimulus Grant, and the Frederick Banting and Charles Best Canada Graduate Scholarships Master’s Award.
Chapter 4: Beyond an Autism Diagnosis: Children’s Functional Independence and Parents’ Unmet Needs
Abstract

Background. High demand for autism services has resulted in gaps in the provision of care. Our objective was to explore the association between children’s functioning and parents’ perceived unmet needs. Methods. We conducted a cross-sectional study of 97 families of school-aged children with an autism spectrum disorder. Log binomial regression was used to examine the relative risk for unmet need. Results. Families of children with high functional independence had lower unmet need compared to families of children with moderate functional independence (RR = 0.81, 95% CI = 0.67-0.99). Those who experienced greater impact of the child’s disability had greater unmet need (RR = 1.22, 95% CI = 1.03-1.45). Conclusions. The child’s functioning and its impact on the family provide insight into unmet need which may inform service planning.
Beyond an Autism Diagnosis:

Children’s Functional Independence and Parents’ Unmet Needs

Children with autism spectrum disorders (ASD), including autistic disorder, pervasive developmental disorder-not otherwise specified, and Asperger’s disorder, have complex needs requiring a broad range of medical, educational, and social supports (Boulet, Boyle, & Schieve, 2009). The main burden of care for children with ASD falls on the family, and parents act as advocate and service coordinator (Kohler, 1999; Thomas, Morrissey, & McLaurin, 2007). Despite efforts to expand support coverage for children with ASD (National Research Council, 2001; Standing Senate Committee on Social Affairs, Science, and Technology, 2007), parents continue to report significant difficulty navigating the service system (Kogan et al., 2008). The identification of characteristics of families who experience greater unmet need has the potential to aid policy makers and service providers in rethinking eligibility criteria for services and in identifying subgroups who may require increased support.

The literature on perceived unmet need—i.e., unmet need from the help-seeker’s perspective (Dunst, Trivette, & Deal, 1988)—is extensive for families of children with a special healthcare condition (for example: Farmer, Marien, Clark, Sherman, & Selva, 2004; Warfield & Gulley, 2006). However, researchers are only beginning to examine characteristics associated with perceived unmet need among families of children with ASD (Ellis et al., 2002; Kogan et al., 2008; Siklos & Kerns, 2006). A limitation of this research is that there has not been a conceptual framework to guide the investigation of the relationships among these characteristics. Such a framework may help to build a profile of the types of families who are likely to require improved support coverage. The
The current study tests a framework which incorporates the child’s level of functional independence, the parent’s perception of the impact of ASD on the family, service use, and several other parent and child characteristics in identifying the level of perceived unmet need. These measures are included because of their demonstrated (Bromley, Hare, Davison, & Emerson, 2004; Ellis et al., 2002; Kogan et al., 2008) or probable association with perceived unmet need. The framework is described in detail elsewhere (Brown, Ouellette-Kuntz, Hunter, & Kelley, 2010) and is presented in Figure 1. The focus is on school-aged children due to the relative lack of research focusing specifically on this age group as well as the unique context of school-aged children who have “aged out” of more extensive preschool services (Akshoomoff & Stahmer, 2006; Madore, 2006).

**Figure 1. Conceptual Framework**

![Conceptual Framework Diagram]

It was hypothesized that one of the main determinants of perceived unmet need is the child’s level of functional independence. Briefly, functional independence is
determined by the child’s overall adaptive skills (i.e., self-help, socialization, and communication skills) and the presence, frequency, and severity of challenging behaviours (i.e., aggression, self-injury, and non-compliance) (Bruininks, Woodcock, Weatherman, & Hill, 1996). Children with ASD show deficits in adaptive skills that are more severe than would be predicted on the basis of their cognitive functioning (Saulnier & Klin, 2007) and age (Klin et al., 2007). Moreover, challenging behaviours are common among children with ASD (Tomanik, Harris, & Hawkins, 2004) and can present an impediment to socialization and learning (Matson & Nebel-Schwalm, 2007). Challenging behaviours and deficits in adaptive skills among children with ASD have a significant impact on parental mental health (Bromley et al., 2004; Hastings & Brown, 2002; Tomanik et al., 2004). Similarly, it is likely that these behaviours will influence parents’ perceptions of unmet need, such that families whose children are on the extremes of the functional independence spectrum will have the greatest levels of unmet need. This may result from the child’s failure to meet eligibility criteria for supports (for those with high functional independence) or from the presence of overwhelming needs that cannot be met by the family or the service system (for those with low functional independence).

Families do not experience disability in the same way. The impact of the child’s disability on the family may be reflected in the changes that result, such as practical burden or social isolation (McConachie, 1994; Stein & Riessman, 1980). Parents of children with ASD report restrictions on socializing and not being able to take the child shopping (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008). However, although some families may feel overwhelmed by their child’s disability and may therefore perceive many unmet needs, others may not view their child’s disability as a burden and
may report few unmet needs. This appraisal may affect the direction or strength of the
association between the child’s functional independence and the parent’s perceptions of
unmet need and so is hypothesized to modify this relationship.

Service use may partially mediate the relationship between functional
independence and perceived unmet need. In many jurisdictions, eligibility for services is
determined not only by the diagnosis itself but also by the severity of the ASD symptoms
(Madore, 2006). The child’s level of functional independence may be associated with his
or her access to services. Service use may in turn affect the parent’s perceptions of need.
For instance, parents whose children receive what they judge to be adequate services will
most likely perceive fewer unmet needs. Thus, service use is likely to explain some of the
association between functional independence and perceived unmet need.

The objective of this paper is to examine the association between the child’s level
of functional independence and the parent’s level of perceived unmet need. The
following hypotheses were made a priori: (1) there will be a nonlinear relationship
between functional independence and unmet need, such that parents of children with the
highest and lowest functional independence will report the greatest levels of unmet need,
(2) the perceived impact of the child’s disability on the family will modify the
relationship between functional independence and unmet need, and (3) service use will
explain some of the association between functional independence and unmet need.

Method

Participants

This was a cross-sectional study. Participants were identified from two databases
at Queen’s University in Ontario, Canada: the National Epidemiologic Database for the
Study of Autism in Canada (NEDSAC) and the Autism Spectrum Disorders – Canadian-American Research Consortium (ASD-CARC). Recruitment was carried out by telephone and written (NEDSAC) or email (ASD-CARC) invitation and is described in detail elsewhere (Brown et al., submitted).

The targeted population included the parent or legal guardian of all children who (1) had a diagnosis of autism (i.e., autistic disorder, pervasive developmental disorder-not otherwise specified, Asperger’s disorder, or autism spectrum disorder\(^1\)), (2) were between six and 13 years of age, and (3) were living in one of the study regions (Manitoba, South Eastern Ontario, Prince Edward Island, or Newfoundland and Labrador) and who had consented to receive information about studies from the two groups at Queen’s University. Of the 499 invited families, 101 agreed to participate, for a participation rate of 20.2%. Three parents did not complete all portions of the study, and one parent did not provide valid data,\(^2\) for a final sample size for this analysis of 97 participants. Children in the sample had a diagnosis of autistic disorder (44.3%), pervasive developmental disorder-not otherwise specified (8.2%), Asperger’s disorder (23.7%), or autism spectrum disorder (23.7%). They had a mean age of 9.41 years (\(SD = 2.11\)), and 86.6% were male.

**Materials**

The survey consisted of (1) the Family Needs Questionnaire (Siklos & Kerns, 2006), (2) the Scales of Independent Behaviour-Revised (Short Form) (Bruininks et al.,

\(^1\) Although not included in the Diagnostic and Statistical Manual of Mental Disorders IV-TR (American Psychiatric Association, 2000) definition of autism, “autism spectrum disorder” is a general diagnosis often used by clinicians in Canada.

\(^2\) One parent’s data was excluded from the analysis because the parent reported 100% unmet need (# unmet needs = # important needs). This results in a proportion of 1.00, which is not supported by the analysis used. (Values must be between 0.01 and 0.99.)
(3) the Impact on Family Scale (Stein & Jessop, 2003), and (4) several questions developed by the research team to collect information on child and parent characteristics.

*Family Needs Questionnaire.* The Family Needs Questionnaire was developed to assess the needs of family members of adults (Kreutzer, Serio, & Berquist, 1994) and children (Waaland, Burns, & Cockrell, 1993) with traumatic brain injury. It has since been modified by Siklos and Kerns (2006) to be pertinent to families of children with ASD or Down syndrome. The Family Needs Questionnaire consists of 51 items: 23 adapted from Waaland et al. (1993) and 28 added by Siklos and Kerns (2006). Each need is first scored as *not important, slightly important, important,* or *very important.* Parents then rate how well each need has been met: *met, partly met,* or *unmet.* Similar to Kreutzer et al. (1994) in the original scale, only responses endorsed by parents as *important* or *very important* are used when tabulating the proportion of unmet needs (= *partly met* or *unmet*). The Cronbach’s alpha for the internal consistency of the scale was .90 when applied to parents of children with ASD and Down syndrome (Siklos & Kerns, 2006).

*Scales of Independent Behaviour-Revised (Short Form).* The Scales of Independent Behaviour-Revised (Short Form) (Bruininks et al., 1996) measures the child’s adaptive skills and the frequency and severity of challenging behaviours. The Support Score weights the adaptive behaviour score (70%) and the challenging behaviour score (30%) to determine the intensity of resources needed for improving or maintaining the individual’s functional independence in home, school, or community settings. It is based on the assumption that these behaviours substantially determine an individual’s functional independence (Bruininks et al., 1996). For the purposes of this study, the Support Score was collapsed into three categories: low functional independence (support
scores in the extensive to pervasive range), moderate functional independence (support scores in the limited to frequent range), or high functional independence (support scores in the infrequent/none to intermittent range). In light of the hypotheses stated previously, children with low and those with high functional independence were compared to children with moderate functional independence. The split-half reliabilities for the Scales of Independent Behaviour-Revised range from .67 to .85. It is correlated with the original Scales of Independent Behaviour ($r = .90$), which was standardized in a group of 1,764 participants representative of the U.S. population (Bruininks et al., 1996).

**Impact on Family Scale.** The Impact on Family Scale (Stein & Jessop, 2003; Stein & Riessman, 1980) is a 15-item scale which assesses the impact of a child’s disability on the family unit. The scale was developed for a study of chronic illness in childhood. The items, chosen based on a review of the literature and interviews with families, reflect economic burden, social and familial impact, and subjective distress and contribute to a single factor reflecting perceived burden. Each item is scored as strongly agree, agree, disagree, or strongly disagree, and items are summed for a total impact score. Cronbach’s alphas for the internal consistency of the scale range from .83 to .89 in the development samples. Construct validity has been demonstrated through the correlation of a higher total score with maternal psychiatric symptoms; child’s poor health, functional status, or psychological adjustment; and increased number of hospitalizations or days of hospitalization (Stein & Jessop, 2003). In the present analyses, total scores were collapsed into tertiles: low, moderate, or high impact on family.

**Service use questions.** The parent was also asked about the child’s use of several services. For the purpose of this analysis, only the use of an educational assistant was
considered, since this is a common publicly available support for children with ASD. Part-time and full-time use were distinguished where part-time use was defined as one-on-one contact for less than a full day or sharing the educational assistant with one or more other students, and full-time use was one-on-one contact for a full day.

*Other measures.* Additional parent and child characteristics were measured. Child characteristics included grade level, gender, ASD diagnosis, the presence of comorbid conditions, the time since diagnosis, and the use of medication for behaviour or attention problems. Parent characteristics included levels of education and income, marital status, changes made to employment as a result of caring for a child with ASD, having another child with a disability, urban or rural residence, and region/province of residence.

*Procedure*

Parents who indicated an interest in the study were sent both an information and a consent form as well as a questionnaire package (Family Needs Questionnaire, Impact on Family Scale, and demographic questions). Once these were returned, they completed a telephone interview (Scales of Independent Behaviour-Revised and service use questions). The study received ethics approval from the Queen’s University Research Ethics Board and from regional ethics boards where required.

*Analyses*

SAS Version 9.2 was used for all analyses (SAS Institute Inc., 2008). Descriptive statistics were derived to characterize the sample, and bivariate associations were used to determine the covariates to be included in the model. To test the association between covariates and functional independence, Chi square tests were used and, where expected cell counts were less than 5, Fisher’s exact test was used. To test the association between
covariates and perceived unmet need, unadjusted log binomial regression models were used.

Regression analyses. Each participant had a number of needs that were important (= important or very important) and a number of these which were unmet (= partly unmet or unmet). The probability of important needs which were unmet was related to a set of independent variables (i.e., functional independence, as well as possible effect modifiers, mediators, and confounding variables). The observed proportion of important needs which were unmet was an estimate of this probability. Because odds ratios for common outcomes may overestimate the magnitude of the association (Barros & Hirakata, 2003), we directly calculated relative risks by fitting a log binomial regression model. This is a generalized linear model (GLM) approach in which the log transformation (log link) of the observed proportion is considered the outcome, while the distribution of important needs is assumed binomial. SAS PROC GENMOD was used (SAS Institute Inc., 2008).

Treatment of confounding variables. All covariates which were significantly associated with functional independence or perceived unmet need were included in the regression analysis. (A liberal $p$ value of .10 was used at this stage.) To produce the most parsimonious model, manual backwards deletion was employed whereby all chosen variables were included in the first step. One variable was removed at a time, starting with the least significant variable, until all variables were significant. (This was determined for relative risks by 95% confidence intervals which did not contain 1.00.)

Treatment of effect modifier. Impact on family was tested as an effect modifier by conducting a stratified analysis of the model at all three levels of impact on family (low, moderate, and high) (Baron & Kenny, 1986; Van Ness & Allore, 2006).
Treatment of mediator. The mediating effect of service use (i.e., use of an educational assistant) was evaluated by testing the following three criteria: (1) that functional independence was significantly associated with perceived unmet need, (2) that functional independence was significantly associated with educational assistant use, and (3) that educational assistant use was significantly associated with perceived unmet need while controlling for the effects of functional independence (Baron & Kenny, 1986). If these three criteria are met, Sobel’s test of mediation can be used in order to determine if use of an educational assistant is a significant mediator in the relationship between functional independence and perceived unmet need (Sobel, 1982).

Treatment of missing data. Information on family income was missing for 3 participants (3.1%) and was therefore imputed using the median value for participants. In addition, information on time since diagnosis was missing for 10 participants (10.3%) and was imputed using the mean value for participants.

Results

Parent and child characteristics are presented in Table 1. Those which had a statistically significant association with functional independence are presented in Table 2. Unadjusted and adjusted associations\(^3\) between the independent variables and perceived unmet need are in Table 3; statistically significant associations are in bold.

\(^3\) Evaluation of the Pearson’s Chi square statistic divided by the degrees of freedom revealed that there was overdispersion in the model (i.e., the standard errors of the parameter estimates were underestimated, resulting in high Type I error). Therefore, a multiplicative overdispersion factor (scale = pearson) was added to the model, whereby the covariance matrix was multiplied by a dispersion parameter (in this case, the square root of [Pearson’s Chi square divided by the degrees of freedom]) (SAS Institute Inc., 2008). This factor inflates the standard errors, making tests of statistical significance more conservative.
Table 1. Sample Characteristics (N = 97)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional independence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>27</td>
<td>27.8</td>
</tr>
<tr>
<td>Moderate</td>
<td>47</td>
<td>48.5</td>
</tr>
<tr>
<td>High</td>
<td>23</td>
<td>23.7</td>
</tr>
<tr>
<td>Diagnosis on the autism spectrum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>43</td>
<td>44.3</td>
</tr>
<tr>
<td>Pervasive developmental disorder-not otherwise specified</td>
<td>8</td>
<td>8.2</td>
</tr>
<tr>
<td>Asperger’s disorder</td>
<td>23</td>
<td>23.7</td>
</tr>
<tr>
<td>Autism spectrum disorder</td>
<td>23</td>
<td>23.7</td>
</tr>
<tr>
<td>Male gender</td>
<td>84</td>
<td>86.6</td>
</tr>
<tr>
<td>Junior/Intermediate (grades 4-8)a</td>
<td>49</td>
<td>50.5</td>
</tr>
<tr>
<td>Diagnosed less than 3 years previously</td>
<td>25</td>
<td>25.8</td>
</tr>
<tr>
<td>Had a comorbid condition</td>
<td>43</td>
<td>44.3</td>
</tr>
<tr>
<td>Taking medication for attention / behaviour problems</td>
<td>41</td>
<td>42.3</td>
</tr>
<tr>
<td>Had full-time educational assistant</td>
<td>38</td>
<td>39.2</td>
</tr>
<tr>
<td><strong>Parent Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent’s level of education</td>
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<td></td>
</tr>
<tr>
<td>University degree or greater</td>
<td>36</td>
<td>37.1</td>
</tr>
<tr>
<td>College degree</td>
<td>35</td>
<td>36.1</td>
</tr>
<tr>
<td>High school or less</td>
<td>26</td>
<td>26.8</td>
</tr>
<tr>
<td>Level of family incomeb</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$85,000 or more</td>
<td>29</td>
<td>29.9</td>
</tr>
<tr>
<td>$45,000 to less than $85,000</td>
<td>42</td>
<td>43.3</td>
</tr>
<tr>
<td>Less than $45,000</td>
<td>26</td>
<td>26.8</td>
</tr>
<tr>
<td>Divorced, widowed, or single</td>
<td>18</td>
<td>18.6</td>
</tr>
<tr>
<td>Made changes to employment</td>
<td>62</td>
<td>63.9</td>
</tr>
<tr>
<td>Had another child with a disability</td>
<td>20</td>
<td>20.6</td>
</tr>
<tr>
<td>Impact on family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>33</td>
<td>34.0</td>
</tr>
<tr>
<td>Moderate</td>
<td>31</td>
<td>32.0</td>
</tr>
<tr>
<td>High</td>
<td>33</td>
<td>34.0</td>
</tr>
<tr>
<td>Region</td>
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<td></td>
</tr>
<tr>
<td>South Eastern Ontario</td>
<td>42</td>
<td>43.3</td>
</tr>
<tr>
<td>Manitoba</td>
<td>11</td>
<td>11.3</td>
</tr>
<tr>
<td>Prince Edward Island</td>
<td>11</td>
<td>11.3</td>
</tr>
<tr>
<td>Newfoundland and Labrador</td>
<td>33</td>
<td>34.0</td>
</tr>
<tr>
<td>Rural residence</td>
<td>34</td>
<td>35.1</td>
</tr>
</tbody>
</table>

*a One child, although primary school-aged (i.e., eligible for the study), was held back in senior kindergarten due to the availability of more intensive supports in the classroom.

*b Values are in Canadian currency.
Table 2. Distribution of Variables Significantly Associated ($p < .10$) with Functional Independence (N = 97)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Functional Independence</th>
<th></th>
<th></th>
<th></th>
<th>Chi square value* (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
<td>Total</td>
<td></td>
</tr>
<tr>
<td></td>
<td>n (row %)</td>
<td>n (row %)</td>
<td>n (row %)</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autistic disorder</td>
<td>11 (25.6%)</td>
<td>22 (51.2%)</td>
<td>10 (23.3%)</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>PDD-NOSb</td>
<td>5 (62.5%)</td>
<td>3 (37.5%)</td>
<td>0 (0.0%)</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Asperger’s disorder</td>
<td>2 (8.7%)</td>
<td>13 (56.5%)</td>
<td>8 (34.8%)</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Autism spectrum disorder</td>
<td>9 (39.1%)</td>
<td>9 (39.1%)</td>
<td>5 (21.7%)</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>43</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8 (61.5%)</td>
<td>4 (30.8%)</td>
<td>1 (7.7%)</td>
<td>13</td>
<td>7.40 (.02)</td>
</tr>
<tr>
<td>Male</td>
<td>19 (22.6%)</td>
<td>43 (51.2%)</td>
<td>22 (26.2%)</td>
<td>84</td>
<td></td>
</tr>
<tr>
<td>Comorbid conditions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>8 (14.8%)</td>
<td>31 (57.4%)</td>
<td>15 (27.8%)</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>One or More</td>
<td>19 (44.2%)</td>
<td>16 (37.2%)</td>
<td>8 (18.6%)</td>
<td>43</td>
<td>10.28 (&lt;.01)</td>
</tr>
<tr>
<td>Taking medications</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Taking</td>
<td>9 (16.1%)</td>
<td>33 (58.9%)</td>
<td>14 (25.0%)</td>
<td>56</td>
<td></td>
</tr>
<tr>
<td>Taking</td>
<td>18 (43.9%)</td>
<td>14 (34.1%)</td>
<td>9 (22.0%)</td>
<td>41</td>
<td>9.68 (&lt;.01)</td>
</tr>
<tr>
<td>Educational assistant</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Part-time or none</td>
<td>10 (16.9%)</td>
<td>27 (45.8%)</td>
<td>22 (37.3%)</td>
<td>59</td>
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<tr>
<td>Full-time</td>
<td>17 (44.7%)</td>
<td>20 (52.6%)</td>
<td>1 (2.6%)</td>
<td>38</td>
<td>18.34 (&lt;.01)</td>
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<tr>
<td>Employment status</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Did not make changes</td>
<td>4 (11.4%)</td>
<td>18 (51.4%)</td>
<td>13 (37.1%)</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Made changes</td>
<td>23 (37.1%)</td>
<td>29 (46.8%)</td>
<td>10 (16.1%)</td>
<td>62</td>
<td>9.56 (&lt;.01)</td>
</tr>
<tr>
<td>Impact on family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>1 (3.0%)</td>
<td>18 (54.5%)</td>
<td>14 (42.4%)</td>
<td>33</td>
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</tr>
<tr>
<td>Moderate</td>
<td>9 (29.0%)</td>
<td>16 (51.6%)</td>
<td>6 (19.4%)</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>17 (51.5%)</td>
<td>13 (39.4%)</td>
<td>3 (9.1%)</td>
<td>33</td>
<td>22.93 (&lt;.01)</td>
</tr>
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</table>

* Where expected cell counts are less than 5, Fisher’s exact test was used.

b PDD-NOS = Pervasive Developmental Disorder-Not Otherwise Specified.
Table 3. Association of Child and Parent Characteristics with Perceived Unmet Need (N = 97)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unmet needsa</th>
<th>RR</th>
<th>95% CI</th>
<th>RR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Functional independence</strong></td>
<td>Low</td>
<td>.78</td>
<td>1.17</td>
<td>1.02-1.33</td>
<td>1.16</td>
</tr>
<tr>
<td></td>
<td>Moderate (referent)</td>
<td>.66</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>High</td>
<td>.55</td>
<td>0.83</td>
<td>0.68-1.02</td>
<td><strong>0.81</strong></td>
</tr>
<tr>
<td><strong>Diagnosis on the autism spectrum</strong></td>
<td>Autism (referent)</td>
<td>.65</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>PDD-NOSb</td>
<td>.75</td>
<td>1.14</td>
<td>0.91-1.43</td>
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<tr>
<td></td>
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<td>Autism spectrum disorder</td>
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<td>1.06</td>
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<td><strong>Gender</strong></td>
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<td>.76</td>
<td>---</td>
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<tr>
<td></td>
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<td>.66</td>
<td>0.87</td>
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<tr>
<td><strong>Grade level</strong></td>
<td>Primary (grades 1-3) (referent)</td>
<td>.64</td>
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<tr>
<td></td>
<td>Junior/Intermediate (grades 4-8)</td>
<td>.71</td>
<td>1.11</td>
<td>0.97-1.28</td>
<td><strong>1.14</strong></td>
</tr>
<tr>
<td><strong>Time since diagnosis</strong></td>
<td>Diagnosed &gt; 3 years ago (referent)</td>
<td>.62</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>Diagnosed &lt; 3 years ago</td>
<td>.69</td>
<td>0.89</td>
<td>0.75-1.06</td>
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<tr>
<td><strong>Comorbid conditions</strong></td>
<td>None (referent)</td>
<td>.63</td>
<td>---</td>
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<td></td>
<td>One or more</td>
<td>.73</td>
<td><strong>1.16</strong></td>
<td><strong>1.02-1.33</strong></td>
<td>---</td>
</tr>
<tr>
<td><strong>Taking medication</strong></td>
<td>Not taking (referent)</td>
<td>.65</td>
<td>---</td>
<td>---</td>
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</tr>
<tr>
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<td>.71</td>
<td>1.09</td>
<td>0.95-1.25</td>
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<td><strong>Educational assistant</strong></td>
<td>Part-time or none (referent)</td>
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<tr>
<td></td>
<td>Full-time</td>
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<td>0.94-1.26</td>
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<td>College degree</td>
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<td>1.06</td>
<td>0.89-1.24</td>
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<td>High school or less</td>
<td>.66</td>
<td>1.01</td>
<td>0.84-1.21</td>
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<tr>
<td><strong>Family income</strong></td>
<td>$85,000 or more (referent)</td>
<td>.66</td>
<td>---</td>
<td>---</td>
<td>---</td>
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<tr>
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<td>$45,000 to less than $85,000</td>
<td>.73</td>
<td>1.10</td>
<td>0.95-1.29</td>
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<td>Less than $45,000</td>
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<td>0.88</td>
<td>0.71-1.08</td>
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<td>Marital status</td>
<td>Unmet needs&lt;sup&gt;a&lt;/sup&gt;</td>
<td>RR</td>
<td>95% CI</td>
<td>RR</td>
<td>95% CI</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>--------------------------</td>
<td>------</td>
<td>----------</td>
<td>------</td>
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<td>Married (referent)</td>
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<td>Divorced, widowed, or single</td>
<td>0.68</td>
<td>1.01</td>
<td>0.85-1.21</td>
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<td>Employment status</td>
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</tr>
<tr>
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</tr>
<tr>
<td>Made changes</td>
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<td>1.15</td>
<td>0.98-1.34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of children with a disability</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 child with disability (referent)</td>
<td>0.66</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>&gt; 1 child with a disability</td>
<td>0.71</td>
<td>1.08</td>
<td>0.93-1.27</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Region</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Ontario (referent)</td>
<td>0.65</td>
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<td>---</td>
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</tr>
<tr>
<td>Manitoba</td>
<td>0.72</td>
<td>1.12</td>
<td>0.91-1.38</td>
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<tr>
<td>Prince Edward Island</td>
<td>0.73</td>
<td>1.13</td>
<td>0.93-1.39</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newfoundland and Labrador</td>
<td>0.66</td>
<td>1.01</td>
<td>0.86-1.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban (referent)</td>
<td>0.68</td>
<td>---</td>
<td>---</td>
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<td>---</td>
</tr>
<tr>
<td>Rural</td>
<td>0.65</td>
<td>0.95</td>
<td>0.81-1.10</td>
<td></td>
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</tr>
</tbody>
</table>

<sup>a</sup> Unmet needs = proportion of unmet needs (i.e., number of important needs which are unmet divided by total number of important needs).

<sup>b</sup> PDD-NOS = Pervasive Developmental Disorder-Not Otherwise Specified.
The unadjusted association between functional independence and perceived unmet need showed that, compared to families of children with moderate functional independence, families of children with high functional independence experienced reduced risk for unmet need ($RR = 0.83$, 95% CI = 0.68-1.02). However, this association did not reach statistical significance. In contrast, families of children with low functional independence were at a significantly increased risk for unmet need compared to families of children with moderate functional independence ($RR = 1.17$, 95% CI = 1.02-1.33).

Variables with a statistically significant association with either functional independence or perceived unmet need ($p < .10$) were tested in the regression analysis. In the adjusted model, variables were deleted one at a time, starting with the least statistically significant, in the following order: (1) the child’s use of medication for attention or behaviour problems, (2) changes the parent made to employment as a result of caring for a child with an ASD, (3) the child’s ASD diagnosis, (4) the child’s gender, and (5) the presence of comorbid conditions in the child. The final model included functional independence and grade level (junior/intermediate [grades 4 through 8] versus primary [grades 1 through 3]). While controlling for grade level, families of children with low functional independence had a significantly increased risk for unmet need compared to families of children with moderate functional independence ($RR = 1.16$, 95% CI = 1.02-1.32). Moreover, families of children with high functional independence had a significantly reduced risk for unmet need compared to families of children with moderate functional independence ($RR = 0.81$, 95% CI = 0.67-0.99).

In order to test impact on family as an effect modifier on the relationship between functional independence and perceived unmet need, the stratified model was examined,
again controlling for grade level. (Refer to Table 4.) While the relationship between functional independence and perceived unmet need appeared to be similar for families who experienced a low or moderate impact compared to the non-stratified model, the situation was different among families who perceived high impact. Specifically, in this group, families of children with high functional independence appeared to experience greater risk for unmet need compared to families of children with moderate functional independence (RR = 1.22, 95% CI = 1.03-1.45). The comparison between low and moderate functional independence did not reach statistical significance in this stratum.

Table 4. Stratified Analysis of the Impact of the Child’s Disability on the Family (N = 97)

| Impact on Family | Functional Independence | Unadjusted Model | | Adjusted Model |
|-----------------|-------------------------|-----------------|-----------------|
|                 | Unmet needs<sup>a</sup> | RR | 95% CI | RR | 95% CI |
| Low             | Low                     | .69 | 1.13 | 0.51-2.49 | 1.49 | 0.65-3.44 |
|                 | Moderate (ref)          | .61 | --- | --- | --- | --- |
|                 | High                    | .39 | 0.65 | 0.42-1.00 | **0.64** | **0.43-0.96** |
| Moderate        | Low                     | .76 | 1.12 | 0.93-1.35 | 1.13 | 0.94-1.36 |
|                 | Moderate (ref)          | .67 | --- | --- | --- | --- |
|                 | High                    | .65 | 0.96 | 0.75-1.22 | 0.95 | 0.74-1.22 |
| High            | Low                     | .79 | 1.09 | 0.94-1.27 | 1.06 | 0.91-1.23 |
|                 | Moderate (ref)          | .72 | --- | --- | --- | --- |
|                 | High                    | **.95** | **1.29** | **.11-1.49** | **1.22** | **1.03-1.45** |

<sup>a</sup> Unmet needs = proportion of unmet need (i.e., number of important needs which are unmet divided by total number of important needs).

<sup>b</sup> Adjusted analysis controls for grade level only, as in Table 3.

The possible mediating influence of educational assistant use was explored next in a non-stratified model. The first two criteria for mediation were met (i.e., low functional independence was significantly associated with perceived unmet need and use of an educational assistant). However, the third criterion was not met; use of an
educational assistant was not significantly associated with perceived unmet need once functional independence was controlled for (RR = 1.01, 95% CI = 0.88-1.15). Sobel’s test was therefore not conducted.

Discussion

Summary of Main Findings

We hypothesized that families of children with high and low functional independence would report greater perceived unmet need than families of children with moderate functional independence, but for different reasons (i.e., failure to meet eligibility criteria for high functional independence vs. overwhelming support needs for low functional independence). This hypothesis was based on an understanding of the Canadian system of autism services (Madore, 2006) as well as anecdotal evidence from previous discussions with families of school-aged children with ASD. Contrary to our hypothesis, however, in the non-stratified model, there appeared to be a linear relationship between functional independence and perceived unmet need.

However, conclusions regarding this relationship cannot be drawn without considering the analysis in which the model was stratified by the impact of the child’s disability on the family unit. Consistent with our second hypothesis, the relationship between the child’s functional independence and the parent’s perceived unmet need appeared to change depending on the extent to which the parent perceived the child’s disability to be a burden on the family. Specifically, among families who experienced a high level of impact, those who had a child with high functional independence actually had an increased risk for unmet need compared to those with a child with moderate functional independence. This finding is consistent with previous literature showing that
families cope with disability in different ways (McConachie, 1994; Stein & Riessman, 1980).

In contrast with our third hypothesis, use of an educational assistant did not explain the relationship between functional independence and perceived unmet need. The use of an educational assistant was chosen to represent service receipt because this is a publicly available resource that is provided to children based on their identified needs in the classroom. It was thought to be the clearest example of the process by which functional independence may influence perceived unmet need, since it is not complicated by other issues of access such as parents’ income or proximity to services. It is possible that a more complex model needs to be devised and that other forms of service use need to be considered in representing service use as a mediator.

**Methodological Strengths**

Although previous studies have identified characteristics that are associated with parents’ perceived unmet needs (Ellis et al., 2002; Granlund & Roll-Pettersson, 2001; Kogan et al., 2008; Siklos & Kerns, 2006), to our knowledge, this is the first to examine these factors systematically in a conceptual framework. Planning for comprehensive services is held back by our limited understanding of the characteristics associated with greater unmet need among families of children with ASD. By using clinical judgment to choose which factors to measure and by exploring interactions between specific factors, it is possible to identify subgroups of families who are at increased risk for unmet need and who may require increased support. We did this by exploring the interaction between the child’s level of functional independence and the impact of the child’s disability on the family rather than only examining their separate influences on perceived unmet need.
Limitations

Due to the low response rate, several sources of sampling bias were considered. To evaluate potential selection bias, children whose families were invited to participate were compared with children of non-invitees from the underlying population (Brown et al., submitted). The two groups were similar in terms of gender ratio. However, children of invitees were slightly younger than those of non-invitees, and sampling regions were not proportionally represented. The younger age of children of invitees may be related to research fatigue among families of older children. In our sample, families of older children (grades 4-8) appeared to have a greater risk for unmet need than families of younger children (grades 1-3), possibly because of the continued loss of early intervention services later into the school years. Therefore, had invitees been slightly older, the overall burden of unmet need in the sample may have been somewhat greater. The non-representativeness of the regions under study is not surprising given that, due to logistical complications, it was only possible to invite a small number of participants from Manitoba compared to the other regions. Because of this, no regional comparisons of unmet need were made.

Among invitees, children of participants were previously compared with children of non-participants in order to determine whether non-response bias affected the results (Brown et al., submitted). There were no statistically significant differences between the two groups on the basis of regional representation or the child’s gender, age, or diagnosis on the autism spectrum. However, it is not possible to determine whether participants differed from non-participants in other ways. For instance, this demographic comparison does not provide an indication of whether parents with high unmet need were more or
less likely to participate. Therefore, caution should be used in considering the
generalizability of the current results, and future studies should aim to replicate this study
with a larger sample.

Implications and Recommendations

Concern about the welfare of children with ASD has been expressed by
government bodies across Canada (Standing Senate Committee on Social Affairs,
Science, and Technology, 2007), the United States (National Research Council, 2001),
and the United Kingdom (All-Party Parliamentary Group on Autism, 2007). This is in
part due to the apparent increase in the prevalence of ASD (Blaxill, 2004). While there is
controversy around whether this trend is due to an increase in awareness, changes in
diagnostic practices, or a true increase in ASD (Fombonne, 2005), the heightened
demand for autism services is clear (Ruble, Hefflinger, Renfrew, & Saunders, 2005). The
resulting strain on the service system has led to an interest in issues of unmet need.

This study demonstrates how the child’s functional independence and the way it is
perceived by parents to impact the family unit can have an effect on parents’ perceived
unmet needs. Families who have difficulty coping with their child’s disability may feel
the burden of unmet need more acutely when the child is nearly independent and is not
receiving the support necessary to fully participate with typical peers in educational,
social, and other activities. This finding adds some evidence to our original hypothesis of
a non-linear relationship between functional independence and perceived unmet need.
However, the finding is more nuanced and points to the possibility of subgroups of
families who may have greater unmet need. Assumptions may be made about the needs
of a child and his or her family on the basis of the child’s diagnosis on the autism
spectrum. However, our findings demonstrate that a more useful indicator of family burden is a functional assessment of the child as well as how the family is dealing with the child’s disability. This finding may signal a need to devote extra resources to these families or to adjust how eligibility criteria for services and supports are devised so that they involve determining how the child and the family are functioning.

This study generates potential research questions which could be answered by future studies. In our analyses, we only examined the overall burden of unmet need and did not analyze whether the types of unmet needs identified differ depending on the child’s functional independence. Future research should consider the possibility that the types of needs that families identify may differ depending on the functional independence of the child. For example, families of children with high functional independence may experience unmet needs for recreational activities or social engagement, while families of children with low functional independence may experience unmet needs for respite or professional support. Furthermore, we did not explore the association between parent and child characteristics and specific unmet needs (e.g., need for financial support). It would be interesting to determine whether the types of characteristics which are associated with unmet need differ depending on the specific need or area of need under study.

Conclusion

The child’s level of functioning and its impact on the family provide insight into parents’ perceived unmet need. Information on high-risk subgroups of families may better enable service providers to devote resources to those families who need extra help to support their child with ASD.
References


Author Note

We gratefully acknowledge the parents who participated in this study. This work was supported by a trainee stipend with the Canadian Institutes of Health Research/Autism Speaks STIHR Autism Spectrum Interdisciplinary Research (ASPIRE) Training Program (J. J. A. Holden), an Autism Ontario Stimulus Grant, and the Frederick Banting and Charles Best Canada Graduate Scholarships Master’s Award.
Chapter 5: General Discussion

Summary of Key Findings

The three manuscripts of this thesis were devised to systematically create and test a framework for exploring the unmet needs of families of school-aged children with an autism spectrum disorder (ASD). Manuscript One aimed to review the literature surrounding needs assessments in this area, specifically those studies which used either a service use or a perceived needs approach. Because there is no universal approach to the treatment of autism symptoms in school-aged children with ASD (Simpson, 2005), it was concluded that service use studies may not adequately capture the unmet need experienced by families. Instead, measures of unmet need should address issues in the process of accessing care as well as gaps in the provision of support from the perspective of the family. A method which examines parents’ perceived unmet needs was recommended, and a framework—which incorporates characteristics thought to influence these needs—was presented.

Manuscripts Two and Three utilized data which were collected specifically for this thesis through a cross-sectional survey of 101 parents of school-aged children with ASD. The objective of Manuscript Two was to describe the types of unmet needs identified by these parents. From the data, it was concluded that there were three main areas of unmet need. These were unmet needs for social inclusion for the child, information about special programs and services, and continuous service receipt, rather than service receipt only in times of crisis.

Finally, the objective of Manuscript Three was to examine the association between children’s level of functional independence and parents’ level of perceived
unmet need. The main result of this analysis showed that the impact of the child’s disability on the family unit moderates this relationship. Specifically, when impact was not taken into account, families of children with low functional independence had greater unmet need and families of children with high functional independence had lower unmet need compared to families of children with moderate functional independence. However, among families who perceived a high level of impact of the child’s disability on the family, families of children with high functional independence actually had greater unmet need than those of children with moderate functional independence.

General Strengths

A major strength of this study is the way in which unmet need was examined. First, while previous studies have not taken into account the relevance of needs to the families (Farmer, Marien, Clark, Sherman, & Selva, 2004; Sloper & Turner, 1992), the Family Needs Questionnaire (Siklos & Kerns, 2006) incorporates an “importance” rating in addition to the “unmet” rating. In a resource-limited system, it is important for planners to prioritize which unmet needs are addressed. The inclusion of the importance rating aids in the interpretation of results and in the translation of findings into recommendations.

Second, although previous research has examined characteristics associated with unmet need among families of children with ASD (for example: Ellis et al., 2002; Kogan et al., 2008), a conceptual framework with which to study the relationships among these characteristics has not been devised. Using a conceptual framework allowed for the exploration of interactions among specific variables (e.g., functional independence and impact on family). These investigations were informed by the literature and by clinical
judgement and made it possible to generate testable hypotheses regarding the relationships among variables. It was therefore possible to identify subgroups of families who may be at increased risk for unmet need and who may require increased support in order to meet their needs. Based on the findings of the current study, modifications to the conceptual framework (e.g., different conceptualization of service use for the mediator component) may be necessary. However, this thesis initiates the process of thinking critically about characteristics thought to affect parents’ perceived unmet needs and of considering these variables in a clinically relevant manner.

General Limitations

The most important limitation to this study is the low response rate of 20.2%. Although it should be noted that response rates in this range are typical for studies of individuals with developmental disabilities, including ASD (Siklos & Kerns, 2006), caution must be used when interpreting the findings of the study. Unlike most studies, it was possible to compare children in the current sample with the underlying population (i.e., children of invitees versus children of non-invitees and children of participants versus children of non-participants). As described in Manuscripts Two and Three, children of invitees were significantly younger than children of non-invitees, and regional representation was non-proportional. However, among invitees, there were no significant differences between participants and non-participants in terms of regional representation or the child’s age, gender, or ASD diagnosis. It was not possible to compare the current sample with the underlying population on the basis of other important variables, such as perceived unmet need. Therefore, considering the small proportion of families who participated in this study, caution must be used in generalizing the current results to the
population as a whole. Future studies should aim to replicate these findings using a larger sample in order to make stronger conclusions that may be used confidently for policy and service planning.

Another implication of the small sample size is a potential lack of power to detect significant differences. Although an a priori power calculation was completed based on an assumed sample size of 100 participants, it is possible that this study did not have the power to incorporate a large number of potential confounding variables in the regression analysis. Variables such as the presence of comorbid conditions in the child or changes made by the parent to employment status were not significant in the regression model, a finding that is somewhat surprising given previous literature (Ellis et al., 2002; Kogan et al., 2008). Before dismissing these variables as important factors in the relationship between functional independence and perceived unmet need, tests of this model should be carried out utilizing a larger sample.

Another limitation of this study was the inability, because of small sample sizes and non-proportional representation of regions, to make geographic comparisons among Manitoba, South Eastern Ontario, Prince Edward Island, and Newfoundland and Labrador. It should be acknowledged that differing service delivery systems and funding availabilities in each region (Madore, 2006) result in differing service access and use. In turn, this differential service use may affect parents’ perceptions of unmet need. Although no relationship between region and perceived unmet need was found in the current study, this may have been due to inadequate power to detect a significant difference. Therefore, the association between region of residence and parents’ perceived unmet needs should be explored in future large-scale studies.
Implications

The findings of Manuscript Two suggest that more can be done by service providers to ensure that families of school-aged children with ASD receive the support that they need. Information about services and other resources should be delivered to families in a more active manner. As the most common service providers for school-aged children, the family physician and the school could play a central role in this. Moreover, parents’ perceived unmet need for social inclusion for their child could be addressed by the school not only by encouraging the development of supported extra-curricular activities for children with ASD but also by fostering an environment of acceptance and understanding in the classroom. Finally, placing families in contact with a case manager or other key worker may increase families’ feelings of ongoing—rather than fragmented—support.

The results of the regression analyses suggest that the child’s level of functioning, as well as the way in which the child’s disability impacts the family, help to identify subgroups of families who are at high risk for unmet need. Future studies should replicate these findings in a larger sample. However, the current study demonstrates that service providers should consider incorporating measures of child and family functioning when determining eligibility for services. These characteristics may provide insight into unmet need that is not revealed simply by knowing a child’s diagnosis on the autism spectrum.

Suggestions for Future Studies

Considering the findings of this thesis, potential questions for future research are generated. For example, there are a large number of needs described by the Family Needs Questionnaire which could be explored. In Manuscript Two, the discussions were limited
to those needs which had high ratings of importance and which were reported by most parents as being unmet. However, it is also useful to look at needs which parents rate as unimportant. For instance, parent-specific needs, such as counselling for the parent and his or her partner, were given low ratings of importance. This suggests, not surprisingly, that parents put the needs of their child before their own needs. However, given the extensive literature on stress and mental health problems in parents of children with ASD (for example: Bromley, Hare, Davison, & Emerson, 2004), service providers should be reminded of the importance of supporting parental needs in addition to child needs. Future studies should examine ways in which parental needs can be addressed by the service system.

As well, the finding of the association between perceived unmet need and the interaction between child functioning and parents’ perceptions of the impact of the child’s disability raises the question of how exactly ASD impacts the family. In Manuscripts Two and Three, more than 65% of parents reported making changes to their employment status in order to care for their child with ASD. Unfortunately, it was not possible to probe further into the specifics of this finding. For example, it is likely that some parents cut work hours in order to act as a caregiver in the home, while others increase work hours in order to fund therapies. Nevertheless, the high percentage of parents who reported making changes to employment underscores the impact of ASD on the family unit. Future studies could explore the way in which parenting a child with ASD impacts the family in terms of income losses (through increased service costs or decreased work hours) and time strain (through increased work hours or increased caregiving hours).
Conclusions

Concern about the welfare of families of children with ASD has been expressed at the policy level in several countries, including Canada (Standing Senate Committee on Social Affairs, Science, and Technology, 2007), the United States (National Research Council, 2001), and the United Kingdom (All-Party Parliamentary Group on Autism, 2007). This thesis addresses the resulting requirement for information about the unmet needs of families of school-aged children with ASD and about characteristics associated with these unmet needs. Such information may be useful to policy makers and service planners in prioritizing the improvement of the system of supports for families of school-aged children with ASD.
References


Appendix A

Flowchart of Recruitment and Study Implementation
Eligible to participate (N = 1,683)¹

Invited to receive information about study (N = 499)²

No response or refused to receive information (N = 324)

Agreed to receive information (N = 175)

Did not return questionnaire & consent form (N = 96)

Returned questionnaire & consent form (N = 79)

Sent reminder (N = 96)

Lost to follow-up (N = 74)

Returned questionnaire & consent form following reminder (N = 22)

Total completed questionnaire (Total for Manuscript Two: N = 101)³

Did not complete telephone interview (N = 4)

Total completed telephone interview (Total for Manuscript Three: N = 97)
Figure Footnotes

1 Total eligible to participate includes $n = 1,592$ NEDSAC, $n = 64$ NEDSAC/ASD-CARC, and $n = 27$ ASD-CARC

2 Total invited to participate includes $n = 408$ NEDSAC, $n = 64$ NEDSAC/ASD-CARC, and $n = 27$ ASD-CARC

3 Total participated (returned questionnaire and consent form) includes $n = 85$ NEDSAC, $n = 11$ NEDSAC/ASD-CARC, and $n = 5$ ASD-CARC
Appendix B

Example Consent Form for NEDSAC Recruitment*

*Section pertinent to thesis highlighted
National Epidemiologic Database for the Study of Autism in Canada (NEDSAC): Consent Form

I have read the information describing the above project and understand what is required of my participation. I understand that the information from this project will be entered into a national database to help researchers better understand the occurrence of autism spectrum disorders in Canada, and to help identify possible variations among regions and over time. I understand that if I choose not to participate, the services and supports our family receives will not be affected in any way. My child does not object to my participation in this study. A copy of this consent form will be signed by the project coordinator and returned to me.

If you are interested in participating, please place a check mark in the box to the left of those items to which you consent (you do not need to consent to all items in order to participate). Mail this consent form back to us in the envelope provided. (If you have more than one child with an autism spectrum disorder, please complete and send back all attached consent forms.) Keep the preceding letter for your records. A member of the NEDSAC project team will be contacting you by telephone within the next four weeks to collect the information for the database.

☐ I agree to be contacted by a member of the NEDSAC project team and to have the information I provide to them included in the National Epidemiologic Database for the Study of Autism in Canada.

☐ I agree to be contacted by a member of the NEDSAC project team every 12 months until my child reaches the age of 15 or until termination of the study to ensure that all demographic and diagnostic information in the National Epidemiologic Database for the Study of Autism in Canada is kept up-to-date. (I understand that if at any time I no longer wish to provide information to update the database, I can inform the NEDSAC project team of this decision and I will not be contacted again.)

Our group is also conducting other studies related to children with autism spectrum disorders. Please indicate, by putting a check mark in the appropriate box, whether you would like to receive information about the following studies. By checking the box, you are not agreeing to participate in the study; you are only agreeing to receive information about it.

☐ I would like to receive information about a study to evaluate the performance of several parent and teacher questionnaires for pervasive developmental disorders in children 2 to 12 years of age.

☐ I would like to receive information about a study to examine unmet needs in families of school aged children with autism spectrum disorders.

Name of parent/legal guardian (please print):________________________________________

Mailing address:_______________________________________________________________

Email: _________________________________________________________________

Telephone number (please include the area code):_____________________________

What is the best time to contact you by telephone? ____________________________

Signature of parent/legal guardian: ___________________________ Date:______________

Signature of project coordinator: ___________________________ Date:______________
Appendix C

Example Interview Script for NEDSAC Recruitment

*Section pertinent to thesis highlighted
Telephone Interview Guide: NEDSAC Information/Status Update Form

In this guide, interviewer’s script is bolded and instructions to the interviewer are italicized. Script/instructions that appear in boxes are only used under certain conditions (explained in box).

Have a copy of the NEDSAC Information/Status Update form ready, the DDI form that was initially completed, and the consent form. Do not fill in anything on the Update form yet; if no information has changed, there is no need to complete this form.

Hello. May I please speak to [name of person on consent form].

If person is available:

This is [interviewer’s first and last name] calling from the National Epidemiologic Database for the Study of Autism in Canada Project. I’m calling to update the information that you provided us with last year. It should take no more than 10 minutes. Would this be a convenient time for you to answer a few questions?

If person says no, ask them for a convenient time to call back, and record this on the consent form. Otherwise, complete the interview as follows.

Could I get your child’s name again? I know you gave it to me last year, but we don’t record it anywhere for confidentiality reasons. If person wants to know why you need to know the child’s name, say it is only for the purposes of the telephone interview.

First check the status of the child on DDI form.

Is [name] still [# 77 status on DDI form] at [agency]?

If the status is the same, do not enter anything on Update form. Otherwise, tick off “No longer on waiting list; not being actively served by agency” or “Discharged” under A. Information/Status Update.

If discharged:

Could you tell me the date they were discharged, and the reason?

Has your child’s name been legally changed since we talked with you last?
If yes, tick off “Initializing Information Update” under A. Information/Status Update.
Ask for the new name, and record the agency number (eg. ON001) followed by the first two initials of the last name and the first two initials of the legal first name, in New Agency Code under C. Initializing Information Update.

If last 3 digits of health card number were provided on DDI form:

Has [name]’s health card number changed?

If yes, tick off “Initializing information update” under A. Information/Status Update. Ask for the last 3 digits of the new health card number and enter them under C. Initializing Information Update.

Does [name] still have [number of siblings given in #2 on DDI form]?

If no, tick off Sibling information update under A. Information/Status Update, and ask how many full or half brothers and sisters the child now has. Enter the number in #2 under D. Sibling Information Update.

How many of these biological siblings are older?

(Must ask & update on update form: new information that was not on old version of DDI form; under D. Sibling Information Update, # 3-9) If there are older siblings, ask how many of these older siblings have been diagnosed with confirmed or suspected Autism Spectrum Disorder, or check unknown if unknown.

How many of these biological siblings are younger?

(Must ask & update on update form: new information that was not on old version of DDI form; under D. Sibling Information Update, # 3-9) If there are younger siblings, ask how many of these younger siblings have been diagnosed with confirmed or suspected Autism Spectrum Disorder, or check “unknown” if unknown.
If the child is a member of a multiple birth and the number of siblings who have been diagnosed with ASD has changed:

You indicated that [name] was a [type of multiple birth].

If multiple birth sibling previously diagnosed, ask:

Does [twin or triplet] still have a confirmed or suspected autism spectrum disorder diagnosis?

If multiple birth sibling not previously diagnosed, ask:

Since we last spoke, has [twin or triplet] been diagnosed a confirmed or suspected autism spectrum disorder?

If yes, enter number diagnosed in #9-10.

Are the first 3 digits of your postal code still [1st 3 digits of postal code on DDI form]?

If no, tick off Demographic information update under A. Information/Status Update, and ask for the first 3 digits of new postal code. Enter under E. Demographic Information Update. Ask and record the date that family moved.

For Southeastern Ontario residents who have moved:

What county is that?

Has [name] been diagnosed with ASD by another person or team since I last spoke with you on [date last interviewed; if first annual update this would be the date shown on the DDI form; if not, date of last annual update which should be recorded in NEDSAC Consent database]?

If yes, tick off Diagnostic information update under A. Information/Status Update and go to box below. If no, confirm that the child’s current diagnosis is [diagnosis listed under #31 on DDI form]. If it isn’t, check that the child still has a diagnosis of ASD. If not, enter the date they were confirmed as non-ASD under F. Diagnostic Information Update.
If child has been diagnosed since last interview:

What is the current diagnosis?

Read off list under “Diagnosis” in F. Diagnostic Information Update. If person is unsure about the specific diagnosis, tick off “ASD/PDD (general diagnosis)”.

Could you tell me who made the diagnosis?

Read off list under “Diagnosing professional(s)”. Tick off all that apply.

Do you know what tests and/or criteria were used to make the diagnosis?

Read off list under “Tests/criteria used to make diagnosis”. Tick off all that apply. Only list tests specifically used to screen for or diagnose ASD under “Other, please specify”. Do not list tests used to assess developmental delay (eg. Vineland Adaptive Behavior Scale). If the latter are the only tests mentioned by the person being interviewed, tick off “unknown”. If you are unsure whether the test is used to screen/diagnose autism, enter the name of the test under “Other, please specify” and verify before entering in NEDSAC.

Where was [name] living when this diagnosis was made?

(Must ask & update on update form: new information that was not on old version of DDI form; under F. Diagnostic Information Update # 26) Specify city, province, and country if not Canada.

Do you remember the date that this diagnosis was made?

Enter date in full, eg. October 5, 1999 under “Date of diagnosis”. If person doesn’t remember month and year of diagnosis, ask if they remember the age at which the child was diagnosed. Enter the answer under “Age at diagnosis”.

For [name] original diagnosis made in [refer to DDI form for date], where were you living when this diagnosis was made?

Specify city, province, and country if not Canada. [PLEASE WRITE ON ORIGINAL DDI FORM IN RED]

We will soon be doing a study that will look at unmet needs in families of school-aged children with autism spectrum disorders. Would you like us to send you information about this study? Receiving information does not mean you need to participate.

If yes, Thank you. We will send you an information package. If no, proceed to next section.
Ending the Interview

Thank you very much for your help. We'll be contacting you again next year to update this information. Is there anything you would like to ask before we end the interview?

If yes, answer questions. If no, tell person that they can call contact number listed in information letter at any time if they have questions.

Thank you again, and goodbye.

If any of the Information/Status Update Form has been filled in, enter the Agency Code shown on the DDI form in the top left of the Information/Status Update Form, and complete Section A. Initializing Information. Fill in the NEDSAC ID in the top right corner. Fill in Date interviewed in Section G of the Information/Status Update form. File until ready to update record in NEDSAC, at which time the date the record was updated should also be entered in Section G. If none of the information has changed there is no need to enter anything on the Information/Status Update form.

In the NEDSAC Consent database, record the date of the update interview.
Appendix D

Email for ASD-CARC Recruitment
Dear parent,

ASD-CARC is conducting a study to investigate needs identified by parents who have an elementary school-aged child with an autism spectrum disorder. We hope to gain an understanding of the types of needs that are important to parents, and whether or not these needs have been met adequately. We are also looking at the barriers faced by families when they try to access services and supports. By examining several child and parent characteristics, we hope to identify the types of families who may be at higher risk for having unmet needs.

Can I participate?
You are eligible to participate if your child has an autism spectrum disorder and was born between 1996 and 2003 (inclusive).

If I participate, what do I have to do?
We are asking parents to provide us with information about their needs, their service use, and several parent and child characteristics. If you agree to participate, you will be sent a written questionnaire, which takes approximately 30 minutes to complete. Once you return the questionnaire, you will be contacted by telephone at a time that is convenient for you in order to complete a telephone interview. This will take approximately 20 minutes.

We will also be asking for your permission to note your participation in this study in the ASD-CARC research registry. ASD-CARC is planning to conduct a longitudinal study of family needs. Noting your involvement in the Research Registry will allow ASD-CARC to contact you in order for you to provide an update about your needs. However, participating in the current study does not mean you have to participate in a follow-up.

What are the benefits and risks?
There are no direct benefits to participating. However, we hope that information from this study will help service planners and providers to ensure that adequate services are available to families of children with an autism spectrum disorder. Results will be provided to various autism societies in Canada, including Autism Ontario and Autism Society Canada.

The risks to participating are minimal. All the information you provide us will be anonymous and will be stored in a secure area. Your answers will not affect the services that you receive in any way.

How can I get involved?
If you would like to participate or if you have any questions about the study, please email Hilary Brown (the study coordinator) at nedsac@queensu.ca. She will be happy to send you a study package once she has your mailing address.

You may also contact us by telephone if you have any questions: Hilary Brown (613-548-4417, ext. 1207) or Hélène Ouellette-Kuntz (613-548-4417, ext. 1198).
Appendix E

Information and Consent Form for South Eastern Ontario Participants
EXAMINING THE NEEDS OF FAMILIES OF ELEMENTARY SCHOOL-AGED CHILDREN WITH AUTISM
INFORMATION LETTER & CONSENT FORM

Introduction

Queen’s University is conducting a study to investigate unmet needs identified by parents who have an elementary school-aged child with an autism spectrum disorder. Funding has been provided by Autism Ontario and by the Canadian Institutes of Health Research.

What is the purpose of this project?

Our goal is to gain an understanding of the types of needs that are important to parents who have a child with autism. We hope to determine whether or not these needs have been met adequately. We are also looking at the barriers faced by families when they try to access services and supports. By examining several child and parent characteristics, we hope to identify the types of families who may be at higher risk for having unmet needs.

Can I participate?

You are eligible to participate if your child has a diagnosis of autism (i.e. autistic disorder, pervasive developmental disorder-not otherwise specified, Asperger’s disorder, or autism spectrum disorder) and is between the ages of six and thirteen, as of January 1, 2009.

If I participate, what do I have to do?

We are asking families to provide us with information about their needs, their service use, and several parent and child characteristics. The written questionnaire is enclosed in this package. It should take about 30 minutes to complete. If you consent to participate in this project, please mail back the signed consent form in the small white envelope provided. Please mail the completed questionnaire in the large brown envelope provided. Once the consent form and questionnaire are returned, we will contact you to complete the telephone interview. A list of things we will ask about in the telephone interview is given on page 2. This interview will take approximately 20 minutes to complete. Since some of the questions concern your child, we encourage you to discuss this project with him/her and respect his/her wishes.

What are the benefits of participation?

There are no direct benefits to participation. However, we hope that information from this study will help service planners and providers to ensure that adequate services are available to families of children with an autism spectrum disorder.
**What are the risks of participation?**

The risks of participating are minimal. All of the information that you provide us will be anonymous and will be stored in a secure area. Your answers will not affect the services that you receive in any way.

**What about confidentiality?**

All information you provide will remain confidential. Once the information has been received from you, it will be entered into a secure database. All individuals who participate are assigned a unique identifier so that no names appear on the forms used to collect information from families, nor are any names entered in the database. Findings will be reported in grouped form so that individuals cannot be identified. The master list linking names and unique identifiers, as well as the forms used to collect information from families, are stored in locked filing cabinets located in a locked room in a secure building in Kingston, Ontario, accessible only to members of the research team. The master list is stored in a separate filing cabinet from the forms used to collect information from families. At the end of the study, all forms related to the project (including data collection forms and consent forms) will be shredded.

**What are my rights if I choose to participate?**

If you decide to participate and then at a later date decide that you no longer wish to participate, you may inform the project director or the project coordinator (see next page for names and contact information), and you will not be contacted further. If at some point you wish to have your child’s information removed from the database, you may contact the project director or the project coordinator and your child’s record will be deleted from the database.

**Information that we collect during the telephone interview**

- [ ] Your child’s everyday skills
- [ ] Problem behaviours that your child may have
- [ ] The services you are receiving, how often you receive these services, and how adequate you think they are

This should take you 20 minutes.
Who do I contact if I have questions or concerns?

Please feel free to contact us with any questions or concerns you may have. We would be glad to help you in any way we can. The contact persons are:

Hélène Ouellette-Kuntz, Project Director
National Epidemiologic Database for the Study of Autism in Canada
Associate Professor, Department of Community Health & Epidemiology
Queen's University
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON  K7M 8A6
oullette@queensu.ca
telephone: 613-548-4417 ext. 1198; 1-866-273-2272 (toll-free)
fax: 613-548-8135

Hilary Brown, Project Coordinator
National Epidemiologic Database for the Study of Autism in Canada
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON  K7M 8A6
hilary.brown@queensu.ca
telephone: 613-548-4417 ext. 1207; 1-866-273-2272 (toll-free)
fax: 613-548-8135

If you have any questions or concerns, you may also contact Dr. William Mackillop, Head, Department of Community Health & Epidemiology, Queen’s University at 613-533-2901 (email: william.mackillop@krcc.on.ca).

If you have any concerns about your rights as a research subject please contact Dr. Albert Clark, Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.
I have read the information describing the above project and understand what is required of my participation. I understand that the information from this project will be used to help researchers better understand the unmet needs of parents who have children with an autism spectrum disorder and to help identify possible predictors of these needs. I understand that if I choose not to participate in the study, the services and supports our family receives will not be affected in any way. My child does not object to my participation in this study. A copy of this consent form will be signed by the project coordinator and returned to me.

If you are interested in participating in this study, please place a check mark in the box to the left of the following statement. Mail this consent form back to us in the small, white envelope provided. Keep the preceding letter for your records. In the large brown envelope, please mail us the completed written questionnaire. Once you send us the consent form and questionnaire, we will contact you to complete the telephone interview.

☐ I agree to complete a written questionnaire and telephone interview in order to provide researchers with information about my family’s needs related to our child with an autism spectrum disorder.

Name of parent/legal guardian (please print): ______________________________________

Mailing address: ________________________________________________________________

Email: __________________________________________________________________________

Telephone number (please include the area code): _________________________________

What is the best time to contact you by telephone? _______________________________

Signature of parent/legal guardian: ___________________________ Date: _______________

Signature of project coordinator: ___________________________ Date: _______________
Appendix F

Information and Consent Form for Prince Edward Island Participants
Introduction

Queen's University is conducting a study to investigate unmet needs identified by parents who have an elementary school-aged child with an autism spectrum disorder. Funding has been provided by Autism Ontario and by the Ontario Council of Graduate Studies.

What is the purpose of this project?

Our goal is to gain an understanding of the types of needs that are important to parents who have a child with autism. We hope to determine whether or not these needs have been met adequately. We are also looking at the barriers faced by families when they try to access services and supports. By examining several child and parent characteristics, we hope to identify the types of families who may be at higher risk for having unmet needs.

Can I participate?

You are eligible to participate if your child has a diagnosis of autism (i.e. autistic disorder, pervasive developmental disorder-not otherwise specified, Asperger’s disorder, or autism spectrum disorder) and is between the ages of six and thirteen, as of January 1, 2009.

If I participate, what do I have to do?

We are asking families to provide us with information about their needs, their service use, and several parent and child characteristics. The written questionnaire is enclosed in this package. It should take about 30 minutes to complete. If you consent to participate in this project, please mail back the signed consent form in the small white envelope provided. Please mail the completed questionnaire in the large brown envelope provided. Once the consent form and questionnaire are returned, we will contact you to complete the telephone interview. A list of things we will ask about in the telephone interview is given on page 2. This interview will take approximately 20 minutes to complete. Since some of the questions concern your child, we encourage you to discuss this project with him/her and respect his/her wishes.

What are the benefits of participation?

There are no direct benefits to participation. However, we hope that information from this study will help service planners and providers to ensure that adequate services are available to families of children with an autism spectrum disorder.
What are the risks of participation?

The risks of participating are minimal. All of the information that you provide us will be anonymous and will be stored in a secure area. Your answers will not affect the services that you receive in any way.

What about confidentiality?

All information you provide will remain confidential. Once the information has been received from you, it will be entered into a secure database. All individuals who participate are assigned a unique identifier so that no names appear on the forms used to collect information from families, nor are any names entered in the database. Findings will be reported in grouped form so that individuals cannot be identified. The master list linking names and unique identifiers, as well as the forms used to collect information from families, are stored in locked filing cabinets located in a locked room in a secure building in Kingston, Ontario, accessible only to members of the research team. The master list is stored in a separate filing cabinet from the forms used to collect information from families. At the end of the study, all forms related to the project (including data collection forms and consent forms) will be shredded.

What are my rights if I choose to participate?

If you decide to participate and then at a later date decide that you no longer wish to participate, you may inform the project director or the project coordinator (see next page for names and contact information), and you will not be contacted further. If at some point you wish to have your child’s information removed from the database, you may contact the project director or the project coordinator and your child’s record will be deleted from the database.

Information that we collect during the telephone interview

- Your child’s everyday skills
- Problem behaviours that your child may have
- The services you are receiving, how often you receive these services, and how adequate you think they are

This should take you 20 minutes.
Who do I contact if I have questions or concerns?
Please feel free to contact us with any questions or concerns you may have. We would be glad to help you in any way we can. The contact persons are:

Hélène Ouellette-Kuntz, Project Director
National Epidemiologic Database for the Study of Autism in Canada
Associate Professor, Department of Community Health & Epidemiology
Queen's University
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON K7M 8A6
oullette@queensu.ca
telephone: 613-548-4417 ext. 1198; 1-866-273-2272 (toll-free)
fax: 613-548-8135

Hilary Brown, Project Coordinator
National Epidemiologic Database for the Study of Autism in Canada
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON K7M 8A6
hilary.brown@queensu.ca
telephone: 613-548-4417 ext. 1207; 1-866-273-2272 (toll-free)
fax: 613-548-8135

If you have any questions or concerns, you may also contact Dr. William Mackillop, Head, Department of Community Health & Epidemiology, Queen’s University at 613-533-2901 (email: william.mackillop@krcc.on.ca).

If you have any concerns about your rights as a research subject please contact Dr. Albert Clark, Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081 or Dr. Kathryn Bigsby, Chair, PEI Research Ethics Board [(902) 368-3998 (collect)].
CONSENT FORM

I have read the information describing the above project and understand what is required of my participation. I understand that the information from this project will be used to help researchers better understand the unmet needs of parents who have children with an autism spectrum disorder and to help identify possible predictors of these needs. I understand that if I choose not to participate in the study, the services and supports our family receives will not be affected in any way. My child does not object to my participation in this study. A copy of this consent form will be signed by the project coordinator and returned to me.

If you are interested in participating in this study, please place a check mark in the box to the left of the following statement. Mail this consent form back to us in the small, white envelope provided. Keep the preceding letter for your records. In the large brown envelope, please mail us the completed written questionnaire. Once you send us the consent form and questionnaire, we will contact you to complete the telephone interview.

☐ I agree to complete a written questionnaire and telephone interview in order to provide researchers with information about my family’s needs related to our child with an autism spectrum disorder.

Name of parent/legal guardian (please print):__________________________________
Mailing address: __________________________________________________________
Email: _________________________________________________________________
Telephone number (please include the area code):______________________________
What is the best time to contact you by telephone? ___________________________
Signature of parent/legal guardian:____________________ Date:__________________
Signature of project coordinator:________________________ Date:_______________
Appendix G

Information and Consent Form for Newfoundland and Labrador Participants
Consent to Take Part in Research

TITLE: Examining the Needs of Families of Elementary School-Aged Children with Autism

INVESTIGATOR(S): Hilary Brown, Project Coordinator, Queen’s University
Hélène Ouellette-Kuntz, Project Director, Queen’s University

SPONSOR: Funding has been provided by Autism Ontario and by the Canadian Institutes of Health Research

You have been invited to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

If you decide not to take part or to leave the study this will not affect your child’s services.

1. Introduction/Background:

Queen’s University is conducting a study to investigate unmet needs identified by parents who have an elementary school-aged child with an autism spectrum disorder. Funding has been provided by Autism Ontario and by the Canadian Institutes of Health Research.

2. Purpose of study:

Our goal is to gain an understanding of the types of needs that are important to parents who have a child with autism. We hope to determine whether or not these needs have been met adequately. We are also looking at the barriers faced by families
when they try to access services and supports. By examining several child and parent characteristics, we hope to identify the types of families who may be at higher risk for having unmet needs.

3. Description of the study procedures and tests:

We are asking families to provide us with information about their needs, their service use, and several parent and child characteristics. The written questionnaire is enclosed in this package. If you consent to participate in this project, please mail back the signed consent form in the small white envelope provided. Please mail the completed questionnaire in the large brown envelope provided. Once the consent form and questionnaire are returned, we will contact you to complete the telephone interview. A list of things we will ask about in the telephone interview is given below:

- Your child’s everyday skills
- Problem behaviours that your child may have
- The services you are receiving, how often you receive these services, and how adequate you think they are

Since some of the questions concern your child, we encourage you to discuss this project with him/her and respect his/her wishes.

You are eligible to participate if your child has a diagnosis of autism (i.e. autistic disorder, pervasive developmental disorder-not otherwise specified, Asperger’s disorder, or autism spectrum disorder) and is between the ages of six and thirteen, as of January 1, 2009.

4. Length of time:

The written questionnaire will take approximately 30 minutes to complete, and the telephone interview will take approximately 20 minutes to complete.

5. Possible risks and discomforts:

The risks of participating are minimal. All of the information that you provide us will be anonymous and will be stored in a secure area. Your answers will not affect the services that you receive in any way.

6. Benefits:

It is not known whether this study will benefit you. However, we hope that information from this study will help service planners and providers to ensure that adequate services are available to families of children with an autism spectrum disorder.
7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records.

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records
The members of the research team will see study records that identify you by name. Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when one of the research team is present.

Use of records
The research team will collect and use only the information you provide to them during the interview and by completing the questionnaire. That is all the information they need for this research study.

Your name and contact information will be kept secure by the research team at Queen’s University in Kingston, Ontario. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for five years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

After your part in this study ends, we may continue to review your records to check that the information we collected is correct.

Information collected and used by the research team will be stored by Queen’s
University. Hélène Ouellette-Kuntz is the person responsible for keeping it secure.

Your access to records
You may ask the researcher to see the information that has been collected about you.

9. Questions:

If you have any questions about taking part in this study, you can contact the investigator who is in charge of the study. That person is: Hilary Brown.

Investigators’ Contact Information:

Hilary Brown, Project Coordinator
National Epidemiologic Database for the Study of Autism in Canada
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON K7M 8A6
hilary.brown@queensu.ca
telephone: 613-548-4417 ext. 1207
fax: 613-548-8135

Hélène Ouellette-Kuntz, Project Director
National Epidemiologic Database for the Study of Autism in Canada
Associate Professor, Department of Community Health & Epidemiology
Queen's University
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON K7M 8A6
helene.kuntz@queensu.ca
telephone: 613-548-4417 ext. 1198; 1-866-273-2272 (toll-free)
fax: 613-548-8135

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through: Office of the Human Investigation Committee (HIC) at 709-777-6974 or Email: hic@mun.ca

After signing this consent you will be given a copy.
Signature Page

Study title: Examining the Needs of Families of Elementary School-Aged Children with Autism

Name of principal investigator: Hilary Brown, Project Coordinator, Queen’s University
                                    Hélène Ouellette-Kuntz, Project Director, Queen’s University

To be filled out and signed by the participant:

If you are interested in participating in this study, please place a check mark in the box to the right of the following statements. Mail this consent form back to us in the small, white envelope provided. Keep the preceding letter for your records. In the large brown envelope, please mail us the completed written questionnaire. Once you send us the consent form and questionnaire, we will contact you to complete the telephone interview. Please check as appropriate:

I have read the consent and information sheet. Yes { } No { }
I have had the opportunity to ask questions/to discuss this study. Yes { } No { }
I have received satisfactory answers to all of my questions. Yes { } No { }
I have received enough information about the study. Yes { } No { }
I understand that I am free to withdraw from the study
• at any time
• without having to give a reason
• without affecting my child’s future services
I understand that it is my choice to be in the study and that I may not benefit. Yes { } No { }
I agree to take part in this study. Yes { } No { }

Name of parent/legal guardian (please print): ____________________________________________

Mailing address: ________________________________________________________________

Email: _________________________________________________________________

Telephone number (please include the area code): ____________________________

What is the best time to contact you by telephone? ____________________________

Signature of parent/legal guardian: ____________________________ Date: ____________

Signature of project coordinator: ____________________________ Date: ____________

Version date: 25 August 2009
Appendix H

Information and Consent Form for ASD-CARC Participants
Introduction

Queen’s University is conducting a study to investigate unmet needs identified by parents who have an elementary school-aged child with an autism spectrum disorder. Funding has been provided by Autism Ontario and by the Canadian Institutes of Health Research.

What is the purpose of this project?

Our goal is to gain an understanding of the types of needs that are important to parents who have a child with autism. We hope to determine whether or not these needs have been met adequately. We are also looking at the barriers faced by families when they try to access services and supports. By examining several child and parent characteristics, we hope to identify the types of families who may be at higher risk for having unmet needs.

Can I participate?

You are eligible to participate if your child has a diagnosis of autism (i.e. autistic disorder, pervasive developmental disorder-not otherwise specified, Asperger’s disorder, or autism spectrum disorder) and is between the ages of six and thirteen, as of January 1, 2009.

If I participate, what do I have to do?

We are asking families to provide us with information about their needs, their service use, and several parent and child characteristics. The written questionnaire is enclosed in this package. It should take about 30 minutes to complete. If you consent to participate in this project, please mail back the signed consent form in the small white envelope provided. Please mail the completed questionnaire in the large brown envelope provided. Once the consent form and questionnaire are returned, we will contact you to complete the telephone interview. A list of things we will ask about in the telephone interview is given on page 2. This interview will take approximately 20 minutes to complete. Since some of the questions concern your child, we encourage you to discuss this project with him/her and respect his/her wishes.

What are the benefits of participation?

There are no direct benefits to participation. However, we hope that information from this study will help service planners and providers to ensure that adequate services are available to families of children with an autism spectrum disorder.
What are the risks of participation?

The risks of participating are minimal. All of the information that you provide us will be anonymous and will be stored in a secure area. Your answers will not affect the services that you receive in any way.

What about confidentiality?

All information you provide will remain confidential. Once the information has been received from you, it will be entered into a secure database. All individuals who participate are assigned a unique identifier so that no names appear on the forms used to collect information from families, nor are any names entered in the database. Findings will be reported in grouped form so that individuals cannot be identified. The master list linking names and unique identifiers, as well as the forms used to collect information from families, are stored in locked filing cabinets located in a locked room in a secure building in Kingston, Ontario, accessible only to members of the research team. The master list is stored in a separate filing cabinet from the forms used to collect information from families. At the end of the study, all forms related to the project (including data collection forms and consent forms) will be shredded.

We will note your participation in ASD-CARC’s Research Registry. ASD-CARC is planning to conduct a longitudinal study of family needs. Noting your involvement in the Research Registry will allow ASD-CARC to contact you in order for you to provide an update on your needs. However, participating in the current study does not mean you have to participate in a follow-up.

What are my rights if I choose to participate?

If you decide to participate and then at a later date decide that you no longer wish to participate, you may inform the project director or the project coordinator (see next page for names and contact information), and you will not be contacted further. If at some point you wish to have your child’s information removed from the database, you may contact the project director or the project coordinator and your child’s record will be deleted from the database.

Information that we collect during the telephone interview

- Your child’s everyday skills
- Problem behaviours that your child may have
- The services you are receiving, how often you receive these services, and how adequate you think they are

This should take you 20 minutes.
Who do I contact if I have questions or concerns?

Please feel free to contact us with any questions or concerns you may have. We would be glad to help you in any way we can. The contact persons are:
Hélène Ouellette-Kuntz, Project Director
National Epidemiologic Database for the Study of Autism in Canada
Associate Professor, Department of Community Health & Epidemiology
Queen's University
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON K7M 8A6
oullette@queensu.ca
telephone: 613-548-4417 ext. 1198; 1-866-273-2272 (toll-free)
fax: 613-548-8135

Hilary Brown, Project Coordinator
National Epidemiologic Database for the Study of Autism in Canada
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON K7M 8A6
hilary.brown@queensu.ca
telephone: 613-548-4417 ext. 1207; 1-866-273-2272 (toll-free)
fax: 613-548-8135

If you have any questions or concerns, you may also contact Dr. William Mackillop, Head, Department of Community Health & Epidemiology, Queen’s University at 613-533-2901 (email: william.mackillop@krcc.on.ca).

If you have any concerns about your rights as a research subject please contact Dr. Albert Clark, Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.
CONSENT FORM

I have read the information describing the above project and understand what is required of my participation. I understand that the information from this project will be used to help researchers better understand the unmet needs of parents who have children with an autism spectrum disorder and to help identify possible predictors of these needs. I understand that if I choose not to participate in the study, the services and supports our family receives will not be affected in any way. My child does not object to my participation in this study. A copy of this consent form will be signed by the project coordinator and returned to me.

If you are interested in participating in this study, please place a check mark in the box to the left of the following statement. Mail this consent form back to us in the small, white envelope provided. Keep the preceding letter for your records. In the large brown envelope, please mail us the completed written questionnaire. Once you send us the consent form and questionnaire, we will contact you to complete the telephone interview.

☐ I agree to complete a written questionnaire and telephone interview in order to provide researchers with information about my family’s needs related to our child with an autism spectrum disorder.

☐ I agree to have my participation in this study noted in the ASD-CARC Research Registry.

Name of parent/legal guardian (please print):___________________________________
Mailing address: ____________________________________________________________
Email: _________________________________________________________________
Telephone number (please include the area code):______________________________
What is the best time to contact you by telephone? _____________________________
Signature of parent/legal guardian: ______________________Date:________________
Signature of project coordinator:_________________________ Date:_______________
Appendix I

Written Questionnaire
EXAMINING THE NEEDS OF FAMILIES OF ELEMENTARY SCHOOL-AGED CHILDREN WITH AUTISM

A study conducted by

Queen's University

c/o 191 Portsmouth Avenue
Kingston, ON
K7M 8A6
EXAMINING THE NEEDS OF FAMILIES OF ELEMENTARY SCHOOL-AGED CHILDREN WITH AUTISM

Thank you for participating in our study. This questionnaire contains questions about your child and your family’s characteristics. It also contains questions about needs which many families who have a child with autism consider to be important. We are interested in exploring your family’s needs and how well you feel they have been met. This questionnaire will take approximately 30 minutes to complete.

The following five questions are about your child who has an autism spectrum disorder:

1. What is your child’s current diagnosis on the autism spectrum?
   - Autistic disorder
   - Pervasive developmental disorder-not otherwise specified
   - Asperger’s disorder
   - Other (e.g. autism spectrum disorder, pervasive developmental disorder, Rett’s disorder, childhood disintegrative disorder): _____________________

2. When was your child first diagnosed with an autism spectrum disorder?
   ________________________________ (mm/yyyy)

3. Overall, how would you rate the severity of your child’s autism spectrum disorder?
   - Mild
   - Moderate
   - Severe

4. Have you been told by your doctor that your child has any other disabilities or chronic mental or health problems? If so, please describe:
   ______________________________________________________________________
   ______________________________________________________________________

5. What is your child’s gender?
   - Male
   - Female

6. What is your child’s date of birth? _________________________(dd/mm/yyyy)
**FAMILY NEEDS** (Modified from the Family Needs Questionnaire: Siklos & Kerns, 2006)

The following is a list of needs which some parents who have a child with autism believe are important. In the column in the middle, please rate how important each need is to your family, using the scale at the top of the page. In the next column, which is shaded in gray, please rate whether each need has been met, using the scale at the top of the page.

<table>
<thead>
<tr>
<th>1. I need to be actively involved in my child’s treatments and therapies.</th>
<th>Very important</th>
<th>Important</th>
<th>Slightly important</th>
<th>Not important</th>
<th>Met</th>
<th>Partly met</th>
<th>Unmet</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. I need to have different professionals agree on the best way to help my child.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<tr>
<td>3. I need to be shown that my opinions are used in planning my child’s treatment, therapies, or education.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<tr>
<td>4. I need to have a professional to turn to for advice or services when my child needs help.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<tr>
<td>5. I need to have help from other family members in taking care of my child.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<td>6. I need to be told why my child acts in ways that are different, difficult, or unusual.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<td>7. I need to be shown what to do when my child is acting unusually or is displaying difficult behaviours.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<td>8. I need to have information regarding my child’s therapeutic or educational progress.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<td>9. I need to have help in deciding how much to let my child do by himself/herself.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<td>10. I need to have help with housework.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<td>11. I need to get enough rest or sleep.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<td>12. I need to get a break from my responsibilities.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
<td>Unmet</td>
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<td>13. I need to spend time with my friends.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
<td>Partly met</td>
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<td>14. I need to be told if I am making good decisions about my child.</td>
<td>Very important</td>
<td>Important</td>
<td>Slightly important</td>
<td>Not important</td>
<td>Met</td>
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<td>15. I need to have other family members understand my child’s problems.</td>
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<td>16. I need to have my child’s teachers understand his/her problems.</td>
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<td>17. I need to have my child’s after-school friends understand his/her problems.</td>
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<td>18. I need to discuss feelings about my child with a parent who has a child with the same disorder.</td>
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<td>19. I need to be reassured that it is not uncommon to have negative feelings about my child’s unusual behaviours.</td>
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<td>20. I need help dealing with my fears about my child’s future.</td>
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<td>21. I need help in remaining hopeful about my child’s future.</td>
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<td>22. I need to be encouraged to ask for help.</td>
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<td>23. I need to have the professionals working with my child to speak to me in terms I can understand.</td>
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<td>24. 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.</td>
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<td>25. I need services continuously rather than only in times of crisis.</td>
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<td>26. I need to have consistent physical therapy for my child.</td>
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<td>27. I need for professionals to be discrete when talking about my child while he/she is in the room.</td>
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<td>28. I need for my child to have friends of his/her own.</td>
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<td>29. I need to have consistent behavioural therapy for my child.</td>
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<td>30. I need weekend and after-school activities for my child.</td>
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<td>31. I need to work with professionals who have expertise with children who have the same disorder as my child.</td>
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<td>32. I need to have consistent occupational therapy for my child.</td>
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<td>33. I need to have time to spend alone with my other children.</td>
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<td>34. I need to have my child to have social activities other than with his/her own parents and siblings.</td>
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<td>35. I need to have consistent speech therapy for my child.</td>
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<td>36. I need to have counselling for myself and my spouse/partner.</td>
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<td>37. I need for the professionals working with my child to understand the needs of my child and my family.</td>
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<td>38. I need for my child’s friends to feel comfortable around my child.</td>
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<td>39. I need to have my child’s therapies continue throughout the summer months and school breaks.</td>
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<td>40. I need to have my questions answered honestly.</td>
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<td>41. I need to have counselling for my other children.</td>
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<td>42. I need information about special programs and services available to my child and my family.</td>
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<td>43. I need to be shown respect by the professionals working with my child.</td>
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<td>44. I need financial support (e.g. from government) in order to provide my child with his/her therapies, treatments, and care.</td>
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<td>45. I need respite care for my child.</td>
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</table>
46. I need the children in my child’s classroom to understand that my child cannot help his/her unusual behaviours and difficulties.

47. I need to have time to spend alone with my partner.

48. I need my child’s school to set up a specialized education plan for my child.

49. I need my child to have a teacher’s aide with him/her at school who has knowledge about, or expertise with, working with children with the same disorder as my child.

50. I need to have my spouse and me agree on decisions regarding our child.

51. I need my child’s doctor and dentist to have expertise working with children with the same disorder as my child.
IMPACT ON FAMILY (Modified from the Impact on Family Scale: Stein & Jessop, 2003)

The following is a list of statements which describe how some parents of children with a disability feel that the disability has affected their family. Please rate whether you agree with each statement, using the scale at the top of the page.

1. Fatigue is a problem for me because of my child’s diagnosis. □ □ □ □
2. We see family and friends less because of the diagnosis. □ □ □ □
3. Sometimes we have to change plans about going out at the last minute because of my child’s state. □ □ □ □
4. We have little desire to go out because of my child’s diagnosis. □ □ □ □
5. I don’t have much time left over for other family members after caring for my child. □ □ □ □
6. I live from day to day and don’t plan for the future. □ □ □ □
7. It is hard to find a reliable person to take care of my child. □ □ □ □
8. My family gives up things because of my child’s diagnosis. □ □ □ □
9. Nobody understands the burden I carry. □ □ □ □
10. Because of my child’s diagnosis, we are not able to travel out of the city. □ □ □ □
11. Sometimes I feel like we live on a roller coaster: in crisis when my child is acting out, OK when things are stable. □ □ □ □
12. People in the neighbourhood treat us specially because of my child’s diagnosis. □ □ □ □
13. Traveling to appointments with therapists and specialists is a strain on me. □ □ □ □
14. I think about not having more children because of the diagnosis. □ □ □ □
15. Sometimes I wonder whether my child should be treated “specially” or the same as a normal child. □ □ □ □
Finally, we would like to know some information about your family. Please answer the following questions:

1. What is your relationship with your child who has an autism spectrum disorder?
   - Mother
   - Father
   - Other (please describe): ___________________________________________

2. What is your average household income per year?
   - Less than $25,000
   - $25,000 to less than $45,000
   - $45,000 to less than $65,000
   - $65,000 to less than $85,000
   - $85,000 or greater

3. What is your highest level of education completed?
   - Less than a high school diploma
   - High school diploma
   - College diploma
   - University undergraduate degree
   - University graduate or professional degree

4. What is your marital status?
   - Married / common law
   - Divorced
   - Widowed
   - Single (never married)

5. Have you (or your spouse) had to make any changes to your employment status in order to support your child with autism? (e.g. cut back on work hours, resign from your position)
   - No
   - Yes

6. Does your child have brothers and sisters?
   - No
   - Yes → How many? _______________________

7. Do any of these brothers or sisters have a medical condition or disability?
   - No
   - Yes → How many have a medical condition or disability? _______________________

Thank you for your participation. Someone will be contacting you shortly for the telephone interview portion of this study. This should take approximately 20 minutes. Is there a time when it is most convenient to call you?
_____________________________________________________________________________

Would you like to receive a copy of the results of this study?
   - Yes
   - No
Appendix J

Telephone Interview Script
Hello, may I please speak to <Insert Name>? I am calling from Queen’s University about a study that you are involved in: Examining the Needs of Families of Children with Autism. Thank you very much for completing the written questionnaire. The last part of the study is a short telephone interview that should take approximately 20 minutes to complete. Is now a good time? <Follow up on missing items from questionnaire.>

We are interested in the types of services that your child is currently using (or has used in the past six months). I will ask you about services used inside and outside of school. For each service, I will ask you how many hours per month that service is used. If you visit the service provider less than monthly, I will ask you the number of visits you make per year. I will also ask you how adequate you feel the service is.

Is your child currently enrolled in an elementary or primary school? (i.e. grades 1 through 8)?

☐ Yes: grade ___________
☐ No → <If No> Is your child currently home-schooled? ☐ Yes ☐ No
<If Yes, skip “In School” questions.>

<table>
<thead>
<tr>
<th>Service</th>
<th>Hours/month</th>
<th>Visits/year</th>
<th>Inadequate</th>
<th>Somewhat inadequate</th>
<th>Somewhat adequate</th>
<th>Adequate</th>
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<td>Physical therapist</td>
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<td>Speech-language pathologist</td>
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<td>In school:</td>
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<td>Outside of school:</td>
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<td>Occupational therapist</td>
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<td>Speech-language pathologist</td>
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<td>Audiologist</td>
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<td>Family physician</td>
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<td>Case manager / social worker</td>
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<td>Respite worker</td>
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<td>Neurologist</td>
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<td>Psychologist</td>
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<td>Psychiatrist</td>
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<td>Other: (Specify)</td>
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<td>Medications: (Specify)</td>
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</table>
Please describe any experiences related to accessing services and supports which you think are particularly important:
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

Thank you. The last portion of the interview will be looking at the everyday skills that your child has as well as any problem behaviours he or she may have. I will read you a list of statements about skills that are used by children at different ages. Please let me know how well your child can do each skill, without any help or assistance. Each item is scored as 0 = never or rarely, even if asked, 1 = does but not well, or about ¼ of the time, may need to be asked, 2 = does fairly well, or about ¾ of the time, may need to be asked, 3 = does very well, always or almost always without being asked. <Start at number 13 and work backward or forward, depending on responses. Continue until four items in a row scored as 0.>

<INSERT SIB-R ADAPTIVE BEHAVIOUR SCALE HERE>

Thank you. Finally, I will read you a list of problem behaviours which may or may not be an issue for your child. If a behaviour is a problem for your child, I will be asking you how often it occurs. This is scored as: Less than once a month, 1-3 times per month, 1-6 times per week, 1-10 times per day, and 1 or more times per hour. I will then ask you how severe you think the problem is. Responses are: Slightly, Moderately, Very, or Extremely.

<INSERT SIB-R MALADAPTIVE BEHAVIOUR SCALES HERE>

This completes our telephone interview. Do you have any questions? Once the study is completed, we will be sending you a summary of the results. Thank you.

(Scales of Independent Behaviour-Revised [Short Form] not included due to copyright protection laws.)
Appendix K

Queen’s University Research Ethics Board Certificate
QUEEN’S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING
HOSPITALS RESEARCH ETHICS BOARD

May 28, 2009

Ms. Hilary Brown
Department of Community Health & Epidemiology
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON K7M 8A6

Dear Ms. Brown,

Study Title: Examining the needs of families of elementary school-aged children with autism
Co-Investigators: H. Ouellette-Kuntz, D. Hunter, E. Kelley

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol and consent form for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair’s signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

➤ Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. (see http://www.queensu.ca/vpr/reb.htm).

➤ Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

➤ Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

➤ Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair’s signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

Albert Clark
Chair, Research Ethics Board

Date May 29, 2009

Study Code: EPID-290-09

➤ Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete.
QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards as defined by the Tri-Council Policy Statement; Part C Division 5 of the Food and Drug Regulations, OHRP, and U.S DHHS Code of Federal Regulations Title 45, Part 46 and carries out its functions in a manner consistent with Good Clinical Practices.

Federalwide Assurance Number: #FWA00004184
#IRB00001173

Current 2009 membership of the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board

Dr. A.F. Clark Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen's University (Chair)
Dr. H. Abdollah Professor, Department of Medicine, Queen's University
Dr. C. Cline Assistant Professor, Department of Medicine
Director, Office of Bioethics, Queen's University
Clinical Ethicist, Kingston General Hospital
Rev. T. Delone Community Member
Dr. M. Evans Community Member
Dr. S. Irving Psychologist, Providence Care, St. Mary's of the Lake Hospital Site
Prof. L. Keeping-Burke Assistant Professor, School of Nursing, Queen's University
Mrs. J. Kotecha Research & Programs Manager, Centre for Studies in Primary Care, Department of Family Medicine, Queen's University
Dr. J. Low Emeritus Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital
Dr. W. Racz Emeritus Professor, Department of Pharmacology & Toxicology, Queen's
Dr. B. Simchison Assistant Professor, Department of Anesthesiology, Queen's University
Dr. A.N. Singh WHO Professor in Psychosomatic Medicine and Psychopharmacology
Professor of Psychiatry and Pharmacology
Chair and Head, Division of Psychopharmacology, Queen's University
Director & Chief of Psychiatry, Academic Unit, Quinte Health Care, Belleville General Hospital
Dr. E. Tsai Associate Professor, Department of Paediatrics and Office of Bioethics, Queen's University
Rev. J. Warren Community Member
Ms. K. Weisbaum LL.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)
Dr. S. Wood Director, Office of Research Services (Ex-Officio)
Appendix L

Prince Edward Island Research Ethics Board Certificate
Project: Examining the Needs of Families of Elementary School-Aged Children with Autism

Co-Principal Investigators: Hilary Brown & Hélène Ouellette-Kuntz

Document(s) Reviewed

- Submission Checklist (Dated June 16, 2009)
- Cover Letter from Hilary Brown & Hélène Ouellette-Kuntz (dated June 29, 2009)
- Recruiting & Consenting Step-by-Step Process (Not Dated)
- Research Protocol (Version 3, Dated June 3, 2009)
- Appendix A: Information Letter & Consent Form (Dated 20 May 2009)
- Appendix B: Written Questionnaires (Not Dated)
- Appendix C: Telephone Interview
- Appendix D: Conceptualization of Variables for Analyses
- Appendix E: Copy of Certificate of Queen’s University Research Ethics Board Approval
- CV for Co-Principal Investigators

Full approval has been granted for the above noted study. This study will require an annual report and request for re-approval to be in place prior to July 30, 2010. Attached is a copy of the Board’s “Continuing Review Reporting Requirements”.

ATTESTATION: This Research Ethics Board complies with Division 5 of the Food and Drug Regulations, the ICH Harmonized Tripartite Guidelines: Good Clinical Practice, and the Tri-Council Policy Statement.

Signature: [Signature]

Name: Kathryn Bigsby, MD, FRCPC
Title: Chair, PEI Research Ethics Board
Appendix M

Memorial University Research Ethics Board Certificate
August 31, 2009

Reference #09.133

Ms. Hilary Brown
C/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON K7M 8A6

Dear Ms. Brown:

RE: “Examining the needs of families of elementary school-aged children with autism”

This will acknowledge your correspondence dated August 25, 2009, wherein you provide a revised consent form, dated August 25, 2009 and requested information for the above noted study.

The Chairs of the Human Investigation Committee have reviewed your correspondence and granted approval of the revised consent form and requested information as submitted.

Please be advised that the Human Investigation Committee currently operates according to the Good Clinical Practice Guidelines, the Tri-Council Policy Statement and applicable laws and regulations.

Sincerely,


Fern Brunger, PhD
John Harnett, MD, FRCPC
Co-Chairs
Human Investigation Committee

C Dr. C. Loomis, Vice-President (Research), MUN
Mr. W. Miller, Director of Planning & Research, Eastern Health
Meeting date: September 3, 2009
Appendix N

Queen’s University Research Ethics Board Certificate for ASD-CARC Addition
September 28, 2009

Ms. Hilary Brown
Department of Community Health & Epidemiology
c/o Ongwanada Resource Centre
191 Portsmouth Avenue
Kingston, ON  K7M 8A6

Re: “Examining the Needs of Families of Elementary School-Aged Children with Autism” EPID-290-09

Dear Ms. Brown,

I am writing to acknowledge receipt of your letter dated September 17, 2009 which included the following:

- Request for approval of an additional method for recruiting families in Manitoba
- Email to be sent to families through the Research Registry
- Copy of the email letter to be sent to parents
- Revised consent form (14Sep09)

I have reviewed this amendment to the recruitment, the letter to be emailed and the revised consent form and hereby give my approval. Receipt of these amended materials will be reported to the Health Sciences Research Ethics Board.

Yours sincerely,

Albert Clark, Ph.D.
Chair
Research Ethics Board

AFC/kr

c.c.: Ms. H. Ouellette-Kuntz, Ongwanada Resource Centre