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Diagnosis and Treatment Barriers Faced by South Asian Families in Canada Who Have Children Diagnosed with an Autism Spectrum Disorder

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Abstract
Autism Spectrum Disorders (ASDs) are characterized by significant limitations in three main areas: social relatedness, verbal and nonverbal communication, and extremely restricted behaviors and interests (American Psychiatric Association, 2000; Rutter, 1978). Research has revealed that families who have children diagnosed with an ASD encounter unique stressors and often report a diminished quality of life when compared to families who have children diagnosed with other psychological disorders (Cassidy et al., 2008; Lee, Harrington, Louie, and Newschaffer, 2008; Sivberg, 2002). Such research, however, has traditionally been conducted with Caucasian families while virtually ignoring ethnic minorities. Because South Asians make up one of the largest non-European ethnic origin groups in Canada, it is vital that research be conducted to examine cultural barriers to autism treatment and to identify unique concerns that affect the experience of this population in dealing with an ASD diagnosis. Participants in this study consisted of eight South Asian parents (seven mothers and one father) who were currently raising a child diagnosed with an ASD in British Columbia and Alberta, Canada. Some common barriers to diagnosis and treatment that were reported by parents included inadequate funding from the government, and communication problems between parents and care-providers. Some cultural barriers, specific to the South Asian community, that parents reported included lack of knowledge regarding autism in the South Asian community, South Asian cultural values in general, and feeling judged by others within the community. When asked by the interviewer how these barriers impacted their overall functioning, 75% of parents reported that they did not reveal their child's ASD diagnosis to their friends and their own family members, including their parents and siblings. Results of the Family Needs Survey (Bailey & Simeonsson, 1988) indicated that the most imperative needs reported by the parents were needs for information, with the strongest need for information regarding services their child might receive in the future. Based on these results, it appears that South Asian caregivers of children with ASDs may experience even greater difficulty when compared to the general population of parents of children with ASD diagnoses.

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DIAGNOSIS AND TREATMENT BARRIERS FACED BY SOUTH ASIAN FAMILIES IN CANADA WHO HAVE CHILDREN DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER

A THESIS
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BY
SOPHIA GREWAL

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MASTER OF SCIENCE IN CLINICAL PSYCHOLOGY

JULY 23, 2010

APPROVED: ______________________________
Susan Tinsley Li, Ph.D.
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Abstract

Autism Spectrum Disorders (ASDs) are characterized by significant limitations in three main areas: social relatedness, verbal and nonverbal communication, and extremely restricted behaviors and interests (American Psychiatric Association, 2000; Rutter, 1978). Research has revealed that families who have children diagnosed with an ASD encounter unique stressors and often report a diminished quality of life when compared to families who have children diagnosed with other psychological disorders (Cassidy et al., 2008; Lee, Harrington, Louie, and Newschaffer, 2008; Sivberg, 2002). Such research, however, has traditionally been conducted with Caucasian families while virtually ignoring ethnic minorities. Because South Asians make up one of the largest non-European ethnic origin groups in Canada, it is vital that research be conducted to examine cultural barriers to autism treatment and to identify unique concerns that affect the experience of this population in dealing with an ASD diagnosis. Participants in this study consisted of eight South Asian parents (seven mothers and one father) who were currently raising a child diagnosed with an ASD in British Columbia and Alberta, Canada. Some common barriers to diagnosis and treatment that were reported by parents included inadequate funding from the government, and communication problems between parents and care-providers. Some cultural barriers, specific to the South Asian community, that parents reported included lack of knowledge regarding autism in the South Asian community, South Asian cultural values in general, and feeling judged by others within the community. When asked by the interviewer how these barriers impacted their overall functioning, 75% of parents reported that they did not reveal their child’s ASD diagnosis to their friends and their own family members, including their parents and siblings. Results of the Family Needs Survey (Bailey & Simeonsson, 1988) indicated that the most imperative needs reported by the parents were needs for information, with the
strongest need for information regarding services their child might receive in the future. Based on these results, it appears that South Asian caregivers of children with ASDs may experience even greater difficulty when compared to the general population of parents of children with ASD diagnoses.

*Keywords/Subject Terms: Autism, South Asian, Family, Children, Treatment Barriers*
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Lastly, I would like to thank the participants of this study for granting me a brief, yet invaluable glimpse into their world. I am in complete awe of the strength that these parents possess and I am truly grateful to have been given the opportunity to be touched by such amazing individuals. The love you have for your children is truly inspiring.
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Introduction

Although once thought to be a relatively rare disorder, the number of children who are diagnosed with an autism spectrum disorder (ASD) has skyrocketed over the last few decades (Ozonoff & Rogers, 2003). Recent studies have indicated the prevalence rate of autism in North America to be 1 in every 150 children (Fombonne, 2003). Autism Spectrum Disorders are characterized by marked limitations in three main areas: social relatedness, verbal and nonverbal communication, and restricted repertoires of behaviors and interests. Although the age of onset occurs before age 3, many children display developmental difficulties within the first 2 years of their lives.

Autism spectrum disorders are unique not only in symptoms displayed, but also in the impact these diagnoses and subsequent treatment can have on parents and caregivers of these children. However, few researchers have focused on how having a child diagnosed with autism can impact a family’s level of functioning. As a result of the ambiguity of the diagnosis, the severity and duration of the disorder, and the distress associated with the child’s persistent deviation from social norms, an ASD diagnosis often presents unique challenges and stressors for families (Altiere & von Kluge, 2009). Research on empirically-based treatments for autism (e.g., Lovaas, 1987) recommends that children with autism receive up to 40 hours of intensive behavior therapy per week. However, because of the high cost associated with such treatment, as well as the shortage of trained behavioral therapists, this level of intensive treatment is often difficult for parents to attain for their children (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Lee, Harrington, Louie, & Newschaffer, 2008).

Research studies on overall family functioning for those families who have children diagnosed with an ASD have found that parental concerns in multiple domains are significantly
higher for parents of children with autism than for parents of children with other diagnoses or
with no psychological diagnoses (Cassidy et al., 2008; Lee, Harrington, Louie, and Newschaffer,
2008; Sivberg, 2002). Overall, research has revealed that parents of ASD children more
frequently report a diminished quality of life as well as higher levels of concern about their
children’s well-being relative to parents of children with other disorders.

Although autism is found equally in all socioeconomic groups, cultures, races, and ethnic
groups (Ozonoff & Rogers, 2003), research on ASD families of diverse racial and ethnic
backgrounds is extremely sparse. Because cultural factors are so interwoven with a child and
family’s thoughts and behaviors, it is vital to study cultural factors that may impact the diagnosis
and treatment of children with an ASD and other psychological disorders (Mandell & Novak,
2005). Different cultural beliefs and values may not only impact the way that parents view their
children with disabilities, but also how they interact with them, their perceptions of support from
their community, and the services they seek for them.

The purpose of this study is to identify treatment barriers for South Asian families who
have children diagnosed with ASDs in Western Canada. Vancouver, the second most ethnically-
diverse city in Canada, has a growing number of South Asian families. According to Statistics
Canada, Canadians of South Asian origin make up one of the largest non-European ethnic origin
groups in Canada (Lindsay, 2001). In 2001, South Asians represented about 3% of the total
Canadian population and this number is growing considerably faster than the overall population
(Lindsay, 2001). With this increase in population, comes an increased need to identify and
examine potential barriers to psychological intervention. The present study involved
interviewing South Asian parents with a child diagnosed with an ASD in order to identify such
barriers.
**Autism Spectrum Disorders**

Beginning in 1938, Kanner (1968) carefully observed and systematically described the behavior and developmental progress of 11 children whose psychological symptoms were previously undiagnosed. He described behavioral patterns and themes that were common amongst all 11 children, as well as those that distinguished them from children with other psychological disorders. Some notable features included a delay in speech acquisition, an inability or disinterest in developing relationships with others, repetitive and stereotyped play behavior, and an obsessive need for maintenance of sameness (Rutter, 1978). Kanner was the first to suggest that these behaviors constituted a unique syndrome that he ultimately labeled *early infantile autism* (Rutter, 1978). He also emphasized that the behaviors observed in children with autism could be differentiated from those found in other childhood disorders such as schizophrenia and childhood psychosis (Kanner, 1968; Rutter, 1978).

Today, Kanner’s initial observations and descriptions of autism make up the essential features required for an ASD diagnosis. According to the Diagnostic and Statistical manual of the American Psychiatric Association (fourth edition; DSM-IV-TR) there are five diagnoses that fall under the umbrella of Pervasive Developmental Disorders (PDDs): Autistic Disorder, Asperger Disorder, Rett disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS; American Psychiatric Association, 2000) and three of these (Autistic Disorder, Asperger Disorder, and PDD-NOS) can be categorized as Autism Spectrum Disorders (Ozonoff & Rogers, 2003). These disorders are characterized by marked limitations in social relatedness and verbal and nonverbal communication, as well as very restricted repertoires of behaviors and interests. Children who meet diagnostic criteria for autistic disorder display deficits in reciprocal social interaction. Such
deficits may include an inability to use nonverbal behaviors to regulate social interaction (e.g., trouble looking others in the eye, few or unusual facial expressions, unusual intonation or voice quality), a failure to develop age-appropriate peer relationships (e.g., trouble interacting in groups and following cooperative rules of games, few or no friends), little sharing of pleasure or interests with others (e.g., enjoying favorite activities without trying to include others, little interest in or reaction to social praise), and a lack of social or emotional reciprocity (e.g., lack of response to others, little to no awareness of others; APA, 2000; Ozonoff & Rogers, 2003; Wing, 1997). The following sections review the core symptoms of ASDs in more detail.

**Social Development.** Typical social development follows a predictable pattern within children. Infants show a preference for human faces, begin to vocalize in response to others around 3 months of age, and use facial expressions and eye contact as primary modes of communication (Volkmar, 1987). Children who are diagnosed with autism, however, often do not follow such a pattern. These infants are not affected by social motivational factors the same way as typically-developing children and often do not develop specific social attachments (Volkmar, 1987). Unlike what is seen in typically-developing children, children with autism tend not to follow their parents around the house or greet them when they return home from an outing (Rutter, 1978). And although such behaviors may appear later in life, appropriate affectionate behaviors tend to be delayed in early childhood (Volkmar, 1987). When they are hurt or upset, they tend not to approach their parents for comfort, but also do not usually physically withdraw from others when physical contact is initiated (Rutter, 1978). Many children diagnosed with autism appear to be content to be left alone in order to engage in self-stimulatory behaviors and other unusual activities (Volkmar, 1987). Social deficits in communication are most apparent in older children as they have difficulties taking another person’s point of view and fail to engage in
social interchange (Volkmar, 1987). In spite of these social difficulties, it has been suggested that children with autism respond differently to attentive versus inattentive parents (Churchill & Bryson, 1972, as cited in Volkmar, 1987) and show differences in reactions to mothers when compared to strangers. These observations suggest that although children diagnosed with autism have increased difficulty in social development, attentive parenting and perhaps intensive treatment may allow these children to approximate more typical social interactions.

**Communication and Language Development.** One of the hallmark symptoms of autistic disorder is impairment in communication, which is often the most common reason that a child with autism is initially referred for an evaluation (Volkmar, 1987). Children diagnosed with autism can have impairments in both receptive and expressive language (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004) and often have serious impairments in skills that are thought to precede language (e.g., preverbal skills; Rutter, 1978). For example, they often fail to display social imitation (e.g., copying or following their parents’ activities) and are delayed in meaningful use of objects (i.e., they may spin the wheels of a toy car rather than use it the way it is intended; Rutter, 1978). Children with autism sometimes engage in make-believe actions that tend to be stereotyped and repetitive, rather than creative, imaginative, and flexible like the pretend play of typically-developing children (Rutter, 1978).

Many children with autism never speak, and those that do engage in verbal behavior, often engage in echolalia (the repetition of vocalizations made by another person), lack spontaneous speech for communication, and have unusual speech tone and rhythm (Volkmar, 1987). Children with autism are almost always impaired in their receptive understanding of spoken language and tend to lack symbolic gesture and mime (Rutter, 1978). Children with autism tend to lack the ordinary back and forth chatter and reciprocal interaction that is seen in
typical conversation (Rutter, 1978). Children diagnosed with autism not only show delays in language when compared to their same-age peers, but also when compared to expectations based on their visual-spatial cognitive ability as measured by their performance IQ’s on an intelligence test (Seltzer et al., 2004). Thus their verbal abilities do not necessarily reflect their abilities on performance-related tasks. Research studies indicate that deficits in communication may ameliorate to some degree by adolescence, but the majority of individuals with autism remain impaired in their communication abilities (Seltzer et al., 2004).

**Play and Stereotyped Behavior.** The third hallmark of autism is the tendency for individuals diagnosed with the disorder to engage in restricted, repetitive behaviors and interests. A behavioral manifestation of this hallmark can be seen in stereotypies, or repetitive motor movements that are often seen in children diagnosed with autism (Seltzer et al., 2004). Cognitive manifestations include obsessions and insistence on sameness (Seltzer et al., 2004). Children often display very rigid play patterns; for example, children may line up toys endlessly, collect curious objects, or make patterns of household routines (Rutter, 1978). Many children diagnosed with autism also appear to have certain preoccupations that prevent them from engaging in other interactions (Seltzer et al., 2004). They may, for example, persistently ask the same stereotypic questions and insist on a particular response. Moreover, it is common for children diagnosed with autism to engage in ritualistic and compulsive behavior (Seltzer et al., 2004). This may take the form of strictly following rigid routine, or compulsive actions that resemble those seen in Obsessive-Compulsive Disorder. Furthermore, children diagnosed with autism often have extreme resistance to changes in the environment, displaying intense distress if something as trivial as a piece of furniture is out of place (Rutter, 1978). Similar to language and communication difficulties, these stereotyped behaviors may abate over time, but research
studies typically show that the majority of individuals diagnosed with autism remain impaired in this domain over their entire lifespan (Rutter, 1978). The developmental course of ASD symptomatology is examined in further detail below.

**Course.** The age of onset for autistic disorder occurs before age 3, with most children displaying developmental difficulties within the first 2 years of life (Ozonoff & Rogers, 2003). When providing a retrospective developmental history, parents often report that their children displayed abnormal social-communicative behaviors and social responsiveness prior to age 3 (Ozonoff & Rogers, 2003). A smaller group of children later diagnosed with autism seem to develop at a normal rate for the first few years of life and then display a loss of communication and social skills (Ozonoff & Rogers, 2003). This regressive pattern is not observed in other development disorders, such as Down syndrome or Fragile X syndrome but affects approximately one-fifth to one-third of children who meet criteria for autistic disorder (Meilleur & Fombonne, 2009). Meilleur and Fombonne (2009) found in a sample of 135 children with a clinical diagnosis of PDD, that 30 regressed in language and other nonverbal skills. Regression was found to occur more frequently in children with an autism diagnosis than in children with an Asperger disorder or PDD-NOS diagnosis (Meilleur & Fombonne, 2009). Subjects who displayed signs of regression also displayed significantly more odd or restricted interests and engaged in more repetitive behaviors. The causes of regression are not yet established, but there are two competing theories that attempt to explain it: (a) the regression is due to complications of early infection, vaccination, or environmental exposure, and (b) the regression is genetically influenced but the genes have a later onset of action (Ozonoff & Rogers, 2003). Because these children tend to develop in a typical fashion for the first few years of life, it may be even more difficult for the parents and extended family members of these children to cope with and fully
understand the child’s diagnosis.

**Prevalence.** Although autism was once thought to be a rare disorder, the number of children who are diagnosed with an autism spectrum disorder (ASD) has significantly increased over the last few decades (Ozonoff & Rogers, 2003). Recent epidemiological surveys indicate that the current prevalence rate of autism is somewhere between 9/10,000 and 11/10,000 (Fombonne, 2003). It is important, however, to differentiate between rates of prevalence and rates of incidence. Prevalence refers to the proportion of individuals in a population who suffer from a defined disorder and incidence refers to the number of new cases occurring (Fombonne, 2003). Therefore this increase in prevalence rates of autism cannot be solely attributed to greater incidence, but may be explained by other factors. Some researchers have claimed that autism rates are higher in immigrants than in the general population; however, other researchers have argued against this theory (Fombonne, 2003). Research has found that ASDs are found equally in all socioeconomic groups, cultures, races, and ethnic groups (Ozonoff & Rogers, 2003; Wing, 1997). One difference that has been consistently observed, however, is between genders. Males are overrepresented amongst those diagnosed with autism, with a male to female ratio of approximately 4:1 (Fombonne, 2003; Ozonoff & Rogers, 2003).

**Interventions.** Because autism is characterized by core deficits in language use, social functioning, and behavioral flexibility, many researchers and clinicians argue that the primary goal of autism treatment should be to ameliorate these core deficits (Bodfish, 2004). Moreover, it is commonly accepted among proponents of autism treatment that intervention must begin early in a child’s life, be intensive, and actively involve family members (Mastergeorge, Rogers, Corbett, & Solomon, 2003). In recent years there has also been a greater emphasis on the use of treatments that have been validated through rigorous empirical study (Mastergeorge et al., 2003).
This may be due in part to the plethora of nonestablished treatments for autism that have been proposed, without empirical evidence, to “cure” the disorder and all of its core deficits. Some of these controversial treatments include holding therapy, music therapy, megavitamins, auditory integration therapy, Gentle Teaching, experimental brain surgery, immunosuppressant therapy and secretin (Bodfish, 2004). Although some of these therapies have undergone scientific testing due to popular media attention and increased parental demands, they have failed to illicit consensus among researchers as an effective way to ameliorate the core symptoms of autism (Bodfish, 2004). Even medical treatments that follow the biomedical approach to autism treatment have been found to be disappointing (Bodfish, 2004). Despite this lack in empirical support, however, there is evidence to suggest that many parents of children diagnosed with autism continue to utilize nonestablished or alternative therapies (Bodfish, 2004). Although such alternative treatments may not prove harmful for a child, it can have detrimental effects on family functioning by increasing financial strain, as well as time and stress related to treatment adherence.

Research on autism treatment has consistently yielded results supporting the effectiveness of one particular form of behavioral treatment, applied behavioral analysis (ABA; Grindle, Kovshoff, Hastings, & Remington, 2009). Behavioral interventions can be differentiated from other forms of autism treatment in the following ways: (a) it focuses on specific behaviors associated with disorder symptomatology rather than the diagnosis as a whole; (b) it emphasizes the child’s immediate environment rather than etiology; and (c) research on treatment is inductive rather than hypothetico-deductive (Lovaas & Smith, 1989). Unlike some other theoretical orientations that may begin with a theory on etiology and subsequently conduct research to either support or refute it, behavioral research attempts to make few inferential leaps
and emphasizes the accumulation of facts piece by piece, collecting as much data as possible before developing comprehensive theories (Lovaas & Smith, 1989).

According to Lovaas and Smith (1989), the ABA approach is based on four tenets: (a) the laws of learning can account for the behaviors displayed by children with autism and provide a basis for treatment; (b) children with autism have many separate behavioral deficits and not a central deficit that if treated, would lead to broad-based improvements; (c) if placed in special environments, children with autism are just as capable of learning as other human beings; and (d) the difficulties encountered by children with autism can be viewed as a mismatch between their nervous system and the environment, as evidenced by their failure to learn in some environments but not others (Lovaas & Smith, 1989). Discrete trial training, a component of ABA and a set of behavioral techniques first described by O. Ivar Lovaas in 1981, involves teaching through discrete teaching trials that consist of a trainer-provided antecedent or stimulus, a response from the child, and a consequence that reinforces a correct response (Mastergeorge et al., 2003). Through a highly directive process known as task analysis, complex behaviors are broken down into their most individual, teachable skills and desired behavior is developed through shaping, chaining and prompting (Mastergeorge et al., 2003). The process of stimulus, response, and consequence is repeated until the target skill is mastered.

In 1987, Lovaas published a highly influential outcome study that reported a significant decrease in symptomatology for children with autism. Children diagnosed with autism were matched on a number of variables and split into either an ABA experimental group or a control group. Children in the experimental group received more than 40 hours per week of one-to-one treatment, peer play training sessions, inclusions into regular education classrooms, and other generalization exercises (Cohen, Amerine-Dickens, & Smith, 2006). Children in the control
group received 10 hours or less of one-to-one treatment (Lovaas, 1989). Follow up results, collected after two or more years of treatment, indicated that children in the ABA group showed significant improvement in their behavioral functioning, with 47% achieving average scores on tests of cognitive functioning and successful first grade performance in public schools (Lovaas, 1987). Prior to Lovaas’s study, other researchers had conducted longitudinal studies on treatment outcomes for individuals diagnosed with autism and found that the majority of these individuals were living in hospitals for mentally retarded or psychotic individuals or in other protective residential facilities (e.g., Rutter, 1970, as cited in Lovaas, 1987). Thus Lovaas’s work provided optimism to both parents and clinicians, suggesting that the symptoms of autism could not only be decreased, but diminished all together.

Other researchers have since replicated the aforementioned Lovaas study. Based on parental preference for treatment modality, Cohen, Amerine-Dickens, and Smith (2006) split a group of children diagnosed with autism into two treatment groups that were matched in age and IQ scores: one in which children received 35 to 40 hours per week of early intensive behavioral intervention (EIBI; a term often used interchangeably with ABA) and a second group in which children participated in special education classes at local public schools. Outcome reports after three years of treatment revealed that children in the EIBI group obtained significantly higher IQ scores and adaptive behavior scores than the comparison group. Moreover, at the end of the third year of treatment, 21 children in the EIBI group were fully included in regular education classrooms and another 11 were included with additional support. In contrast, only one child from the comparison group was included in a regular classroom. In addition to increased cognitive functioning, researchers have also found that treatment based on ABA may produce significant increases in social, emotional, and adaptive functioning (Eikeseth, Smith, Jahr, &
Although Cohen, Amerine-Dickens, and Smith (2006), along with other researchers, were able to replicate Lovaas’s (1987) results and provide support for the use of ABA with children diagnosed with autism, the difference on outcome measures between the ABA group and the comparison group was smaller than the difference found in Lovaas’s initial study. These differences in outcome may be in part due to the vast symptomatic differences found among children diagnosed with ASDs. Several researchers have described a number of pretreatment characteristics that serve as good prognostic indicators for children with autism. Some of the more common indicators include IQ level, presence of imitation ability, presence of language, symptom severity, social responsiveness, and younger age at intervention (Sallows & Graupner, 2005). Moreover, researchers have also found that the greatest treatment effects can be found in ABA programs if the following conditions are satisfied: (a) children are younger than 4 years at the onset of intervention; (b) treatment is intensive and long-term (up to 40 hours per week for 2 or more years); (c) parents play an active role in the implementation and designing of treatment programs; (d) children have one-to-one relationships with their therapists; (e) intervention occurs within the child’s natural environment; and (f) children are included in regular classrooms at school (Eikeseth et al., 2007). Therefore, although EIBI is deemed the most effective treatment for autism in research and clinical circles, there are a number of treatment variables and obstacles to autism treatment that families can potentially encounter. One such obstacle may include a lack of social and financial support from the federal government for treatment services.

**Autism Spectrum Disorders in Canada**

Because this study focuses on Canadians, the following section provides contextual information regarding Canadian federal and provincial support for ASD evaluations and
treatment. Canada was the first nation in the world to include specific protection of the rights of individuals with disabilities in its constitution, the Charter of Rights and Freedoms (Puttee, 2002, as cited in Baker, 2007; 2008). However, although Canada has a reputation of being a nation that takes a positive, human rights approach to public policy (Jongbloed, 2003, as cited in Baker, 2008), the Canadian federal government does not directly fund treatment programs for individuals with autism (Baker, 2008). The Supreme Court of Canada determined in November of 2004, that provinces should independently determine whether or not to fund ABA services for children diagnosed with an ASD (Baker, 2007).

Most provinces in Canada partially fund autism treatment for preschool children (Norris, Paré, & Starky, 2006). This research study will focus specifically on individuals living in two Canadian provinces: British Columbia and Alberta. Therefore, funding for autism treatment in these two provinces will be reviewed in depth. British Columbia currently provides funding for ABA programs through the Ministry of Children and Family Development (MCFD). The MCFD provides families of children age 5 and younger with an ASD diagnosis of up to $22,000 Canadian dollars (CAD) per year to assist with the cost of autism intervention services (MCFD, 2009). Such services include the use of behavior consultants, speech-language pathologists, administrative costs, and training costs, while excluding services such as childcare, respite, and medical services. Upon a child’s sixth birthday, however, autism funding drops significantly to only $6,000 CAD per year (MCFD, 2009). Although autism researchers emphasize the need for early intervention, MCFD’s policy to reduce funding for children ages 6 and up leaves many families in desperate need of financial assistance (Baker, 2008).

In contrast to British Columbia, the province of Alberta provides families with $40,000 (CAD) or more per child for services such as autism therapy, respite services, child care, and
school support, per year (Madore & Paré, 2006). Children are eligible to receive this amount from the provincial government through Alberta Children and Youth Services and through the Family Support for Children with Disabilities program until their 18th birthday (Madore & Paré, 2006). Although British Columbia provides families with less funding than Alberta, other provinces provide an even lower level of financial support. For example, Manitoba provides up to a maximum of $6,000 CAD per year for the home-based portion of ABA programming for school-aged children (Madore & Paré, 2006).

The discrepancy in funding between British Columbia and Alberta highlights the incongruence in monetary support available to families of children diagnosed with an ASD in Canada. Individual provinces have, however, recently developed public policies with the intent of providing individuals and families affected by autism with a higher level of care and services. For example, the provincial government of Québec has developed a program that provides financial assistance to mothers and fathers who stay at home to care for their special-needs children (Baker, 2008). However, parents in some provinces face waiting lists of a year or more in order to have their children assessed for an ASD through government funded services and thus must purchase services privately or lose the ability to provide their children with early intervention (Baker, 2008). These policies suggest that although Canadian society has made strides towards providing families and individuals affected by ASDs with an increased level of care and support, significant work still remains to be done (Baker, 2008).

An ASD diagnosis can present many challenges for parents and other family members of these children. The next section reviews the stresses, quality of life, and family functioning issues experienced by families of children with an ASD diagnosis.
Family Functioning

In spite of continually expanding research on the etiology, course, and treatment of ASDs, few researchers have focused on how having a child diagnosed with autism impacts family functioning. An autism diagnosis presents unique challenges and stressors for families due to a number of symptoms and behaviors that are unique to ASDs (Altiere & von Kluge, 2009).

Lee, Harrington, Louie, and Newschaffer (2008) conducted a study to compare quality of life ratings and parental concerns in families with children diagnosed with ASDs to those diagnosed with attention deficit disorder or attention-deficit/hyperactivity disorder (ADD and ADHD) and to typical controls from a U.S. national sample. The researchers analyzed cross-sectional parent-reported data from the 2003 National Survey of Children’s Health (NSCH) for families with children between ages 3 to 17 years. Quality of life questions on the NSCH, which served as the outcome measure of this study, incorporated such themes as caregiving burden, quality and frequency of family outings and family meals, religious service attendance, parental employment, days of school missed, repetition of a grade in school, and engagement in community service.

Results indicated that parental concerns in multiple domains were significantly higher for parents of children with autism than for parents of children in the two comparison groups. Overall, parents of children with ASDs more frequently reported a diminished quality of life as well as higher levels of concern about their child’s well being relative to the other parents. More specifically, relative to families of ADD/ADHD or unaffected children, families of children with ASDs reported a higher level of child-caring burden, a higher likelihood of quitting a job because of child-care issues, more school days missed, more repeated grades, and less participation in
activities and community services.

A recent study in Ireland revealed similar difficulties reported by parents and caregivers of children diagnosed with autism. When asked to describe the impact their child’s diagnosis had on their family, the two most commonly cited difficulties were continual stress and strain, and the social restrictions the child placed on the family (Cassidy et al., 2008). Some other themes that were discovered included fear and uncertainty regarding the child’s future and embarrassment surrounding their child’s diagnosis. Most parents also reported that the majority of their social support came from family, whereas others in the sample reported support from friends, neighbors, and church members. Astoundingly, a third of these parents reported that they had no support from any of the aforementioned sources. In addition to family impacts, parents of children with autism reported difficulties directly related to their child’s symptoms. When parents were asked to identify the problems with their children that they had most difficulty in dealing with, the majority of parents mentioned speech and communication difficulties. The next most frequently discussed were the child’s temper tantrums, aggressive behaviors, and non-compliance.

If families of ASD children engage in fewer social and community-related activities, they may increase their social isolation and decrease opportunities for extrafamilial social support. Altiere and von Kluge (2009) measured parents’ perceptions of social support when they analyzed family dynamics and coping behaviors of families with a child diagnosed with an ASD. The researchers collected self-report data from 26 pairs of parents from the southeast Michigan area. The purpose of this study was to examine mothers’ and fathers’ perceptions of family coping mechanisms, perceptions of social support, and levels of family cohesion and adaptability. Although Altiere and von Kluge hypothesized that mothers would have higher
ratings of family cohesion than fathers, they found that mothers and fathers agreed in their ratings of cohesion, adaptability, and satisfaction with family functioning but differed significantly in their ratings of perceived social support. Fathers perceived less social support than mothers and reported that they had lost friends because others did not understand the struggles associated with having a child with autism. Both male and female caregivers who rated themselves as more enmeshed in their family cohesion also reported more perceived social support. These findings suggest that the fathers of children with autism may have perceived more social isolation and less understanding from their friends regarding the hardships associated with their children’s ASD diagnoses. Moreover, such perceptions were also found to be associated with less family cohesion, a factor that may adversely affect family functioning as a whole.

Family functioning is not only an important factor in determining how a family is coping as a whole, but can also impact a child’s ASD symptomatology. Kelly, Garnett, Attwood, and Peterson (2008) found a significant association between severity of ASD symptomatology and anxiety/depression in children diagnosed with autism and other PDDs. These researchers found that family conflict predicted anxiety and depression within ASD children more than positive family or peer influences, and that anxious and depressive symptoms exacerbated ASD symptomatology. Although it is unclear whether family conflict plays a causal role in the development of anxiety or depression within children with ASDs, its impact on a child’s ASD symptomatology warrants the attention of all professionals working with families affected by autism.

One way to increase positive functioning for ASD families may be to engage in ABA or EIBI therapy. Although a number of studies have demonstrated the effectiveness of such interventions with children on the autistic spectrum, very few have focused on the impact of
EIBI on family functioning. Grindle, Kovshoff, Hastings, and Remington (2009) interviewed 53 parents from the United Kingdom whose children had received at least 2 years of EIBI in order to obtain first-person accounts of the parents’ experiences with running home-based EIBI programs. These interviews revealed that parents were generally positive about EIBI and reported practical benefits for themselves, their ASD children, and their non-ASD children. Such benefits included support for their children’s challenging behaviors, a wider social network, better interactions between their ASD and non-ASD children, and more free time for themselves. The authors also outlined some of the difficulties encountered by these parents, such as difficulty recruiting new therapists for treatment and insufficient funding for the programs. In spite of these difficulties, however, the majority of parents reported that their family functioning had improved as a result of the EIBI programs and also stated that they would recommend EIBI to other families of children with autism.

Although these studies illustrate that families of children with ASDs experience unique and challenging difficulties related to their children’s diagnosis and treatment, it is important to note that all of these studies focused on Caucasian, middle to upper-middle class caregivers and children. Therefore it is unclear whether other ethnic or cultural groups experience similar barriers to diagnosis and treatment for their children as well similar benefits.

Cultural Factors

Although researchers have found that autism is found equally in all socioeconomic groups, cultures, races, and ethnic groups (Ozonoff & Rogers, 2003), the vast majority of research literature in the field of ASDs has focused on Caucasian samples. This trend began in 1938 with Kanner, whose original group of 11 children displaying autistic features were of either Anglo or Jewish descent (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Even Hans
Asperger, the Austrian pediatrician after whom the disorder is named, primarily studied Anglo children in Vienna, Austria. However, because cultural factors are so interwoven with our thoughts and behaviors, it is vital to study cultural factors that may impact the diagnosis and treatment of children with autism (Mandell & Novak, 2005).

The term “culture”, although often difficult to define, can be viewed as a “highly variable system of meanings, which are learned and shared by a people of an identifiable segment of a population” (Rohner, 1984, as cited in Betancourt & Lopez, 1993, p. 630). Cultural values have a strong effect on how individuals experience their world and can vary widely depending on the specific group being considered (Desai, 2006). For example, some members of the Mojave Indian tribe found in Arizona, California, and Mexico, believe that mental retardation and other developmental disorders are the result of misdeeds committed by parents (Green, Sack, & Pabrum, 1981, as cited in Dyches et al., 2004) and it is believed in some Latino cultures that a child’s mental retardation or developmental disability are punishment for a parent’s sins (Skinner, Bailey, Correa, & Rodriguez, 1999). Alternatively, African American communities often emphasize the importance of all children, regardless of developmental level or disability, a belief system that is reinforced in church and religious beliefs (Rogers-Dulan & Blacker, 1995, as cited in Dyches et al., 2004). These varying beliefs may not only impact the way that parents view their children with disabilities, but also how they interact with them, their perceptions of support from their community, and the services they seek for their children.

The present study focuses specifically on South Asian families. The South Asian community is one of the largest minority groups in Canada and in 2001, represented about 3% of the total Canadian population. This community is also growing considerably faster than the overall population (Lindsay, 2001). However, despite the increasing South Asian population
within Canada, there has been little to no research on psychological treatment barriers faced by this group.

Although the term “South Asian” encompasses a number of different nationalities, such as Indian, Pakistani, and Bangladeshi, these groups share a number of similar cultural values and characteristics. In most South Asian cultures, the family unit is the most central force around which the community functions (Meer & Vandecreek, 2002). Family members are involved in nearly all decisions pertaining to individual members, and individual needs are often second to the needs of the family (Ao, 2006; Meer & Vandecreek, 2002). Unlike the majority culture of North America, South Asian families often consist of more members than just the nuclear family of parents and children, and also extend to include parents, grandparents, aunts, and uncles. Oftentimes, paternal grandparents have as much or more say in a child’s life than do parents themselves. The individual is often expected to make sacrifices for his or her family and to follow familial roles (Ao, 2006; Desai, 2006). Interestingly, researchers have found that these values are often intact in South Asian families, even when living in large metropolitan areas where extended family may be physically separated and not living in the same household. In addition to making major life decisions, an individual’s accomplishments are often reflected upon an entire family (Meer & Vandecreek, 2002). Academic accomplishments, professional successes, and respectability of a person’s chosen spouse are all matters of family pride and respect and are reflective of how well a child is raised by his or her family (Meer & Vandecreek, 2002). Thus, this emphasis on immediate and extended family involvement may impact South Asian parents’ functioning in ways that are significantly different from parents who adhere to more Western values. Because research has focused almost exclusively on Caucasian children in Western societies, the effects of extended family involvement have not yet been researched with
families who have children diagnosed with autism. More research is required in order to determine how such involvement may impact a child’s treatment and parents’ ability to cope with the autism diagnosis and subsequent treatment.

Similarly to the South Asian culture’s emphasis on family, Indian families and other South Asians heavily emphasize conformity to social norms (Daley, 2004). In a study that provided data on the process of symptom recognition, help-seeking, and initial diagnosis of a Pervasive Developmental Disorder in children in India, 45% of parents in the study first noticed social difficulties, such as a lack of interest in other people, poor eye contact, and lack of interest in playing with other children as core deficits as compared to communication or repetitive behavior problems (Daley, 2004). Those parents who were first concerned with medical issues, such as seizures, reported that it took significantly longer for their children to receive a PDD diagnosis. Furthermore, although it may seem as if the South Asian culture’s emphasis on social functioning serves a beneficial function in early detection of PDD symptomatology, research has found that parents in India reported that they noticed something different about their child between 6 and 10 months later than has been previously found in the U.S. (Daley, 2004). Therefore this emphasis on adherence to social norms may result in delayed help-seeking behaviors by South Asian parents.

There are a number of cultural values that may impact a family’s help-seeking behaviors. For example, researchers have suggested that some South Asian families may not immediately seek services for their children, especially daughters, for fear that they may not be able to successfully arrange marriages for them when they are of marrying age (Dyches et al., 2004). The South Asian culture’s emphasis on adherence to social norms may also prevent parents from seeking out help for their children, for fear of social rejection or loss of face. Although parents
may suspect that their child is not developing at a typical rate, parents may wait to see if the symptoms will resolve on their own. In Daley’s (2004) study, parents waited as long as 2 years and 8 months before seeking help from a professional in the medical field. Some explanations for this delay in help-seeking may include a lack of awareness regarding autism among medical professionals in India, the presence of comorbid disorders (Daley, 2004), and perhaps fear of social rejection by parents.

Different cultural groups also tend to have different expectations of children’s development and this can significantly impact a child’s developmental prognosis (Stein, Flores, Graham, Magana, & Willies-Jacobo, 2002). Unrealistic expectations of a child’s abilities can result in delayed diagnosis, delayed care, and failure to address important issues with providers (Stein et al., 2002). Cultural differences may also influence the type of interventions parents choose for their children. Levy, Mandell, Merhar, Ittenbach, and Pinto-Martin (2003) found that parents of Latino children diagnosed with autism were six times more likely than parents of other ethnicities to use nontraditional treatment strategies for their children. Some researchers suggest that ethnic minorities may be less likely to view ASD symptoms as related to a health condition and therefore may be less likely to seek treatment through traditional medical systems (Mandell & Novak, 2005). However, it is currently unclear whether South Asian families are more open to alternative forms of autism treatment than their majority culture counterparts. Although South Asians often view medical doctors as “next to God” (Daley, 2004, p.1331), many South Asians equate psychological professionals with mysticism, voodoo, and astrology (Meer & Vandecreek, 2002). However, such views may also differ based on a person’s level of acculturation and education.

Because this study focuses exclusively on South Asians living in Canada, it is important
to consider how South Asians families’ experiences in Canada and history of migration/immigration may or may not impact their children’s diagnoses and treatment. This section will review the migration history of South Asians in Canada, as well as the current Canadian context toward South Asian individuals.

The first group of immigrants from India arrived in Canada in the early 1900’s. However, in 1904, Indian immigrants were restricted from entering Canada and were not granted immigration rights again until the 1960’s (Aycan & Kanungo, 1998). After the 1960’s, there was a rapid and continual influx of immigrants of South Asian descent. Between 1996 and 2001, the number of individuals in Canada who identified as South Asian grew by 33%, while the overall population grew by only 4% (Lindsay, 2001). Today, the South Asian community is one of the largest minority groups in Canada, with almost 1 million members (Tran, Kaddatz, & Allard, 2005).

In spite of their growing presence in Canada, however, South Asians, like many other ethnic minority groups, often report difficulties in acculturation and discrimination. A study that examined Indo-Canadians’ acculturation and socialization beliefs found that while most Indo-Canadians endorsed a more “integrated” socialization attitude, which suggests an interest in interacting with the larger society while simultaneously preserving one’s ethnic identity, the second most preferred attitude was “marginalization”, which occurs when an individual is not willing to either maintain the culture of origin nor interact with members of the majority culture (Aycan & Kanugo, 1998). This notion of feeling marginalized is important in that it may affect how an individual interacts with the majority culture. Perceptions of prejudice or discrimination may lead some South Asian parents to be reluctant to establish relationships with members of the majority culture and this may subsequently affect their ability and willingness to seek out
services for their children, particularly from members of the majority culture. It is important to note, however, that these perceptions may in fact be warranted. Berry and Kalin (1995) found in a national survey of ethnic attitudes in Canada that second generation Indo-Canadians were rated higher in preference ratings than first generation immigrants (as cited in Aycan & Kanugo, 1998). It was also revealed that Sikhs and Indo-Pakistanis were rated lowest with respect to their favorableness by mainstream Canadians. Therefore this cultural group is not only faced with the difficulties associated with adjustment to a new culture, or to two different cultures for those born in Canada, but are also judged poorly and viewed negatively by the majority culture. Furthermore, although 25% of South Asian adults have a university degree, compared with 15% of those in the overall population, the average income of South Asian Canadians is approximately $4,000 lower than the national average of $30,000. All of these factors undoubtedly impact not only how South Asian families function in general, but also how families cope with difficult situations, such as receiving an autism diagnosis for one or more of their children. In the United States, Latino children have been found to have a lower probability of receiving services for disabilities. Interestingly, the predicting factor associated with level of service is not socioeconomic status, but familiarity with the majority culture (Bailey, Skinner, Rodriguez, Gut, & Correa, 1999). Therefore, although socioeconomic status may be an important factor in determining the quality and quantity of services that children with autism receive, familiarity and comfort with Canadian culture may be even more indicative of the quality of such services received by South Asian families. Because many South Asians report feelings of marginalization and are often the targets of discrimination in Canada, Canadian South Asian parents may be especially vulnerable to treatment barriers for their children. Furthermore, South Asian families may be even more susceptible to specific cultural barriers due to South Asian
cultural values such as a heavy focus on familial and social relatedness.

**Aim of the Present Study**

Given the challenges experienced by families who have children with an ASD diagnosis and the potential cultural factors that may be implicated, the present study attempted to identify diagnosis and treatment barriers for South Asian Canadian parents of children with ASDs. The primary research goals were to understand specific barriers that are unique to South Asian families, as well as to examine barriers that may be common to all families of children diagnosed with ASDs. The present study improves upon previous studies by combining questionnaire and interview formats and by focusing exclusively on the experiences of South Asians.

The following hypotheses are based on the preceding literature review and will be evaluated in the present study.

**Hypotheses**

1. It is hypothesized that South Asian families will report fewer hours of therapy per week for their children than the 40 hours per week that is recommended by autism researchers.

2. It is hypothesized that some common themes discussed by families will include financial barriers to treatment, difficulties in recruiting therapists to work with their children, perceptions of diminished quality of life, higher child caring burden, and less involvement in community activities and services.

3. It is hypothesized that in addition to the common barriers reported by all families of children diagnosed with autism, South Asian families will report unique barriers that may be attributed to their cultural experiences as South Asians living in Canada.
Method

Participants

Participants in this study included seven female and one male adult parents of children diagnosed with an ASD who voluntarily participated in the study. Inclusion criteria for participants were as follows: participants were required to identify with a South Asian ethnic background, have one or more children with an ASD diagnosis, be currently raising a child or adolescent diagnosed with an ASD in their home, be fluent enough in English to comprehend and sign the informed consent forms, and be living in British Columbia or Alberta, Canada.

Design and Procedure

This study was reviewed and approved by the Institutional Review Board at Pacific University. Special care was taken to ensure that study procedures met Canadian ethical research criteria as well. Research participants were recruited through email advertisements, a recruitment posting on an online discussion forum for parents of children with autism, and through materials sent out to previous clients by a clinical psychologist currently working in the Greater Vancouver area. All recruitment materials were presented in English. Those individuals who fit the inclusion criteria and who were interested in participating in the study contacted the principal investigator and set up a time and location for an interview. Prior to conducting the interviews, the informed consent form was reviewed with each participant and each participant was assured that participation in the study was completely voluntary and that he or she was free to withdraw from the study at any time. Seven interviews were conducted in person, with five interviews conducted in participants’ homes and two interviews conducted at a local coffee shop or restaurant. One interview was conducted over the telephone. All participants spoke with the principal investigator for their interviews.
All materials were presented verbally during the in-person or telephone interviews. The interviews averaged 90 minutes and were conducted entirely in English.

**Measures**

**Demographic Information.** Basic demographic information was collected verbally from all participants. Such information included age, income, number of years living in Canada, the age of their child, information regarding the type of services their child is currently receiving, and other demographic information.

**Barriers to Diagnosis and Treatment.** Barriers to diagnosis and treatment were identified by asking participants questions that were adapted from interviews conducted by Sanchez (2005) in her study aimed at identifying barriers for Latino families living in the US. These questions were initially developed based on variables identified through a review of the literature on Latino families with children with disabilities. However, questions were modified and further questions were added in order to address variables unique to South Asian families of children with ASDs.

**Family Needs.** Family needs were assessed using the Family Needs Survey (FNS) developed by Bailey and Simeonsson (1988). This measure was originally developed in order to assess the functional needs of parents with young children with disabilities and has been used in research with Caucasian, Asian, Latino, and African-American populations (Bailey & Blasco, 1990; Bailey & Simeonsson, 1988; Sanchez, 2005). Item selection for the FNS was based on a comprehensive review of the literature, discussions with early interventionists, data collected in previous surveys, and the authors’ own clinical experience (Bailey & Simeonsson, 1988). Based on this methodology, the authors were able to compile a survey of 35 items that can be grouped into the following categories: needs for information, needs for support, explaining diagnoses to
others, community services, financial needs, and family functioning.

The authors of this survey hold that family assessment can be helpful in allowing clinicians to understand the needs of the individual child, the needs of the family, and to determine appropriate interventions to meet the child’s and family’s needs (Bailey & Simeonsson, 1988). The FNS is considered to be a reasonably valid and reliable measure of family needs and can be used to facilitate the development of individualized plans to help families who have young children with disabilities (Sexton, Burrell, & Thompson, 1992). Among Caucasian populations, the FNS demonstrated internal consistency scores of .91 and factor analyses revealed that every item on the FNS was useful in identifying the calculated factor structure. The FNS also demonstrated good stability of ratings over a 6-month period: these ratings were .67 and .81 for mothers and fathers, respectively.

Researchers have also found that the FNS is an effective tool in identifying family needs for minority and low-income families. Bailey and Blasco (1990) found that mothers of Black and Hispanic ethnic backgrounds endorsed the use of the FNS at levels that matched or exceeded those of White mothers. Moreover, minority mothers were more likely (68%) to endorse preference for verbal reports of their needs than White mothers (53%). This provides further support for the use of the FNS in a verbal interview, as utilized in the current study. However, it is important to note that these studies did not include minorities of South Asian background and there is currently no research on the reliability or validity of the FNS when used with South Asian individuals.
Results

Demographic Information

Participants in the study included seven South Asian mothers and one South Asian father of a child diagnosed with an ASD. Participants ranged in age from 31 to 41 years old and were all in heterosexual marriages at the time of the interviews. The average household income was $100,714 Canadian dollars per year and ranged from $50,000 to $170,000. Three families were dual-earner with two parents working outside of the home and five families were single-earner with fathers working outside the home. Four participants (50%) reported living with extended family members, such as parents and in-laws. All participants in the study had at least some college education and were fluent in a variety of languages including, Punjabi, Hindi, Bengali, and English. Five participants reported English as their primary language. The remaining three participants reported Punjabi, Hindi, and Bengali as their primary languages. Two of the participants were born in Canada, two were born in England, three were born in India, and one was born in Bangladesh. Of the six participants who were born outside of Canada, the shortest amount of time spent living in Canada was 5 years and the longest was 36 years.

Demographic information was also collected regarding participants’ children who had an ASD diagnosis. All participants reported having only one child with an ASD diagnosis. The children diagnosed with an ASD included five males and three females. They ranged in age from 3 years old to 13 years old, with four children under the age of 6 and four children 6 years old and older. Only one of the parents reported that their child was also diagnosed with mental retardation and epilepsy. Three parents reported other comorbid diagnoses, such as Attention-Deficit/Hyperactivity Disorder and eczema.
Diagnostic and Treatment Services

In addition to demographic information, participants were asked questions regarding their past and current experiences with the diagnosis and treatment of their children diagnosed with an ASD. Five participants reported that their child was diagnosed with an ASD at 3 years of age, and three reported that their child was diagnosed between the ages of 4 and 7. When asked if an Autism Spectrum Disorder was the first diagnosis they received, six responded “yes”, and two responded “no”. The two other diagnoses that were received by these children were “delayed speech” and epilepsy. Although all participants stated that their children were currently receiving treatment services, only six out of the eight (75%) parents reported that their children were currently receiving ABA treatment. All six of these parents reported that they were receiving services from the same behavioral consultant, who is a Board Certified Behavior Analyst and who is currently one of the only South Asian consultants in British Columbia. The parents reported an average of 13 hours of therapy for their children per week ($M = 13.44, SD = 10.64$), which is substantially below the 40 hours per week that is recommended by autism researchers (e.g., Lovaas, 1989).

Two of these six parents reported that their children were also receiving treatment services at school and one parent reported that their child was receiving treatment services at school only. One parent reported that her child was previously receiving ABA services but was now seeing a speech-language pathologist only. Refer to Table 1 for a summary of ABA treatment services received by participants’ children.
Participants’ Use of ABA Treatment Services

<table>
<thead>
<tr>
<th>Number of Participants</th>
<th>Currently Using ABA</th>
<th>Previously Used ABA</th>
<th>Never Used ABA</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

\( n = 8 \)

Barriers to Diagnosis and Treatment

Parents were asked a number of questions regarding potential barriers to the diagnosis and treatment of the children with an ASD. Each of the five barrier questions are listed along with a summary of participants’ responses.

Question 1: Had you any prior knowledge of autism before your child was diagnosed with this disorder? When asked whether they had any prior knowledge of autism before their child was diagnosed, only three out of the eight parents (38%) reported that they had heard of the term before their child was diagnosed.

Question 2: What specifically made you know something was wrong with your child? The majority of participants (75%) reported that they first began having concerns because of delayed speech or a complete lack of verbal ability. Two parents (25%) also reported that their children did not display eye contact and three (38%) stated that their children displayed repetitive behaviors and became fixated on certain objects. One parent, whose child also had a diagnosis of epilepsy, reported that her daughter began to have seizures and spent 2 months in the hospital prior to the onset of her ASD symptomatology.

Question 3: Who did you first talk to after you thought something was wrong with your child? Six participants (75%) reported that they first saw a general physician when they thought something was wrong with their child. One parent stated that she sought the help of a
family member who worked with children and one parent went to a hospital due to her daughter’s seizures. Four participants (50%) also reported using home remedies to alleviate their child’s symptoms, which included a biomedical approach, including a gluten- and dairy-free diet as well as natural supplements, and naturopathic remedies.

**Question 4: What did you think was wrong with your child prior to receiving the diagnosis of autism?** Most participants (75%) stated they thought their child had an expressive language disorder or delayed speech and one parent stated that she thought her child had delayed development in general. One participant reported that she thought her child only had a seizure disorder.

**Question 5: Why do you think your child has autism/ what is the cause?** Four participants (50%) stated that they believed vaccinations caused their child’s symptomatology, two (25%) stated a belief in genetic factors, and two (25%) stated that they did not know the cause. One parent reported that she often blamed herself for her child’s diagnosis, in spite of her knowledge that parents were not to blame for their child receiving an ASD diagnosis.

**Additional Questions: Specific Barriers.** Participants were also asked about specific variables or treatment barriers that negatively impacted their child’s care (see Table 2 for a summary of these barriers and refer to the appendix for a complete list of questions asked). The most commonly endorsed variable by participants was inadequate funding for their child’s services; all participants living in British Columbia endorsed this item, while the participant currently living in Alberta was the only one who did not endorse this item. The second most endorsed item was communication problems between parents and treatment providers, with five (63%) participants endorsing this as a barrier for their child’s treatment services. Cost of treatment and lack of time in parents’ schedules were the next most endorsed items (50%) as
barriers to treatment.

Table 2

*Specific Barriers to Treatment*

<table>
<thead>
<tr>
<th>Treatment Barrier</th>
<th>Number of “Yes” Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td>1</td>
</tr>
<tr>
<td>Cost of Treatment</td>
<td>4</td>
</tr>
<tr>
<td>Inadequate Funding</td>
<td>7</td>
</tr>
<tr>
<td>Transportation</td>
<td>3</td>
</tr>
<tr>
<td>Communication Problems</td>
<td>5</td>
</tr>
<tr>
<td>Lack of Time in Your Schedule</td>
<td>4</td>
</tr>
<tr>
<td>Family Problems</td>
<td>1</td>
</tr>
<tr>
<td>Marriage Problems</td>
<td>1</td>
</tr>
<tr>
<td>Personal Problems</td>
<td>2</td>
</tr>
</tbody>
</table>

\( n = 8 \)

**Family Needs**

The Family Needs Survey (FNS) is divided into six sections: needs for information, needs for support, explaining diagnoses to others, community services, financial needs, and family functioning (Bailey & Simeonsson, 1988). Results of the FNS were analyzed by calculating percentages of “yes” responses to individual items on each scale.

**Needs for Information.** Results of the survey indicated that the most pressing needs reported by the parents were on the scale measuring needs for information, with the strongest need being, “I need more information about the services my child might receive in the future”. All participants endorsed this item on the survey and all but one participant (88%) endorsed a
need for more information about how to teach their child. Six participants (75%) endorsed the items, “I need more information about how to handle my child’s behavior”, “I need more information about how to play with or talk to my child”, and “I need more information about the services that are presently available to my child”. The next most pressing need endorsed by families was a need for support. All participants endorsed the item, “I need to have more time to myself” and six participants (75%) endorsed the item, “I need reading materials about other parents who have similar children to mine”. Sixty-three percent of participants endorsed the items, “I need to have more friends that I can talk to” and “I need to have more opportunities to meet and talk with other parents of children with disabilities”.

Table 3

*Family Needs Survey Yes Responses to Needs for Information*

<table>
<thead>
<tr>
<th>I need more information…</th>
<th># Yes</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>About my child’s condition or disability</td>
<td>4</td>
<td>50</td>
</tr>
<tr>
<td>About how to handle my child’s behavior</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>About how to teach my child</td>
<td>7</td>
<td>88</td>
</tr>
<tr>
<td>About how to play with or talk to my child</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>About services that are presently available to my child</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>About services my child might receive in the future</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>About how children grow and develop</td>
<td>5</td>
<td>63</td>
</tr>
</tbody>
</table>

\[a_n = 8\]

**Explaining Diagnoses to Others.** The next most commonly endorsed scale by participants was a need for assistance in explaining their child’s autism diagnosis to others. Five participants (63%) endorsed the items, “I need more help in explaining my child’s condition to
either my spouse or my spouse’s parents” and “I need help in explaining my child’s condition to
other children”.

Table 4

*Family Needs Survey Yes Responses to Explaining to Others*

<table>
<thead>
<tr>
<th>I need more help…</th>
<th># Yes</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>In explaining my child’s condition to either my spouse or my spouse’s parents</td>
<td>5</td>
<td>63</td>
</tr>
<tr>
<td>In explaining my child’s condition to other children</td>
<td>5</td>
<td>63</td>
</tr>
</tbody>
</table>

\(^a_n = 8\)

**Community Service Needs and Financial Needs.** Participants also endorsed items regarding community and financial needs. Seventy-five percent of participants endorsed the items, “I need more help in paying for therapy, day care, or other services my child needs” and “I need help locating babysitters or respite care providers who are willing and able to care for my child”.

**Main Concerns**

Participants were asked a number of open-ended questions regarding cultural and treatment barriers for their families and children. When asked what their main concern for their child with an ASD was today, some common themes emerged. Six participants (75%) reported concern regarding their child’s future and whether or not their child would be able to lead an independent life in the future. One participant stated that she and her husband constantly worry about their son’s future and wonder, “Will he be okay when we’re not here?”. Five participants (63%) reported concern regarding their child’s social relationships and lack of social interactions with their peers. One parent reported that she was worried her son would not be able to remain in an integrated classroom in the future and another stated that her son did not fit in at school. Two
participants (25%) reported concerns regarding academic functioning and another two expressed that they worried about their child’s difficulty with language and lack of communication abilities. Only one participant expressed concern regarding her child’s aggressive behaviors.

**Cultural Barriers**

Participants were asked about specific cultural variables that negatively impact their child’s care or their overall family functioning. The most commonly endorsed variables were lack of knowledge about autism in the South Asian community (75%), South Asian cultural values (75%), and feeling judged by others within the South Asian community (75%).

Participants were also asked how South Asian cultural values impact their child’s treatment and their family’s overall functioning. The most common theme that arose from this question was a high level of secrecy regarding their child’s diagnosis. Five of the eight participants (63%) reported that they did not share their child’s ASD diagnosis with most family members and friends. Three participants (38%) reported that they did not inform their own siblings or their spouses’ siblings about the diagnosis and had no extended family involvement in their child’s treatment. They stated that they felt isolated from the rest of the South Asian community and avoided attending family functions such as weddings and other public affairs. These participants reported that they were worried that their children would be judged by family members and others within the South Asian community. One participant stated that she was afraid that the “autism label” would negatively impact her child. Another mother stated that she does not wish “to share with the community” and that she and her husband were “more comfortable with Canadian professionals than with members of [their own] community”. Two participants (25%) stated that the lack of knowledge regarding ASDs in the South Asian community resulted in negative reactions from members of the community and that this
significantly impacted their own functioning. One participant reported that although her close relatives were aware of her child’s diagnosis, members of her spouse’s family did not “acknowledge” the diagnosis and did not “realize the urgency to help him get better”. This participant reported that this denial expressed by her in-laws resulted in a lack of structure for her son, thus leading to challenges in implementing his behavioral treatment.

**The Role of Professionals**

Participants were also asked, “If you were able to talk to professionals and let them know what to change about the care that your child or you have received, what would it be?” Similar to the results of the FNS, the most prevalent theme that emerged from this question was a need for professionals to provide parents with more information regarding services available to their children. Two participants (25%) stated that they would like to receive more information on the effects of diet on ASD symptomatology and more information regarding complimentary or alternative treatments. Two other participants stated that professionals should provide more information and support to parents when their children are first diagnosed with an ASD and to clearly outline the steps that a parent needs to take upon receiving this diagnosis. One participant stated that it would be helpful to have more information about teenage girls with ASDs and more information on how to best cope with problem behaviors. Another participant reported that it would be helpful if professionals advocated for families to receive more financial support. Two participants reported that they had had very positive experiences with their behavioral consultants and teachers and did not offer any suggestions to improve the quality of services received from professionals working with ASD children.

**Helping Other Families**

When asked the question, “What do you think would help families in your same
all participants stated that more information regarding the diagnosis and treatment of ASDs would be helpful, as well as an increased awareness regarding ASDs in the South Asian community. One participant stated that it would be helpful for families if they “felt it was okay for [autism] to not be a label; if [autism] wasn’t looked upon any differently than a medical condition”. Two participants reported that support groups for South Asian parents of children with ASDs may be helpful. However, one participant also stated that parents may not attend such support groups due to the high level of secrecy they are often attempting to maintain regarding their child’s diagnosis. Two participants (25%) also reported that having more South Asian psychologists and behavioral consultants would be helpful in order to bridge some cultural and language gaps between families and professionals. One participant stated that parents should receive more information on self-care and respite services in order to avoid burnout.

**Governmental Support**

Participants were also asked how their provincial government could change or improve in order to better meet their needs. All but one participant from British Columbia (BC) stated that the BC government should increase funding and provide more tax breaks for families of children diagnosed with an ASD. Two participants (25%) suggested that the government provide greater access to information and education regarding ASDs and their treatment, especially for South Asian parents. One participant stated that increasing awareness of ASDs through the media and encouraging parents to seek help for their children may be beneficial to all South Asians families. The participant who is currently living in Alberta stated that she would not suggest anything for the Alberta provincial government to change.
Discussion

The purpose of this study was to identify diagnosis and treatment barriers for South Asian families who have children diagnosed with ASDs in Canada. The number of children being diagnosed with ASDs has continued to increase over the past few decades, as have the number of South Asians living in Canada. Prevalence rates of autism and other ASDs are equal across all racial and ethnic groups, yet the majority of research on families impacted by ASDs has been conducted with Caucasian families. Prior to this study, no previous research had investigated barriers faced by South Asian parents who have children with these diagnoses.

Overall, results appear to support the research questions and hypotheses formulated at the onset of this study. The first hypothesis was that South Asian families would report fewer hours of therapy per week for their children than the 40 hours per week that is recommended by autism researchers. This hypothesis was supported; those participants who were currently receiving ABA treatment services for their children reported an average of 13 hours of therapy per week, which is substantially lower than 40 hours per week.

It was also hypothesized that some common themes discussed by families would include financial barriers to treatment, difficulties in recruiting therapists to work with their children, perceptions of diminished quality of life, higher child caring burden, and less involvement in community activities and services. This hypothesis was mainly supported, as some common barriers to diagnosis and treatment reported by parents included inadequate funding from the government and communication problems between parents and care-providers. The parents also discussed themes related to diminished quality of life, higher child caring burden, and less involvement in community activities. However, participants did not spontaneously report difficulties in recruiting therapists to work with their children, as was hypothesized.
The final hypothesis was that in addition to the common barriers reported by families of children diagnosed with autism, South Asian families would report unique barriers that may be attributed to their cultural experiences as South Asians living in Canada. Participants did indeed report cultural barriers, which appear to be specific to South Asian groups. Such barriers included a lack of knowledge regarding autism within the South Asian community, South Asian cultural values in general, and feeling judged by others within the community. When asked by the interviewer how these barriers impacted their overall functioning, 75% of parents reported that they did not reveal their child’s ASD diagnosis to their friends and their own family members, including their parents and siblings. Parents often stated they did not feel embarrassed by their child’s diagnosis, but were afraid of what effect the “autistic” label would have on their children. Parents also reported that because of their desire to keep their child’s diagnosis hidden, they often felt isolated from family members and the South Asian community; they felt unable to attend family functions, such as weddings and birthday parties, and did not confide in their South Asian friends about the difficulties they encountered due to their child’s diagnosis and treatment. Although Caucasian families in previous studies have also reported feelings of isolation from their friends and communities, it appears as though this level of isolation may be exacerbated in South Asian families, due to the high level of secrecy surrounding their child’s ASD diagnosis. Altiere and von Kluge (2009) found that Caucasian parents, especially fathers, reported perceptions of social isolation and less understanding from their friends regarding hardships associated with their child’s diagnosis. However, these parents did not report hiding their child’s ASD diagnosis from either their family members or their friends. Therefore the perceived need to hide their child’s ASD diagnosis and subsequent social isolation appears to be a unique phenomenon in the South Asian community.
Although there were no specific hypotheses developed regarding the Family Needs Survey (FNS), it is important to note that results of the FNS indicated that the most imperative needs reported by the parents were needs for information, with the strongest need for information regarding services their child might receive in the future. All participants endorsed this item on the survey and all but one participant endorsed a need for more information about how to teach their child. The next most pressing needs endorsed by families were the need for support and the need for assistance in explaining their child’s autism diagnosis to others.

In summary, it appears as though South Asian parents who have children diagnosed with ASDs report similar barriers to treatment as those described in previous research with Caucasian families, as well as unique barriers that may not be present in other cultural or ethnic groups.

**Treatment Access and Utilization among South Asians**

Most parents in the current study reported that their children were diagnosed with an ASD by the age of 3. The results of this study support previous findings that Indian children who have comorbid medical conditions, such as epilepsy, take significantly longer than children without such comorbid disorders to receive a PDD diagnosis (Daley, 2004). The only parent in the current study who reported a comorbid epilepsy diagnosis stated that her child was not diagnosed with autism until she was between the ages of 5 and 7. However, it is important to note that this was the experience of one family in particular and may not represent a pattern that is seen in all children with comorbid medical diagnoses.

The results of the present study also suggest that young South Asian parents in Canada, who are well-educated and financially secure, still have difficulty obtaining the recommended number of therapy hours for their children diagnosed with an ASD and have difficulty effectively communicating with their care providers. These results support previous researchers’ findings
with Caucasian families who also reported insufficient funding as a significant barrier to
treatment (Grindle et al., 2009). In fact, some parents in the current study reported that their
children were receiving even fewer therapy hours per week than Lovaas’s control group in his
seminal 1987 study (Lovaas, 1989). These results are particularly unsettling, considering the
demographics of the participants in this study. Participants reported an average household
income of $100,714 Canadian dollars per year. The income level for participants in this study is
substantially higher than the average household income for South Asian Canadians, which is just
under $26,000 Canadian dollars per year (Lindsay, 2001). All participants in this study also
reported at least some post-secondary education. Therefore it can be hypothesized that parents
who earn a lower household income and who have not obtained post-secondary education may
have even more difficulty providing their children with the recommended level of treatment.

Bailey et al. (1999) stated that parental familiarity with the majority culture is more
predictive of treatment service receipt than socioeconomic status for Latino children. This
appeared to be the case in the present study, as the socioeconomic status of the families was
relatively high. However, neither familiarity with the majority culture nor acculturation was
directly assessed in the present study. Because the majority of the participants in this study,
however, were immigrants, it can be assumed that foreign-born parents had less familiarity with
the majority culture than Canadian-born participants.

Additionally, although participants in the present study appeared to be reasonably
familiar with the majority Canadian culture, their lack of experience with the Canadian mental
health system may help explain their difficulties attaining the recommended level of care for
their children. Furthermore, although parents did not spontaneously report difficulties in therapist
recruitment, the limited number of therapy hours that these children are receiving may indicate
such difficulties. Because they were not explicitly asked about such difficulties by the researcher, they may have endorsed this as a barrier to treatment if they had been explicitly asked about therapist recruitment and retention.

Although the participants’ children are receiving lower than recommended hours of ABA treatment, some South Asian parents appear to be pursuing other forms of treatment as well. Perhaps due to the lack of consensus in the medical and mental health field regarding the most effective care for children diagnosed with autism, researchers have uncovered ethnic disparities in the utilization of treatment services (Mandell & Novak, 2005). Some of these disparities may stem from discrepancies in beliefs regarding the cause of autism. Mandell and Novak (2005) reported that Asian/Pacific Islander and Latino families are less likely than Caucasian families to endorse physical and medical causes of autism, thus leading to lesser utilization of traditional medical systems for treatment. Interestingly, four participants (50%) in the present study stated that they believed vaccinations caused their child symptomatology and 50% of participants also reported using home remedies or alternative treatments to alleviate their children’s symptoms. These results may indicate that some South Asian families are more likely to endorse a belief in a biological cause of autism and subsequently utilize more alternative forms of treatment, such dairy-free diets, in order to treat their children’s ASD symptoms. This finding appears to contradict Mandell and Novak’s (2005) argument that ethnic minorities may be less likely to view ASD symptoms as related to a health condition. However, it does support the notion that ethnic minority parents may be more likely to utilize alternative forms of treatment than majority culture parents (Feinglass et al., 2007; Mandell & Novake, 2005). The use of such treatments have not yet been supported through empirical research and thus may be problematic if used in lieu of, rather than in addition to, behavioral treatments that have been scientifically-validated. If
parents believe in vaccinations as the primary cause of their children’s’ ASDs, they may be more susceptible to exploitation and potential heartbreak associated with the promise of an autism “cure”.

**Cultural Barriers to Treatment for South Asians**

Five participants in this study reported English as their primary language, and the remaining three participants reported that they were fluent in English despite other primary languages. It is surprising to note that despite this high level of fluency in English, 63% of participants endorsed communication problems with treatment providers as a specific barrier to treatment. This finding suggests that communication difficulties extend beyond language barriers and other factors may be influencing parents’ abilities to communicate effectively with their children’s treatment providers. In a study that examined communication between South Asian patients and general physicians, researchers found ethnic group differences between the length and quality of consultations; when compared to White patients, South Asian patients who were fluent in English had shorter consultation times with their physicians and physicians spent less time giving information to South Asian patients (Neal et al., 2006). Thus in spite of fluency in the dominant language, South Asian individuals are still facing communication barriers with their health care providers. One explanation for such communication barriers may be due to the omnipotence that doctors are accorded in South Asian culture (Daley, 2004). If doctors and mental health professionals are highly esteemed as experts within their fields, South Asian individuals may be less likely to question their methods or rationale for treatment, or to indicate ways in which the treatment may not be working for their family or extended family, thus leading to less effective communication between them. Additionally, physicians and mental health professionals may be interacting with patients and clients in ways that promote less open
and effective communication. However, the exact nature of these barriers is unclear at this time and may be an important area for future research.

Additionally, all six participants who were reportedly using ABA services for their children were receiving services from the same South Asian behavioral consultant. This may suggest that South Asian parents, even those who are fluent in English and have spent a substantial amount of time living in Canada, are more comfortable and perhaps better able to work with professionals who also have a South Asian ethnic background. One parent stated that it was helpful to work with a South Asian consultant because her consultant had a better understanding of the stigma around mental health diagnoses in the South Asian community and she was therefore more confident in this consultant’s likelihood to be discrete when meeting her in public.

Parents appear to be concerned with maintaining this level of discretion and confidentiality due to the lack of awareness regarding ASDs in the South Asian community. Parents reported that this lack of knowledge leads to judgments and negative reactions from others within the community. Although perceptions of negative judgments from one’s community may negatively impact any parent, regardless of ethnic or racial background, they may be especially detrimental to the functioning of South Asian parents. South Asian culture places great importance on social relatedness and adherence to social norms (Ao, 2006; Daley, 2004; Desai, 2006). Therefore South Asian individuals may experience even greater levels of distress if they perceive negative reactions to their child’s diagnosis and treatment from their family and community members.

When asked whether they had any prior knowledge of ASDs before their child was diagnosed, only three of the eight participants reported hearing the term “autism” before their
child’s diagnosis, thus illustrating how little is known regarding ASDs within this population and the public at large. Because of the perceived lack of knowledge and understanding within the South Asian community specifically, parents in this study reported a high level of secrecy surrounding their child’s diagnosis and treatment. Sixty-three percent of participants reported that they had not shared their child’s diagnosis with their own family members and close friends for fear of negative judgment. One mother reported that she was hesitant to participate in the present study because she was afraid that others might discover her child’s diagnosis. She also reported that she was in contact with another mother who had refused to participate in the study as a result of the same fear. These reports illustrate the intense anxiety and fear that these parents battle in relation to their children’s diagnosis.

This finding, along with the South Asian culture’s emphasis on family interrelatedness, suggests that the South Asian parents in the current study may experience a significant level of distress due to this secrecy. Because South Asian families often consist of more members than the nuclear family unit (Meer & Vandecreek, 2002), South Asian parents may be more significantly impacted by isolation from their extended and immediate family members than other ethnic groups. Thus, in spite of living in a country where South Asians make up one of the largest ethnic minority groups, parents feel isolated from their ethnic group, as well as their own families. This may, in turn, lead to further decreases in overall functioning and quality of life, thereby leading to parents’ decreased ability to provide the most optimal level of care for their children and themselves (Altiere & von Kluge, 2009).

**Clinical and Professional Implications**

Results of this study indicate that the most pressing need for South Asian families of children diagnosed with an ASD is a need for more information regarding services available to
their children. When asked what their main concern was for their child, most participants reported significant concern regarding their children’s future and services that may or may not be available to them as they get older. These results are similar to those found by Cassidy et al. (2008) in their study with Irish parents and caregivers of children diagnosed with autism. Cassidy et al. found that fear and uncertainty regarding their child’s future was a prevalent theme discussed by parents. The results of the present study also suggest that professionals need to provide parents with clear and easily accessible information regarding funding and treatment services that are currently available to children diagnosed with an ASD, as well as any changes in these services as their children age. Such information may currently be available for parents and therefore may need to be advertised in a more effective manner and more readily available to those parents who need it. The Autism Society of British Columbia (ASBC) provides a list of Internet sites that are devoted to providing information and support to parents of children diagnosed with ASDs and other disabilities (http://www.autismbc.ca/links.php). Other resources include websites by the Families for Early Autism Treatment of British Columbia (FeatBC, 1996; http://wwwfeatbc.org) or Feat of Alberta, which are volunteer organizations of parents and professionals working for universal access to autism treatment. Although these resources do exist and are undoubtedly beneficial for these families, it is important to note that they are not geared specifically towards South Asian individuals and may be difficult to access for those individuals who have difficulty with the English language.

Some participants in the present study also emphasized the need for a consolidated source of information that walks parents through the initial steps that must be undertaken when their child is first diagnosed with an ASD. One parent stated that information on alternative forms of treatment, such as biomedical approaches, may also allow parents to make more educated
decisions regarding their children’s care. Furthermore, although all participants in this study were fluent in English, many participants stated that ASD literature that is translated into different languages such as Punjabi and Hindi may also be beneficial for those parents who do not speak English as their primary language, as well as for extended families who are less acculturated.

Such literature may also allow for increased awareness regarding ASDs within the South Asian community in general. Most parents reported significant fear associated with perceived judgment from others within the South Asian community and felt they had no choice but to keep their child’s diagnosis a secret. This “double life”, as described by one parent, may not be perceived by parents as necessary if awareness of ASDs is increased within South Asian and Canadian society. Parents of children diagnosed with ASDs have previously reported that the majority of their social support came from their families (Cassidy et al., 2008). Thus by isolating themselves from their families, South Asian parents may be jeopardizing their overall well being, as well as their ability to provide the best level of care for their children. Because social and familial relatedness is such an integral part of the South Asian culture, the detrimental effects of social isolation may be even more pronounced for these families. Therefore health care professionals in Canada should make an active effort to increase awareness about ASD diagnoses in the South Asian community in order to improve the lives of their South Asian clients.

In addition to the need for more information, parents also reported a need for increased funding from their federal or provincial government. All participants currently living in British Columbia endorsed inadequate funding as a treatment barrier. The participant who is currently living in Alberta, however, did not. As outlined previously, the Alberta provincial government
provides almost twice as much funding for children under age 6 diagnosed with an ASD than the
government of British Columbia (Madore & Paré, 2006). For children between the ages of 6 and
18, this discrepancy increases to more than six times as much funding for children in Alberta
compared to British Columbia (MCFD, 2009). Although parents in British Columbia have been
fighting for increases in funding for years, professionals may be able to assist families in this
movement by increasing awareness of ASDs and their impact on children and families.
Professional may be able to increase awareness through the use of media outlets such as
television and radio programs, and by organizing fundraising campaigns.

In addition to providing parents with information regarding their child’s care and
increasing awareness of ASDs in the South Asian community, professionals may also help South
Asian families by creating support groups or other forms of social support for South Asian
parents who have children with disabilities. Although their fear of judgment may prevent some
parents from taking advantage of such programs, others may benefit from establishing
relationships with parents who face similar difficulties and barriers. McCabe (2008) found that
being with other parents who also have children with disabilities allowed Chinese parents to cope
with their own experiences by sharing experiences and mentoring each other. Parents reported
that interacting with other parents of children with autism allowed them to develop relationships
that were less discriminatory than the ones they experienced with others in society. Therefore a
support group specifically for South Asian parents may provide parents with a forum to practice
self-care and provide support to each other, thereby increasing their own functioning and ability
to care for their children. Moreover, an electronic mailing list or Internet forum geared specifically
towards South Asian parents and caregivers may be equally effective in providing social support,
but with more anonymity. This may provide South Asian parents with the ability to connect with
one another and make social contacts in a protected way.

**Limitations and Future Directions**

There are a number of limitations to this study that should be considered when interpreting these results. The first limitation is the nature of the study sample; the sample in this study was small in size and may not be representative of the entire South Asian population in Canada. There were only eight participants in the study, all of whom were well educated and in good financial standing. All participants were asked to volunteer between 60 and 90 minutes of their time and it is likely that those parents who chose to participate are members of a subgroup of South Asian parents who have the time and resources to be able to spend up to 90 minutes with a stranger. It is also possible that those individuals who chose to participate in the study and took the time to contact the researcher may also have the ability to overcome more treatment barriers than those who did not. Moreover, seven of the eight participants in the study were female; therefore it is possible that the results of the study may have been impacted by the gender of the parents who participated. Given these potential areas of bias within this sample, it is vital that further research be conducted with South Asian parents of children diagnosed with ASDs in order to truly gain a truly holistic picture of the treatment barriers they encounter.

In addition to recruiting a more representative sample, future research may benefit from the use of a comparison group. There is currently limited research on how the diagnosis and treatment of an ASD affects family functioning in general and therefore it may be beneficial to compare different cultural groups on family functioning in order to determine whether there are truly unique barriers encountered by different cultural and ethnic groups. The use of standardized measures in addition to the FNS may be a valuable contribution to such studies. Utilizing standardized measures, such as a measure of quality of life, a depression or anxiety scale, or an
acculturation measure, can provide a more objective understanding of these families’ experiences.

Changes in recruitment methods may also prove beneficial for future research. Attempting to recruit participants from local religious temples and other public arenas, such as local South Asian media outlets (e.g., newspapers and radio stations) that are popular amongst South Asian individuals may prove effective in reaching a larger number of participants and a more heterogeneous sample of South Asians. Furthermore, increasing the time period for recruitment and employing a snowball recruitment procedure may also allow researchers to reach more potential participants. Lastly, although this may have allowed for more comfortable interactions between participants and the principle investigator, some parents may have been deterred from participating in the current study because the principle investigator of the current study was of South Asian descent. Future researchers may benefit from further emphasizing the confidential nature of the study and from using researchers who are of other ethnic backgrounds to conduct interviews so that families may request a matched-ethnicity or different-ethnicity interviewer.

In addition to the difficulties encountered by these families, it is also important to note that those parents who participated in this study are incredibly resilient and appeared to be coping well in spite of their difficulties. It would be incredibly valuable for researchers to focus on how families who have children with ASDs cope with the many stressors associated with this diagnosis and how such coping skills can be improved in other parents who are not faring as well. Many parents in the current study expressed that in spite of the barriers they encountered, they would do nearly anything to provide the most effective care for their children. Moreover, in spite of the stress associated with their child’s diagnosis and treatment, all participants in this
study expressed that their spouses were significant sources of support for them.

Conclusions

The results of this study suggest that South Asian parents who are currently living in Canada and who have children diagnosed with an ASD are experiencing significant distress related to their children’s diagnoses. In addition to the common difficulties reported by all parents of children with these diagnoses, South Asian parents appear to encounter unique barriers to diagnosis and treatment. Although these difficulties are often faced by families alone, it is the responsibility of mental health professionals who work with this population to not only gain a better understanding of these barriers, but to also change their intervention services in order to provide more effective and culturally-sensitive services. Based on the current study, it appears that multi-level changes are required in order to meet the needs of families of children with ASDs in British Columbia and Alberta. Such changes may take the form of governmental policy changes, more private agency work, and efforts to increase public awareness of ASDs. Community-level changes that allow for direct aid to families can also help alleviate the tremendous level of stress that these families encounter on a day-to-day basis.

The purpose of this study was to gain brief, yet invaluable access to the world of South Asian parents who have children diagnosed with autism and other ASDs. It is the hope of this researcher that the information granted by these parents will be utilized by policy makers and mental health services providers to help improve the lives and overall functioning of these parents and children.
References

doi:10.1007/s10826-008-9209-y


Appendix

Interview Questionnaire
Adapted from Sanchez, 2005

Section 1. Demographic Information/Caregiver

1. **What is your age?** __________
2. **Gender** __________
3. **What is your occupation?** _______________________
   _______________________
4. **Are you married, divorced, separated, in a relationship, or single?**
   _______________________________________________________
5. **What is your household yearly income?** ______________
6. **How many people do you have living in your household?** ________
   **What is your relationship to these people?**
   _______________________________________________________
7. **What level of education have you completed?** _____________
8. **What languages do you speak?** _________________________
9. **What is your primary language?** _________________________
10. **How fluent are you in your second language?** ______________
11. **In what country were you born?** _________________________
12. **How many years have you lived in Canada?** ______________
13. **How many children do you have?** _________________________
14. Answer yes or no: in your immediate family has there been anyone who has been diagnosed with any of the following disorders?

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Parents</th>
<th>Sibling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asperger’s Disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pervasive Developmental Disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developmental Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Retardation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

15. Are any of your other children diagnosed with a disorder?

Section 2 – Demographic Information/Child

16. What is the age of your child with autism? _______________

17. What is the gender of your child with autism? ___________

18. What type of classroom is your child in? _________________

19. How old was your child when he/she received the diagnosis of autism? __________

20. Was autism the first diagnosis your child received? Yes  No

21. If no…

How many diagnoses did your child receive before he/she received the diagnosis of autism? ________________
22. Do you know the IQ number of your child with autism?

23. Does your child have any other conditions such as the following?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Retardation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Epilepsy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fragile X Syndrome</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

24. Is your child receiving treatment services at this moment? ____________

25. Where does your child receive treatment services? _____________________
    (school, private, clinic, in the home, social service agency)

26. Do you currently work with a behavioral consultant?  Yes  No

27. If yes, what level of education/qualification does your consultant have?

28. How many hours of treatment per week does your child receive?  
    _____________________

Section 3: Barriers to Diagnosis and Treatment of Autism

29. Had you any prior knowledge of autism before your child was diagnosed with this disorder?  _____________

30. What specifically made you know something was wrong with your child?  
    (People told them; they noticed symptoms)

28. Who did you first talk to after you thought something was wrong with your child?
29. Have you ever tried any home remedies to alleviate your child’s symptoms?

30. If yes, what types of home remedies?

31. What did you think was wrong with your child prior to receiving the dx of autism?

32. Why do you think your child has autism/ what is the cause?

33. Yes or No. Do you think any of the following has impacted the care of your child with autism?

<table>
<thead>
<tr>
<th>Language</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost of Tx</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Inadequate Funding</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Transportation</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Communication Problems</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Problem</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>----------------------------------------</td>
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<td>----</td>
</tr>
<tr>
<td>Lack of time in your schedule</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Problems</td>
<td></td>
<td></td>
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<tr>
<td>Marriage Problems</td>
<td></td>
<td></td>
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<tr>
<td>Personal Problems</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

34. What is the main concern you have for your child with autism today?

35. Do you think that any of the following have impacted you, your child’s development or your child’s autism treatment?

<table>
<thead>
<tr>
<th>Sensitive Issue</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of knowledge about autism in the South Asian community</td>
<td></td>
<td></td>
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<tr>
<td>Extended family involvement</td>
<td></td>
<td></td>
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<tr>
<td>South Asian cultural values</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling judged by others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling embarrassed by your child’s diagnosis or treatment</td>
<td></td>
<td></td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

36. How do you think that this affects your child’s treatment? Your family’s overall functioning?
37. If you were able to talk to the professionals and let them know what to change about the care of that your child or you have received, what would it be?

38. What do you think would help families in your same situation?
39. How do you think the BC government (or behavioral consultant) has helped you 
and what do you think they can change or improve?
Family Needs Survey
(Bailey & Simmeonsson, 1988)

Family Needs Survey
Please help us to understand the needs of your family. I will ask you a list of common needs. For each one indicate whether it is a need you actually have, if you are not sure, or if it is a need that you do not have.

<table>
<thead>
<tr>
<th>Need for Information</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I need more information about my child’s condition or disability.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I need more information about how to handle my child’s behavior.</td>
<td></td>
<td></td>
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<tr>
<td>3. I need more information about how to teach my child.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I need more information about how to play with or talk to my child.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5. I need more information about the services that are presently available to my child</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6. I need more information about the services my child might receive in the future.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>7. I need more information about how children grow and develop.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Need for Support</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. I need to have someone in my family that I can talk to more about problems.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I need to have more friends that I can talk to.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I need to have more opportunities to meet and talk with other parents of children with disabilities.</td>
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<td></td>
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<tr>
<td>11. I need to have more time just to talk with my child’s teacher or therapist.</td>
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<td></td>
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<tr>
<td>12. I would like to meet regularly with a counselor (psychologist, social worker, psychiatrist) to talk about problems.</td>
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<tr>
<td>13. I need to talk more to a religious figure who could help me deal with problems.</td>
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<tr>
<td>14. I need reading materials about other parents who have similar child to mine.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>15. I need to have more time to myself.</td>
<td></td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Explaining to others</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. I need more help in how to explain my child’s condition to his or her siblings.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I need more help in explaining my child’s condition to either my spouse or my spouse’s</td>
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</tbody>
</table>
parents.

<p>| | | |</p>
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</thead>
<tbody>
<tr>
<td>18.</td>
<td>My spouse needs help in understanding and accepting our child’s condition.</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>I need help in explaining my child’s condition to other children.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Community Services</th>
<th>Yes</th>
<th>No</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>20.</td>
<td>I need help locating a doctor who understands me and my child’s needs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>I need help locating a dentist who will see my child.</td>
<td></td>
<td></td>
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<tr>
<td>22.</td>
<td>I need help locating babysitters or respite care providers who are willing and able to care for my child.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>I need help locating a day care center or preschool for my child.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>I need help getting appropriate care for my children during religious services.</td>
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<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Financial Needs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>25.</td>
<td>I need more help in paying expenses such as food, housing, medical care, clothing, or transportation.</td>
</tr>
<tr>
<td>26.</td>
<td>I need more help in getting special equipment for my child’s needs.</td>
</tr>
<tr>
<td>27.</td>
<td>I need more help in paying for therapy, day care, or other services my child needs.</td>
</tr>
<tr>
<td>28.</td>
<td>I or my spouse need more counseling or help in getting a job.</td>
</tr>
<tr>
<td>29.</td>
<td>I need more help paying for babysitting or respite care.</td>
</tr>
<tr>
<td>30.</td>
<td>I need more help paying for toys that my child needs.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Functioning</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>31.</td>
<td>Our family needs help in discussing problems and reaching solutions.</td>
</tr>
<tr>
<td>32.</td>
<td>Our family needs help in learning how to support each other during difficult times.</td>
</tr>
<tr>
<td>33.</td>
<td>Our family needs help in deciding who will do household chores, child care, and other family tasks.</td>
</tr>
<tr>
<td>34.</td>
<td>Our family needs help deciding on doing recreational activities.</td>
</tr>
</tbody>
</table>
1. Study Title

Cultural Barriers Faced by South Asian Families in Seeking Treatment for Children Diagnosed with Autism

2. Study Personnel

<table>
<thead>
<tr>
<th>Name</th>
<th>Principal Investigator</th>
<th>Thesis Supervisor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institution</td>
<td>Pacific University</td>
<td>Pacific University</td>
</tr>
<tr>
<td>Program</td>
<td>School of Professional Psychology</td>
<td>School of Professional Psychology</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:sophiag@pacificu.edu">sophiag@pacificu.edu</a></td>
<td><a href="mailto:susanli@pacificu.edu">susanli@pacificu.edu</a></td>
</tr>
<tr>
<td>Telephone</td>
<td>(503) 906-0188</td>
<td>(503) 352-2610</td>
</tr>
</tbody>
</table>

3. Study Location and Dates

The study location and date will be agreed upon by you and the principal investigator of this study. The interview may occur in your home, or in another quiet location within the Greater Vancouver area. The interview may take anywhere between 45 and 90 minutes. If you are unable to meet in person, a telephone interview can also be arranged.

4. Study Invitation and Purpose

You are invited to participate in a research study about South Asian families who are raising children with an autism diagnosis, conducted by Sophia Grewal, B.A., from the School of Professional Psychology at Pacific University. You have been asked to participate in this study because you identify with a South Asian cultural background and have a child with an autism diagnosis. This study will help identify cultural barriers that are unique to South Asian families and therefore aid in professionals’ abilities to meet the needs of South Asian families in the treatment of autism. The purpose of this research is to help researchers and professionals who work with South Asian children with autism and their families improve their knowledge by identifying the cultural and treatment barriers experienced by such families and by gaining a better understanding of the culture experiences of the South Asian population. The responses that you provide during this interview will be used to gain a better understanding of how professionals can better help South Asian children with autism.
5. Study Materials and Procedures

You will be asked a series of questions related to cultural barriers for treatment, as well as some basic demographic questions such as the age and race of your child, and questions related to your child’s diagnosis and current treatment. You will also be asked a list of questions from the Family Needs Survey (FNS; Bailey & Simeonsson, 1988). This measure was developed to assess the functional needs of parents with young children with disabilities and will be used to gain a better understanding of your family’s needs.

6. Participant Characteristics and Exclusionary Criteria

We will be recruiting participants who identify with a South Asian ethnic background and who have one or more children with an autism diagnosis. Participants must be currently raising a child or adolescent diagnosed with autism in their home and be currently living in Canada. All participants must be fluent enough in English to comprehend and sign the informed consent forms. Those who are unable to comprehend and provide informed consent will be excluded from the study. Individuals who have biological children that are diagnosed with autism but are not currently raising their children at home will also be excluded.

7. Anticipated Risks and Steps Taken to Avoid Them

The following section provides information on possible risks and how we will address any risks that occur. We will make every effort to protect your confidentiality when addressing concerns that arise through the course of this study.

You may have a temporary negative emotional reaction to questions in the interview or when expressing concerns and experiences related to raising a child with autism. The likelihood of such a reaction is moderate and it is anticipated that such a reaction will be mild. However, it is important for you to understand that you are free to withdraw from the study at any time and that you may choose to not answer a question that you do not wish to answer. The investigator will also provide you with a list of low-cost referrals for support groups and other therapeutic services to address any distress or parenting concerns that you may have.

Another risk is the possibility of sensitive information being disclosed to the investigator by you that requires confidentiality to be broken in order to address concerns regarding danger to self or others, or ongoing acts of abuse or violence. If there is any disclosure of acts of historical or ongoing child abuse, or intentions to engage in dangerous or self-harming behaviors, confidentiality will be broken and the appropriate authorities will be notified as required by British Columbia law and our professional code of ethics. Cases of clear child abuse, including physical abuse, sexual abuse, or exploitation by the parent, both historical and present, will be reported. Any citizen of B.C. is required to report any situation in which a child needs protection to the Ministry of Children and Family Development.
8. Anticipated Direct Benefits to Participants

There are no direct financial or individual benefits to you or your child for participating in this study. However, your participation will help provide a better understanding of South Asian families who have children diagnosed with autism to researchers and professionals. You may also experience a positive reaction to expressing your needs and being provided with a forum in which you are able to describe your experiences in raising a child with autism. No treatment will be provided for your child or your family during this research project.

9. Clinical Alternatives (i.e., alternative to the proposed procedure) that may be advantageous to participants

Not applicable.

10. Participant Payment

You will not be compensated for participation in this study.

11. Medical Care and Compensation In the Event of Accidental Injury

During your participation, it is important to understand that you are not a Pacific University clinic patient or client, nor will you be receiving a complete psychological evaluation as a result of your participation in this study. If you or your child are injured during your participation in this study and it is not due to negligence by Pacific University, the researchers, or any organization associated with the research, you should not expect to receive compensation or medical care from Pacific University, the researchers, or any organization associated with the study.

12. Adverse Event Reporting Plan

Any adverse events will be reported to the supervisor of this study, as well as any appropriate authorities at Pacific University such as Pacific University’s Institutional Review Board.

13. Promise of Privacy

The only people who will be aware of your participation in this study will be the primary investigator and thesis supervisor. Any treating health care professionals will not know of your participation in this study. The researchers of this study will not know any information regarding you or your child’s treatment or the identity of any health care professionals unless you choose to reveal this to us. Any information that you provide during your interview will not be disclosed to others without written permission, except if necessary to protect your rights or welfare or if required by law. Your interview and FNS responses will be stored separately from your informed consent forms and will not include any identifying information. Your answers to the interview will be recorded on paper documents that will be identified using a confidential participant number and your name will not appear on any of these documents with responses to interview
questions. All materials will be stored in a locked briefcase or file cabinet and will be destroyed 5 years after the study is completed, as specified by the American Psychological Association. Any electronic files containing participant responses will be password protected.

If the results of this research are published or discussed in conferences, no information will be included that would reveal your identity. Any information that is obtained during this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

14. Voluntary Nature of the Study

Your decision whether or not to participate will not affect your current or future relations with Pacific University. Furthermore, it will not affect your relationship with any health care professionals, treating clinicians, or treatment clinics. If you decide to participate, you are free to not answer any questions or withdraw at any time without prejudice or negative consequences. If you choose to stop participation in the study, you can say “stop” or “no”.

15. Contacts and Questions

The researcher(s) will be happy to answer any questions you may have at any time during the course of the study. Complete contact information for the researchers is noted on the first page of this form. If the study in question is a student project, please contact the faculty advisor. If you are not satisfied with the answers you receive, please call Pacific University’s Institutional Review Board, at (503) 352 – 1478 to discuss your questions or concerns further. All concerns and questions will be kept in confidence.

16. Statement of Consent

I have read and understand the above. All my questions have been answered. I am 18 years of age or over and agree to participate in the study. I have been offered a copy of this form to keep for my records.

<table>
<thead>
<tr>
<th>Participant’s Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investigator’s Signature</td>
<td>Date</td>
</tr>
</tbody>
</table>
17. Participant contact information

This contact information is required in case any issues arise with the study and participants need to be notified and/or to provide participants with the results of the study if they wish.

Would you like to have a summary of the results after the study is completed?  ___Yes  ____No

Participant’s name: (Please Print) _________________________

Street address:  ________________________________

Telephone:  ________________________________

Email:  ________________________________