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It's all in how you see it: Predicting parents' treatment selection for their children with Autism Spectrum Disorders

Brianne Drouillard

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It's all in how you see it:
Predicting parents' treatment selection for their
children with Autism Spectrum Disorders

Brianne E. Drouillard

A Thesis
Submitted to the Faculty of Graduate Studies
through the Department of Psychology
in Partial Fulfillment of the Requirements for
the Degree of Master of Arts at the
University of Windsor

Windsor, Ontario, Canada

2012

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It's all in how you see it: Predicting parents' treatment selection for their
children with Autism Spectrum Disorders

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Declaration of Originality

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication.

I certify that, to the best of my knowledge, my thesis does not infringe upon anyone's copyright nor violate any proprietary rights and that any ideas, techniques, quotations, or any other material from the work of other people included in my thesis, published or otherwise, are fully acknowledged in accordance with the standard referencing practices. Furthermore, to the extent that I have included copyrighted material that surpasses the bounds of fair dealing within the meaning of the Canada Copyright Act, I certify that I have obtained a written permission from the copyright owner(s) to include such material(s) in my thesis and have included copies of such copyright clearances to my appendix.

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Abstract

The purpose of the present study was to identify the relations between nine dimensions of parents' cognitive representations of ASD, their acceptance of their children's ASD, and their treatment selection for their children with ASD. Parents of children with ASD aged 21 years and younger ($N = 124$) completed an online survey, with 10 of those parents completing telephone follow-up interviews. Logistic regression analyses revealed that stronger beliefs in personal control over one's child's ASD were associated with selection of medication-based treatments, while stronger beliefs in external causes of ASD were associated with selection of metabolic treatments. Correlation analyses also revealed that lower levels of acceptance were associated with selecting greater numbers of treatments, regardless of empirical support. Results suggest that programs aiming to increase parents' acceptance and teach parents to be more "research savvy" may help promote selection of evidence-based treatments for children with ASD.

Dedication

This research is dedicated to the children with ASD and their parents I have come to know and admire over the past several years. I have learned so much from all of you. Especially to the two families I have been honoured to feel a part of, I continue to find so much inspiration in your strength, courage, love, and humour. To my boys, you have taught me more about life than you will ever know. This is for you.

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would be without the three of you and I hope that I will one day have the opportunity to pay you back for all you have done for me.

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Introduction

What is ASD?

Autism Spectrum Disorders (ASD) are a group of neurodevelopmental disorders associated with impairments in communication and social interest, and the presence of stereotyped or repetitive behaviours (American Psychiatric Association [APA], 2000). Although Leo Kanner first identified what he called “autistic disturbances of affective contact” in 1943, it is only in recent decades that the general public has learned of ASD, primarily through films such as *Rainman* and *Mercury Rising*, and recent media coverage highlighting parents of children with ASD, such as celebrity mother Jenny McCarthy (Jones & Harwood, 2009). This dramatic increase in public knowledge of ASD has been accompanied by a dramatic increase in the number of children diagnosed with ASD each year (Chakrabarti & Fombonne, 2005; Prior, 2003). Presently, it is estimated that approximately 1 in 88 children have ASD (Centers for Disease Control and Prevention [CDC], 2012).

With ASD increasingly becoming a topic of public interest, the number of proposed treatments for ASD has also increased (National Autism Center [NAC], 2009), with some even claiming to offer a “cure” for children’s ASD without providing empirical support for this claim (e.g., McCarthy, 2007). Unfortunately, upon learning that their children have ASD, parents are often emotionally overwhelmed and vulnerable to believing these unsupported claims (Seigel, 1997). For this reason, parents’ treatment selection for their children with ASD is of particular interest to researchers studying methods of improving access to evidence-based services among children with ASD.

Receiving a Diagnosis of ASD

For most parents of children with ASD, receiving the diagnosis of ASD leads them to

experience mixed emotions (Gray, 1993; Mansell & Morris, 2004; O'Brien & Daggett, 2006; Siegel, 1997). Many parents have had to wait several months for diagnosis and experience a sense of relief and validation that their suspicions have finally been verified (Mansell & Morris, 2004; Midence & O'Neil, 1999; Sullivan, 1997; Wachtell & Cater, 2008). Often simultaneously, however, many parents experience shock, disbelief, and a deep sense of loss upon receiving the diagnosis (Avdi, Griffin, & Brough, 2000; Midence and O'Neill, 1999; O'Brien & Daggett, 2006; Piper & Howlin, 1992; Wachtell & Carter, 2008). It appears that, although parents have likely been concerned about their children's development for several months and may have even suspected that their children would be diagnosed with ASD, they commonly come to the assessment appointment hoping that their suspicions will not be confirmed (Gray, 1993).

In addition to the initial shock, parents often experience emotional strain because they feel they have not properly protected their children, or that they may have somehow inflicted ASD on their children; they worry about their children's future independence and realize that they must redefine their relationship with their children to accommodate this new information (O'Brien & Daggett, 2006). Particularly because their children do not differ in physical appearance from children with typical development, parents often struggle with reconciling their "post-diagnosis" child and their "pre-diagnosis" child (Mansell & Morris, 2004; O'Brien & Daggett, 2006). As such, many parents go through a phase of grieving for "the children that could have been", similar to the grieving process of parents who have experienced the deaths of their children (Mansell & Morris, 2004; Wachtell & Carter, 2008).

This process of grieving has been described as a complex experience involving shock, denial, guilt, isolation, panic, anger, bargaining, acceptance, and hope (Valman, 1981, as cited in Shapiro, 1983), with parents continuously cycling between periods of sadness, acceptance, and

stress at various points in their children's development (Tunali & Power, 1993). One parent of a child with ASD aptly described her experience within this cycle as the following: "Initial Shock – Denial, Anger, Disbelief, Why us? Why him? Why? – Acceptance – Anger to *do* something to help him/us. Tired, frustrated, sometimes calm-ish! Always on the go, worry. A yo-yo!" (Mansell & Morris, 2004, p. 404).

Although the stages of grieving experienced by parents after learning that their children have ASD share many similarities with the stages of grieving experienced by parents after the deaths of children, there are several important distinctions. First, when parents experience the deaths of children, members of their primary support system often share their grief and act as significant sources of comfort. When children are diagnosed with ASD, however, many parents experience feelings of isolation from members of their primary support system, who are often unaware of the child's diagnosis or avoid the parents because they may be unsure about how to behave around them. As Sullivan (1997) described:

The news of your child's autism does not get announced in the local paper. There is no gathering of family and friends at which your pastor solemnly announces the diagnosis. The news sits heavily on your shoulders, and it's up to you to decide how and when, or even if, you announce it. (p. 1010).

Additionally, the grieving process for parents of children with ASD occurs at the same time as they are being asked to make important decisions regarding their child's treatment and to plan for their child's future (O'Brien & Daggett, 2006). These almost contradictory demands placed on parents may serve to complicate their emotions, leading them to feel grief and hope simultaneously. Boss (1999) termed this experience "ambiguous loss" and asserted that it often leads parents to fail to adapt their family roles and routines to accommodate their child with

ASD, repress their feelings of grief and mourning, question their beliefs and value systems, experience exhaustion, and have difficulty making thoughtful decisions on behalf of their children.

Accepting the Diagnosis of ASD

With the complicated emotional reactions many parents experience in response to their child's diagnosis of ASD, it is understandable that the process of coming to accept their child's diagnosis is often quite difficult for parents. In relation to ASD, acceptance is often described as involving two components: (a) recognizing the children's realistic limitations and (b) maintaining awareness that significant improvement can occur with intervention (Mansell & Morris, 2004). In this sense, it should be noted that accepting children's diagnoses of ASD does not mean believing that the children cannot improve and, therefore, not seeking interventions to help the children achieve their full potential. In fact, an important component of acceptance is the realization that vast improvement is possible with high quality intervention.

Despite previous beliefs that parents' acceptance of their children's developmental disabilities improves over time, it has been demonstrated that parents tend to cycle between phases of despair and acceptance at various stages of their children's development (Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010). Furthermore, it has been shown that, on average, parents of children with ASD report significantly lower levels of acceptance of their children's disabilities than do parents of children with other developmental disabilities such as Down Syndrome (Zembar & Yildiz, 2010). One recent study demonstrated that two-thirds of mothers and one-half of fathers of children with ASD had not resolved (i.e., did not accept) their child's diagnosis (Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010). Although only a minority of parents of children with ASD achieve full acceptance of their child's diagnosis,

parents who have achieved this acceptance often report that coming to terms with their child's diagnosis of ASD was an integral and "life changing" step in their journeys to help their children (Midence & O'Neil, 1999; O'Brien & Daggett, 2006).

Through analyzing in-depth interviews with several parents of children with ASD, Pianta, Marvin, Britner, and Borowitz (1996) asserted that parents who had achieved acceptance of the diagnosis of ASD were able to acknowledge the positive and negative consequences of the diagnosis, did not obsess about the causes of their children's ASD, and demonstrated realistic understandings of their children's abilities and challenges. In contrast, parents who had not achieved acceptance of the diagnosis demonstrated confusion regarding several aspects of the diagnosis, held unbalanced views of the consequences of the diagnosis (i.e., all negative or all positive), lacked energy and motivation, maintained unrealistic beliefs regarding their children's abilities and challenges, and often appeared detached from their emotions in relation to the diagnosis.

Selecting Treatments for a Child with ASD

Parents are also faced with the task of selecting treatments for their children, in addition to struggling to accept the diagnosis. This is an additional task put on parents immediately upon, or sometimes prior to, receiving the diagnosis. Parents often view it as overwhelming to sort through a bewildering number of proposed treatments of unequal effectiveness (e.g., Francis, 2005; NAC, 2009; Valentine, 2010).

Importance of early, evidence-based intervention. It is now widely accepted that early intervention (i.e., intervention beginning before the age of four) is associated with the most positive outcomes for children with ASD overall (e.g., Miriam Foundation, 2008; Children's Mental Health Ontario, 2003; Rogers, 1996). Although early intervention is important for

children with many types of disabilities (Ramey & Ramey, 1998), it may be particularly important for children with ASD as previous studies have demonstrated that young children with ASD make significantly more gains through intervention than young children with other developmental disabilities such as Cerebral Palsy (Guralnick, 2005; Rogers, 1996). This finding may point to a somewhat unique neuroplasticity in young children with ASD, highlighting the need for intervention during this “critical period” of neurodevelopment (Dawson, 2008; Rogers, 1996).

With the known benefits of early intervention, many parents of children with ASD feel pressure to select treatments for their children as soon as possible, often without support from professionals (Hillman, 2006; Lilley, 2011; Valentine, 2010; Wachtell & Carter, 2008). Unfortunately, this pressure to decide quickly often leaves parents vulnerable to the claims of many empirically unsupported treatments that the treatments are effective or even offer a cure for ASD (Francis, 2005). Although there is presently no cure for ASD (Howlin & Moore, 1997; Roberts, 2004), parents often maintain hope that the ASD will one day disappear (e.g., Danta, 2006). Accordingly, parents often try empirically unsupported treatments with their children (alone or in combination with other treatments) in the hopes of miracle recovery (Christon, Mackintosh, & Myers, 2010; Mandell & Novak, 2005). Parents often feel that there is no harm in trying empirically unsupported treatments with their children. However, this approach risks wasting the time, energy, and financial resources of children with ASD and their families (Children’s Mental Health Ontario, 2003).

Additionally, many empirically unsupported treatments for ASD have been associated with serious side effects. For example, there is a lack of empirical support for medication-based treatments (used independently) for ASD (Children’s Mental Health Ontario, 2003). Although

some medication-based treatments such as Haloperidol, Risperidone, and Clomipramine have been associated with reductions in aggression, self injury, and stereotyped behaviour in individuals with ASD, they have also been associated with harmful side effects such as sedation, seizures, and dyskinesias (Children's Mental Health Ontario, 2003). The gluten/casein-free diet, touted as a "miracle cure" by celebrity mother Jenny McCarthy (e.g., McCarthy & Kartzinel, 2009), has also been found to be associated with potential medically harmful side effects such as deficiencies in essential amino acids and suboptimal bone development (Arnold, Hyman, Mooney, & Kirby, 2003; Heiger, England, Molloy, Yu, Manning-Courtney, & Mills, 2008; Mulloy, Lang, O'Reilly, Sigafos, Lancioni, & Rispoli, 2009). Similarly, although facilitated communication received significant media attention as a key which may unlock the thoughts and emotions of individuals with ASD, it has been widely discredited due to empirical evidence that it is most often the thoughts and emotions of treatment facilitators, not individuals with ASD, being communicated (Perry, Bryson, & Bebko, 1998). As such, this treatment is associated with many serious risks, including emotional distress to individuals with ASD and their families (Children's Mental Health Ontario, 2003).

What is known about parents' treatment selection. Despite the demonstrated benefits of early, evidence-based intervention and the risks of empirically unsupported treatments, empirical support is often not the most influential factor in parents' treatment selection for their children with ASD. As one study demonstrated, the four treatments parents most frequently reported selecting for their children with ASD (i.e., speech therapy, visual schedules, sensory integration, and applied behavior analysis, respectively) varied significantly in terms of empirical support (Green et al., 2006). Similarly, Wong and Smith (2006) found that 52% of parents of children with ASD report having used complementary or alternative (i.e., empirically

unsupported) treatments with their children, compared to only 28% of parents of children with typical development.

The mounting evidence that empirical support is not the most influential factor in parents' treatment selection for their children with ASD has left many clinicians and researchers wondering which factors are most important in these parents' treatment selection. Despite the importance of this question, relatively few empirical studies have been conducted on the topic and the findings are inconsistent. Callahan, Henson, and Cowan (2008) found that parents' treatment selection for their children with ASD was significantly influenced by the social validation of the proposed treatments (i.e., the social acceptability of the goals, procedures, and outcomes). This finding may be helpful in understanding why some parents continue to select facilitated communication as a treatment for their children with ASD, despite its demonstrated ineffectiveness.

There is presently conflicting evidence regarding the influence of children's characteristics on parents' treatment selection. For example, Goin-Kochel et al. (2007) found that younger children with ASD were more likely to receive behavioural treatments and older children with ASD were more likely to receive psychopharmacological treatments. Conversely, however, a more recent study found no associations between children's ages and the types of treatments selected by parents (Dardennes, Al Anbar, Prado-Netto, Kaye, Contejean, & Al Anbar, 2011). In addition, although Goin-Kochel et al. (2007) found that children diagnosed with Asperger's Disorder were more likely to receive psychopharmacological treatments than children diagnosed with Autistic Disorder or Pervasive Developmental Disorder Not Otherwise Specified, Dardennes et al. (2011) did not find a relation between the severity of children's ASD symptomology and the types of treatments selected by their parents.

These conflicting findings may be better understood by considering methodological differences between the two studies. For example, Goin-Kochel et al. (2007) used a primarily American sample of parents (i.e., 77.5% American), while Dardennes et al. (2011) used a sample of parents from France. The healthcare funding of various ASD treatments varies widely between these two countries and likely acts as a confounding variable in comparisons between these studies. In addition, the children of interest in the study by Dardennes et al. (2011) (mean age = 13.5 years) were much older than the children of interest in the study by Goin-Kochel et al. (2007) (mean age = 8.3 years). This age difference between the children from each study likely acts as another confounding variable which must be considered.

Culture may also affect parents' treatment selection for their children with ASD. One study found that Latino parents of children with ASD living in Philadelphia were six times more likely than parents of children with ASD from other cultural groups to select non evidence-based treatments for their children (Levy, Mandell, Merhar, Ittenback, & Pinto-Martin, 2003). Similarly, Mandell and Novak (2005) argued that the interaction between the cultural backgrounds of parents of children with ASD and the resources available in the community may influence parents' treatment selection.

Parents' beliefs about the causes of their children's ASD have also been shown to affect their treatment selection. For example, Dardennes et al. (2011) found that parents who blame early traumatic experiences for their children's ASD were less likely to select behaviour-based therapies and the Picture Exchange Communication System (PECS), whereas parents who attributed cause to an illness during pregnancy were more likely to select psychopharmacological treatments. Additionally, parents who believed their children's ASD to be caused by food allergies were more likely to select detoxification, special diets, and vitamin-based treatments

and less likely to select psychopharmacological treatments for their children. Finally, parents who believed that brain abnormalities were a causal factor in their children's ASD were less likely to select vitamin-based treatments for their children.

In another study, these researchers also found that parents who held external causal attributions (i.e., believed in environmental causes) were more likely to select special diets and vitamin-based treatments (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010). In Taiwan, Shyu, Tsai, & Tsai, (2010) found that parents who perceived food allergies as having caused their children's ASD were more likely to avoid certain food products, while parents who believed in supernatural causes of their children's ASD were more likely to try strategies such as consulting fortune tellers, changing the children's names, and praying.

Taken together, these findings demonstrate that parents' treatment selection appears to be influenced by several interconnected factors, rather than by any one factor alone. A qualitative study in Taiwan concluded that parents' treatment selection is influenced by their causal attributions, perceived treatment effects, children's preferences, and the fit of the children and parents with the treatment providers (Shyu, Tsai, & Tsai, 2010). Similarly, Mandell and Novak (2005) asserted that parents' perceptions and interpretations of the symptoms of ASD, their beliefs about the causes and course of the disorder, and their past experiences with healthcare providers all contribute significantly to parents' treatment selection for their children with ASD.

Self-regulation model of illness behaviour. A theoretical model which has recently been applied to the study of parents' treatment selection for their children with ASD is Leventhal's self-regulation model of illness behaviour (Leventhal, Leventhal, & Contrada, 1999; Leventhal, Meyer, & Nerenz, 1980). This model proposes that individuals form "common sense" cognitive representations of their illnesses. These cognitive representations consist of individuals'

judgments regarding five dimensions: (a) identity, (b) cause, (c) consequences, (d) timeline, and (e) control/cure. The identity dimension includes both the individual's label for the health threat (e.g., ASD, diabetes) and the symptoms the individual associates with the threat (e.g., difficulty communicating, fatigue). The cause dimension represents the individual's beliefs about the causes of the health threat (e.g., vaccines, sedentary lifestyle). The consequences dimension includes both the imagined and real ways in which the individual's life has been affected by the health threat (e.g., social isolation, loss of work time). The timeline dimension includes the individual's beliefs regarding the length of time over which the health threat developed, the duration of the health threat, and the length of time necessary for recovery. Finally, the control/cure dimension of the model represents the extent to which the individual believes the health threat can be controlled, kept from progressing, and cured.

These five dimensions of illness representations help individuals to formulate an understanding of the various aspects of their illnesses and enable them to plan their next steps in response to their health threats. Based on these cognitive representations, individuals select coping strategies to use in response to various difficulties associated with their illnesses (Leventhal, Leventhal, & Contrada, 1999; Leventhal, Meyer, & Nerenz, 1980). Additionally, individuals' cognitive representations of their illnesses have been demonstrated to predict their psychological wellbeing (Hagger & Orbell, 2003) and medication adherence (Brewer, Chapman, Brownlee, & Leventhal, 2002).

Although Leventhal's model (Leventhal, Leventhal, & Contrada, 1999; Leventhal, Meyer, & Nerenz, 1980) was originally intended to be applied to individuals' cognitive representations of their own illnesses, Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) in France have recently applied the model to study parents' cognitive representations of

ASD. They aimed to explore the associations between the treatment selection of parents of children with ASD and the illness perceptions of those parents. In this study, 89 participants completed the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002) modified for ASD, which measured the five dimensions of parents' cognitive representations of their children's ASD (i.e., illness representations). Participants also completed a demographic questionnaire and indicated which treatments they were currently using or providing for their children.

Al Anbar et al. (2010) found that parents' cognitive representations of ASD were associated with their treatment selection for their children in several specific ways. Parents who viewed ASD as having more serious consequences for themselves and their children were more likely to select what the researchers termed "educative treatments" (i.e., behaviour therapy, social skills therapy, Treatment and Education of Autistic and Communication-related handicapped Children [TEACH], and the Picture Exchange Communication System [PECS]; p. 821). Parents who held stronger beliefs in a cyclical timeline of ASD were more likely to select psychopharmacological treatments for their children. Parents who held stronger beliefs in their ability to control their children's ASD were also less likely to select metabolic treatments, such as special diets and vitamin regimens, and psychopharmacological treatments for their children. Parents who had more negative emotional reactions to the diagnosis of ASD were also less likely to select behavioural treatments for their children. The researchers found even stronger relations between parents' causal beliefs about ASD and their treatment selection for their children. Specifically, parents who had stronger external causal attributions for their children's ASD (i.e., believed their children's ASD was caused by environmental factors) were more likely to select metabolic treatments such as special diets and vitamin regimens for their children.

Although this study was pioneering in its exploration of the relations between parents' cognitive representations of ASD and their treatment selection for their children, it had some limitations. First, participants were given only a "short list of treatments" to indicate "those they were using or providing for their child" (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010, p. 820). Using this list of treatments in the study likely hindered the identification of treatments not listed. Additionally, parents were instructed to indicate only which treatments they were *presently* using or providing for their children, thus not accounting for previous and anticipated (i.e., waitlisted) treatments.

Another limitation of this study was that, although the researchers modified the identity scale of the IPQ-R (Moss-Morris et al., 2002) to include ASD-specific symptoms, they drew their items from the diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders-III- Revised (APA, 1987), which is now outdated. Finally, the researchers left the original, general causes of health concerns (e.g., stress, aging, alcohol) items on the Causes subscale of the IPQ-R (Moss-Morris et al., 2002), and did not add causes often believed to be associated with ASD (e.g., vaccines, food allergies). Therefore, this measure may not have been a valid indication of parents' causal attributions in relation to their children's ASD.

The Present Study

The present study empirically investigated the relations between parents' cognitive representations and their treatment selection for their children with ASD, as an extension of the exploratory work of Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010). The limitations of the previous study were addressed by modifying the IPQ-R (Moss-Morris et al., 2002) to include ASD-specific symptoms as outlined in the DSM-IV-TR (APA, 2000), an expanded list of treatments which allowed parents to indicate those they were currently using

with their children as well as past and planned treatments, and a list of ASD-specific causes. In addition, the present study included a measure of social desirability in order to control for this potentially confounding variable in all analyses. Since associations between parents' cognitive representations of their children's ASD and their treatment selection have only recently begun to be studied, the present study also incorporated several exploratory open-ended questions for qualitative analysis.

As the present study aimed to investigate parents' treatment selection for their children with ASD, a participatory action research (PAR) framework was utilized to ensure that the goals, methods, results, and conclusions of the study were relevant, responsible, and helpful to parents of children with ASD. PAR is a model of conducting research wherein individuals from the population of interest (e.g., parents of children with ASD) act as active collaborators in the research process, rather than passive objects of others' examination (Whyte, Greenwood, & Lazes, 1989). Although this philosophy of research is applicable to all researchers working with living participants, it is believed to be particularly valuable in better understanding and improving health service delivery to individuals from minority backgrounds (McAllister, Green, Terry, Herman, & Mulvey, 2003). Within the present study, two mothers of children with ASD acted as important collaborators (i.e., Parent Advisors) in the research process. These Parent Advisors were seen as well-qualified for the position as, in addition to each having a child with ASD, they are both employed in the ASD field, actively involved in the local ASD community, and are frequently sought out by other parents of children with ASD in the community for advice.

The original Parent Advisor for the present study helped select the topic of investigation based on her own experiences and challenges in selecting treatments for her child with ASD, and

helped to select and refine the measures to ensure that they were accessible and relevant to parents. She also had an active role in recruiting other parents of children with ASD to participate in the study. The second Parent Advisor participated in analyzing and interpreting the obtained results from the study.

As noted by McAllister, Green, Terry, Herman, and Mulvey (2003), including individuals from the population of interest as coinvestigators in public health-related research is not only a matter of respect, but also improves the ability of researchers to identify, understand, and effectively address key public health issues. As such, it is believed that this collaboration with Parent Advisors in the present study helped to ensure that all aspects of the study addressed concerns relevant to parents of children with ASD through methods that were likely to yield the most useful results for individuals with ASD and their families.

An additional contribution of the present study is that it was one of the first studies to examine parents' acceptance of their children's ASD and its associations with their treatment selection for their children. Although these associations had not been specifically studied in the past, previous research was interpreted to indicate that specific relations were expected. For example, it has been shown that parents with higher levels of acceptance of their children's ASD have more realistic understandings of the abilities and limitations of their children (Pianta, Marvin, Britner, & Borowitz, 1996). This finding was interpreted to indicate that parents with higher levels of acceptance of their children's ASD may be less likely to select non evidence-based treatments promising a "miracle cure" for their children. Boss (1999) has also asserted that parents who are still struggling with ambiguous loss and who, therefore, maintain low levels of acceptance of their children's ASD often have difficulty making thoughtful decisions on behalf of their children. This finding was interpreted to indicate that parents with lower levels of

acceptance of their children's ASD may be more susceptible to the claims of non evidence-based treatments and may be more likely to select these treatments for their children.

Several other researchers have conjectured about the relations between parents' acceptance of their children's ASD and their treatment selection. For example, in 1997, Siegel hypothesized that "Parents who are unable to accept their child's autism... are susceptible to quick fixes for autism or other treatments not supported by empirical data" (p. 758). Here again it was hypothesized that parents with lower levels of acceptance of their children's ASD will be more likely to select non evidence-based treatments for their children. Similarly, Mandell and Novak (2005) hypothesized that:

Families that believe autism is a curable condition may follow a treatment regimen designed to cure the disorder... Families that believe autism is a chronic condition whose symptoms and related disability may be alleviated but not cured may make different, perhaps more stable, treatment decisions. (p. 112)

Most recently, a more specific hypothesis regarding the relation between parents' acceptance of their children's ASD and their treatment selection has been articulated. When discussing the results of their study of the effects of acceptance on the wellbeing of fathers of children with intellectual disabilities, MacDonald, Hastings, and Fitzsimons (2010) mentioned that:

One would hypothesize that parents better able to stay with difficult emotions [i.e., parents with higher levels of acceptance] will be more likely to implement behaviour management techniques that may initially lead to increased occurrence of aversive behaviour problems or simply require parents to actively engage with their children. (p. 35).

This hypothesis suggests that parents with higher levels of acceptance of their children's ASD may be more likely to select evidence-based behavioural treatments for their children with ASD.

The purpose of the present study was to identify the relations between parents' cognitive representations of their children's ASD, acceptance of their children's ASD, and treatment selection for their children with ASD. It was believed that, if associations were found, this would have implications for clinicians working with parents during initial diagnosis and afterwards, particularly since both acceptance and cognitive representations have been demonstrated to be amenable to change through intervention (Blackledge & Hayes, 2006; Petrie, Chapman, Ellis, Buick, and Weinman, 2002).

Hypotheses

Hypotheses of the present study were based on both the findings of previous studies and on untested hypotheses previously offered by researchers studying ASD.

Hypothesis I: Cognitive representations of ASD.

1a: Belief in consequences. It was predicted that parents with cognitive representations of ASD which include higher beliefs in the severity of ASD and its impact on various aspects of their children's functioning (i.e., higher scores on Consequences subscale of the IPQ-RA-E) would be more likely to select behavioural treatments for their children (e.g., Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010).

1b: Belief in timeline. It was predicted that parents with cognitive representations of ASD which include higher beliefs in a cyclical course of ASD symptomology (i.e., higher scores on the Timeline [Cyclical] subscale of the IPQ-RA-E) would be more likely to select medication-based treatments for their children (e.g., Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010).

1c: Belief in control. It was predicted that parents with cognitive representations of ASD which include higher beliefs in personal control over ASD (i.e., higher scores on the Personal Control subscale of the IPQ-RA-E) would be less likely to select medication-based, special diets, and vitamin-based treatments for their children (e.g., Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010).

1d: External causal beliefs. It was predicted that parents with cognitive representations of ASD which include higher beliefs in external causes (e.g., pollution, diet, germ or virus, poor medical care in the past) of their children's ASD would be more likely to select special diets and vitamin-based treatments for their children (e.g., Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010).

1e: Emotional representations. It was predicted that parents with more negative emotional reactions to the diagnosis of ASD (i.e., higher scores on the Emotional Representations subscale of the IPQ-RA-E) would be less likely to select behavioural treatments for their children (e.g., Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010).

Hypothesis II: Acceptance of children's ASD.

2a: High acceptance of ASD. It was predicted that parents with higher levels of acceptance of their children's ASD (i.e., lower scores on the AAQ-II-A) would be more likely to select evidence-based treatments for their children (MacDonald, Hastings, & Fitzsimons, 2010; Mandell & Novak, 2005; Siegel, 1997).

2b: Low acceptance of ASD. It was predicted that parents with lower levels of acceptance of their children's ASD (i.e., higher scores on the AAQ-II-A) would be more likely to select non evidence-based treatments for their children (e.g., MacDonald, Hastings, & Fitzsimons, 2010; Mandell & Novak, 2005; Siegel, 1997).

Exploratory. Factors influencing parents' cognitive representations of ASD and their acceptance of their children's ASD were also explored.

Method

Participants

Respondents. Participants were 124 parents of children with ASD. In order to maximize recruitment of participants, no restrictions were placed on the gender of the parent or the geographic location of the parent in the current study. Participants were recruited by handing out flyers and speaking with parents at parenting and disability-related events in Ontario through organizations such as: the Summit Centre for Preschool Children with Autism, the Windsor-Essex Chapter of Autism Ontario, St. Mary's Family Learning Centre, and Autism Services Incorporated of Windsor and Essex County. In addition, participants were recruited through advertisements on several online forums and emails sent through parent organizations. For a complete list of the ASD-related organizations and listservs through which parents were recruited, please see Appendix A.

The majority of participants (91.1%) were mothers, White (79.8%), and identified themselves as being married or in common-law relationships (80.6%). 49.2% were in the 35 to 44 year age range. Most participants reported having graduated from college or university (75.8%) and, although many reported having an annual household income of \$75 000 and over (46%), a substantial portion (21.8%) reported having an annual household income of \$25 000 to \$49 999. Most participants were from the United States (45.2%) or Canada (25%); however, Australia, India, Indonesia, Singapore, and the United Kingdom were also represented in the sample. For more information regarding the demographic characteristics of participants, please see Table 1.

Table 1

Respondent Demographic Information

Variable	Number	(%)
Race/Ethnicity (<i>N</i> = 124)		
Black	2	1.6
Chinese	6	4.8
Filipino	3	2.4
Latin American	2	1.6
South Asian (East Indian, Pakistani, Sri Lankan, etc.)	3	2.4
Southeast Asian (Cambodian, Indonesian, Laotian, Vietnamese, etc.)	2	1.6
White	99	79.8
Other	6	4.8
Gender (<i>N</i> = 124)		
Male	10	8.1
Female	113	91.1
Age (<i>N</i> = 124)		
18 - 34 years	20	16.1
35 - 44 years	61	49.2
45 - 54 years	35	28.2
55 - 64 years	7	5.6
Marital Status (<i>N</i> = 124)		
Single	8	6.5
Married/Common Law	100	80.6
Separated	9	7.3
Divorced	6	4.8
Annual Household Income (<i>N</i> = 120)		
Under \$25,000	11	8.9
\$25,000 - \$49,999	27	21.8
\$50,000 - \$74,999	24	19.4
\$75,000 and over	57	46.0

Education ($N = 124$)

High School or Less	7	5.6
Some College/University	22	17.7
College/University or Post Graduate	94	75.8

Employment Status ($N = 122$)

Full Time	41	33.1
Part Time	35	28.2
Unemployed	42	33.9
Retired	3	2.4

Current Country of Residence ($N = 124$)

Australia	21	16.9
Canada	31	25.0
India	3	2.4
Indonesia	1	0.8
Singapore	1	0.8
United Kingdom	2	1.6
United States of America	56	45.2

Children. The age of the parents' children was restricted to 21 years and under in the present study, as the National Standards Report – which was used in the present study to classify treatments in terms of their levels of empirical support – reviewed the efficacy of proposed treatments for children with ASD only under the age of 21 (NAC, 2009). The majority of children (84.7%) were male, White (74.2%), and their mean age was 8.83 years. All parents reported that their children had received diagnoses on the Autism Spectrum. Their mean age at diagnosis was 47.87 months. For more information regarding the demographic characteristics of participants' children, please see Table 2.

Table 2

Children Demographic Information

Variable	Number	(%)
Race/Ethnicity (<i>N</i> = 123)		
Black	3	2.4
Chinese	4	3.2
Filipino	2	1.6
Latin American	3	2.4
South Asian (East Indian, Pakistani, Sri Lankan, etc.)	3	2.4
Southeast Asian (Cambodian, Indonesian, Laotian, Vietnamese, etc.)	1	0.8
White	92	74.2
Other	13	10.5
Gender (<i>N</i> = 123)		
Male	105	84.7
Female	18	14.5

Materials

Since the present study took place online, the following questionnaires were provided in electronic format to participants. Therefore, some elements of the formatting were adapted to accommodate this type of survey distribution. The instructions, items, and rating systems remained unchanged, however.

Demographic Questionnaire. The questionnaire, designed for this study, consisted of 14 items regarding parent and child demographics (e.g., gender, age, marital status, income, education, employment status, age at diagnosis, and race/ethnicity) and 1 item regarding treatments selected in the past, currently being used, or for which parents are currently waitlisted. For a copy of the demographic questionnaire, please see Appendix B. The list of treatment options was compiled in accordance with the 37 intervention strategies reviewed by the National Autism Center (2009). As shown in Table 3, the National Autism Center (2009) classified 11 treatments as empirically “established”, 21 treatments as “emerging”, and 5 treatments as “unestablished” by reviewing the supporting research evidence and rating each treatment according to the Scientific Merit Rating Scale (SMRS: NAC, 2009).

The National Autism Center evaluated five dimensions of the supporting evidence in order to assign a SMRS rating between 0 and 5 to each proposed treatment: (1) research design, (2) measurement of the dependent variable, (3) measurement of the independent variable or procedural fidelity, (4) participant ascertainment, and (5) generalization (National Standards Report, NAC, 2009). SMRS ratings of 3, 4, or 5 indicate that the treatment has been studied with sufficient scientific rigor to say that the treatment is “established”. SMRS ratings of 2 indicate that the treatment is “emerging”, but that there is not yet enough empirical support behind the treatment to classify it as established. SMRS ratings of 1 or 0 indicate that the

Table 3

National Autism Center Classifications of each Reviewed Intervention

Established	Emerging	Unestablished
Antecedent package	Augmentative/alternative communication device	Academic interventions
Behavioural package	Cognitive behavioural intervention package	Auditory integration training
Comprehensive behavioural treatment for young children	Developmental relationship based treatment	Facilitated communication
Joint attention intervention	Exercise	Gluten/casein-free diet
Modeling	Exposure package	Sensory integrative package
Naturalistic teaching strategies	Imitation-based interaction	
Peer training package	Initiation training	
Pivotal response treatment	Language training (production)	
Schedules	Massage/touch therapy	
Self management	Multi-component package	
Story-based intervention package	Music therapy	
	Peer-mediated instructional arrangement	
	Picture exchange communication system	
	Reductive package	
	Scripting	
	Sign instruction	
	Social communication intervention	
	Social skills package	
	Structured teaching	
	Technology-based treatment	
	Theory of mind training	

*Note. Classifications based on the Scientific Merit Rating Scale, developed by the National Autism Center.

treatment is “unestablished”, as it has not yet been studied with sufficient scientific rigor to substantiate any claims of efficacy in treating ASD.

Revised Illness Perception Questionnaire- Autism (English). For the purposes of the present study, the Revised Illness Perception Questionnaire-Autism (English) (IPQ-RA-E) was created by further modifying the Revised Illness Perception Questionnaire first adapted for ASD by Al Anbar, Dardennes, and Kaye (2010) in France. Permission to use and modify this measure was obtained from Dardennes (see Appendix C). For a copy of this revised measure, please see Appendix D.

The Illness Perception Questionnaire (IPQ: Weinman, Petrie, Moss-Morris, & Horne, 1996) was originally developed to quantify individuals' illness representations in accordance with Leventhal's self-regulation model of illness behaviour (Leventhal, Meyer, & Nerenz, 1980). Unfortunately, low internal consistency within two of the subscales was a limitation of the measure in its original form (Moss-Morriss, Weinman, Petrie, Horne, Cameron, & Buick, 2002). Moss-Morris and colleagues (2002) developed the revised Illness Perception Questionnaire (IPQ-R) to improve the internal consistency of the Control/Cure and Timeline subscales, and to include newer components of Leventhal's self-regulation model of illness behaviour (Leventhal, Leventhal, & Contrada, 1999): cyclical timeline perceptions, illness coherence, and emotional representations of illness. The IPQ-R is comprised of 73 items representing nine subscales designed specifically to measure the various aspects of illness representations proposed by Leventhal's self-regulation model of illness behaviour (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Leventhal, & Contrada, 1998): identity, causes, timeline (acute/chronic), timeline (cyclical), consequences, personal control, treatment control, emotional representations, and illness coherence.

The Identity subscale of the IPQ-R is designed to measure the number of symptoms an individual experiences and the number of symptoms an individual directly attributes to his/her illness. This subscale is quantified by summing the number of symptoms experienced and the number of symptoms attributed to the illness (e.g., pain, sleep difficulties). On the remaining subscales of the IPQ-R, individuals indicate on a 5-point Likert-type scale ranging from “strongly disagree” to “strongly agree” the extent to which they agree or disagree with a series of statements. The Cause subscale of the IPQ-R is designed to measure an individual’s beliefs about the causes of his/her illness (e.g., stress or worry, hereditary). The Timeline (Acute/Chronic) subscale of the IPQ-R is designed to measure how chronic the individual perceives the illness to be (e.g., “My illness will last a short time”), while the Timeline (Cyclical) subscale of the IPQ-R is designed to measure how cyclical or episodic an individual perceives the course of the illness to be (e.g., “My symptoms come and go in cycles”).

The Consequences subscale of the IPQ-R is designed to measure the negative consequences an individual perceives are related to his/her illness (e.g., “My illness strongly affects the way others see me”). The Personal Control subscale of the IPQ-R is designed to measure the amount of control an individual feels over his/her illness (e.g., “There is a lot which I can do to control my symptoms”). The Treatment Control subscale of the IPQ-R is designed to measure the extent to which the individual feels that the illness can be controlled or cured through treatment (e.g., “My treatment will be effective in curing my illness”). The Emotional Representations subscale of the IPQ-R is designed to measure an individual’s positive or negative emotional reactions to the illness (e.g., “I get depressed when I think about my illness”). Finally, the Illness Coherence subscale of the IPQ-R is designed to measure the extent to which the individual understands the illness (e.g., “The symptoms of my condition are puzzling to

me”).

The psychometric properties of the IPQ-R have been studied extensively and are accepted as an improvement over those of the original IPQ (Figueiras & Alves, 2007; Moss-Morriss et al., 2002; Wittkowski, Richards, Williams, & Main, 2008). Adequate construct validity of the nine subscales has been demonstrated through exploratory and confirmatory factor analyses (Hagger & Orbell, 2003; Moss-Morriss et al., 2002). The nine subscales of the IPQ-R have good internal reliability, with Cronbach's alpha values ranging from .79 (Timeline Cyclical) to .89 (Timeline Acute/Chronic) (Moss-Morriss et al., 2002). The three-week test-retest reliability for each subscale of the IPQ-R range from .46 to .88, with only the Personal Control subscale having a correlation below .50 (Moss-Morriss et al., 2002). The test-retest reliability for each subscale of the IPQ-R has also been examined over six months, demonstrating correlations greater than .5 for all subscales except the Timeline Cyclical subscale.

The subscales of the IPQ-R have adequate discriminant validity with the Positive and Negative Affect Scale (Watson, Clark, & Tellegen, 1988), with correlations ranging from .01 to .36 (Moss-Morris et al., 2002). Only the Emotional Representations subscale correlated somewhat highly (.54) with negative affect. The subscales of the IPQ-R have also been shown to have adequate known group validity by producing significantly different scores from individuals with acute pain and individuals with chronic pain (Moss-Morriss et al., 2002). In addition, illness representations have been shown to account for an additional 15% of variance in Sickness Impact Profile scores (Bergner, Bobbitt, Carter, & Gilson, 1981) above the 42% of variance accounted for by illness severity, demonstrating predictive validity (Moss-Morriss et al., 2002). Additional evidence of the predictive validity of the IPQ-R is that illness representations have been shown to significantly account for 27% of the variance in physical fatigue and 20% of the

variance in mental fatigue (Moss-Morriss et al., 2002).

The IPQ-R was first revised for use with parents of children with ASD in 2005 by Al Anbar, Dardennes, and Kaye. The IPQ-RA (Al Anbar, Dardennes, & Kaye, 2005) consists of 73 French language items measuring the same nine subscales as the IPQ-R: Identity, Causes, Timeline (Acute/Chronic), Timeline (Cyclical), Consequences, Personal Control, Treatment Control, Emotional Representations, and Illness Coherence. Al Anbar, Dardennes, and Kaye (2005) did, however, modify the phrasing of IPQ-R items to assess parents' representations of their children's ASD instead of individuals' representations of their own illnesses and by changing the word "illness" in the IPQ-R to the word "disorder" in the IPQ-RA. This was thought to more accurately reflect the nature of ASD. The symptom checklist in the identity scale was also modified to include the symptoms of ASD outlined in the Diagnostic and Statistical Manual of Mental Disorders-III- Revised (APA, 1987).

With the permission of the authors of the IPQ-R and the IPQ-RA, the IPQ-RA-E was designed by modifying the IPQ-RA in three ways: (1) presenting items in English using the phrasing from the original IPQ-R (Moss-Morriss et al., 2002), (2) updating the Identity subscale to include the symptoms of ASD outlined in the Diagnostic and Statistical Manual of Mental Disorders-IV-TR (APA, 2000), and (3) modifying the Cause subscale to include statements pertaining to causes more specifically associated with ASD (e.g., vaccine injury). These ASD-specific causes were developed using those mentioned in Furnham and Buck's (2003) Lay Beliefs about Autism Questionnaire (as has been done by Dardennes, Al Anbar, Prado-Netto, Kaye, Contejean, and Al Anbar [2011]) as well as additional causes popularly cited by parents of children with ASD. This new IPQ-RA-E consists of 78 items.

Acceptance and Action Questionnaire-II (Autism). The Acceptance and Action Questionnaire-II (AAQ-II: Bond et al., in press) was used in the present study to assess parents' acceptance of their children's ASD. Permission to use and modify this measure was obtained from Bond (see Appendices E and F, respectively). For a copy of this revised measure, please see Appendix G.

Originally, the AAQ-II was designed to assess individuals' general tendencies toward acceptance (i.e., "the willingness to experience unwanted private events, in order to pursue one's values and goals", [Hayes, Wilson, Gifford, Follette, & Strosahl, 1996]). It was designed to address the weaknesses of comprehension and reliability inherent in the original AAQ developed by Hayes et al. (2004). The AAQ-II is comprised of 10 items which are rated on a 7-item Likert scale ranging from "never true" to "always true" (e.g., "It's OK if I remember something unpleasant").

The psychometric properties of the AAQ-II have been studied recently in 2816 participants across six samples (Hayes et al., 2011) and it was concluded that the AAQ-II measures the same construct as the original AAQ ($r = .97$), but has the advantage of improved psychometric consistency. The AAQ-II has demonstrated good internal reliability, with Cronbach's alpha coefficients of the six tested samples ranging from .78 to .88 (Hayes et al., 2011). In addition, the AAQ-II has good three-month test-retest reliability, with a correlation of .81, and twelve-month test-retest reliability, with a correlation of .79 (Hayes et al., 2011).

In terms of predictive validity, higher scores on the AAQ-II (i.e., more experiential avoidance) have been found to be associated, as expected, with higher scores on the Beck Depression Inventory-II (Beck, Steer, & Brown, 1996), higher scores on the Depression Anxiety Stress Scales (Lovibond & Lovibond, 1995), and greater psychological distress one year later

(Bond & Hayes, 2002) as measured by the General Health Questionnaire (Goldberg, 1978). The AAQ-II has also demonstrated adequate convergent validity with the White Bear Suppression Inventory (Wegner & Zanakos, 1994), with a correlation of .63 (Bond et al., 2002). In addition, the AAQ-II has demonstrated excellent divergent validity with the Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1960), with a nonsignificant correlation of -.09 between these two measures (Bond et al., 2002).

For the purposes of the present study, the AAQ-II was modified to create the Acceptance and Action Questionnaire-II (Autism) (AAQ-II-A) by rephrasing the 10 items to refer specifically to individuals' acceptance in relation to their children's ASD (e.g., "It's OK if I remember something unpleasant about my child with ASD"). This type of modification has also recently been performed by MacDonald, Hastings, and Fitzsimons (2010) in order to measure parents' acceptance of their children's intellectual disabilities.

Marlowe-Crowne Social Desirability Scale- Short Form. Although the AAQ-II has been found not to be significantly associated with the Marlowe-Crowne Social Desirability Scale (Bond et al., 2011), this relation has not yet been studied using the AAQ-II-A or the IPQ-RA-E. As such, the Marlowe-Crowne Social Desirability Scale- Short Form (MCSDS-SF: Strahan & Gerbasi, 1972) was included in the present study in order to control for possible confounds within these measures. Permission to use this measure was not necessary to obtain, since this measure is in the public domain. For a copy of this measure, please see Appendix H.

The original MCSDS (Crowne & Marlowe, 1960) was developed in order to detect and quantify individuals' (intentional or unintentional) attempts to present themselves in a socially desirable or undesirable light. It was comprised of 33 items consisting of statements which respondents are asked to judge as "true" or "false" based on their experiences (e.g., "I never

hesitate to go out of my way to help someone in trouble”).

In terms of psychometric properties, the original MCSDS has demonstrated good internal reliability, with a calculated reliability coefficient of .88 using the Kuder-Richardson formula (Crowne & Marlowe, 1960). Additionally, the MCSDS has also been demonstrated to have excellent one-month test-retest reliability, with a correlation of .89 between tests (Crowne & Marlowe, 1960). As expected, the MCSDS is also significantly correlated ($r = .35$) with the Edwards Social Desirability Scale, demonstrating convergent validity with this measure (Crowne & Marlowe, 1960).

As the present study involved several measures, a short form of the original MCSDS, developed by Strahan and Gerbasi (1972), was used in order to minimize potential fatigue effects and strain on participants. The MCSDS short form (MCSDS-SF; Strahan & Gerbasi, 1972) is comprised of ten items from the original MCSDS (Crowne & Marlowe, 1960; e.g., “I’m always willing to admit when I make a mistake”, “I like to gossip at times”). The MCSDS-SF has demonstrated adequate internal reliability, with calculated reliability coefficients ranging from .59 to .70 in four different populations (Strahan & Gerbasi, 1972). In addition, the MCSDS-SF has demonstrated excellent convergent validity with the original MCSDS, with a correlation above .80 between the measures (Strahan & Gerbasi, 1972).

Open-Ended, Exploratory Survey Questions. Four open-ended, exploratory survey items were developed specifically for the present study in addition to the previously mentioned quantitative measures. Please see Appendix I for a copy of these open-ended items. These items provided parents with the opportunity to respond freely to questions surrounding their goals for treatment programs, the most important factors in their treatment selection, how their feelings about ASD have changed since initial diagnosis, and their conceptualizations of ASD.

In-Depth Interview Questions. In an effort to develop a more in-depth understanding of how parents think of ASD, acceptance, and treatment selection, a semi-structured follow-up interview protocol was also developed. This interview consisted of a series of six questions designed to provide additional insight into parents' responses to the online questionnaire items. Parents were asked about what ASD means to them, what has influenced the way they think about ASD, what it means to accept one's child's ASD, what has influenced their acceptance, what challenges they have experienced in selecting treatments, and what advice they would like to offer other parents of children with ASD. Please see Appendix J for a copy of these in-depth interview questions.

Procedure

Participants were asked to follow the link provided in the recruitment advertisements and flyers to an Internet website that had been set up for the current study. Upon navigating to the Internet site, participants were presented with a consent form to participate in the online study. This form contained information regarding the potential benefits and risks of participating in the present study. Please see Appendix K for a copy of this consent form. For the purposes of the study, clicking the "Yes" in response to the item "I consent to participate" was taken to indicate that participants had given their informed consent to participate.

Next, participants were presented with the demographic questionnaire, as Reips (2011) demonstrated that early presentation of demographic items is associated with lower dropout rates and fewer missing data in online research. The IPQ-RA (English), the AAQ-II (A), and the MCSDS were then presented in counterbalanced order (determined by the child's birth month) to control for possible fatigue effects. That is, each participant completed each of these three measures, but their order of presentation varied between participants. At this time, participants

had the option to respond to several open-ended questions designed to gather exploratory information regarding factors influencing their cognitive representations of ASD and their treatment selection for their children. These questionnaires (including both the survey items and the open-ended items) took participants an average of 51.13 minutes to complete. Although this completion time was longer than the originally estimated completion time based on pilot testing with a Parent Advisor (20 minutes), it should be noted that the online administration format of the survey allowed parents to leave their computers or take short breaks between items. It is believed that this flexible administration is largely responsible for the longer completion time in the actual study.

Once all measures were completed, participants were asked to enter their email addresses if they wanted to participate in a draw for one of ten \$20 electronic gift cards as a token of thanks for participating. This draw took place upon completion of data collection for the present study. Several smaller incentives were offered in the present study rather than fewer larger incentives in order to afford participants greater likelihood of being selected and because the monetary value of incentives has been found to be unrelated to response quality in online research (Goritz, 2004). By presenting participants with an electronic gift card as an incentive, participants' home addresses did not need to be obtained, maximizing the participant confidentiality and privacy. Finally, participants were asked to indicate whether they agreed to be contacted by the primary researcher for a follow-up interview over the telephone. All participants were then presented with a printable letter of information describing the background, purpose, and hypotheses of the current study. This post-study letter of information also contained links to the National Standards Report (NAC, 2009) and the Evidence-Based Practices for Children and Adolescents with Autism Spectrum Disorders report (Children's Mental Health Ontario, 2003), which contain

thorough reviews of the empirical evidence for several proposed treatments for ASD and recommendations for parents when selecting treatments for their children. For a copy of this post-study letter of information, please see Appendix L.

From the participants who agreed to be contacted for the follow-up telephone interview, ten were selected by convenience to complete these more in-depth interviews. Although only participants living in the United States and Canada were selected, an effort was made to include participants from diverse areas of these two countries. These participants were contacted by telephone, explained what the interview would involve, and assured that confidentiality would be strictly respected. Interviews were then scheduled with participants who had given their informed consent to the primary investigator orally. These interviews took place over the telephone and required approximately twenty minutes to complete. Interviews were digitally recorded and later transcribed by trained undergraduate research assistants. All data were collected between June 21, 2012 and August 9, 2012.

Results

Preliminary Analyses

Before beginning the tests of hypotheses in the present study, the data set was assessed to identify missing data and outliers. A total of 12 cases were excluded listwise from subsequent analyses due to a survey host error which resulted in failing to present these participants with the demographic questionnaire. Only the remaining 134 cases were included for further examination. Since missing data comprised only 1.44% of this data set, cases containing missing data were excluded listwise from analyses, as recommended by Schafer (1999). Within the data set, a total of 5 outliers (i.e., values greater than 2.5 standard deviations from the mean) were identified and were excluded from subsequent analyses because it appeared that these participants had meaninglessly endorsed items (e.g., selected "1" for every item in a questionnaire). An additional 3 participants were excluded from analyses because their children were born prior to 1991. This left a total of 124 cases in the present data set.

In addition, the extent to which the assumptions of logistic regression had been met in the data set was determined for the first set of hypotheses. These assumptions include: (a) statistical independence of outcomes, (b) linearity of the logit, (c) multicollinearity, and (d) adequate sample size (i.e., 50 participants per predictor variable) (Field, 2009; Wright, 2000). Since each participant completed the online questionnaire only once, the assumption of independence of outcomes was said to have been met. Examination of interactions between predictors and their log transformations did not reveal any significant violations of the assumption of linearity of the logit. Tolerance values were greater than 0.1 and Variance Inflation Factor (i.e., VIF) values were less than 10 for each predictor variable, indicating no issues with multicollinearity in the present data set. Finally, with a total of 124 participants and no more than two predictor

variables per logistic regression analysis, the assumption of adequate sample size was met in the present data set.

Since the second set of hypotheses in the present study was tested using bivariate correlations (Pearson's r), the extent to which the assumptions of this method of data analysis had been met in the present data set was determined as well. These assumptions include: (a) interval-level data and (b) a normally-distributed sampling distribution (Field, 2009). The AAQ-II-A and the section of the Demographic Questionnaire concerning treatments selected by parents both yield interval-level data, so this assumption was said to have been met in the present data set. Additionally, the extent to which the assumption of normally-distributed variables was met in the present data set was determined by examining skewness values, kurtosis values, and histograms for the variables of interest.

For all variables, the skewness values were between -2 and 2, indicating appropriate symmetry of the distributions for the variables (Cohen, Cohen, West, & Aiken, 2003). For all variables, the kurtosis values were between 3 and -3, indicating roughly mesokurtic distributions (i.e., distributions with appropriately high peaks and sharp tails) (Cohen, Cohen, West, & Aiken, 2003). Finally, visual inspection of the histograms for each variable revealed distributions approximating normality. Thus, the assumption of normally-distributed variables was said to have been satisfied in the present data set.

Descriptive statistics. Participants in the present study completed measures of the treatments they had selected for their children with ASD, their acceptance of their children's diagnosis of ASD, and several aspects of their cognitive representation of ASD. The descriptive statistics for these study variables are outlined below.

Treatments selected. Parents in the present study reported selecting several treatments for their children with ASD. The five most commonly selected treatments were antecedent package, behavioural package, academic interventions, schedules, and gluten/casein-free diet, respectively. Please see Table 4 for a detailed view of parents' selections. The treatments selected by parents were also categorized into levels of empirical support (i.e., established, emerging, or unestablished) according to the National Standards Report (NAC, 2009). Parents reported selecting an average of 16 treatments for their children with ASD, the majority of which were classified as empirically "emerging". Please see Table 5 for a detailed view of the levels of empirical support of treatments selected by parents of children with ASD.

Table 4

Treatments/Interventions Selected by Parents

Intervention	Total		Past		Present		Waitlist	
	#	%	#	%	#	%	#	%
Antecedent package	98	79	32	25.8	51	41.1	15	12.1
Behavioural package	89	71.8	24	19.4	54	46.9	10	8.1
Academic interventions	87	70.2	21	16.9	54	43.5	12	9.7
Schedules	81	65.3	24	19.4	57	46	1	0.8
Gluten/casein-free diet	76	61.3	33	26.6	31	25	12	9.7
Social skills package	76	61.3	22	17.7	44	35.5	9	7.3
Comprehensive behavioural treatment for young children	73	58.9	27	21.8	33	26.6	11	8.9
Language training (production)	72	58.1	24	19.4	39	31.5	9	7.3
Auditory integration training	71	57.3	28	22.6	8	6.5	17	13.7
Story-based intervention package	70	56.5	29	23.4	35	28.2	6	4.8
Sensory integrative package	68	54.8	26	21	28	22.6	13	10.5
Exercise	67	54	12	9.7	50	40.3	4	3.2
Cognitive behavioural intervention package	61	49.2	11	8.9	37	29.8	13	10.5
Modeling	60	48.4	24	19.4	27	21.8	10	8.1
Naturalistic teaching strategies	60	48.4	16	12.9	36	29	9	7.3
Augmentative/alternative communication device	57	46	16	12.9	30	24.2	10	8.1
Developmental relationship-based treatment	57	46	19	15.3	23	18.5	14	11.3
Initiation training	57	46	17	13.7	32	25.8	8	6.5
Language training (production and understanding)	57	46	11	8.9	35	28.2	11	8.9
Self management	57	46	24	19.4	23	18.5	10	8.1
Social communication intervention	54	43.5	15	12.1	22	17.7	17	13.7
Joint attention	53	42.7	10	8.1	31	25	12	9.7

intervention								
Scripting	53	42.7	22	17.7	21	16.9	10	8.1
Massage/touch therapy	52	41.9	27	21.8	19	15.3	6	4.8
Picture exchange communication system	52	41.9	25	20.2	19	15.3	6	4.8
Sign instruction	44	35.5	28	22.6	11	8.9	5	4
Music therapy	41	33.1	22	17.7	9	7.3	9	7.3
Peer-mediated instructional arrangement	38	30.6	10	8.1	20	16.1	8	6.5
Peer training package	38	30.6	12	9.7	17	13.7	9	7.3
Structured teaching	36	29	10	8.1	15	12.1	11	8.9
Exposure package	32	25.8	6	4.8	14	11.3	12	9.7
Imitation-based interaction	32	25.8	13	10.5	14	11.3	5	4
Pivotal response treatment	30	24.2	9	7.3	9	7.3	12	9.7
Technology-based treatment	30	24.2	4	3.2	15	12.1	11	8.9
Facilitated communication	29	23.4	5	4	13	10.5	10	8.1
Multi-component package	27	21.8	7	5.6	9	7.3	11	8.9
Theory of mind training	27	21.8	6	4.8	8	6.5	13	10.5
Other	21	19.4						
Reductive package	16	12.9	3	2.4	3	2.4	11	8.9

**Note.* Some parents did not indicate when they had used each treatment with their children.

Table 5

Number of Treatments Selected with each Level of Empirical Support

Empirical Classification	<i>N</i>	<i>M</i>	<i>SD</i>	Min.	Max.
Established	121	5.76	3.29	0	11
Emerging	122	7.94	6.11	0	21
Unestablished	124	2.52	1.47	0	5
Total	119	16.26	10.27	0	37

**Note.* Empirical classifications are in accordance with the National Standards Report (NAC, 2009).

Acceptance. Participants completed the AAQ-II-A as a measure of their acceptance of their children's diagnosis of ASD. Recall that higher scores on the AAQ-II-A represent lower levels of acceptance. Table 6 displays the descriptive statistics for the AAQ-II-A.

Cognitive representations of ASD. Participants completed the IPQ-RA-E as a measure of their cognitive representations of their children's ASD. For the purposes of the present study, the Consequences, Cyclical Course, Personal Control, and Emotional Representations subscales were of interest. Table 6 also displays the descriptive statistics for these subscales of the IPQ-RA-E.

Table 6

Descriptive Statistics for Study Variables

Measure/Subscale	<i>N</i>	<i>M</i>	<i>SD</i>	Min.	Max.
IPQ-RA-E					
Consequences Subscale	124	23.96	4.36	13	30
Cyclical Course Subscale	122	11.76	3.19	5	20
Personal Control Subscale	124	23.30	4.98	9	30
Emotional Representations Subscale	122	16.31	7.11	1	30
AAQ-II-A	123	53.93	9.48	29	70

**Note.* Higher scores on the AAQ-II-A represent lower levels of acceptance.

Tests of Hypotheses

Since the outcome variables for Hypothesis I (a through e) were dichotomous (i.e., “use” or “non-use” of behavioural, medication-based, or metabolic treatments), binomial logistic regressions were used in these analyses (Cohen, Cohen, West, & Aiken, 2003). Although discriminant analysis may also be used in examining relations between several predictors and a categorical dependent variable, this type of analysis has more restrictive assumptions (e.g., normally-distributed predictors; Wright, 2000); thus, logistic regression was used in the present study. Predictor variables were entered hierarchically in order of their predictive power as demonstrated by Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010). The bonferonni adjustment for multiple tests was not used in these analyses in accordance with the recommendations of Perneger (1998). Since there were only three statistical tests being performed and hypotheses were informed by previous research, applying the bonferonni adjustment would likely have over-inflated the type-II error rate (i.e., the chances of failing to detect a truly significant result) in the present study. Instead, Perneger’s (1998) recommendation of simply describing each test of significance performed was followed.

Prior to conducting any tests of hypotheses, bivariate correlations between parents’ scores on the MCSDS-SF and the other variables of interest were examined. Since parents’ scores on the MCSDS-SF were not significantly correlated with parents’ scores on any of the other variables of interest, it was unnecessary to include social desirability as a control variable in subsequent analyses.

Hypothesis I: Cognitive representations of ASD. Table 7 presents a summary of the results of the logistic regression analyses testing this first set of hypotheses.

Table 7

Logistic Regression Analyses Predicting Types of Treatments Selected

Step	Variables Entered	B	SE	Wald's χ^2	R^2	e^B	95% CI for Exp(B)	
							Lower	Upper
Behavioural Treatments								
1	Belief in Consequences	0.08	0.05	2.16	0.03	1.08	0.97	1.20
2	Emotional Representations	0.03	0.04	0.37	0.03	1.03	0.94	1.11
Medication-Based Treatments								
1	Belief in Cyclical Timeline	-0.08	0.13	0.40	0.01	0.92	0.70	1.20
2	Belief in Personal Control	0.43	0.21	4.12*	0.21	1.54	1.01	2.33
Metabolic Treatments								
1	Belief in External Causes	0.33	0.10	11.51**	0.18	1.40	1.15	1.69
2	Belief in Personal Control	0.02	0.05	0.19	0.19	1.02	0.92	1.13

* $p < .05$, ** $p = .001$.

1a: Belief in consequences. Higher beliefs in the severity of ASD and its impact on various aspects of one's child's functioning did not significantly predict group membership for selecting behavioural treatments, Block $\chi^2(1, N = 124) = 1.08, ns$. Therefore, this hypothesis was not supported in the present study.

1b: Belief in timeline. Higher beliefs in a cyclical course of ASD symptomatology did not significantly predict group membership for selecting medication-based treatments, Block $\chi^2(1, N = 124) = 0.40, ns$. Therefore, this hypothesis was not supported in the present study.

1c: Belief in control. Higher beliefs in personal control over one's child's ASD significantly predicted group membership for selecting medication-based treatments, Block $\chi^2(1, N = 124) = 4.12, p < .05$, correctly predicting 93.7% of participants' group membership. This model accounted for approximately 21% of the variation in parents' selection of medication-based treatments for their children with ASD (Nagelkerke $R^2 = 0.21$). Belief in personal control over one's child's ASD was the only significant predictor of selecting medication-based treatments ($B = 0.43, Wald = 4.12, p < .05$). Parents with greater beliefs in their personal control over ASD were more likely to select medication-based treatments for their children (odds ratio = 1.54; 95% CI = 1.01 to 2.33). Therefore, this hypothesis was supported in the present study.

Higher beliefs in personal control over one's child's ASD did not significantly predict group membership for selecting metabolic treatments, Block $\chi^2(1, N = 124) = 1.90, ns$. Therefore, this hypothesis was not supported in the present study.

1d: Belief in external causes. Higher beliefs in external causes (i.e., pollution, diet, germ or virus, poor medical care in the past, altered immunity, vaccine injury, food allergies, toxic metals in the bloodstream, videos the child watched) of one's child's ASD significantly predicted group membership for selecting metabolic treatments, Block $\chi^2(1, N = 124) = 11.51, p = .001$,

correctly predicting 71.3% of participants' group membership. This model accounted for approximately 18.3% of the variation in parents' selection of metabolic treatments for their children with ASD (Nagelkerke $R^2 = 0.183$). Belief in external causes of one's child's ASD was a significant predictor of selecting metabolic treatments ($B = 0.33$, Wald = 11.51, $p = .001$). Parents with greater beliefs in external causes of ASD were more likely to select metabolic treatments for their children (odds ratio = 1.40; 95% CI = 1.15 to 1.69). Therefore, this hypothesis was supported in the present study.

1e: Negative emotional representations. More negative emotional reactions to one's child's diagnosis of ASD did not significantly predict group membership for selecting behavioural treatments, Block $\chi^2 (1, N = 122) = 0.37, ns$. Therefore, this hypothesis was not supported in the present study.

Hypothesis II: Acceptance of children's ASD. Table 8 presents a summary of the results of the bivariate correlation analyses testing this second set of hypotheses.

2a: High acceptance of ASD. Parents' scores on the AAQ-II-A (which measures parents' experiential avoidance of their thoughts and emotions relating to their child's ASD) were significantly positively correlated with the number of empirically supported treatments they selected for their children, $r = .179, p < .05$. Therefore, data from the study supported an alternative hypothesis. In other words, parents with higher levels of acceptance of their children's ASD selected significantly fewer empirically supported treatments for their children than did parents with lower levels of acceptance of their children's ASD. Parents' acceptance of their children's ASD accounted for 3.20% of the variance in the number of empirically supported treatments they selected for their children, $R^2 = 0.032$. According to Cohen (1988), this

Table 8

Bivariate Correlation Analyses Predicting Empirical Classifications of Treatments Selected

Variables	1	2	3
1. (Lack of) Acceptance	-		
2. Established Treatments Selected	0.18*	-	
3. Unestablished Treatments Selected	0.21*	0.63**	-

* $p < .05$. ** $p < .001$.

represented a small effect size.

2b: Low acceptance of ASD. Parents' scores on the AAQ-II-A (which measures parents' experiential avoidance of their thoughts and emotions relating to their child's ASD) were significantly positively correlated with the number of empirically unsupported treatments they selected for their children, $r = .211, p < .05$. Therefore, this hypothesis was supported in the present study. In other words, parents with lower levels of acceptance of their children's ASD selected significantly more empirically unsupported treatments for their children than parents with higher levels of acceptance of their children's ASD. Parents' acceptance of their children's ASD accounts for 4.45% of the variance in the number of empirically unsupported treatments they selected for their children, $R^2 = 0.044$. According to Cohen (1988), this represented a small effect size.

Exploratory Quantitative Analyses

Since many of the hypotheses in the present study were not supported by data collected from the present sample, the data were explored in greater detail in order to more closely examine possible reasons behind this. The following results should, therefore, be reviewed with caution, as they were not guided by previous research or subjected to the same level of statistical scrutiny as the main study findings. As noted by Hand (1998), this type of "data fishing" can be dangerous because, with enough examination, almost any data set will yield patterns of some kind. What is not clear without significance testing, though, is whether or not these patterns are merely the result of random variance.

An unexpected correlation was found between the number of evidence-based treatments and the number of non evidence-based treatments selected by parents. More specifically, parents who selected more evidence-based treatments for their children with ASD also reported selecting

more non evidence-based treatments for their children with ASD, $r = .63$, $p < .001$. According to Cohen (1988), this represented a large effect size.

Additionally, parents ($N = 20$) who reported selecting the most (i.e., 30 or more) treatments for their children were compared to parents ($N = 11$) who reported selecting the fewest (i.e., 5 or fewer) treatments for their children in an attempt to identify additional variables which may affect the number of treatments selected by parents. As expected based on other findings from the present study, parents who reported selecting the most treatments for their children had AAQ-II-A scores reflecting lower levels of acceptance ($M = 51.73$) than parents who reported selecting the fewest treatments for their children ($M = 34.15$).

Although there were little difference between the age, education level, or household income of the parents in either group, children of parents who reported selecting the fewest treatments were found to be older ($M = 13$ years) than children of parents who reported selecting the most treatments ($M = 9$ years). Children of parents who reported selecting the fewest treatments were also diagnosed at a later age ($M = 51.33$ months) than children of parents who reported selecting the most treatments ($M = 36.29$ months). Another interesting difference between parents who reported selecting many treatments and parents who reported selecting few treatments was their countries of residence. Parents who reported selecting the fewest treatments lived in Australia (36.4%), the United States (36.4%), and Canada (27.3%), while parents who reported selecting the most treatments lived in the United States (65%), Canada (20%), Australia (10%), and India (5%).

It was also of interest to compare parents who selected only empirically supported treatments for their children ($N = 8$) to parents who selected only empirically unsupported treatments for their children ($N = 5$). Several differences were found between these groups.

Perhaps most strikingly, parents who selected only empirically supported treatments for their children had AAQ-II-A scores reflecting higher levels of acceptance ($M = 47.12$) than parents who selected only empirically unsupported treatments for their children ($M = 60.80$).

Additionally, more of the parents who selected only empirically supported treatments for their children were highly educated (100% reported completing college or postgraduate study) than parents who selected only empirically unsupported treatments for their children (40% reported completing some college, 40% reported completing college or postgraduate study, 20% reported completing high school or less). Parents who selected only empirically supported treatments for their children identified as White (62.5%), Filipino (25%), and Southeast Asian (12.5%), while parents who selected only empirically unsupported treatments for their children identified as White (100%).

In terms of child-related variables, it was found that children of parents who selected only empirically supported treatments were younger ($M = 9$ years of age) than children of parents who selected only empirically unsupported treatments ($M = 14$ years of age). Similarly, children of parents who selected only empirically supported treatments were diagnosed at younger ages ($M = 37.25$ months of age) than children of parents who selected only empirically unsupported treatments for their children ($M = 64.75$ months of age). Finally, children of parents who selected only empirically supported treatments were diagnosed more recently ($M = 37.25$ months ago) than children of parents who selected only empirically unsupported treatments ($M = 82.75$ months ago).

Parents ($N = 11$) with the highest levels of acceptance of their children's ASD (i.e., parents with AAQ-II-A scores of 40 or lower) were also compared with parents ($N = 11$) with the lowest levels of acceptance of their children's ASD (i.e., parents with AAQ-II-A scores of 65 or

higher). It was found that parents with the lowest levels of acceptance had stronger beliefs in their personal control over their children's ASD ($M = 26$) than parents with the highest levels of acceptance ($M = 22.18$). Interestingly, parents with the highest levels of acceptance of their children's ASD reported having more negative emotional reactions to the diagnosis of ASD ($M = 18.36$) than did parents with the lowest levels of acceptance ($M = 12.91$). It also appeared that more of the parents with the highest levels of acceptance of their children's ASD were highly educated (100% reported completing college or postgraduate study) than parents with the lowest levels of acceptance (72.7% reported completing college or postgraduate study, 27.3% reported having some college education).

Parents with the lowest levels of acceptance of their children's ASD reported identifying as White (81.8%), Black (9.1%), and South Asian (9.1%), while parents with the highest levels of acceptance reported identifying as White (63.6%), Other, (18.2%), Filipino (9.1%), and South East Asian (9.1%). Additionally, parents with the lowest levels of acceptance of their children's ASD lived in the United States (54.5%), Canada (36.4%), and Australia (9.1%), while parents with the highest levels of acceptance of their children's ASD lived in the United States (36.4%), Canada (27.2%), Australia (18.2%), and India (18.2%). There were no differences between the two groups on child-related factors.

Next, parents ($N = 11$) with the most negative emotional reactions to their children's ASD diagnoses (i.e., parents with scores of 25 or higher on the IPQ-RA-E emotional representations subscale) were compared to parents ($N = 24$) with the least negative emotional reactions to their children's diagnoses (i.e., parents with scores of 10 or lower on the IPQ-RA-E emotional representations subscale) in order to explore possible underlying factors associated with this construct. It was found that children of the parents with the most negative emotional reactions to

their children's diagnoses were diagnosed more recently ($M = 43.25$ months ago) than were the children of parents with the least negative emotional reactions to their children's diagnoses ($M = 64$ months ago). Interestingly, parents with the most negative emotional reactions to their children's diagnoses endorsed more external causes ($M = 4.55$) for their children's ASD than did parents with the least negative emotional reactions to their children's diagnoses ($M = 1.17$).

Thematic Analysis of Open-Ended Survey and Interview Questions

Data gathered from the four exploratory items and the in-depth interviews were analyzed using the method of conducting thematic analysis recommended by Braun and Clarke (2006). In accordance with this method, data were first read through and initial themes were noted. These initial themes, developed by the primary investigator, were then read through by the primary investigator, Parent Advisor, and research advisor for the study and were collated to form larger themes. One exception to this is that parents' responses to the four exploratory items were analyzed by only the primary researcher and the Parent Advisor. Throughout this process, the specific aspects of each theme were refined and clear definitions and labels were generated for each theme. Finally, particularly vivid quotations which accurately reflected each theme and the overall story of the data set were selected for inclusion in the final report. This procedure helped to ensure that results accurately reflected the experiences of parents of children with ASD. Themes were reported in order of the number of parents whose comments comprised each theme (i.e., from most parents to fewest parents).

Ultimate goal for child's treatment/intervention. Parents ($N = 116$) responded to the first open-ended survey item, which asked what their ultimate goal was for their children's treatment or intervention programs. The following themes were developed according to the procedures described above.

To live a happy and fulfilling life. Parents ($N = 27$) reported that their ultimate goal for their children's treatment was for them to be able to achieve the highest quality of life. For example, parents' responses included: "To teach my son skills...so he can have a happy and productive life", "For him to live well", and "I want to improve the quality of his life to the fullest extent possible".

To be able to live independently. Parents ($N = 25$) reported that their ultimate goal for their children's treatment was for them to eventually have the ability to live independently. For example, parents' responses included: "For him to be independent and successful at what he chooses to do in life", "That he be able to function independently", and "Functional, independent, tax-paying adult".

To reach his/her full potential. Parents ($N = 24$) often reported that their main goal for their children's treatment programs is to help their children achieve the most they are capable of. For example, parents' responses included: "To help him function better, not to cure" and "For her to be the best her she can be".

To fully recover from ASD. Parents ($N = 17$) reported that their main goal for their children's treatment program is for their children to no longer have ASD. For example, parents' responses included: "Complete indistinguishability from same-age peers", "Complete recovery", and "Back to normal".

To master specific skills. Parents ($N = 16$) reported that their ultimate goal for their children's treatment program was for their children to gain skills in specific areas. For example, parents' responses included: "Verbal appropriate communication, social interactions, and significant reduction in sensory processing issues", "For him to achieve developmental, speech, and physical goals on his peers' level", and "I would love her to be able to go to the toilet

without prompting 100% of the time and say 'I love you mum'".

To form relationships with others. Parents ($N = 11$) reported that their main goal for their children's treatment program is for their children to form meaningful relationships with others. For example, parents' responses included: "To help him make friends and fit in" and "Ability to form relationships".

Most important factor when selecting treatments for a child with ASD. Parents ($N = 117$) responded to the second open-ended survey item, which asked about the most important factor to them when they selected treatments for their children with ASD. The following themes were identified:

How well the treatment works. Parents ($N = 24$) reported that their main concern when selecting treatments for their children is how well the treatment works with their children. For example, parents' responses included: "That I am able to see results" and "Do they work well with my child?".

That the treatment is a good fit for the child. Parents ($N = 22$) reported that their main concern when they were selecting treatments for their children was that the treatment addresses their children's specific needs and characteristics. For example, parents' responses included: "Geared towards his needs", "How suitable it is for my son", and "How they will specifically target a problem my child has on an individual level".

That the treatment is evidence-based. Parents ($N = 21$) reported that their main concern when selecting treatments for their children is that the treatment has empirical support. For example, parents' responses included: "The science behind it" and "Research-based with proven success".

That the treatment is not harmful. Parents ($N = 10$) reported that their main concern

when selecting treatments for their children is that the treatment will not harm their children. For example, parents' responses included: "Firstly, that it will not harm my child" and "That they cause little or no harm to my son's health or wellbeing".

Cost and availability of the treatment. Parents ($N = 10$) reported that practical issues are their main concern when selecting treatments for their children with ASD. For example, parents' responses included: "What's available" and "Money/insurance".

Advice from professionals and other parents of children with ASD. Parents ($N = 9$) reported that advice from professionals working in the field of ASD and other parents of children with ASD are their main concern when selecting treatments for their children with ASD. For example, parents' responses included: "Recommendations by psychologist and pediatrician" and "Listening to other parents' experiences".

Changes in feelings about child's ASD from diagnosis to present. Parents ($N = 116$) responded to the third open-ended survey item, which asked how their feelings about their children's diagnoses have changed over time. The following themes were identified:

More accepting of the diagnosis now. Parents ($N = 32$) reported that their acceptance of their children's ASD had increased since their children were diagnosed. For example, parents' responses included: "I have become more accepting of it but without losing resolve to continue intensive therapies", "The immediate grief has passed and I am sometimes hopeful, sometimes resigned", and "From grieving to complete acceptance of the diagnosis of my child".

My feelings have not changed. Parents ($N = 19$) reported that their feelings about their children's diagnosis had not changed at all over time. For example, parents' responses included: "Not changed", "Not really – there is no cure", and "It's still very recent, too hard to tell, very overwhelmed and sad still".

More optimistic about child's future now. Parents ($N = 15$) also reported feeling more optimistic about their children's futures than they had when their children were first diagnosed. For example, parents' responses included: "From hopeless to extremely positive", "More optimistic now", and "I am more confident that my child will be successful in what he chooses for himself in life".

Better understanding of ASD now. Parents ($N = 12$) reported that they now had a much better understanding of ASD than when their children were first diagnosed. For example, parents' responses included: "Complete understanding of the condition", "Better understanding of the spectrum and influences and effects", and "I feel more confident now; I know a lot more about ASD".

Describing ASD in a single word. Parents ($N = 110$) responded to the fourth open-ended survey item, which asked them to describe ASD in one word. Since parents' responses varied so widely and did not readily lend themselves to themes, these data are displayed in Figure 1.

Figure 1

Parents’ Responses When Asked to Describe ASD in One Word



**Note.* Larger fonts indicate more frequently occurring words

Interview Question 1: Meaning of ASD to parents. Parents ($N = 10$) who participated in the in-depth follow-up interview were asked to talk about what ASD meant to them. The following themes were identified:

Medical explanations. Parents ($N = 8$) offered somewhat medicalized, scientific descriptions of ASD. For example, parents' responses included: "A very complex disorder...Underneath, there are genuine neurological problems" and "It's a genetic condition".

A different way of seeing the world. Parents ($N = 4$) reported viewing ASD as a different way of seeing the world. For example, parents' responses included: "A group of people who perceive the world differently through their emotions, mentally and physically, and in a sensory sense" and "Interacting with the world differently".

Not a tragedy – something that can be lived through. ($N = 4$) Parents reported viewing a diagnosis of ASD not as a tragedy but as just another part of life. For example, parents' responses included: "It's something that's not going to be cured. It's not a death sentence. It's not as bad as people make it out to be" and "Nothing necessarily needs to be fixed, but worked with".

Pop culture view of ASD. Parents ($N = 2$) offered descriptions of ASD that reflected representations of ASD in the media and popular culture. For example, one parent responded, "My child is exactly like Sheldon from The Big Bang Theory...he says what's on his mind, doesn't understand why it's not right to tell the truth when the truth will hurt people's feelings...".

Interview Question 2: Factors influencing how parents think about ASD. Parents ($N = 10$) who participated in the in-depth follow-up interview were asked to describe the factors that influence how they think about ASD. The following themes were identified:

Research, reading, and expert opinion. Parents ($N = 7$) reported that their views of ASD were shaped in large part through reading ASD literature and hearing the views of experts in the field. For example, parents' responses included: "A lot of books and psychologists...a lot of research as well" and "Evidence-based research".

Their own child. Parents ($N = 4$) reported that their views of ASD were largely shaped by their experiences with their own child. For example, one parent responded, "My personal experience with my son".

Interview Question 3: How parents define acceptance of their children's ASD.

Parents ($N = 10$) who participated in the in-depth follow-up interview were asked to describe what it means to accept one's child's diagnosis of ASD. The following themes were identified:

Having a balanced view of the child. Parents ($N = 5$) described accepting a child's diagnosis as maintaining a balanced view of the child and realizing that the child is unique and not necessarily sick. For example, parents' responses included: "Realizing that your child is unique in such a way that is not necessarily going to fit him into the cookie cutter mould that society has for children and teens" and "You don't have to fix them. They are who they are".

Consequences of not accepting a child's diagnosis. Parents ($N = 5$) also emphasized the consequences of not accepting the diagnosis, particularly for the child. For example, one parent responded, "It's one of the biggest factors in helping your child...If they can't accept it then they are going to do a huge disservice and injustice to the child".

Not giving up on the child's potential. Parents ($N = 4$) conceptualized accepting one's child's diagnosis of ASD as understanding that the child has limitations, but maintaining an awareness of the child's potential. For example, one parent responded, "To accept their abilities and limitations, [although] I'm always pushing their limitations because you don't want to

underestimate them”.

End of grieving/mourning process. Parents ($N = 2$) described accepting one's child's diagnosis of ASD as completing a process of grieving or mourning for the loss of their “hoped for” child. For example, one parent responded, “There's this mourning period where you have to accept that your life is never going to be what you thought it was going to be”.

Interview Question 4: Factors influencing parents' acceptance of their children's ASD. Parents ($N = 10$) who participated in the in-depth follow-up interview were asked to outline the factors that they felt influenced their acceptance of their children's ASD. The following themes were identified:

Community support or barriers. Parents ($N = 6$) reported that members of their communities affected their acceptance of their children's ASD. Some parents reported that community members provided support to them, while others reported that community members acted as barriers to their acceptance of their children's ASD. For example, parents' responses included: “We had a lot of support, which really helped...a lot of professional and family support” and “Some of our family members didn't take it well and that's hard”.

Education. Parents ($N = 3$) cited learning more about ASD as a major factor which influenced their acceptance of their children's ASD. For example, one parent responded, “The more we understand autism, we get a higher level of acceptance”.

Receiving the diagnosis. Parents ($N = 3$) reported that receiving the diagnosis of ASD from a professional increased their acceptance of their children's ASD. For example, one parent responded, “The diagnosis – having it confirmed by a professional who you trust”.

Always accepted their child's ASD. Some parents ($N = 2$) reported having accepted their children's ASD from their first suspicions. For example, one parent responded, “We were the

ones who noticed something was amiss and then went looking for a diagnosis...I was able to give up being a 'normal mother' right from the get-go".

Interview Question 5: Parents' challenges in selecting treatments for children with ASD. Parents ($N = 10$) who participated in the in-depth follow-up interview were asked about their biggest challenges in selecting treatments for their children with ASD. The following themes were identified:

Knowing which treatments will work. Parents ($N = 5$) reported experiencing challenges in knowing which treatments would be effective for their individual children. For example, one parent responded, "Nothing works for every kid and it's hard to figure out".

Forming positive relationships with professionals. Parents ($N = 4$) reported experiencing difficulty forming positive working relationships with professionals involved in their children's treatment plans. For example, parents' responses included: "Being able to trust the service provider" and "Even though we had a diagnosis, the doctors pushed drugs".

Availability/location. Parents ($N = 3$) reported that the availability and location of treatments were challenging factors in their treatment selection. For example, one parent responded, "Location and offering of treatment".

Looking into supporting research. Parents ($N = 3$) reported that having to find and evaluate the empirical support behind each treatment was challenging during their treatment selection. For example, one parent responded, "I read research...I wanted to know that scientific research was done on it".

Sense of responsibility and guilt. Parents ($N = 2$) reported that experiencing feelings of responsibility and guilt in relation to their children made their treatment selection challenging. For example, one parent responded, "When you take on the responsibility for helping your child

and they aren't getting better as fast as you want them to, there's really no one to point a finger at but you".

Cost. Parents ($N = 2$) reported that the cost associated with certain treatments was a major challenge for them throughout the process of treatment selection. For example, one parent responded, "For us and everybody else, one of the biggest challenges is financial".

Interview Question 6: Advice for other parents selecting treatments for children with ASD. Parents ($N = 10$) who participated in the in-depth follow-up interview were asked to outline their advice for future parents of children with ASD selecting treatments for their children. The following themes were identified:

Know the services. Parents ($N = 5$) advised future parents to be knowledgeable about the services available in their area, currently being used by their children, and currently under study. For example, parents' responses included: "Work with professionals that are in your child's life" and "Make sure that you understand the services".

Accept your child's diagnosis. Parents ($N = 3$) advised future parents of children with ASD to quickly accept the diagnosis in order to begin selecting treatments as soon as possible. For example, parents' responses included: "Stop trying to make them be something they're not and accept them for who they are. I think that will take a lot of pressure off the parents" and "Don't be looking for something to cure your child. There's so many other options out there that you could be doing to help your child".

Pay attention to the research. Parents ($N = 3$) advised future parents to consider the empirical support behind each treatment when selecting treatments for their children. For example, one parent responded, "Research. Make sure there is something behind it".

Trust your instincts. Parents ($N = 3$) in the present study advised future parents to listen

to their instincts about which treatments will be best for their children, regardless of empirical or expert support. For example, one parent responded, "If the things suggested to you don't feel right or you really don't think it's going to work for your child, don't do it".

Find a support system. Parents ($N = 2$) in the present study advised future parents to cultivate a support system for themselves involving family, friends, and professionals. For example, one parent responded, "Find a support group, find some friends that will listen to you...give you just that shoulder to lean on".

Be an advocate for your child. Parents ($N = 2$) advised other parents to take on the role of an advocate for their children in order to ensure that their children receive the best treatments possible. For example, one parent responded, "In order to get help for your child, you have to be that voice they don't have".

Additional comments. Parents ($N = 10$) who participated in the in-depth follow-up interview were given the opportunity to voice any additional comments they had in regards to their conceptualizations of ASD, acceptance of ASD, or treatment selection for children with ASD. One major theme evolved from these comments.

Life goes on – children with ASD can accomplish so much. Parents ($N = 3$) commented on the importance of not ruminating on their feelings of loss upon receiving their children's diagnoses, but instead to maintain positivity and focus on supporting their children. For example, parents' responses included: "Don't think your world is over because your child has Autism...their world is just beginning" and "Your child can do a lot more than people might think and the world might tell you".

Discussion

The purpose of the present study was to identify the relations between parents' cognitive representations of their children's ASD, acceptance of their children's ASD, and treatment selection for their children. Although some of the findings from the French study by Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) were replicated, many were not. This comparison is explored in greater detail below.

Review of Study Hypotheses

Hypothesis I: Cognitive representations of ASD. Results of the present study demonstrated that parents' cognitive representations of their children's ASD were significantly related to their treatment selection in certain specific ways.

1a: Belief in consequences. It was predicted that parents with stronger beliefs in the severity of ASD and its impact on various aspects of their child's functioning would be more likely to select behavioural treatments for their children. Results of the present study failed to support this association. Parents with stronger beliefs in the severity of ASD and its impact on various aspects of their children's functioning were not significantly more likely to select behavioural treatments for their children.

1b: Belief in timeline. It was predicted that parents with cognitive representations of ASD which include higher beliefs in a cyclical course of ASD symptomology would be more likely to select medication-based treatments for their children. Results of the present study failed to support this association. Parents with stronger beliefs in a cyclical course of ASD symptomology were not significantly more likely to select medication-based treatments for their children.

1c: Belief in control. It was predicted that parents with cognitive representations of ASD

which include higher beliefs in personal control over ASD would be less likely to select medication-based, special diets, and vitamin-based treatments for their children. Contrary to this prediction, the results of the present study indicated that parents with cognitive representations of ASD which include higher beliefs in personal control over ASD were more likely to select medication-based treatments for their children. These stronger beliefs in one's ability to control or cure one's child with ASD may also be reflected qualitatively in the comments of parents who indicated that their main goal for their children's treatment was recovery.

Through conducting post hoc, exploratory analyses, it was found that parents with the lowest levels of acceptance of their children's ASD had stronger beliefs in their personal control over their children's ASD than did parents with the highest levels of acceptance. It makes intuitive sense that parents who feel they have a high degree of control over their children's ASD experience lower levels of acceptance of their children's diagnoses (perhaps even believing that they have the power to "cure" their children). Medication-based treatments likely appeal to these parents because they operate under the assumption that the child's ASD is caused by some type of chemical imbalance within the child which can be counteracted by the medication.

Results of the present study failed to support the hypothesized relation between belief in personal control over ASD and selection of metabolic (i.e., special diets and vitamin-based) treatments.

Id: Belief in external causes. It was predicted that parents with stronger beliefs in external causes of their children's ASD would be more likely to select metabolic treatments for their children. Results of the present study supported this hypothesis. This finding is consistent with previous findings by Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010), who found that parents with strong environmental causal attributions for their child's ASD were more

likely to select nutritional and detoxification treatments for their children. Qualitative data from the present study indicating that many parents struggle with feelings of responsibility and guilt over their children's ASD and experience difficulty finding reliable information may also help to shed some light on this finding. Parents who believe that an external factor such as receiving a vaccine cause their children's ASD are likely more apt to experience feelings of guilt in relation to their children's ASD. Similarly, parents who experience greater difficulty accessing accurate information about the causes of ASD may be more likely to blame external factors such as vaccines for their children's ASD.

It is perhaps not surprising that parents who more strongly believed that their children's ASD was caused by factors such as vaccine injury, altered immunity, and pollution in the environment were more likely to select special diet and vitamin-based treatments for their children. These parents may be attempting to "counteract" the effects of the harmful stimuli which they believe caused their children to have ASD.

Ie: Negative emotional representations. It was predicted that parents with more negative emotional reactions to the diagnosis of ASD would be less likely to select behavioural treatments for their children. Results of the present study failed to support this association. Parents with more negative emotional reactions to their children's ASD diagnoses were not significantly less likely to select behavioural treatments for their children.

Hypothesis II: Acceptance of children's ASD. Since the majority of parents in the present study reported selecting at least one treatment within each NAC (2009) classification of empirical support (i.e., established, emerging, unestablished), it was not considered meaningful to search for associations between parents' acceptance of their children's ASD and their likelihood of selecting a treatment within each category of empirical support. Instead, data were

examined to determine whether there were relations between parents' acceptance of their children's ASD and the number of treatments parents selected within each classification of empirical support.

2a: High acceptance of ASD. It was predicted that parents with higher levels of acceptance of their children's ASD would report selecting more evidence-based treatments for their children. Contrary to this prediction, the results of the present study indicated that parents with higher levels of acceptance of their children's ASD reported selecting fewer evidence-based treatments for their children. This result was not consistent with the conjectures of many researchers studying ASD (e.g., MacDonald, Hastings, & Fitzsimons, 2010; Mandell & Novak, 2005; Siegel, 1997); however, this finding is an important advancement in better understanding parents' treatment selection for their children with ASD.

As suggested by the Parent Advisor for the present study after reviewing the qualitative results, parents with higher levels of acceptance of their children's ASD may have a more holistic view of their children's ASD. That is, they may be more willing to recognize the positive aspects of their children's ASD as well as the negative aspects, instead of conceptualizing their children's ASD only in terms of symptoms needing to be alleviated. Therefore, instead of selecting a treatment for each symptom of ASD observed in their children, parents with higher levels of acceptance may select fewer treatments which they believe will improve their children's overall functioning. This notion of parental acceptance of ASD representing a more holistic view of the child with ASD is consistent with previous research by Mansell and Morris (2004) and Pianta, Marvin, Britner, and Borowitz (1996), indicating that parents with higher levels of acceptance of their child's ASD diagnosis are better able to acknowledge their children's strengths as well as challenges.

2b: Low acceptance of ASD. It was predicted that parents with lower levels of acceptance of their children's ASD would report selecting more non evidence-based treatments for their children. Results of the present study supported this hypothesis. This result may also be explained by the notion that parents with lower levels of acceptance of their children's ASD may have more fragmented, symptom-focused conceptualizations of their children's ASD. It may be that their attempts to ameliorate each individual symptom of their children's ASD leads them to select more treatments, on average, than parents with higher levels of acceptance who view their children's ASD more holistically. This would be consistent with previous research by Pianta, Marvin, Britner, and Borowitz (1996), which indicated that parents with low levels of acceptance of their children's diagnoses of ASD are often confused about several aspects of the diagnosis and tend to have unbalanced beliefs about the consequences of the diagnosis.

Although the finding that parents with lower levels of acceptance of their children's ASD selected both more empirically supported treatments and more empirically unsupported treatments for their children may seem somewhat paradoxical, the result becomes clearer with further inspection. What these results actually demonstrate is that parents with lower levels of acceptance select more treatments for their children *in general* than parents with higher levels of acceptance, regardless of empirical support. In other words, it appears that parents with lower levels of acceptance of their children's ASD take on a "shotgun approach" to treatment selection, whereby they try almost every treatment available with their children, regardless of the empirical support for the treatments. Parents in the present study selected an average of 16 treatments, with 6 from the empirically "established" classification, 8 from empirically "emerging", and 2 from empirically "unestablished". This finding is consistent with results of a study by Call, Delfs, and Findley (2011) that parents report that they would ideally spread their time and

financial resources out over several ($M = 40.8$) treatments for their children with ASD. Findings from an unpublished manuscript by Drouillard, Gragg, Miceli, and Voelker (2012) that the majority of parents of children with ASD believe that every treatment is effective in some way may also shed light on parents' reasoning behind this "shotgun approach".

This "shotgun approach" to treatment selection can also be observed in people with serious illnesses such as cancer. For example, results from a study by Richardson, Sanders, Palmer, Greisinger, and Singletary (2000) demonstrated that 83.3% of individuals with cancer reported having used at least one complementary/alternative medicine (CAM) treatment (e.g., spiritual practices, vitamins/herbs, special diets). Even more interestingly, 24.7% of the participants (the largest group in their study) reported using seven or more CAM treatments. In a similar study, 93.1% of individuals with cancer at the end of life reported using CAM treatments and use of CAM treatments was associated with longer time spent living with cancer, the presence of multiple types of cancer, and expectation of cure (Choi et al., 2012). Although this latter study did not directly examine the number of CAMs used by each participant, the sum of the number of individuals who reported using each CAM (1093) was much greater than the sample size of the study (604), indicating that many participants reported selecting multiple CAMs. When considered in light of these results, it appears that the "shotgun approach" to treatment selection may be associated with unrealistic hope of recovery or a sense of desperation in regard to one's child's ASD.

Proposed Explanations for Discrepancies between Present and Past Research

Although the present study had much in common with an earlier study conducted by Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010), there were several important differences which may help to account for the discrepant results. First, participants from the

present study most commonly reported living in the United States (45.2%) and Canada (25%), whereas all participants in the Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) study lived in France. According to these authors, parents of children with ASD in France often adopt a more psychological and less medical view of ASD, considering it to be more of a stable feature than an illness needing to be cured (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010). In the United States and Canada, a diagnosis of ASD is often seen as a “personal tragedy”, with parents of children with ASD experiencing significantly more despair and less hope for their children’s future than do parents of children with typical development (Hebert & Koulouglioti, 2010).

It is also important to note that the healthcare systems in France and in Canada and the United States are likely very different. As mentioned by parents in the present study, the cost associated with a particular treatment is often an important factor for parents when selecting treatments for their children with ASD. The discrepant healthcare coverage for children with ASD in different countries, therefore, may have affected the results of the present study and helps to explain why results are somewhat inconsistent between the present study and Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean’s (2010) study.

The children of participants in the Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) study were also older ($M = 13.11$ years) than children of participants in the present study ($M = 8.83$ years). Although Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) found that the ages of children with ASD did not affect the types of treatments received, an American study by Goin-Kochel et al. (2007) found that younger children with ASD were more likely to receive behavioural treatments than were older children. This study also found that older children with ASD were more likely to receive psychopharmacological

treatments than were younger children (Goin-Kochel et al., 2007). It should be noted that the children in Goin-Kochel et al.'s (2007) study were much closer in age ($M = 8.30$ years) to children in the present study. As also demonstrated in the exploratory quantitative findings of the present study, parents of younger children tend to try more treatments with their children than parents of older children, likely due to widespread recognition of the importance of early intervention. As such, the large age difference between children in the Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) study and the present study likely accounts for some of the discrepancies in findings between the studies.

An additional factor which may account for much of the discrepancy in results between the original Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) study and the present study is that the original study presented participants with only a "short list of treatments" (pp. 1139) from which to indicate those they were currently using with their children. In the present study, participants were presented with a list of 37 treatments in accordance with those reviewed in depth by the National Autism Center (2009). This expanded list allowed participants to more accurately report the treatments they had selected for their children with ASD. Participants in the present study were also asked to specify the treatments they had used with their child in the past, were currently using, or were on waitlists for. This allowed for treatments which has been selected by parents for their children but which were not currently being used by their children to be accounted for in the present study.

All participants in the present study completed the questionnaire online. This differed significantly from participants in the study by Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) in which over half of the participants completed the questionnaire in pencil-and-paper format in the presence of a researcher. Although social desirability was not found to

be significantly associated with any of the variables of interest in the present study, it is possible that the in-person format of the Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) study enhanced the influence of social desirability in their sample. Since social desirability was not controlled for in the statistical analyses performed by Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010), it is reasonable to hypothesize that this variable may also help to explain some of the discrepancy between the results in the original study and in the present study.

Taken together, although the study by Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) was quite useful as an initial source of hypotheses for the present study, the differing sample of participants, treatment options, and questionnaire administration options of this study and the present study created many confounding variables which could not be accounted for in the statistical analyses conducted in the present study. As such, follow-up research on the present study should utilize an integration of the exploratory quantitative and qualitative findings from this study to generate hypotheses which can more accurately be addressed by the data likely to be collected.

Exploratory Quantitative Findings.

Post hoc analyses of data from the present study revealed that, in addition to lower levels of acceptance, younger child age and living in the United States were associated with selecting a greater number of treatments for one's child with ASD. Parents of younger children with ASD may not have had a chance to fully come to terms with the implications (both for themselves and their children) of their children's diagnoses. It is also possible that this may be explained by a possible cohort effect for child age. For example, the original paper by Andrew Wakefield and colleagues, in which it was suggested that the measles, mumps, and rubella (MMR) vaccine was

implicated in causing ASD, was published in 1998. This paper was not retracted until 12 years later, in response to a ruling made by the UK General Medical Council's Fitness to Practice Panel (Editors of the Lancet, 2010). The treatment selection of many parents of children diagnosed with ASD after 1998, therefore, was likely affected by this highly publicized study. As shown in the present study, several parents of children with ASD continue to believe that their children's ASD was caused by external factors (e.g., vaccine injury), despite the fact that this study has now been widely discredited. Additionally, the predominance of the "medical model" of disability in the United States may lead parents living there to conceptualize ASD as an illness to be cured instead of a lifelong characteristic which can be improved through intensive intervention.

Similarly, post hoc analyses revealed that lower levels of acceptance, older child age, older child age at diagnosis, greater time since diagnosis, lower levels of education, and identifying as White were associated with selection of empirically unsupported treatments for one's child with ASD. Again, it appears as though parents with lower levels of acceptance of their children's ASD may not be as concerned with the empirical support behind each treatment as they are with the purported benefits of each treatment. It generates some hope, however, to note that parents of younger and more recently diagnosed children appear to be more likely to select empirically supported treatments than parents of older and less recently diagnosed children. Perhaps public knowledge of the limitations of the original Wakefield et al. (1998) study, as well as of the various well-established treatments available for children with ASD, is increasing over time.

Post hoc analyses also revealed that low levels of acceptance of one's child's ASD were associated with stronger beliefs in personal control over one's child's ASD, lower levels of

education, living in the United States, and identifying as White. It may be that the more medicalized view of ASD in North America as opposed to other regions yields lower levels of acceptance of individuals' disabilities and, instead, favours a more problem-focused approach to disability. Individuals with lower levels of education may be less likely to challenge these views, resulting in lower levels of acceptance of ASD among these individuals.

Additionally, post hoc analyses revealed that more negative reactions to one's child's diagnosis of ASD were associated with greater beliefs in external causes of one's child's ASD (e.g., vaccine injury, pollution in the environment). In other words, it appears that parents who believe that their children were born "typical" but, through some event or stimulus, developed ASD have lower levels of acceptance of their children's ASD. This is consistent with research by Pianta, Marvin, Britner, and Borowitz (1996), which demonstrated that parents who had not achieved acceptance of their children's ASD were overly focused on the causes of their children's ASD.

Somewhat surprisingly, more negative emotional reactions to one's child's diagnosis of ASD were also found to be associated with higher levels of acceptance. Although this may initially seem counterintuitive, it makes sense when we recall that the AAQ-II-A actually measures parents' willingness to experience uncomfortable thoughts and emotions related to one's child's ASD in order to achieve a certain goal (e.g., selecting a high-quality treatment for one's child). It appears that parents with lower levels of acceptance of their children's ASD may not allow themselves to fully experience the uncomfortable thoughts and emotions which naturally arise after receiving the diagnosis of ASD.

An unexpected correlation was also found between the number of evidence-based treatments and the number of non evidence-based treatments selected by parents. More

specifically, parents who selected more evidence-based treatments for their children with ASD also reported selecting more non evidence-based treatments for their children with ASD. This was the strongest relation found in the present study. It appears that, although lower levels of acceptance of one's child's ASD are associated with selecting more evidence-based and non evidence-based treatments for one's child, a stronger predictor of the number of non evidence-based treatments selected is the number of evidence-based treatments selected. A significant number of parents seem to be selecting "whatever treatments they can get" for their children, regardless of the empirical support behind each individual treatment. This inference is also supported by the finding that, of the five treatments parents most commonly reported selecting, three (i.e., antecedent package, behavioural package, and schedules) were classified as empirically "established" and two (i.e., academic interventions and gluten/casein-free diet) were classified as empirically "unestablished". As previously discussed, this "shotgun approach" to treatment selection may be associated with a sense of desperation and unrealistic hope of recovery for one's child's ASD. When considered in light of qualitative findings from the present study, the "shotgun approach" to treatment selection may also be associated with a more compartmentalized or symptom-focused conceptualization of ASD. Individuals with this view may consider each symptom of ASD separately and select a treatment which they believe will help ameliorate that specific symptom. These parents likely also have lower levels of acceptance as they may have not yet integrated the various aspects of the diagnosis of ASD into one inclusive conceptualization.

Exploratory Qualitative Findings

Thematic analysis of qualitative data from the present study was conducted on a question-by-question basis with the assistance of the parent advisor and the research supervisor

for the study. For the purposes of the discussion, however, the overarching themes from responses to the open-ended questions will be examined in greater detail below.

Conceptualizations of ASD. Parents in the present study appeared to hold dichotomous views in relation to their children's ASD. An overarching theme representing one of these viewpoints is that children with ASD do not need to be "fixed" or forced to blend in with children with typical development. This sentiment is reflected in one mother's definition of acceptance of her child's diagnosis, "Realizing that your child is unique in such a way that is not necessarily going to fit him into the cookie cutter mould that society has for children and teens".

Alternatively, another overarching theme which emerged through parents' responses to the open-ended questions is that many parents wish for their children with ASD to be "normal" and no longer show symptoms of ASD. This desire was reflected in the words of one parent who reported that her biggest goal in her child's intervention was for her child to achieve "complete indistinguishability from same-age peers" and another parent who reported that her goal for her child's treatment was for her child to achieve "complete recovery".

These divergent views may provide further evidence for the notion that parents with higher levels of acceptance of their children's ASD may view their children more holistically, while parents with lower levels of acceptance of their children's ASD may have more fragmented, symptom-focused views of their child. For example, when asked about their ultimate goal for their child's intervention program, several parents offered symptom-focused responses such as "Verbal, appropriate communication, social interactions, and significant reduction in sensory processing issues". When asked the same question, however, several other parents offered more holistic responses such as "For her to be the best her she can be". It may be that the former parent had a higher level of acceptance of his/her child's ASD than the latter

parent. Consistent with previous findings that parents' acceptance of their children's ASD does not necessarily increase over time (e.g., Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010), the same parents sometimes offered statements reflecting both sides of this dichotomy in response to different questions.

Treatment selection. Parents in the present study reported that several factors were influential in their treatment selection for their children with ASD. The importance of practical considerations when selecting treatments was a repeated theme throughout parents' responses to the open-ended items. Of these practical considerations, the cost and availability of treatments in their community were the most frequently mentioned. This theme was reflected in the words of one parent who asserted that "for us and everybody else, one of the biggest challenges [to selecting treatments] is financial" and another parent who admitted that one of the most significant challenges she faced when selecting treatments for her child with ASD was the "location and offering of treatment".

Besides practical considerations, an additional overarching theme in parents' responses was the reported importance placed on empirical support for treatments by parents of children with ASD. Nearly all parents in the present study reported considering empirical support when selecting treatments for their children with ASD. For example, one parent described his treatment selection process, saying "My methods are more research based...I read research...I wanted to know that scientific research was done on it", while another parent advised future parents of children with ASD selecting treatments for their children to "research. Make sure there is something behind it".

This finding is interesting when considered in conjunction with other results from the present study demonstrating that, on average, parents reported selecting 5.76 treatments

classified as empirically “established”, 7.94 treatments classified as empirically “emerging”, and 2.52 treatments classified as empirically “unestablished”. It appears that, although parents report that empirical support is important to them when selecting treatments for their children with ASD, their actual treatment selection is not consistent with these reports. One possible explanation for this discrepancy is that parents may not always fully understand what is meant by “empirical support” for a given treatment or where this information is available. This explanation is consistent with previous findings from an unpublished manuscript by Drouillard, Gragg, Miceli, and Voelker (2012) demonstrating that parents of children with ASD often do not independently read scientific journal articles to ascertain information about the empirical support for various proposed treatments. Instead, they frequently report relying on healthcare professionals, the internet, community ASD organizations, and other parents of children with ASD for information on the empirical support for various treatments. Unfortunately, these sources may not always offer valid and reliable information to parents, which may lead many parents to unknowingly select empirically unsupported treatments for their children.

An additional overarching theme may also help shed light on this discrepancy between parents' reported and actual emphasis on empirical support for proposed treatments for ASD. Parents' responses to several open-ended questions formed an overarching theme of listening to their instincts or “gut feelings” when selecting treatments for their children with ASD. Furthermore, several parents admitted to placing more importance on their parental instincts than on professional recommendations or empirical support when selecting treatments for their children. In the words of one mother, “The experts don't really know any better than you do. They can just give you options and say ‘Here's what available and what has worked for other people’, but only you as a parent know for sure”. In this sense, parents may be considering

empirical support when selecting treatments for their children with ASD, but simultaneously placing more importance on their own instincts about which treatments will be most effective and the “best fit” for their children.

Finally, an overarching theme of the importance of supportive relationships for parents of children with ASD emerged throughout parents' responses to several open-ended questions. Parents in the present study spoke of the importance of social support in a variety of contexts, such as when coming to terms with their children's diagnoses and when selecting treatments for their children. Parents also emphasized the importance of positive relationships not only within the immediate family, but also within the extended family, with friends, with other parents of children with ASD, and with professionals working with the child and family. For example, when asked to offer their advice to future parents of children with ASD, one parent replied “Talk to other parents... when you speak to other parents you hear stories and what their thoughts are and all that and that kind of makes it more real so it also gives yourself support”, while another parent advised future parents to “work with professionals that are in your child's life...with your pediatrician, with the school counselor, the teacher ‘cause they see your child...in a light that you don't”.

Several parents also spoke of the negative consequences of not having a system of social support in place. As one mother recalled, “Some of our family members didn't take [the diagnosis] well and that's hard”. Many parents also recalled receiving little support from professionals working with their children. For example, one mother asserted that “the hardest challenge is that...the doctors pushed drugs”, while another parent confessed “Sometimes I also have a lot of frustration with each doctor telling me I'm wrong when I know that I'm not and I can see my child getting better”.

Limitations of the Present Study

Recruitment for the present study largely took place online through ASD-related listservs and organizations. Although many of these organizations were for parents of children with ASD in general (e.g., Autism Ontario), many of them were also for parents of children with ASD interested in particular treatments for ASD or proposed causes of ASD (e.g., GFCFkids, medicaidforhbot, VacInfoCoalition). Many of the groups with the largest online presence represented non-mainstream opinions in terms of recommended treatments and proposed causes of ASD. Therefore, individuals with these opinions may have been overrepresented in the present sample. Additionally, 75% of participants in the study reported having graduated from college or university. Parents with high levels of education, then, were overrepresented in the sample and the study findings may be less generalizable to parents who have not graduated from college or university.

Some of the data collected in the present study were retrospective (e.g., recalling the length of time parents had used certain treatments with their children). This method may have compromised the accuracy of the data in some cases, particularly for parents of older children who may have had to recall treatments used over a decade ago with their child. A related limitation of the present study is that several parents did not respond to demographic questionnaire items which asked about when they had used each treatment with their child (in the past, presently, or future [waitlisted]). Due to this, data about the length of time each treatment was used with each child could not be examined in the present study.

Parents in the present study were also recruited from diverse geographic locations, mostly in the U.S., Canada and Australia. This diverse sampling was necessary to accumulate a large enough sample of parents, but prohibits results of the present study from generalizing to a

specific group of parents of children with ASD. Also, since parents of children up to the age of 21 participated in the present study, findings do not necessarily apply to parents' treatment selection for their children with ASD of certain specific ages.

Strengths of the Present Study

Despite the limitations of the present study, there were also many positive aspects and improvements on previous research. The present study addressed the limitations of Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean's (2010) study by modifying the IPQ-R (Moss-Morris et al., 2002) to include ASD-specific symptoms as outlined in the DSM-IV-TR (APA, 2000). The present study also included an expanded list of 37 treatments which allowed parents to indicate those they were currently using with their children as well as past and planned treatments. Finally, the present study addressed another limitation of the original study by Al Anbar, Dardennes, Prado-Netto, Kaye, and Contejean (2010) by revising the Causes subscale of the IPQ-R to include ASD-specific causes taken from Furnham and Buck's (2003) Lay Beliefs about Autism Questionnaire (as has been done by Dardennes, Al Anbar, Prado-Netto, Kaye, Contejean, and Al Anbar [2011]) as well as additional causes popularly cited by parents of children with ASD.

The present study was the first to empirically examine the relations between parents' acceptance of their children's ASD and their treatment selection for their children. With ASD researchers long alluding to a possible relation between these constructs, findings taken from the present study add to the knowledge currently available in the literature. Professionals can use their knowledge of this established relation between parents' acceptance of their children's ASD and their treatment selection for their children to help foster acceptance from the original diagnosis of ASD.

As associations between parents' cognitive representations of their children's ASD and their treatment selection have only recently begun to be studied, an additional strength of the present study was that it incorporated several exploratory open-ended questions for qualitative analysis. The findings from these qualitative analyses add a richness to the results of the present study and help readers to interpret quantitative results in a manner which more accurately reflects the opinions of parents of children with ASD. The participatory action research framework utilized in the present study also helped to ensure that the goals, methods, results, and conclusions of the study were relevant, responsible, and helpful to parents of children with ASD.

Implications and Future Study

Findings from the present study significantly contribute to our knowledge of factors influencing parents' treatment selection for their children with ASD and have important implications for professionals working with parents of children with ASD. Results of the present study suggest that parents with low levels of acceptance of their children's ASD often appear to employ a "shotgun approach" to treatment selection, whereby they try nearly every treatment available with their children. This means that parents with lower levels of acceptance of their children's ASD generally select more treatments for their children and, perhaps more importantly, select more empirically unsupported treatments for their children with ASD. Furthermore, this "shotgun approach" also appears to be utilized by individuals with cancer who hope for complete recovery, particularly those approaching the end of life or who have multiple types of cancer (e.g., Choi et al., 2012). The parents who employed a "shotgun approach" to treatment selection in the present study may be similar to these individuals with cancer, selecting many treatments for their children in the hopes that one of them will be effective in returning their children to "normal".

Workshops focusing on increasing parents' acceptance of their children's ASD through interventions such as Acceptance and Commitment Therapy (e.g., Blackledge & Hayes, 2006) may therefore be beneficial, especially for parents of newly diagnosed children, in terms of increasing selection of empirically supported treatments and reducing parents' likelihood of selecting empirically unsupported treatments for their children with ASD. Future studies should evaluate the efficacy of acceptance-focused interventions for the specific purpose of reducing parents' selection of unsupported treatments for their children with ASD.

Results of the present study also provide some support for the application of the self-regulation model of illness behaviour (Leventhal, Leventhal, & Contrada, 1999; Leventhal, Meyer, & Nerenz, 1980) to parents of children with ASD. In the present study, the dimensions of the model significantly associated with parents' treatment selection for their children with ASD were control/cure and cause. Parents' beliefs about their degree of control over their children's ASD was the strongest identified predictor of their treatment selection (i.e., high beliefs in personal control over one's child's ASD predicted selection of medication-based treatments), while parents' beliefs about the cause of their children's ASD were also associated with their treatment selection (i.e., high beliefs in external causes predicted selection of metabolic treatments).

Although parents' acceptance and cognitive representations of their children's ASD affected their treatment selection for their children, several other factors are also important to consider. Of particular importance are practical considerations such as the cost and availability of each treatment within the local community; support or lack of support from family, friends, other parents, and professionals; empirical support for each treatment; and parents' "gut feelings" about each treatment. Although treatment constraints due to high cost and lack of

availability in many areas are unfortunate realities for many parents of children with ASD, factors such as social support and parents' "gut feelings" about ASD treatments are likely much more amenable to change. Parents' instincts are valuable and should certainly not be ignored or minimized by professionals; however, professionals may use this knowledge to collaborate with parents when selecting treatments, ensuring that the knowledge they base their decisions on is accurate. Future research examining the effectiveness of community education seminars and workshops promoting the importance of these factors in terms of their influence on the quality of treatments received by children with ASD would be beneficial.

Finally, results of the present study also demonstrated that, although most parents report that empirical support is an important factor in their treatment selection for their children with ASD, parents' actual treatment choices do not consistently reflect this claim. This finding implies that there is a significant disconnect between research and parents of children with ASD. It may be that parents of children with ASD do not know where to find reliable information about the empirical support for various treatments, have difficulty understanding the scientific literature, or are not aware that the sources of information they most commonly report using (i.e., healthcare professionals, the internet, community ASD organizations, and other parents of children with ASD; Drouillard, Gragg, Miceli, & Voelker, [2012]) are not always reliable. Future research focusing on better understanding the reasons behind this disconnect between research and parents, and how to bridge the gap, would likely be beneficial in terms of helping more parents of children with ASD select empirically supported treatments for their children.

Conclusions

Overall, results from the present study suggest that parents' treatment selection for their children with ASD is a complicated process with many influences. Many factors which were

found to be associated with parents' treatment selection (e.g., parents' beliefs about the causes of their child's ASD, parents' beliefs about the empirical support behind proposed treatments) were often found to be based on inaccurate or unsupported claims. This tendency often leads many well-intentioned parents to unknowingly select empirically unsupported, or even potentially harmful, treatments for their children with ASD. Additionally, low levels of acceptance of one's child's diagnosis of ASD was demonstrated to be associated with a "shotgun approach" to treatment selection, involving selecting significantly more treatments – regardless of empirical support – than parents with higher levels of acceptance. Parent-focused programs aiming to increase parents' knowledge of ASD, its causes, and the evidence behind various proposed treatments, in addition to programs aiming to increase parents' acceptance of their children's diagnoses of ASD, would likely be beneficial in terms of increasing the likelihood of children with ASD receiving evidence-based interventions.

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Appendix A: Complete List of ASD-Related Organizations and Listservs used for Recruiting

ASD-Related Organizations

Summit Centre Preschool for Children with Autism
 Autism Ontario, Windsor-Essex Chapter
 Autism Ontario
 Autism Services Incorporated of Windsor and Essex County
 St. Mary's Family Learning Centre
 Potential Program, Windsor-Essex Chapter
 Potential Program, Hamilton Chapter
 Autism Ontario, Chatham-Kent Chapter
 Autism Ontario, Durham Chapter
 Autism Ontario, Grey Bruce Chapter
 Autism Ontario, Halton Chapter
 Autism Ontario, Huron-Perth Chapter
 Autism Ontario, Kingston Chapter
 Autism Ontario, London Chapter
 Autism Ontario, Niagara Chapter
 Autism Ontario, North Bay Chapter
 Autism Ontario, Ottawa Chapter
 Autism Ontario, Peel Chapter
 Autism Ontario, Peterborough Chapter
 Autism Ontario, Sault Ste. Marie Chapter
 Autism Ontario, Sudbury Chapter
 Autism Ontario, Toronto Chapter
 Autism Ontario, Cornwall Chapter
 Autism Ontario, Waterloo Chapter
 Autism Ontario, Wellington Chapter
 OAARSN Adult Autism News Bulletin
 Autism Speaks

ASD-Related Listservs

Autism
 Autism Society of Greater Tucson
 Parents of Autism UK
 Sacramento Autistic Spectrum and Special Needs Alliance
 AuTeach
 64
 ABAsupportgroup
 abasupportgroup

ABRAutism
actionforautismdiscussion
ActivitySchedules
ADAPTMICHIGAN
aicardisyndromemild
AllergyRelatedVaccineInduce...
appsforautism
ASD_ASER
ASPENBergenCounty
asperger_autism
asperger_autism_12up
asperger_college
AspergersSupport
AspergerSupport
ASSEW_Waukesha
aubiomedgroup
austinasdsupport
aut-home-fam
Aut-N-Indiana
AutDads
autism-adviser
autism-aspergers
autism-comorbidity
autism-CT
autism-cures
autism-diet
AUTISM-FBI
Autism-Florida
Autism-Indiana
autism-indonesia
Autism-Mercury
Autism-Mercury-BioMed-UK
autism-newmexico
autism-oregon
Autism-Software
Autism-Spectrum
autism-stlkids
autism-test-treat
AUTISM-togetherinautismorg
Autism-visual
autism_alabama
Autism_Chatboard
autism_families_delhi

autism_in_children
Autism_iron
autism_list
autism_marriage
Autism_Mercury
Autism_Recovery
autism_support_group
autism_sweden
autism_talk
Autism_Therapist
Autism_TodayNC
Autism_UK
autism_wa_vetc
autismaba
autismcure
autismfamilycircle
autismfc
autismgrapevine
AutismIndia
AutismInMarin
AutismInNebraska
autisminsanantonio
AutismIowa
autismknowledge
autismmoderatetosevere
autismnvc
autismsocal
AutismUK
Autistic_Spectrum
AutisticDailyLiving
AutisticSelfAdvocacyNetwork
biofeedback
BiomedicalTreatmentforASDinBC
bridgeovertroubledwater4u
Chicago_Talks_Autism_Mind
childdevdelays
childrenwithautism
childrenwithautisum
columbus-autism-support
Crystal_Healing_Foundation
ddshoptalk
DEFEATAUTISM
digidoodlez

diskusi-autis
doing-the-best-we-can
DTT-NET
EnzymesAndAutism
epilepsycured
FairfaxAutismNetwork
Family_Autism_Center
floortimers
GFCFKids
HDOTherapyforAutism
HENASD
HighFunctioningAutism
Homeschoolers_with_Special_Needs
HomeschoolingAutismToday
HomeschoolingPDDandAutismchild
Hopeforhealingchildren
Houston_Schools_for_ASD
hugsfeelgood
IndianAmericansWithAspergers
jeanandmikec
jewishautisticparents
jewishspecialneeds
kansasautismadvoc
LCCARE
LDS_Autism
LivingWellWithAutism
LosAngelesFamiliesforEffectiveAutismTreatment
medicaidforhbot
Michigan_FEAT
MNAutism-support
mo-feat
MOCHA-Seattle
Nancy Morrison Autism Listserv
NASP-IG-Autism-PDD
NZ_Aspergers
opengautism
pa_autismsupport
pacdd
panhandleautismsociety
parentsofautisticchildren2
parentsofpddkids
PDD-NOSfamily
pecanbread

pervasivedevelopmentaldisorder

poac-or

salemco_autism

SCDKids

seattleasnews

secretin_Autism

Seroussi-Info

single-parents-and-autism

SoCal-Autism

southflorida_autism

Special-Education

StemCell_for_Autism2

TEACCH

Texas-Autism-Advocacy

theautismworkshop

transferfactorautism

triautism

UK-oneparent-autism

UTAutismBiomedical

VacInfoCoalition

VitaminK

YaskoProtocol

Appendix B: Demographic Questionnaire

Please let us know a bit about yourself.

1. Your Gender: a) Male b) Female

2. Your Age: a) 18-34 years b) 35-44 c) 45-54 d) 55-64 e) 65+

3. Your Marital Status:

a) Single

b) Married and Living with partner

c) Separated

d) Divorced

4. Your Household Income:

a) Under \$25,000

b) \$25,000 - \$49,999

c) \$50,000 - \$74,999

d) \$75,000 and Over

5. Your Education:

a) High School or Less

b) Some College

c) College or Post-Graduate

6. Employment Status:

You:

a) Full-Time

b) Part-Time

c) Unemployed

d) Retired

Your Spouse/Partner:

a) Full-Time

b) Part-Time

c) Unemployed

d) Retired

7. Child's birthday: month (a) _____ & year (b): _____

8. Is your child (a) a boy? or (b) a girl?

9. Child's birthplace:

City/town (a): _____, province/state (b): _____, country (c): _____

10. Your current city/town of residence:

City/town (a): _____, province/state (b): _____, country (c): _____

11. Your relationship to your child:

a) birth parent b) other caregiver (adoptive/foster parent, grandparent, etc.)

12. Child's age at diagnosis: My child was _____ months old when diagnosed with autism.

13. Time since child's diagnosis: It has been _____ months since my child was diagnosed with autism.

14. Which race or ethnicity do you identify with the most for yourself and for your child?

(Check one in both columns)

Race or Ethnicity	a) You	b) Your Child
a) Aboriginal		
b) Arab		
c) Black		
d) Chinese		
e) Filipino		
f) Japanese		
g) Korean		
h) Latin American		
i) South Asian (East Indian, Pakistani, Sri Lankan, etc.)		
j) Southeast Asian (Cambodian, Indonesian, Laotian, Vietnamese, etc.)		
k) West Asian (Afghan, Iranian, etc.)		
l) White		
m) Other (please specify): _____		

15. What treatments for ASD has your child had?

Please check whether each treatment was used in the **past** (not currently using), is **presently** being used, or will be used in the **future** (currently waitlisted) and indicate the **number of months** your child participated in each treatment (if applicable).

Treatment	Past	Present	Currently Waitlisted	Number of Months Used
<p>a) Academic interventions</p> <p>These interventions are designed to teach individuals with ASD to recognize and identify mental states (i.e., a person's thoughts, beliefs, intentions, desires and emotions) in oneself or in others and to be able to take the perspective of another person in order to predict their actions.</p>				
<p>b) Antecedent package</p> <p>These interventions involve the modification of situational events that typically precede the occurrence of a target behavior. These alterations are made to increase the likelihood of success or reduce the likelihood of problems occurring. Treatments falling into this category reflect research representing the fields of applied behavior analysis (ABA), behavioral psychology, and positive behavior supports.</p>				
<p>c) Auditory integration training</p> <p>This intervention involves the presentation of modulated sounds through headphones in an attempt to retrain an individual's auditory system with the goal of improving distortions in hearing or sensitivities to sound.</p>				
<p>d) Augmentative/alternative communication device</p> <p>These interventions involved the use of high or low technologically sophisticated devices to facilitate communication. Examples include but are not restricted to: pictures, photographs, symbols, communication books, computers, or other electronic devices.</p>				
<p>e) Behavioural package</p> <p>These interventions are designed to reduce problem behavior and teach functional alternative behaviors or skills through the application of basic principles of behavior change. Treatments falling into this category</p>				

reflect research representing the fields of applied behavior analysis, behavioral psychology, and positive behavior supports.				
<p>f) Cognitive behavioural intervention package</p> <p>These interventions focus on changing everyday negative or unrealistic thought patterns and behaviors with the aim of positively influencing emotions and/or life functioning.</p>				
<p>g) Comprehensive behavioural treatment for young children</p> <p>This treatment reflects research from comprehensive treatment programs that involve a combination of applied behavior analytic procedures (e.g., discrete trial, incidental teaching, etc.) which are delivered to young children (generally under the age of 8). These treatment programs may also be referred to as ABA programs or behavioral inclusive program and early intensive behavioral intervention.</p>				
<p>h) Developmental relationship-based treatment</p> <p>These treatments involve a combination of procedures that are based on developmental theory and emphasize the importance of building social relationships. These treatment programs may also be referred to as the Denver Model, DIR (Developmental, Individual Differences, Relationship-based)/Floortime, Relationship Development Intervention, or Responsive Teaching.</p>				
<p>i) Exercise</p> <p>These interventions involve an increase in physical exertion as a means of reducing problem behaviors or increasing appropriate behavior.</p>				
<p>j) Exposure package</p> <p>These interventions require that the individual with ASD increasingly face anxiety-provoking situations while preventing the use of maladaptive strategies used in the past under these conditions.</p>				
<p>k) Facilitated communication</p>				

<p>This intervention involves having a facilitator support the hand or arm of an individual with limited communication skills, helping the individual express words, sentences, or complete thoughts by using a keyboard of words or pictures or typing device.</p>				
<p>l) Gluten/casein-free diet</p> <p>These interventions involve elimination of an individual's intake of naturally occurring proteins gluten and casein.</p>				
<p>m) Imitation-based interaction</p> <p>These interventions rely on adults imitating the actions of a child.</p>				
<p>n) Initiation training</p> <p>These interventions involve directly teaching individuals with ASD to initiate interactions with their peers.</p>				
<p>o) Joint attention intervention</p> <p>These interventions involve building foundational skills involved in regulating the behaviors of others. Joint attention often involves teaching a child to respond to the nonverbal social bids of others or to initiate joint attention interactions.</p>				
<p>p) Language training (production)</p> <p>These interventions have as their primary goal to increase speech production. Examples include but are not restricted to: echo relevant word training, oral communication training, oral verbal communication training, structured discourse, simultaneous communication, and individualized language remediation.</p>				
<p>q) Language training (production and understanding)</p> <p>These interventions have as their primary goals to increase both speech production and understanding of communicative acts. Examples include but are not restricted to: total communication training, position object training, position self-training, and language programming strategies.</p>				

<p>r) Massage/touch therapy</p> <p>These interventions involve the provision of deep tissue stimulation.</p>				
<p>s) Modeling</p> <p>These interventions rely on an adult or peer providing a demonstration of the target behavior that should result in an imitation of the target behavior by the individual with ASD. Examples include live modeling and video modeling.</p>				
<p>t) Multi-component package</p> <p>These interventions involve a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations. These treatments do not better fit one of the other treatment “packages” in this list nor are they associated with specific treatment programs.</p>				
<p>u) Music therapy</p> <p>These interventions seek to teach individual skills or goals through music. A targeted skill (e.g., counting, learning colors, taking turns, etc.) is first presented through song or rhythmic cuing and music is eventually faded.</p>				
<p>v) Naturalistic teaching strategies</p> <p>These interventions involve using primarily child-directed interactions to teach functional skills in the natural environment. These interventions often involve providing a stimulating environment, modeling how to play, encouraging conversation, providing choices and direct/natural reinforcers, and rewarding reasonable attempts.</p>				
<p>w) Peer-mediated instructional arrangement</p> <p>These interventions involve targeting academic skills by involving same-aged peers in the learning process. This approach is also described as peer tutoring.</p>				
<p>x) Peer training package</p> <p>These interventions involve teaching children without disabilities strategies for facilitating play and social interactions with children on the</p>				

<p>autism spectrum. Peers may often include classmates or siblings. Common names for intervention strategies include peer networks, circle of friends, buddy skills package, Integrated Play Groups™, peer initiation training, and peer-mediated social interactions.</p>				
<p>y) Picture exchange communication system</p> <p>This treatment involves the application of a specific augmentative and alternative communication system based on behavioral principles that are designed to teach functional communication to children with limited verbal and/or communication skills.</p>				
<p>z) Pivotal response treatment</p> <p>This treatment is also referred to as PRT, Pivotal Response Teaching, and Pivotal Response Training. PRT focuses on targeting “pivotal” behavioural areas — such as motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues, with the development of these areas having the goal of very widespread and fluently integrated collateral improvements.</p>				
<p>aa) Reductive package</p> <p>These interventions rely on strategies designed to reduce problem behaviors in the absence of increasing alternative appropriate behaviors. Examples include but are not restricted to water mist, behavior chain interruption (without attempting to increase an appropriate behavior), protective equipment, and ammonia.</p>				
<p>bb) Schedules</p> <p>These interventions involve the presentation of a task list that communicates a series of activities or steps required to complete a specific activity. Schedules can take several forms including written words, pictures or photographs, or work stations.</p>				
<p>cc) Scripting</p> <p>These interventions involve developing a verbal and/or written script about a specific skill or situation which serves as a model for the child with ASD. Scripts are usually practiced</p>				

repeatedly before the skill is used in the actual situation.				
<p>dd) Self management</p> <p>These interventions involve promoting independence by teaching individuals with ASD to regulate their behavior by recording the occurrence/non-occurrence of the target behavior, and securing reinforcement for doing so. Examples include the use of checklists (using checks, smiley/frowning faces), wrist counters, visual prompts, and tokens.</p>				
<p>ee) Sensory integrative package</p> <p>These treatments involve establishing an environment that stimulates or challenges the individual to effectively use all of their senses as a means of addressing overstimulation or understimulation from the environment.</p>				
<p>ff) Sign instruction</p> <p>These interventions involve the direct teaching of sign language as a means of communicating with other individuals in the environment.</p>				
<p>gg) Social communication intervention</p> <p>These psychosocial interventions involve targeting some combination of social communication impairments such as pragmatic communication skills, and the inability to successfully read social situations. These treatments may also be referred to as social pragmatic interventions.</p>				
<p>hh) Social skills package</p> <p>These interventions seek to build social interaction skills in children with ASD by targeting basic responses (e.g., eye contact, name response) to complex social skills (e.g., how to initiate or maintain a conversation).</p>				
<p>ii) Story-based intervention package</p> <p>These treatments involve a written description of the situations under which specific behaviors are expected to occur. Social Stories™ are the most well-known story-based interventions and they seek to answer the “who,” “what,” “when,” “where,” and “why” in order to improve perspective-taking.</p>				

<p>jj) Structured teaching</p> <p>Based on neuropsychological characteristics of individuals with autism, this intervention involves a combination of procedures that rely heavily on the physical organization of a setting, predictable schedules, and individualized use of teaching methods. These treatment programs may also be referred to as TEACCH (Treatment and Education of Autistic and related Communication-handicapped CHildren).</p>				
<p>kk) Technology-based treatment</p> <p>These interventions require the presentation of instructional materials using the medium of computers or related technologies. Examples include but are not restricted to Alpha Program, Delta Messages, the Emotion Trainer Computer Program, pager, robot, or a PDA (Personal Digital Assistant).</p>				
<p>ll) Theory of mind training</p> <p>These interventions are designed to teach individuals with ASD to recognize and identify mental states (i.e., a person's thoughts, beliefs, intentions, desires and emotions) in oneself or in others and to be able to take the perspective of another person in order to predict their actions.</p>				
<p>mm) Other (please specify):</p> <p>_____</p>				

Appendix C: Permission to use IPQ-RA

RE: Permission to use IPQ-RA Print all Turn on highlighting

☆ DARDENNES Roland R.DARDENNES@ch-sainte-anne.fr via uwindsor.ca to me show details Aug 26 Reply

Dear Miss Drouillard,

It is a pleasure to give you my authorization.
 As you may know there is a website with all versions, translations, and adaptations of the generic IPQ-R.
<http://www.uib.no/ipq/index.html>
 There is no English version, but, as we translated and adapted the IPQ-R for Autism from the generic IPQ-R, it will be easy to find English wording. For the illness identity scale, we adapted and shortened the DSM-III-R criteria. Thus, you will find English equivalent of the items we used.

I would be happy to get a copy of your Master thesis, once finished.

Good luck,

Pr. Roland Dardenes

De : Brianne Drouillard [mailto:drouillb@uwindsor.ca]
Envoyé : vendredi 26 août 2011 03:14
À : r.dardenes@gmail.com
Cc : DARDENNES Roland
Objet : Permission to use IPQ-RA

Dear Mr. Dardenes,

I am currently in the early phases of planning my MA thesis study on the relation between parents' acceptance, illness perceptions, and treatment selection for their children with autism spectrum disorders, and I was wondering if you might grant me permission to use the Revised Illness Perception Questionnaire (Autism Version) as one of my study measures. I plan to post all of the study measures online in order to allow maximum recruitment of participants. Since the study will take place in Canada, I was also wondering if there is also an English version of the Revised Illness Perception Questionnaire (Autism Version) available in addition to the French version used in your published studies.

Thank you for your consideration.

All the best,

*Brianne Drouillard, B.A. (Hons)
 M.A. Candidate, Child Clinical Psychology
 University of Windsor
 Department of Psychology
 401 Sunset Avenue
 Windsor, ON N9B 3P4
drouillb@uwindsor.ca*

Appendix D: IPQ-RA-E

<u>Your views about your child's Autism:</u>				
Listed below are a number of symptoms that you may or may not have observed in your child with Autism. Please indicate by ticking <i>Yes</i> or <i>No</i> whether you have observed any of these symptoms in your child, and whether you believe that these symptoms are related to your child's Autism.				
Symptom	My child has experienced this symptom since being diagnosed with Autism		This symptom is related to my child's Autism	
	Yes	No	Yes	No
1. Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction				
2. Failure to develop peer relationships appropriate to developmental level				
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)				
4. Lack of social or emotional reciprocity				
5. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)				
6. Marked impairment in the ability to initiate or sustain a conversation with others				
7. Stereotyped and repetitive use of language or idiosyncratic language				
8. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level				
9. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus				
10. Apparently inflexible adherence to specific, nonfunctional routines or rituals				
11. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)				
12. Persistent preoccupation with parts of objects				

We are interested in your personal views of how you now see your child's Autism. Please indicate how much you agree or disagree with the following statements about your child's Autism by ticking the appropriate box.

	Views about your child's Autism	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1.	My child's Autism will last a short time.					
2.	My child's Autism is likely to be permanent rather than temporary.					
3.	My child's Autism will last for a long time.					
4.	My child's Autism will pass quickly.					
5.	I expect my child to have Autism for the rest of his/her life.					
6.	Autism is a serious disorder.					
7.	My child's Autism has major consequences on my life.					
8.	My child's Autism does not have much effect on my life.					
9.	My child's Autism strongly affects the way others see him/her.					
10.	My child's Autism has serious financial consequences.					
11.	My child's Autism causes difficulties for those who are close to him/her.					
12.	There is a lot which I can do to control my child's Autism symptoms.					
13.	What I do can determine whether my child's Autism gets better or worse.					
14.	The course of my child's Autism depends on me.					
15.	Nothing I do will affect my child's Autism.					
16.	I have the power to influence my child's Autism.					
17.	My actions will have no effect on the outcome of my child's Autism.					
18.	My child's Autism will improve in time.					
19.	There is little that can be done to improve my child's Autism.					

20.	My child's treatment(s) will be effective in curing his/her Autism.					
21.	The negative effects of my child's Autism can be prevented (avoided) by his/her treatment(s).					
22.	My child's treatment(s) can control his/her Autism.					
23.	There is nothing which can help my child's Autism.					
24.	The symptoms of my child's Autism are puzzling to me.					
25.	My child's Autism is a mystery to me.					
26.	I don't understand my child's Autism.					
27.	My child's Autism doesn't make sense to me.					
28.	I have a clear picture or understanding of my child's Autism.					
29.	The symptoms of my child's Autism change a great deal from day to day.					
30.	My child's Autism symptoms come and go in cycles.					
31.	My child's Autism is very unpredictable.					
32.	My child goes through cycles in which the symptoms of his/her Autism get better and worse.					
33.	I get depressed when I think about my child's Autism.					
34.	When I think about my child's Autism I get upset.					
35.	My child's Autism makes me feel angry.					
36.	My child's Autism does not worry me.					
37.	My child having Autism makes me feel anxious.					
38.	My child having Autism makes me feel afraid.					

Causes of my child's Autism

We are interested in what you consider may have been the cause of your child's Autism. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your child's Autism rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your child's Autism. Please indicate how much you agree or disagree that they were causes for your child by ticking the appropriate box.

Possible Causes	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. Stress or worry					
2. Hereditary- it runs in my family					
3. A germ or virus					
4. Diet or eating habits					
5. Chance or bad luck					
6. Poor medical care in his/her past					
7. Pollution in the environment					
8. His/her own behaviour					
9. His/her mental attitude (e.g., thinking about his/her life negatively)					
10. Family problems or worries					
11. Overwork					
12. His/her emotional state (i.e., feeling down, lonely, anxious, empty)					
13. Ageing					
14. Alcohol					
15. Smoking					
16. Accident or injury					
17. His/her personality					

18. Altered immunity					
19. Vaccine(s)					
20. Food allergies					
21. Toxic metals in bloodstream					
22. Videos he/she watched					
23. My own behaviours/actions					
24. His/her actions in a past life					
25. Reproductive technologies used in his/her conception					
26. Illness during pregnancy					
27. Brain abnormalities					
28. Chemical imbalance					

In the spaces below, please list in rank-order the three most important factors that you now believe caused *your child's* Autism. You may use any of the items from the box above, or you may have additional ideas of your own.

The three most important causes in my opinion:

1. _____
2. _____
3. _____

Appendix E: Permission to Use AAQ-II**Re: Permission to use the AAQ-II** | X | X | X

Print all Turn on highlighting

show details Aug 26 Reply

☆ **Frank Bond** F.Bond@gold.ac.uk via uwindsor.ca to me

Hi Brianne,

That is fine. Good luck with your research.

Kind regards,

Frank

Professor Frank W. Bond, PhD
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Email: F.Bond@gold.ac.uk

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Fax: +44 (0)20 7919 7873

Website: <http://www.goldsmiths.ac.uk/psychology/staff/bond.php>**Brianne Drouillard**
26 August 2011 02:24

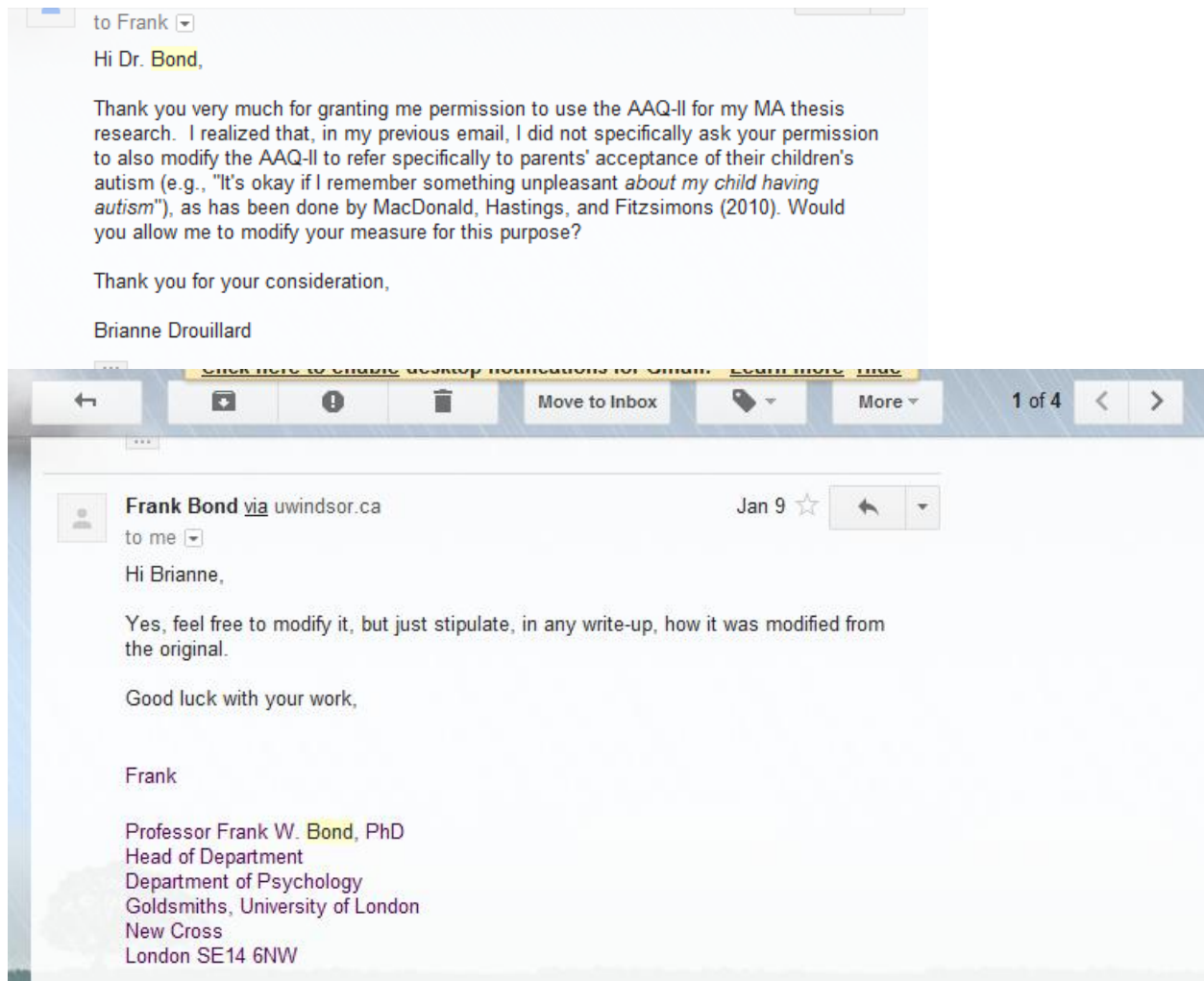
Dear Mr. Frank W. Bond,

I am currently planning my MA thesis study on the relation between parents' acceptance, illness perceptions, and treatment selection for their children with autism spectrum disorders, and I was wondering if you might grant me permission to use the Acceptance and Action Questionnaire-II as one of my study measures. I plan to conduct the study online in order to allow maximum recruitment of participants.

Thank you for your consideration.

All the best,

Brianne Drouillard, B.A. (Hons)
M.A. Candidate, Child Clinical Psychology University of Windsor
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Appendix F: Permission to Modify AAQ-II

Appendix G: AAQ-II-A

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

	1	2	3	4	5	6	7
	Never true	Very seldom true	Seldom true	Sometimes true	Frequently true	Almost always true	Always true
1. It's okay if I remember something unpleasant about my child having Autism.	1	2	3	4	5	6	7
2. My painful experiences and memories of my child having Autism make it difficult for me to live a life that I would value.	1	2	3	4	5	6	7
3. I'm afraid of my feelings toward my child having Autism.	1	2	3	4	5	6	7
4. I worry about not being able to control my worries and feelings toward my child having Autism.	1	2	3	4	5	6	7
5. My painful memories about my child having Autism prevent me from living a fulfilling life.	1	2	3	4	5	6	7
6. I am in control of how Autism affects my life.	1	2	3	4	5	6	7
7. My emotions about my child having Autism cause problems in my life.	1	2	3	4	5	6	7
8. It seems like most parents of children with Autism are handling their problems better than I am.	1	2	3	4	5	6	7
9. Worries about my child having Autism get in the way of my success.	1	2	3	4	5	6	7
10. My thoughts and feelings related to my child having Autism do not get in the way of how I want to live my life.	1	2	3	4	5	6	7

Appendix H: MCSDS-SF

Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is *true* or *false* as it pertains to you personally.

Item	True	False
1. I'm always willing to admit it when I make a mistake.		
2. I always try to practice what I preach.		
3. I sometimes try to get even rather than forgive and forget.		
4. I never resent being asked to return a favour.		
5. I like to gossip at times.		
6. At times I have really insisted on having things my way.		
7. I have never deliberately said something that hurt someone's feelings.		
8. There have been occasions when I felt like smashing things.		
9. There have been occasions when I took advantage of someone.		
10. I have never been irked when people expressed ideas very different from my own.		

Appendix I: Open-Ended, Exploratory Survey Items

1. What is your ultimate goal for your child's treatment/intervention?
2. What is the most important thing to you when selecting treatments/interventions for your child?
3. How have your feelings about your child's ASD changed from when he/she was first diagnosed to now?
4. If you could describe ASD in one word, it would be _____.

Appendix J: In-Depth Interview Questions

1. What does ASD/Autism mean to you?

2. What factors do you think influence how you think about Autism?

3. What do you think it means to accept that your child has Autism?

4. What factors do you think influence your acceptance of your child's Autism?

5. What were your major challenges in selecting treatments for your child with Autism?

6. What advice do you have for other parents selecting treatments for their children with Autism?

Appendix K: Consent Form**LETTER OF INFORMATION AND CONSENT TO PARTICIPATE IN RESEARCH**

Title of study: It's all in how you see it: Predicting parents' treatment selection for their children with Autism Spectrum Disorder

You are asked to participate in a study by Brianne E. Drouillard, B.A. (Hons.), from the Psychology Department at the University of Windsor as part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at (519) 253-300, Ext. 2227.

PURPOSE OF THE STUDY

The study will examine the extent to which various factors predict parents' treatment selection for their children with ASD. This information may help professionals in guiding parents toward selection of evidence-based treatments for their children with ASD.

PROCEDURES

If you volunteer to participate in the study, you will be asked to provide responses to various questions online. This will take approximately 20 minutes.

You will also be given the opportunity to provide written responses to four open-ended questions concerning your goals for your child's treatment/intervention program, your reactions to your child's diagnosis of ASD, and how you think about your child's ASD.

POTENTIAL RISKS

You might feel mild discomfort, anxiety, or sadness while answering the questions as you recall receiving your child's diagnosis, think about your child having ASD, and think about how you selected treatments for your child. You can access professional support by dialing 416-486-2242 (in Canada) or 1-800-273-8255 (in the United States) should you require help with psychological reactions as a result of participating in this study.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR SOCIETY

You may benefit directly by feeling more confident in your treatment selection decisions for your child with ASD and/or by confronting your feelings associated with your child's diagnosis. Alternatively, you may not directly benefit from taking part in this study. However, you will be providing information which may help future parents to select evidence-based interventions for their children with ASD.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you the opportunity to enter a draw for one of ten \$20 electronic gift cards to Amazon.com/ca. If you are the winner of a gift card, it will be emailed by September 30, 2012 to the email address you provide.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will not be disclosed without your permission. The researchers will keep the data from this study locked in a secure location for seven years after the study is completed. All data and forms will be shredded or deleted after seven years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time *before* you submit your questionnaire online without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study. Once you have submitted your questionnaire, you will *no longer* be able to withdraw your information as there will be no way to identify and locate your specific questionnaire.

If you do not wish to take part in the study once you have started, simply exit the questionnaire. You will be sent directly to the Draw page and you can enter the Draw even if you choose to withdraw from the study. If you would like to participate, complete the questionnaire and submit it. You will be sent directly to the Draw page after you have clicked submit.

FEEDBACK OF THE RESULTS OF THE STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by October 31, 2012 and will be posted online at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, please contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4, (519-253-3000, Ext. 3948), Email: ethics@uwindsor.ca

SIGNATURE OF RESEARCH PARTICIPANT

I understand the information provided for the study **It's all in how you see it: Predicting parents' treatment selection for their children with Autism Spectrum Disorder** as described in this document. My questions have been answered to my satisfaction, and I agree to participate in this study.

SIGNATURE OF INVESTIGATOR

There are the terms under which I will conduct research.

(signature of investigator will be electronically inserted)

Date

[Click to consent]

[Click to decline]

Click [here](#) to print a copy of the Letter of Information and Consent to Participate for your records.

Appendix L: Post-Study Letter of Information



Title of study: It's all in how you see it: Predicting parents' treatment selection for their children with Autism Spectrum Disorders

You participated in a study by Brianne E. Drouillard, B.A. (Hons.) from the Psychology Department at the University of Windsor. This study is part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at mgragg@uwindsor.ca or Brianne at drouillb@uwindsor.ca.

PURPOSE OF THE STUDY AND BACKGROUND INFORMATION

- With the widespread use of unsupported treatments for Autism Spectrum Disorders (ASD), it is important to identify factors associated with selection of these treatments that may be possible to change.
- Two of the most challenging tasks for parents of recently diagnosed children are developing an understanding of ASD and accepting the diagnosis of ASD.
- The purpose of the present study is to identify the relations between nine aspects of parents' understandings of ASD, their acceptance of their children's ASD, and their treatment selection for their children.

EXPECTED FINDINGS OF THE STUDY

- a) Parents with stronger beliefs in the severity of ASD and its impact on various aspects of their child's functioning will be more likely to select behavioural treatments for their children;
- b) Parents with stronger beliefs in a cyclical course of ASD will be more likely to select drug-based treatments for their children;
- c) Parents with stronger beliefs in their personal control over their child's ASD will be less likely to select drug-based, diet-based, and vitamin-based treatments for their children;
- d) Parents with stronger beliefs in external causes of their child's ASD (e.g., vaccines, pollution) will be more likely to select diet-based and vitamin-based treatments for their children;
- e) Parents with more negative emotional reactions to their child's diagnosis of ASD will be less likely to select behavioural treatments for their children;
- f) Parents with higher levels of acceptance of their child's ASD will be more likely to select supported treatments for their children; and
- g) Parents with lower levels of acceptance of their child's ASD will be more likely to select unsupported treatments for their children.

FEEDBACK OF THE RESULTS OF THE STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by February 1, 2013 and will be posted online at www.uwindsor.ca/autism (click on 'Student Research' and 'Brianne Drouillard').

PSYCHOLOGICAL SUPPORT

You can access professional support by contacting your family physician or by dialing **1-800-448-1833** for the Canadian National Crisis Hotline or **1-800-273-8255** for the US National Crisis Hotline, should you require help with psychological reactions as a result of participating in this study.

MORE INFORMATION ON SELECTING TREATMENTS FOR CHILDREN WITH ASD

For more information on the empirical support for various treatments for children with ASD and tips on how to select the best treatments for your child, please visit:

http://www.kidsmentalhealth.ca/documents/EBP_autism.pdf

and

<http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf>

Vita Auctoris

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PLACE OF BIRTH: Windsor, Ontario

YEAR OF BIRTH: 1987

EDUCATION: St. Anne Secondary School
2001 – 2005

University of Western Ontario
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