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Family Perspectives on the Ontario Autism Intervention Program

A Mixed Methods Study

by

Michelle Turan

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Family Perspectives on the Ontario Autism Intervention Program

A Mixed Methods Study

by

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ABSTRACT

The Autism Intervention Program (AIP) in Ontario has been in place providing intensive behavioural intervention (IBI) to children with autism spectrum disorder since 1999 (Perry et al., 2008). This IBI program involves teaching children using applied behaviour analytic (ABA) principles for 25-40 hours per week, in the family home or in an IBI centre. The use of ABA-based methods for teaching skills and decreasing problem behaviour to children with autism has the most evidence to date, and therefore remains in high demand by families within the province. The purpose of the current study was to examine parent perspectives about the Ontario Intensive Behavioural Intervention program for children with autism. A mixed methods design was used to investigate a sample (N=110) of parents who completed the Family Perspectives on IBI Questionnaire (FPIQ) and the Measure of Processes of Care (MPOC) rating scale. In addition, a small focus group (N = 3) was conducted with three parents who had completed the questionnaires. The study investigated parents' overall satisfaction of IBI, and variables that predicted satisfaction.

The results of the study indicate that parents were satisfied with their child's outcomes, and they wanted IBI to extend longer, even across the lifespan in some instances. Families felt that the IBI program needed to be evaluated separately with respect to the funding body, and the clinical team. Parents were dissatisfied with the manner in which funding was delivered for the program, how assessment decisions about their children's IBI services were made, and the financial impact that IBI had for many of them. In terms of the clinical team, although some families were dissatisfied with the number and quality of therapists, or the number of meetings with their Supervising Therapist (ST), they were very satisfied with the close relationships they formed with their team, and the individualized clinical goals provided by some teams. An examination of the direct funded option (DFO) vs. the direct service option (DSO) found that the DFO families felt they had more control over their services, but they expressed more dissatisfaction overall.

DEDICATION

I dedicate this dissertation to my son, Charlie.

You make everything better.

I love you more.

ACKNOWLEDGEMENTS

It is without question that the completion of a PhD involves a team of support. Support comes in many forms and from many people. First, I would like to thank my advisor, Dr. Elizabeth Starr. From a somewhat rocky start to a relatively smoother end, from academic discussions that were occasionally interspersed with personal reveals, I have appreciated your attention to detail, your sense of humour, but most of all, being able to remove all of your tracked changes to my written work. Thank you also to my patient dissertation committee whose commentary at my proposal defense challenged me to reconsider many aspects of this study.

On a personal level, thanks goes out to my family and friends. So many people have faced my grimace when asking me how my dissertation is going, but I thank them for still asking, knowing that their questioning came from a place of caring and support, and perhaps an interest in seeing me socially again. Thank you to my best friend Kelly, who tolerated my procrastination texts from Starbuck's or the library, who always was my number one supporter, and whose gifted bottle of Veuve Clique sits waiting to be uncorked (in her company), hopefully one day soon.

I owe my greatest thanks to my husband, Robert, and my son Charlie. Robert has been a patient supporter throughout this course of study, always cheering me on, and allowing me the distance I have needed to make it to this point. To Charlie, my perfect 9-year old boy, I look forward to showing you that, in the evenings, or at your baseball or hockey games, I do not have to sit with my laptop anymore. More importantly, I hope that you have learned that working towards personal or professional goals can be done with a family while still having fun in life and reserving time for the most important of things, such as you.

Finally, I would like to thank the families of children with autism who never fail to inspire in their ability to love, support and advocate for their children. As a mother, I am humbled by your strength, courage and willingness to do whatever it takes to help your children. You are indeed warriors and champions.

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LIST OF ABBREVIATIONS

ABA	Applied Behaviour Analysis
ASD	Autism Spectrum Disorder
AIP	Autism Intervention Program
EI	Early Intervention
EIBI	Early Intensive Behavioural Intervention
IBI	Intensive Behavioural Intervention
FPIQ	Family Perspectives on IBI Questionnaire
MPOC	Measures of Processes of Care
PPM 140	Policy/Program Memorandum 140

CHAPTER I

INTRODUCTION

The prevalence of autism has reached alarming rates for reasons that have been unidentified. The Center for Disease Control and Prevention (CDC) states that the rate of autism is currently 1 in 68 children in the United States (CDC, 2014). These large numbers result in increasing demands for support and government funding from families, schools and communities. In 2004, the Autism Society of Canada released a White Paper indicating that early diagnosis and intervention can cut lifetime assistance costs by 50% (Autism Society of Canada, 2004). This suggests that early intervention is a necessary route for individuals with autism. In 1999, the New York State Department of Health recommended that early intervention programs for children with autism should be intensive (i.e., minimum of twenty hours per week), and incorporates the principles of applied behaviour analysis (New York State Department of Health, 1999). The evidence supporting applied behaviour analysis as the foundation to effective behavioural intervention for children with autism is strong (Connor, 1998) and it is deemed to be an “efficacious” intervention (Chambless & Hollon, 1998), or one that will benefit many children with Autism Spectrum Disorder.

The definition of Autism Spectrum Disorder (ASD) is a term that has undergone changes in the latest edition of the Diagnostic and Statistical Manual (DSM) in 2013 (American Psychiatric Association, 2013). However, at the time this research was conducted, the fourth edition (DSM-IV) was the tool used to define and diagnose ASD. ASD was an overarching term that included the specific categories of Autistic Disorder, Asperger’s Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS), Childhood Disintegrative Disorder and Rett’s Disorder (American Psychiatric Association, 2003). In early intervention studies, children who received a diagnosis of Autistic Disorder were the children eligible to receive intensive behavioural treatment. A diagnosis of Autistic Disorder was given based on the following symptoms: Qualitative impairment in social interaction (e.g., failure to develop peer relationships appropriate to developmental level), qualitative impairments in communication (e.g., delay in, or total lack of, the development of spoken language), and restricted, repetitive and stereotyped patterns of behaviour, interests and activities (e.g., inflexible adherence to specific, nonfunctional routines or rituals) (American Psychiatric Association (2003).

Although symptoms of autism can be seen in the first year of life (Zwaigenbaum, Bryson, Rogers, Roberts, Brian, & Szatmari, 2005), children with autism in Canada are generally not being diagnosed this early and the age of diagnosis is inconsistent. The range in age of diagnosis also varies geographically from a median age of 39 months in Newfoundland to a median of 55 months in Southeastern Ontario (Oulette-Kuntz et al., 2009). In order to receive intervention services in Ontario, children must have already received the diagnosis of autistic disorder (DSM-IV), like many of the studies described below.

Political pressure from families to fund autism intervention services began in Ontario over 15 years ago. A number of lawsuits initiated by parents in Ontario (e.g., Deskin/Wyneberg, 1998) sparked political interest in accommodating the needs of children with autism. In 2000, the Ministry of Community and Social Services (now the Ministry of Children and Youth Services) established province-wide “Intensive Behavioural Intervention” (IBI) as a service for these children up until age six. This service involves the application of the principles of applied behaviour analysis (ABA) over 25 to 40 hours per week in order to alter some of the behavioural features of autism. Since 2003, Ontario has doubled spending to more than $112 million annually (Government of Ontario, 2007) and research has begun to demonstrate the effectiveness of this program (Freeman & Perry, 2010; Perry et al., 2008). Despite demonstrated effective child outcomes, the Intensive Behavioural Intervention program (IBI) has not met the needs of many families in the province. Long waitlists of up to 1000 children (Howlett, 2007) meant that many children did not receive IBI services as they either "aged-out" (i.e., service was terminated when the child reached age six) or they were due to enter the school system. Many parents were disappointed with not receiving IBI (Howlett, 2007) and the lack of equivalent services within the education system. Because of parent demand, age cutoffs in Ontario's IBI program have now been removed and school-based ABA services are now available. Thus, parents have been very effective in advocating for these services that have been shown in the research literature to effectively change children's learning trajectories. However, what is interesting about the implementation of IBI is the variability that exists in the delivery of this service.

In terms of how the program is actually delivered, each of a number of core features in IBI may vary on a local or regional basis. For example, the intervention may be delivered at home, in a classroom, or in a centre. The goals that are selected may be derived from a published curriculum guide (e.g., the Assessment of Basic Language and Learning Skills; ABLLS) (Sundberg & Partington, 1998), or may be cooperatively developed between clinical supervisors and parents. The materials that are used to teach the children may include store-bought materials, homemade flashcards, or the use of real objects from the child's environment—the latter suggesting integration of the program with the home environment, and the parents. In addition, parents or caregivers may participate in IBI at varying levels.

The features of the program that remain relatively static across the province are a) the delivery of an “intensive” program (25 - 40 hours per week) over a sustained period of time (i.e., at least two years); b) having a “behavioural” focus, meaning that changes in the behaviour of children are sought in measureable, observable ways; c) “early,” meaning that children are receiving the intervention at a young age (i.e., less than 4 years of age); d) be “ABA,” in that the strategies are based on the principles of applied behaviour analysis (e.g., using reinforcement, systematic instruction, task analyses, data-based treatment decisions); and e) “one-to-one,” where instruction is delivered to one child by one teacher (Maurice, Green & Luce, 1996).

However, intensive behavioural intervention programs may vary in a number of other areas. For example, the IBI may incorporate a parent-training component and expect parents to implement some one-to-one teaching hours (Lovaas, 1987), or parents may work as the managers of their home programs (Grindle, Kovshoff, Hastings & Remington, 2009) hiring and supervising teams of instructors. This variability in the delivery of IBI is surprisingly common given its scientific origin. Research has not adequately explored these program differences and their effect on the outcomes of children with autism. Although intensive behavioural intervention is supported by a solid evidence-base, continued research is needed to examine the features within IBI that can be manipulated to increase the effectiveness for children and their families.

IBI as conducted in the Lovaas (1987) study included parents in the delivery of instructional sessions to maximize the number of hours the children were receiving. This level of parental involvement is not always possible, and in Ontario’s IBI program, the inclusion of parents in meetings, and responsiveness to families’ needs and concerns is defined as a service objective in IBI programming (Perry, 2002). However, level of responsiveness is not currently being evaluated and the satisfaction of families who have received the Ontario IBI service has yet to be examined in the literature. Including caregiver perspectives in the development of treatment plans for children with autism has been shown to enhance the long-term sustainability of the treatment (Moes & Frea, 2002). How the variable features and outcomes of the provincial IBI program affect the perspectives of families warrants consideration. For example, are parents who receive more months of service more satisfied with IBI? Are the parents whose child had a better outcome more satisfied? Are the parents who were given more control in the programming more satisfied than other parents in the IBI program? Knowing the answer to some of these questions may increase the effectiveness of Ontario's IBI program and ensure its long-term sustainability.

The purpose of this study was to explore the views of families within the Ontario IBI program. Specifically, this study examined whether satisfaction of IBI is related to a number of variables (i.e., features of the IBI service delivery, characteristics of the child, and features related to the family), which are defined within Chapter Two. This research was completed through the administration of a questionnaire and by conducting a focus group with a subset of caregivers who had responded. The study explored the various aspects of the IBI service delivery model in Ontario and the effect that these have had on children with autism and their families who have completed the program.

The next chapter will outline the relevant research that has been conducted on intensive behavioural intervention outcomes for individuals with autism both internationally and in Ontario's provincial program, as well as the effects of these programs on the families.

GLOSSARY OF TERMS

APPLIED BEHAVIOUR ANALYSIS (ABA): the science in which procedures derived from the principles of behaviour are systematically applied to improve socially significant behaviour to a meaningful degree and to demonstrate experimentally that the procedures employed were responsible for the improvement in behaviour (Cooper, Heron & Heward, p. 14).

AUTISM INTERVENTION PROGRAM (AIP): the Ontario Ministry-funded program for individuals with autism across the province. This intervention program includes the Intensive Behavioural Intervention (IBI) program, and transition support programs for children to assist in making the transition from IBI to schools (Ministry of Child and Youth Services, 2013).

EARLY INTENSIVE BEHAVIOUR(AL) INTERVENTION (EIBI): the term used to describe ABA-based programs that are implemented at a young age (e.g., younger than three years), intensively (25 – 40 hours per week), and over a prolonged period of time (e.g., greater than two years).

INTENSIVE BEHAVIOUR(AL) INTERVENTION (IBI): a synonymous term for EIBI, and used to refer to the services in the Ontario government-funded autism program (Perry, 2011).

CHAPTER II

LITERATURE REVIEW

This chapter begins with a description of the defining features of Autism Spectrum Disorder. It then continues with a brief discussion of the nature of applied behaviour analysis and the evidence for its application as an early intervention for children with autism. The review will then focus on a consideration of the outcome research conducted to date on IBI programs both nationally and internationally (e.g., Lovaas, 1987), with a particular emphasis on research concerning Ontario’s Autism Intervention Program (AIP) (e.g., Perry, 2011). The AIP includes a number of services for children with autism, such as IBI, transition to school support (i.e., the “Connections” program) and ABA services (i.e., a less intensive goal-directed support for parents) (MCYS, 2013). However, for the purposes of this study, the terms AIP and IBI will be used interchangeably to describe the IBI component of the program only.

The factors that have been found to affect the outcomes of children in these programs are then discussed, followed by a description of the research on parent perspectives regarding intensive behavioural programs. Following that is a discussion of functional contextualism that provides the epistemological framework for this dissertation. The chapter concludes with a consideration of the rationale for the proposed research, the specific research questions that will be addressed, and some hypotheses of the results.

Autism Spectrum Disorder

As mentioned in Chapter One, according to the fourth edition of the DSM (APA, 2003), autism spectrum disorder (ASD) is an overarching term used to describe a range of diagnoses that includes Autistic Disorder, Asperger’s Syndrome, Pervasive Developmental

Disorder Not Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder (CDD) and Rett’s Disorder (APA, 2003). Because children receiving services in intensive behavioural programs are most commonly those diagnosed with Autistic Disorder, only this category of autism spectrum disorders will be discussed here. For ease of reading, the term Autistic Disorder will be used interchangeably with autism throughout this paper. As mentioned in the introduction, autism is defined as a neurodevelopmental disorder characterized by 1) qualitative impairments in social interaction, 2) qualitative impairments in verbal and nonverbal communication, and 3) restrictive, repetitive and stereotyped patterns of behaviour (APA, 2003). The degree of impairment in each of these domains depends on the individual (Koegel & Koegel, 1995), and approximately four times as many boys are diagnosed with ASD than girls (Frombonne, 1999). Intellectual disability is present in approximately 50-70% of individuals with ASD (Matson & Shoemaker, 2009) and autism is found across all socioeconomic levels and ethnicities. The presentation of the characteristics of autism can appear quite different across individual children. For example, impairments in communication may range from not speaking at all, to repeating every word that another person has said (i.e., echolalia). The socialization impairments may range from a child not interacting with other individuals at all, to wanting to interact socially, but having restricted conversational interests, and lacking social reciprocity. Behavioural impairments may be represented by severe self-injurious behaviour (e.g., headbanging), occasional outbursts or tantrums, and insistence on sameness and routines (Chen, Rodgers & McConachie, 2009).

Because the diagnostic characteristics of autism can be present in varying degrees, finding one intervention to benefit all persons with this disorder is unlikely. Fortunately, there has been some success in identifying treatments and interventions that ameliorate the deficits (and/or excesses) in communication, social skills and behaviour for many children with autism. Empirical validation of behavioural approaches for individuals with autism is extensive (Schreibman & Ingersoll, 2005), and applied behaviour analysis (ABA), when used to guide intensive behavioural intervention is currently the most evidence-based intervention for children with autism (e.g., National Research Council, 2001; Maurice, Green & Luce, 1996).

Applied Behaviour Analysis

Cooper, Heron and Heward (2007) define applied behaviour analysis as "the science in which tactics derived from the principles of behaviour are applied to improve socially significant behavior, and experimentation is used to identify the variables responsible for the improvement in behaviour" (p. 690). Applied behaviour analysis is classified as a science given its history in basic research by B.F. Skinner, where experimental manipulations were conducted with animals and based on the "three-term contingency" (the antecedent-behaviour-consequence model of behaviour) (Cooper, Heron & Heward, 2007). The three-term contingency became the basis for "operant behaviour." Operant behaviour, or consequence-based "learned" behaviour, is differentiated from behavioural responses that are automatic, or reflexive, and is referred to as "respondent behaviour" (Cooper, Heron & Heward, 2007). These principles of behaviour demonstrated that organisms are born with the ability to respond automatically to environmental stimuli (i.e., reflexive behaviour), but can also learn to respond to environmental stimuli when consequences followed behaviour (operant behaviour). This delineation provided the foundation for the field of "behaviour analysis," which included both a philosophy of science, known as "radical behaviourism," as well as an application of this science to human behaviour - known as applied behaviour analysis (Cooper, Heron & Heward, 2007). It is from this scientific field that principles such as reinforcement, punishment, and stimulus control have originated (Michael, 1993).

Applied behaviour analysis as a branch of behaviour analysis and as a field within psychology has seven dimensions, as described in a seminal article by Baer, Wolf and Risley (1968). According to Baer et al. (1968) research that is to be described and published as emanating from the applied behaviour analytic field must be *applied*, *behavioural*, *conceptual*, *effective*, *analytic*, *technological*, and have *generality*. The dimension of *applied* suggests that ABA must aim to make changes that are socially significant to the individual instead of seeking to prove some theory (as in basic research). The *behavioural* emphasis is on human behaviour (hence behavioural), and what people can be observed to do, and not what they say, providing for objectivity in measurement. All work in ABA must include adherence to behavioural principles (i.e., be *conceptual*) which allows for the development of techniques that can be expand(ed) systematically instead of a "bag of tricks" to be discarded after each application. An intervention is described as *effective* when it makes a significant effect on the individual's behaviour for practical value, meaning that the change procedure need not demonstrate an effect that is significant at a group level in order to be a successful intervention. To be *technological,* the interventions must be described in such detail so as to be replicable. Interventions must be demonstrated to be *analytic* in that they must show verifiable change, demonstrated by showing changes in behaviour only when the independent variable is applied. Finally, for interventions to be classified under the umbrella of applied behaviour analysis, they must demonstrate *generality*, where the effects of the intervention can prove durable over time, in a wide variety of environments, or by spread(ing) to a wide variety of related behaviours (Baer et al., 1968).

In the past 50 years behaviour analytic research has been conducted in an increasing number of areas where behaviour change has been targeted. This has ranged from the creation of reinforcement techniques (e.g., Kazdin & Bootzin, 1972) to modifying classroom behaviour (e.g., Hall, Lund & Jackson, 1968), toilet training (Azrin & Fox, 1971), research methods and data collection (Bijou, Petersen & Ault, 1968), and autism (Risley, 1968). In more recent years its application has expanded to include topics of social importance such as gambling (e.g., Dixon, Marley & Jacobs, 2003), behaviour-based safety practices (e.g., Sulzer-Azaroff, & deSantamaria, 1980), language and cognition (e.g., Barnes-Holmes, Dymont, Roche & Grey, 1999), dementia and Alzheimer’s (e.g.,Trahan, Kahng, Fisher & Hausman, 2011), organizational behaviour management (e.g.,Wilder, Harris, Casella, & Postma , 2011), behavioural economics (e.g., Ito, 2001), attention deficit hyperactivity disorder (Binder, Dixon & Ghezzi, 2000) and autism and developmental disabilities (e.g., Matson, Turygin, Beighley, Rueski, Tureck & Matsik, 2012). Much of the continued growth of the field of ABA is largely due to the successes of its application as an intervention with young children with autism.

Applied behaviour analysis and autism. Research on the use of applied behaviour analysis with children having autism has spanned sixty years (Handleman & Harris, 2002). Early behavioural research in autism sought to demonstrate that control over the autistic behaviour could be gained (e.g., training responding to lever pressing), and that maladaptive behaviour could be altered (e.g., reducing tantrum behaviour or aggression). Eventually it was realized that therapeutic gains could be made using the principles of ABA (e.g., increasing eye contact, establishing toilet training, imitation, language) (Margolies, 1977).

This body of research led to a seminal control group study by Lovaas (1987) which directly compared an intensive and non-intensive application of behavioural teaching to two groups of children with autism. The findings from this study, described below, have become a primary source for supporting intensive behavioural approaches for teaching children with autism.

Early intensive behavioural intervention (EIBI). Lovaas (1987) applied the principles of applied behaviour analysis to intensive teaching for children with autism in a control-group study, providing the foundation for what would become an evidence-based treatment model and demonstrating that improvements in both the cognitive and functioning levels of children with autism could be made. The 59 participants in the study were divided into an experimental group (*n* = 19), control group one (*n* = 19), and control group two (*n* = 21). All children were independently diagnosed with autism and entered the study at an age less than 46 months. The mean chronological age was 34.6 months and 40.9 months for the experimental group and control group 1 respectively (the age of control group 2 was not provided). Pretreatment mental age scores were determined based on the Bayley Scales of Infant Development (Bayley, 1993), the Cattell Infant Intelligence Scale (Cattell, 1960), the Stanford-Binet Intelligence Scale (Thorndike, 1972), and the Gesell Infant Development Scale (Gessell, 1949). To adjust for variations in the mental age score attributable to a young chronological age, a prorated mental age was calculated for a chronological age of 30 months. In the experimental group, 2 of the 19 participants scored in the normal range of intellectual functioning, 7 in the moderate range of intellectual disability, and 10 in the severe range of intellectual disability. Clinical presentations of the experimental and control group were described as similar at intake in terms of imaginary play and speech, and were described as an “average or below average” sample of children with autism. Children in the experimental group received 40 hours per week of individual instruction, while children in control group 1 received 10 hours of instruction per week. The second control group did not receive any treatment but were followed up at 6 years of age. Because of staffing limitations or family distance from the treatment centre, participants were not randomly assigned to the control or experimental group (Lovaas, 1987).

Children in the intervention group received in-home intervention by several trained staff and their parents (who also taught their children outside of treatment hours) for a minimum of two years to a maximum of six years (information on the total number of months of treatment for each child was not provided). When the children entered into kindergarten, intervention hours were reduced to 10 hours per week. Participants who had not achieved “normal functioning” by grade one received a total of six years of treatment. The teaching procedures for the intervention group and control group 1 were based on the operant conditioning model where positive reinforcement and discrimination training methods were applied to increase learning of new behaviour. Problem behaviour, such as aggressive behaviour, was responded to by planned ignoring, time out, shaping of more appropriate social behaviour, or aversive procedures (e.g., saying “no!” in a firm voice or by the delivery of a knee slap). Aversive procedures were only used as a last resort, and only with the experimental group (the emphasis was, and is still is on using positive procedures, and physically aversive procedures have been eliminated in current IBI treatment). Treatment goals included reducing problem behaviours (e.g., aggression) and increasing communicative behaviour (e.g., receptive and expressive language) in years one and two respectively. In the third year, observational learning, expression of appropriate and varied emotions, and academic skills were introduced, with the goal of mainstreaming the participants into general education classrooms (Lovaas, 1987).

The results of the Lovaas (1987) study indicated that 47% of the children in the experimental group (*n* = 9) were mainstreamed into general education classrooms, were classified as "indistinguishable" from their peers at follow-up, and had gained a mean of 30 IQ points as compared to control group 1. In terms of normal intellectual functioning, only two participants in the experimental group met this criterion at intake, but 12 did at discharge. The number of participants within the moderate to severe range of intellectual functioning in the experimental group was reduced from 10 to 3. The children in both control groups showed little improvement following more than two years of programming, as their scores on IQ [1]tests remained unchanged between intake and follow-up (Lovaas, 1987).

Lovaas' (1987) study generated a number of critical responses in the literature. Schopler, Short and Mesibov (1989) criticized Lovaas' (1987) outcome measures, participant selection process (i.e., the IQ measures of participants at intake), and the lack of randomization in the study. Schopler et al. (1989) suggested that selecting IQ and classroom placement were poor choices for outcome measures, and that instead, measures pertaining to the diagnosis of autism, such as communication skills, behavioural problems, and social skills would have been more appropriate. It was argued that classroom placement as an outcome measure may have been more related to parental advocacy and changing educational philosophy than child skill level, and that changes in cognitive measures might have been the result of increased compliance during testing by the participants. Finally, the selection of participants was criticized. In particular, the use of the prorated mental age

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[1] The term "IQ" is used throughout this paper due to the reference as such in the literature, although it should be noted that "cognitive ability" or "cognitive levels" would be a more accurate term for this measure.

(PMA) instead of a ratio IQ score was problematic. It was suggested by Schopler et al. that this was an attempt to have the participants appear lower functioning at intake.

Lovaas, Smith and McEachin (1989) responded to this and other critical reviews stating that the outcome measures were selected because of their standardized qualities and generalizeability. Lovaas and his colleagues also conducted a follow-up study on the same participants (McEachin, Smith & Lovaas, 1993) at 13 years of age to challenge the notion that the children were simply more compliant at the post treatment IQ test. In this study, the participants were compared directly to their peers, and 9 of the 18 participants were declared "indistinguishable." With regard to the use of the prorated mental age (PMA) score, Lovaas et al. indicated that it was chosen since ratio and deviation I.Q.s could be derived. Selection of participants above the 11 months PMA was an attempt to prevent participants not having autism from being included, since when cognitive levels (i.e., IQ) are very low, it is difficult to differentiate autism from profound intellectual disabilities (Lovaas, 1989). Finally, McEachin et al. (1993) suggested that replication of the study by independent investigators would further strengthen the findings from the Lovaas (1987) study.

A number of follow-up studies have been conducted since Lovaas' (1987) seminal work. These studies have repeatedly demonstrated that children with autism can make significant gains with intensive behaviourally-based intervention (Eikeseth, Smith, Jahr & Eldevik, 2002) in comparison to less intensive (Eldevik, Eikeseth, Jahr & Smith, 2006), or less behaviourally-based approaches (Eikeseth, Smith, Jahr & Eldevik, 2007; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005).

Eikeseth et al. (2002) evaluated the effects of one year of intensive intervention for two groups of children with autism between the ages of four and seven years (mean age of 5.5

yrs.). These children were divided into two groups: an intensive behavioural intervention group (*n* = 13), and an eclectic intervention group (*n* = 12). Both groups received an average of 28 hours of treatment. The intensive intervention was based on the Lovaas model (with the exception of the use of aversive stimuli), and the eclectic intervention incorporated numerous interventions including Project TEACCH (Treatment and Education of Autistic and Communications-Handicapped Children; Mesibov, Shea, & Schopler, 2005), sensory motor therapies, ABA, and other techniques the researchers described as developed from personal experiences. Techniques were selected by a multi-disciplinary school team, and each child received a different combination of interventions, which were delivered 1:1 in a therapy room in the child's school (Eikeseth et al.).

At intake the two groups did not differ significantly on the measured variables (intellectual functioning, visual spatial skills, language functioning, and adaptive behaviours), although the eclectic group did score higher on average. The results of the study indicated that the behavioural group had made more gains than the eclectic group on all measures with statistically significant differences noted in IQ (i.e., cognitive ability), language, and adaptive behaviour. The researchers reported that the children in the behavioural group were more likely to have cognitive scores in the average range, than the eclectic group following treatment, although this finding was not statistically significant (Eikeseth et al., 2002).

In a follow-up study, Eikeseth, Smith, Jahr and Eldevik (2007) conducted assessments on the same two groups of students from Eikeseth et al. (2002) at a mean age of eight years, two months. Hours of intensive behavioural intervention were reduced for both groups once they began attending school. The behavioural group went from 28 hours to 18 hours and the eclectic group went from 29 to 16 hours. The students in the behavioural treatment group showed greater gains over the eclectic treatment group in the areas of IQ, language and adaptive skills. In terms of IQ, the students in the behavioural group gained an average of 25 points, whereas the eclectic group gained only 7 points. With respect to adaptive skills, the behavioural group showed an increase ranging from a minimum of 9 points in daily living skills, to a maximum of 20 points in communication, whereas the eclectic group lost 4.5 points on the mean score in communication, lost 7.2 points on the mean score in daily living skills, and lost 1.4 points on the mean score in socialization on the Vineland Adaptive Behaviour Scales. Between the behavioural and eclectic treatment group, differences in social emotional functioning were small following the intervention, although the behavioural group demonstrated fewer social and behavioural problems (Eikeseth et al., 2007). This study extended the findings of Eikeseth et al., (2002) and demonstrated the superiority of intensive behavioural treatments over eclectic interventions for two groups of children.

Eldevik, Eikeseth, Jahr and Smith, (2006) conducted a retrospective study of low-intensity (approximately 12 hours per week) school-based interventions, comparing behavioural and eclectic treatments for children with autism and intellectual disability. The participants in the behavioural group consisted of 13 children (10 boys), with a mean age of 53 months, while the eclectic group included 15 children (14 boys), with a mean age of 49 months. Similar to the Eikeseth et al. (2002) study described above, students were assessed pre and post treatment on a number of measures. Intellectual functioning was assessed using the Bayley Scales of Infant Development (Bayley, 1993), the Stanford-Binet Intelligence Scales (Thorndike, Hagen & Sattler, 1986) and the Weschler Intelligence Scales (Weschler, 1989). Language functioning was assessed using the Reynell Developmental Language

Scales (Reynell, 1990), while adaptive behaviour was assessed using the Vineland Adaptive Behaviour Scales (VABS) (Sparrow et al., 1994), and non-verbal intelligence was measured using the Merrill-Palmer Scale of Mental Tests (Stutsman, 1948), and finally, autism symptomology data were taken through observation and interviews, as in Lovaas (1987) where presence of a particular symptom (e.g., no words, not affectionate, no toy play, no peer play, stereotypical behaviours, severe tantrums, and not toilet trained) was scored as a 1, and absence of this symptom was scored as 0.

At intake, there were no significant differences between the two groups. The behavioural group averaged 12.5 hours of instruction per week for 20 months, while the eclectic group received 12 hours of instruction per week for 21 months. Although Eikeseth et al.'s (2006) study demonstrated that the participants in the behavioural treatment group made larger gains, these gains were more modest than in their previous study (Eikeseth et al., 2002) where the intensity was much higher. The findings from this study suggest that intensive behavioural treatments are more effective than eclectic treatments. However, 12 hours per week may not be sufficient to achieve optimal effects (Eldevik et al., 2006).

Howard, Sparkman, Cohen, Green, and Stanislaw (2005) also conducted a study comparing treatments for young children with autism. In this study, three groups of children with autism receiving three intervention approaches were compared. The first group that received intensive behaviour treatment (IBT group) consisted of 29 children (mean age of 31 months) who received one-to-one instruction for 25-40 hours per week. The second group of 16 children (mean age of 37 months) received eclectic interventions, consisting of a combination of interventions termed "autism educational programming" (AP) in either a 1:1 or 1:2 teacher to student ratio for 30 hours per week. The third group of 16 children (mean age of 35 months) received “generic educational programming” (GP) which consisted of small group instruction in an early, non-intensive public school setting for 15 hours per week. Dependent measures included cognitive skills, nonverbal skills, receptive and expressive language, communication, self-help skills, social skills and motor skills, measured using a variety of standardized tests. The children in all three groups showed similar scores across all measures at intake (Howard et al, 2005).

Following 14 months of intervention, the IBT group demonstrated statistically significant improvements in mean scores across most of the domains with the exception of motor skills, and this group had higher mean scores in all domains than the other two groups combined. The scores for the IBT group following treatment were in the normal range for cognitive skills, non-verbal skills, communication, and motor skills. In comparison, the mean increase in the scores of AP and GP group was not statistically significant (although mean scores did improve), and motor skills was the only domain in which these two groups scored in the normal range post-treatment (Howard et al., 2005). These findings are consistent with the earlier studies demonstrating that intensive behavioural intervention is more effective over alternative methods for young children with autism.

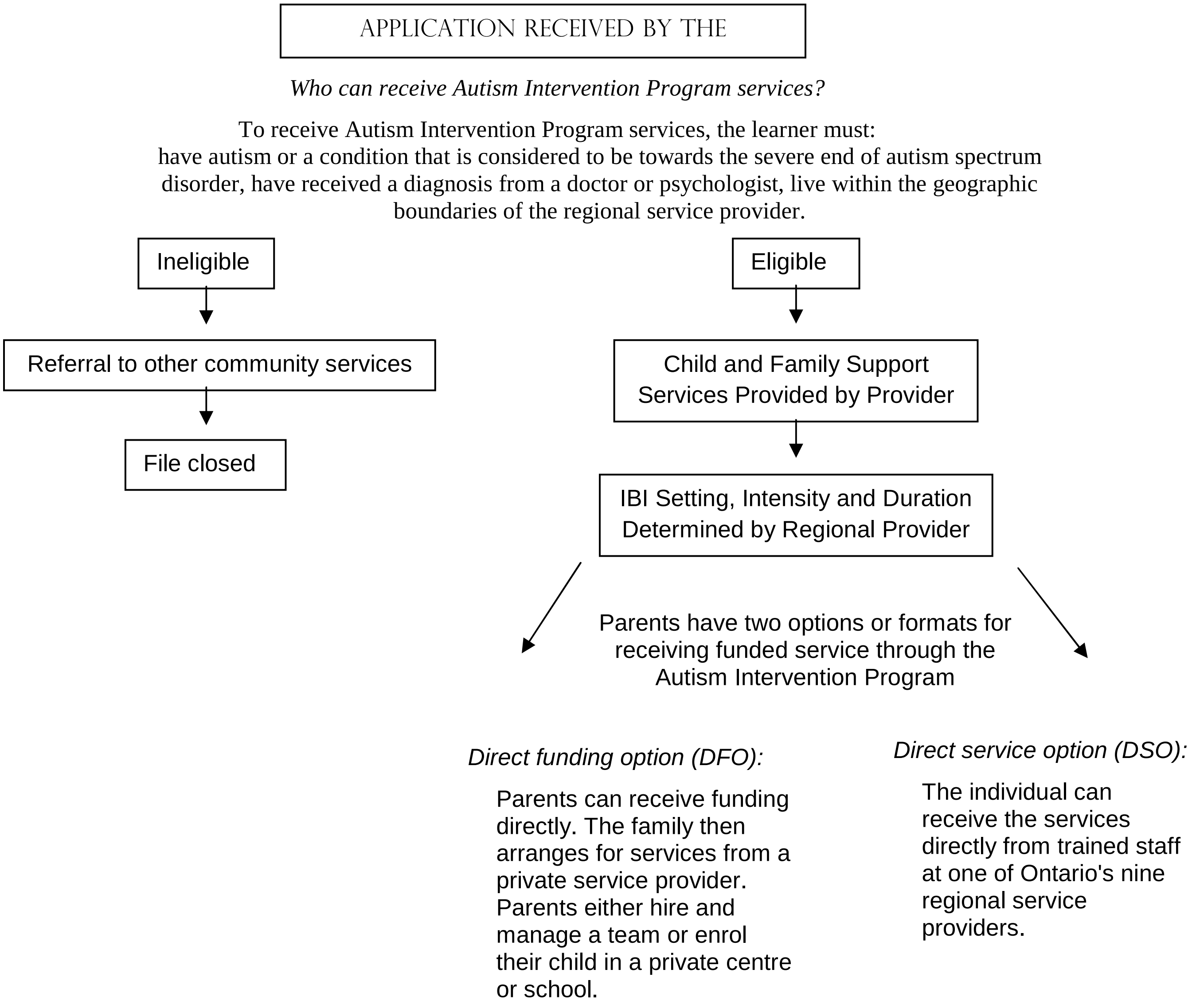
Finally, in a 2010 meta-analysis by Virues-Ortega (2010), 26 outcome studies on behavioural intervention and autism were reviewed and statistically analyzed to measure the collective effectiveness of ABA-based interventions for individuals with autism. This review described how studies using repeated measures demonstrated consistency of treatment effects and diminished the likelihood or effect of control group bias. However, given that the number of studies using group randomization was rare compared to the use of quasi-random assignment, concerns regarding ethics and internal validity arise. For example, in at least one study participants were assigned to a particular treatment group due to therapist availability. The overall conclusion of the meta-analysis, however, was that ABA intervention, when delivered over a long-term period can have positive effects on intellectual functioning, language development, acquisition of daily living skills and social functioning in children with autism. Future researchers in this area need to consider using clinical trials by having a no treatment control group, or ensuring standardization across groups, establishing treatment integrity measures, and comparing interventions in isolation rather than combined "eclectic" interventions (Virues-Ortega, 2010).

Jacobson, Mulick and Green (1998) estimated there would be a cost savings of $656,000 to $1,082,000 per child for ages 3 - 55 years, in the state of Pennsylvania when three years of early behavioural intervention are delivered between the ages of two years and entry into school. The estimate of cost of services over the lifespan is based on individuals receiving early intervention that leads to either average functioning or participating in education with little or no support, as compared to their peers with autism who did not receive intervention. The presumption is that adults without early intervention may need to be institutionalized or receive intensive adult services and families would incur additional costs to support these individuals as dependents.

The findings of these studies have become a primary source for supporting intensive behavioural approaches for teaching children with autism. The Lovaas (1987) study, in addition to the subsequent studies, has led to ABA-based practices becoming a recommended intervention for children with autism. For example, the New York Department of Health's Clinical Practice Guidelines for children with autism birth to 3 years of age (2001) recommended Applied Behaviour Analysis (ABA) as an important element in any early intervention program for children with autism (New York State Department of Health, Early Intervention Program, 1999).

The supporting evidence for early behavioural intervention has increased demand for programs of this nature. Intensive early intervention programs using ABA for children with autism are becoming available worldwide as can be seen with empirical studies on the topic being done in Japan (Arikawa, 2009), Norway (Eikeseth, 2009), the U.K. (Hastings, 2001), Italy (Valenti, Cerbo, Masedu, DeCaris, & Sorge, 2010), and Canada (Perry, 2002). Given the extent of evidence for these programs, both American and Canadian governments are now funding behaviourally-based intensive early intervention for young children with autism (Sagharian 2007; Livingston, 2004). In 2000, the Ontario Ministry of Community and Social Services (now the Ministry of Children and Youth Services [MCYS]) established province-wide “Intensive Behavioural Intervention” (IBI), an ABA service for all children diagnosed with autism. Making ABA interventions accessible to children with autism in Ontario was a direct result of the research findings of a number of studies. In Ontario, the Autism Intervention Program has been funded for 13 years (MCYS, 2011).

Ontario’s autism intervention program and outcome data. In their Autism Intervention Program Guidelines the Ontario Ministry of Children and Youth Services (2006) define the service to be delivered to children with autism from nine regional agencies across the province. These regional centres partner with community agencies to make services accessible to families (MCYS, 2006). Once a child has been given a diagnosis of autism, they are then eligible to apply for the IBI program with their regional centre. At that point, the parents wait for an assessment to deem eligibility for the IBI program (see Figure 1). If



Who can receive Autism Intervention Program services?

To receive Autism Intervention Program services, the learner must: have autism or a condition that is considered to be towards the severe end of autism spectrum disorder, have received a diagnosis from a doctor or psychologist, live within the geographic boundaries of the regional service provider.

Parents have two options or formats for receiving funded service through the Autism Intervention Program

Direct funding option (DFO):

Parents can receive funding directly. The family then arranges for services from a private service provider. Parents either hire and manage a team or enrol their child in a private centre or school.

Direct service option (DSO):

The individual can receive the services directly from trained staff at one of Ontario's nine regional service providers.

Figure 1. Ontario’s Intensive Behavioural Intervention Program Service Model (Turan, 2014).

deemed eligible, the family then goes on a waiting list to obtain to either obtain the direct funding option (DFO) where a private agency is hired by the family or the direct service option (DSO) where service is obtained directly from the regional program. This differentiation was created for those families who had purchased existing services while on waitlist, allowing them to continue with those private services if they desire (Specialized Instructional Strategies, 2014). To purchase private services, the cost would be greater than what is provided by the regional programs, and therefore incurred by the families, although the families could then select a service provider whom they liked, who worked for them, and possibly gave families more options in terms of location of the service and/or hours. The direct service option would mean that the family would be assigned a team from a regional centre, and they would either have to travel to the center during the required hours, or the team would provide intervention in the family home. There would be no cost to families for the services in the DSO.

The Program Guidelines (MCYS, 2006) also describe the features of the program. The intervention must begin early in the child's life, and the teaching must be delivered in an intensive format, defined as 20 to 40 hours per week of one-to-one instruction. The teaching must be systematic and use techniques from the field of applied behaviour analysis. The learning plans that define the goals for each child must incorporate plans to ensure that goals will be maintained, as well as generalized across environments. The skills that are taught must be selected on the basis that they will serve a functional purpose in the individual's life. The emphasis of the learning goals is on the child achieving independence with each skill that is taught.

The curriculum that defines the child’s intervention goals must be individualized, but also comprehensive so as to ensure all areas of need are being addressed. One key feature is that all skills must be regularly measured since decisions to continue or alter instructional methods must be data-based. Because the program is meant to be sensitive to family values, culture and language preferences, there is a necessity to directly involve the families (Perry, 2002).

Each of the nine regional agencies delivers this program under the direction of a clinical director who oversees a team of clinical supervisors. These supervisors oversee teams of senior therapists, who are responsible for designing and supervising the IBI programs for six to eight children being taught by teams of three to five instructor therapists. The instructor therapists are responsible for working one-to-one with the children; either in the family’s home or in a clinic setting teaching skills that have been decided by the senior therapist in consultation with the family and the clinical supervisor (MCYS, 2006). The high number of staff required makes IBI an expensive service to deliver.

In Ontario, the funding for the AIP program is sponsored by the provincial government and is ostensibly available to all eligible children with autism. However, long waitlists for the program are increasing the demands for program expansion, and it is argued that increasing the funding for these services will continue to have long term cost-benefits (Motiwala, Gupta, Lilly, Ungar, & Coyte, 2007). Couper (2004) indicated that in Australia, parents were funding their own IBI programs at a cost of $10 to $20,000 per year. Families will continue to pursue these services through either demand for government funding or through purchase, when they can afford it. This demand stems from the available research supporting IBI effectiveness. In order to prove that the cost is warranted, the benefit of these programs to individual children with autism must be continually evaluated.

Only three outcome studies of IBI in Ontario have been conducted to date. Perry et al. (2008) conducted a retrospective study of the IBI program examining the progress of children following exit from the program in which the data from the files of 332 children (276 boys and 56 girls) were examined. The children ranged in age from two to seven years, with a mean age of 4.5 years at the time of entry into the program, and received 20 to 40 hours per week of intervention for approximately two years. The children in this study were classified into three subgroups according to initial level of functioning based on their Vineland Adaptive Behaviour Composite (ABC) standard scores: Group A (higher functioning) with an ABC score of 60 or above (n = 78); Group B (intermediate functioning) with scores between 50 and 59 (n = 126); and Group C (lower functioning), with ABC scores of 49 or lower (n = 96) (Perry et al., 2008). Scores on the Childhood Autism Rating Scale (CARS) was also used as a measure of progress in this study. A cumulative CARS score across 15 domains (i.e., relationship to people, imitation, emotional response, body, object use, adaptation to change, visual and listening response, taste-smell-touch response and use, fear and nervousness, communication, activity level, intellectual responses and general impressions) places a child in either a mild, moderate or severe category (i.e., scores ranging from 15 to 60 respectively).

The results of the study found that children who had a cognitive assessment at both intake and discharge (n = 127) had an average increase of 12 points in their IQ estimate (i.e., the combined score of one or more of the following: the Bayley Scales of Infant Development (Bayley, 1993), The Wechsler Preschool and Primary Scale of Intelligence (3rd

Ed.) (WPPSI-3; Wechsler, 2002), the Stanford-Binet Intelligence Scale: Fourth Edition (SB: FE; Thorndike, Hagen, & Sattler, 1986); or another unspecified test) which was statistically significant. In addition, the researchers reported that 50 percent of the children receiving IBI appeared to have fewer severe autism symptoms at the time of discharge, as measured by the Childhood Autism Rating Scale (CARS) (Schopler, Reichler, & Renner, DeVellis & Daly, 1980). In this study, 50 percent of participants (n = 138) were indeed presenting with less severe symptoms at exit, as they were rated on the CARS to be in a milder category (n = 138) (Perry et. al., 2008).

Perry et al., (2008) also examined the developmental trajectory of the children as measured by their rate of development by dividing the VABS ABC score by the child’s age at intake and exit. In addition, a measure of the rate of development during IBI was calculated by taking the difference between the developmental rate at intake and exit and dividing this by the duration of the IBI intervention in months or the time interval between the two developmental rate measures (i.e., intake and exit VABS ABC scores). The mean initial rate of development was .32 at intake, and increased during IBI to .77. Specifically, group A more than doubled their learning rate (2.5) as compared to a typical child’s developmental rate (1.0) (Perry et al., 2008). This finding suggests that IBI may increase the rate at which children learn, thereby increasing the developmental slope in their learning trajectory.

Overall, Perry et al. (2008) described the outcomes of children with autism in the Ontario IBI program as heterogeneous, in that the effectiveness of IBI varied across the participants. For example, although 75% of the children in the study did make improvements in the IBI program, only 11% of the participants achieved average functioning (as defined by standard scores on cognitive and/or adaptive functioning assessments in the low or average range, and CARS scores close to or in the non-autism range). Perry et al. (2008) describe this result as being similar (when compared to similar children at intake) to the “best outcomes” in the literature following intensive behavioural treatment.

Freeman and Perry (2010) conducted a study examining the outcomes in the Toronto Preschool Autism Program. Contrary to the previous study, which examined outcomes for children throughout Ontario, this study exclusively examined outcomes for children in the Toronto IBI program. The methodology used in this study was identical to that previously described (see Perry et al., 2008) with the children divided into groups A, B and C (as per VABS ABC standard scores) and used the same dependent measures (i.e., autism severity, adaptive behaviour, developmental rate, and cognitive levels). In this study, there were 89 participants (73 boys and 16 girls), with an age range of 20 to 83 months and mean age of 53.64 months. The duration of IBI intervention received by the children ranged from 5 to 47 months (*M* = 19.39 months), and the hours per week was suggested to be 25 to 40 hours, although no data were provided to substantiate these numbers (Freeman & Perry, 2010).

The adaptive skills for the three groups of children following intervention significantly improved in all domains (communication, daily living skills, socialization, motor, and overall ABC age equivalent) as measured by the Vineland Adaptive Behavior Scales (Sparrow et al., 1984). However, standard scores on the VABS were stable overall. The researchers suggested that the children were gaining skills, but because the VABS standard scores control for age, their rate of learning was slower than their chronological age maturation. However, the initial higher and medium functioning groups at intake did show significant increases in communication as measured by the VABS communication standard scores, whereas the communication scores of the lower functioning group decreased. This suggests that the individuals in this lower functioning group were falling further behind their same-aged peers. In terms of cognitive scores, only 20 children had been assessed at intake and exit, and they showed a significant increase in IQ at 11 points on average (Freeman & Perry, 2010).

Following receipt of the IBI program, statistically significant improvements were found in autism severity as measured by the CARS scores for all three groups of children. Of the children who scored in the mild/moderate range at entry (*n* = 48), 44% moved into the non-autism range at discharge, 46% were still rated in this category at discharge, while 10% moved into the severe range. Children scoring in the severe range at entry made positive changes as 65% improved and moved into the mild/moderate range, and the best outcome was that 13% moved into the non-autism range at discharge. Twenty three percent of the children remained in the severe category at exit. Freeman and Perry (2010) described how overall, 77% of children who began in the severe range of autism improved, whereas only 44% of those participants who began in the mild range could be said to have improved (Freeman & Perry, 2010), thus demonstrating the effectiveness of the IBI program for children at the severe end of the autism spectrum.

Most recently, Flanagan, Perry and Freeman (2012) investigated the differences between individuals with autism who were on the IBI waitlist as opposed to those who received the IBI service. The researchers examined the files of 61 children in IBI service and matched them with 61 children who had been on the waitlist (for at least 12 months) according to age and initial assessment (T1) data (i.e., autism severity, cognitive skills and adaptive skills). By examining the files at identical pre- (T1) and post- (T2) periods using the same outcome measures as at the initial assessment, the researchers were seeking to identify any predictors of outcomes.

The results indicated that no significant differences were found between the children at the T1 period. There was a greater interval between T1 and T2 for the IBI group (i.e., mean of 10 months longer) and the researchers described statistically controlling for this issue during the analysis. In terms of cognitive ratings, 18% of children from the IBI group had IQ estimates in the “normal range,” as opposed to 3.3% in the waitlist group. Very few children moved into a “normal range” for adaptive skills (i.e., 4.8% in the IBI group, 0% in the waitlist group), however large gains were noted for some (i.e., 14.8% of IBI children jumped 15 points or higher, as opposed to 1.6% in the waitlist group). In terms of predictors of outcomes, only younger initial age in the IBI group was a significant predictor of outcome ($p < .001$).

The outcomes of the Ontario IBI program support the findings from previous research (e.g., Howard et al., 2005; Eikeseth et al., 2007; 2002; Lovaas, 1987) that early intervention based on the principles of applied behaviour analysis is beneficial for young children with autism. However, there are a number of limitations to the studies described above. Only the most recent Ontario study (Flanagan et al., 2012) included a control group in the study, and even then the two groups were not randomly selected, nor were they equally matched during the final assessment. In addition, a great deal of variability is possible in the delivery of IBI, and treatment integrity measures were not taken in any of these studies, since they were file reviews, and specific details on the implementation of the treatment itself were lacking. This control group limitation is common across the early intervention treatment studies. Future research needs to consider defining the methods being used in the IBI program and measuring the treatment integrity of these methods. This would provide a starting point to determine which features of IBI are delivered consistently, and which are not. This could allow for an understanding of how particular features of IBI could be enhanced for better outcomes.

However, some features of the IBI service are quite difficult to measure. For example, how are concepts such as “individualized” being measured? How are the regional agencies defining “being sensitive to families’ culture?” Although data continues to be collected by the Ministry of Children and Youth Services on the implementation of the program, measurement of the goals described above have yet to be measured and disseminated. To date, research within the Ontario program has been conducted on child outcomes and parent participation only, despite the fact that there are a number of other variables that may influence the effectiveness of this intervention.

Variables Affecting Outcomes in Early Intervention Research

Lechago and Carr (2008) identify that a limitation of the IBI research to date is the vague or incomplete description of the independent variables in many studies (e.g., not specifying individual participant treatment hours, level of familial involvement, curricular goals, etc.). They describe how complex the delivery of IBI programs is, and how the explicit description of the independent variables affects the interpretation and replication of the procedures. Alternatively, although studies often include many details of the independent variables, there may be a lack of consistency about how IBI is delivered, as not all features of the service are described in the studies. Lechago and Carr suggest that the following features of the IBI programs be explicitly described in the research: duration and intensity of the service, amount and type of parental involvement and training, therapist experience and training, supervisor involvement and training, as well as the specific instructional procedures and measurement (Lechago & Carr, 2008). Matson (2008) also suggests that dependent variables in IBI have not been sufficiently researched. For example, he argues that IQ and autism severity are often correlated (i.e., the lower the IQ, the more severe the autism), and determining which variable is affected by EIBI is difficult to assess. In terms of methodology, Matson suggests the inclusion of control groups or the use of multiple baseline designs, randomized or matched assignment, and treatment integrity measures. Finally, he recommends that social validity or consumer satisfaction measures are included for the purposes of increasing parental support for the intervention (Matson, 2008).

Therefore, factors that may affect outcomes in IBI can be classified into three categories: structure of the IBI service (as an independent variable), characteristics of the child (as dependent variables), and the role of the family (as both independent and dependent variables). With regard to the latter, both the role that the family plays in the intervention process (e.g., delivering therapy, generalizing skills) as well as the effect that the intervention has on the family (e.g., ability to go out as a family given reduction in child problem behaviour) may be critical features affecting the success of early intervention. Research is beginning to examine some of these variables and is described below.

EIBI has been modeled on the Lovaas (1987) study and subsequent guidelines (Lovaas, 2002) provided in many of the autism intervention programs throughout the world. In most situations the programs are intensive, 25 to 40 hours per week, delivered one-to-one to a child with autism using the principles of applied behaviour analysis, and implemented as early in the child’s life as possible. However, these program features may vary for a number of reasons (e.g., funding, staffing, age of diagnosis), and these differences may have an effect on the outcomes of the children receiving this treatment. The specific components of the Lovaas model that are critical to treatment outcomes remain a question for research.

Research to date has been conducted on some of the features within the service delivery of IBI that may vary across programs, how characteristics of the children (e.g., autism severity, cognitive level, adaptive skills, etc.) affect the outcomes of the program, and finally how the families have participated or felt about the delivery of the intensive program with their child. Each of these areas of research is described below.

Features of EIBI service delivery. The manner in which EIBI is delivered varies according to the program. Some of the variations in the service may include: the number of hours received by the child on a weekly basis, the number of months the child receives IBI, the age at which the service is provided to the child, and how the staff supervise and support the program that the child is receiving. Although there may be additional variations in the delivery of the IBI service (e.g., location of service, variety of staff members, the inclusion of other services), these are the areas have received research attention to date.

Age and intensity of service. Itzchak and Zachor (2011) examined the outcomes post-treatment for 78 children who were 15 - 35 months of age at the outset (no mean age given), and following one year of intensive behavioural intervention or an eclectic (integration of several treatment approaches) centre-based program. In a previous study by Zachor and Itzchak (2010), no significant differences between the two intervention approaches on child outcomes were found, so the group data were examined to determine predictors of outcomes in early intervention in the 2011 study. Specifically the researchers wanted to see whether there were child or parental characteristics that affected the outcomes of children with autism. Characteristics related to service delivery in this study are discussed in this section while discussion relating to child characteristics and outcomes can be found in a later section of this chapter.

The children's scores on adaptive behaviours (as measured by the VABS) (Sparrow et al., 1984), verbal and non-verbal abilities as measured by the Mullen Scales of Early Learning (MSEL) (Mullen, 1995), and autism severity as measured by the Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, & LaCouteur, 2000) were obtained pre- and post-one year of service. Itzchak and Zachor (2011) found that child age was a significant predictor of cognitive gains following a behavioural intervention program. The researchers calculated the difference between the MSEL at the beginning and following one year of intervention and examined the result across age groupings of children. There was a 3% variation, which approached significance ($p < 0.1$) for age affecting outcomes, where children who were younger at the start of the intervention gained more cognitive skills following one year of intervention. However, when the score was compared to the combination of the age and education of the mother, there was a significant statistical finding that the older, more educated mother and the younger child led to better cognitive outcomes (Itzchak & Zachor, 2011). This study provides some initial support that providing service to a child at a younger age may have some predictive outcome, although maternal age and education of the mother confounds the result, making it insufficient as an independent predictor of outcome. However, additional studies have also investigated age of the child as a variable affecting outcomes.

Perry et al. (2011) examined outcomes related to age for 332 children, two to seven years of age (mean of 4.5 years) that received IBI through the Ontario Autism Intervention Program. The files of children within the IBI program were examined for entry and exit assessments, which included autism severity (CARS), adaptive behaviour (VABS), and cognitive level (various combinations of tests; Perry et al., 2008 described above). Following the intervention (as described above in Perry et al., 2008), the number of adaptive skills acquired and the cognitive ability of children in the program were negatively correlated with age at entry. That is, children who were younger (i.e., < 48 months) at the start of the IBI service tended to score higher in adaptive skills and cognitive ability at discharge. In addition, children who were younger than four years of age at entry into the program had significantly (clinically and statistically) lower scores on the CARS at the time of exit from the program, as compared to older children (Perry et al., 2011). These findings suggest that earlier entry into IBI programs may result in better cognitive and lower severity outcomes for children with autism at discharge.

Granpeesheh, Dixon, Tarbox, Kaplan, and Wilke (2010) grouped 245 participants by age at program entry (2 to 12 years of age, mean age of 6.15) to examine whether variable treatment hours had differential effects depending on the age at which the children began IBI. The children were classified into “age group 1” (range of 2 to 5.15 years of age), “age group 2” (range of 5.15 to 7 years of age), and “age group 3” (range of 7 to 12 years). The children received an average of 76 treatment hours (range of 20-168) per month of intensive behavioural intervention in a large-scale community based program. The hours received were then classified into a “low intensity,” “medium intensity,” and “high intensity.” It appears that no child received less than 20 hours of service per month (i.e., approximately 5 hours per week), and therefore 20 hours/month was considered a low intensity of service. The study then examined the relationship between treatment hours, age, and the number of objectives mastered. The results indicated that the youngest group had the best response (i.e., mastered the most number of learning objectives) to low intensity treatment, as compared to the other two groups. When the youngest group received the highest number of hours (i.e., 40 hours/week or greater), their results matched those in the middle age group in terms of mastery of behavioural objectives. The middle age group showed greater gains with greater treatment hours. The group of older children did not show any increase in mastery of objectives when they were receiving a greater number of hours, suggesting that their learning rates may stabilize after a certain number of treatment hours. The researchers concluded that maximizing treatment hours might be most beneficial for the youngest children. In this study, the researchers noted that 40 hours might not represent the ceiling on the number of hours that could maximize the rate of learning. However, the researchers found that children over seven years of age did not master more behavioural objectives with increased hours. These findings suggest that maximizing treatment hours (40 and above) is best for children in the middle age range, and that fewer treatment hours may be effective for the youngest and oldest children (Grenpeesheh et al., 2010).

Luiselli, Cannon, O’Malley and Sisson (2000) also examined age and intensity of service (i.e., number of hours per week, duration in months, and total hours) on the outcomes of children with autism in IBI. In their study, 16 children were examined retrospectively following their receipt of home-based IBI services. The children were divided into two groups; those who received services prior to three years of age (*n* = 8) and those who received services following three years of age (*n* = 8). The progress made by the participants was measured by achievement across domains (i.e., communication, cognition, fine motor, gross motor, social-emotional, and self-care) on one of two assessments (i.e., the Early Learning Accomplishments Profile; ELAP (Glover et al., 1998), or the Learning

Accomplishments Profile (LAP) (Sanford and Zelman, 1981). The children received IBI in their homes and the hours per week, the total numbers of months in service, and the cumulative hours of service received were used as independent variables in this study. The results indicated that children who began IBI service following the age of three received on average a significantly greater number of hours per week (mean of 15.6 hours as compared to 11.8 in the under three group). Children who began service prior to the age of three had more months of service (11.6 as compared to 7.12 in the over three age group) and more cumulative hours (583.5 as compared to 455.00) but this did not differ significantly from those receiving service after three years of age. Both groups (under three and over three years of age at the start of service) showed significant improvement across all domains following the IBI service, with no significant differences across groups. However, for all children, the number of months that service was received (i.e., duration of treatment) was a significant predictor for increases in communication ($p < 0.002$), cognitive ($p < 0.001$), and the social-emotional domain ($p < 0.001$) (Luiselli et al., 2000). These findings suggest that a minimum of 11.8 hours per week across 11.6 months of IBI service may be sufficient to make significant changes on learning assessments, whether or not service began prior to three years of age. However, it is the total number of months in service that may lead to the increase in gains that are made in communication, cognitive and social-emotional domain. The intensity of the service and the age at which IBI begins are clearly defined features of the program that can be measured and evaluated, but factors such as the amount of staffing provided may also affect the outcomes of children in IBI programs.

Clinical staff. A potentially critical variable in the effectiveness of an IBI program is the clinical staff. Given the intensive one-to-one structure, along with the requirement to take data, make daily clinical decisions, and analyze the effects of treatment on a regular basis, the skills and training of the staff directly influences the quality of the program. However, the staffing structure may vary considerably across programs. Eikeseth, Hayward, Gale, Gitlesen, and Eldevik (2009) examined the amount of clinical supervision that was provided to oversee staff and the implementation of IBI programming to see what effect this had on the learning outcomes of the children. In this study, each child had one consultant who provided a minimum number of supervision sessions with the child's tutors (i.e., the one-to-one therapists) and parents. The 21 children who participated in this study had a mean intake age of 34.9 months, and were assessed on intellectual functioning (WPPSI-R), visual spatial IQ (Merrill-Palmer Scale of Mental Tests), language functioning (Reynell Developmental Language Scales) and adaptive behaviours. The treatment hours for each child averaged 34.2 hours per week across 50 weeks of the year. Following 14 months of treatment, the individual results on the standardized assessments were directly compared across children to see if supervision that the child's team received was a variable affecting the outcome scores. The results indicated that the amount of supervision received ranged from 2.9 to 7.8 hours/month and took place either in the child's home or at a school team meeting. Following treatment, the mean IQ of the group increased from 54 to 71 and a significant correlation was found between the intensity of supervision and the amount of IQ score change ($p > 0.05$), and this was the only significant correlation. Eikeseth et al. (2009) noted that every hour of supervision was equivalent to a 0.21 increase in IQ score in their study, but they stated that the effect of supervision is not necessarily linear as optimal levels of supervision may vary per individual child and family, and the effectiveness of such supervision may be dependent on the competency of the therapist.

These studies describe how factors related to the service delivery of IBI may have an effect on outcomes. Given the combined findings of these studies, it is apparent that benefits of IBI can be maximized by ensuring that children receive services as early as possible for the purposes of either increasing the amount of time receiving IBI services, or for capitalizing on the time when children might be just starting to learn new skills. In addition, the levels of supervision that are provided by a program may directly affect the outcomes for the individual children. These factors need to be considered when developing and implementing IBI services. However, features that cannot necessarily be controlled by the program delivering the IBI service also warrant consideration. These are factors related to the characteristics of the individual children as they enter the early intervention program and this is discussed next.

Child characteristics and intervention outcomes. Children with autism are unique in their abilities and being taught in an early intervention program requires recognition of how these differences may affect learning. A number of studies have considered the variations in the skill sets or characteristics of children with autism and examined the impact that these have on the outcomes of early intervention. Research to date has considered the responsiveness of the child to initial teaching, the severity of autism, and cognitive ability. These studies are discussed below.

Child responsiveness to IBI may be seen early in the teaching of skills. Weiss (1999) conducted a study to examine how differential learning rates at the onset of IBI programs affects child outcomes at the time of exit. In this study, 20 children with autism, 20 to 65 months of age (mean age of 41.5 months) were receiving home-based intervention for 40 hours per week. All children were assessed using the CARS and the VABS at intake and following two years of treatment. The rate of learning for each child was assessed by examining the days to mastery for the first 5 targets, and the number of days to mastery that the first 30 targets were learned across nine initial programs (i.e., non-verbal imitation, object manipulation, matching 3D objects, receptive commands, receptive labels, verbal imitation of sounds, verbal imitation of two words, expressive labels, and social questions).

Following intervention, nine of the twenty participants moved from the severe rating (i.e., scores of 37 - 60) on the CARS to a non-autistic rating (i.e., scores below 30), and four additional children scored as non-autistic in the end, although still presenting with characteristics of autism. Four children moved from the severe range to the mild-moderate range (i.e., scores between 30 - 36), and three remained in the severe range. VABS ratings at intake were well below the average score of 100. The mean intake score was 49.85 (range of 38 – 63) but increased to 83.6 (range of 41-125) following treatment, with eight children scoring greater than 100. Finally, there was a lot of variability in the rate of learning in the initial nine programs. For example, in receptive language the range of days to mastery of the targets was 30 to 548 (mean of 110). In terms of skill acquisition within a particular program (e.g., non-verbal imitation), the rate at which the child learned the first five items was positively correlated with the rate that they learned the full 30 items ($p = 0.001$). In addition, acquisition of the first five learning targets was also moderately correlated with score changes on the CARS ($p = 0.004$) and VABS ($p = 0.001$). More days to mastery of the first five targets were inversely correlated with outcomes on the VABS and CARS. In terms of specific programs, changes in the CARS and VABS scores post-intervention could be predicted by the rate at which the child progressed in three of the initial programs (i.e., verbal imitation, receptive commands, and object manipulation). These findings support behavioural intervention delivered intensively over two years as a method to decrease autism severity and increase adaptive skills. In addition, the overall outcomes for the individual child might be predicted by their rate of learning in early program targets (Weiss, 1999).

Another factor that might influence the outcomes of IBI services is the severity of autism and the intellectual functioning of the child at the start of the program. In the Itzchak and Zachor (2011) study described above, the researchers found that other characteristics in addition to age may predict IBI outcomes. Comprehensive evaluations were conducted prior to intervention, and then following one year of intervention on the 78 children (71 boys and 7 girls), ages 15 – 35 months. The children were assessed using the Autism Diagnostic Interview-Revised (ADI-R) to diagnose autism (Lord, Rutter, & LeCouteur, 1994), the ADOS to assess social and communicative functioning (Lord et al., 2000) the Mullen Scales of Early Learning (MSEL) (to evaluate cognitive abilities, and the VABS to assess adaptive skills, although these last two tests were not completed with every child at the end of year one (Itzchak & Zachor, 2011).

Results of the Itzchak and Zachor (2011) study indicated that autism severity at baseline was the best predictor of outcomes, in that children with less severe autism (as defined by ADI-R ratings at entry) made more gains following one year of intervention, as indicated by a 40% improvement in Vineland scores. In addition, higher cognitive ability at baseline resulted in higher Vineland scores at the end of year one for the group of participants. Further, the researchers divided the participants into a high autism severity group and a low autism severity group, based on ADI-R scores, and examined how their entry MSEL scores predicted their VABS scores. A significant positive correlation was found between the children with severe autism symptoms and higher verbal abilities at baseline (as compared to severe autism and lower verbal abilities) and better scores on adaptive skill measures at exit. There was also a small but significant contribution of maternal age and education contributing to 4% of the variation in outcome, where the greater the age and education of the mother, the better the adaptive skills outcome in the child (Itzchak & Zachor, 2011).

Perry et al. (2011), in addition to their finding that age had an impact on IBI outcomes, also found that autism severity and cognitive levels were predictors of effectiveness. The researchers analyzed features of the AIP IBI delivery that may have affected the results of 332 participants. As described above, these 332 participants were assessed at both entry and exit to the Ontario IBI program, using the CARS for autism severity, the VABS for adaptive functioning, a combination of assessments for cognitive rating, and intake and exit VABS ABC scores for developmental rate. The children were then classified into seven categories of outcomes, which were Average Functioning, Substantially Improved, Clinically Significantly Improved, Less Autistic, Minimally Improved, No Change, and Worse (Perry et al., 2011). Explicit definitions and boundaries for these categories were not specified in the study. Examination of the diagnostic category (i.e., AD, PDD-NOS, or ASD) revealed a significant correlation between autism severity and IQ, and overall outcome. In terms of autism severity, the researchers found that there were modest negative correlations with initial CARS total scores and all outcome variables. Thus, the higher the initial CARS score (i.e., the more severe the autism features), the more likely it was that gains would be minimal across the CARS, VABS, and cognitive assessments. In terms of IQ ratings, significant correlations were found between IQ and outcome variables. Therefore, children with higher IQ scores at intake (T1) were associated with better results on the outcome variables at the time of the second assessment (T2) (and vice versa). However, the researchers also conducted a regression analysis, which indicated that the initial autism severity rating at entry did not function as a predictor of outcomes with the exception of IQ. Perry et al., looked specifically at children who were considered as having the best outcomes, or classified as Average IQ at discharge (*n* = 32; 28 boys, 4 girls), and found that there was a significant change in CARS total scores (i.e., two standard deviation decrease). Of those children, four still scored in the autism range on the CARS, although these children were close to the cutoff score. Gains were also seen in adaptive behaviour on the VABS with large jumps in communication (mean of 30 points), and IQ estimates for 13 children showed a mean gain of 40 points. The children in this subgroup had autism that was rated as milder at intake with lower CARS scores (by one standard deviation point), and 10 of the children (29%) scored in the non-autism range at post-intervention as compared to 6% of the children from the rest of the sample. In conclusion, the initial cognitive level of the children was the greatest predictor of outcome. Those children who attained average functioning had either higher developmental levels at intake, or began treatment at a younger age (Perry et al., 2011).

In an earlier study, Itzchak and Zachor (2007) examined intellectual functioning and autism severity on outcomes for young children with autism in ABA early intervention programs. The researchers retrospectively examined the outcomes of 29 children with autism (25 boys and 4 girls) who were; 20 to 32 months of age (mean age of 26.6 months). All of the children were enrolled in an IBI program at a centre. The program consisted of intensive delivery of instruction, in a one-to-one format for 35 hours per week. The Bayley Scales of Infant Development (BSID-II) measured the cognitive ability of preverbal children, while the Stanford-Binet Intelligence Scale Fourth Edition was used for verbal children. The ADI-R and the ADOS were used as measures of autism severity, and developmental-behavioural scales were used to measure various developmental skills in six domains (imitation, receptive language, expressive language, play, nonverbal communication skills and stereotyped behaviour). These scales were based on developmental lists of skills and norms that the researchers had approved by two child developmental specialists, and were completed based on the child’s progress charts pre- and post- intervention. Children were then divided into a high IQ (HIQ) group, and a low IQ (LIQ) group based on their cognitive assessments to assess the effect of IBI on their cognitive abilities at intake and outcome following IBI. In addition, the children were divided into two groups to assess the effects of their autism severity on outcomes: a high communication group (HC) and a low communication group (LC), and a high social (HS) and a low social (LS) group based on their ADOS – module 1 (language and communication and reciprocal social interaction) (Itzchak & Zachor, 2007).

The results indicated that there was significant change in the six developmental-behavioural domains and mean IQ scores significantly increased from a mean of 70.67 to 87.90 over the intervention period. Both low and high IQ groups showed significant progress across the domains post intervention. A significant difference was noted between the high and low IQ groups in terms of progress across the domains, with the high IQ group making significantly greater progress in receptive language and play skills and the low IQ group making greater gains in imitation skills. In terms of autism severity, both the HS and LS group demonstrated significant changes in the developmental domains following intervention ($p < 0.001$). However, the HS group showed better progress across the receptive and expressive language domain. There was no significant difference between the HS and LS group in IQ scores following the intervention. There was a high, although not significant correlation between ADOS reciprocal social interaction scores and IQ ratings ($p < 0.01$), suggesting that higher IQ scores are correlated with fewer social interaction deficits. Overall, the children who had higher initial cognitive levels and fewer social interaction deficits had better outcomes in terms of developmental skills, specifically in receptive language, expressive language and play skills (Itzchak & Zachor, 2007).

The literature described above explains how characteristics of the child entering IBI can have an impact on outcomes. These characteristics include the severity of autism presentation (Itzchak & Zachor, 2011; Perry et al., 2011), the cognitive levels (i.e., IQ) at intake (Perry et al., 2011; Itzchak & Zachor, 2007), as well as the way the child responds to the initial teaching programs (Weiss, 1999). Specifically, children who were assessed in early IBI as either having less severe autism, greater cognitive ability, fewer social interaction deficits, or greater responsiveness to instruction demonstrated better outcomes following a period of at least one year of intervention. These findings contribute to the evidence identifying some of the components within IBI that may lead to better child outcomes. One more category of variables that may play a role in the effects of ABA interventions is the role and characteristics of the family, and this is discussed below.

IBI and the family. Research has demonstrated that the characteristics of the family and their role in IBI has an effect on the outcomes of IBI. Specific attention has been paid to the impact of IBI programs on the home environment, familial stress levels, and the adjustment of siblings.

Hastings (2003) investigated the behavioural adjustment of siblings of children with autism who were receiving IBI, as related to their typical peers by surveying siblings' biological mothers. A total of 78 siblings were discussed in the responses to the questionnaire: 35 brothers and 43 sisters, having a mean age of 6.17 years (range of 4 to 16 years). Mothers were asked to formulate responses based on only one sibling in the family if there were several. Measures included the Autism Behaviour Checklist (ABC) to measure the severity of symptoms of the child with autism, and the Family Support Scale (FSS), an 18-item measure used to evaluate social support available to the family. From the latter measure, scores were derived to evaluate the helpfulness of both informal and formal sources of support on the participating mother and the family as a whole. Informal supports included one’s spouse, family, or friends, while formal sources included professionals or other community services, including the early intervention program supports. A sibling behavioural adjustment assessment was conducted using the Strengths and Difficulties Questionnaire (SDQ). This questionnaire evaluates conduct problems, emotional problems, hyperactivity and peer problems, as well as prosocial behaviour (Hastings, 2003).

The results of the study were divided into the siblings’ overall behavioural adjustment compared to normative data, and the family’s available social support and its relationship with sibling behavioural adjustment results. Siblings in this study were significantly different on three of the SDQ problem domains (i.e., peer problems, hyperactivity, and conduct problems) and the total behaviour problems score compared to a normative sample. The siblings were rated as having fewer behaviour problems in all cases, suggesting that intervention for the child with autism may provide some benefits for the siblings. For example, the parent might view the behaviour of their child without autism (i.e., the sibling) differently and therefore rate it as less severe given improvements given the parent’s new understanding or perspective on behaviour. In terms of social support levels, there was a correlation between low ABC scores of the child with autism (i.e., less severe autism), higher formal social support and fewer behavioural problems in siblings, whereas this effect is not seen at higher levels of ABC scores. This finding suggests that when the children with autism are rated as having fewer severe symptoms, and formal social support is in place, the siblings will have fewer behavioural adjustment problems. The researchers concluded that ABA interventions have no negative effects on the siblings in the home. They conclude that further research should address the dimensions of available support from early intervention programs that may be beneficial for families, how siblings in intervention groups with varying intensities might have different experiences, and how the siblings view the intensive intervention for the family (Hastings, 2003).

Given that programs may be run in the community (e.g., Perry et. al, 2008) or in the home setting (e.g., Weiss, 1999), the demands on families participating in EIBI can look quite different. For example, home-based programming demands environmental modifications to the house in order to provide a space for the intervention, and often requires the presence of a responsible adult (other than the therapist) at all times when the child is being instructed. This arrangement may have a negative impact on one or many family members. A community IBI placement, on the other hand, requires travel to and from the agency, and less contact with the instructors. In the Lovaas (1987) study, parents were actively involved in the programming, and even participated alongside therapists in delivering instruction (Smith, Eikeseth, Klevstrand & Lovaas, 1997). This level of involvement may have differential effects on the family members, and also differential effects on the child.

One particular effect of intensive intervention may concern stress experienced by the family. In a brief report examining parental stress and the outcomes of children receiving community-based behavioural intervention in Ontario, Shine and Perry (2010) examined mothers' stress levels pre-intervention and compared it with child outcome levels post-intervention. The researchers retrospectively examined the results of the Parenting Stress Index (PSI) completed at the time of intake. The PSI results of 151 mothers were compared to the results of their child's outcomes (as measured by the CARS, VABS, and rate of development during IBI) (as described above in Perry et al., 2011). The only significant correlations noted by the researchers were the scores on the VABS, ABC and the PSI scores, suggesting that higher stress in mothers at the start of IBI is correlated with lower adaptive behaviour skills of the child at program exit. Although not statistically significant, children with poorer outcomes had mothers with higher distress ratings at intake than children with modest outcomes. The mothers of children with modest outcomes had higher PSI ratings (i.e., higher stress) than mothers with children in the good outcome group, suggesting that either parental stress is impacted by how severely affected the child is at intake, or that increased stress levels may play a role in the outcomes of the child at exit (Shine & Perry, 2010). However, additional information as to whether there may have been additional stressors on the family, or whether features of the child's IBI program may have played a role in outcomes was not examined. In addition, maternal stress levels were not measured at the end of the program; therefore no conclusion about the effect of IBI on mothers' stress levels can be made. More data on the relationship between the IBI service, the family, and the clinical outcomes for the child are needed. One area that is being explored is the perspective of families who have received IBI (Grindle, Kovshoff, Hastings & Remington, 2009; Solish & Perry, 2008; Trudgeon & Carr, 2007; Dillenburger, Keenan, Gallagher & McElhinney, 2004; Boyd & Corley, 2001; Perry, Prichard & Penn, 2006). Familial perspectives on IBI may provide additional information that can assist in identifying features of the service that affect child outcomes.

Parent Perspectives on Intensive Behavioural Intervention

A number of studies have examined the views of parents whose children with autism have been enrolled in early intervention programs. These studies have investigated different levels of parental involvement in IBI, satisfaction with IBI outcomes, the impact of having IBI take place in the family home, as well as how the views of parents at different stages in early intervention programs may change.

Levels of parental involvement may vary in early intervention programs. The most intense level of involvement is where parents serve as Instructor Therapists and teach their children on their own, or as part of a team. When parents are actively trained to be instructors, they acquire a variety of skills useful for their child's program, which can provide opportunities for generalization and long term maintenance of the skills learned by their children (Schreibman & Ingersoll, 2005). When parents are not involved and trained in the delivery of IBI they may feel disconnected and lack the confidence to follow through on treatment recommendations (Larsson, 2003). Lovaas (2003) argued that the parents were integral to treatment success. In order to prevent inconsistencies in the treatment, he felt that parents in the home setting needed to use the same behavioural strategies and reinforce the skills that are being taught in the clinical setting. Therefore, a certain level of involvement by parents is recommended by researchers, and prescribed in the design of numerous IBI programs including the Ontario IBI program (MCYS, 2012).

Solish and Perry (2008) conducted a survey regarding parent involvement in behavioural intervention programs in Ontario. The questionnaire was administered to 48 parents of children with autism: 40 biological mothers, 1 foster mother, and 7 fathers. All children were receiving IBI services from the provincially funded program. The therapists who worked with the children (n = 34) also completed the questionnaire. The parent involvement questionnaire was created for the purposes of the study to assess the relationship between levels of parent involvement and five correlates of involvement: self-efficacy, perception of child progress, belief in IBI, knowledge and stress. In addition, the VABS data were available for all children. Specifically, the scores on communication, daily living and socialization domains were examined in relation to the levels of parent involvement (Solish & Perry, 2008).

The results of the study indicated that the level of parent involvement was positively and significantly correlated with self-reported scores of self-efficacy, knowledge and general belief about the intervention. In addition, the VABS ABC score was significantly correlated with involvement, suggesting that either more parental involvement may increase adaptive skills in the children, or that children with higher adaptive skills have parents who are more involved. However, consideration must be made as to how parents are included in the program, such as when and how they are expected to participate in training sessions, and whether the program’s expectations fit with the parents’ abilities or preferences. These factors may influence the views that the parents have on the intervention program, their level of involvement, and their ratings of satisfaction with the service and/or the outcomes.

Grindle, Kovshoff, Hastings and Remington (2009) conducted interviews with 53 parents of children who had been in home-based IBI programs in the U.K. for more than two years. Using semi-structured interviews with open-ended questions, Grindle et al.

investigated the perceptions of parents regarding the benefits and pitfalls of running home ABA programs (Grindle et al., 2009).

The results of the study were divided into practical benefits vs. difficulties for the family, impact on family relationships, emotional impact and overall evaluations of EIBI. In terms of benefits for the child with autism, every parent indicated at least one benefit, such as language progress. Practical benefits for the parents were reported by 75% of the respondents with 86% of mothers indicating that the additional support in the home was helpful. Other benefits included releasing the parents for time for other activities (e.g., household chores), and increasing their social network, and 25% of parents reported that having the program in their home led to improvements in their own abilities to use behaviour management techniques. The survey questionnaire also asked about benefits for other children (i.e., siblings) in the home, of which 75% of parents reported at least one practical benefit, such as learning about autism and ABA. The program was said to have improved parent-child (with autism) relationships, and sibling-child relationships, and one third of parents indicated that parent-sibling relationships improved as well (Grindle et al., 2009).

The difficulties for families participating in home-based IBI programs in Grindle et al.'s (2009) study were described as being both external and internal to the family unit. Most of the families (i.e., two-thirds) reported having difficulty with the education system and 40% reported that their school system was "ignorant of EIBI" (p. 48), and would not provide IBI services, which led many families to self-funding their programs. This financial demand was met by a number of parents spending their savings, remortgaging their house, or going into debt. Another difficulty reported by families involved the employment of therapists. The issues that were raised included difficulty with recruiting therapists, the high turnover of therapists, and unreliability (e.g., lateness) or intrusiveness of therapists. In addition, the structure of the program often included teaching in all parts of the home, which two-thirds of families described as disruptive or impacting on their privacy.

Parents reported that administration of the program was difficult given paperwork demands (i.e., billing for funding), and the need to create teaching resources. Some of the difficulties within the family context included the child with autism's sibling(s) receiving less attention, the child missing out on socialization or opportunities to exercise, the deterioration of the child's relationship with the sibling (reported in one-fifth of responses) or the deterioration of the spousal relationship (in one third of cases; Grindle et al., 2009).

Two-thirds of parents reported that overall expectations of the program were met or exceeded. However, one-third were disappointed that the intervention did not result in normality. Overall, evaluation of the EIBI program by this small number of families was positive, as over three-quarters of parents reported that EIBI was the right choice for the family given child progress and the positive impact on the family. Ten percent of parents reported that although the EIBI program was the right choice for their child, it was not necessarily the best choice for their family. Approximately one-quarter of parents indicated that they would warn other families about the possible negative effects on the family life (Grindle et al., 2009). Grindle et al. recommended that future research should involve the development of a survey instrument to measure parent perception on program-related variables (Grindle et al., 2009).

Trudgeon and Carr (2007) investigated the experiences of 16 parents from nine different families running their own home-based EIBI program in the U.K. The children with autism (*n* = 9; 8 boys, 1 girl) in this study were all described as having mild to moderate autism at intake, ranging in age from 4 to 9 years old (mean not given). A semi-structured qualitative interview was conducted consisting of four categories of questions: setting up the EIBI program, the effects of the program on family life, perceived benefits and disadvantages of the program, and facilitators and hindrances to running the program. Families were selected for inclusion in this study because they a) had a child diagnosed with autism, b) were currently running home-based ABA programs and had been doing so for at least three months for at least 30 hours per week, and c) were receiving supervision from qualified supervisors. The resulting themes that emerged from the questionnaire responses related to environmental adjustments, funding, social and family relationships, life choices, psychological, program demands, tutor (i.e., instructor therapist) issues, disappointments/challenges, and benefits.

A number of demands from the program that were placed on parents had an impact on their lives. Seven couples noted the impact of having to create space for the program to run in their home. The demand to contribute to teaching hours and make teaching materials was reported as a pressure by three couples. Having IBI staff was considered demanding for the families because of the intrusion of people into the home, the difficulties in tutor recruitment, difficulties in managing scheduling, and difficulty with team consistency and reliability. However, one mother and one couple indicated that the tutors provided emotional support (Trudgeon & Carr, 2007).

Parents also reported the tribunal funding process (in the U.K.) as difficult, and all of the families except for one identified this practice as stressful. Even when funding was obtained, the need to demonstrate that the funding was still needed throughout the program was identified by one couple as a constant burden. On the other hand, some parents reported that the tribunal experience was positive, as they gained a better understanding of EIBI and had more motivation to continue with the programming. For those who were not awarded funding, financial stress was identified as an ongoing problem (Trudgeon & Carr, 2007).

Trudgeon and Carr (2007) also found that the parents noted both social and career impacts on the family. The social impact of EIBI was positive for two couples at the outset of the program, given increased interactions with other adults (i.e., the therapists). However, the effect of autism (e.g., problem behaviour) on undertaking social activities outside the home was identified as a problem for four couples. Socialization within relationships was also affected: two couples indicated that their marital relationship was strengthened while one mother indicated that the program contributed to her divorce. Four couples indicated that the program was beneficial for the sibling(s) as they were either able to do more things as a family, or there were increased interactions of the sibling with the child with autism (Trudgeon & Carr, 2007).

A number of parents also found that participating in the EIBI program had an impact on their career (e.g., prevented continuing education). Although no fathers indicated that career was an issue for them, other life choices were impacted, such as delaying the decision to have more children.

The children’s progress in the IBI program led to feelings of empowerment for two families, as they had a better understanding of autism and how the teaching could be applied to daily events. Also, the child’s progress often increased the possibility of the family attending social and leisure events. However, one father in the study indicated that he had difficulty in the initial acceptance of the ABA methods (Trudgeon & Carr, 2007).

Although some of the experiences reported in these interviews were negative such as the withdrawal of support from local services during the ABA programming and concern about transition to school without ABA staff, more of the experiences reported were positive and included the provision of support to at-home mothers, an increased understanding of their children with autism, and the ability to engage in more family activities. Overall, parents rated their experience with the EIBI program as positive. The researchers indicated that severity of autism may play a role in the outcomes reported by parents as the children in this study were all described as being mild to moderate in severity at intake. The researchers suggested that future research might also compare the reports of parents whose children were enrolled in home-based vs. a school-based ABA program (Trudgeon & Carr, 2007).

A study conducted in Ireland also explored the perceptions of parents in home-based ABA programs (Dillenburger, Keenan, Gallagher & McElhinney, 2004). This study involved interviewing two groups of parents: those who were just beginning intensive programs and those who had completed two years of programming. The parents in this study had received general ABA training for 18 weeks, which did not specifically focus on IBI, but rather on general behavioural principles. This method of training was intended to provide parents with the opportunity to tailor their own home programs based on their new knowledge and to use the skills they had learned to generalize the skills being taught in the home program. The 22 families were divided into two groups; the long-term group (LTG) (n = 12), whose child had been receiving ABA-based treatment in their homes for more than two years (average of 35.5 months), and the short-term group (STG) (n = 10) who had been receiving ABA treatment for less than one year (average of 6.1 months). The ranges of ages of the children in both groups were similar (3 to 12 years and 3 to 13 years) although older children were in the

LTG (mean age of 91 months) as compared to the STG (46 months) (Dillenburger et al., 2004). The interview questions were designed to evaluate the IBI program’s social validity, which included parent’s perspectives on the significance of the goals within the program, the appropriateness of the intervention strategies used within the program, and the importance of the outcomes (Dillenburger et al., 2004).

No significant differences were found between the STG and the LTG in terms of the goals, independence, quality of life, skills development and maintenance, and social interaction in the children’s lives. The interventions were rated as effective and having an important impact on the lives of their children. Three families in the LTG and no families in the STG rated the ABA interventions as not effective for their children in the domain of self help skills. Two families in the LTG rated the ABA interventions as not effective for social skills. The families responded positively to the effect of ABA on family life (e.g., “we are now approaching normal family life,” “more manageable”), although one parent indicated that the work and financial burden was difficult (e.g., “a lot of time and energy was used up on implementing ABA programs”). All parents reported that ABA had a positive impact on how they felt about themselves (e.g., “made me more confident and relaxed,” “confident as a mother”), and on their child’s life overall (Dillenburger et al., 2004). Overall, the study indicated that parents were satisfied with the outcomes of ABA programming in terms of validity of goals, the appropriateness of intervention strategies, the outcomes on their child’s quality of life, the parents’ own feelings of confidence, and the overall impact on the family (Dillenburger et al., 2004). The severity of autism was not reported in this study; therefore it cannot be determined whether the degree of change in the children had an impact on the family’s ratings of the program.

Boyd and Corley (2001) examined parental satisfaction ratings of IBI and whether children were “recovering” from autism (as defined by Lovaas’ 1987 criteria). A survey was conducted with 22 families of children with autism (i.e., 16 boys, 6 girls) who had received IBI services in California. Most of the children (n = 20) began services before the age of four, with a mean length of service of 23 months (range of 9 to 36 months). Eleven children had received more than two years of treatment, while 11 children had received less than two years, and two children had received less than one year of treatment. The case files of the children were reviewed to locate instances of recovery, followed by the mail out of a parent questionnaire.

Overall satisfaction of the program was high, as 69% of parents indicated that they were satisfied (25%) or very satisfied (44%) with the implementation of the ABA program. In terms of outcomes, satisfaction ratings were slightly lower as the rating of very satisfied decreased to 25% and the rating of satisfied increased to 44%. The level of intervention received was sufficient to meet their child’s needs according to 10 parents, although 3 parents indicated that it was not and 2 parents were unsure. The results indicated that no child had achieved recovery, as indicated by normal intelligence and placement in a regular education classroom without a one-to-one aide. However, seven children were rated by parents as having normal intellect following the intervention. Three of these children were enrolled in a special education class and four were placed in a regular education classroom with a one-to-one aide. Parents of two children continued IBI methods at home (i.e., discrete trial training) and were judged to have intellectual disabilities. Eleven children attended a special day class (six children having a one-to-one aide), and four children were enrolled in private schools with small classes (two of those children had a 1:1 aide) (Boyd & Corley, 2001).

The parents were also asked to rate the areas in which their children improved the most. These were language (63%), compliance (31%) and pre-academic skills (31%). The areas in which parents noted the least amount of improvement were pragmatic language (50%), and socialization (31%). The level of expressive language skills following IBI ranged from the child being verbal (56%), to non-verbal (19%) or using an augmentative system (e.g., picture exchange communication system; PECS) (25%). In addition to IBI, families reported that they purchased services such as speech language therapy (63%) and occupational therapy (13%) or private tutoring (31%). Overall, 15 of 16 parents indicated that they would recommend the EIBI program to other parents of children with autism even though none of the children “recovered” from autism (i.e., had their diagnosis removed), and only half of the children acquired verbal language skills. The researchers suggested that a broader comparative investigation of community IBI programs be conducted to identify what participant characteristics and treatment parameters correlate with better outcomes in the children (Boyd & Corley, 2001). Overall, the parent satisfaction research suggests that families rate IBI programs favourably despite the variable outcomes of children. Additional data is needed regarding the aspects of the IBI program that may affect outcomes of parent satisfaction, such as whether parents respond differentially if they are involved in home-based programs as compared to centre-based programs, or whether particular goals selected for the child are in alignment with the family’s goals and values, and what impact this has on satisfaction. Qualitative features of the IBI program are also variable and may influence the rating of the treatment program in general.

In a study conducted by Perry, Prichard and Penn (2006), perspectives on what defines quality intensive intervention was gathered via surveying professionals and parents in the Ontario Autism Intervention Program. Of 57 professionals who returned the survey questionnaire, 11 were clinical directors, 28 were senior therapists or supervisors, and 13 were other autism professionals. A total of 20 parents participated in the survey, and their children with autism had a mean age of 5.7 years and had a mean length of involvement in IBI of 2.7 years. The survey consisted of four questions, three of which were identical across groups. The groups were asked to rate features of IBI under a variety of categories (e.g., generalization) according to their importance in an intervention program. In addition, the survey questionnaire asked one open-ended question about current issues in IBI. One question was reserved for professionals, which asked whether characteristics of quality IBI programs should be measured subjectively (i.e., ratings) or objectively (i.e., observations) (Perry et al., 2006).

The top three features of IBI that defined quality according to both groups were: creating opportunities for generalization, administering reinforcers of the appropriate type, and using effective behaviour management strategies. There was a lot of variability between and across groups. For example, parents rated the varying of task presentations, creating opportunities for generalization, and using effective behaviour management strategies as most important whereas clinical directors rated administering appropriate reinforcers, generalization, child-directed learning opportunities, and behaviour management strategies as most important. The responses to the question about measurement preferences indicated that the professionals preferred objective measurement, as could be expected. Finally, additional issues needing consideration in IBI according to parents and professionals (results were not defined separately here) included linkages between IBI, home and school (36 responses) (e.g., parents involved and/or trained, consistency across therapists, home and school, and effective communication across therapists, parents and supervisors), the therapist having appropriate skills (29 comments) (e.g., positive attitude, creative, good rapport with child), regular supervision and training as provided by the program (28 comments) (e.g., informed by research), and that the program is applied and adapted appropriately (e.g., to meet daily needs of the child) (18 comments). The results of this survey indicate that the features that define quality within IBI may differ between professionals and parents.

Hume, Bellini and Pratt (2005) argue that social validity is a necessary measure in early intervention programs as many practices that are recommended by interventionists are not being implemented by parents, suggesting a disconnect between professionals and families. Hume et al. conducted a survey of 195 parents of children with autism (range of 2 to 8 years; mean age 5.44 years) in the state of Indiana. The survey questionnaire included questions about all services that parents with autism were choosing to obtain, and the number of hours that were received of each. The questionnaire asked about the settings in which services were being provided, and the strategies or curricular areas used within the interventions. Parents were asked to rate the interventions on a Likert scale as to whether the service was effective in contributing to their child's growth, and an evaluation of the delivery of the service was also requested. The parents evaluated the level of parent participation, the quality of progress reports, the number of integration opportunities, the outcomes for their child, and the effectiveness of case management (Hume et al., 2005).

The services that were most frequently obtained by parents were speech therapy, occupational therapy, classroom aides, augmentative communication, recreational therapy, inclusion supports, and social skill development supports. Only relevant findings from this study will now be discussed. First, 66% of the families reported receiving fewer than the 25 hours per week that Hume et al., (2005) identify as the recommended number of hours for early intervention for children with autism in an intensive program. Interventions such as Floortime (Wieder & Greenspan, 2003) and recreational therapy were perceived by parents to have better outcomes than other treatments in particular developmental areas, yet the research on these interventions does not support these treatments (National Research Council, 2001). Hume et al. (2005) suggest that treatments that include greater levels of parent consultation or training may influence the perceived outcomes of the intervention. The researchers concluded that future research should include social validity measures with parents, particularly with respect to assessing identified goals, treatment procedures and outcomes, as well as barriers to receipt of particular services (Hume et al., 2005).

Culture and social validity. Social validity measures are useful in evaluating IBI services to ensure that family views are represented. For example, families of diverse cultures may perceive goals and outcomes of early intervention quite differently from one another. This topic is beginning to be examined in the literature.

Mandell and Novak (2005) suggested that culture might play a role in autism treatment selection. The researchers articulated that there may be differences in the presentation of autism across cultures due to genetics or environment, or differences in the interpretation of the symptoms of autism depending on culture, and that interpretation of symptomology may impact the treatments selected accordingly. For example, social difficulties tend to be identified first in “Indian” (South Asian) culture whereas language difficulties tend to be identified first in the dominant North American culture. Beliefs about the cause and course of autism may also vary across cultures, leading to an interest or non-interest in seeking treatment (e.g., Latino families' belief that they can do little to alter fate). Interactions with the professionals and services in health care systems may also be idiosyncratic. The authors suggest that familial views across cultures are a necessary consideration in research on social validity, early intervention, and autism (Mandell & Novak, 2005).

Olmsted et al. (2010) compared the views of Hispanic and non-Hispanic families about early intervention using a standardized survey on family outcomes, and investigated whether the language the survey questionnaire was written in (i.e., English or Spanish) affected the responses of the Hispanic participants. The participants were 3140 families of children at risk for disabilities and whose children were enrolled in an early intervention program in Illinois. The Family Outcome Survey (FOS) is a standard assessment used with families across the states of Indiana and Texas who are receiving early intervention services. The researchers sought responses from both non-Hispanic and Hispanic families although the survey was only available in English. The survey was subsequently translated into Spanish, distributed to new Hispanic families in Illinois and the results were directly compared with the results of the English-language survey previously completed by both the non-Hispanic and Hispanic families from Indiana and Texas (Olmsted et al., 2010). The survey assessed the families' satisfaction with their own learning outcomes as well as their satisfaction with program variables. There were five components of "family outcomes:" parent understanding of their child's strengths; needs and abilities; advocating for services and knowing their rights as parents; helping their children to develop and learn; having support systems; and accessing the resources in the community.

The results indicated significant differences between the responses of the Hispanic participants on the Spanish survey compared to Hispanic parents completing the English survey in terms of outcomes for children. On all 15 items of the survey, the Spanish language survey means were significantly lower. For example, the Hispanic families responding to the Spanish survey had a mean rating of 4.7 (on a 7-point Likert scale, with 7 being high) in terms of evaluating satisfaction of their outcomes, and when compared to the Hispanic families responding in English (mean of 5.4), and non-Hispanic families (mean of 5.5), this result is statistically significant. This suggested that when the Hispanic families responded in their native language, they were less satisfied with their outcomes, although this result was not seen among the Hispanic families who completed the English-language survey. The greatest difference was noted for items relating to the parents' understanding of his/her child's development, knowing about services, knowing how to help their children develop and learn, having someone to call for help, and accessing childcare. In addition, the Hispanic group of participants who responded to the English-language surveys had significantly lower ratings (than the Hispanic families responding to the Spanish survey) on three items: comfort with professionals; having someone to talk to; and the child participating in community activities. In terms of features of the early intervention program, Hispanic families completing the Spanish survey reported lower ratings of the service in terms of helpfulness. However, when services were rated as more family-centered, higher ratings of satisfaction outcomes were indicated. The article describes how the values of English-speaking Hispanic families may be more aligned with the English "primary" culture, by way of acculturation (i.e., adaptation to the mainstream culture) and therefore explain why services would be rated higher when responding in English. Therefore, these results suggest that there may be different cultural values depending on the primary language spoken by the parent(s). These values can affect the perception of services, particularly if the services do not consider differences in family values. The researchers recommended that family-centered practices be implemented in early intervention, consisting of coordination of services, effective communication, flexibility, and providing a sense of partnership between the families and the professionals, in order to recognize how culture may affect the satisfaction and thereby the delivery of early intervention services (Olmsted et al., 2010). The Olmsted et al. (2010) study supports the necessity of a social validity assessment in early intervention. This assessment must consider cultural diversity in the assessment of family satisfaction with intervention services.

Additional considerations of parent perspectives. Parents of children with autism are unique in their life circumstances, regardless of their experiences with services. It has been identified that parents of individuals with developmental disabilities (DD) such as autism experience both positive and negative effects of having a child with a DD (Perry, 2004). Perry (1990) identified how parents of children with autism experienced stress related to their perception of their child's levels of difficulty. The parents in the Perry study also identified stressors such as needing to "runaround" to access services, resources (e.g., such as personal competence), and "family system resources," such as spousal relationships was identified. Other studies have also indicated that stress for families may be increased as the children with autism get older (Sabih & Sajid, 2008), and that social supports can help lessen the stress for the family (Dunn, Burbine, Bowers & Tantleff Dunn, 2001). Therefore, parents in IBI programs are experiencing high stress prior to entering the program, and the impact of the program on this stress warrants consideration. This consideration reinforces the need to understand the context for the family prior to and during any autism intervention.

The view that the environmental context (e.g., family) plays a crucial role in the effects of intervention represents a contextual worldview. Such a worldview provides the framework for the proposed research. Functional contextualism forms the epistemological framework for this research and is described below.

Functional Contextualism

The current study is framed by a functional contextualist epistemology that defines the values on which this research is based. Functional contextualism is a philosophy of science which seeks to predict and influence events, is associated with the science of behaviour analysis (Fox, 2005; Fox, 2006), and has originated from both the concepts of pragmatism and contextualism. It has been argued that the science of behaviour analysis is best understood from a contextual framework given that the interaction between the environment and behaviour is the unit of analysis. In addition, that which is known about the world comes from direct contact with it, and given that every person's contact with the world is different suggests that knowing is defined at the individual level (Hayes & Ghezzi, 1997).

Fox (2005) explains the contextualist's approach as viewing ideas that are "verified by human experiences, with an idea's meaning essentially defined by its practical consequences, and its truth by the degree to which those consequences reflect successful action" (p. 10). The goal-oriented analysis and applied utility of this approach is advantageous to educational research. Further, the search for manipulable variables in the environment will allow for a more rigorous, testable approach that can change or influence psychological events (Fox, 2006). That is, understanding that current context affects behaviour allows for environmental interventions to be designed, implemented, and experimentally evaluated.

Functional contextualism is a useful concept for framing social validity research in IBI given that purpose and utility for the individual (i.e., the family and the child with autism) is considered the purpose of research in this worldview. Examining those events in the environment that have affected the outcomes for the individual child with autism and their family are essentially examinations of function and context. Although this particular study does not seek to manipulate events, it examined how the arrangement of the IBI environment affects the satisfaction outcomes for families of children with autism. This analysis could establish events (e.g., number of supervision hours on family satisfaction) that could be manipulable in future experimental studies. The idea of context as a consideration in the delivery of behavioural services is not new. Several studies have examined how attention to the environment in which intervention services are provided could be beneficial.

Moes and Frea (2000) compared the implementation of two treatment plans, one that was defined as “prescriptive” and one defined as “contextualized”. The researchers described a “prescriptive” approach to intervention as one that was exclusively defined by the clinician, containing a highly structured protocol with standardized procedures. A “contextualized” approach was defined as one that included assessment of the setting, and the values and beliefs of the family in order to increase the compatibility of the intervention with the family’s life. The behavioural treatment plans were implemented in the family home of a 3-year-old boy with autism, his parents and his 4-year-old brother. Particular routines that were problematic within the home were selected as areas of training and generalization. The contextualized approach as compared to the prescriptive approach included the parents selecting a functional communication statement that they were comfortable with (e.g.., “I need help, please”) instead of the clinician’s choice (e.g., “Can I have a break please?”) as well as specific procedures that were selected that emphasized parent styles (e.g., reinforcing compliance) (Moes & Frea, 2000).

The results indicated that both treatments were effective in altering problem behaviour. The prescriptive phase was implemented first, followed by the contextualized phase. This ordering of conditions suggests that it may have been the combined treatments that were effective and concluding that the contextualized conditions were more effective is not possible. However, in interviews, the parents felt the prescriptive approach left them feeling uncertain about the effects and how well the plan fit their resources, constraints, beliefs, values, goals, abilities, and needs. With the contextualized plan, the parents were more satisfied, and rated the behavioural intervention plan much higher and fitting to their life. These results were maintained three months later. Given that the family expressed increased satisfaction with the contextualized conditions it is likely that this would lead to greater compliance with the intervention plan, as well as an increased chance of maintenance and generalization (Moes & Frea, 2000). Studies such as this one need to be considered as initial steps in understanding the role that context may play in the success of behavioural interventions. To date, examination of satisfaction in behavioural intervention has been restricted to social validity measures, which may be restrictive.

Social validity was initially described as a concept by Wolf (1978) where he suggested that the goals, procedures, and outcomes of behavioural interventions should be evaluated by the consumers of such interventions. In 1999, Carr, Austin, Britton, Kellum, and Bailey reported that only 13% of articles in the foremost behaviour analytic journal (i.e., the *Journal* *of Applied Behavior Analysis*) were reporting measures of social validity. These measures typically included Likert scales where consumers rated their satisfaction in particular areas. Schwartz and Baer (1991) suggested that social validity measures serve two functions: a) the collection of a representative sample of consumer opinions and b) the use of these opinions to support existing practices or to make changes as needed. However, these authors noted that researchers seeking to verify the effectiveness of their work were collecting social validity data rather than seeking out criticisms and thus the social validity surveys may have been biased. Given that studies are beginning to incorporate more qualitative data on satisfaction in early intervention in the research on parent satisfaction, as described above, it may be possible to get more disparate views on early intervention and perhaps an understanding of key issues that may not be obvious to program personnel who are designing the consumer satisfaction surveys.

Summary of the literature

In summary, despite criticisms (Schopler et al., 1989) of the original Lovaas (1987) study, early intensive behavioural intervention has been established as an effective treatment for individuals with autism (Lovaas et al., 1989; Eikeseth et al., 2002; Howard et al., 2005; Eldevik et al., 2006; Eikeseth, et al., 2007; and Virues-Ortega, 2010). This treatment can have great long term cost implications for government (Jacobson, Mulick & Green, 1998). The Ontario Autism Intervention Program (Perry, 2002) is well underway in providing these services across the province (MCYS, 2011), with good results to date (Perry et al., 2008; Freeman & Perry, 2010). Research has established some variables of EIBI programming that can increase effectiveness, such as delivering service to younger children (Itzchak & Zachor, 2011; Perry et al., 2011; Granpeesheh et al., 2010, Luiselli et al., 2000; Flanagan et al., 2012), providing more total hours of service (Granpeesheh et al., 2010, Luiselli et al., 2000), and having high levels of supervision (Eikeseth et al., 2009). In addition, factors such as early responsiveness to IBI (Weiss, 1999), severity of autism at intake (Itzchak & Zachor, 2011; Perry et al., 2011), and cognitive levels at intake (Perry et al., 2011; Itzchak & Zachor, 2007) affect the results of IBI. IBI outcomes may be affected by parent stress levels (Shine & Perry, 2010), and involvement by parents in IBI is affected by their perceived self-efficacy, knowledge and beliefs about IBI (Solish & Perry, 2008). However, the effects of IBI can be positive given increased behavioural adjustment of siblings (Hastings, 2003) as well as many other benefits (e.g., language progress of their child, additional support, improved family life etc.) (Grindle, et al., 2009; Dillenburger et al., 2004; Boyd & Corley, 2001) and parents generally report IBI experiences as favorable. However, negative aspects of receiving IBI services are also reported (e.g., systemic issues, finances, staffing, home intrusiveness, social and career aspects, not reaching particular goals etc.) (Grindle et al., 2009; Trudgeon & Carr, 2007; Dillenburger et al., 2004; Boyd & Corley, 2001). The variability of the positive and negative aspects of IBI is further highlighted by Prichard and Penn (2006) where views on what constitutes “good” IBI varied between parents and professionals, suggesting that measures of quality need to socially valid and family-centred, or parents may resort to treatments that are not evidence-based (Hume, et al., 2005). The notion of family-centered is critical when families may have values that may be different from the professionals with whom they are working, as is often the case when the parent and the professional are from different cultures (Olmsted et al., 2010).

Measurement of “Satisfaction”

The measurement of satisfaction is complex given the subjectivity of responses.

However, McNaughton outlined four reasons why measuring parent satisfaction in early childhood intervention programs (for autism) is so important:

(a) Parents have the responsibility (for) and control of a child's development, and their decisions concerning success and failure should have primacy (Bernheimer, Gallimore, & Weisner, 1990; Guralnick, 1989);

(b) Information about parent satisfaction (and dissatisfaction) can be used to develop better services and prevent program rejection (Upshur, 1991; Wolery, 1987);

(c) Parent participation in programs may be increased by including parents in evaluative decision making (Bailey, 1987; Conn-Powers, Ross-Allen, & Holburn, 1990); and

(d) Consumer satisfaction data may be used to convince other audiences (e.g., funding agencies, administrators) of the usefulness of a program (Scheirer, 1978) (McNaughton, 1994, p. 28).

Understanding the parent perspective in early intervention (EI) is extremely important because how parents perceive the intervention will have direct implications for the uptake and/or continuation of services for their children. Parent resistance to implementing intervention is related to attrition. Therefore, it is important to identify the attitudes of parents (Cornoyer & Johnson, 1991).

The first step in gathering perspective data includes creating a construct of satisfaction. McNaughton (1994) has identified this as a problem in the existing literature, and claims that many of the early intervention studies have tended to lack a clear definition of satisfaction, and/or the definition of satisfaction has not been apparent at the outset of the study. In his review of the literature, McNaughton found definitions of satisfaction were not consistent in the EI literature as compared to more consistent measures of satisfaction in research in other fields (i.e., business, medical care, social services). This is a problem because it prevents social service fields from having some variables that are representative of satisfaction across studies. He suggested that the inclusion of parent expectation of service outcomes at the onset as well as the end of services is important in the evaluation of satisfaction in early intervention, or more broadly, social services. This inclusion of "expectation," which was not often seen in the studies he examined is important as a measure within the satisfaction construct. McNaughton also suggested that additional factors be considered as possibly influencing satisfaction in EI, besides expectation. These include: assistance in accessing therapy and social services; assistance in planning for the future; family instructional activities; information for parents; personal and family growth; personal family assistance; public attitudes and social support; quality of specialized child care; and education and support with basic resources. McNaughton suggests that these areas are as important as child outcomes for a thorough representation of the construct.

McNaughton (2007) described how the measures of satisfaction in the early intervention literature involving researcher-developed tools but that one standard tool did not predominate (McNaughton, 2007). The satisfaction tool or measure, as he sees it, should include both Likert and open-ended questions and should not be restricted to one type of data but should consider all options (e.g., questionnaires and interviews). McNaughton specifically indicated that focus groups were a promising avenue for determining parent satisfaction.

In a 1997 study, Wessell, Buysley and Tyndell measured professional and parent perspectives of early intervention using focus groups. The focus groups were an asset to the researchers as they provided data with depth rather than breadth alone (more typical of survey data). The researchers identified the need for research on consumer satisfaction in early intervention that is conducted outside of the agency providing the service, since relying only on agency-administered tools often inflates the results. In addition, they argue that standardized tools (or quantitative measures) alone may be insufficient given the lack of reliability of the instruments. Adding focus groups as a method to understand the experiences and perspective of parents may provide a representative set of data that is richer in its details.

The administration of satisfaction tool(s) to participants should maximize recruitment methods to ensure that all possible participants are reached, while recognizing that participants who have not received the service for a long period of time will be less likely to respond. Data on these participants should include the respondent's parental role, their age and socioeconomic status, the age of the child, the severity of the child's disability and the type and intensity of services provided, as well as the expectations, and priorities of parents about the service. (McNaughton, 2007). All of these points were considered in the development of the methodology for this research study, and how they have been incorporated is described in Chapter Three.

Rationale and Purpose of the Proposed Research

To date, research regarding the Ontario Intensive Behavioural Intervention program has only addressed child outcomes (Freeman & Perry, 2010; Perry et al., 2008), parental involvement (Solish & Perry, 2008), parental stress (Shine & Perry, 2010) and views on quality teaching in IBI (Perry & Penn, 2006). What remains to be learned is whether the parents of children who have completed the IBI program in Ontario, are satisfied with the service they received, and whether their satisfaction is dependent on particular aspects of the program. Investigating satisfaction as a function of variable features within the services of the program constitutes an expansion of the concept of social validity. The extent of social validity assessment to date has been limited to the caregiver approving of the clinician-selected intervention. Allowing for parents to review and give feedback on all areas of the service delivery will provide more detailed data on the social validity of IBI. Data collected in this area may provide a foundation for an IBI program that considers the contextual fit for each individual family.

The purpose of this study was to examine the relationship between parent satisfaction in the Ontario IBI program and the features that are variable within that program with the intention of providing data to support existing structure and delivery, and to inform for potential program changes. Specifically, this research examined whether satisfaction of IBI is related to the variables that have been described in this chapter. These variables include: features of the IBI service delivery, characteristics of the child, and features related to the family.

Answers to the following research questions were sought:

1. Do parents express overall satisfaction with the IBI program?
2. Do parent ratings of IBI satisfaction vary according to the following aspects:
    a. Personal agreement with program philosophy and goals?
    b. Child outcomes in terms of cognitive ratings, autism severity, and school placement?

c. Features of the IBI program: home vs. centre based delivery, age at entry, hours per week of service, total months of service, amount of program and therapist supervision, and quality of interactions with program personnel?

d. Impact of the program on the family: parental employment and health, familial relationships (i.e. spousal and/or extended family and/or other children), and families' community and social interactions?

e. Cultural or linguistic differences between the parents and the professionals?

These research questions were examined through the use of survey and focus group methods. Survey designs are quantitative methods used to describe the "attitudes, opinions, behaviours, or characteristics" of a particular population (Cresswell, 2005, p. 354). Weisberg, Krosnick and Bowen (1996) describe how measuring attitudes is necessary, since assuming how people feel is often inaccurate. Although cause-and-effect conclusions cannot be drawn with survey methodology because of the lack of experimental manipulation (Cresswell, 2005), measuring the views and opinions of parents who have completed the IBI program must be considered as one measure of the overall effectiveness of the program, given the need for generalization of programming. That is, methods that are used in IBI sessions can also be used at home with parents to increase the likelihood that skills will be maintained and demonstrated in all of the child's environments. In addition, parental views may influence the long-term stability of the service, given that parents have been responsible for the program's inception and many of the program changes over time (e.g., removal of age cutoff). Subsequent to the analysis of the questionnaire data, a focus group of a subsample of parents who completed the questionnaire was held to explore the concepts and opinions expressed by the caregivers in greater detail.

The use of open-ended questions in the focus group allowed participants to share their experiences and is unconstrained by the perspective of the researcher (Creswell, 2005). The focus group allowed parents to provide additional information on their views of the Ontario IBI program and provided additional qualitative data for this study. Chapter Three outlines the procedures for the survey and focus group implementation.

Chapter III

METHOD

Research Design

This study is an investigation into parent satisfaction of the Ontario IBI program using a mixed methods design (Cresswell, 2005). Mixed methods design involves the use of both quantitative and qualitative data to provide a better understanding of the research problem than one type of data alone (Cresswell, 2005). This investigation into parent satisfaction involved the use of both and focus group methodology in an explanatory design format (Cresswell, 2005). This format is considered a two-phase model where primarily quantitative data is collected first, and is then followed by collection of qualitative, in this case focus group data.

The survey methodology involved the use of two questionnaires: a Family Perspectives in IBI Questionnaire (FPIQ) (developed by the researcher, the development of which is described below), and a Measures of Processes of Care (MPOC) questionnaire (King, Rosenbaum & King, 1995). The purpose of the second questionnaire was to determine the concurrent validity of the FPIQ, as well as to provide additional data regarding caregiver perception of the IBI services they received. A cross-sectional survey design was used with data collected at one point in time (i.e., between May and September of 2013) to measure the current opinions of parents (Cresswell, 2005). While the researcher-developed family perspective questionnaire contained both quantitative and qualitative components for analysis, the second questionnaire (i.e., the MPOC) provided only quantitative data, and the focus group only provided qualitative data.

The follow up focus group was the second phase in the explanatory design. As Cresswell (2005) points out, focus groups can serve a number of purposes. They can investigate outliers or extreme cases, explain particular results, identify emerging themes, and/or examine multi-levels in the data (e.g., group analysis vs. individual analysis) (Cresswell, 2005). As will be described below, the focus group used in the current study attempted to obtain all four types of information.

Bryne and Humble (2007) outline a number of advantages to the mixed methods design. First, including more than one method of data collection can strengthen the data. Secondly, social phenomena (e.g., attitudes) can be complex and different approaches can lead to a better understanding of these complexities. The mixed methods approach allows the researcher to both confirm and explore questions at the same time and this allows a researcher to construct and confirm theory in the same study. One additional advantage is that when contradictory results emerge, explanations can be given through the additional data collection method (Bryne & Humble, 2007).

Phase 1: Quantitative

Participants. The sample for this survey consisted of parents or caregivers[2] whose children received IBI services from the Autism Intervention Program in Ontario in the last five years or who were currently receiving service. This timeline was selected to maximize the number of potential participants while still ensuring that they are able to recall details of the program. As a result of the recruitment techniques described below, 110 participants were included in this study.

Demographic information. The final sample consisted of 110 respondents to the questionnaire, 63.5% (n = 70) of whom were mothers, 6.4% (n = 7) were fathers, 1.8% were

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[2] The term parents will be used throughout the remainder of this document for consistency.

grandmothers (*n* = 2), and one respondent (0.9%) was a foster mother of the children with ASD. As can be seen in Table 1 below, the respondents ranged in age from 16 to 57 years of age (M = 41) and there was an average of two children (range 1-5) per family. The majority of participants were married (65.5%). However, 1.8% of participants identified themselves as either single, living with a partner, separated or divorced.

Only 66 respondents (60%) indicated their income level, which ranged from less than $20,000 to over $150,000. The education level of the participants was variable, with 33.6% of participants having completed a college or university degree, 12.7% having completed a graduate degree, and 7.3% having completed only secondary school. Similar results were found for the secondary caregiver in the home with 40.9% having some college or university education, 12.7% having completed secondary school education, 8.2% having a graduate degree, and 0.9% having an elementary school education.

In terms of employment, 32.7 % of the participants (Caregiver 1) were employed full-time, 21.8% were not employed, 16.4% were employed part-time, or in school (0.9%). Of the second caregiver in the household, 60.9% were employed full-time, 4.5% were unemployed, 2.7% were employed part-time, and 1.8% of the individuals were in school.

As seen in Table 2, the majority of the respondents and their partners were Caucasian (60%, and 57.3% respectively). In terms of immigration status, 64.8% were born in Canada. Of the 15.45% of participants who indicated they were not born in Canada, 57 identified themselves as Canadian citizens, 6 as landed immigrants, and 1 as “other”. Other ethnicities of participants and their partners included South Asian (3.6%, 4.5%), Middle Eastern (2.7%, 1.8%), Southeast Asian (1.8%, 1.8%), Chinese (0%, 0.9%) and African Canadian (0.9%, 0.9%) respectively. English was the language spoken at home for 72.2% of participants,

Table 1
Demographic Information by Caregiver

	Caregiver 1		Caregiver 2	
Gender	%	N	%	N
Female	65.5	72	9.1	10
Male	7.3	8	60	66
No response	27	30	30.9	34
Caregiver Status				
Mother	63.5	70	5.5	6
Father	6.4	7	56.4	62
Grandmother	1.8	2	1.8	2
Grandfather	0	0	0.9	1
Foster mother	0.9	1	0	0
Foster father	0	0	0.9	1
Stepfather	0	0	2.7	3
No response	27.3	30	31.8	35
Relationship status				
Married	65.5	72	–	–
Single	1.8	2	–	–
Living with partner	1.8	2	–	–
Separated	1.8	2	–	–
Divorced	1.8	2	–	–
No response	27.3	30	–	–
Education				
Graduate degree	12.7	14	8.2	9
Undergraduate degree	18.2	20	14.5	16
Community college	15.5	17	26.4	29
Secondary school	7.3	8	12.7	14
Elementary	0	0	0.9	1
No response	56.3	51	37.3	41
Employment				
Full-time	32.7	35	60.9	67
Part-time	16.4	18	2.7	3
Not currently employed	21.8	24	4.5	5
In school	0.9	1	1.8	2
No response	28.2	31	30.9	34

Table 1 Continued

Demographic Information by Caregiver

Item	Caregiver 1		Caregiver 2	
Income	%	N	%	N
>$150 000	10	11	−	−
$100 - 150 000	16.4	18	−	−
$80 - 99999	10.9	12	−	−
$60 -79999	11.8	13	−	−
$40 - 59999	4.5	5	−	−
$20 - 39999	2.7	3	−	−
< $20000	3.6	4	−	−
Prefer not to answer	10.9	12	−	−
No response	29	32	−	−
Community				
Urban	36.4	40	−	−
Suburban	21.8	24	−	−
Rural	12.7	14	−	−
No response	29.1	32	−	−

Table 2

Caregiver Ethnicity and Immigration Status

Category	Caregiver 1		Caregiver 2	
Race/Ethnic Background	<u>%</u>	<u>N</u>	<u>%</u>	<u>N</u>
Caucasian	60	66	57.3	63
South Asian	3.6	4	4.5	5
Middle Eastern	2.7	3	1.8	2
Southeast Asian	1.8	2	1.8	2
African Canadian	0.9	1	0.9	1
Aboriginal	0	0	0.9	1
Chinese	0	0	0.9	1
No response	27.3	30	30.9	34
Born in Canada				
Yes	63.6	70	55.5	61
No	15.45	17	16.3	18
No response	20.9	23	28.18	31
Immigration status				
Canadian citizen	52.7	57	45.3	49
Landed immigrant	5.5	6	4.6	5
Other (not specified)	0.9	1	0.9	1
No response	42.5	46	54.6	59
Main Language Spoken at Home				
English	72.2	78	–	–
Arabic	0.9	1	–	–
Spanish	0.9	1	–	–
French	0.9	1	–	–
Gujarti	0.9	1	–	–
Italian	0.9	1	–	–
Nepali	0.9	1	–	–
No response	22.7	25		

although additional languages included Arabic, Spanish, French, Gujarti, Italian, and Nepali (1 parent each) with 22.7% not responding to the question.

Recruitment. Multiple methods were used for recruiting participants for the study over a period of five months. Each of these is described below.

Email distribution. Initially, the link to the online survey questionnaire was attached to a flyer and sent out to 37 personal contacts of the researcher, the chapter managers or point-of-contacts (or both) for each chapter of Autism Ontario (as indicated on its website), and the Clinical Director or another point of contact known to the researcher or found on the Ministry of Children and Youth Services of Ontario (MCYS) website (MCYS, 2013) for each IBI program's regional agency. The community agencies that support the regional autism program were also contacted by email, as were all of the agencies providing ABA services as listed on the MCYS website (MCYS, 2013). Additional emails were sent as follow-ups to contacts made via the agency's websites or Facebook pages.

Facebook. Facebook is a tool that is being more widely used by researchers to recruit participants for research studies (Chu & Snider, 2013). This social networking website reaches millions of people, interested in the topic of autism alone. For example, Autism Speaks, a well-known international organization for autism awareness has over 1,000 000 followers (Social Bakers, 2013), and Autism Ontario has over 2000 followers (Autism Ontario, 2013).

The questionnaire link was posted to the researcher's professional Facebook site. Facebook was also used to post the questionnaire link to many community agencies and parent groups (see Appendix A). In a Facebook message, that was sent privately, the researcher sent the information letter as an attachment (Appendix B), copies of the flyer

(Appendix D), and a copy of the University of Windsor Research Ethics Board approval letter (Appendix E). A short biography of the researcher (Appendix F) was added to these private messages after a few early responses, since it was being requested by some of the respondents. In addition, two Facebook ads were purchased to run on sites that the researcher deemed relevant to the topic.

Twitter. A Twitter account was set up and new and original Twitter messages, or "tweets" were sent out every one to three days, and the FPIQ link was re-tweeted weekly. This Twitter account linked to the Facebook account described above, as well as to a Pinterest account described below.

Pinterest. Pinterest is an image-sharing website where users can upload or "pin" pictures or videos of their interests, and group them into categorical folders (Wikipedia, 2013). Users then subscribe to the folders of friends where they can pin or "like" the images (i.e., click on a "like" button that endorses the image and then spreads the image to their "friends" on Pinterest). For this reason, Pinterest is a valuable marketing tool as "likes" or "repins" (i.e., users selecting an image from their friends' folders and posting into their own folders) act as third party endorsements for the product (Whitecavage, Widgeon, & Overbey, 2012).

A folder on the Pinterest site included the advertisement for the online questionnaire. The goal was for the survey link to then be repinned by the researcher at least three times per week, and hopefully be repinned by others.

***LinkedIn*. "**LinkedIn" has become the professional's version of Facebook. This website allows one to maintain a community of professional contacts for the purposes of networking or job hunting. A profile on LinkedIn allows a professional to make additional connections through the contacts of their colleagues. In addition, an individual can join groups of professionals who are interested in particular subject areas, for the purposes of sharing information or jobs. This website is an ideal tool for participant recruitment by way of sharing the questionnaire link on group sites, or contacting other professionals who would be willing to share the link with their clients.

The researcher shared the survey link via LinkedIn to many professionals and groups. The LinkedIn site was monitored daily for any new groups or contacts that could be made to expand the recruitment pool.

Website advertisements. When contact with a person or agency was initiated via Facebook or email, it was requested that the agency consider posting a link to the questionnaire on their website, if they had one. For some agencies, additional ethics applications were required to describe the research that was being conducted and in all, but one instance the timelines for these applications seemed too great, and were not submitted. In the case of one submission, the application was completed and the questionnaire information was subsequently posted.

Flyer distribution. A flyer was created with a link to the questionnaire and it was sent via email to a number of contacts. In addition, the flyer was sent via email to new Facebook contacts. Additional flyers were sent out via regular mail and are described below.

Internet postings. News sources (e.g., CBC, CTV) use the Internet to post their recent stories, and they allow the reader to make comments on the information by way of comment boxes below every story. In order to attract more participants to this research study, the researcher commented and posted a link to the survey on relevant media articles (e.g., autism, developmental disabilities, special education, etc.).

Online paid advertisements. Advertisements were purchased and posted for up to three months on each of Facebook (as described above), and “Kijiji.” Kijiji is an online tool that functions like the classifieds section of a newspaper, where items and services can be advertised, or listed for sale or wanted for purchase. These ads were used as a supplemental recruitment strategy to the existing methods. One of the benefits was that Facebook ads collected data for every click that was made on the survey link, thus allowing the researcher to see that the ad was reaching potential participants.

Paper questionnaire distribution. In addition to online completion, parents also had the option for completing paper versions of the questionnaire regardless of the recruitment method. Parents or professionals could request to receive a copy of the hard copy of the questionnaire that included the letter of information, the informed consent form, and a pre-addressed stamped envelope. In addition, a presentation was made at the annual general meeting of Autism Ontario in June of 2013, and paper versions of the letter, consent form, questionnaire and self-addressed stamped envelopes were distributed to attendees.

Operational Framework

In order to conceptually organize the specific factors that the literature has presented on parent satisfaction of IBI, an operational framework was created to guide the construction for the Family Perspectives on IBI Questionnaire (FPIQ). Operational frameworks can be considered “a network (...) of interlinked concepts that together provide a comprehensive understanding of a phenomenon” (Jabareen, 2009, p. 50).

Seven steps were involved in creating the framework: 1) review of the literature (or data), 2) categorization of the data from the literature 3) naming the concepts, 4) deconstructing and categorizing the concepts, 5) integrating the concepts, and 6) synthesizing. The seventh step, validating the framework, was completed through data collection (Jabareen, 2009) and confirmatory factor analysis.

The resulting organizational framework is described below and presented in Figure 2. Parent satisfaction in IBI may be measured by the feedback from parents and conceptualized as possibly dependent upon: the child's outcomes, features of the IBI services, parent agreement with philosophy, and cultural differences between the professional provider and the parent.

Procedure

The quantitative portion of the data contained the two questionnaires; the Family Perspectives on IBI Questionnaire (FPIQ) and the Measures of Processes of Care (MPOC) (King, Rosenbaum & King, 1995) questionnaire. These methods were designed based on the research literature as described in Chapter Two, and synthesized in the operational framework.

Instruments. The Family Perspectives on IBI Questionnaire (FPIQ) was created to evaluate the research questions, while the previously published and validated Measures of Processes of Care (MPOC) tool was used to validate the FPIQ and also to see whether families were satisfied with the family-centred approach of the professionals and the agency. Each of these instruments is described below.

Family perspectives on IBI questionnaire (FPIQ). The author developed this questionnaire based on research findings from both parent satisfaction and outcome research in early intensive behaviour intervention, as defined in the operational framework. The

Figure 2. Operational framework for parent perspective study

questionnaire consisted of 100 questions; 69 Likert scale questions, 14 fill-in-the-blank questions, 16 check-from-a-list questions, and 1 open-ended question. Three different types of Likert scales were used in the FPIQ. The first was an agreement scale with six possible ratings (i.e., “strongly agree,” “somewhat agree,” “neither agree nor disagree,” “somewhat disagree,” “strongly disagree,” and “not applicable.” The second type was a scale that was used alongside the agreement scale and asked parents to rate the importance of the item that was just rated, ranging from 1 (“unimportant”) to 5 (“very important”). For example, one question states “My knowledge of autism has increased as a result of the IBI program” and respondents were asked to indicate their level of agreement with this statement, and also how important the area was to them. The third type of Likert scale had participants rate statements concerning the quantity of IBI. For example, respondents were asked to rate the number of hours their child was receiving per week as “too much,” “just right,” or “not enough.” All scales were labeled with words (e.g., “strongly agree”), instead of numbers, to help clarify the meanings of scale points for respondents (Weisberg, 1996). The remaining questions required selections from a list (e.g., “What other services was your child receiving during IBI?”) and parents checked all that apply from a supplied list of potential services. Space was available to allow respondents to provide more details or additional information (e.g., “Were there areas within your child’s IBI program that you feel were not adequately addressed?”).

The questionnaire was available in both a paper version (see Appendix A) and an online version. The online version of the questionnaire was created using Fluid Surveys© (http://fluidsurveys.com) a web-based software program licensed by the University of Windsor. This program allowed for a number of secure options (e.g., anonymous responses, non-saving of IP addresses, options to save and return to the questionnaire with a private password, etc.). The survey questionnaires were then printed, and responses were manually entered into Statistical Package for the Social Sciences (SPSS) (SPSS, 2012) for subsequent data analysis.

The questionnaire began with a few questions to determine inclusion eligibility. The remaining questions were divided into six sections: satisfaction with how IBI services were provided and the child's outcomes, effects on the family's lifestyle, demographic information, and cultural considerations. The questionnaire concluded with questions about the child's transition to their current educational placement.

IBI service provision. In this section of the questionnaire, parents were asked to indicate their satisfaction about areas of their child's IBI programming and the resulting outcomes. Specifically, the questions asked about parents' satisfaction with the skills learned by their child, choices in the services that they were given as parents, changes to the parents' level of knowledge around ABA techniques and teaching their child, and the overall impact that the IBI program had on their child's ability to communicate, socialize and avoid problem behaviour.

Effects on family lifestyle. Questions in this section of the FPIQ pertained to effects of the IBI program on the family and their lifestyle. Specifically, the questions investigated the relationships between family members and the effect the IBI program had on the career and health of the parents.

Cultural and religious consideration. The next section of the FPIQ was developed to assess whether the cultural background and/or religious preferences of the family were given acceptable consideration in the development and implementation of the IBI program for their child. Specifically, the questions asked whether parents felt the professionals in the IBI program understood their cultural heritage, and whether the goals and materials selected for use within their child's program reflected their heritage, and whether this was or was not important to the families.

Demographic information. The questionnaire concluded with a section asking about demographic information on the following: employment, income, marital status, education level, ethnic background, birth country (and years in Canada) languages spoken in the home and outside, level of language understanding, number of children, birth date of children, and the number of caregivers in the home. Finally, the questionnaire included a request to participate in a follow-up focus group, and an invitation to participate in a draw for one of four $25.00 gift certificates to Tim Hortons.

Measures of Processes of Care (MPOC) Questionnaire. King, Rosenbaum and King (1995) developed the MPOC Questionnaire to assess parent perceptions about interactions with health care professionals and organizations during the time their children were receiving services. Several studies have found the MPOC to be a reliable measure of parent perspectives on therapeutic services received by their children using both the 56-item questionnaire (Himuro, Kozuka & Mori, 2012) and the 20-item questionnaire (Arnadottir & Egilson, 2012). The questionnaire was originally developed with 101 questions around five factors: Enabling and partnership; providing general information; providing specific information about the child; coordinated and comprehensive care for the child and family; and respectful and supportive care (King, et al. 1995). Following pilot testing and factor analysis, the survey was condensed into both a 56-item and a 20-item questionnaire (King, King & Rosenbaum, 2010), the latter of which was used in the current study.

McMaster (2013) demonstrated that the MPOC displayed good internal consistency (Cronbach's alphas ranging from .63 to .96) and test-retest reliability resulted in intraclass correlation coefficients ranging from .78 to .88. Previous concurrent validity studies of the MPOC-56 identified that almost all of the factors in the MPOC correlated with the Client Satisfaction Questionnaire (CSQ). The MPOC-20 was also compared to the CSQ and significant and positive correlations (range of 0.40 - 0.59) were found across the five scales and the CSQ, indicating that results on the MPOC-20 could be considered valid measures of satisfaction of the family-centered practices of the organization from which the services were being obtained (King, King & Rosenbaum, 2004). Thus, the MPOC (20) is considered a useful measure of parent perspectives on family-centered practices of professionals and organizations.

Quantitative Data Analysis

Data analysis occurred in two phases. Initially the quantitative survey data were cleaned and manually inputted into SPSS. A second check by a research assistant ensured that the data codes assigned to each questionnaire response were accurate and that the data entered into the SPSS spreadsheet were correct. The qualitative responses from the FPIQ were then entered into an Excel spreadsheet and categorized by question, to be analyzed following the quantitative data, and using the same steps as analysis of the focus group data, to be discussed below.

Analysis began with the computation of descriptive statistics to describe the sample from the survey. These statistics included means, ranges, and standard deviations for all demographic and categorical variables (i.e., dependent and independent variables), as well as frequencies for both scale responses and importance measures.

Inferential statistics comprised the greater part of the data analysis and was used to answer the research questions. Pearson *r* correlation coefficients were used to determine the relationship between overall satisfaction and the survey variables. Following this, two multiple regressions were computed to identify the amount of variance in each satisfaction variable and an overall mean satisfaction that was attributable to each of the variables.

An analysis of multicollinearity was conducted using SPSS, followed by a factor analysis of the variables. Multicollinearity is where there are intercorrelations between variables that would make isolating the effects of the independent variables on the dependent variables difficult. Correlations that are too low or too high can indicate multicollinearity (Field, 2009). The regression analysis was then re-run using the resulting factors as variables. Additional predictor variables for satisfaction were sought based on descriptive categories (e.g., Direct Funding Option (DFO) vs. Direct Service Option (DSO). The results of these analyses were then compared to the ratings of importance of each feature as given by the parents on the FPIQ.

Reliability and Validity of the Instruments. Reliability of the Family Perspectives on IBI Questionnaire was measured using Cronbach’s alpha statistic with the goal of exceeding 0.70, which is the recommended statistic for a developing questionnaire (Rattray & Jones, 2005). In addition, corrected item-total correlations were used to assess internal consistency meaning that item scores in a category were compared to total scores in a category (with the item removed) (i.e., corrected), thus allowing duplicate questions to be identified and removed (Rattray & Jones, 2005).

Validity is a measure of whether a study can accurately provide inferences about the research questions it intended with the data that was collected (Field, 2009). The MPOC was used as a measure to assess concurrent validity of the family perspective questionnaire.

Phase 2: Qualitative

Lens of the Researcher

The researcher of the current study is a professor in a program for teaching professionals to implement intensive behavioural intervention, and a Board Certified Behavior Analyst. Prior to this role, the researcher was a clinician in several regional and private IBI programs for seven years, during both the inception and initial delivery of the program across the province. In addition, the researcher is a mother of two stepchildren in their twenties as well as the biological mother of a nine-year old boy. Therefore, this researcher brings both an IBI clinical lens and a parent lens to the data.

Focus Group

Recruitment. At the end of the questionnaire, participants were asked to indicate if they would be willing to participate in a focus group with a few other participants (maximum of 10). Focus group participants were selected from among those indicating their willingness, and who were in in close geographical proximity to each other and to the researcher due to financial constraints. The focus group was conducted following data collection and analysis of the two questionnaires. This allowed for themes that emerged in the questionnaires to be explored in more depth during the focus group.

The focus group session included eight open-ended questions (Appendix F) and was two hours in length. The session was audiotaped for transcription and analysis purposes. An assistant moderator attended and took notes so as to compare to primary researcher's notes and establish some reliability for later data analysis. Follow-up questions were asked when the researcher needed clarification of a response.

Participants. Forty-eight people completing the survey indicated their interest in participating in the focus group, with all regions of the province represented. However, because of geographical constraints, the focus group was scheduled to take place in the GTA. Although six participants in the GTA were interested, ultimately, only three participants were able to attend. All three participants were mothers of boys with autism: Kelly, Natalie, and Debbie[3].

Focus group analysis. Analysis of the focus group data began during the session, as suggested by Krueger (2002). As responses were given, the researcher probed for additional information when any statement was unclear. Both the researcher and the research assistant's notes contained information that could add to the analysis (e.g., noting emotions of participants), and following the focus group, a debriefing session was held between the researcher and research assistant where notes were discussed and compared (Onwuegbuzie, Dickinson, Leech & Zoran, 2009).

The focus group was transcribed verbatim and the transcript was printed and then cut into sections by participant statements (Krueger, 2002). Statements were sorted into groups according to whether they answered the question or not. Those that did not were set aside and were reviewed at the end. Those that did answer the question remained under their particular heading. Additional factors or themes were derived from statements that did not fall into the above criteria. All data were refined through the additional splitting of categories and subcategories as needed (Dey, 1993).

"Tree diagrams" (i.e., connected flow charts) were then created to see the "layers" within the data (Cresswell, 2005) to analyze the connections across themes, and to define boundaries between them. The diagrams were used to place similar ideas together and to

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[3] These are not the actual names of the participants.

draw arrows to indicate the direction of relationship to other groups of ideas within the trees. These groupings formed a theme, which was then compared to the findings from the questionnaires for the purposes of further validating the questionnaire (i.e., “triangulation”; Cresswell, 2005). Therefore, emerging themes from the focus group were compared to existing themes from the quantitative data, and if matched, the focus group theme was titled in a similar way. Themes that seemed to fit together but did not match the quantitative data were given their own names. Finally, additional themes that arose from the focus group were also added to a related branch in the tree, if there was one. In addition, particular quotations from the focus group were selected to represent each of the theme areas, and were listed below each section in the tree diagram.

Data were sorted first by the primary researcher into the initial categories (i.e., by question and/or added categories). The research assistant then reviewed the data for agreement of classification. Together the primary researcher and assistant discussed how the data should be further themed. The additional themes were then generated, and the data were re-sorted accordingly. Disagreements that occurred about the placement of data into a theme resulted in further discussion until consensus between the researcher and the assistant was achieved. This involved either discussion and determination of the appropriate theme for the particular response statement or the creation of a new theme in which to categorized the statement. Interrater reliability (Kazdin, 1992) was then measured by comparing the number of statements that yielded disagreement. Therefore, placement of statements into particular categories was compared to indicate agreement or disagreement. When there was extended discussion about a particular statement, the statement was set aside for later discussion. Following the sorting of all statements, the “discussion” statements were re-introduced.

Because the primary researcher had more knowledge and experience with the context of what parents were discussing the researcher made all final decisions related to the thematic location of statements. Disagreements as to which category statements belonged to were evaluated using a point-by-point agreement formula (agreement/agreement + disagreement X 100) (Kazdin, 1992) to provide an overall inter-rater agreement score.

CHAPTER IV

RESULTS

Introduction

The chapter begins with an analysis of the demographic information of the participants, followed by the descriptive results from the questionnaires. A crosstabs analysis of the DSO vs. DFO services model was conducted to determine if there were significant differences in the responses depending on the funding model used. These results are discussed within each section as relevant. A principal component analysis identifying factors from the independent variables is then described followed by a multiple regression analysis identifying which factors caused variation within and across satisfaction measures. The results of these analyses are followed by the qualitative data from the focus group and the questionnaire.

Quantitative Results

FPIQ Reliability and Validity. The FPIQ was assessed for reliability and validity through and examination of content and internal consistency.

Content validity. The FPIQ was distributed to five professionals and five parents for review and feedback on questionnaire structure and content. Four participants returned the questionnaires, and provided feedback on the content. Overall, all four participants indicated satisfaction with the content and format, although length was indicated as a possible problem. Three questions were modified based on the feedback that was received.

Internal consistency. All data were examined for outliers using Zscores, and those outliers were removed. A check on normality for all data were run, and those data with kurtosis or skewness outside of +1 and -1 were transformed and rechecked. Those data with only slight ranges outside +1 or -1 were accepted for kurtosis, whereas the other data were removed. All data were examined using Cronbach's alpha and met good internal consistency at an alpha of 0.7 for each of the response categories on the questionnaire.

Descriptive Statistical Analysis. Descriptive statistical analyses identified a number of trends in the data, to be described below. Initially, the data were examined to identify patterns of missing data.

Missing Data. The range of missing data is listed in Table 3. Missing data were given a score of 99 in SPSS which was a number not used in the coding of available data. Up to 15% of missing data can be given a score of 99 without altering the statistical findings (Cresswell, 2006), however missing data in this study sometimes exceeded 15%. Therefore, the option to "exclude cases listwise" was chosen to remove all missing data from the statistical analysis (Williams, 2014). However, no participants were excluded fully, simply the responses in to particular FPIQ questions that were left blank.

IBI service provision. While the majority of participants responding to this question (48.2%) received services using the Direct Service Option, 30.9% of participants used the Direct Funding Option. However, a substantial number of participants (20.9%) did not respond to this item as seen in Table 4. The mean age of the children when IBI began was 5.3 years (*SD* = 2.2), with a range of 1-17 years), and the mean age that IBI ended was 8.01 years (*SD* = 3.1) with a range of 4-18 years. Compared to the Lovaas (1987) study (mean age 4.08 years), the respondents in this survey had children that entered the IBI program at slightly older ages, however the ages were comparable to the Ontario IBI (Toronto) study whether the mean was also 5.3 years (Freeman & Perry, 2010).

Table 3

Missing Data

Questions	Range of Missing Data
Numbers	N
1-10	0
11-20	0-10
21-30	11 - 36
31-40	11 - 36
41-50	12 - 18
51-60	24 - 32
61-70	21 - 34
71-80	21 - 28
81-90	23 - 29
91-100	25 - 28

Table 4

IBI Service Provision

Items	Percentage of Responses	Number of Participants
Type of IBI	%	N
Direct Service	48.2	53
Direct Funded	30.9	34
No response	20.9	23
	M (SD)	Range
Age For Services		
Age When IBI Began	5.26 (2.2)	1-17 years
Age When IBI Ended	8.01 (3.1)	4 -18 years
Hours Per Week	23 (8.5)	0 - 40 hours
Months Since IBI Finished	19.2 (24.7)	0-120 months

Respondents received a mean of 23 hours per week of IBI service (*SD* = 8.5) with a range of 0 to 40 hours, suggesting that some respondents indicated that they were no longer receiving service rather than indicating the amount of service they did receive while in the program. Although 20 respondents were still receiving services, the respondents who were finished IBI, had been finished for 19.2 months, and 12 participants had been finished services for more than five years.

The first section of the questionnaire asked parents about their expectations of the IBI program for their child. Throughout the questionnaire, there were questions about IBI satisfaction. The responses to these items can be seen in Table 5 below. First, in terms of expectations for child outcomes, “communication would improve” was the item endorsed most frequently (32.4%), followed by “behavior problems would decrease” (26.8%) and “academic skills would be improved” (25%). A smaller number of responses fell into the category of “making friends” (12.1%). Only 2.4% of parents expected that “autism would be cured.” In terms of whether caregivers felt that their expectations were met, there was a range of responses. While 29% of parents “strongly agreed,” and 30.9% “somewhat agreed” that their expectations were met, 10% of parents “somewhat disagreed,” and 16.4% “strongly disagreed” about whether their expectations of IBI were met.

Overall, caregivers were generally “very satisfied” (27.3%) or “somewhat satisfied” (26.4%) with the program, but 10% were “somewhat dissatisfied” and 9.1% of participants were “very dissatisfied.” However, it was apparent that caregivers’ satisfaction with IBI varied over time. While the majority “strongly agreed” and “somewhat agreed” that “satisfaction with IBI increased with time” (55.4%), 21.8% did not feel that their satisfaction increased over the time they were in the program, while 10% “neither agreed nor disagreed”

Table 5

IBI Expectations and Satisfaction Ratings

Subcategories and Items	Percentage of Responses	Number of Participants
Expectations (check as many as apply)	%	N
Communication would improve	32.4	93
Behaviour problems would decrease	26.8	77
Learn academic skills	25	72
Child would make friends	12.1	35
Autism would be cured	2.4	7
Other	1	3
IBI program Met Expectations		
Strongly agree	29	32
Somewhat agree	30.9	34
Neither agree nor disagree	9	10
Somewhat disagree	10	11
Strongly disagree	16.4	18
Not applicable	1.8	2
Missing	2.7	3
Overall Satisfaction		
Very satisfied	27.3	30
Somewhat satisfied	26.4	29
Not satisfied	10	11
Extremely dissatisfied	9.1	10
Missing/No response	27.3	30
IBI Satisfaction Increased Over Time		
Strongly agree	37.2	41
Somewhat agree	18.2	20
Neither agree nor disagree	10	11
Somewhat disagree	9.1	10
Strongly disagree	12.7	14
Missing/No response	12.7	14
Impact of IBI		
Large positive impact	39.1	43
Small positive impact	19.1	21
Small negative impact	2.7	3
Large negative impact	7.3	8
I do not know	2.7	3

Table 5 continued

IBI Expectations and Satisfaction Ratings

Subcategories and Items	Percentage of Responses	Number of Participants
If you had the choice, would you have continued IBI?	%	N
Yes, in the same way it was delivered previously	31.8	35
Yes, although I would want it delivered differently	24.5	27
No, it was the right time to leave IBI	12.7	14
I do not know	2.7	3
Missing/No response	28.2	31
Looking back, would you choose the IBI program again?		
Would definitely select IBI again	44.5	49
Maybe would select IBI again	10.9	12
Probably would not select IBI again	7.3	8
Definitely would not select IBI again	4.5	5
I do not know	2.7	3
Missing/No response	30	33
Satisfaction with IBI's Consideration of Other Services		
I do not know/I did not discuss my services with them	21.8	24
Somewhat satisfied	20.9	23
Very satisfied	20	22
Somewhat dissatisfied	7.3	8
Very dissatisfied	5.5	6
Missing/No response	24.5	27

that their satisfaction increased over time. Overall, 58.2% of parents reported that IBI had a positive impact on their lives while 10% indicated that IBI had a negative impact on their lives.

If given the opportunity to continue IBI, 31.8% of parents indicated they would select it again, in the same way it had been delivered. Although 24.5% of participants indicated that they would continue IBI again as well, they indicated that they would want it "delivered differently." Finally, 12.7% of parents indicated that it was the right time to leave IBI. In terms of whether they would choose IBI again based on their experiences, almost half (44.5%) indicated that they would "definitely select IBI again" and 10.9% would "probably select IBI again." However, 7.3% of parents felt that they probably would not select IBI again and 4.5% would definitely not select IBI again.

Parents were also asked about their satisfaction regarding how the IBI program took the goals of other services the families were receiving (such as speech therapy or music therapy) into consideration when planning the program. For the most part, parents expressed high or moderate satisfaction (20% and 20.9% respectively), although 12.8% reported dissatisfaction. It is worth noting that 21.8% either did not know whether IBI included their goals from other services, or the parents did not discuss their other services with their IBI team.

Amount of service. Table 6 outlines the participants' views on the amount of service they received. In terms of hours/week, most participants felt their hours were "just right" (37.2%,), although many also felt the hours were insufficient (33.6%). Just under 3% felt their hours were too many. In terms of hours per day of intervention, most participants (56%) felt their hours were just right, but 19.1% felt the hours were not enough. Whereas

Table 6

Satisfaction Ratings: Amount of Service

Item	Not Enough		Just Right		Too Much		No Response/	
	%	N	%	N	%	N	%	N
No. of treatment hours per week	33.6	37	37.2	41	2.7	3	26.3	29
No. of months of service	50	55	23.6	26	1.8	2	23.6	27
No. of hours per day	19.1	21	50.9	56	4.5	5	25.4	28
No. of therapists	12.7	14	56.3	62	6.3	7	24.5	27
No. of ST meetings	16.4	18	55.4	61	1.8	2	25.4	29
No. of program meetings	18.2	20	51.8	57	5.5	6	23.6	27

50% of participants felt that they did not have enough months of service, 23.6% felt the number was just right, and 1.8% felt that there were too many months of service.

Most respondents felt that the number of therapists, as well as the number of program meetings and meetings with the ST were sufficient (56.3%, 55.4%, and 51.8% respectively). However, 18.2% and 16.4% of families felt that the number of program meetings and meetings with STs were insufficient respectively, and 12.7% felt that the number of therapists were insufficient.

Parent control, choice and training. Parents were asked about their inclusion in the IBI program by the clinical team. Inclusion was defined in the survey questions as having control, or choice in the methods and goals that were selected for their child’s program. These questions sought to identify whether parents felt included in this aspect of IBI programming. How this affected their satisfaction of IBI is considered later in this chapter. Overall, caregivers indicated agreement with having choice and control over teaching methods and goals. As seen in Table 7, more than 60% of caregivers indicated “strong agreement” or “agreement” that they had control over the way that teaching was delivered, what goals were selected for their child to work towards, and having choices in those goals.

However, 26.1% of parents either somewhat, or strongly disagreed that they had control over the way teaching was structured within their IBI program. In the crosstabs analysis (Table 8) between the DFO and DSO service, a significant difference ($p < 0.01$) was found between the participants in terms of the control over teaching procedures. Parents in the DSO reported having less control of teaching procedures and 86.7% of respondents who “strongly disagreed” that they had control were from this group of parents.

Table 7

Satisfaction Ratings: Parent Control and Choice

Item	Strongly Agree		Somewhat Agree		Neither Agree nor Disagree		Somewhat Disagree		Strongly Disagree		N/A or No Response	
	%	N	%	N	%	N	%	N	%	N	%	N
Control over Goals	36.4	40	37.3	41	2.7	3	8.2	9	8.2	9	7.2	8
Choices in Goals	30.9	34	36.4	40	7.3	8	11.8	13	6.4	7	7.2	8
Control over Teaching	27.3	30	36.4	40	5.3	6	9.7	11	16.4	18	4.5	5
Choices in Teaching	17.3	19	28.2	31	18.2	20	18.2	20	10	11	8.2	9
Choices in Service	27.3	30	20.9	23	5.5	6	14.5	16	17.3	19	14.5	16
Methods Acceptable	47.3	52	25.5	28	5.5	6	5.5	6	3.6	4	12.7	14
Goals Acceptable	42.7	47	30.9	34	6.4	7	6.4	7	1.8	2	11.8	13

Table 8

Cross tabulation results across service type

Variables	X^2	*df*	Sig.
I had control over the teaching procedures	13.264a	4	0.01**
I was given choices in the way service was provided	11.325b	5	0.045*
I consider the methods used in IBI to be acceptable	9.463c	4	0.051
I have learned how to implement IBI treatment with my child	4.319a	5	0.504
The program has negatively affected my family's finances	13.981d	5	0.016*

$^{*}p < .05$ $^{**}p < .01$ $^{***}p < .001$

a 4 cells (40.0%) have expected count less than 5. The minimum expected count is 2.67.
b 5 cells (41.7%) have expected count less than 5. The minimum expected count is .79.
c 6 cells (60.0%) have expected count less than 5. The minimum expected count is 1.98.
d 7 cells (58.3%) have expected count less than 5. The minimum expected count is .75.

Parents reported satisfaction (i.e., "very satisfied" or "somewhat satisfied") with the choices they were given in the way teaching was delivered (45.5%), although there were more parents that responded "neither agree nor disagree" here (18.2%) than in other questions on this topic, and more than a quarter of parents (28.2%) disagreed that they were given choices in the way teaching was delivered. Having choices in the structure of IBI service was also rated similarly to choices in teaching and goals as 48.2% of parents agreed that they were satisfied with the choices that they had. However, there was also high disagreement as 31.8% indicated dissatisfaction in terms of the choices they were given for the structure of IBI. The crosstabs analysis between the DSO and DFO indicated significant differences between the two groups ($p < 0.05$). The DSO group represented 82.4% of the "strongly disagree" category about getting choices in service as compared to 17.6% in the DFO group (see Table 8). However, given the number of cell counts below the five, these results need to be interpreted with caution.

Finally, the parents were asked whether the methods that were used in IBI were acceptable to them. Although parents may or may not have had choices in the methods of interventions used within IBI (e.g., positive reinforcement, chaining, video modeling, etc.), whether these strategies that were used were acceptable to the families is an important measure of social validity. Most parents (72.8%) responded that they ("strongly" or "somewhat") "agree" that the methods used within IBI were acceptable, although 28.8% of parents "somewhat disagreed", and 5.5% "strongly disagreed" about the acceptability. In an analysis between the two groups of parents (i.e., DSO and DFO), there was a significant difference ($p < 0.05$) in ratings of acceptability. For the respondents that indicated, "strongly disagree," 100% came from the DFO group. However, 80% of "somewhat disagree" responses came from the DSO group. In terms of agreement with the acceptability of methods, > 60% of the responses indicated “somewhat” or “strongly agree” came from the DSO group. This indicates that parents in the DSO group were more likely to indicate acceptability of the methods used in IBI.

The majority of caregivers (just over 70%) felt that they had an acceptable level of involvement with their child’s program (see Table 9), while just over half reported that they had an acceptable amount of training (50.9%), in addition to learning how to implement IBI (60%). “Training,” and “learning to implement IBI” is differentiated here because whereas training may include more general knowledge-based training (e.g., autism, ABA), learning to implement IBI consists of more individualized training with families so that they could teach in the same way as the therapists. Almost half of the parents agreed that they learned about IBI strategies (42.6%) and autism (40%), compared to 10% who did not feel that they learned the strategies. There was no significant difference between the DSO and the DFO group in terms of the parents feeling they had learned to implement IBI.

Child outcomes. The parents were asked questions about their child’s outcomes from IBI across a number of categories. Parents were asked to identify whether their child made improvements in various communication, social, and self-help skills, as well as whether there were positive changes in their child’s overall presentation of autism (i.e., decrease in severity and maintenance of learned skills). Table 10 outlines the overall child outcomes that the parents reported following IBI. Over 40 % of caregivers believed that the severity of their child’s autism had decreased and more than 70% indicated that their child was still using the skills that they had learned during the IBI program. No significant differences were found between the DSO and the DFO group.

Table 9

Satisfaction Ratings: Parent Training and Involvement

Category	Strongly Agree		Somewhat Agree		Neither Agree nor Disagree		Somewhat Disagree		Strongly Disagree		N/A or No Response	
Item	%	N	%	N	%	N	%	N	%	N	%	N
Level of Involvement	42.7	47	29.1	32	3.6	4	5.5	6	2.7	3	16.4	18
Learned to Implement IBI	40	44	20	22	12.7	14	3.6	4	3.6	4	20	22
Acceptable Amount of Training	28.2	31	22.7	25	8.2	9	14.5	16	8.2	9	18.2	20
Knowledge of Strategies	1.8	2	41.8	46	19.1	21	9.1	10	0	0	28.2	31
Knowledge of Autism	0	0	40	44	20.9	23	10	11	0	0	29.1	32

*Communication, socialization and self help skills***.** Overall, parents reported the greatest area of improvement as being in the area of communication skills (see Figure 3), with 74.1% reporting improvements in understanding others, and 71.7% reporting an improvement in their child's ability to speak. A considerable amount of improvement was identified in the area of social interactions. Specifically, 72.6% of parents noted improvements in their child's ability to interact with adults, 72.6% reported improvements in the interactions with their family, and 66% of parents identified improvements in sibling interactions. In the category of self-help skills, parents reported improvements in the ability of their child to clean themselves (62.6%), dress themselves (59.9%), self-feed (46%), as well as eat a variety of foods (41.7%). parents also noted improvements around toileting skills, such as toileting independently at 52.7%, and being diaper free was noted by 45.4% of parents. However, 37.1 % and 50.8% of parents in toileting and being diaper free respectively responded to this question with "not applicable," or the data were absent.

As also seen in Figure 3, some parents, however, felt that either the severity of their child's autism had not decreased (13.6%) or that problem behavior had actually become worse (7.2%). There were also two specific skill areas in which caregivers either noted "no improvements" or indeed that the behavior had worsened during IBI. Specifically, 36.3% of parents responded that "making friends" showed no improvement or got worse (1.8%), and that their child's "ability to sleep" did not improve (20.9%) or got worse (3.6%).

Table 10
Satisfaction Ratings: Overall Child Outcomes

Rating	Severity of Autism Decreased		Child is Still Using the Skills	
	%	N	%	N
Strongly Agree	3.18	35	48.1	53
Somewhat Agree	37	37	22.7	25
Somewhat Disagree	4.6	4	4.5	5
Strongly Disagree	10	11	3.6	4
Neither Agree nor Disagree	18.1	20	7.2	8
N/A	1.8	2	3.6	4
Data Missing	0	1	10	11

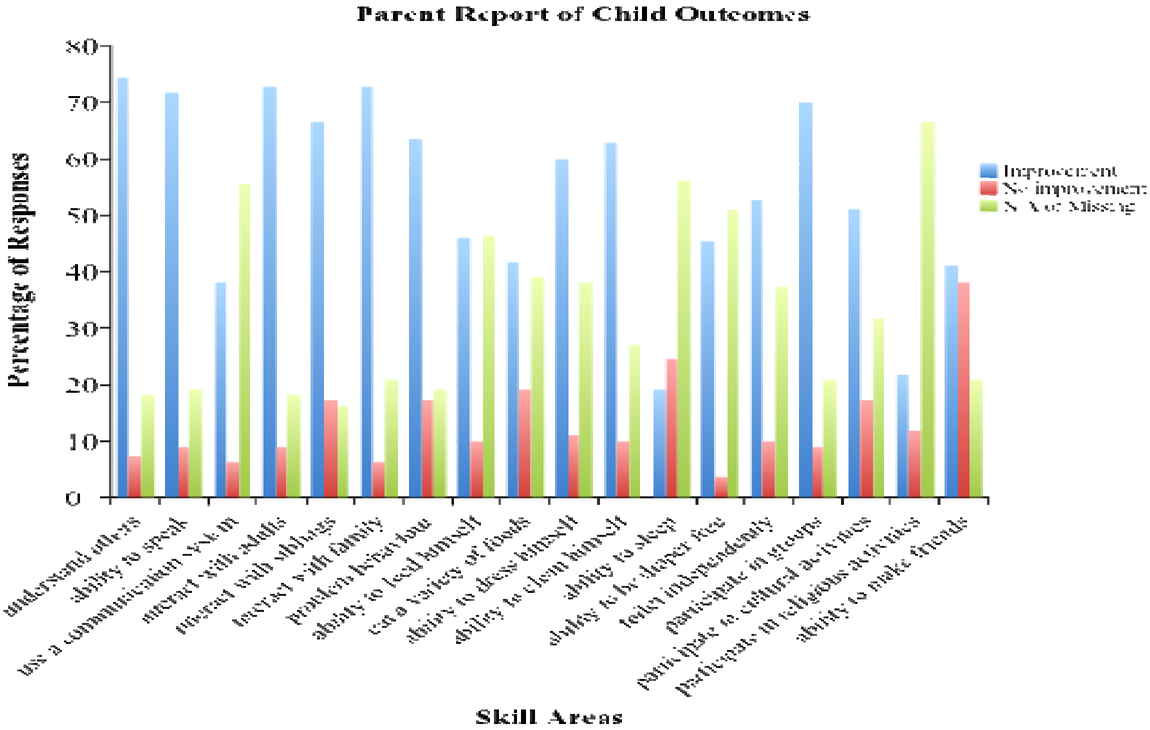

Figure 3. Parent report of child outcomes

Current educational placement. The parents were asked about their child's current educational placement, type of classroom, educational support or assistance, as well as whether their child was prepared for school upon leaving IBI (Table 11). From the 70% of parents who responded to these questions, "public school" dominated as the type of school attended (58.2%), although 6.4% said "private school," and 6.4% said "other" (see Table 11). Of those parents responding in the "other" category, four indicated that their child was "still in IBI," two children were "not currently placed" and one child was in an "autism unit." The type of classroom the children attended were mostly the "same classroom" as same-aged peers (32.7%) and a "developmental/special education/autism classroom" (24.5%), although 8.2% attended a combination of both. In terms of educational support, 35.5% of the children had a full-time educational assistant, 20% had a part-time educational assistant (EA), 7.3% felt their child did not need an EA, and 6.4% did not have an EA but the parents were asking for one. Finally, in terms of whether parents felt their child was prepared for school upon leaving IBI, 21% felt that their child was prepared, 20% felt their child was not prepared, 13.6% indicated that their child was prepared but not to their satisfaction, 5.5% indicated it was too soon to tell, and 4.5% did not know. Finally, 7.3% indicated it was not applicable. There were no significant differences between the DFO and the DSO recipients.

IBI Effects on the Family. The participants responded to a number of questions regarding the effects of IBI on different aspects of their life, such as their relationships, career and stress levels. Table 12, and Figure 4 describe the percentage of agreement to each of the items in the questionnaire.

Table 11

Child's Educational Placement and Outcomes

Type	Percentage of Responses	Number of Participants
Type of School	%	N
Publicly-funded school	58.2	64
Private school	6.4	7
Daycare/preschool	0.9	1
Home school	0.9	1
Other (please specify)	6.4	7
Missing	27.3	30
Type of Classroom		
Attends the same classes as other students of the same age/grade	32.7	36
Developmental/special education/autism classroom	24.5	27
Attends regular class and some special education classes	8.2	9
Not applicable	7.3	8
No response/Missing	27.3	30
Educational Support		
Yes, works full-time with my child	35.5	39
Yes, works part– time with my child	20	22
No, s (he) does not need one	7.3	8
No, but we are asking for one	6.4	7
No response/Missing	30.9	34
Prepared for School Upon Exiting IBI		
Yes, absolutely	20.9	23
Yes, but not to my satisfaction	13.6	15
No, my child is struggling	20	22
It is too soon to tell	5.5	6
I do not know	4.5	5
Not applicable	7.3	8
No response/Missing	28.2	31

Table 12

Satisfaction Ratings: Relationships, Religion and Finances

Item	Agree		Neither Agree nor Disagree		Disagree		Missing/Not Applicable	
	%	N	%	N	%	N	%	N
Negatively affected my family's finances.	47.2	52	1.8	2	15.4	17	35.4	39
Increased my stress level.	40.9	45	36.3	5	24.5	27	30	33
Improved relationship with spouse/partner.	22.7	25	23.6	26	19	21	34.5	38
Improved/is improving relationship with community.	22.7	25	30.9	34	30.9	14	33.6	37
Improved relationship with extended family.	17.2	19	32.7	36	14.5	16	35.4	39
Negatively affected other children’s extracurricular activities	17.2	19	10	11	28.1	31	44.5	49

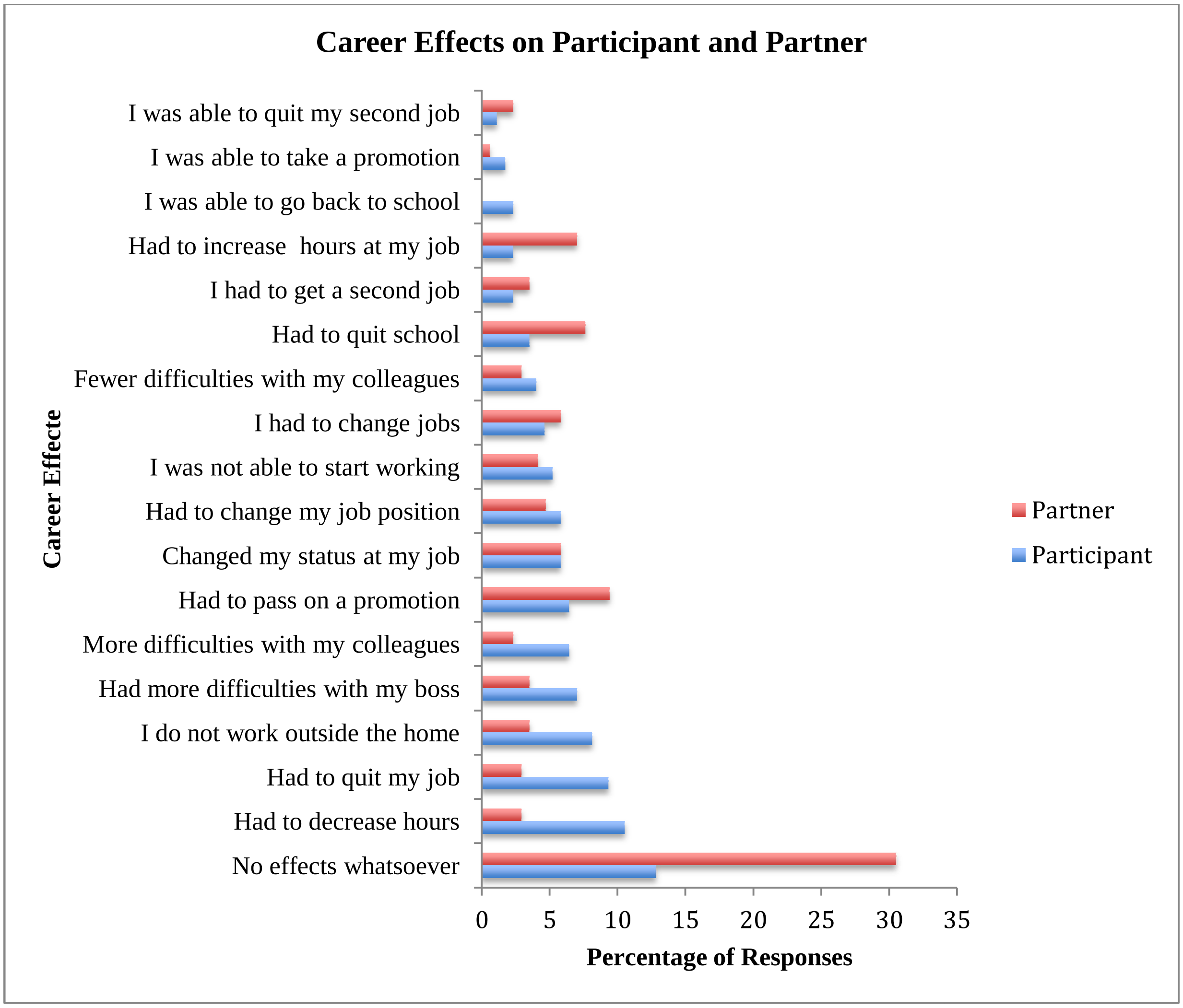

Figure 4. IBI Effects on the Career

Relationships, stress and finances. In general, the responses were evenly divided across the rankings. For example, 32.7%, 30.9%, and 23.6% of parents neither agreed nor disagreed about IBI improving relationships with their extended family, their community, or their spouse respectively. A number of parents disagreed that relationships were improved with their community (30.9%), with their spouse (19%), and with their extended family (14.5%). However, some parents did note improvement, as the relationship with one's extended family was improved by IBI in 17.2% of families, and with their spouse and community in 22% of parents responding.

By far the majority of parents responding to the question indicated that IBI created a negative effect on stress (40.9%) and on finances (47.2%). Significant results ($p < 0.05$) were noted between the DSO and the DFO group on the question of financial effects. Within the "strongly agree" category, 60% of responses were from the DFO group. Within the "strongly disagree" and "somewhat disagree" rating, 84.6% and 100% of the responses were from parents receiving the DSO. This finding suggests that parents within the DFO funding group were more affected financially (see Table 8).

Career effects. The participants were also asked questions about the effects that participating in the IBI program had on their career as well as the career of their partner. As seen in Figure 4, 12.8% of participants who responded to this question felt that IBI had no effect on their career compared to 30.5% indicating that participating in the IBI program had "no effect" on their partner's career. This suggests that the participant was typically the parent who was more affected. Just over 10% of participants identified having to either decrease the number of hours they worked, or having to quit their job altogether (9.3%) compared to approximately 6% and 3% of partners having to do so respectively. On the other hand, 2.3% of participants and 9.4% of partners actually increased their work hours. Approximately 7% of participants and their partners reported having more difficulties with colleagues (7.6%,) or with the boss (7%). Differences between the DSO and the DFO groups were not identified. Additional details about these effects are described in the qualitative data.

Other services. Parents reported that their children received a number of other services during their IBI treatment. As seen in Table 13, the most popular services received were Speech Therapy (19.6% of responses) and Occupational Therapy (18.6% of responses) with notably beneficial effects reported (84.7% and 76.7% respectively reported some or great benefit). Just over 11% of respondents used special diets and vitamin supplements with 67.6% and 77.7% respectively of those using them reporting favourable effects. However, 29.4% of parents who implemented the gluten/casein free diet noted no benefits. Other interventions were also accessed by parents such as Floortime (*n* = 26), sensory integration (*n* = 21), play therapy (*n* = 19), facilitated communication (*n* = 19), and auditory integration (*n* = 15) suggesting some uptake of these services, with greater than 50% of those participating indicating they were of some, or great benefit.

Cultural and religious considerations. Parents were also asked about their ethnicity, culture, religion, and whether IBI was considerate of these features of their lives. As described above and shown in Table 2, at least 15.5% of the participants and 16.6% of their partners were born in another country. In 72.2% of these cases, the main language spoken at

Table 13

Other Services Received During IBI Treatment

	Access		Benefit							
Service	Used the Service		Some/great Benefit		Do not know		No Benefit		Did Not Use/Missing	
Speech therapy	19.6	59	84.7	50	1.6	1	13.5	8	46.3	51
Occupational therapy	18.6	56	76.7	43	7.1	4	16	9	49	54
Vitamin Supplements	11.9	36	77.7	28	11.1	4	5.5	2	69	76
Gluten/Casein free diet	11.2	34	67.6	23	2.9	1	29.4	10	69	76
Floortime	8.6	26	73.0	19	19.2	5	7.6	2	76.3	84
Sensory Integration	6.1	21	76.1	16	9.5	2	14.2	3	80.9	89
Play therapy	6.3	19	76.1	16	15.7	3	0	0	82.7	91
Facilitated communication	6.3	19	57.8	11	10.5	2	31.5	6	82.7	91
Auditory integration	4.9	15	66.6	10	6.6	1	2.6	4	86.3	95
Physiotherapy	3.3	10	40.0	4	20	2	40	4	90.9	100
Chelation therapy	1.9	6	50.0	3	50	3	0	0	94.5	104

home was English. Thus, 27.8% of parents spoke a language other than English at home.

A small number of participants on average (*n* = 17) responded to the IBI program's consideration of the cultural and language preferences of families as seen in Table 14. Although response rates were low for this subsample of the participants, and thus detailed analysis is not possible, there were data worth noting overall and in specific areas. For example, difficulties with English made IBI more difficult for at least one parent (0.9%), and two parents indicated that the IBI staff did not understand their culture (1.8%). In terms of the IBI program's consideration of culture and religion in the goals that were selected for their children, six (5.4%) participants felt that IBI did not consider their culture or religion in these goals. Finally, seven families disagreed with whether IBI considered culture an important part of the IBI programming and only two families (1.8%) agreed that it was.

Measures of importance. Throughout the questionnaire, parents were asked to identify how important the particular area was to them. For example, if the question was "I had control over the teaching procedures that were implemented with my child," there was a follow-up importance question that stated, "Please rate the importance of this item to you." In general, parents reported all items in the questionnaire to be "somewhat important" or "very important", with few responses indicating not important (see Table 15). The high rankings suggest that the items listed throughout the questionnaire were very relevant for families. Responses were categorized according to area of the operational framework, and were ranked from the greatest to the least number of respondents who indicated "very important," and each of these is discussed below.

Table 14

IBI and Culture, Language and Religion

Item	Agree (Strongly or Somewhat)		Disagree (Strongly or Somewhat)		Not Applicable		Neither Agree Nor Disagree		Missing Data/No Response	
	%	N	%	N	%	N	%	N	%	N
Speaking a different language has made the IBI program more difficult	0.9	1	6.3	7	21.8	24	4.5	5	66.3	73
My cultural background was different from the staff in the IBI program	8.1	9	5.4	6	3.6	4	7.2	8	75.4	83
My cultural background was understood by the staff in the IBI program	10.9	12	1.8	2	2.7	3	8.1	9	76.3	84
My cultural background was considered an important part of IBI programming	1.8	2	6.3	7	2.7	3	9	10	78.1	86
My cultural background was considered in the IBI goals	2.7	3	5.4	6	2.7	3	8.1	9	80.9	89
My religion was considered in the IBI goals	3.6	4	5.4	6	2.7	3	9	10	79	87
My cultural background was considered in the materials	1.8	2	4.5	5	2.7	3	9	10	81.8	90
My religion was considered in the materials	3.6	4	5.4	6	2.7	3	8.1	9	80	88

Table 15

Parent Ratings of Importance Across Categories

Category	Total Responses[1]	Very Important		Somewhat Important		Unimportant		Missing Data/ No Response	
Satisfaction-Related Questions	N	%	N	%	N	%	N	%	N
IBI meeting expectations	108	73	80	16	18	0.9	1	1.8	2
Decrease in severity of autism	107	71.8	79	10.9	12	2.7	3	2.7	3
Satisfaction with IBI increased over time	99	37.2	41	18.2	20	12.7	14	10	11
Features of IBI Service									
Number of IBI months	84	66.3	73	4.5	5	0.9	1	23.6	26
Number of treatment hours per week	84	63.6	70	8.1	9	0.9	1	23.6	26
Number of treatment hours per day	85	60	66	10.9	12	0.9	1	22.7	25
Staff understood IBI impact on family	96	59.1	65	20	22	1.8	2	12.7	14
Number of therapists	85	46.3	51	23.6	26	0.9	1	22.7	25
Number of ST meetings	85	45.5	50	20.9	23	0.9	1	22.7	25
Number of IBI program meetings	85	37.3	41	30	33	0.9	1	22.7	25
Child Outcomes									
Child's problem behaviour	86	65.5	72	7.3	8	1.8	2	21.8	24
Child's ability to speak	88	62.7	69	7.3	8	3.6	4	20	22
Child's ability to understand other people	90	62.7	69	11.8	13	1.8	2	18.2	20
Child is still using the skills from IBI	95	61.8	68	18.1	20	1.8	2	13.6	15
Child's ability to interact with other children	89	60.9	67	14.5	16	0.9	1	17.3	19
Child's ability to interact with family	88	60.9	67	13.6	15	1.8	2	20	22
Child's ability to participate in group settings	85	57.3	63	16.4	18	0.9	1	22.7	25
Child's ability to make friends	81	53.6	59	11.8	13	0.9	1	26.4	29
Child's ability to interact with adults	90	50.9	56	17.3	19	1.8	2	1.8	2
Child's ability to independently use the toilet	69	47.3	52	10.9	12	0.9	1	2.7	3
Child's ability to interact with siblings	66	45.5	50	15.4	17	1.8	2	18.2	20
Child's ability to be diaper-free in the daytime	49	42.7	47	6.3	7	0.9	1	36.4	41
Child's ability to clean self	69	40	44	20	22	0.9	1	30.9	34

Table 15 cont’d

Parent Ratings of Importance Across Categories

Category	Total Responses	Very Important		Somewhat Important		Unimportant		Missing Data/ No Response	
Child Outcomes cont’d	N	%	N	%	N	%	N	%	N
Child's ability to dress self	70	39.1	43	21.8	24	0.9	1	27.3	30
Child's ability to participate in extracurricular activities	74	36.4	40	17.3	19	0.9	1	32.7	36
Child's ability to feed self	68	34.5	38	13.6	15	1.8	2	38.2	42
Child's ability to sleep through the night	60	32.7	36	9.1	10	1.8	2	1.8	50
Child's willingness to eat a variety of foods	73	28.2	31	15.4	17	3.6	4	33.6	37
Child's ability to use a communication system	54	21.8	24	13.6	15	2.7	3	1.8	66
Child participating in religious activities	47	20	22	9.1	10	2.7	3	57.3	63
Family Effects									
IBI had a negative effect on my family's finances	73	40	44	16.4	18	3.6	4	33.6	37
IBI increased stress level of my family as a whole	70	33.6	37	14.5	16	3.6	4	36.4	30
IBI increased my stress level	73	32.7	36	19.1	21	2.7	3	33.6	37
IBI improving parent relationship with other child	69	27.3	30	10.9	12	5.5	6	37.3	41
IBI improved relationship with spouse	74	26.4	29	13.6	15	2.7	3	32.7	36
IBI improved relationship with the community	71	13.6	15	20	22	2.7	3	35.5	39
Effects on sibling's extracurricular	65	20	22	16.4	18	2.7	3	40.9	45
IBI negatively affected religious practices	60	8.2	9	7.3	8	10.9	12	45.5	50
Philosophy, Control and Choice									
Learning IBI strategies	82	60.9	67	8.2	9	0.9	1	25.5	28
Methods in IBI acceptable	100	59.1	65	20	22	0.9	1	11	10
Goals in IBI acceptable	100	59.1	65	21.8	24	0.9	1	11	10
Choices in IBI services	100	57.3	63	18.2	20	0.9	1	9.1	10
Control over IBI goals	105	55.5	61	30	33	0.9	1	4.5	5
Level of parent involvement	95	53.6	59	21.8	24	0.9	1	13.6	15
Learning to implement IBI	106	52.7	58	18.2	20	0.9	1	3.6	4
Choices in IBI goals	104	51.8	57	35.4	39	0.9	1	5.5	6
Learning about autism	90	49.1	54	10.9	12	0.9	1	27.3	30
Control of IBI teaching procedures	108	48	53	30.9	34	0.9	1	1.8	2

Table 15 cont'd

Parent Ratings of Importance Across Categories

Category	Total Responses	Very Important		Somewhat Important		Unimportant		Missing Data/ No Response	
Cultural Considerations	N	%	N	%	N	%	N	%	N
Language different from IBI staff	11	3.6	4	0.9	1	1.8	2	90	99
Culture background understood by staff	16	0.9	1	1.8	2	4.5	5	85.5	94
Cultural background considered in IBI programming	14	0.9	1	1.8	2	4.5	5	87.3	96
Cultural background was considered in the IBI goals	15	0.9	1	0.9	1	6.4	7	86.4	95
Cultural background was considered in the IBI materials	14	0.9	1	0.9	1	5.5	6	87.3	96
Religious practices were considered in the goals	15	0	0	2.7	3	5.5	6	86.4	95
Religious practices were considered in the IBI materials for my child	14	0	0	0.9	1	5.5	6	87.3	96

[1] The categories "neutral" and "not very important" have been removed to fit the page

Satisfaction-related questions. Parents were asked questions related to satisfaction with elements of the IBI program throughout the FPIQ, and in three areas they were asked to identify how important these were to them. A number of parents identified that “IBI meeting their expectations” and “autism severity decreasing” was “very important” (73% and 71.8% respectively). Just over one third (37%) of parents listed IBI satisfaction increasing over time as “very important,” however, all three questions on satisfaction had a high number of responses ($n > 99$) and proportionately most responses were in the ranking of important (“very” or “somewhat”).

Features of the IBI service. In the area of IBI features, the highest ratings of importance were given to the number of months of service, the number of treatment hours per week and the number of treatment hours per day with 66.3%, 63.6%, and 60% of parents listing these as “very important” respectively. These areas were followed in importance by: ratings of staff understanding of the impact that IBI had on the family (59.1%), the number of therapists that were important (60.9%) followed by “acceptability of IBI methods” and goals (59.1%), “choices in IBI service” (57.3%), “control over goals” (55.5%), “parent involvement” (53.6%), “learning to implement IBI” (52.7%), “choices in IBI goals” (51.8%), “learning about autism” (49.1%), and “control of teaching procedures” (48%). In this category, parents rated everything as “very important” or “important,” with the exception of “control over teaching procedures” (3.6% of respondents rated “not very important”).

Cultural considerations. Finally, cultural considerations had the lowest number of responses given that this was a subsample of the population (range of 11 - 16 responses). Of these responses, more items were considered “unimportant” across all ratings, with the exception of “language different from IBI staff.” In terms of cultural background and importance within IBI, only 1.8% of respondents indicated that these were “somewhat” or “very important.” In the area of “religious practices in goals, ” and “religious practices in materials” no participants rated these as “very important,” 2.7% of participants rated them “somewhat important,” and almost 5% of participant responses were rated as being “not very important” or “unimportant.” This small sample of parents suggests that most feel that language differences are important to IBI, culture may be, and religion is not as important. However, there were still a number of parents who rated these items as important and these should be considered when planning IBI programs.

Measures of Processes of Care (MPOC) results. The parents were asked to respond to the MPOC instrument as a measure of the Ontario’s IBI program’s ability to provide family-centered care and also to establish concurrent validity of the FPIQ. In total, 71.29% of participants responded to the questions on the MPOC as can be seen in Table 16. Possible responses range from 0 (not at all) to 6 (to a very great extent) on the MPOC. Means and modes of the participants’ responses were calculated and are presented in Table 16. Overall, means were higher (indicating greater satisfaction) in the questions asking about the “people” (i.e., professionals) in IBI (3.8 - 4.5), and lower in response to questions about the “organization” (i.e., the centre that is responsible for providing IBI) (2.8 - 3.2). Most parents responded 4 or higher in terms of communication (i.e., being told the results of assessments”) (M = 4.5), and support (i.e. “felt cared for” and “not rushed” by professionals, “made to feel competent”) (M = 4.4, 4.4, and 4.3 respectively). The parents also rated teamwork, getting written info, and being treated as an equal in the 4 - 5 range. The parents overall were less satisfied with the way in which treatment choices were explained to them (M = 3.9), or

Table 16

Measure of Processes of Care Survey Instrument (n = 77)

Item	Measure		
The people:	M	SD	Mode
Help you feel competent as a parent	4.3	1.6	6
Provide you with written info about what your child is doing in therapy	4.2	1.6	6
Provide a caring atmosphere rather than just give you written information	4.4	1.6	6
Let you choose when to receive information and what type of information you want	3.7	2	6
Look at the needs of your "whole child"	4.3	1.8	6
Make sure one team member worked with your family a long time	4.3	1.7	6
Fully explain treatment choices to you	3.9	1.9	6
Provide opportunities for you to make decisions about treatment	3.8	1.8	6
Provide enough time to talk so you don't feel rushed	4.4	1.7	6
Plan together so they are all working in the same direction	4.3	1.7	6
Treat you as an equal rather than just as the parent of a client	4.2	1.9	6
Give you information about your child that is consistent from person to person	4.2	1.8	5
Treat you as an individual rather than the typical parent of a child with a disability	4.3	1.8	6
Provide you with written information about your child's progress	4.2	1.8	6
Tell you about the results from assessments	4.5	1.6	6
The organization			
Gives you information about the types of services available in the organization or community	3.2	1.8	2
Has information available about your child's disability	3.2	1.8	2
Provides opportunities for the entire family to obtain information	3	1.9	3
Has information available to you in various forms	2.8	1.9	2
Provides advice on how to get other information or how to contact other parents (for support)	3	2	0

involved them (M = 3.8), and whether they had choices in the information they could receive (M = 3.7).

When the parents responded to the questions about "the organization," all ratings fell below an average score (i.e., 3.5), suggesting dissatisfaction. Parents rated "information being available in various forms" the lowest (M = 2.8), followed by "advice on how to contact other parents or get more information for them or their whole family" (M = 3), and "providing information about the disability or available services in the community" (M = 3.2) the highest, but still below an average rating. Overall, the parents were not satisfied with the organization through which they received services, and moderately satisfied with the professionals' ability to include them as a part of the IBI team and in making treatment decisions. Significant correlations were found between all the means of the independent variables in the FPIQ and some or all of the mean ratings on the MPOC (Table 17) Therefore, concurrent validity of the FPIQ with the MPOC is evident. However, IBI's inclusion of other service goals had only significant negative correlations with MPOC 7 (i.e., "To what extent do the people who work with your child full explain treatment choices to you?") and MPOC 16 ("To what extent does the organization give you information about the services offered at the organization or in your community?").

Inferential Statistics. Factor analyses, using principle components analysis were first conducted prior to the regression analysis.

Factor analysis. The operational framework developed for this research was based on that described in the literature review in Chapter Two. In this framework, five categories of independent measures (i.e., child outcomes, cultural considerations, philosophy

Table 17

Concurrent Validity of Independent Variables and MPOC Scores

MPOC Question	Overall Satisfaction
MPOC 1	0.296**
MPOC 2	0.538**
MPOC 3	0.561**
MPOC 4	0.532**
MPOC 5	0.627**
MPOC 6	0.373**
MPOC 7	0.562**
MPOC 8	0.607**
MPOC 9	0.557**
MPOC 10	0.574**
MPOC 11	0.625**
MPOC 12	0.595**
MPOC 13	0.650**
MPOC 14	0.604**
MPOC 15	0.555**
MPOC 16	0.512**
MPOC 17	0.438**
MPOC 18	0.515**
MPOC 19	0.356**
MPOC 20	0.393**

$^{*}p < .05$ $^{**}p < .01$ $^{***}p < .001$

and knowledge, features of IBI, and family effects) were created, each containing subcategories that aligned with questions from the survey questionnaire (e.g., self help skills, social interactions, etc.).

A principal component analysis (PCA) of all 62 variables with orthogonal rotation (varimax) was conducted in SPSS to first assess whether all the variables combined together represented a good model (see Table 18). The Kaiser-Meyer-Olkin measure (KMO) verified the sampling adequacy of the analysis (Field, 2009) and the Bartlett test of sphericity was used to check the likelihood of an identity matrix. The KMO resulted in a score of 0.715, which was above the acceptable limit of 0.5 (Field, 2009), but the Bartlett's test of sphericity indicated that the differences between the variables were not sufficiently large enough for a PCA ($\chi^2 = -67.759$, $p = 1.00$). Given that the combined model was not a suitable fit, and the number of variables was so large, a PCA was conducted within each category, to identify whether all the variables under each subcategory should remain, and then whether each independent variable should remain or be removed. This analysis allowed for the categories of variables to be examined independent of one another.

The first category examined was the "Features of IBI". The KMO for this group was 0.64, which was above the acceptable limit of 0.5 (Field, 2009), and Bartlett's test of sphericity indicated that the differences between the variables were sufficiently large for a PCA ($\chi^2 = 480$, $p < 0.001$). Items with loadings less than 0.80 were excluded from the analysis, yielding a five-factor solution (see Table 18). The category of "Child Outcomes" was explored and analysis of individual question responses resulted in an output indicating

Table 18

Factor Analysis Results - Family Effects

Factor Loading Category	Eigenvalue				
Family Effects	1	2	3	4	5
Relationship with other children	**0.832**	0.096	-0.168	-0.162	–
Relationship with spouse	0.103	**0.873**	-0.014	-0.06	–
Increased stress on the family	0.036	0.006	-0.067	**0.925**	–
Negatively impacted siblings' extracurricular activities	**0.913**	0.048	-0.125	0.085	–
Features of IBI					
Number of treatment hours/week	0.094	**0.915**	-0.141	-0.013	0.082
Number of treatment hours/day	0.101	**0.847**	-0.309	0.107	0.034
Number of therapists	0.002	-0.015	0.196	0.15	**0.814**
Number of ST meetings	0.004	0.155	0.11	**0.859**	0.113
Number of program meetings	0.051	0.062	-0.144	**0.866**	-0.012
Control over the goals	**0.832**	0.073	0.154	0.041	0.081
Choices in the goals	**0.875**	-0.003	0.013	0.045	0.184
Child Outcomes					
Child is still using the skills	0.037	**0.848**	0.079	-0.108	–
Child's ability to speak	0.202	**0.803**	0.175	0	–
Child's ability to use a communication system	**0.813**	0.196	0.032	-0.183	–
Child's ability to dress self	**0.843**	0.194	0.147	0.068	–
Child's ability to clean self	**0.809**	0.307	0.112	-0.149	–
Child's ability to be diaper free	-0.191	0.15	0.015	**0.858**	–
Child's ability to participate in a group	**0.825**	0.279	0.134	-0.157	–
Cultural Considerations			–	–	–
Language different from staff	**0.82**	–	–	–	–
Cultural background different from staff	**0.908**	–	–	–	–
Culture understood by staff	**0.855**	–	–	–	–
Culture was included in the programming	**0.902**	–	–	–	–
Religion was considered in the materials	**0.913**	–	–	–	–
Culture was considered in the goals	**0.867**	–	–	–	–
Philosophy and Knowledge					
Knowledge of autism	0.154	**0.906**	–	–	–
Knowledge of IBI strategies	0.233	**0.873**	–	–	–
Methods acceptable	**0.809**	0.185	–	–	–
Family Effects					
Relationship with other children	**0.832**	0.096	-0.168	-0.162	–
Relationship with spouse	0.103	**0.873**	-0.014	-0.06	–
Increased stress on the family	0.036	0.006	-0.067	**0.925**	–
Negatively impacted siblings' extracurricular activities	**0.913**	0.048	-0.125	0.085	–

that the matrix contained negative eigenvalues. This result could be due to linear dependency or too much missing data. Therefore, the PCA was rerun with the mean scores of each variable (see Table 19), and resulted in a KMO of 0.876, and a Bartlett score of 0.020, $p < .001$). Loadings less than 0.80 were excluded from the analysis, yielding a four-factor solution. The category of “Cultural Considerations,” with an acceptable KMO (0.927) and a Bartlett score ($p < .001$), resulted in only one factor being represented with six variables. Acceptable KMO (0.689) and Bartlett ($p < .001$) results were also found with the “Philosophy and Knowledge” category, where two factors were determined across three variables. Finally, “Family Effects,” with a KMO of .526, and a Bartlett score where $p < .001$ yielded three factors across four variables (i.e., Eigenvalues > 0.8). This analysis yielded a model with 27 variables remaining across five factors.

The remaining 27 variables from each of the categories were recombined and a PCA was rerun. These variables yielded a KMO of 0.763 and Bartlett ($\chi^2 = 359.109$, $p < 0.001$) suggesting that the model was a good fit for factor analysis. From this group, seven factors were extracted. For each of the factors, there were two, three or four variables that could be combined. However, the alignment of these factors did not always seem to make sense. For example, although an attempt was made to combine the variables, some factors combined items that were not logically grouped together. For example, “child’s ability to use a communication system” would be combined with “relationship with spouse” and “child’s ability to dress self.” Therefore, this combined PCA was discarded and the factor analysis within the categories (Table 18) was used for analysis.

Multiple regression. A multiple regression analysis was conducted to examine the relationship between the parent satisfaction of IBI and the 27 independent variables that may

Table 19

Combined Principal Component Analysis with Identified Variables

Factor Loaded Variable	Eigenvalue						
Item	1	2	3	4	5	6	7
Knowledge of IBI strategies	0.23	0.08	**0.747**	-0.145	-0.072	-0.004	0.073
Knowledge of autism	0.396	0.159	**0.666**	-0.214	-0.17	0.019	-0.052
Methods acceptable	0.072	0.064	**0.59**	0.206	-0.056	0.335	-0.062
Language different from staff	0.016	**0.864**	0.112	0.155	0.005	0.104	0.046
Cultural background different from staff	0.042	**0.902**	0.111	-0.058	0.068	0.164	-0.044
Culture understood by staff	0.141	**0.814**	0.182	-0.234	0.168	0.046	-0.08
Religion was considered in the materials	0.088	**0.863**	0.136	-0.043	0.176	0.159	-0.073
Child is still using the skills	0.171	0.116	**0.738**	0.082	0.169	0.284	-0.069
Child's ability to speak	0.271	0.215	**0.705**	-0.089	0.062	0.121	0.105
Child's ability to use a communication system	**0.818**	0.005	0.183	-0.13	-0.173	-0.013	0.056
Child's ability to dress self	**0.795**	0.154	0.273	-0.168	-0.137	-0.138	-0.018
Child's ability to clean self	**0.852**	0.053	0.244	0.021	-0.116	0.057	0.044
Child's ability to be diaper free	-0.482	0.192	**0.502**	-0.014	-0.285	-0.324	-0.111
Child's ability to participate in a group							
Number of treatment hours/week	-0.028	-0.053	0.014	**0.93**	-0.002	0.085	0.021
Number of treatment hours/day	-0.218	-0.05	-0.116	**0.897**	0.168	0.081	0.003
Number of therapists	-0.356	0.114	-0.026	-0.074	0.277	**0.359**	0.415
Number of ST meetings	-0.216	0.177	0.012	0.055		-0.001	0.024
Number of program meetings	-0.243	0.182	-0.056	0.109	**0.812**	-0.053	-0.107
Control over the goals	0.002	0.242	0.302	0.047	0.153	**0.751**	-0.093
Choices in the goals	0.275	0.13	0.25	0.013	-0.029	**0.772**	-0.139
Increased stress on the family	0	-0.149	0.133	-0.073	**-0.158**	-0.042	0.785
Relationship with other children	-0.082	0.069	-0.007	0.075	**-0.096**	0.311	0.097
Relationship with spouse	**-0.189**	-0.005	0.117	-0.115	-0.046	0.016	**-0.793**

function as predictors. Initially, all data were checked for multicollinearity where variables are too highly correlated making it difficult to determine the contribution of an individual variable (Field, 2000). In “Child Outcomes”, the variables that were deleted due to multicollinearity (VIF > 0.3) were “dressing self”, and “group setting participation”. In “Features of IBI”, the variable “hours per day” had to be removed due to multicollinearity. In the “Philosophy and Knowledge,” as well as “Family Effects” categories, no multicollinearity was found in the data. Finally, in the “Cultural Considerations” category, multi-collinearity was indicated (VIF > 0.3) when the following variables were included: religious materials, culture in the programming, cultural background different from staff. These variables were then removed prior to conducting the multiple regression analysis. This analysis left 20 variables to enter into the regression analysis.

Initially the factors (i.e., Philosophy and Knowledge, Cultural Considerations, Child Outcomes, Features of IBI Service, and Family Effects) were entered into the regression as means of a number of variables. Essentially, each variable that was found under each factor was reduced to a mean score, which was then recombined to create an overall mean score of the factor. This cluster mean (i.e., cluster of variables) was then compared to means in each of the independent variables for satisfaction, as well as a mean of the clustered variables (i.e., satisfaction measures combined). This method allowed for an examination of predictor variables for each satisfaction variable and the combination would allow for an overall measure of satisfaction to be examined in relation to the variable cluster from each factor. The results indicated which factors would effectively predict variability in the satisfaction measures. The ANOVA results are presented in Table 20.

Table 20

Multiple Regression Overall: Anova Results

Categories	Program Expectations		Severity of Autism Decreased		IBI Satisfaction Increased		Satisfaction with IBI's Inclusion of Other Services		Overall Satisfaction		Satisfaction Measures Combined	
	F	Sig.	*F*	Sig.	*F*	Sig.	*F*	Sig.	*F*	Sig.	*F*	Sig.
Philosophy and Knowledge	8.23	.003**	8.04	.000***	22.33	.000***	5.27	.003**	1.45	.23	2.86	.040**
Cultural Considerations	11.49	.003**	5.46	.006**	12.54	.000***	1.33	.27	.77	.46	7.59	.001***
Child Outcomes	7.59	.001***	2.19	.082	3.82	.010	2.25	.10	.60	.72	.60	.72
Features of IBI Service	.60	.724	1.78	.115	.24	.95	0.53	.78	.41	.86	3.79	.002**
Family Effects	2.21	.099	.15	.958	2.21	.09	2.21	.09	2.21	.09	1.23	.30

$^{*}p < .05$ $^{**}p < .01$ $^{***}p < .001$

An initial examination of the ANOVA suggests that the factors Philosophy and Knowledge, Cultural Considerations, and Features of IBI had significant predictive value for the combined satisfaction measures (F-ratio of 2.86, $p < .01$, F-ratio of 7.59, $p < .001$, and F-ratio of 3.79, $p < .01$ respectively), indicating that high ratings in each of these categories predicted higher satisfaction ratings overall. In terms of the individual satisfaction measures, statistical significance was found between ratings on the Philosophy and Knowledge factor and all satisfaction categories with the exception of "overall satisfaction." Therefore, parents who were more satisfied with their philosophical agreement or knowledge learned from the IBI program would be more likely to rate higher satisfaction with program expectations being met, the changes in their child's autism severity, increased satisfaction throughout the program, and the way in which the IBI program included the goals of their other services. Satisfaction ratings of Cultural Considerations and Child Outcomes were also found to be significant with respect to satisfaction with program expectations ($p < .01$ and $p < .001$ respectively). Therefore, those parents who were satisfied with the cultural considerations of the IBI program would be more likely to report that IBI met their expectations. Regressions were then run at the individual independent variable level, to see whether particular questions were predictive of some or all of satisfaction ratings. The results are presented in Table 21 below.

The results of the analysis suggest that there are a number of factors that affect satisfaction within the Ontario IBI program. In terms of "program expectations," whether methods were rated as acceptable and whether their child was still using the skills they learned in IBI were significantly and positively correlated at the $p < .001$ level. Whether the family's culture was understood by the staff was also positively correlated with program

Table 21

Multiple Regression Results

Factors	Program Expectations			Severity of Autism Decreased			IBI Satisfaction Increased			Satisfaction with IBI's Inclusion of Other Services			Overall Satisfaction			Satisfaction Measures Combined		
Philosophy and Knowledge	*B*	SE	β	*B*	SE	β	*B*	SE	β	*B*	SE	β	*B*	SE	β	*B*	SE	β
Constant	0.00	0.88		1.06	0.80		-0.65	0.62		0.25	1.51		1.11	0.27		4.13	0.78	
Knowledge of IBI strategies	0.05	0.21	0.03	0.07	0.23	0.04	0.68	0.21	0.42	1.01	0.38	0.36***	-0.07	0.07	-0.13	-0.34	0.25	-0.19
Knowledge of autism	0.21	0.25	0.40	0.05	0.21	0.03	-0.13	0.21	-0.08	-0.59	0.36	-0.22	0.13	0.07	0.24**	-0.18	0.26	-0.09
Methods acceptable	0.52	0.13	0.43***	0.53	0.12	0.5***	0.56	0.11	0.46***	0.54	0.19	0.33*	-0.04	0.04	-0.13	0.28	0.13	0.21*
Cultural Considerations																		
Constant	2.31	0.42		2.57	0.38		1.92	0.39		3.33	0.62		1.23	0.11		2.17	0.30	
Language different from staff	0.11	0.11	0.14	0.14	0.10	0.19	0.23	0.1	0.31*	0.01	0.15	0.02	-0.04	0.03	-0.18	0.12	0.08	0.21
Culture understood by staff	0.19	0.10	0.27**	0.12	0.09	0.2	0.17	0.08	0.24**	0.17	0.14	0.19	0.02	0.03	0.13	0.12	0.06	0.24* *
Child Outcomes																		
Constant	0.44	0.96		2.53	1.51		-0.51	1.87		-1.26	3.33		2.503	0.76		7.15	2.79	
Child is still using the skills	0.83	0.17	0.79***	0.58	0.24	0.60*	0.86	0.36	0.718*	0.99	0.55	0.65	0.14	0.12	0.46	0.31	0.45	0.20
Child's ability to speak	0.11	0.23	0.07	0.00	0.36	0.01	0.13	0.43	0.071	0.36	0.6	0.17	0.04	0.14	0.08	-0.27	0.66	-0.12
Child's ability to use a communication system	-0.64	0.25		-0.29	0.39	-0.23	-0.92	0.55	-0.411	-0.85	0.85	-0.35	-0.1	0.19	-0.18	-0.03	0.73	-0.01
Child's ability to clean self*	0.42	0.26	0.22	-0.54	0.36	-0.44	-0.39	0.55	-0.177	-0.83	0.82	-0.29	-0.28	0.19	-0.44	-0.58	0.67	-0.30
Child's ability to be diaper free	-0.23	0.25	-0.11	-0.14	0.25	-0.11	0.41	0.26	0.243	0.39	0.77	0.13	-0.07	0.09	-0.18	-0.39	0.45	-0.19
Child's ability to participate in a group	0.38	0.24	0.21	0.58	0.45	0.47	0.91	0.48	0.42**	1.13	0.72	0.45	-0.15	0.17	-0.24	-0.21	0.84	-0.11

Table 21 cont’d

Multiple Regression Results Across Factors

Factors	Program Expectations			Severity of Autism Decreased			IBI Satisfaction Increased			Satisfaction with IBI's Inclusion of Other Services			Overall Satisfaction			Satisfaction Measures Combined		
Features of IBI	*B*	SE	β	*B*	SE	β	*B*	SE	β	*B*	SE	β	*B*	SE	β	*B*	SE	β
Constant	4.34	1.47		3.60	1.27		3.47	1.48		7.32	2.21		1.39	0.39		3.29	1.44	
Number of treatment hours/week	0.62	0.42	0.34	0.03	0.35	0.02	0.05	0.41	0.03	0.38	0.57	0.17	-0.10	0.11	-0.21	-0.62	0.39	-0.31
Number of therapists	-0.44	0.41	-0.24	0.07	0.34	0.05	-0.14	0.40	-0.08	-0.46	0.58	-0.19	0.13	0.11	0.26	0.73	0.38	0.36^{**}
Number of ST meetings	-0.38	0.36	-0.14	-0.61	0.29	-0.25^{**}	0.17	0.35	0.06	0.01	0.46	0.01	0.04	0.09	0.05	-0.39	0.34	-0.13
Number of program meetings	-0.21	0.34	-0.08	-0.24	0.29	-0.09	-0.27	0.34	-0.09	-0.69	0.50	-0.19	-0.06	0.09	-0.08	-0.84	0.33	-0.27^{*}
Control over the goals	0.64	0.47	0.21	1.09	0.40	0.39^{***}	0.25	0.47	0.08	-0.08	0.71	-0.02	-0.06	0.13	-0.07	1.24	0.46	0.37^{*}
Choices in the goals	-0.53	0.40	-0.20	-0.38	0.34	-0.16	0.04	0.4	0.02	-0.23	0.59	-0.06	-0.01	0.11	-0.01	-0.15	0.39	-0.05
Family Effects																		
Constant	6.78	1.58		3.47	1.45		7.83	1.55		13.17	1.67		1.15	0.46		5.49	1.23	
Increased stress on the family	0.15	0.17	0.13	0.05	0.16	0.05	-0.05	0.16	-0.04	-0.40	0.17	-0.29^{*}	0.03	0.05	0.08	-0.02	0.13	-0.03
Relationship with other children	0.01	0.02	0.12	0.00	0.01	0.03	0.01	0.02	0.08	-0.01	0.02	-0.02	-0.01	0.04	-0.06	0.06	0.01	0.06
Relationship with spouse	-0.89	0.37	-0.34^{*}	0.02	0.35	0.01	-0.91	0.37	-0.34^{*}	-1.67	0.39	-0.52^{*}	-0.01	0.11	-0.02	-0.48	0.29	-0.24

$^{*} p < .05$ $^{**} p < .01$ $^{***} p < .001$

expectations at the $p < .01$ level, suggesting that if parents feel that their culture is understood, then they also rate that the program met their expectations. Finally, parent ratings of whether IBI improved the spousal relationship, was significantly and negatively correlated ($p < .05$) with program expectations. That is, when parents rated that their relationship was improved by IBI, then they rated expectations as not being met, and if they rated that their relationship was not improved by IBI, then they rated IBI expectations as being met. This result will be discussed further in the next chapter.

Parents responded to whether their child's autism had reduced in terms of severity as a result of IBI. Whether the methods were acceptable and the child was still using the skills was positively and significantly related to ratings of autism severity decrease ($p < .001$ and $p < .05$ respectively). Having control over the goals was positively correlated with severity decrease at the $p < .001$ level, suggesting that parents who rated having sufficient control also rated positive changes in autism severity. A negative correlation was found between the number of ST meetings and ratings of autism severity improvement. This finding indicates that the more satisfied the parents were with the number of meetings with the ST, the more likely they were to rate autism severity as improved (i.e., decreased severity).

Whether or not IBI satisfaction increased over time while participating in the IBI program was significantly predicted by a number of variables. The rating of acceptability that parents gave the IBI methods was a predictor of IBI satisfaction increasing over time ($p < .001$). In addition, if the child was still using the skills and whether the parents' language was different from the staff was a significant positive predictor ($p < .05$).

Another area of satisfaction concerned whether the parents felt satisfied with the way in which the IBI team included the goals of their other services. Four variables were significantly related to this dependent measure. First, parent satisfaction with their learning of IBI strategies was found to be positively and significantly correlated at the $p < .001$ level suggesting that parents who learned IBI strategies were more satisfied with the way in which the IBI team did or did not incorporate the goals of other services. The acceptability of IBI methods, as well as whether IBI increased stress on the family was positively and negatively correlated respectively, with the parents' satisfaction with the inclusion of other service goals ($p < .05$). Therefore, when the parent rated stress as higher for the family during IBI, they rated less satisfaction with IBI's inclusion of other service goals. Finally, another negative correlation at the $p < .05$ level was found between IBI's effect on the marital relationship and inclusion of other service goals. Thus, when the marital relationship was rated as negatively affected by IBI, then inclusion of other service goals was rated positively.

In terms of overall satisfaction predictors, ratings regarding appropriate number of program meetings were negatively correlated with overall satisfaction ($p < .05$). Therefore as meeting numbers went up, satisfaction went down. In addition, methods being rated as acceptable, and having control over the goals selected within IBI were also significant positive predictors of satisfaction at $p < .05$. Each of the independent measures of satisfaction also demonstrated a number of predictors, as was described. Therefore, quantitative analysis indicates a number of statistically significant relationships between variables in the operational framework and individual and combined measures of satisfaction.

As discussed in Chapter Three, there were a number of open-ended questions in the survey and a focus group was held following the survey data collection. Both of these sources provided additional detail related to the factors that affected satisfaction. These results are discussed below.

Qualitative Results

For various questions in the survey, there was an opportunity for parents to add additional comments. Comments could be made on items concerning “the delivery of the IBI program,” “any other areas of improvement and IBI, ” “the effects of IBI on your or your partner’s career,” “the effects of IBI on your family life,” “current educational support and the transition from IBI,” and finally “your satisfaction with the Ontario IBI program.” In addition, space was given at the end of the survey for parents to add any additional comments. These data were analyzed following the completion of the focus group, and the findings from both sets of qualitative data are described below.

Focus Group

Setting. The focus group was held in a private community room in the public library in a suburb of the Greater Toronto Area (GTA) that comfortably sat the participants, the researcher and the research assistant. Two microphones and data recorders were in the middle of the table and refreshments were available. The focus group took place on a weekday evening and lasted just over one and a half hours.

Participants. Kelly is a working mother in her 40s with one child, whose son with autism is 18 years old and who received IBI at various periods throughout his life, using both the DFO and DSO options. Kelly’s son received IBI when the provincial program began for almost a year when he was five years old. At six years of age, he was discharged from the program (given the earlier age limits of the program), and thus Kelly continued paying for her own IBI services until he was a teenager. As a teenager he was able to access IBI services through the government-funded (direct services) option again and received five years additional years of IBI. Kelly describes her son as having acquired communication skills but not until his teens, which she credits to IBI. Natalie is a college student in her twenties and has three children, the youngest of whom has autism, and is six years old. Natalie describes her son as having made great gains in DSO IBI and how he has good language skills and a lively personality. Natalie's son had been in the direct service model of IBI for two years. At the time of the focus group he had been out of the program for six months.

Debbie is a stay-at-home mother with two children and her youngest child is a five-year-old son with autism. She describes her son as having struggled to learn throughout IBI and who still has many challenges. Debbie's son began IBI services just before the age of three through the direct funding option, and at the time of the focus group, was being slowly discharged from these services. Debbie and her husband have decided to continue his IBI services for half-days paying for it themselves following his discharge.

The questions that were asked during the focus group are presented in Appendix F. The resulting data from the focus group were first sorted according to the questions that were asked and then were analyzed thematically using the tree diagram strategy described in Chapter three. Four overarching themes emerged from the data: *IBI-Related Stress*; *Child and Parent Outcomes Resulting from IBI*; *Parental Control of IBI program;* and *Service Delivery*. Table 22 outlines the general themes and subthemes that were identified.

Overview of Qualitative Results

With respect to the receipt of IBI services overall, both the mothers in the focus group and those responding to the open-ended questions on the survey largely agreed that the receipt of IBI services was of great benefit to their child. Focus group participants spoke highly of their children's outcomes, and expressed the desire to have had IBI continue, had that been possible, and how the amount of service was insufficient. The focus group participants spoke extensively

Table 22

Focus Group Emerging Themes and Subthemes

Theme	Subthemes
IBI -Related Stress	• Access to IBI services • Maintaining IBI services • Child-related stress • Support for child and family • Personal relationships
Child and Parent Outcomes	• Child gains across domains • Lack of generalization of skills • Lack of benefit for some children • Change in parenting style • Parents learned skills • Parents made personal changes • Advocacy
Parental Control of IBI	• Lack of control and choices in IBI • Dissatisfaction with service model • Scheduling control • Opposition to IBI teaching methods • Lack of communication • Support from IBI clinical team • Individualization of IBI program
Service Delivery	• Amount of service • Timing of service • Waitlist • Transition to school • IBI therapist training and managing • Relationships with clinical team

about the difficulties they encountered attaining or maintaining IBI services for their children, and survey respondents added the point that service limitations led to the need to purchase IBI privately, at great personal expense. Several parents who selected DFO described a greater feeling of control over their IBI program, however they also indicated a great deal of dissatisfaction around the structure of the system to finance the program. The distinction between the service or funding provider and the clinical IBI provider came up repeatedly as a necessary distinction in terms of satisfaction.

Additional information was provided on the issue of staffing IBI programs, as well as the difficulties in trying to communicate with schools. There was a recurring discussion in the focus group around the struggle these parents encountered in many areas of their lives, and how they overcame or did not overcome particular challenges, and how advocacy skills were developed by many of the parents during the program. Several parents made overt recommendations around the structure of the program and these are discussed in the discussion chapter. Following, is a discussion of four major themes that emerged from both the focus group and the comments provided by parents on the survey.

IBI-related stress. Feelings of stress were prevalent in the lives of the parents. It was evident that families who responded throughout the questionnaire as well as the focus group experienced a great number of hardships in trying to support their child with autism, and there was either a general lack of support available to them, or the supports were not effectively coordinated (as will be discussed later). Parents frequently mentioned the word “stress” in their responses to the open-ended questions (e.g., “stress of having to deal with a child that can’t communicate”).

Parents identified the stress related to one of four aspects: access to and receiving IBI services (i.e., assessment processes, financial impact) child-related stress (i.e., scheduling and preparation, and problem behaviour), support for the child and family (i.e., across services) and personal relationships.

Waiting for services and decisions around IBI services was a struggle for these families. They expressed how they were constantly fighting for services and questioning the process and the decisions that were made for their child by service providers.

> *The only time we felt stressed with IBI program was when it was time for our son's assessments and reports. There was so much pressure to score well to continue therapy and the reports were usually so negative that it was stressful to hear. Our team was not the source of our stress but [rather] the government body that provided our direct funding (Survey respondent).*

The process and decisions that were made around access to services were described as stressful, and supports to assist in this process were not evident. The parents expressed a lot of dissatisfaction with the process for accessing services. When service was to begin, the parents described how decisions were made between the direct funding option (DFO) and the direct service option (DSO) that were unrelated to the families' needs or preferences, and this caused a great deal of emotional stress. The process for allowing ongoing service or to terminate services was described as very difficult emotionally. This process of making service decisions was standardized, according to prescribed "Clinical Benchmarks" (Perry, 2010). These benchmarks are indicators used to measure whether the children are benefiting from IBI and should continue, have benefitted and are ready to move on (to school) or are not benefitting (i.e., not learning) and should be discharged from the program. Parents described these service delivery decisions as being too standardized and not meeting their needs at an individual level, causing them personal distress.

> *. . .to discontinue services only based on the idea that [my child now has] academic skills is wrong. Our child had some academic skills, however he did not have the ability to integrate into a mainstream classroom or . . . have self regulation skills at school. This impacted his ability to learn and function..and unfortunately [this] was overlooked. I was left back at square one, and had to look to other private therapies once he was discharged. This current program I feel would benefit kids that are higher functioning, but unfortunately these [higher functioning] kids are left to their own devices and slip through the cracks of the entire system. (Survey respondent)*

The termination of services following assessments left families without ongoing support. Debbie described how difficult it was to experience the clinical benchmark assessments. She described how an evaluator came to her house every six months to evaluate her son for 20-30 minutes. Given the amount of time that her child had been in service, she felt that this short period of time was not sufficient to evaluate his progress, and that the previous six months needed to be given more consideration. Debbie did not feel the assessment was representative of her son’s skills and he was discharged from the IBI program due to the lack of progress. She described how devastating this was for her, her feelings of powerlessness, and how this assessment left her crying for days.

> *For me (IBI) felt like my lifeline . . . my total support system. My lifeline. Then, with my son’s services ending, it is like somebody was saying ‘You need to cut off and go all own your own’. And I . . . I don’t know even know where to start. It's been three years, I can't even imagine doing this on my own. . . and you know he is only five. I've got a whole lifetime ahead of me. . . I am not ready for this. I was panicking. . . (Debbie)*

Following IBI termination, parents described feeling alone and isolated. Kelly describes how her son was learning steadily with intervention and yet he was discharged by the funding provider. She describes the emotions of this process and how she would cry, and how lost she felt at what to do, having only full-time school as the place for her son in the future. The feelings of these parents suggest that supports were not in place to make transition from IBI smoother and less difficult emotionally. Debbie indicates that she and another family opted to file an appeal about their discharge from IBI. She felt that this was a good option for parents, even though she and another family she knew had both been turned down. The fact that Debbie had attempted to appeal the decision is indicative of the continued fight that parents have made to access services for their children.

The stress that IBI created for the family was extensive and the topic of financial impact came up as one problem area. This financial impact was either due to the family's necessary changes in employment (e.g., quitting a job, reducing hours) or the need to purchase private services and make additional money to do so.

Job changes were often a direct result of the scheduling of the IBI program. Parents indicated that the structure of the service caused difficulties on their job due to the need to pick up or drop off their child up during work hours. This resulted in one parent either having to leave their job to accommodate the IBI hours, or one parent having to change their job to one that had more flexibility in the hours worked.

> *I had trouble with the rigid pickup and dropoff times for my child. There was NO leeway for any reason whatsoever. There are either no after school programs, or no public transportation available, to allow a second parent to maintain a job. I had to start my own business which I could work flexible hours and/or from home in order to accommodate my autistic kid's education. (Survey respondent)*

The schedule for IBI was described as "rigid" and "rigorous", and made it difficult for many families to work outside the home. One family described how they were lucky to have services in their home, as otherwise they would have had to drive 60 km to the nearest centre.

The location of IBI services also had an impact on parental employment. Several parents mentioned the requirement for them to stay living in a particular place in order to get services, and the impact this had on their work.

> *We have had to stay in the same location as we would have lost our spot on the waiting list. My husband has then had to commute over an hour each way to get to work and back as we were so tied to the location we were in. (Survey respondent)*

Only one of the three mothers in the focus group, Kelly, was employed and worked during the receipt of IBI services and she described a number of issues related to her employment. At one point she was given 30 days of therapy funding and she had to take a leave of absence from her job. She then described how she eventually lost her job.

> *Well I was knew it was coming because you know it's coming right? . . . All the years went by and I was still there... right? Then people talk 'Oh she gets special treatment' . . . and I would (want to) say to people. . . 'I (haven't) slept for like a week . . .and (my colleagues) don't need to know what happens to me in the home with my kid. . .We were afraid to get phone (calls) from school. . . Eventually I ended up losing my job and I believe it was because of it. . . They get fed up. . . they needed somebody there from nine to five and I was . . on the phone looking for services for [my] kid. (Kelly)*

Even managing the IBI program for families had direct impact on their employment, as one parent had to leave or reduce their work hours to manage the demands on the schedule.

> *Because we were forced to go to a centre for our son that took us a 30-45 minute drive to get to I couldn't keep working my job. My husband then had to pickup an extra part time job and is now working the two jobs just so we can continue on. . . We still do this because our daughter is in service now. (Survey respondent)*

There was also the predicament that families faced in terms of planning for the end of IBI services. One family described how this impacted their employment because they would need to earn more money to support purchase of services in the future.

> *My partner has to work in [the] mid-night shift in order to arrange paid IBI after his therapy is over. She is diabetic and we have [a] small 4 year daughter. If we would receive part time Ontario funded IBI, she [my partner] will spend quality time with family by changing her job to day time and she is less stress[ed] (Survey respondent)*

There were a few families who described how the IBI program was structured in a way to reduce the effects on their career. For example, one family described how their IBI was provided in a day care setting and therefore did not interrupt their workday. Other families described being lucky because they had very flexible employers or their own business (although it was negatively impacted), or they had a clinical IBI team that worked hard to help the families with their schedule.

Parents commented the most about the financial impact of IBI throughout the survey's open-ended questions. Many parents mentioned paying for or not being able to pay for private services. This need to pay for services was due to waitlists, insufficient funding, or discharge from the program. The cost and the emotional toll on the family were extensive, and bankruptcy and poverty were descriptors of the impact.

> *We avoided bankruptcy by going to a credit counselor and having them take over negotiations with creditors. We are 4 years into a 5-year payback program and are now living below the poverty line. It has left us financially devastated. No family should be put in debt like this, the program required so much money in order to meet the requirements to continue receiving funding... it's just wrong!!!! The financial stress has had a huge impact on the health of all of us; heart attack, depression, anxiety, etc, etc. (Survey respondent)*

The amount of money that was spent by families before, during, and following IBI, was also described. Two parents indicated that they had spent over $100,000 for services, which depleted of retirements account and savings. Another parent needed to purchase a car simply to get to the agency where services were being delivered, and several other parents identified transportation costs as a big problem.

> *Because we were waitlisted for IBI we went to a private school for 2 years. It costed [sic] us over 100K which we had to mortgage our house for. Something is not right here......(Survey respondent).*

Even when parents obtained funding, choosing the DFO option meant still having to pay money out-of-pocket. Several parents described how the DFO option was open only to parents who could afford it, since the funding was not sufficient to cover the amount needed. This impasse forced parents to choose the DSO option.

The impact of IBI also extended to the marital and social relationships of these participants. Relationships with spouses, family and friends were often described negatively, and several parents described the dissolution of their marriage.

> *While my son was in IBI, his father and I, who were separated because of the stress of our family life, continued to be separated because our parenting techniques changed and [we] were no longer on the same page. I learned everything that I could and applied as much as I could to improve my son's chances of success while his father did not appreciate being "told what to do." He did not approve of the changes that were required in his parenting and did not make those necessary adjustments. Because my children are the most important thing in my life, my relationship with their father is, I feel, beyond repair. (Survey respondent).*

The central focus for the women in the focus group was their child with autism, and their other children, and this had a direct negative effect on their marital relationships. Despite this, the relationships with their other children were described as improved, either due to changes in parenting practices or improvements in the child with autism, allowing the parent to devote more time to the other children.

There were impacts on relationships outside the family home as well. Debbie described how she learned who her friends were after her son was diagnosed and the disappointment of realizing there were many friends and family members that she could not count on.

> *We really found out who our family and friends were . . . the people who are willing to stand beside you while your kid has his meltdown. They might not do anything, but at least stand beside you and call you the next day and [still want to] be your friend. I don't want the people to tell me how to better parent, but I don't want the people to*

> *not acknowledge that my son has autism either.... I think that was one of my hardest parts of [my son's] diagnosis. [The] people that I thought were my friends and family that I counted on turned out not to be (Debbie).*

Several parents described how the behaviour of their child also caused a great deal of stress. Kelly in the focus group, described how her son would hit her before IBI, and how IBI has led to decreases in her stress levels because of the changes in behaviour.

> *It is absolutely destroying watching your child lying on the ground like that. And I would cry for hours and hours and hours and because he got the therapy and he learnt how to express himself and to communicate and he learnt how to control himself and he learnt how to learn, he just… he went from a kid screaming on the floor kicking, punching me in the face, [and] he chipped one of my teeth. I was abused so badly by my kid [but] he is not like that anymore and I'm no longer like this stressed out woman . . .I have got part of myself again and that's what the IBI did for me. (Kelly).*

The topic of problem behaviour recurred in the focus group and came up in the comments on the survey. Problem behaviour improvements or non-improvements had a great impact on the lives of the families in terms of either decreasing or exacerbating the stress that was experienced.

> *You go to the store and [your child is] laying on the floor screaming and kicking and then you have people coming at you telling you what you are doing wrong with your kid and you are [actually] doing the right thing with your kid. When you have people staring at you, it just puts a tremendous amount of stress upon you because you have to deal with your kid and [ignore the people]. (Debbie)*

For several parents, IBI changed their perspective on problem behaviour. They learned how to handle the behaviour, which decreased their stress level. The focus group parents were confident about the way in which IBI addressed problem behaviour or how the IBI professionals taught them to handle problem behaviour. This training for parents was very important. However, in the survey responses, one parent mentioned that their provider did not address the most severe problem behaviour, suggesting some inconsistencies across programs, but also still underlining the importance of this issue.

The stress described by these families was acceptable to them, because of the positive outcomes. Although stresses such as financial or scheduling were a result of the IBI program, it is not clear whether the stress experienced by families was due to the nature of having a child with autism, regardless of enrollment in IBI. These outcomes or changes are described next, as well as the way in which parents were also changed during or following IBI services.

Child and parent IBI outcomes. The parents described IBI as a "lifeline," suggesting that they highly valued the service that they received. Not only did their children made great gains throughout IBI, but IBI also personally affected the parents and their family. Participation in IBI resulted in changes to parenting style and helped develop many parent's abilities to advocate for their children. The focus of these parents always remained the skills of their child.

All three parents in the focus group credited IBI as the reason that their child had made gains and they described the progress their children made as very significant.

> *I don't think [my son] would be where he is today [if not for IBI]. . . I just saw him almost transformed into something I didn't recognize and now . . . this kid is amazing to watch and see, he teases, and he loves giggle, . . . and . . . I see his personality is emerging and I'm like 'WOW'! Even our family [and] friends who do see him, they say "Wow, look at the changes in him! It's brilliant!"(Debbie)*

Debbie and Natalie explicitly described how they saw their child's personality emerge. For example, Natalie commented on seeing her son's sense of humour, and his increased empathy toward other children.

> *A little boy in school fell and he was bleeding and [my son] went over there [and] was trying to help him, to calm him down. . .He used to not want to be helpful. . .he has empathy now. He actually cares about his peer. (Natalie)*

Natalie spoke with great excitement about her son's progress. This expression of empathy by her son was really a breakthrough as she saw it, as children with autism tend to be characterized as lacking empathy. Therefore, for Natalie, this expression by her son may have differentiated him from his autism diagnosis, as individuals with autism often do not express empathy, indicating great progress.

Debbie described how meaningful it was for her child to learn how to shower and brush his teeth independently.

> *He was able to take a shower . . . on his own and wash his own face, and wash his own hair, and brush his own teeth. I said OMG. Because these things to everybody else it's so little, but to us its the biggest thing in the world (Survey respondent)!*

Communication was a skill that was important to many parents, with at least one family in the open-ended questions indicating that their child had made great progress in this area. In the focus group, Kelly described hearing her son's voice for the first time and his progression into communication at an older age.

> *I saw speech coming. I mean he was 11 or 12 when he actually could hear his voice—. . . steadily through his teenage years and . . . [he] can write his address. If he expresses verbally you can't really understand him, but if you say 'Write it down,' he will write whatever you ask him to write. . . (Kelly)*

The parents highly valued the skills acquired by their children. In the open-ended questions in the survey, more parents more often than not reported great gains in their child, and some parents indicated that their gains resulted specifically from their private (DFO) program rather than the DSO program (thus implying that they had received both). Two parents attributed their child's gains to having more than three years of service (this aspect will be discussed later in another section). Like those of the focus group parents, the gains mentioned by parents on the open-ended questions (from the FPIQ) were also in the areas of communication and self help skills. Three families also identified academic skills as having improved as a result of their IBI program.

A couple of parents indicated that IBI skills were not generalized and how the departure from IBI programming (following discharge) led to a decrease in future gains, and some loss of skills, suggesting that improvement from IBI may not be permanent for all children.

> *Several improvements did not last or did not generalize beyond the IBI setting. My son has returned to eating a very narrow range of foods. He has never washed his hands for us or at school, despite doing so at IBI. His aggressive behaviour has increased dramatically since completing the program even though his workers were able to eliminate most of it while he was there (Survey respondent).*

In addition, two parents described their children as getting worse, specifying anxiety or emotional trauma in particular, and felt that IBI methods were not acceptable to them.

> *My son was traumatized emotionally by his experience with IBI. He was afraid to enter the room where his therapy took place for weeks after we terminated the therapy. The testing and goal setting determined that he was at a nursery school level when he was actually doing grade level work in senior kindergarten at school. We have no confidence in the validity of the testing, goal setting aspects. We also have no confidence in the effectiveness of this therapy and would not recommend it to anyone (Survey respondent).*

All three parents in the focus group described how their parenting style had changed through the parent training that was included in the IBI program (which one parent felt should be mandatory), or through simply learning from observing the staff. This learning was positive for the women and their families.

> *It totally changed my parenting style. Totally did, cause I wasn't raised to be taught to teach my kids like that, like when I had to do something when I was a kid, I did it. And I wasn't, you know, I wasn't told to, I just was never shown how to do things and how to break things down. So when I had to learn how to do that with him, it just became like a second nature and totally changed how I parent him and how I parent my other two as well. And then, just for my personality, I tried to integrate my personality and into what they taught me so that I can use it everyday and not feel like I am being told how to parent (Natalie).*

Natalie described how she would learn by simply watching the therapists, and how copying their behaviour made her more effective in communicating with her son. In general, the gains were shared between the children and the parents. Kelly also discussed how she learned to interact differently with her son, although she tried to separate being a therapist from being a parent, her more important role.

The parents also described how some of these experiences had led to them making personal changes. For example, Natalie described how she now has her driver's license because of a battle she endured in accessing the bus with her stroller. Because of the difficulties that she faced concerning riding the bus with her child, she decided to obtain her driver's license. Essentially, she was driven to change her own skills because of the needs of her child. These women in the focus group were willing to do whatever was needed, as Kelly described; "You become a warrior, you become a fighter, you become like everything to get the services for your child."

These parents learned to advocate for their children. These advocacy skills may have come from the receiving of IBI services and knowing what their child should have, or simply from the struggle of having to maintain such a challenging life, and trying to obtain any services they could.

The ability of parents to advocate for their children was evident throughout their discussions about appealing for more services, dealing with school entry, advocating in the community (e.g., getting the stroller onto the bus), and responding to members of the community about their child's autism.

The need to advocate was often directly related to getting access to services.

> *I am amazed how you have to fight for those services. In this day and age, I think its crazy. . . This day and age, I think it's unbelievable the things I have to do to get the services! (Natalie)*

It was repeatedly evident that the parents had to push to get their needs met. The mothers in the focus group related with one another on the struggles they endured. These struggles were most evident in the school system. For example, Debbie would question the school about her son's education, and because she was dissatisfied with their responses, she decided to transfer him to another school.

> *I [enrolled] (my son) to (a) different school because the board has not prepared for [him]. They did not have any plans put in place . . . I said 'You know what? I am not comfortable with this.' And I remember someone saying to me, 'You know, you have to trust this. We do know what we are doing.' And I went 'But you are not showing me you know what you're doing. Like, I am asking you specific questions, you are not giving me answers. (Debbie)*

The advocacy required of these mothers in the schools repeatedly emerged throughout the focus group. The mothers discussed how they mediated between IBI and the schools. They described having to explain to the schools how their child should be taught, based on their learning in IBI. Kelly specifically advocated and paid for her son's Educational Assistants (EAs) to attend IBI workshops to get additional training to help her son.

> *When my son was in elementary school, we actually had a couple of EAs, take workshops . . .. [We] offered to pay [the EAs] for the day because [it was] a Saturday. They didn't really have to do it, but because they liked [our son] and obviously they wanted to make their job easier. I actually got three EAs to come with me at one point. I had to beg them to come. (Kelly)*

The learning that happened in IBI seemed to teach the parents what could be possible for their children, and they sought the same level of services in their child's school. Essentially, parents wanted options and control over their child's learning, or they needed to see that someone was in control and working towards the needs of their child and family.

Parental control of IBI program. Throughout the focus group the mothers identified a lack of control and choices with respect to the delivery of services, but an appreciation of individualized support and considerations in IBI. The responses to the open ended questions on the questionnaire indicated that those parents also felt a lack of control and choice regarding their children's programs at times, and they felt that communication was sometimes lacking. Families who were able to access the DFO indicated having control over their IBI program in many areas.

IBI services were designed to offer service choices to families when they were eligible for funding. That is, when the child was due to come off the waitlist, they were to be given a choice of having either the direct service option (DSO), or direct funding option (DFO). This choice was designed to support families who may have already had an existing IBI program which they would want to continue. However, the mothers in the focus group described how there was not actually a choice between service providers as they had originally been told. When they were contacted by the regional agency, they were presented with only one of the two options. If they wanted to begin service at that moment, they had to choose the option presented, otherwise they would have to go back on the waiting list. Two respondents to the questionnaire confirmed this to be the case for them as well. In the focus group, Debbie described how her son's best outcomes were dependent on time, and how earlier access to services was better for her child, as she had been told. She said her decision to accept DFO was a decision made out of "fear," as time was slipping away.

> *So I mean when we had 24 hours to decide, I was like 'Oh my god, what am I getting into? . . . He is not even three yet, . . . Is it too early? Am I gonna, you know, mess up this one opportunity that you get?' They really put the pressure on [you] to make a decision right then and there. . . . I was afraid I would make the wrong decision [and] I would just totally mess everything up and it would have a negative impact on him. (Debbie)*

The choice between DSO and DFO was described as misleading. The choices are not always presented simultaneously, or parents are not provided with the information needed to make an informed decision as to the service they would prefer.

> *When we got on the waitlist, I wish they had told us to start. . . researching . . . direct funding . . .to know . . . what to look for … on how to go about finding a provider. We were out of luck, but against the odds, we honestly came across the one that we went to and I don't regret it for a moment. It was probably the best decision we ever made. But,if it hadn't been for that option I don't know what we would have done in retrospect. And I don't even know how we would have even come about to find one. (Natalie)*

Some parents indicated that they wished the funding provided them options outside of IBI, as they believed their child's gains were not solely attributable to the IBI. Two parents attributed their child's gains to biomedical interventions and maturation and were not willing to credit IBI for all the positive changes their child had made.

> *Our family chose a multi-disciplinary approach to my son's treatment using an intense behavioural/educational/attitudinal IBI program together with many biomedical interventions (diet manipulation, supplementation and many other complementary treatments). The biomedical interventions had a tremendous effect. It was like he came out of a fog and was interested in people which we hadn't been since he was one and a few months old. The home-based program was his rehabilitation. . . I personally feel that more families should be allowed or approved for Direct Funding. . .(Survey respondent)*

This inability of the parents to have control over their service providers suggests that the parents were at the mercy of the funding structure. The control of the services was with the funding agency, and this was increasingly evident during periods of assessment. Debbie describes the control held by the funding agency.

> *. . . A 20-30 minute visit with another instructor, they just take notes and they do their own evaluations for another half an hour. They don't look at a whole 6 month block . . . you know every six months you've got to go through it and they held all the strings and all the power, didn't matter what my kid had done up until then. They held all the power (Debbie).*

Families who were receiving DFO reported a great deal of control over their IBI services in terms of the number of meetings or contact they had with staff. Control over the schedule in IBI was described as an issue for many families. Lack of flexibility in dropoff and pickup times was noted as difficult although the families who received services from a DFO provider described more control over the schedule and how convenient this was for them.

Some opposition to the teaching methods used in IBI was described, and this might be a difference in learning philosophy between the parents and the professionals. Therefore, despite extensive gains noted by many parents, there were still parents who felt that IBI was not the treatment approach they would choose for their child. On the open-ended survey questions, one parent felt that the clinical team in the IBI DSO was even secretive in their delivery of IBI.

> *[In] the three months that my son was in a DSO program, I had no knowledge of what they were doing and they were very secretive and I was not allowed to see my child when I was there. When he was in DFO, I was involved. However, the team knew better than I did what some of his goals should have been. (Survey respondent)*

The issue of poor communication was also raised in the focus group discussion. Two of the mothers discussed how lack of communication about the services for their child was an issue for them. This lack of communication was with their IBI funding provider (i.e., the regional agency) and the Ministry of Children's Services. One parent was told she would be on the waitlist for two years, and at four months was suddenly given an option to choose between direct service (DSO) and direct funding (DFO). Debbie was not prepared for the direct funding option as the option came up sooner than what had been previously communicated to her. She had not yet had the chance to research providers and no support was provided in this regard.

> *And for us we did not even see it coming. We were told it was a two-year waiting list and it was only like four months we were on the waiting list. So, I wasn't even looking and wasn't even thinking and I've got actually 24 hours to decide whether I wanted the money or not. And then it was like okay so I took the money and then it was like*

> *okay now what will I do? I gotta find a provider, I didn't even know what I was looking for in a provider, you know, so that part of it, that was very stressful. (Debbie)*

It was clear throughout the focus group, that the women were unhappy with the way in which service decisions were made, and presented to them, yet they felt powerless to change this. They described emotions such as fear. They discussed fear about long waitlists, fear of making the wrong service decision, and fear of not getting services in time. There was a lack of confidence in all the women with regards to their child and attaining needed services. Overall, the parents expressed dissatisfaction with communication from their funding providers, and occasionally from their clinical team. As will be described below, when more individual, tailored support is provided, families reported more satisfaction.

There was a clear differentiation between the support, compassion and understanding that parents expressed having received from their clinical IBI team, as opposed to the individuals and/or the system surrounding the IBI funding initiation and termination. When supports were individualized to the family by the clinical team, the mothers in the focus group expressed particular satisfaction. When a general standard protocol was implemented (e.g., during assessments, as described above), the parents expressed great dissatisfaction with the process.

All the women in the focus group described how important the individualized nature of the service was for their families. The clinical teams often implemented goals for the children that were unique for the particular family. For example, Debbie described how the therapists came to the house to help them with their child’s unwillingness to sit in his car seat, or his limitations in eating a variety of different foods. On an occasion when Debbie’s son was ill, the IBI therapist made use of Skype to interact with him and to continue teaching. In addition, Skype was used to allow Debbie to see her son in the therapy session since he would get upset if she was ever present. Kelly discusses how the IBI team considered her upcoming wedding in the goals they developed for her son.

> *I happened to remarry in the same year that he started the program. I wanted him to be [the] ring bearer and they actually customized a program for him to walk (down the aisle). Oh my God, I was so nervous. Is he really gonna pull this off? . . . and they sent one of the therapists to the wedding to be with him . . . and they worked on it for like two weeks or so before the wedding. . . I cried when I had to leave, when he was getting discharged (Kelly).*

Overall, the parents described how they felt they were special to the team and did not feel as if they were just another “number,” contrary to the experiences with the funding agency. Therefore, having choices and control was important to the parents, but also seeing that the IBI program was tailored to their individual needs was quite valuable.

Service delivery. The parents responded extensively to the open-ended FPIQ questions with comments regarding the nature of IBI service delivery. These included comments about the amount of service that was received, when the service began, the extensiveness of the waitlist, and the difficult transitions to other services (i.e., the school system).

Parents described the limited intensity (hours and total months) of the IBI service and how more hours would have led to better outcomes for their children. It was clear that several parents understood the intensity requirements as recommend in the research (e.g., Lovaas, 1987), and felt that they were being underserviced in the IBI.

> *Unfortunately we were in provincially-funded IBI which limits to 24 hours per week. I seriously believe if my child had the recommended 44 hours a week he would have made even more gains than he did. (FPIQ respondent).*

Generally parents reported that their child did not get enough months of service, and that they would have continued if they could have. However, in terms of hours of service per week over this period of time, a few families mentioned the need for flexibility in their weekly hours, and how they would have increased or decreased hours to fit their child and their family's needs.

Several parents indicated that the IBI service started too late (i.e., older than four years) indicating that these families were not paying privately to access the treatment while on the waitlist—they were waiting until the funding began to obtain IBI. Similarly, the parents in the focus group also felt that the term of service was too short, and that hours were often below what had been recommended in the research. They described wanting to have IBI continue, even across the lifespan.

> *My child was diagnosed at two years of age. At that time it was difficult to find a Behavioral Therapist. We managed to locate someone, it took two years. My child began IBI at four years of age. Because funds were limited the child only received twelve hours a week. We saw a great deal of progress with regards to functional and communication skills. After literally hounding [the regional provider], my son finally received funding at seventeen. Apparently the oldest person on their lists. Our program was already in place and with the funding we were able to increase the hours of IBI. Even at seventeen years of age we saw great progress! This needs to continue in the adult years as well. (FPIQ respondent)*

There were a number of very specific comments about the staffing difficulties within the IBI program. Comments focused around the number of therapists that were provided by the IBI program, the training and qualifications of therapists, and the challenges of managing therapists within the team. First, the numbers of therapists was reported as too few.

> *I think if we had more therapists, we'd have a lot less acrimony. [There were two] therapists that caused most of the problems, and we would have been able to ask for other therapists in their team. Team meetings were never positive, but we were able to get good things out of them sometimes too. (FPIQ respondent)*

There were a number of parents who indicated that their therapists were insufficiently trained. Because of this, the parents were not always satisfied with the therapists that they were assigned.

> *It was extremely frustrating to keep getting sent ITs [i.e., Instructor Therapists] that knew less about Autism and IBI than I did. Some were not trained at all. Our provider had explained to us that there was more demand for service than there was properly trained available IT's [sic]. (FPIQ respondent)*

Another issue was raised around consistency of therapist and staff turnover. Parents reported that they had many different therapists, and how difficult this was for them. It was described that the agency had a “rotating door” and this had an impact on the programming that was provided. In addition, the mandatory Psychologist supervision was not highly regarded.

> *There was too much staff revolution. One [therapist] became a Senior Therapist, another [was] off on maternity leave, team members mov[ed] around, etc... We were charged supervision hours from our Psychologist but rarely saw them. Sometimes we were between ST's [sic] when someone quit and we were still getting charged hours but we were not receiving visits from them nor updates in programming. Often data [were] not up to date. (FPIQ respondent)*

Two of the women in the focus group discussed the relationships they had with staff, and the intimacy of these relationships was evident, as described by Debbie below. The clinical team was described as a “second family.” Both the focus group participants and the questionnaire respondents described how personal these relationships were, and how they felt that the staff would often go above and beyond their responsibilities, suggesting high satisfaction with the quality of the clinical team. It was mentioned how this was not likely to be something they would get from their school relationships.

> *. . .and there [was an] open door policy. I mean, I could have a bad day... I cried numerous times in their office. . . I would tell them just about anything. And I loved it when I've been having a bad day and he was having a bad day and I am like ‘I am*

> *really sorry', they're like 'Just go! This is what we get paid for. Just go home and relax!' You know, I never had anyone say this before. You always feel like it's your [the mom's] responsibility. You take care of him. You make him feel better, and [as a mom, you] feel guilty [when you] give him to someone else. But they always make me feel okay (and they would say) 'you know this is what we do'. They [then] text me and tell me 'He is fine' and 'Relax. He is good you know'. I feel relieved, you know? I don't know if every [IBI provider is like] that. For us it was one of the key things that we found really helpful. (Debbie)*

The transition to school following the termination of IBI services was very difficult for families. The intensity of the service, the level of individualization and the amount of interaction with the staff was much greater in IBI than in school. The ending of IBI services for families was difficult because the parents felt that the school system was not able to successfully provide services in a manner that was consistent with IBI.

> *Although it seems my child made great strides I feel that this was just the beginning. If he was allowed to stay in the Regional program I believe he could have actually gained many more skills. His IQ score were actually getting higher. I wish that IBI was involved in schools. (FPIQ respondent).*

There were changes in the amount of communication that these parents received from the schools as compared to IBI. When the mothers described their communication with schools, they were consistently dissatisfied, as they met a lot of resistance from school staff, and this led to negative opinions regarding the school's capacity to support and teach their children. All three women described this battle between schools and parents. Debbie discussed her role and the disappointing lack of involvement she has had in her son's educational programming, which is understandable given the "open door policy" she had described within the IBI program. Natalie described the repeated phone calls she would receive from the school, due to her son's problem behaviour, requiring her to pick him up, which would be not a situation that would occur in IBI, making it difficult for the parents to adjust. This school transition leaves a support gap for families.

> *I got really pissed off at school because two weeks in a row they called me to get him. And he is doing the Connections program[4] one. So there was somebody coming from [IBI] and showing the school how we do everything, this is what he needs, his reports systems . . . Everything was going fantastic until she [teacher] dropped his rewards program. . . So, I am going in there and I am upset with them. . .(Natalie)*

The three focus group participants each had different IBI service experiences: either direct service, direct funding or a combination of both, but all were satisfied with the clinical services they had received as was described above. Having direct service in a multidisciplinary agency was useful for Natalie as she described how her son was able to access additional services (i.e., pediatrician, occupational therapy, infant and child programs). She described how her son's additional needs (i.e., ADHD) were identified because he was in this agency, and how the services were provided during his day and at the centre, which was very convenient for her. However, IBI was always the priority for these parents (the "front-runner") and adding in other services was not necessarily of interest at the end of the day, so they were not often accessed. Families who responded to the open-ended questions in the FPIQ mostly expressed satisfaction with their clinical services in the IBI program, although several did indicate wanting other services as well.

Parental suggestions for the IBI program. Both parents responding to the open-ended questions on the FPIQ and those in the focus group had a number of suggestions about improving the Autism Intervention Program. The suggested improvements included financial reimbursement or a funding increase for families, equivalent delivery in the amount of IBI given, and offering more flexibility and choice.

The discrepancies in the amount of money provided for therapy and the amount that parents had to pay for DFO was repeatedly problematic, and it was suggested that the

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[4] A provincial program for transitioning the children from IBI into school

funding amount should increase. There was a general feeling that recognition of the stress and financial hardships that families endured while waiting for services, or continuing services, or purchasing their own services was lacking from the funding organization and the government. The need for services to occur over longer periods or indefinitely, and for all children or all functioning levels was suggested by many parents.

Several parents indicated that the funding model should be completely direct funding. That is, parents should receive the money directly and be able to choose their service provider, which might allow them more individualization in clinical methods. Therefore, all three parents in the focus group expressed satisfaction with the IBI program from a clinical perspective although the delivery of the services were dissatisfactory in terms of assessment processes and length of services.

Research Questions

Below is a consideration of each of the research questions posed in Chapter Two. The findings are discussed with respect to all data provided in the mixed methods approach.

Do parents express overall satisfaction with the IBI program? Overall, parents do express satisfaction with the IBI program as defined by child outcomes. The parents indicated in the FPIQ that they would have continued the service if they could have, and they described how the service was very beneficial to their child and their family. However that satisfaction is clearly contingent on the individual experiences of the parents and how their service was provided to them. There are a number of constraints to satisfaction, as was described and will be highlighted below.

Do parent ratings of IBI satisfaction vary according to the following aspects? There were a number of areas in the literature that identified the following research questions as pertinent to satisfaction in IBI. In the current study, many of these variables did affect parents' ratings of satisfaction within the Ontario Autism Intervention Program.

a. Personal agreement with program philosophy and goals. Parents identified the importance of control and choice throughout this study, with different experiences depending on their service. Several parents expressed dissatisfaction with their involvement in goals, and others were satisfied when there was individualized goals designed specifically for their child's or their family's needs.

b. Child outcomes in terms of cognitive ratings, autism severity, and school placement? Overall, parents were satisfied with their child's outcomes, although a few parents noted dissatisfaction or were not willing to attribute their child's gains to IBI. Gains made by the children were in communication, academic and social skills, although the latter was said to be lacking by some parents. In addition, parents were satisfied when problem behaviour was addressed but dissatisfied when it was not.

***c. Features of the IBI program: home vs. centre based delivery, age at entry, hours per week of service, total months of service, amount of program and therapist supervision, and quality of interactions with program personnel*?** Parents were dissatisfied with the amount of service that they received in terms of total months, and they felt the therapists were not all equally trained and qualified. The families regarded their interactions with the clinical personnel with high regard, and close relationships and support were described. When the IBI personnel were responsible for the assessment of their children and access to services, parents were dissatisfied with these individuals and the process.

d. ***Impact of the program on the family: parental employment and health, familial relationships (i.e. spousal and/or extended family and/or other children), and families'***

community and social interactions? Parents expressed much dissatisfaction with the effects that IBI had on their family, although several parents indicated that the effects were worth the gains for their child. Significant dissatisfaction was identified with the financial impact of IBI and effects on the career of either the participant or their partner. Other issues (e.g., marital dissolution) identified by individual participants were not significant enough to indicate that they would predict the overall satisfaction of these families.

e. Cultural or linguistic differences between the parents and the professionals? The ability of the IBI program to consider culture also had a significant effect on satisfaction. However, there were few respondents to these questions and thus the area warrants further investigation. Families responding to these questions though expressed that their culture was not understood in some cases, or that it was not considered in the goals for their child. This finding suggests that cultural and language differences may need to be further examined in relation to IBI satisfaction.

CHAPTER V

DISCUSSION

The Ontario Autism Intervention Program has been a support for many children with autism and their families (Perry et al., 2008). The demand for the service alone suggests it is meeting some need in Ontario communities and that need will not be decreasing any time soon (Howlett, 2007), given the prevalence of children being diagnosed with autism at 1 in 68 (CDC, 2014). As the demand for service continues in Ontario, a thorough examination of exactly what need the program is meeting as well as which aspects of the program are most necessary in order to continue the services in a socially and fiscally responsible manner. In addition, critical examination of the program may contribute to an understanding of the pieces of IBI that are most influential for learning (Lechago & Carr, 2008). The purpose of this study was to investigate factors that contribute to parent satisfaction within the Ontario Autism Intervention Program. A number of factors identified within this study provide a framework for consideration. This framework is a functional contextual (Fox, 2005) view of both the clinical and service design of the program.

Previous to this study, analysis of the Autism Intervention Program in Ontario has been limited to child outcomes, clinical service quality, or parent involvement (Perry et al., 2011; Perry et al. 2006, Solish & Perry, 2008). This research has been fundamental to the sustainability of the provincial program, as well as innovative in its consideration of quality markers in IBI (Perry et al. 2006), and questioning the reasons that parents are more, or less involved in the program (Solish & Perry, 2008). Despite these valuable pursuits there are limitations to this research. The examination of quality indicators in IBI has been limited to clinical considerations (e.g., quality of therapists, etc.), and the investigation of parent involvement variables has been restricted to characteristics of the parents (e.g., self efficacy, belief in the program) without explicitly investigating the characteristics of the program. Examination of the IBI service delivery model (both the clinical capacity as well as the administrative structure), along with a consideration of the overall impact on, and perspective of families was overdue. Ivey (2004) identified how parents have very strong feelings and concerns about outcomes for their children and how important it is for professionals to collaborate with the families. Yet the amount of collaboration between professionals in the IBI program and families was unknown. Grindle and Remington, (2014) identified the importance of understanding the impact of intervention programs on families.

The current study provided the groundwork for a comprehensive understanding of IBI effectiveness in Ontario from the families' perspective, and, to the researcher's knowledge, is the first study to investigate this topic in Canada. As such, it makes several contributions to the current literature. In addition, this study is the first to use a mixed methods approach to parent satisfaction in IBI, which helped to gather both breadth and depth in the data. The findings from this research helps to inform the framework for future IBI services. This framework considers parent perspectives about the existing model. The following discussion will highlight the strengths of Ontario IBI program, and make suggestions for improvement to the program.

Parents receiving intensive behavioural intervention in a number of countries have generally been satisfied with their services (Trudgeon & Carr, 2007; Boyd & Corley, 2001), and although this is also true in Ontario as well, satisfaction rates were not overwhelming. Of the parents who responded regarding their overall satisfaction in the current study, two thirds rated that they were satisfied or very satisfied with the program, and one third were not satisfied or extremely dissatisfied. Although many parents described the life changing effect it had on their child with autism and how this “saved” their child and their family, there was still a great deal of discontent. When discussing the impact that IBI had on the lives of the families within the study, more than 80% indicated that it had a positive impact; however 14% did indicate that the impact was negative for them, 4% did not know and 2% of data were missing. Despite the overall positive view of the AIP and its effect on the family, the negative responses raise questions about flaws within the service model that warrant exploration.

The international studies were limited in that families were primarily asked about satisfaction with the implementation of IBI and satisfaction with their child’s outcomes, and not specific features of the service itself. In Boyd and Corley’s (2001) study for example, there was a difference in ratings on satisfaction based on the more general question about IBI implementation as compared to satisfaction of their child’s outcomes. Parents in that study expressed more satisfaction about their child’s outcomes and less satisfaction with the implementation of IBI. This variability in satisfaction suggests there are different elements that parents are evaluating and that child outcome is not the only contributing factor to satisfaction. Asking parents about their satisfaction with an IBI program without defining the aspects of the program may result in a view of satisfaction that is too narrow, and may not provide a thorough evaluation. In the current study, it became clear that IBI satisfaction is a construct, where measurement involves an analysis of multiple layers of data.

IBI Satisfaction Construct

“IBI satisfaction” is a construct that this study sought to define and measure. Whether or not parents were satisfied with the IBI program was assessed using the FPIQ, the MPOC measurement tool, and a focus group. The literature described in Chapter Two was used to formulate the operational framework upon which IBI satisfaction was measured. The findings from the questionnaire and the focus group validated a number of the variables within that framework, and provided additional variables that seem to function as factors of satisfaction. It is evident from the results of this study that there are many features of IBI in Ontario that are highly regarded, and a number that need to be improved.

Parent Satisfaction with the IBI program

There are a number of factors in Ontario IBI's program that have affected parents' satisfaction of the program as a whole. These factors include: child outcomes, IBI program agents (funding organization vs. clinical team), context of IBI (contextual fit, parent philosophy and choice, culture, family-centeredness), the family impact of IBI (finances, relationships, stress), features of the service (amount, staffing), and transitions (to school). In the quantitative analysis, only two factors (i.e., cultural considerations and features of the IBI service) had a statistically significant relationship to all questions about satisfaction. However, other factors arose those clearly impacted families' views of the service. These combined results are discussed below beginning with child outcomes, the reason for which IBI was originally developed (Perry, 1999).

Child outcomes. The IBI literature has repeatedly demonstrated that intensive ABA-based treatment results in effective outcomes for children with autism regardless of the country (e.g., Eikeseth et al., 2007; 2002, Howard et al., 2005; Lovaas, 1987; Perry et al., 2011). Therefore, it is not surprising that this study found that some satisfaction measures were dependent on parents' views on their child's outcomes. Parents are expecting their child to improve in their skills during early intervention; therefore their satisfaction with the program is at least partly dependent on such improvements. The focus of IBI has consistently been on the outcomes of the children. Research results provide a rationale for the program (i.e., its necessity, and its intensity) as well as for government funding. The positive outcome for the child is the fundamental purpose of early intervention and this measure determines one area of satisfaction (Boyd & Corley, 2001). Within this study the parents responding had children who entered IBI at ages slightly older than the Lovaas (1987) student and the Ontario IBI study (Perry et al., 2008), although it was similar to the Toronto IBI study (Freeman & Perry, 2010). Variability in satisfaction, particularly with respect to child outcomes may have been due to the age at entry for the children. As was described earlier, research supports IBI at younger ages for improved outcomes (Flanagan, Freeman & Perry, 2012; Itzchak & Zachor, 2011; Perry et al., 2011). However, both the variability in satisfaction ratings and the results of the qualitative analysis suggest that there are a number of factors besides child outcomes that affect satisfaction within the Ontario IBI program.

IBI service differentiation. The current study found that measuring IBI satisfaction within Ontario requires an operational definition of the service. When parents responded to questions about the IBI program, there was a differentiation between the agents (i.e., people responsible for carrying out the organization’s services) and the organization in their responses. It became clear in both the quantitative and qualitative results that parents emotionally separated the clinical IBI team (i.e., those that design and implement the ABA interventions for their child) from the funding team, or regional service provider (i.e., the organization responsible for the allocation or removal of IBI funding and/or services, and the structure of the program). For example, the parents in the focus group described the clinical team as being a support system to them, and how they had strong connections with these professionals, and how leaving the team when IBI ended was quite difficult. Yet, within that same discussion, the parents also described a power differential between them and the funding providers (“They hold all the power”), and how communication about services was often unclear. Because two service delivery options are available in Ontario (i.e., hiring privately (DFO) or choosing the government-funded service (DSO)), these results may be unique to this provincial program. In Trudgeon and Carr’s study for example (2007), it seemed that parents solicited funding from the government, with parents obtaining their services privately and there was no direct service model. As a result, other studies have not needed to differentiate parent satisfaction based on type of funding. In the current study, however, the results indicate that parents were unhappy with the funding process for early intervention despite being satisfied overall, thus suggesting that parents considered these aspects separately.

The funding organization. It was evident from both the questionnaires and the focus group that parents were dissatisfied with the funding system and/or organization of the IBI program. Parents responded with dissatisfaction about the waitlist for services, the communication about the IBI service, and the methods of assessment and discharge. It was clear that parents felt they were insufficiently supported in their access to services.

The funding organization was not perceived as “family-centered,” as defined by the MPOC scale, where parents rated questions about the organization quite low compared to their ratings of the clinical team. Overall, it was clear that parents felt as if the persons or organization responsible for the funding and the access to services had little regard for the needs of the family. Parent responses on both the open-ended FPIQ questions and in the focus group indicated that parents felt the waitlist was too long, the structure of the funding model was inequitable, insufficient, and poorly managed, and that the level of control held by the regional programs was excessive. Particularly difficult for families were the methods and processes that were used to assess whether services should continue or cease.

It seems that parents have clear views about the organization of the service. The use of choice in service delivery would seem to be one avenue in which parents could feel more control over their services. However, up to this point, the only built-in choice in IBI was the direct service vs. direct funded option. The results of this study indicate that this was often not a choice offered to parents simultaneously, thereby forcing them to choose to start service now and get the model of service available to them, or wait for the availability of the other service. Another difficulty with the organization of IBI was the ongoing waitlists. Without changes in the funding or structure of the service, these waitlists will continue. Parents who can afford it fund their own IBI programs at extensive cost. The families who cannot afford it, or do not have access to private services in their geographical regions, are left waiting. Once service has begun, however, the clinical team was highly regarded overall.

The clinical team. From the parent's perspective, some of the best features of the IBI program involved the decisions and actions of the clinical team. The focus group parents indicated that the clinical teams provided a great deal of social support by way of being available to families ("open door policy") and by demonstrating and understanding the parents' need for a break in the day. The tailoring of IBI goals to individual needs of the families was one way in which parents felt satisfied with their IBI program. Despite the fact that IBI, by definition, always considers individualization to be a hallmark characteristic, this feature may be more presumed than operational. One family described how IBI goals changed with a changing senior therapist, suggesting that goals were sometimes driven by the professionals instead of the parents. The literature on IBI has yet to define interventions in these programs as individualized beyond the level of skills assessment and curriculum. Research on the individualization of interventions and methodologies to fit the needs and preferences of families is lacking and warrants consideration.

Although the clinical teams received mostly positive feedback from families, there were a few areas that resulted in less satisfaction. The level of parent involvement and training was not reported to be consistently satisfactory. Some parents felt that they were not included and the treatment was “secretive.” Including parents in IBI programs is foundational to the structure (e.g., Lovaas, 1987). A level of consistent parental involvement should be required of all IBI programs in a manner that is individualized (in content, intensity and scheduling) to parent needs. Although most FPIQ respondents felt that their team was well qualified, a few parents indicated that they had therapists who were insufficiently trained or educated. The province of Ontario has yet to implement standards around qualifications of ABA therapists despite attempts to do so internationally (Behavior Analyst Certification Board, 2014) and despite indicators that therapist skill level is a feature of quality IBI (Perry et al., 2006).

Parents who felt that there were too many program meetings were more likely to rate their experiences as less satisfactory. In addition, parents who rated the number of supervisory meetings with their ST as too few and unsatisfactory was predictive of less satisfaction with their child’s overall outcome in terms of autism severity. This finding suggests that the meetings with the ST were quite beneficial for the family and they wanted more, which was similar to the research by Eikeseth at al., (2009) where cognitive level results (i.e., from IQ measures) from IBI were significantly correlated with the intensity of supervision received. Therefore, the families' view in the current study regarding the adequacies of the supervision of their child's program from the ST may be reflective of and somewhat attributable to their child's outcomes. The level of supervision provided in IBI is a clinical variable that may affect the quality of IBI, and may require a permanent and defined place in the clinical service model (Eikeseth et al., 2009). IBI models might consider establishing a minimum level of supervisor involvement with the families throughout the intervention.

The role that therapists play in the IBI program was significant and respondents identified the number and quality of therapists as relevant to their satisfaction. The number of therapists was a significant predictor of satisfaction and parents indicated that having only one or two therapists was insufficient for their child's generalization of skills. The establishment of fixed therapist numbers might satisfy the families and benefit the children in the future. Therapist numbers are currently determined by the availability or affordability (in DFO) of staff or they are determined by clinical team decisions (e.g., length of shifts, how therapists are assigned to children, etc.). With the direct service option, parents have little control over the staffing that is provided, but in the directly funded model parents are able to make demands related to the numbers or quality of their staff. Ultimately, the context of the IBI intervention is an important consideration. In order to provide the most effective treatments, consideration of how the program fits for individual families will lead to generalization and effective long-term outcomes.

Context of IBI. The functional contextual view is one that can define both research and clinical practice in the Ontario Autism Intervention Program. Behaviour Analysts believe that function and goal setting are fundamental to applied behaviour analysis in all its applications, including IBI (Wolf, 1978). However, the methodology to measure whether a goal is a functional target for a client, or in alignment with their values and their context is still lacking in ABA and its implementation, particularly in IBI programs. In the current study, a number of areas can be considered under the umbrella of "context." These include the contextual fit for the family, the consideration of culture in program direction and implementation, and the overall family-centered approach of the IBI service.

Benazzi, Horner and Good (2006) stated that effective behaviour intervention plans must have "contextual fit," a term used to describe how a plan's procedures must align with the "values, skills, resources, and administrative support of those who must implement the plan" (p. 161). In examining the results of the current study it is clear that the IBI program is not meeting this objective. At the root of contextual fit is the idea of "family-centered planning," defined as a move away from expert-driven treatment, towards an equal partnership with professionals where parents are informed and supported to make treatment decisions in (King, et al., 1996). In IBI, the notion of "family-centered" has yet to be well defined, but doing so could bring more satisfaction for parents and better outcomes for children.

Parent philosophy and choice. Parents in the current study generally rated the methods used in IBI as being acceptable and those parents who believed the IBI methods were acceptable and who had input in deciding the goals of the program were more satisfied than other parents. However, the clinical team needs to consider that some families may not believe in the methods that are being used in IBI, and this can also alter the level of involvement of parents in IBI (Shine & Perry, 2008). Supervising therapists may want to consider educating families about their methods prior to service implementation, and even offering choices in these methods prior to intervening.

Once in the IBI program, however, parent satisfaction tended to increase over time. When parents rated the methods within IBI as being acceptable, they also gave higher ratings to IBI meeting their expectations. Therefore, “buy-in” to the strategies and techniques will likely to lead to more parent involvement, more parent satisfaction, and result in better outcomes for the child. Focus group participants indicated that IBI led to changes in their parenting style because they saw methods working effectively in IBI. This observational learning suggests that effective parent training involves teaching parents directly with their own children. The IBI program should involve the parents by allowing them to observe the clinical sessions, and directly teach their own child although cultural or language differences may make this more difficult.

Cultural diversity in IBI. Cultural factors have not been considered in the IBI literature, yet they warrant investigation. In this study, although a small sample size, the cultural considerations that were made in the IBI programming were factors that significantly affected parent satisfaction of the Ontario IBI program. When the goals and objectives of the program are more aligned with cultural values, there would be increased satisfaction. However, IBI teams may not adequately acknowledge the role that culture may play in the formation of intervention or educational goals for individuals with autism.

Given that IBI goals are often far-reaching and encompass all aspects of the individual’s life (e.g., academic skills, toileting skills, self help skills, vocational skills, etc.) the program may need to be even more culturally aware than schools. For example, teaching a child to eat using a fork, a skill that may be common in IBI programming may not be relevant for all cultures. Making the assumption that such goals are common for all families may alienate some families and lead to differences in the direction of the clinical goals.

As discussed in Chapter Four, cultural and religious aspects of the IBI program do not seem to be meeting the needs of family. This finding is likely a shortcoming in IBI as the assessment tools used in the program (e.g., ABLLS) lack cultural relevance for non-western families. If the IBI staff is over-reliant on these tools to develop goals and teaching plans, then it is likely that culture and religion are neglected. Based on results from the current study, it is evident that more work is needed for IBI to adequately consider family perspectives with respect to culture, as it may impact educational priorities (Mandell & Novak, 2005) and goals, selection of materials for teaching, and how IBI methods may, or may not align with the family's values.

Family-centredness of the IBI program. The MPOC assessment is designed to measure family-centeredness of intervention programs by measuring five factors; enabling and partnership; providing general information; providing specific information about the child; coordinated and comprehensive care for the child and family; and respectful and supportive care. In all areas, participants rated family-centredness of the IBI program between 3 and 4.4, which is relatively low for a 7-point scale (with 7 indicating "to a great extent"). One parent expressed the ideal as being that "good therapists work closely with the parents so that you are all working towards the same goals." Although parents who participated in the focus group expressed a great deal of satisfaction with their level of involvement, some parents indicated that they felt left out of the program which may explain the lower ratings in the MPOC. It is possible that parents feel limited in their ability to make choices and decisions surrounding their IBI treatment program and this contributed to the low scores in this area. Ultimately, it is the family who is impacted by the structure of the

Autism Intervention Program and the impact on their life is a necessary measure of IBI outcomes.

The Family Impact of IBI. This study indicates that the impact of IBI on the family is substantial. IBI has positively changed lives for many families, but at a great cost to their finances, health, and relationships. Although the negative correlation between IBI meeting expectations and IBI improving spousal relationships was the only statistically significant predictor of satisfaction found, there were a number of other important findings in the open-ended questions, in areas such as finances, relationships and stress.

The parents in this study indicated that the majority would continue the IBI services if they had the option. Given the recent Perry (2012) findings demonstrating that children entering IBI at older ages in Ontario do not have the same outcomes as younger children, continued pursuit of IBI services by families of newly diagnosed children will likely continue. This same determination to obtain early intervention services at all costs was described as a stress by Grindle et al. (2009), Trudgeon and Carr (2007) and Dillenberger et al. (2004). This inevitably maintains the stress for parents in this study.

An additional stress for parents was the effects on their marital relationship throughout IBI. Considering that some parents described the dissolution of their marriage, it is possible that their relationship was sacrificed because the investment in their child’s outcomes, and this became their priority. In their research, Trudgeon and Carr (2007) reported there were more marital relationships that were affected negatively than positively, causing increased stress or removing stress for the families. However, stress effects can be reduced with social support.

Grindle and Remington (2014) describe predictors of parental stress in IBI (in

Hastings & Johnson, 2001). The researchers described how lower stress in parents was associated with good social support and a greater belief in IBI, and higher stress was associated with more severe autism in the child. Therefore, those parents with limited social relationships may require additional support from the IBI program, and this might be a necessary feature of the service.

Features of the service. Although the amount of IBI intervention provided (i.e., hours and months of service) has been determined to have a variable effect on child outcomes (Granpeesheh et al., 2010; Luiselli et al., 2000), it was apparent that these variables did not predict satisfaction in the current study. However, a number of responses to the open-ended questions and the focus group participants indicated that service length was insufficient, started too late, or was not representative of what the research (e.g., Lovaas, 1987) suggests. Other features that also impacted satisfaction were the amount of parental control, choice and involvement in the IBI program. Parents were consistently dissatisfied with the amount of service they received or the timing of the termination of service. When service was terminated, most parents enrolled their children in school, which was not described as a good transition for the child of several parents. The differences in educational and behavioural methods and goals, communication, and support were quite different between IBI and school, and not satisfactory for the parents.

There is no question that in general parents in the current study feel that the IBI program is effective, and this supports the extant literature. However, families are also reporting that there needs to be some improvements in the service. This study identified a number of areas that could shape the future service of the IBI program in Ontario if family satisfaction is a goal.

Strengths and Limitations of the Study

As described in the introduction, this study is the first parent perspective study on the IBI program in Ontario. The use of a mixed methodology allowed for both quantitative and qualitative data, which is regarded as beneficial when research is evaluative and exploratory in nature (Cresswell, 2006). In addition, the inclusion of parents who have recently completed the IBI program as well as parents who are currently completing the IBI program provides a solid representation of the current state of the service. The inclusion of parents receiving either the direct service or the direct funding options also allows for a more comprehensive understanding of parent experience.

The length of the FPIQ was both a strength and limitation of this research. The questionnaire length allowed for a depth of exploration that would not be possible in a more condensed version. The questions covered five exploratory areas (demographics, child outcomes, family affects, culture, and family-centeredness), each of which was comprised of a minimum of five questions, allowing for a rich data set on the one hand, but potentially limiting the sample on the other. It is possible that some parents either chose not to respond to the questionnaire, or did not complete it because of its length. In addition, the lack of translation possibility meant that the questionnaire was restricted to English speakers and this limited the amount of data that was collected concerning culture and language.

Because the paper questionnaire was being distributed by the professionals, or other parents, there was no way of knowing to whom the survey was given, which individuals had returned the questionnaire, and who had not. This prevented individual reminders and follow-ups being sent to those individuals. It also makes it impossible to know if responders and non-responders differ in any significant way (i.e., in terms of program satisfaction or demographic variables) and limits the generalization of the results to the larger population of past and present IBI program participants.

In addition, the possibility exists that responses given by the paper survey respondents differed from those obtained through the online questionnaire, simply due to the topography of the response. However, because only four participants completed paper copies of the questionnaire, separate analyses to determine any significant differences between the two formats was not possible.

The use of the MPOC tool was also a strength of this study as it provided concurrent validity of the FPIQ and also provided a measure of the IBI programs ability to be family-centred. This psychometrically valid tool aligned with the findings of the Family Perspectives Questionnaire in that parents were moderately satisfied with the IBI programs inclusion of families.

The purpose of including a focus group following data analysis of the questionnaire responses was to explore particular aspects of the FPIQ or the MPOC in more depth. Although the focus group findings may not generalize to the population of parents participating in the IBI program, the focus group data enriched the details provided in the questionnaire and allowed for a more in-depth understanding of the views of the parents. However, only three participants attended the focus group, providing a very small sample for analysis. Finally, because the participants in the questionnaire were primarily mothers, it cannot be determined whether the experiences of fathers were similar or not.

Future Research

This study identifies a number of potential areas for future research concerning IBI programs. Some of the key areas concern cultural considerations in IBI, and the clinical and service differences between DSO and DFO providers.

The current study suggested that understanding of a family's culture leads to better ratings of satisfaction of the IBI service. Professionals in IBI would benefit from training in "intercultural competency, " (Byram, 1997) learning to communicate effectively with individuals from other cultures, in order to learn and understand the differences in educational views or parenting practices.

The families in this study were receiving services from DSO or DFO providers, and there were distinct differences between the services, as was described by some of the families. It would be useful to further investigate the qualitative features of the different services. For example, do levels of individualization in the goals vary? Do the levels of parent involvement and communication vary depending on whether parents are paying for the service directly or are having to employ their own therapists (as could be possible in a DFO)? For example, a parent may have more options in terms of their level of involvement, and this involvement may impact on their child's outcomes. Do parents in DSO programs have more or less control overall?

This type of exploration leads to questions of research methodology. Grindle and Remington (2014) identify qualitative studies as ideal for identifying themes in parent experiences in IBI, and the use of these themes and examining their relationship with adjustment could be examined in a quantitative analysis. Pursuing survey design and qualitative methods in research may enable ABA to be embraced within other disciplines that use these methods, such as education. Currently, the field of ABA restricts their methods to single subject design, due to the value of experimental control for demonstrating behavioural change. However, the delivery of IBI to children with autism and their families involves more than direct behavioural change. There are environmental systems and affects that must be considered outside of the immediate behaviour of the child. Alternative research methodologies can provide exploratory data to inform the design of IBI programs to maximally benefit the child and the family as a whole.

Conclusion

Ultimately the IBI program was designed to improve the outcomes of children with autism in Ontario, and this goal is being met (Perry et al., 2010; Perry et al., 2008). However, not all children are obtaining this service and families are seeking out the service privately, out-of-pocket to great personal financial detriment. Even when the families are getting access to services, the process often causes a great deal of stress. Despite the good clinical outcomes, the service is time-limited and in the end, parents return to either fighting for more support, or are struggling because of the lack of support. There are improvements that can be made to this system both administratively and clinically that warrant further discussion, and further research, both in Canada and internationally. It is no longer sufficient to focus only on the provision of clinical hours without consideration of the perspectives of the family. The greatest long-term outcomes will be found when IBI is considered a service for the family, and not exclusively a service for the child.

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APPENDICES

Appendix A
FPIQ (see attached)

Appendix A

Parent Perspectives on the Ontario Autism Intervention Program:
A Questionnaire

Appendix B

Correlation Matrix

Correlation Matrix

		Met Program Expectations	Severity of Autism Decreased	Rate Satisfaction	IBI Satisfaction Increased Over Time	Satisfaction with IBI's Inclusion of Other Goals
Knowledge of autism	Pearson Correlation	.267*	0.151	-0.079	.543**	.279*
	Sig. (2-tailed)	0.019	0.184	0.491	0	0.028
	N	77	79	78	80	62
Strategy knowledge	Pearson Correlation	.280*	0.212	0.166	.396**	-0.009
	Sig. (2-tailed)	0.014	0.063	0.149	0	0.948
	N	76	78	77	79	60
Methods acceptable	Pearson Correlation	.404**	.394**	-0.108	.581**	.339**
	Sig. (2-tailed)	0	0	0.334	0	0.006
	N	96	98	82	96	65
Speaking a different language	Pearson Correlation	.311**	.321**	-0.098	.461**	0.139
	Sig. (2-tailed)	0.006	0.004	0.385	0	0.273
	N	78	78	80	79	64
Culture understood by staff	Pearson Correlation	.361**	.325**	0.019	.435**	0.204
	Sig. (2-tailed)	0.001	0.003	0.869	0	0.106
	N	78	80	81	80	64
Child is still using the skills	Pearson Correlation	.394**	.519**	-0.035	.626**	.272*
	Sig. (2-tailed)	0	0	0.759	0	0.031

Correlation Matrix cont'd

		Met Program Expectations	Severity of Autism Decreased	Rate Satisfaction	IBI Satisfaction Increased Over Time	Satisfaction with IBI's Inclusion of Other Goals
	N	88	91	79	91	63
Child's ability to speak	Pearson Correlation	.282*	.463**	0.028	.525**	0.235
	Sig. (2-tailed)	0.01	0	0.805	0	0.063
	N	82	84	78	85	63
Child's ability to use a communication system	Pearson Correlation	0.13	0.047	0.06	.381**	0.097
	Sig. (2-tailed)	0.396	0.748	0.696	0.007	0.573
	N	45	49	45	49	36
Child's ability to clean self	Pearson Correlation	.429**	0.174	0.04	.423**	0.149
	Sig. (2-tailed)	0	0.129	0.737	0	0.26
	N	76	78	74	79	59
Child's ability to dress self	Sig. (2-tailed)	0.638	0.949	0.66	0.461	0.943
	N	45	47	46	47	35
Child's ability to participate in a group	Pearson Correlation	.336**	0.157	0.063	.535**	.351**
	Sig. (2-tailed)	0.002	0.16	0.579	0	0.005
	N	80	82	79	83	62
Treatment hours/ week	Pearson Correlation	0.093	-0.013	0.015	-0.006	0.012
	Sig. (2-tailed)	0.411	0.911	0.898	0.96	0.925
	N	80	80	80	81	64

Correlation Matrix cont’d

		Met Program Expectations	Severity of Autism Decreased	Rate Satisfaction	IBI Satisfaction Increased Over Time	Satisfaction with IBI's Inclusion of Other Goals
Number of therapists	Pearson Correlation	-0.023	0.041	-0.095	-.218*	-0.194
	Sig. (2-tailed)	0.838	0.714	0.398	0.047	0.125
	N	80	82	81	84	64
Number of ST meetings	Pearson Correlation	0.037	.296**	-0.075	-0.05	-0.118
	Sig. (2-tailed)	0.744	0.007	0.507	0.653	0.354
	N	80	82	81	83	64
Number of program meetings	Pearson Correlation	-0.093	0.128	-0.035	-0.053	-0.096
	Sig. (2-tailed)	0.412	0.25	0.758	0.632	0.45
	N	80	82	81	83	64
Control over the goals	Pearson Correlation	.428**	.341**	-0.051	.544**	.311*
	Sig. (2-tailed)	0	0	0.652	0	0.012
	N	100	102	82	95	65
Choices in the goals	Pearson Correlation	.441**	.266**	-0.003	.584**	.355**
	Sig. (2-tailed)	0	0.007	0.981	0	0.004
	N	99	101	82	96	65
Increased stress on the family	Pearson Correlation	-0.012	0.16	-0.029	-0.157	-0.011
	Sig. (2-tailed)	0.918	0.159	0.798	0.16	0.933
	N	78	79	81	81	65
Relationship with other children	Pearson Correlation	-0.103	-0.034	-0.001	0.03	-0.054
	Sig. (2-tailed)	0.371	0.769	0.992	0.793	0.671
	N	78	78	80	79	64

Correlation Matrix cont’d

		Met Program Expectations	Severity of Autism Decreased	Rate Satisfaction	IBI Satisfaction Increased Over Time	Satisfaction with IBI's Inclusion of Other Goals
Relationship with spouse	Pearson Correlation	-0.122	-.262*	-0.096	-0.141	.265*
	Sig. (2-tailed)	0.283	0.019	0.392	0.208	0.033
	N	79	80	82	82	65

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

Appendix C
Letter to Families Requesting Survey Participation

LETTER OF INFORMATION FOR CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: **Parent Perspectives on the Ontario Autism Intensive Behavioural Intervention (IBI) Program**

You are asked to participate in a research study conducted by **Michelle Turan, doctoral student, and supervised by Dr. Elizabeth Starr, faculty,** from the Educational Studies program at the University of Windsor. The results of this study will be used for the purposes of contributing to the dissertation.

If you have any questions or concerns about the research, please feel free to contact Michelle Turan, turan@uwindsor.ca (905-220-6662), or Dr. Starr; estarr@uwindsor.ca (519-253-3000 ext. 3836).

PURPOSE OF THE STUDY

The purpose of this study is to examine the delivery of the Ontario Autism Intensive Behavioural Intervention program and how the structure or outcomes of the program affect parent satisfaction.

PROCEDURES

If you volunteer to participate in this study, I would ask you to do the following things:

Respond to the survey that is either mailed to you or accessed online
Participate in a focus group (optional) following the survey
It is expected that participation within this study will be approximately one half hour for the survey completion and (if participating) three hours or less for the focus group.

POTENTIAL RISKS AND DISCOMFORTS

Minimal risks or discomforts are expected

Some participants might find it uncomfortable to respond to questions on the survey or discuss their opinions in the context of a focus group.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Participants can expect to benefit from the opportunity to voice their opinions on the services they received, as well as support the continued growth and development of intervention research for children with autism, particularly in Ontario.

PAYMENT FOR PARTICIPATION

All participants will be entered into a draw for 10, $10 gift certificates for Tim Horton’s.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. On the survey, there are no names requested, and no identifying information is given. Should you agree to participate in the follow-up focus group, only first names will be requested, and names will be changed when data is shared with others. Only the researcher and a second recorder will know the first names of individuals in the focus group.

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 without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

Reasons for withdrawing a participant from this study include: the use of foul or abusive language towards one's self or another person during the focus group session.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

Findings from this study will be available following data analysis. These findings can be obtained by contacting the researcher directly.

Date when results are available: December, 2013

SUBSEQUENT USE OF DATA

This data will be used in subsequent studies.

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

___________________________________ ___________________

Signature of Investigator Date

Appendix D

Was your child enrolled in the Ontario Autism Intervention Program and receiving Intensive Behavioural Intervention (IBI)?

Your feedback is needed!

I am a doctoral student at the University of Windsor seeking the assistance of families to provide their perspectives on the Ontario IBI program. I am requesting your help. I am looking for families who have completed the IBI program within the last two years. Can you please use the link below to complete a survey on your experience in the IBI program?

IBI Parent Perspective and Satisfaction Survey

If you would like to complete the survey on paper instead, please email me turan@uwindsor.ca, or phone me: Michelle Turan 905.[redacted]
Thank you for your consideration.

Appendix E

Appendix F

Michelle Turan is a doctoral candidate in the University of Windsor's Educational Studies program. Michelle is interested in parent perspectives on autism intervention services in Ontario.

Michelle has been the Coordinator of the Autism and Behavioural Science Graduate Certificate at Mohawk College for the past 8 years, and has also taught courses at Brock University, Western University and Sage Colleges.

Michelle is a Board Certified Behavior Analyst and a published researcher in the area of error correction in discrete trial training.

Michelle is also married, and is the mother of 1 son, who is 7 years old, and 2 stepchildren who are 27 and 24 years old.

Appendix G
Focus Group Questions

1. First, if you could introduce yourself, and let us know:
    - how old your child with ASD is now and
    - what grade they're in, and
    - how long you were in the provincial IBI program and
    - whether you were receiving direct funding or direct service. (go around the table in a certain order so that you can register this on the recorder)

2. What do you think about the IBI program's effect on your resources, such as your time, or your money or your space? (perhaps....?)
   How could this have been different?
   Why do you think IBI had this effect?

3. How did your personal philosophy of interacting or teaching your child fit with the IBI's approach?

    - How has the IBI program affected your knowledge about autism and your beliefs about interacting with your child?

4. Do you think the the IBI program has had an effect on your other services or your receipt of such services? What effect might there have been? (e.g., school, respite etc.)

5. From your perspective, what do you see as the best features or aspects of the IBI program?
    - Do you feel that there are any particular problems with the way that IBI is currently being delivered to families within Ontario?
    - How do you feel the program could be improved?

6. Given what you know now, and where your child is at in school, or overall, would you have changed the way in which you received IBI or whether you received it at all?

7. What influenced you to select direct service vs. direct funding, and how do you feel about your decision?

8. For those of you who received services through the direct funding option: describe what it was like to receive funding and locate and manage staffing for your program. How did that go for you?

9. For those who received services through direct service; describe what it was like to receive services within this format?

10. Of all the things we discussed tonight, what to you is the most important?

11. Is there anything else that you would like to say?

VITA AUCTORIS

NAME:	Michelle Turan
PLACE OF BIRTH:	Hamilton, ON
YEAR OF BIRTH:	1975
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