

PARENT AND FAMILY FACTORS RELATED TO CHILDREN'S PROGRESS  
IN INTENSIVE BEHAVIOURAL INTERVENTION

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## ABSTRACT

The goal of this study was to examine the relationship between parent and family demographic, psychosocial, and involvement factors and the progress of children with Autism Spectrum Disorder (ASD) in Intensive Behavioural Intervention (IBI). Children's cognitive rates of development and parents' perceptions of children's progress were used to measure children's progress in IBI. Demographic (socioeconomic status, marital status, maternal employment, and having other children with disabilities), psychosocial (parent distress, and coping), and involvement (parent involvement in IBI, and self-efficacy surrounding involvement) factors were related to children's progress in various ways. Specifically, maternal employment, and parental involvement in IBI were predictors of increased cognitive rates of development, and coping was a predictor of increased parental perceptions of children's progress. Clinical implications include empirical evidence for encouraging parents to be involved in their children's treatment, along with evidence supporting maternal employment.

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Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication (including social-emotional reciprocity, nonverbal communication, and social relationships), and repetitive behaviours and interests (i.e., routines and rituals, restricted interests, and sensory issues) (DSM-5; APA, 2013). Intensive Behavioural Intervention (IBI), a time-intensive program utilizing Applied Behaviour Analysis (ABA) techniques, has been shown to be an effective treatment of Autism (e.g., Eldevik et al., 2009; Freeman & Perry, 2010; Perry et al., 2008), and thus has become the treatment of choice for this population. However, there is still a large amount of variability in children's outcomes, which may be due to many different factors. Recent studies have examined factors relating to the child (e.g., age and IQ; Perry, Blacklock, & Dunn Geier, 2013) and intervention (e.g., model of supervision; Eikeseth, Hayward, Gale, Gitlesen, & Eldevik, 2009), however, the parent and family aspect remains largely unexamined to date. There is a small amount of literature suggesting that high levels of parent stress may be associated with less positive child outcomes (e.g., Osbourne, McHugh, Saunders, & Reed, 2008; Robbins, Dunlap, & Plienis, 1991; Shine & Perry, 2010), but there are many other parent and family factors that have not yet been examined in this context, for example, demographic factors, psychosocial factors, parents' involvement in their children's treatment programs, and their self-efficacy surrounding this involvement. The goal of this study was to examine the relationship between children's progress in IBI and several of these under- and un-examined parent and family factors. Specifically, family demographic factors (socioeconomic status [SES], marital status, maternal employment, and having other children in the family with a disability), psychosocial factors (parent distress, and coping), and parents' involvement and self-efficacy surrounding their involvement in their children's IBI

program, were examined in this study for interrelationships among these variables as well as how they relate to and predict children's progress in IBI.

### **Family Demographic Factors**

Demographic factors have the potential to have a significant impact on many different outcomes for children with ASD and their families. There is, however, a lack of research about how some of these demographic factors relate to the treatment outcomes of children with ASD. The two demographic factors included in this study that have been examined in previous literature are SES and maternal employment. SES was significantly positively correlated to the outcomes of children with ASD in a study by Robbins and colleagues (1991), which was focused on the relationship between parent stress and children's outcome in a family oriented training program. Outside of ASD literature, a study by Falconnier (2009) examined the effects of SES on different types of treatments for depression. This study found that lower SES was related to poorer outcomes in all treatment groups. Both of these findings demonstrate that SES has the potential to have an impact upon the effectiveness of many different treatment modalities.

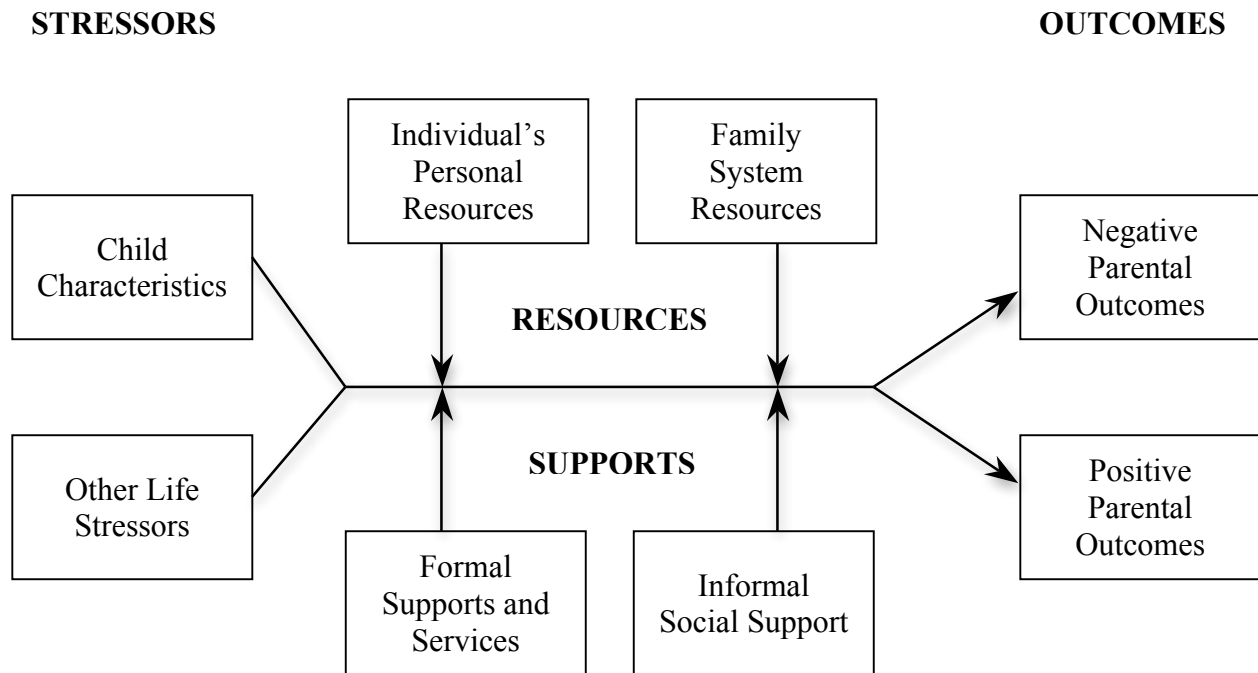
Buehler and O'Brien (2011) studied maternal well-being in relation to employment in a typically developing population and found that mothers who were employed outside of the home reported fewer depressive symptoms than mothers who were not. In the present study, the relationship between children's progress in IBI and their family's demographics (SES, parents' marital status, maternal employment, and having other children with a disability in the family) were examined. Although these variables have not been examined extensively in the literature, and there is no theoretical basis for a directional hypothesis, I believe relationships may exist, based on the limited amount of research available and clinical experience. Many of these demographic factors appear to have the potential to relate indirectly to variables that have been



shown to have an impact on child outcomes. For example, lower levels of SES may create difficulties for families in terms of service access; this financial difficulty could increase parents' level of distress, which has been shown to relate to poorer outcomes for children with ASD.

### **Psychosocial Factors**

**Parent Distress.** Parents of children with ASD are at risk to experience elevated amounts of stress (Bromley, Hare, Davidson, & Emerson, 2004; Koegel et al., 1992; Sanders & Morgan, 1997). As their experiences of stress can be complex, Perry (2004) conceptualized a model of stress for families of children with developmental disabilities (DD) (see Figure 1). In this model, the parents' distress would be considered a *negative parental outcome* and would be based on two sets of stressors (*child characteristics*, e.g., age, IQ, behaviour problems, etc., and *other life stressors*, e.g., financial burdens, employment stressors, etc.), which are mediated (or perhaps moderated) by resources (the *individual's personal resources*, such as coping skills, and the *family's resources*, e.g., SES, marital status, etc.) and supports, both *formal supports and services* and *informal social support*.



*Figure 1.* Perry's (2004) model of stress in families of children with Developmental Disabilities

Only a few studies have examined the relationship between parental stress and the intervention outcomes of children with ASD (Osborne et al., 2008; Robbins et al., 1991; Shine & Perry, 2010). While these studies examined different interventions and utilized different measures of stress, they all found a negative relationship between initial levels of parental stress and children's outcomes after the intervention was implemented, indicating that parents with higher levels of initial stress had children with less optimal outcomes. While these findings are correlational in nature and do not demonstrate a causal relationship between parental stress and intervention outcome, they do suggest that the two are related and have the potential to affect each other. As there is evidence of a negative relationship between parent distress and children's

outcomes in previous research, we expected to see a similar relationship in the present study, in regards to children's progress in IBI.

**Coping.** Coping skills can have a large impact on the experience of distress both at the individual and family level. Problem-focused and emotion-focused are two classes of coping that have been defined in previous literature (Lazarus & Folkman, 1984). Problem-focused coping involves engaging in active strategies to bring about change in the self or the environment in order to modify the distress-causing situation, for example, information gathering or help seeking. Emotion-focused coping involves the regulation of emotions in order to change the impact of the stressor or the way the stressor is perceived. Some examples of these strategies are avoidance and denial (Lazarus & Folkman, 1984). Several studies have shown that problem-focused or task-oriented coping strategies are associated with lower levels of distress for parents of children with autism (Diamond, 2005; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). As parental distress has been shown to relate to children's outcomes, and coping can have an impact on the experience of distress, it was an important variable to examine in this study. Coping skills may also have an impact on the parents' perceptions of their children; parents with strong and adaptive coping skills may be able to recognise and appreciate small changes in their children throughout treatment.

### **Parent Involvement in IBI**

**Involvement.** Parents' involvement in their child's IBI program has been emphasized by professionals, however, very little research on this topic exists. The majority of this research is in regards to parents conducting formal treatment sessions with their children, and being IBI therapists themselves (e.g., Hastings & Johnson, 2001). Solish and Perry (2008) conducted a study in order to operationalize the construct of parental involvement in IBI, incorporating forms

of involvement other than conducting formal IBI sessions, including involvement in their child's program through goal setting, involvement with the agency by attending meetings and maintaining regular contact with the program staff, attending parent training programs, and working on generalization of skills with their children outside of IBI. Their research led to the creation of the Parent Involvement Questionnaire (PIQ; Solish & Perry, 2008; Solish, Perry, & Shine, submitted), which was used in the current study to obtain a measure of parents' involvement in their children's IBI program, as well as their self-efficacy surrounding their involvement.

**Self-efficacy.** The term self-efficacy describes a person's belief that he or she is able to perform a particular task successfully (Bandura, 1989). This construct is based on a person's perception of this ability and skill level, rather than an objective measure of ability. Van den Hoofdakker and colleagues (2010) conducted a study examining the moderating effect of parenting self-efficacy on their children's treatment response for ADHD. Parenting self-efficacy refers to parents' perception of themselves as competent in their parenting role. This study did not find maternal variables to be predictors of children's treatment outcomes, however, mothers' parenting self-efficacy moderated children's treatment effects. Children whose mothers had more positive views of their parenting self-efficacy had greater treatment effects in the examined treatment, as compared to those in the treatment as usual condition. This difference was not seen in mothers with less positive parenting self-efficacy beliefs.

In the current study, parents' self-efficacy, specifically in regards to participation in their child's IBI program (being involved with the IBI agency, trying to work on generalization of skills being taught, etc.), was examined in relation to their children's progress in IBI, and their level of involvement in their child's program. It has been suggested that higher levels of self-

efficacy have the potential to lead to higher levels of involvement, as research has demonstrated that higher levels of self-efficacy make people more likely to persevere and succeed in the relevant task (Zimmerman, 2000). Previous research on the Parent Involvement Questionnaire (Solish & Perry, 2008; Solish et al., submitted) demonstrated moderate correlations between parental involvement and self-efficacy surrounding their involvement (Solish, 2010), and we expected similar findings in the current study. We also expect this relationship between parental involvement and parents' self-efficacy surrounding their involvement in IBI will relate to children's progress.

Demographic factors, psychosocial variables, and parents' involvement in IBI were examined in the current study to determine how they relate to each other, and to children's progress in IBI. As SES has been shown to have a positive relationship with children's progress (Robbins et al., 1991), it was expected that a similar relationship would emerge in the present study. As coping can have a significant impact on an individual or family's experience of distress, and distress has been demonstrated to relate negatively to children's outcomes (Osborne et al., 2008; Robbins et al., 1991; Shine & Perry, 2010) a relationship between parental distress and children's progress was expected in the present study, and a potential indirect relationship of coping through parental distress was anticipated. Based on previous research surrounding self-efficacy and parents' involvement in their children's IBI program, a positive relationship was expected between self-efficacy and involvement. As involvement is strongly emphasized by professionals, it was expected that higher levels of parental involvement would relate to children's progress. The relationships between these variables and children's progress in IBI have the potential to provide insight into what is accounting for some of the large unexplained

variability in children's outcomes. This may have important clinical implications for the implementation of IBI, as well as the well-being of these children and their families.

### **Measures of Children's Progress**

Frequently, standardized measures are used to assess children's progress in IBI. Parents, however, have varied beliefs surrounding their children's progress throughout IBI, and these beliefs do not always correspond to the results of standardized assessments (Blacklock, Weiss, Perry, & Freeman, 2012). Blacklock and colleagues (2012) compared parents' perception of children's progress to standardized measures of children's progress in IBI, and found that parental perceptions, though somewhat correlated, did not correspond closely to standardized assessment measures. This difference could represent parental optimism or it may demonstrate that parents are seeing more subtle changes in their children that are not being detected by standardized measures (Blacklock et al., 2012). For this reason, the present study included both standardized measures of progress and parents' perception of children's progress as dependent variables.

As the parent and family factors described above remain largely under-examined, and in some cases, un-examined in the literature, this exploratory study aimed to answer the following questions:

- How are the three sets of family-related independent variables (families' demographics, psychosocial variables, and involvement/self-efficacy surrounding involvement in IBI) related to each other?
- How are each of the family-related independent variables related to:
  - a) standardized assessments of children's progress?
  - b) parents' perception of children's progress?

- Which combination of family variables, considered simultaneously, best predict:
  - a) standardized assessments of children's progress?
  - b) parents' perception of children's progress?

A breakdown of the variables included in this study and a description of how they were measured is provided below in the Measures section.

## **Method**

### **Procedure**

The data for this study were collected as part of a waitlist controlled, prospective study of IBI, and were used with permission of the original study's authors (Perry, Dunn Geier, & Freeman, in preparation). Participants for this study were recruited through three of the nine publicly funded regional Autism Intervention Programs in Ontario: Surrey Place Centre, the lead agency in the Toronto region; Kinark Child and Family Services, the lead agency in the Central East region; and the Children's Hospital of Eastern Ontario, lead agency for the Eastern region. Ethics approval was obtained from all three Centres at the outset of this larger study, and the Human Participants Research Committee in the Office of Research Ethics at York University approved the current study.

Children who were beginning IBI, and those on the wait list for entry into the program were recruited for the study; the families of children who had been granted entry into the program constituted the IBI group, and those on the wait list were included in the control group. Prior to beginning the initial assessment, informed consent was obtained from the parents for a psychological assessment and participation in the study generally. A developmentally appropriate test of cognitive functioning (one of the four described below) was administered to the child. The parents completed an interview, the Vineland Adaptive Behavior Scales – Second

Edition (VABS-II; Sparrow, Cicchetti, & Balla, 2005), and the appropriate demographic and psychosocial measures for the initial time point. Approximately one year later, the families were contacted again to schedule their second assessment. Informed consent was obtained again, and a developmentally appropriate cognitive measure (generally the same test administered in the first assessment) was administered, and the parents completed an interview and the relevant measures. After each assessment, a registered clinical psychologist gave each of the children a diagnosis of Autistic Disorder, or Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) based on the DSM-IV-TR (APA, 2000) diagnostic criteria.

Many of these assessments took place at York University, and the author participated in several of the child assessments and parent interviews conducted. The sample for this study consisted of a subset of the IBI group in the original study, who had completed all of the measures needed for the present study.

### **Participants**

The sample consisted of the parents of 28 children, between the ages of 43 and 80 months at intake ( $M = 59.11$ ,  $SD = 11.43$ ), receiving publicly funded IBI in Ontario (see Tables 1 and 2 for child characteristics).



Table 1

*Child Characteristics: Gender and Diagnosis*

	<i>n</i>	%
Gender ( <i>n</i> = 28)		
Male	26	93
Female	2	7
DSM-IV Diagnosis ( <i>n</i> = 28)		
Autistic Disorder	22	79
PDD-NOS	6	21

Table 2

*Child Characteristics: Initial Cognitive, and Adaptive Behaviour Levels*

	<i>M (SD)</i>	Range
Cognitive Full Scale IQ ( <i>n</i> = 27)	47.20 (20.53)	20.78 – 98.91
VABS-II Adaptive Behavior Composite ( <i>n</i> = 28)	63.00 (10.45)	44 – 83

**Measures**

**Demographics.** A family information form was used to gather information about the family, including whether there were other children in the family with a disability, the parents' marital and employment status, and highest completed level of education. An adaptation of The Barratt Simplified Measure of Social Status (BSMSS; Barratt, 2012) was utilized to obtain a score for SES. This measure is based on Hollingshead's (1975) research, and was originally meant for college students, however we have adapted it for use with parents, with permission of the author. The BSMSS involves coding the parents' highest level of education and their

occupation in order to obtain a total score (a continuous variable that can range from 8 to 66) representing the family's SES.

**Parent Distress.** Parent distress was measured at the time of the child's intake into IBI using the Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995). The PSI-SF is composed of 36 items, rated on a 5-point Likert scale ranging from 1 = *Strongly Disagree* to 5 = *Strongly Agree*, used to measure stress in the parent-child system. This measure includes three subscales: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. A Total Stress score can be calculated by summing the scores from the three subscales. The test-retest reliability for the Total Stress score is 0.84 ( $\alpha = .91$ ). In this study, the Parental Distress subscale of the PSI-SF was used to represent parent distress because parents of children with autism tend to have elevated scores on the Parent-Child Dysfunctional Interaction and Difficult Child subscales simply as a function of their child's characteristics (Perry, 2004). The Parental Distress subscale is made up of 12 items and measures distress experienced by the parent based on personal factors related to parenting, as opposed to stressors, such as child behaviour and social problems. Raw scores on this subscale can range from 12 to 60, with higher scores indicating increased levels of distress. Raw Scores can be converted to percentile ranks with a raw score of 25 representing an average score at the 50<sup>th</sup> percentile. A raw score of 33 represents the 85<sup>th</sup> percentile and scores above that point are considered "elevated". The percentile ranks in this sample range from below average (i.e., very low stress) at the 5<sup>th</sup> percentile to above average between the 95<sup>th</sup> and 99<sup>th</sup> percentiles (i.e., very high stress). The Parental Distress subscale of the PSI-SF has a test-retest reliability of 0.85 ( $\alpha = .87$ ). Independent validity research has not been conducted on the Short Form of the PSI; however, it is highly correlated with the PSI full-length version ( $r = .94$ ) (Abidin, 1995).

**Coping.** The Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin, Olson, & Larsen, 1991) was given to the parents to measure family coping at intake into IBI. The F-COPES is a 30-item measure designed to obtain the effective problem-solving behaviours and attitudes families use to respond to problems. This measure is comprised of five subscales: Acquiring Social Support, Reframing, Seeking Spiritual Support, Mobilizing Family to Acquire and Accept Help, and Passive Appraisal. The final subscale, Passive Appraisal, represents emotion-focused forms of coping, and the answers are reverse coded. Items are answered on a 5-point Likert scale ranging from 1 = *strongly disagree* to 5 = *strongly agree*. Scores can either be reported on the individual subscales, or summed to provide a total score, which was used in the present study. Total scores can range from 30 to 150, with higher scores indicating increased coping behaviours, but there are no specific cut off scores or ranges considered to be problematic. Reliability for the entire scale has been measured to be  $\alpha = .77$  with test-retest reliability of  $\alpha = .71$  (McCubbin et al., 1991).

**Parent involvement and self-efficacy.** The Parent Involvement Questionnaire (PIQ) (Solish & Perry, 2008; Solish et al., submitted) was used to measure the two constructs of parent involvement and self-efficacy at the second assessment following a year of IBI. This questionnaire includes items about parents' involvement in their child's IBI and their self-efficacy in regards to this involvement pertaining to four different factors: Formal IBI Involvement, Child Program Involvement, Training Involvement, and Agency Involvement. Each item was rated on a 5-point Likert scale with specific verbal anchors depending upon the question (e.g., ranging from not at all to frequently). As the majority of parents in this sample were not providing formal IBI to their children, the Formal IBI factor was not included in the present study (as was done by Solish et al., submitted). Therefore, Parent Involvement was

calculated from the mean of 15 items asking about parents' involvement with their child's program (i.e., *How familiar are you with your child's specific IBI program goals?*), agency (i.e., *How often do you communicate directly with your child's IBI program staff either on the phone or in person?*), and training (i.e., *How many hours of behavioural parent training courses have you attended?*). Mean scores ranged from 2.00 to 4.27, with higher scores reflecting more involvement. In this sample, the involvement score from the PIQ had acceptable reliability,  $\alpha = .75$  for 15 items.

Self-efficacy scores are comprised of the mean of 12 items, four items for each area of involvement measured: Child Program Involvement, Training Involvement, and Agency Involvement, asking how *difficult*, *effective*, and *confident* the parents feel being involved in their child's IBI, and whether they feel their involvement *makes a difference* in their child's progress. The "*difficult*" items are reverse coded as they have a negative focus. Items are rated on a 5-point Likert scale ranging from 1 = *not at all* to 5 = *extremely*. Mean scores ranged from 2.17 to 4.67, with higher scores reflecting more self-efficacy. This score has good reliability,  $\alpha = .82$  for 12 items. Higher mean scores reflect greater parent involvement and self-efficacy.

**Standardized assessments of children's progress.** To measure the children's progress in IBI in a standardized manner, scores from the two assessments (the first at intake and the second after one year of IBI) were used. These assessments included a standardized, individually administered cognitive test along with other measures. Several different cognitive tests were used for this study, selected based on the appropriateness for the child's level of functioning. These tests include the Mullen Scales of Early Learning (AGS edition) (Mullen, 1995), the Wechsler Preschool and Primary Scale of Intelligence, third edition (WPPSI-III; Wechsler, 2002), the Wechsler Intelligence Scale for Children, fourth edition (WISC-IV;

Wechsler, 2003), and the Stanford-Binet Intelligence Scales, fifth edition (SB5; Roid, 2003). All of the standardized tests provide a Full Scale IQ (FSIQ) score with a mean of 100 and a standard deviation of 15, although Ratio IQs (Mental Age/Chronological Age x 100) had to be used in some cases when children's scores were too low to obtain a normative score. The Mullen (1995), intended for children from birth to 68 months, provides scores in four cognitive domains: Visual Reception, Fine Motor, Receptive Language, and Expressive Language. The Mullen demonstrates adequate reliability demonstrated by split-half coefficients ranging from .75 to .83 for the scales, and concurrent validity has been demonstrated. The WPPSI-III (Wechsler, 2002) is intended for children between 2 years 6 months and 7 years 3 months. The FSIQ has been demonstrated to have an internal consistency coefficient of .96, demonstrating excellent reliability, and construct, convergent, and discriminant validity have also been demonstrated. The WISC-IV (Wechsler, 2003), intended for children between 6 years 0 months and 16 years 11 months, includes a Verbal Comprehension Index, Perceptual Reasoning Index, Working Memory Index, and Processing Speed Index. The WISC-IV has excellent reliability, with a reliability coefficient of .96, and validity was demonstrated through exploratory and confirmatory factor analyses. The SB5 (Roid, 2003) is intended for individuals from 2 years to adults. The average reliability coefficient for the FSIQ is .98 demonstrating excellent reliability, and adequate validity has been demonstrated.

All but four children in this sample completed the same cognitive test at both their initial and second assessments. The use of the same test at both assessments is important for the reliability of the measurement of children's progress, so that slightly different scales or tasks on the various tests do not confound any changes over time. Twenty-two children completed the Mullen Scales of Early Learning at both assessments, two children completed the WPPSI-III at

both assessments, individual children completed the SB5 at the first assessment and the Mullen at the second assessment; the Mullen at the first assessment and SB5 at the second assessment; the Mullen at the first assessment and WPPSI-III at the second assessment; the WPPSI-III at the first assessment and the WISC-IV at the second assessment.

For the purposes of the present study, the standardized measure of children's progress in IBI was based on children's cognitive rate of development during IBI, as defined and used in previous research (e.g., Perry et al., 2008; Perry et al., 2011). The cognitive rate of development was calculated by dividing the change in cognitive age equivalent or Mental Age (MA) from the initial assessment (T1) to the second assessment after 1 year in IBI (T2), by the duration of

$$\text{treatment: } \frac{T2 \text{ MA} - T1 \text{ MA}}{\text{Duration of IBI}}$$

**Parents' perception of children's progress.** The Parent Involvement Questionnaire (PIQ) also includes questions about children's progress in five domains: social and play skills, academic skills, communication skills, self-help skills, and problem behaviours. Parents were asked, "How would you rate your child's improvement in [*domain*] since the IBI program began?" and provided with a 5-point Likert scale ranging from 1= *got worse* to 5= *substantially improved*. The parents' ratings from these five questions were averaged to obtain a score for parents' perception of children's progress. This score has excellent reliability,  $\alpha = .90$  for 5 items.

All constructs and variables included in the study are summarized in Table 3.

Table 3

*Summary of the Study Variables and Methods of Measurement*

Variable	Measure	Score
<b>Demographics</b>		
SES	Adapted BSMSS	<ul style="list-style-type: none"> <li>Based on parents' highest level of education and occupation (range: 8 – 66)</li> </ul>
Marital Status	Family Information Form	<ul style="list-style-type: none"> <li>Married</li> <li>Not Married</li> </ul>
Maternal Employment Status	Family Information Form	<ul style="list-style-type: none"> <li>Part/Full time</li> <li>Not working</li> </ul>
Other children with a disability	Family Information Form	<ul style="list-style-type: none"> <li>One or more other child</li> <li>No other children</li> </ul>
<b>Psychosocial</b>		
Parent Stress	PSI-SF	<ul style="list-style-type: none"> <li>Parental Distress subscale</li> </ul>
Coping	F-COPES	<ul style="list-style-type: none"> <li>Total score</li> </ul>
<b>Parent Involvement in IBI</b>		
Involvement	PIQ	<ul style="list-style-type: none"> <li>Mean of 15 items scored on 5-point Likert scale</li> </ul>
Self-efficacy surrounding involvement	PIQ	<ul style="list-style-type: none"> <li>Mean of 12 items scored on 5-point Likert</li> </ul>
<b>Child Progress</b>		
Cognitive rate of development during IBI	Standardized Cognitive measure	$\frac{T2 MA - T1 MA}{\text{Duration of IBI}}$
Parents' Perception of Children's Progress	PIQ	<ul style="list-style-type: none"> <li>Mean rating of child's improvement in 5 domains (5-point Likert scale): social and play skills, academic skills, communication skills, self-help skills, and problem behaviour.</li> </ul>

## Results

Prior to any analyses being conducted, the distributions of the variables used in this study were examined for normality, skewness and kurtosis. While not all variables were normally distributed, there were no severe deviations from normality and it was determined that no transformations were necessary. Missing variables in the PIQ were manually imputed for three participants using logical judgment. Question 13 (*“Please provide your best estimate of how many hours per week you are involved in training related to autism and IBI:”*) was left blank for these participants, and these values were inferred based on their responses to questions 11 (*“How many hours of behavioural parent training courses have you attended?”*) and 12 (*“How many hours of behavioural lectures, presentations and workshops, and/or conferences have you attended?”*).

Tables 4 and 5 present the descriptive statistics for the family demographics, psychosocial factors, and involvement in IBI variables examined in this study. Table 6 presents the descriptive statistics for the two measures of children’s progress.



Table 4

*Family Characteristics – part I*

	<i>n</i>	%
Marital Status ( <i>n</i> = 28)		
Married	22	79
Not Married	6	21
Maternal Employment ( <i>n</i> = 27)		
Part/Full Time	10	37
Not Working	17	63
Presence of another child with a disability ( <i>n</i> = 28)		
One or more other children with disability	7	25
No other child with disability	21	75

Table 5

*Family Characteristics – part II*

Measure	<i>M (SD)</i>	Range
Socioeconomic Status (BSMSS) ( <i>n</i> = 28)	36.29 (14.57)	12 – 61
Parent Distress (PSI-PD) ( <i>n</i> = 22)	29.18 (9.29)	14 – 47
Coping (F-COPES) ( <i>n</i> = 24)	96.67 (12.13)	79 – 120
Involvement in IBI (PIQ) ( <i>n</i> = 28)	3.24 (0.55)	2.00 – 4.27
Self-efficacy (PIQ) ( <i>n</i> = 28)	3.73 (0.62)	2.17 – 4.67

Table 6

*Outcome Variable Characteristics*

Measure	<i>M (SD)</i>	Range
Cognitive rate of development (Standardized assessment of children's progress) ( <i>n</i> = 27)	0.74 (0.55)	-0.10 – 1.67
Parents' perception of children's progress (PIQ) ( <i>n</i> = 28)	3.98 (0.74)	2.60 – 5.00

**How are the three sets of family-related independent variables (i.e., families' demographics, psychosocial variables, and involvement/self-efficacy surrounding involvement in IBI) related to each other?**

As many of the variables being examined in this study have not been examined in previous research, the goal of this research question was to explore the different relationships among the variables included in the study. Since several of the variables were ordinal or categorical, non-parametric, Spearman correlations were utilized, and independent *t*-tests or chi-square tests were conducted when appropriate to examine the nature of the relationship demonstrated by the correlations between dichotomous variables. Missing data were excluded from analyses pairwise, in order to avoid deleting whole cases with missing data, as there were many different variables and the sample size was relatively small. Correlations were examined, not in terms of statistical significance (though this is indicated in the tables), but rather in terms of the strength of the relationship utilizing Cohen's (1992) convention, where 0.10 to 0.29 is a weak effect, 0.30 to 0.49 is a moderate effect, and 0.50 and above is a strong effect. Table 7 presents the correlations among these variables.

Table 7

*Correlations of Family Demographic and Psychosocial Variables and Parent Involvement in IBI*

	1	2	3	4	5	6	7
1. SES	--	--	--	--	--	--	--
2. Marital status	.38*	--	--	--	--	--	--
3. Maternal employment	.29	.04	--	--	--	--	--
4. Other children with a disability	.14	.10	-.28	--	--	--	--
5. Parent distress	-.20	-.02	-.19	-.22	--	--	--
6. Coping	-.18	-.22	.01	.19	-.26	--	--
7. Involvement	.04	-.39*	.00	.26	-.48*	.17	--
8. Self-efficacy	-.20	-.14	-.01	.23	-.30	.11	.13

\* $p < .05$ 

Shading indicates moderate effects

SES was moderately correlated with marital status in our sample, in a logical direction. An independent  $t$ -test showed that mothers who were married ( $M = 39.16$ ,  $SD = 14.14$ ) had significantly higher SES, than those who were unmarried ( $M = 25.75$ ,  $SD = 11.73$ ) ( $t(26) = 2.12$ ,  $p = .04$ ). Maternal employment was also somewhat correlated with SES. However, the  $t$ -test showed that, although mothers who worked, ( $M = 42.20$ ,  $SD = 8.90$ ), had higher SES than those who did not work ( $M = 33.94$ ,  $SD = 16.22$ ) this difference was not significant ( $t(25) = 1.48$ ,  $p = .15$ ).

Marital status was generally unrelated to the other variables but was moderately correlated with parents' involvement in their child's IBI program. Somewhat surprisingly, the direction of this relationship indicates that parents who were single ( $M = 3.63$ ,  $SD = .36$ ) were

significantly more involved in their child's IBI program, than parents who were married ( $M = 3.13$ ,  $SD = .55$ ) ( $t(26) = 2.11$ ,  $p = .05$ ).

*Maternal employment* was correlated with having other children with a disability, and was one of the higher correlations in this study. A chi square test showed that mothers who had additional children with a disability were less likely to work (14%), and mothers who did not have additional children with a disability were more likely to work (45%), however this was not a significant difference ( $\chi^2(1) = 2.10$ ,  $p = .15$ ). Maternal employment was also weakly correlated with distress, and unrelated to coping, involvement in IBI, and self-efficacy surrounding involvement. The correlation between maternal employment and involvement in IBI was surprisingly low.

Having *other children with a disability* was not strongly correlated with any of the other variables, rather surprisingly (although there were only seven families with additional children with disabilities). Perhaps surprisingly, there was a weak negative correlation with parent distress. An independent  $t$ -test suggested that parents with more than one child with a disability ( $M = 26.43$ ,  $SD = 8.96$ ) show somewhat lower levels of distress than those with no other children with a disability ( $M = 30.47$ ,  $SD = 9.46$ ), however this was not a significant difference ( $t(20) = .95$ ,  $p = .36$ ). Having other children with a disability was also positively correlated with coping, involvement, and self-efficacy. As noted above, mothers with additional children with disabilities were less likely to be employed.

*Parent distress* was weakly related to coping (higher distress related to lower coping), moderately related to parent involvement, and self-efficacy. That is, parents with higher levels of distress at the start of IBI reported lower levels of involvement in their child's IBI program

and lower self-efficacy about their involvement. Distress was also weakly negatively correlated with SES, maternal employment, and having other children with disabilities, as already noted.

*Coping* was only weakly positively correlated with involvement in IBI and self-efficacy surrounding involvement. As already noted, coping was negatively correlated with stress as expected (though only weakly).

*Parent involvement* was significantly correlated with marital status, and parental distress, as mentioned above. Very surprisingly, involvement in IBI, and self-efficacy about that involvement were very weakly correlated with each other.

*Self-efficacy* about involvement in their child's IBI program, as noted already, was related (negatively) to parental distress, i.e., parents with higher initial distress reported lower self-efficacy about their involvement.

**How are each of the family-related independent variables related to: a) standardized assessments of children's progress? b) parents' perception of children's progress?**

Eight different demographic, psychosocial and involvement variables were examined in this study (as described in Table 3). See Table 8 for the results of the correlations between these variables and the two outcome measures: standardized assessments of children's progress represented by cognitive rate of development, and parents' perception of children's progress. The two dependent variables were correlated only moderately with each other ( $\rho = .43, p < .05$ ), supporting the logic of examining them separately.

Table 8

*Correlations of Demographic, Psychosocial, and Involvement Variables with Measures of Child Progress*

	Cognitive rate of development	Parents' perception of children's progress
SES	.33	-.19
Marital status	-.06	-.20
Maternal employment	.64*	.11
Other children with a disability	-.20	.03
Parent distress	-.41	-.32
Coping	.19	.53*
Involvement	.45*	.33
Self-efficacy	-.08	-.05

\* $p < .05$

Lighter shading indicates moderate effects

Darker shading indicates strong effects

**a) Standardized assessments of children's progress.**

*Demographic variables.* SES was moderately correlated with children's cognitive rate of development during IBI. Children from families with higher SES made more cognitive gains during IBI. Somewhat surprisingly, maternal employment had a strong correlation with the standardized assessments of children's progress (although maternal employment was correlated weakly,  $\rho = .29$ , with SES). An independent  $t$ -test showed that children of mothers who were working, either part- or full-time, had substantially higher rates of development during IBI ( $M = 1.21$ ,  $SD = .42$ ), than children of mothers who did not work outside of the home ( $M = .50$ ,  $SD = .40$ ) ( $t(24) = -4.32$ ,  $p < .001$ ). Marital status was unrelated, and having other children with a

disability in the family was weakly negatively correlated with children's cognitive rate of development. An independent *t*-test showed that children in families with multiple children with disabilities ( $M = .53, SD = .47$ ) had somewhat lower rates of development than those in families where they were the only child with a disability ( $M = .80, SD = .56$ ). However this difference was not statistically significant ( $t(25) = .65, p = .29$ ).

*Psychosocial variables.* Parental distress was moderately negatively correlated with standardized assessments of children's progress in IBI. That is, higher levels of parental distress prior to IBI were related to lower cognitive rates of development for children during the year of IBI. This was as expected based on the literature (e.g., Shine & Perry, 2010), which has also found a negative relationship between parental distress and children's treatment outcomes. Coping was weakly correlated with standardized measures of progress.

*Involvement.* Parents' involvement in IBI was significantly and moderately correlated to children's cognitive gains. Higher levels of parental involvement in their child's IBI were related to children having higher cognitive rates of development. However, parents' self-efficacy surrounding involvement in IBI showed no relationship to children's gains.

In summary, the standardized outcome of children having higher cognitive rates of development after one year in IBI was related to mothers working, higher levels of parental involvement in IBI, lower levels of pre-IBI parental distress, and higher reported levels of SES.

#### **b) Parents' perception of children's progress.**

*Demographic variables.* Most of the family demographic variables examined in this study: SES, marital status, and maternal employment status, were weakly correlated with parents' perception of children's progress, and the presence of one or more other children with a disability was completely unrelated. SES was weakly negatively correlated with parents'

perception of children's progress; parents with higher SES perceived that their children were making less progress. An independent *t*-test demonstrated that unmarried parents ( $M = 4.23$ ,  $SD = .82$ ) rated their children's progress as somewhat higher than married parents ( $M = 3.91$ ,  $SD = .72$ ). However the difference between the two groups was not significantly different ( $t(26) = .93$ ,  $p = .36$ ). Mothers who were employed ( $M = 4.12$ ,  $SD = .77$ ) had ratings of perceived progress that were similar to those of mothers who were not employed ( $M = 3.92$ ,  $SD = .75$ ) ( $t(25) = .78$ ,  $p = .52$ ).

*Psychosocial variables.* Parental distress had a moderate negative relationship with perceived progress, suggesting higher levels of pre-IBI parental distress was related to lower parent ratings of children's progress. Coping had a somewhat surprising relationship with parents' perception of their children's progress, in terms of its magnitude. There was a strong positive relationship between these two variables, in which parents with higher levels of coping perceived their child to be making more progress.

*Involvement.* Parental involvement in their child's IBI program was moderately correlated with parents' perception of progress. Parents with higher levels of involvement in their children's IBI program perceived their children to be making more progress in IBI. Self-efficacy surrounding involvement in IBI had almost no relationship to parents' perception of their children's progress.

In summary, parents' perceptions of children's progress were related to higher levels of family coping, higher levels of parental involvement in IBI, and lower levels of pre-IBI parental distress. Interestingly, the two measures of child progress had different relationships with several of the family variables examined. SES demonstrated a positive relationship with the standardized measure of progress and a negative correlation with the perception based measure



of progress, demonstrating that children from higher SES homes were making more gains, however, their parents' perceptions did not reflect this. A much stronger relationship emerged between maternal employment status and children's cognitive rate of development than the perception-based measure. The opposite was true of coping; a much stronger relationship was seen between coping and parents' perceptions than children's cognitive rates of development.

**Which combination of family variables, considered simultaneously, best predict: a) standardized assessments of children's progress? b) parents' perception of children's progress?**

As many of the demographic, psychosocial, and involvement variables examined in this study were found to be intercorrelated with each other, regression analyses were conducted in order to better understand the potential effect these variables have on the two measures of children's progress. Initially, hierarchical regressions were conducted, with child characteristics typically reported to be related to outcomes (age and IQ at the initial assessment) entered at the first step, in order to control for them. As neither of these child characteristics demonstrated significant contributions to the prediction of children's progress, they were dropped to conserve degrees of freedom, as the sample size is relatively small for the number of predictors being examined (VanVoorhis & Morgan, 2001). Variables were selected based on the correlations described above, and the same set of four predictors (*maternal employment, parent distress, coping, and involvement*) was used for both outcomes. These variables were chosen as they represented all three areas of family variables (demographic, psychosocial, and involvement), and demonstrated moderate to strong correlations with one or both dependent variables. As this research was exploratory, and there was no theoretical rationale for any specific order of entry of variables, stepwise regression analyses were utilized.

**a) Standardized assessments of children's progress.** A stepwise regression was conducted to determine which of the four parent and family variables selected predict children's cognitive rates of development. The model generated from these variables was significant ( $F(2, 18) = 9.34, p < .01$ ) and accounted for 50.9% of the variance in child progress. The final model included *maternal employment* and *parent involvement* (see Table 9). *Parent distress*, and *coping* were excluded from the model by the SPSS program based on statistical criteria. Maternal employment was a significant predictor of children's cognitive rates of development, and accounted for 37.6% of the variance. Involvement was also a significant predictor of the standardized measure of progress, accounting for an additional 13.4% of the variance.

Table 9

*Stepwise Regression for Standardized Assessments of Children's Progress*

Model	<i>B</i>	<i>SE B</i>	$\beta$
Maternal Employment	.75	.19	.68***
Involvement	.36	.16	.37*

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

**b) Parents' perception of children's progress.** A second stepwise regression was conducted to determine which parent and family variables predict parents' perception of children's progress. The same parent and family variables were entered: *maternal employment*, *parent distress*, *coping*, and *involvement*. The model generated from these variables was significant ( $F(1, 20) = 9.64, p < .01$ ). *Coping* was the only variable included in the model, and it accounted for 32.5% of the variance (see Table 10).

Table 10

*Stepwise Regression for Parents' Perception of Children's Progress*

Model	<i>B</i>	<i>SE B</i>	$\beta$
Coping	.04	.01	.57**

\*\* $p < .01$ **Discussion**

The goal of this research was to explore multiple parent and family factors (Demographic, Psychosocial, and Involvement), which remain largely unexamined in the research literature, in relation to two different measures of children's progress in publicly funded IBI in Ontario. The first indicator of children's progress involved a standardized measure of child progress (cognitive rate of development during IBI). Children having a higher rate of development was related to parents reporting higher levels of SES, mothers working (either part- or full-time), lower levels of parental distress, and higher levels of parental involvement in their child's IBI program. When these parent and family variables were examined simultaneously to determine whether they predicted children's progress, maternal employment and parents' involvement in their child's IBI program emerged as significant predictors, together accounting for a large proportion of outcome variance.

Maternal employment status may be a significant predictor of children's progress for a variety of reasons. Mothers' working was related to higher levels of SES in this study. This may be demonstrating that mothers' working outside of the home is important for the extra income provided. As the measure of SES utilized in this study is a combined score of occupation and education attained, it is also possible that mothers who work outside the home have more education, or may be more achievement oriented. In addition, previous research has found a

connection between employment status and maternal well-being. Mothers who are employed (either part- or full-time) have been shown to report fewer depressive symptoms than unemployed mothers (Buehler & O'Brien, 2011). It is believed that employment provides mothers with support and resources that are not available to those who do not work outside the home (Buehler & O'Brien, 2011). It may be that working allows mothers to have a break from their children, and gives them an identity outside of being the mother of a child with ASD. As with any correlational finding, the direction of this effect is unclear. It could be that the children who make good cognitive gains differ in some ways that make it easier for their mothers to work outside the home. It is also possible that this finding is due to a third unknown variable that is having an impact on children's progress. As a large proportion (37.6%) of variance in children's progress in IBI was accounted for by mothers' employment, it would appear that this variable has the potential to improve both maternal well-being (Buehler & O'Brien, 2011) and their children's progress in IBI. Future research should examine maternal employment in more detail in order to understand the benefits for mothers and for children.

The other significant predictor of standardized measures of children's progress in IBI was parental involvement in IBI. This finding has very important clinical implications, which will be discussed below, and also provides evidence for the emphasis that clinicians have placed on parents' involvement in their children's IBI program.

Increased levels of parental involvement were related to lower levels of parental distress. While parental distress did not emerge as a significant direct predictor of children's progress in this study, as expected based on previous research, it may be indirectly involved in other parent variables that are related to children's progress. Maternal employment may reduce parental distress due to the financial assistance it provides to the family, the support and self-esteem

mothers can obtain through employment, and the opportunities provided for the mother during time spent away from their child at work. Distress also may be indirectly affecting children's progress through its relationship with involvement in IBI and self-efficacy surrounding parents' involvement; parents with lower levels of distress were found to be more involved in their child's IBI program, which was predictive of children making more progress, and to have higher levels of self-efficacy surrounding their involvement in IBI.

Surprisingly, self-efficacy surrounding parents' involvement in IBI was only weakly related to parents' involvement. As these variables were drawn from the same measure, and previous research on this measure demonstrated moderate correlations, we would have expected at least a moderate correlation between these variables (Solish, 2010). This discrepancy may be due to differences in the two samples. Another possible explanation may be due to a difference in the way the scores were calculated. In this study, the self-efficacy and involvement scores were averaged across the different types of involvement, whereas, Solish (2010), examined the types of involvement and self-efficacy separately (i.e., Child Program Involvement, Agency Involvement, and Training Involvement, were all calculated separately, and the self-efficacy scores for each type of involvement were calculated separately as well). As the purpose of Solish's (2010) study was to examine the PIQ as a measure, self-efficacy and involvement scores were calculated for each of the areas of involvement. In the current study, as many variables were being explored, the areas of involvement in the PIQ were combined to calculate one involvement and one self-efficacy score both for conceptual and practical reasons. Conceptually, in this study, parents' involvement was conceptualized as a single concept, as opposed to the various areas of involvement the PIQ measures, and practically, it was important to reduce the number of variables examined in this study, as the sample was relatively small, and many

different variables were being explored. More research is needed to determine the most appropriate approach to scoring parent involvement and self-efficacy on this measure, and the concept generally, in order to determine the nature and strength of the relationship, and how it affects children's progress in IBI.

Single parents were more involved in their children's IBI programs than parents who were married. Future research is needed on this topic in order to determine if it is common for single parents to be more involved in their child's intervention program, and attempt to decipher possible causes. The inclusion of a measure of marital quality or satisfaction would be important in future research on this topic.

The second measure of child progress examined in this study was parents' perception of their children's progress in IBI. Parents' perception that their children made more progress in IBI was related to higher levels of family coping, lower levels of parental distress, and parents' being more involved in their child's IBI program. The only variable found to significantly predict parents' perception of children's progress in the regression, however, was family coping. Coping being a predictor is logical, as the measure of outcome is perception based, and families' coping strategies would influence how they perceive their children's progress. An overall optimistic attitude, or positive response bias, could have been a third variable affecting ratings of both family coping, and parents' perception of children's progress. While parental distress did not predict parents' perception of children's progress, it may have had an indirect effect through coping, as distress and coping were negatively correlated with each other as would be expected, and previous research has shown that coping is related to fewer symptoms of depression, and fewer parent and family problems for the parents of children with autism (Dunn et al., 2001; Hastings & Johnson, 2001).

This study has shown that parent and family factors do have an impact on children's progress in IBI when measured using standardized methods and parental perceptions of progress. While these findings are correlational in nature and do not demonstrate causation, this study shows that demographics, psychosocial factors, and involvement in IBI relate to children's progress in different ways, both directly and potentially indirectly. This unique contribution to the research literature has important theoretical implications for future research regarding the actual mechanisms of effect and also has clear clinical implications.

### **Clinical Implications**

Some of the findings from this study have implications for clinical practice in terms of IBI and children with ASD. This study showed that parental involvement in IBI was related to children's progress and was demonstrated to be a significant predictor, with children making more progress when parents were more involved. This demonstrates that it is important for parents to be involved in their child's IBI program, including being aware of and participating in the setting of their child's program goals, communicating with the IBI agency on a regular basis, participating in parent training opportunities, and working on generalization of skills outside of formal IBI. Although it has been common practice to encourage parent involvement, this study provides actual empirical evidence of how important this involvement can be for children's outcomes.

Another finding from this study that has important clinical relevance involves mothers' employment. There may be financial benefits to working, but, additionally, this finding suggests that not only is maternal employment not detrimental for children, it may actually be beneficial for child outcome. However, the directionality of this finding is uncertain. Possibly children making good progress allows mothers to go out to work. The strong relationship between coping

and perceived outcome suggests that providing parents with supportive interventions focused on improving coping skills and strategies may help with parents' well-being. Interventions targeting task-oriented coping may help parents advocate for their child, obtain more services, and so on. Even teaching reframing and positive appraisal could help parents change the way they think about their children. Parents' perception of their child's progress may be important for their well-being, especially when the outward characteristics of the child may not change substantially.

### **Limitations**

The present study addressed important previously unexamined questions in the IBI literature and advances research on parental factors involved in children's progress in IBI. It does, nevertheless, have a number of limitations that are important to acknowledge. The sample used for this study was relatively small, and may not be representative of the larger population of families and children with ASD, although it was quite diverse.

In particular, many correlations were reported, the sample size was small for regression analyses, and we had a ratio of cases to variables that was lower than generally recommended (VanVoorhis & Morgan, 2001). Furthermore, because the study was exploratory and there was a lack of a theoretical basis for the order of entry of variables into a regression, stepwise regression analyses were utilized which may capitalize on chance. Thus, some findings may be the result of Type I error. Yet, because of the sample size and associated power limitations, some variables may not have emerged as significant because of Type II error which is an important consideration given this is a first exploration of this research topic. Further research should be conducted to examine parent and family variables with larger samples and more stringent regression methods.



Additional caveats include those associated with particular measures used in the study. The Parent Involvement Questionnaire used in this study is relatively new in its development and further research on this measure is needed. There are different ways to calculate scores on the PIQ and additional research would be beneficial to determine the optimal scoring approach. Also, it is important to keep in mind that the standardized measure of children's progress does not represent the children's absolute outcome, but their rate of development in cognitive abilities following one year of IBI. Depending on the child's cognitive level at the start of IBI, a particular rate of development will lead to different outcomes by the end of a year of treatment.

Nevertheless, this study provides a unique contribution to the field of IBI research, and has begun to address the gap in identifying sources of large amounts of previously unexplained variability in the outcomes of children with ASD. The results of this study have important clinical implications for the implementation of IBI, including encouraging parents to be actively involved with their child's treatment program, and encouraging coping strategies which may increase parents' positive perceptions of the progress their children are making.

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