

The Parent Involvement Questionnaire: Measuring Parents' Involvement in Behavioural Intervention for their Children with an Autism Spectrum Disorder

Abstract

Professionals in the field have emphasized the importance of parents' involvement in Intensive Behavioral Intervention (IBI) programs for their children with an autism spectrum disorder (ASD); however, little research has explored this involvement or what it entails. A parent self-report questionnaire was designed, in which parents' involvement, along with other factors related to involvement, were operationalized and measured. Questionnaires were completed by 105 parents of children with ASD. To create a theoretically sound and statistically reliable measure of involvement, an exploratory factor analysis of 20 involvement items was conducted. This resulted in a good-fitting four-factor model, in which four distinct types of involvement emerged: formal IBI, child program, training, and agency involvement. These results demonstrate that there are several different ways that parents can be involved in their children's IBI program. Implications for working with parents are discussed.

A significant number of studies now show that early, intensive instruction using the methods of Applied Behavior Analysis (ABA), sometimes termed Early Intensive Behavioural Intervention (EIBI) or simply Intensive Behavioural Intervention (IBI), can result in dramatic improvements (e.g., large IQ gains) for at least some children with an Autism Spectrum Disorder (ASD) (see meta-analyses by Eldevik et al., 2009; 2010; Reichow, 2012), although outcomes are highly variable. Clearly child characteristics, such as initial IQ and young age at admission to IBI (e.g., Perry, Blacklock, & Dunn Geier, 2013), are important sources of this variability in outcomes, as well as aspects of the treatment itself such as intensity and supervision model (e.g., Makrygianni & Reed, 2010; Reichow, 2012).

While the empirical literature about IBI continues to expand, there are some areas that remain under-researched to date. Notably, although clinicians acknowledge that family involvement is crucial to enhancing outcomes of IBI (or potentially undermining them), limited research has empirically evaluated or explored parents' involvement and what this involvement entails. Therefore, researchers in the ASD field (e.g., Eikeseth, 2009; Hastings & Johnson, 2001; Kasari, 2002; Sallows & Graupner, 2005; Strauss et al., 2012; Wolery & Garfinkle, 2002) concur that additional empirical data concerning the family and the family's role in IBI is required.

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However, before we can systemically evaluate whether increased parent involvement results in children making greater progress in therapy, as many would assume clinically, what is needed is a theoretically meaningful and statistically sound way of measuring parent involvement. To our knowledge, this is something that has not been addressed adequately in the IBI literature to date.

The majority of existing research about parent involvement in IBI has focused on parents conducting formal teaching sessions, acting as therapists, or attending parent training programs. A number of studies from various countries describe programs in which parents have been successfully trained to conduct formal IBI teaching sessions with their children, as direct members of the therapy team (e.g., Hastings & Johnson, 2001; McConachie & Diggle, 2007). Research has shown that, through appropriate training, many parents learn to be consistent, effective behaviour-change agents for their children, and can play a vital role in treatment generalization and maintenance (Green, 1996; Lovaas, 1987; Lovaas, Koegel, Simmons, & Long, 1973; McEachin, Smith, & Lovaas, 1993).

While parents can play an integral role in their children's treatment program, expecting all parents to attend intensive parent training programs and/or to run formal IBI teaching sessions in their home may not be feasible or realistic given other stressors and commitments (e.g., the needs of other family members, work schedules, mental health concerns, etc). It is commonly recognized that parents of children with ASD are often highly stressed, more so than parents of typically developing children or those with other special needs (e.g., Bromley, Hare, Davidson, & Emerson, 2004). For these parents, it is vital to recognize and to emphasize that there are other ways to be "involved." In order to devise a definition of involvement that goes beyond parents acting as therapists, we reviewed the literature about general parent involvement practices in educational interventions (i.e., not ABA/IBI specific) for children with disabilities and children with ASD. This research suggests a broader understanding of the term involvement for parents, including activities such as: attending education planning meetings, workshops, and training about ASD; promoting the integration of school goals into the home environment;

making phone calls to the school or program; observing or volunteering in the classroom; and participating in evaluations of children's progress (Benson, Karlof, & Siperstein, 2008; Gavidia-Payne & Stoneman, 1997; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999). Furthermore, Kuhn and Carter (2006) employed a broad definition of how parents of children with ASD can be involved in their children's growth, by assuming an active role in their child's development, engaging in interactions with their child, and identifying strategies that minimize maladaptive and maximize adaptive behaviours.

In an earlier pilot study, we developed and evaluated a measure that operationalized involvement and explored potential predictors of involvement (Solish & Perry, 2008). Results from this study were based on responses from 48 parents of children with ASD receiving publicly funded IBI services in one of four agencies across Ontario. The questionnaire used in this research proved to be a fairly reliable measure but the internal consistency of the 6-item involvement scale was only minimally acceptable (Cronbach's $\alpha = .66$), and it was clear that revisions to this involvement scale were indicated.

The objective of the current study was to extend and expand on this previous work in order to create a statistically sound and theoretically meaningful measure of parent involvement in IBI, the Parent Involvement Questionnaire. We initially conceptualized that three different, but likely related, types of involvement could be measured (i.e., agency involvement, child program involvement, and training involvement). Multiple items pertaining to each of these involvement types were developed and included in the revised measure described below. We report here on the factor structure of the Parent Involvement Questionnaire, and suggest directions for future research using this measure.

Materials and Methods

Participants

A total of 105 caregivers of children with ASD (92 biological mothers or female guardians and 13 fathers) from diverse backgrounds participated in this study (see Table 1 for parent demographic information). The children (81

Table 1. Parent Demographic Information

	Mothers <i>n</i> (%)		Fathers <i>n</i> (%)	
Language(s) Spoken at Home ^a				
English		70 (66.7)		
English and other		30 (38.6)		
Other only		3 (2.9)		
Marital Status ^b				
Married/Common Law		90 (85.7)		
Single-Parent		15 (14.3)		
Highest Level of Education ^{c,d}				
Elementary School – High School	16	(15.4)	16	(17.0)
Some College/University	17	(16.3)	14	(14.9)
Diploma/Undergraduate Degree	49	(47.1)	41	(43.6)
Professional/Graduate Degree	22	(21.2)	23	(24.5)
Employment ^{c,d}				
Part-time	22	(21.2)	4	(4.3)
Full-time	45	(43.3)	84	(89.4)
No paid employment	37	(35.6)	6	(6.4)
Cultural Orientation (Schwartz, 2006) ^{c,e}				
West European	2	(1.9)	2	(2.1)
English-speaking	68	(65.4)	66	(68.0)
Latin American	7	(6.7)	8	(8.2)
East European	4	(3.8)	0	(0)
South Asian	12	(11.5)	11	(11.3)
Confucian influenced	6	(5.8)	5	(5.2)
African and Middle Eastern	5	(4.8)	5	(5.2)

^a *n* = 103 ^b *n* = 105 ^c *n* = 104 (mothers) ^d *n* = 94 (fathers) ^e *n* = 97 (fathers)

males and 23 females, 1 gender missing) had parent-reported diagnoses of Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), or an unspecified PDD/ASD. Children ranged in age from 3 to 16 years, with a mean age of about 7 at the time of the study (see Table 2 on the following page for child demographic information).

Some standardized assessment data were collected from the children's clinical files at their respective IBI agencies, with parents' consent (*n* = 91) as seen in Table 3 on page 38.

Measure

Parent Involvement Questionnaire. The Parent Involvement Questionnaire was originally created for use in our previous research (Solish &

Perry, 2008). Categories and specific questions for the questionnaire were rationally derived from a number of sources including a review of the general literature about parent involvement and the minimal literature about parent involvement in IBI, as well as by consulting with experienced IBI professionals and pilot testing with parents. After completing our previous study, we used the results, feedback, and responses from parents to make some revisions. The revised version of the questionnaire was used in the current study. The full questionnaire is composed of questions measuring different types of involvement (discussed in detail below), as well questions measuring factors deemed to be related to involvement (i.e., self-efficacy, belief in IBI, parent positive and negative impact, and knowledge of ASD and IBI), not discussed in the present paper. (For

Table 2. Child Demographic Information

	<i>n</i> (%) or <i>M</i> (<i>SD</i>)	
Gender ^a		
Male	81	(77.9)
Female	23	(22.1)
Age at the time of the study ^b (months)	83.44	(32.38)
Age when started IBI ^b (months)	59.81	(30.17)
Diagnosis (parent report) ^c		
Autistic Disorder/Autism	59	(57.3)
PDD-NOS	5	(4.9)
ASD	39	(37.9)
Therapy location ^c		
Home-based	19	(18.4)
Centre-based	71	(68.9)
Combination (home, centre, school)	13	(12.6)
Birth order ^b		
No siblings	20	(19.6)
First born	25	(24.5)
Second born	35	(34.3)
Third born or later	22	(21.6)

^a *n* = 104 ^b *n* = 102 ^c *n* = 103

more details about the other sections of the measure, please refer to Solish and Perry, in preparation).

In the Parent Involvement Questionnaire, the concept of parent involvement in the child's IBI program is comprised of 24 items. It was conceptualized that three different, but likely related, types of involvement could be measured: agency involvement, child program involvement, and training involvement. The first section, agency involvement (6 items) measures parent's participation in the agency from which the child is receiving services (e.g., *how often do you communicate directly with your child's IBI program staff either on the phone or in person?*). The second section, child program involvement, includes 12 items focusing on four areas (academic skills, social and play skills, communication skills, and self-help skills). Parents are asked to what extent they do formal IBI sessions in each area (e.g., *to what extent do you do formal IBI sessions focusing on your child's academic skills? e.g., letter identification, counting, printing, math, reading, etc. in a structured teaching situation*). A parallel set of questions addresses generalization in the four areas (e.g., *to what extent do you try to generalize your child's academic skills? e.g., if*

you are at the grocery store and you are working on counting do you ask your child to put 5 apples into a bag?). Parents are also asked how many hours per week they estimate implementing formal IBI sessions and deliberately generalizing skills, as well as their degree of familiarity with their child's specific IBI program goals. The third section, training involvement (6 items), is based on parents' participation in IBI or behavioural training, as well as the extent to which they seek out learning opportunities (e.g., *how many hours of behavioural lectures, presentations, workshops, and/or conferences have you attended e.g., where you have been taught advanced behavioural techniques, or you have learned about research on behavioural intervention?*).

Involvement questions are answered on a 5-point Likert scale (with an option for not applicable for some questions). In different sections of the questionnaire varying descriptors are used with the Likert scale to provide guidance for selecting a response (e.g., 1 = *never*, 3 = *sometimes [once per week]*, 5 = *frequently [daily]*). Higher scores reflect greater parental involvement. For further details on the development of this measure, contact the authors directly or see Solish (2010).

Table 3. IBI Entrance Assessment Data from File Review

	<i>n</i> (%) or <i>M</i> (<i>SD</i>)	
Adaptive measure used ^a		
VABS	20	(32.3%)
Vineland-II	36	(58.1%)
SIB-R	5	(8.1%)
ABAS	1	(1.6%)
Mean estimate of adaptive composite (standard score)	57.48	(13.12)
Cognitive measure used ^b		
Mullen	39	(72.2%)
Bayley	6	(11.1%)
Stanford Binet-5	3	(5.6%)
WPPSI-III	3	(5.6%)
WISC-IV	2	(3.7%)
Leiter-R	1	(1.9%)
Mean estimate of IQ standard score	45.31	(21.52)
Mean CARS score ^c	36.92	(6.35)
CARS category ^c		
Not Autistic	5	(9.6%)
Mildly-Moderately Autistic	24	(46.2%)
Severely Autistic	23	(44.2%)

^a *n* = 62. *Vineland Adaptive Behavior Scales Interview Edition, Survey Form (VABS; Sparrow, Balla, & Cicchetti, 1984); Vineland Adaptive Behavior Scales, Second Edition (Vineland-II; Sparrow, Cicchetti, & Balla, 2005); Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996); Adaptive Behavior Assessment System (ABAS; Harrison & Oakland, 2000).*

^b *n* = 54. *Mullen Scales of Early Learning (Mullen, 1995); Bayley Scales of Infant Development (3rd edition) (Bayley, 2005); Leiter International Performance Scale-Revised (Roid & Miller, 1995); Stanford-Binet Intelligence Scales, Fifth Edition (SB-V; Roid, 2003); Wechsler Preschool and Primary Scale of Intelligence (3rd edition) (WPPSI-3; Wechsler, 2002); Wechsler Intelligence Scales for Children (4th edition) (WISC-IV; Wechsler, 2003).*

^c *n* = 52. *The Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988).*

Procedure

Following ethics approval from the University and participating agencies, parents were either mailed or given a package containing: a cover letter of support written by the clinical director at the agency (assuring their participation or non-participation would have no impact on services received); an information letter detailing the purpose of the study; a consent form; the Parent Involvement Questionnaire; and a child demographic information sheet. When a completed consent form and questionnaire were returned to the researcher, a copy of the parent's consent was mailed to the agency so that the child's clinical file data could be released. After the study was completed, a thank-you letter and summary of results was sent to participants and agencies.

Of the 105 children in this sample, 82 (78%) were receiving services from six of the nine publicly funded regional IBI programs in Ontario (see Perry et al., 2008 for a description of the program). These include centre-based and home-based programs administered by trained, supervised staff (see Perry et al., 2008 for more details of the program model). The response rate for parents of children receiving publicly funded services was about 15%. The remaining 23 children (22%) were receiving services from a number of privately funded programs across Ontario. The response rate for these families could not be accurately calculated, because information about the study was distributed through list serves and posted on websites. In terms of the actual number of packages distributed, the response rate was comparable to publicly funded families at about 16%. As there

were no significant differences on any of the main variables of interest in this study between the groups receiving publicly and privately funded IBI services, the groups were combined.

Results

Exploratory Factor Analysis of the Involvement Items

Given the lack of previous research about the distinction among different involvement types, an exploratory factor analysis (EFA), using Ordinary Least Squares extraction and an oblimin rotation, was conducted to test our theory that some involvement items would be more closely inter-related than others. Before the EFA was conducted, an expectation maximization (EM) algorithm was implemented to impute any missing values in the involvement variables. For extensive details on models explored and the various fit statistics examined, please see Solish (2010).

Although the Parent Involvement Questionnaire contained three sections, which we had expected might empirically form three factors; in fact, a four-factor model seemed to best represent the data and be conceptually meaningful. The child program involvement items clearly fell into two separate factors; formal IBI and generalization. The choice of the four-factor model was based on examination of the change in slope of the scree plot and various fit statistics, which were best for this four-factor model, especially compared to the three-factor model (and other models) (see Solish, 2010 for details)

However, within the four-factor model, four of the items were deemed problematic (they were endorsed very infrequently and/or did not load on any factor) and were consequently dropped. After removing these four items simultaneously, the EFA was repeated with the remaining 20 items to ensure that the factor structure remained the same and none of the other loadings were substantially affected. Results showed that the four-factor solution continued to be the best solution and all 20 remaining items loaded as well or better on the same factors as in the first EFA (see Solish, 2010 for details).

Rotated factor loading estimates for this final four-factor model with 20 items are seen in Table 4 on the opposite page. On the final EFA,

all items had positive loadings on one of the four factors, with the strength of the loadings ranging between .32 and .99. The four factors were named: Formal IBI Involvement (Cronbach's $\alpha = .95$; 5 items), Child Program Involvement ($\alpha = .79$; 6 items), Training Involvement ($\alpha = .73$; 3 items), and Agency Involvement ($\alpha = .72$; 6 items). The overall involvement scale demonstrated good reliability with a Cronbach's alpha of .82 with all 20 items included. As discussed below, there may be reasons not to include the Formal IBI involvement factor in certain situations. Reliability of the Parent Involvement Questionnaire without the Formal IBI factor is, $\alpha = .77$, demonstrating acceptable to good levels of reliability.

Communality estimates for items in this model are shown in Table 4, and the root mean square off-diagonal residuals value (RMR) was 0.04, which suggests a good-fitting model (Hu & Bentler, 1999). The inter-factor correlations are displayed in Table 5 on page 41. When controlling for other factors, about 18% of the variance in the collection of observed variables is explained by Factor 1 (formal IBI involvement), 13% is explained by Factor 2 (child program involvement), 8% is explained by Factor 3 (training involvement), and 7% is explained by Factor 4 (agency involvement).

While this four-factor model is both conceptually meaningful and is the most parsimonious model that adequately accounts for the observed data, it describes a slightly different structure from the three types of involvement initially conceptualized in the Parent Involvement Questionnaire. As described in the measures section above, the child program involvement section initially included questions about parents generalizing skills as well as parents conducting formal IBI sessions. However, based on the results from the EFA it was clear that there was a distinction between the items related to conducting formal IBI sessions and those related to promoting generalization of skills. Furthermore, as can be seen in Table 6, formal IBI involvement was significantly correlated only with agency involvement, and unrelated to the other two involvement variables, whereas child program involvement (i.e., the generalization items without the formal IBI items), agency, and training involvement, were all correlated with one another. In addition, about one quarter of parents reported not being involved in formal IBI sessions in any capacity. Thus, they answered n/a to each of these ques-

Table 4. Rotated Factor Loadings for the Four Factor Model with 20 Items

	Factor 1 "formal IBI involvement"	Factor 2 "child program involvement"	Factor 3 "training involvement"	Factor 4 "agency involvement"	Communality
Formal IBI sessions – communication skills	0.99				.93
Formal IBI sessions – self-help skills	0.91				.80
Formal IBI sessions – academic skills	0.87				.73
Formal IBI sessions – social/play skills	0.87				.80
Hours per week conducting IBI sessions	0.86				.83
Generalization – social/play skills		0.75			.53
Generalization – communication skills		0.73			.53
Hours per week promoting generalization		0.73			.50
Generalization – self-help skills		0.70			.41
Generalization – academic skills		0.59	0.24		.47
Familiarity with child's program goals	0.24	0.44			.31
Hours of behavioural parent training courses			0.90		.75
Hours of behavioural lectures/workshops/conferences			0.79		.59
Hours per week involved in training activities			0.38		.35
Hours per week involved in child's IBI agency				0.76	.54
Watching the child in therapy sessions				0.68	.39
Receiving individual coaching/feedback from IBI staff				0.56	
Communicating with IBI staff				0.39	
Attending review meetings/input into goal setting				0.38	
Completing homework provided by the IBI staff		0.30	0.22	0.32	

Table 5. Inter-Factor Correlations for the Revised Four Factor Model

	Factor 1	Factor 2	Factor 3
Factor 2	-.01		
Factor 3	.12	.26	
Factor 4	.38	.26	.18

tions and their scores are considered as missing data for the formal IBI involvement scale of the measure. Therefore, there appeared to be both statistical and theoretical differences between the formal IBI involvement factor and the other three involvement types.

Table 6. Correlations Among the Involvement Observed Variables

	Child Program	Agency	Training
Agency	.36**		
Training	.29**	.24*	
Formal IBI	.03	.32**	.10
**p < .01	*p < .05		

Discussion

Clinicians in the ASD field concur that parents' involvement in their children's behavioural intervention programs is beneficial and should be strongly encouraged. However, there is very limited research empirically evaluating or exploring the construct of parent involvement in IBI. Therefore, in this study we sought to define and measure parent involvement in IBI.

A theoretically sound and statistically reliable measure of the construct of parent involvement in IBI was developed. This was achieved by conducting an EFA that yielded a four-factor model of involvement with good model-data fit. The factors in this model suggested the following four types of involvement: formal IBI involvement (i.e., structured teaching), child program involvement (e.g., promoting generalization across developmental areas), training involvement (participation in various IBI and behavioural training

opportunities), and agency involvement (participation in various aspects of the child's IBI program in conjunction with the agency from which the child is receiving services).

While this four-factor model is slightly different from the three-factor model that was initially conceptualized, we believe it is both more comprehensive and meaningful. Results of the factor analysis clearly suggested that child program involvement was comprised of two separate ways parents could be involved in programming for their children; by providing opportunities for their children to generalize skills learned in naturalistic therapy settings, and by conducting formal teaching sessions. This emphasizes the importance of one of the goals of this study, which was to demonstrate that parent involvement in IBI consists of much more than parents conducting discrete trial training with their children with ASD. The distinctiveness of parents' involvement in formal IBI sessions was further highlighted by the fact that while the other three involvement types (child program, training, and agency) were all correlated with one another, this was not the case for formal IBI involvement. Furthermore, about one quarter of parents reported not being involved in formal IBI sessions in any capacity, despite participating in their children's programs in other ways. Thus, it is possible that there is something unique about the families who are able to implement these formal teaching sessions, in addition to being involved in other capacities. As it would seem that many parents (at least in our sample) are not involved in conducting formal IBI sessions, the decision to include the formal IBI involvement factor in future versions of the measure should be made based on the nature of the sample. Dropping the formal IBI items resulted in a slight decrease in the internal consistency of the total score, however.

Although we believe this study makes a unique contribution to the literature and explores an important, yet under-researched area, it is not without limitations. First, the response rate was quite low (about 15%), and thus there is the possibility that there is something unique about the families who decided to participate in this research (i.e., they may be highly committed to IBI). However, it is important to note the diversity of this sample in a number of ways (e.g., parents' education, family ethnicity, and

children's developmental level; see Tables 1 and 2). Furthermore, there was a range of scores on each of the involvement subscales, demonstrating that the families who participated varied in their amount of involvement, and were not exclusively those who were highly involved in their child's programs. The current study was also limited by a modest (though acceptable) sample size for the EFA, and thus it would be advisable to cross validate this research with a larger number of families, and/or using a Confirmatory Factor Analysis methodology.

There are a number of important clinical implications emerging from this work. Namely, by adopting a broad conceptualization of parent involvement, researchers and clinicians in the IBI field will be able to recognize the diverse ways that parents can participate in their children's intervention programs. Acknowledging that parent involvement consists of more than parents conducting formal teaching sessions or attending parent-training sessions will allow professionals to encourage and value involvement in ways that may be more feasible and realistic for individual families.

Future research should include prospective longitudinal studies evaluating children's progress in IBI programs. By including the Parent Involvement Questionnaire developed and evaluated in the current study, researchers can systematically explore whether children's progress is significantly influenced by parents' involvement, amongst other factors. If this is found to be the case, it speaks to the need for IBI programs to promote additional parent involvement opportunities and for increased funding to be devoted to the parent component of these programs (without reducing the services provided to the children). A prospective study investigating outcomes of children in IBI programs in Ontario has been completed and is forthcoming (Perry, Dunn Geier, & Freeman, in preparation). A recent conference presentation based on that dataset explored parent factors related to children's outcomes and showed a modest relationship of parent involvement (using the Total Involvement score excluding Formal IBI) to children's developmental gains (Shine & Perry, 2013).

In future research, it will also be beneficial to explore how clinicians can increase parents'

involvement in their children's intervention programs. In a companion study to the present paper, a number of factors (e.g., parents' belief in the effectiveness of IBI, knowledge of autism and IBI, and self-efficacy surrounding their involvement) were investigated, in the hopes that these factors could be targeted and possibly increase parents' involvement indirectly (for details see Solish & Perry, in preparation).

Overall, the current model of involvement, including formal IBI, child program involvement, parent training, and agency involvement items, provides researchers with a comprehensive, detailed, and statistically sound way to obtain rich information about the ways that parents can participate in their children's IBI education and programming. The ultimate goal of research in this area is to determine whether increased parental involvement in children's IBI programs results in children making greater progress in therapy, something that is believed to be true clinically, but has yet to be demonstrated by empirical research. The current study attempts to contribute to this goal with the creation of a conceptually meaningful and statistically reliable measure of parent involvement that can be used in future research.

Key Messages From This Article

Professionals: There are many ways for parents to be involved in their children's IBI programs other than conducting formal sessions with their children. Encourage parents to be involved in these other ways.

Policymakers: As it is sometimes difficult for parents to conduct formal IBI sessions with their children, it is important to include other, less demanding forms of involvement into programming.

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