

## BRIEF REPORT: Parents' Perception of Progress Versus Children's Actual Progress in Intensive Behavioural Intervention

### Abstract

*Parents' perceptions of their child's progress in Intensive Behavioural Intervention (IBI) are important because they may affect parental involvement and selection of intervention. A previous study by our team found that the vast majority of parents have a positive perception of progress in IBI and that parents are seeing changes across a range of domains. The current study explored parents' perceptions about their child's progress in IBI and compared these perceptions to the child's actual progress on standardized measures. The participants included 27 children enrolled in the Toronto Partnership for Autism Services (TPAS) IBI program. We found that most parents had positive feelings about their child's progress in IBI. However, these perceptions were not significantly related to children's actual progress.*

Currently, Intensive Behavioural Intervention (IBI) is the most empirically supported form of therapy for young children with autism spectrum disorders (ASDs) (Perry et al., 2008). Standardized measures are typically used in research to track children's progress (e.g., increased IQ scores). Although little information is available in the current literature regarding parents' perceptions of child progress, our previous research suggests that parents have a range of beliefs regarding how their child is progressing through the IBI program (Weiss, Blacklock, Perry, & Freeman, 2010). For example, they may see great improvements in the child that they attribute to IBI; they may perceive small improvements that are not apparent on standardized tests; or they may perceive the child to be unchanged and not value skills that may have been mastered in IBI. Clinical experience suggests that these perceptions may not necessarily correspond well to measureable changes in standardized measures of progress.

Parents' perceptions of progress are important in their own right because they may affect the selection and implementation of interventions (Schreibman, 2000), and parental involvement (Solish & Perry, 2008). If parents attribute major progress in their child to a particular therapy, they are more likely to obtain that therapy for their child, have it implemented as well as possible, and be involved in their child's treatment. Conversely, if parents perceive their child's progress to be minimal, they may not implement it well, or they might remove their child from the program, possibly prematurely. Thus, parents' perceptions about their children's progress may be linked with quality of intervention for the child and, thereby, possibly to children's outcomes.

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Again, little information is currently available regarding parents' perceptions of child progress in IBI programs. A recent study by our team found that the vast majority of parents have a positive perception of progress, and that parents report seeing improvement across a range of domains (Weiss et al., 2010). These domains included expressive language, focus/attention, receptive language, routines, alternate forms of communication, eye contact, social interaction, behaviour, pre-academic and early academic skills, computer skills, playing with toys, toileting, gross motor, transitions, pointing, self-help, and fine motor (Weiss et al., 2010). However, that study did not examine parent perceptions of progress in comparison to the child's actual progress. Thus, the purpose of the current study was to gather information about parents' perceptions about their child's progress in IBI and compare these to the child's actual progress in IBI, based on standardized measures.

## Method

### Participants

Our participants were the parents of 27 children enrolled in the Toronto Partnership for Autism Services (TPAS) IBI program. All children were male, and ranged in age from 43 to 81 months at the start of IBI ( $M = 55.96$ ,  $SD = 10.37$ ). Twenty children had a diagnosis of Autistic Disorder, while seven children had a diagnosis of Pervasive developmental disorder not otherwise specified (PDD-NOS).

### Procedure

The current study is part of a larger project that was approved by York University and Surrey Place Centre. Children were assessed at entry

to the TPAS program and again after one year of IBI. Parents' perceptions of progress were measured after one year of IBI.

### Measures

*Parent perceptions* were measured by asking open-ended questions about how IBI was going, whether they saw any changes in their child, and whether or not they attributed these changes to IBI.

*Children's actual progress* was assessed for autism severity, verbal and nonverbal mental age, and adaptive level. Autism severity was based on the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988); cognitive abilities were assessed using either the Mullen Scales of Early Learning (Mullen, 1995) or the WPPSI-3 (Wechsler, 2002); and adaptive skills were based on the Vineland Adaptive Behavior Scales-II (Sparrow, Cicchetti, & Balla, 2005), which includes scores for Communication, Daily Living Skills, Socialization, Motor Domains, and the Adaptive Behavior Composite.

## Results

Parents' comments about their child's progress were grouped (by consensus of the first two authors) into four categories: negative, mixed, positive, or strongly positive. Parents' perceptions were predominantly positive. Eleven (41%) parents' comments were classified as being strongly positive; 11 (41%) as positive, five (18%) as mixed, and none were negative.

Table 1 shows mean change in the children's scores (post minus pre). One-way ANOVAs were conducted for each score to test for differences among the three perceived outcome

Table 1. Comparison of Actual Progress (Change Scores) Across Parent Perception Categories

	Strongly Positive ( <i>n</i> = 11) M (SD)	Positive ( <i>n</i> = 11) M (SD)	Mixed ( <i>n</i> = 5) M (SD)	ANOVA F (2, 24)
CARS Total	-2.6 (4.8)	-2.0 (3.0)	0.7 (4.0)	1.19
Verbal MA	10.6 (7.3)	11.0 (7.0)	7.4 (11.3)	0.36
Nonverbal MA	19.0 (9.0)	11.7 (8.1)	8.8 (7.4)	3.21
Adaptive ABC Age	9.9 (8.2)	14.2 (7.1)	10.1 (10.1)	0.88

groups (i.e., mixed, positive, strongly positive). There were no statistically significant differences across groups, although the “mixed” group tended to show less progress.

## Discussion

We found that most parents have strongly positive or positive perceptions about their child’s progress after one year of IBI. However, these perceptions did not correspond completely to actual progress on standardized measures. This could indicate a generally optimistic viewpoint among parents, which may be a good coping strategy, or it may be that parents are aware of more subtle changes in their children that are not apparent from standardized measures.

Although there were not strong relationships between parents’ perceptions and children’s actual progress, there does seem to be a trend suggesting such a relationship, at least for some variables. For Nonverbal cognitive ability, for example, children whose parents were strongly positive had made gains, on average, of 19 months in nonverbal MA (more than would be typical in a 12-month period), compared to a 12-month gain in the “positive” group and about a 9-month gain in the “mixed” group. With a larger sample and more power, these differences might have emerged as significant.

In the future, it would therefore be important to look at this question with a larger sample size (i.e., more statistical power). In addition, it would be interesting to use additional aspects of actual progress (e.g., language, maladaptive behaviour) that may be more salient and observable for parents, as well as more specific and reliable perception measures (e.g., rating scales of perceived change as used in Solish & Perry, 2008). Future studies could also compare mothers’ and fathers’ perceptions, examine whether parents’ ratings change with increased time in IBI, and assess how parent ratings affect treatment selection and parent involvement.

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## Key Messages From This Article

**People with disabilities:** Parents think that IBI therapy really helps their child.

**Professionals:** Parents have a positive view of their child’s progress in IBI therapy. The way professionals measure progress may not always reflect the changes parents are noticing.

**Policymakers:** Parents have a positive view of their child’s progress in IBI therapy.

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