

## The TRE-ADD Preschool Parent Training Program: Program Evaluation of an Innovative Service Delivery Model

### Abstract

*This paper describes an innovative behavioural service delivery model for preschoolers with autism and their parents. The program was evaluated using standardized child and parent measures, as well as consumer satisfaction in a sample of 27 families. Results indicated that parents increased their knowledge of behavioural principles, children's skills increased significantly across domains relative to 10 waitlist comparison children, there was no change in parents' stress or family harmony, and parents were very satisfied with the program. However, parents did not feel confident about their ability to continue a home program unaided and children were receiving less than optimal amounts of intervention following the program.*

Autism involves pervasive deficits in socialization, communication, and behaviour and, often, intellectual disability as well. It is a disorder which has, in the past, been considered very difficult to treat effectively. In recent years, Intensive Behavioural Intervention (IBI) has been recommended by various authorities as the treatment of choice for preschoolers with autism (aged 2 to 5), based on evidence of good efficacy (Green, 1996; National Research Council, 2001; New York State Department of Health, 1999; Perry & Condillac, 2003; Schreibman, 2000). IBI programs involve highly intensive teaching (e.g., 20 to 40 hours per week of 1-to-1 teaching for 2 years) by well trained and supervised staff and may include a parent training component.

In Ontario, the Ministry of Children and Youth Services designed a program based on best practices and has funded IBI since 2000 (Perry, 2002). Prior to 2000, IBI was not available in publicly funded settings and there was pressure on service providers to assist these children. Even since 2000, many preschool children remain on wait lists for IBI because of capacity-building challenges, limited resources, and deployment of IBI dollars to older children. Thus, service providers struggle to provide at least some support to these families, many of whom remain on wait lists.

The Treatment, Research and Education for Autism and Developmental Disorders (TRE-ADD) Preschool Parent Training Program was developed in the spring of 1997, before the Provincial IBI program existed. It was our attempt to respond to the community's needs at the time in a way that was within our fiscal and other logistical limitations but was,

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nevertheless, based on current research literature. Since a similar situation again exists as of this writing (although for different reasons), we offer this program description and evaluation to the field as a potentially useful service delivery model for providing cost-effective services to preschoolers with autism and their families. We emphasize that we do not recommend this program as equivalent to an IBI program in any way; we view it as simply as a stop gap measure which may be feasible for families on waiting lists for IBI or whose children are not eligible for provincial IBI funding.

## The TRE-ADD Preschool Parent Training Model

The primary clinical objective of the program was to train parents of preschool children with autism in the fundamental techniques of behavioural intervention and to support the practice of these techniques in the home. Our specific goals were:

1. To train parents in behavioural teaching techniques;
2. To provide parents with accurate information about diagnosis and treatment;
3. To provide parents with emotional support and opportunities to contact other parents;
4. To decrease parents' stress and improve family harmony;
5. To improve skills and behaviour in preschoolers with autism;
6. To facilitate parents' accessing other appropriate services; and
7. To evaluate the effectiveness of the program.

The Preschool Program was a 3-month intervention which began with a comprehensive developmental and diagnostic assessment and then provided a combination of individual 1-to-1 instruction by trained staff and a group parent training model with individual coaching. Each group of six to eight families participated once a week for about 3 hours for 11 weeks. Each of the weekly sessions had three parts. During the first

part of each session, *parents* received the didactic group instruction by the two Group Leaders (and sometimes the supervising Psychologist or a guest speaker). The content of these sessions began with the basics about autism and related disorders, then moved into the behavioural teaching principles (e.g. selecting goals, instructional skills, prompting, reinforcement, correcting errors, teaching communication and managing problem behaviour) and ended with material on family issues and stress management. Concurrently, trained therapists worked with the *children* (based on individualized goals derived from the assessment). During this time the Senior Therapist (and sometimes the Psychologist) circulated and provided support and supervision to the 1-to-1 therapists. In the second part of each session, parents were expected to apply the principles they were learning to their own child, with coaching, feedback, and encouragement from their child's 1-to-1 therapist. The therapist also gave them homework to do, which became the foundation of a home program, gradually building up the time and expectations, as appropriate to the child's and family's needs and abilities. The Senior Therapist and Group Leaders (and sometimes the Psychologist) circulated to support and assist in these activities. In the final portion of each session, the *parents* returned to the group setting to exchange information and support with other parents and receive their homework readings. During this time, the *children* engaged in a group activity such as a craft, song, or game, designed to help improve their play and social skills.

## Program Evaluation

In our Program Evaluation, we set out to address five research questions:

- 1 Did parents improve in their knowledge and skills? We expected they would, based on standard knowledge measures as well as by direct report.
- 2 Did children improve relative to comparison children? We hypothesized that children's skill development would be greater than that of children on the waitlist for the program.
- 3 Did the program impact on family functioning? We hypothesized that our program

would result in decreased stress and improved family functioning, because giving parents skills, information, and support would be helpful to them. We predicted that this would be the case, even though we were also placing demands on them, which some people have suggested might increase family stress.

- 4 Were parents satisfied with the service? We hoped they would be but wanted to hear positive or negative feedback.
- 5 Did parents feel equipped to continue a home program? We wanted to address this crucial question given that we knew this program was by no means sufficient to meet the needs of these children, but wanted to know whether parents were able to continue with a home program, given this as a basis.

The evaluation of the program involved a pre-post waitlist Comparison Group research design. However, it came to our attention during the assessments with Comparison families that, in fact, some were receiving a considerable amount of intervention elsewhere while, nevertheless, remaining on the wait list for our program. Thus, in this report, we will present the findings from our Intervention group compared with two other samples of children and families from whom we collected all the same data: *Comparison Group A*: a small group ( $n = 5$ ) of wait list children receiving very little or no intervention; and *Comparison Group B*: a small group ( $n = 5$ ) of children receiving fairly intensive intervention elsewhere (such as home-based ABA, specialized preschool for children with autism, Section 19 classroom, etc.).

## Method

Ethics approval to evaluate the program was obtained through the Research Ethics Committee at Thistleton Regional Centre (Toronto, ON).

### Participants

Families (both mothers and fathers in most cases) of 38 children participated in one of five rounds of the Preschool Program between 1997 and 2000. The first group, which involved 5 families, was considered a pilot, following which we changed and refined a number of aspects of the program and thus, we did not use their data

here. There were 4 dropouts out of 38, quite a low rate based on our anecdotal comparisons with other programs. In addition, two families who completed the intervention were unavailable for the post-treatment assessment. Thus, most analyses presented here are based on data from 27 Intervention completers from Groups 2, 3, 4, and 5, as well as the 10 Comparison children in Groups A and B (described earlier).

The children in the intervention group (21 boys and 6 girls) ranged in age from 23 months to 5½ years and were diagnosed with either Autistic Disorder ( $n = 18$ ) or Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS) ( $n = 9$ ). Other characteristics of the participants are shown in Table 1. Kruskal-Wallis non-parametric tests for 19 continuous variables indicated only one significant difference across groups, which was for the Vineland Adaptive Behavior Scales (VABS) raw Social domain score, such that the Intervention group was lower than the two Comparison groups. Thus, it can be concluded that the groups were roughly equivalent on developmental and diagnostic variables prior to treatment.

### Measures

Developmental level was determined based on the *Bayley Scales of Infant Development* (Bayley, 1993), a standardized, norm-referenced measure of children's cognitive level, and the *Vineland Adaptive Behavior Scales* (VABS; Sparrow, Balla, & Cicchetti, 1984), a norm-referenced parent-interview measure of adaptive behaviour, which includes Communication, Daily Living Skills, Socialization, and Motor Skills.

Specific developmental skill levels were measured prior to and following the program using the *Brigance Diagnostic Inventory of Early Development* (Brigance, 1991), which is a criterion-referenced developmental measure involving a combination of testing the child directly and obtaining information from parents. Since it does not provide standardized scores, we derived seven specific scores relevant to the intervention and to the children's developmental level. These were: 1. *Self-help Skills* (136 items: feeding, dressing, toileting, washing); 2. *Pre-speech* (39 items: responsive, gestures, babbling); 3. *Expressive Language* (95 items: labels, body parts, sentences, questions); 4. *Receptive Language* (64 items: pic-

Table 1. Developmental and Diagnostic Characteristics of the Three Groups

	Intervention (n = 27)		Comparison A (n = 5)		Comparison B (n = 5)		$\chi^2(2)$
	M	(SD)			M	(SD)	
Age (months)	44.33	(12.14)	57.60	(18.23)	53.20	(11.12)	4.25 (ns)
MA (months)	15.88	(6.06)	21.60	(12.24)	23.60	(8.08)	4.68 (ns)
VABS ABC Age Eq. (months)	16.22	(4.53)	23.40	(13.22)	21.60	(6.27)	4.58 (ns)
VABS ABC Composite (std.)	55.93	(10.14)	55.00	(16.99)	55.20	(7.69)	0.72 (ns)
• Communication (raw)	26.93	(10.28)	36.40	(19.30)	37.80	(15.16)	3.69 (ns)
• Daily Living (raw)	29.22	(10.30)	39.60	(20.40)	37.60	(9.91)	3.01 (ns)
• Socialization (raw)	28.63	(7.44)	35.40	(13.54)	37.20	(4.21)	6.16*
• Motor (raw)	41.84	(9.87)	44.00	(20.81)	49.50	(7.94)	2.49 (ns)
CHAT score (# of 5 symptoms)	3.07	(1.33)	2.60	(1.82)	2.20	(0.84)	3.06 (ns)
CARS Total score	36.00	(3.58)	39.40	(7.53)	37.40	(3.58)	1.81 (ns)
• Not Autistic	0		1	(20%)	0		
• Mild Autism	17	(63%)	1	(20%)	2	(40%)	
• Severe Autism	10	(37%)	3	(60%)	3	(60%)	
DSM-IV Diagnosis							
• Autistic Disorder	18	(67%)					
• PDD-NOS	9	(33%)					

\*  $p < .05$

ture vocabulary, body parts, follows directions); 5. *Pre-academic Skills* (93 items: books, colours, shapes, concepts); 6. *Social-emotional Development* (65 items: basic social interaction, emotional expression); and 7. *Play Skills* (57 items: toy play, imitates children, pretend play).

Diagnostic information collected included: the *Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition* (DSM-IV; American Psychiatric Association, 1994) criteria for Autistic Disorder (Intervention group only) by an experienced Psychologist; the *Checklist for Autism in Toddlers* (CHAT; Baron-Cohen, Allen, & Gillberg, 1992; Baron-Cohen et al., 1996), a screening measure tapping developmentally early signs of autism; and the *Childhood Autism Rating Scale* (CARS; Schopler, Reichler, & Renner, 1988), a diagnostic observation measure in which a trained observer rates the child's behaviour on 15 characteristics of autism. A reliability probe on 4 children from the present sample indicated excellent reliability (95% agreement within ½ point).

Parents' knowledge of behavioural principles was evaluated pre- and post- using a 20-item multiple choice test called the *Behavioral Vignettes Test* (BVT; Heifetz, Baker, & Pease, 1981). In addition, we asked them whether or not they had learned certain specific skills we intended to teach (e.g., how to give clear instructions, break tasks down into small steps) and how helpful those skills were to them.

Family stress was measured pre- and post- using Factor 1 (Parent and Family Problems) of the *Questionnaire on Resources and Stress-F* (QRS-F; Friedrich, Greenberg, & Crnic, 1983), which is designed specifically to measure stress in families with a handicapped or chronically ill member. To measure family functioning, we used the *Family Environment Scale* (FES; Moos & Moos, 1981), specifically the Family Relations Index which includes items related to cohesion, expressiveness, and conflict.

In addition, a detailed *Parent Satisfaction* interview was conducted by one of our research staff (not involved in the clinical group) with every participating family following the intervention. This included structured questions about what parents learned and how helpful those skills were; numeric ratings of their satisfaction with the staff, the program, and the assessment; information on how much home programming and other services the child was receiving; and some open ended questions to solicit their feedback (positive and/or negative) in their own words. The evaluation form is available from the authors.

## Results

### 1. Did Parents Improve Their Knowledge and Skills?

We asked parents whether they had learned more about Autism, and virtually all (97%) said they had and 78% said the information was “very helpful.” We also asked them what skills they learned and, if they had learned them, how helpful those skills were in working with their child. Results are shown in Table 2.

On the standardized pre-post measure testing knowledge of behavioural principles, the BVT, parents in the Intervention group improved significantly in their knowledge of behavioural principles based on a Wilcoxon non-parametric test of matched pairs ( $z = -3.52$ ;  $p < .001$ ), from a mean score of 8.83 (SD = 2.93) to 11.79 (SD = 2.77), whereas neither Comparison group changed significantly.

### 2. Did the Children Improve Relative to the Comparison Groups?

Children in the Intervention and both Comparison groups showed developmental maturation over the period of time of the study and, in fact, the Brigance Total score increased significantly (when using  $p < .05$ ) in all three groups by Wilcoxon tests of matched pairs, as would be expected for a developmentally-based measure not corrected for age (Table 3). However, the Intervention group evidenced statistically significant changes ( $p < .01$  or  $.001$ ) on all but one of the specific subscales, and appeared to be superior in this respect even to the relatively intensive intervention group, Comparison group B, who improved significantly only on Expressive Language. Comparison group A did not show significant improvements on any of the subscales. Although there are potential statistical issues because of the Comparison group sample size and the unknown psychometric properties of the scores, the degree of improvement in the Intervention group appears to exceed the increase which might be expected by virtue of development as inferred from the Comparison groups’ data.

### 3. How Did the Program Impact on Family Functioning?

Virtually all parents (96%) reported experiencing the supportive aspect of the group via the leaders and, especially, via informal conversations with other parents, which were perceived to be very helpful in 75% of families and some-

Table 2. Parents’ Reported Gains in Knowledge and Skills

Skills Learned	% yes	If yes, how helpful?		
		very	somewhat	not very
teaching self-help skills	97%	68%	25%	7%
developing communication	93%	48%	44%	7%
encouraging play & social skills	90%	56%	40%	4%
breaking tasks into small steps	93%	79%	18%	4%
motivating child to learn	93%	70%	30%	
giving clear instructions	93%	74%	26%	
handling behaviour problems	87%	60%	36%	4%

Table 3. Children's Developmental Skills Gains on Brigance Pre- and Post- for Three Groups

	Intervention (n = 27)		Comparison A (n = 5)		Comparison B (n = 5)	
	Pre M (SD)	Post M (SD)	Pre M (SD)	Post M (SD)	Pre M (SD)	Post M (SD)
<i>Brigance Subscale Raw (maximum items)</i>						
Self-help Skills (136)	53.67 (21.97)	61.70*** (21.31)	77.40 (41.97)	83.00 (40.99)	79.40 (26.96)	82.00 (19.33)
Pre-speech (39)	31.07 (6.32)	32.07 (5.98)	31.60 (6.84)	33.40 (5.51)	37.40 (1.67)	37.20 (2.05)
Expressive Language (95)	7.74 (11.83)	10.11** (14.96)	12.40 (17.69)	17.80 (24.43)	8.80 (8.41)	13.60* (12.24)
Receptive Language (64)	9.11 (11.38)	13.36*** (15.07)	8.00 (12.31)	13.60 (16.20)	12.00 (7.18)	17.20 (8.79)
Pre-academic Skills (93)	7.63 (11.54)	13.26** (17.16)	28.20 (33.18)	28.00 (33.08)	5.80 (1.30)	12.40 (15.47)
Social-emotional (65)	22.37 (8.63)	25.56*** (9.37)	24.80 (16.93)	29.40 (20.17)	22.40 (7.02)	25.40 (7.30)
Play Skills (57)	16.77 (10.74)	19.41*** (11.12)	22.80 (18.14)	25.00 (20.88)	23.00 (5.70)	25.00 (8.75)
Total (549)	148.37 (64.31)	175.37*** (78.51)	205.20 (130.81)	230.20* (150.69)	188.80 (37.37)	212.80* (35.69)

\*  $p < .05$     \*\* $p < .01$     \*\*\* $p < .001$

what helpful in the other 25%. When asked whether the program helped them deal with their feelings and stresses, 80% said yes and, of those, 64% found it very helpful and 28% somewhat helpful in this respect.

However, the scores from the standardized pre-post measures did not change significantly on either the family harmony measure or the family stress score for any of the three groups (Table 4). Thus, we found no evidence that the demands we placed on parents to conduct intervention with their child resulted in increased or decreased family stress. However, it may be clinically significant that stress remained the same in our Intervention group when compared to the increase in stress seen in Comparison group B (receiving relatively intensive intervention elsewhere) who had comparable stress scores at pre-treatment. Also, interestingly, from a clinical point of view, the Comparison group A families (receiving minimal intervention) had the lowest family harmony and highest family stress of the three groups.

#### 4. Were Parents Satisfied with the Service and the Staff?

Parents were asked to rate their satisfaction with the program along a number of dimensions on a scale from 1 to 10 with 1 meaning "not at all satisfied" and 10 being "extremely satisfied." Based on data from 30 parents, their ratings were, for the most part extremely positive, with means of 9.2 ( $SD = 1.2$ ) for the overall program, 9.3 ( $SD = 1.2$ ) for the Group Leaders, 9.2 ( $SD = 1.3$ ) for the 1-to-1 Therapists, and 8.5 ( $SD = 1.9$ ) for the Senior Therapists (who had little contact with the parents). Many positive comments were made in response to the open-ended questions.

Parents were also asked to provide feedback about how useful they found the Psychological Assessment. Virtually all families (93%) had received a diagnosis prior to attending our program, but only about half (53%) had been given a clear assessment of their child's developmental level. The vast majority of parents (86%) rated the TRE-ADD (including feedback session and written report) as "very helpful" and

Table 4. Scores on Family Measures Pre- and Post- for Three Groups

	Intervention (n = 27)		Comparison A (n = 5)		Comparison B (n = 5)	
	Pre M (SD)	Post M (SD)	Pre M (SD)	Post M (SD)	Pre M (SD)	Post M (SD)
Family Harmony	10.46 (3.66)	11.04 (4.55)	3.75 (5.85)	7.00 (7.21)	11.20 (3.27)	12.20 (3.70)
Family Stress	8.58 (4.91)	8.38 (4.59)	10.75 (3.77)	11.33 (4.73)	8.60 (3.29)	10.40 (3.21)

the remaining 14% as “somewhat helpful.” Regarding the feedback from the assessment, 93% reported getting a clear understanding of the diagnosis and 97% a clear understanding of the child’s developmental level. Every family (100%) said the recommendations were helpful for their child. Most families (75%) shared copies of the written report with one or more other people, including their family physician, pediatrician, Special Services at Home (SSAH) or contract workers, other agencies, and family and friends.

### 5. Did Parents Feel Equipped to Continue a Home Program?

The vast majority of parents (90%) said they had learned to set goals for their child’s continued development and 93% said they had learned how to adapt the general behavioural principles for their child. When asked to rate, on a scale from 1 to 10 how useful the information and skills gained would be to them in the future, there was a range from 4 to 10 with a mean of 8.8 ( $SD = 1.5$ ).

However, when asked how confident they felt about carrying on with a home program, ratings ranged from 1 to 10 with a mean of 7.1 ( $SD = 2.4$ ). When asked what additional supports they would need to carry on with home programming, many parents mentioned needing consultation, supervision, and troubleshooting in designing, modifying, and evaluating their home program and help finding and training therapists. Some mentioned needing other services including counselling and respite for themselves, and assistance finding speech therapy, day cares, and appropriate school programs for their children.

We asked parents, at the conclusion of the program, how many hours per week of home programming they were actually doing, how many hours were being done by others (like contract workers or ABA therapists), and how many hours the child spent in other structured settings (like school or preschool). According to parent reports, children were receiving a wide range of behavioural programming hours, from none or virtually none to 30 hours per week. Only a small proportion (14%) of the families reported doing more than 20 hours per week (which is considered best practice), another 25% were doing 11 to 20 hours, and 61% were doing 10 or fewer hours. Children also spent varying amounts of time in school and other settings.

## Discussion

The TRE-ADD Preschool Parent Training Program is an innovative behavioural service delivery model. Because we built in a Program Evaluation, we can show demonstrable improvements in parents’ knowledge and skills and in children’s skills over the course of the intervention, relative to two small Comparison groups receiving minimal or other fairly intensive intervention. Our Evaluation indicated that family stress did not increase and that parents are very satisfied with the assessment, the intervention, the staff, and the model. The Parent Training Program was only intended as a first step—a step in the right direction, but not enough by itself. The Program Evaluation suggests that it was, indeed, an effective first step.

However, most parents did not feel very confident about being able to continue on their own;

they need ongoing support and consultation. The intensive behavioural intervention services these children needed were not available in publicly funded settings at the time and most families could not afford private services. It is disappointing, but important to note that even the self-report data from parents (which might be expected to involve some inflation as a result of expectancy effects), even collected shortly after the termination of the program, indicates that children are not receiving very intensive intervention. Informal perusal of the parent questionnaires and sporadic clinical follow up indicated no clear relationship between parents' enthusiasm and satisfaction with the program and the intensity of follow up intervention they were providing or obtaining for their child. This underscores the need for caution in interpreting parent satisfaction as a meaningful indicator of outcome.

The reality is that some parents follow up effectively after the conclusion of the program and many others are less effective and this is likely to have a direct effect on outcomes for children. Longer term follow up of some of these children indicates that outcomes were highly variable (Condillac & Perry, 2002).

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