



Parent-directed, intensive early intervention for children with pervasive developmental disorder

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Abstract

We examined parent-directed, intensive early intervention for children with Pervasive Developmental Disorder. Children's parents recruited paraprofessional therapists and requested consultations on how to implement the UCLA treatment model in their homes (Smith & Lovaas, 1998). Parents and therapists then received six one-day workshops over a five-month period, with additional consultations for the next 2–3 years. Six boys participated (intake age 35–45 months, intake IQ 45–60). The study addressed 1) the children's skill acquisition during the first five months of treatment; 2) outcome 2–3 years later; 3) treatment quality; and 4) parents' impressions. Five of 6 children rapidly acquired skills when treatment began, but only 2 clearly improved on standardized tests at the 2–3 year follow-up. Therapists usually employed correct treatment procedures but were less consistent than therapists employed at a clinic. Parents reported high satisfaction with treatment. These mixed results highlight the need for multimodal assessment of parent-directed treatment. © 2000 Elsevier Science Ltd. All rights reserved.

1. Introduction

Many hundreds of studies have documented the effectiveness of applied behavior analytic treatment (ABA) for children with autism and other pervasive developmental disorders (PDD; Matson, Benavidez, Compton, Paclawskyj, &

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Baglio, 1996). Moreover, since the 1980s, researchers have indicated that ABA may yield large benefits when implemented intensively (25+ hours per week) and early (during the preschool years). For example, investigators have reported average gains of approximately 20 points in IQ (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Lovaas, 1987; Harris, Handleman, Gordon, Kristoff, & Fuentes, 1991) and other standardized test scores (Harris, Handleman, Kristoff, Bass, & Gordon, 1990; McEachin, Smith, & Lovaas, 1993), as well as less restrictive school placements (Fenske, Zalenski, Krantz, & McClannahan, 1985; Lovaas, 1987).

Though investigators have emphasized the need for replicating these outcomes in studies with improved methodologies (Smith, 1999), existing research, combined with case studies that have presented treatment in a format accessible to a general audience (e.g., Maurice, 1993), has led to a dramatic rise in requests from families for intensive, early ABA treatment. This demand has posed at least two major practical problems for service providers and families. First, the demand far exceeds the supply of professionals who have the training and experience necessary to provide high-quality treatment. Second, because of the intensity of services, it is prohibitively expensive to employ professionals to deliver all of the treatment. The most common solution to these problems has been for professionals to assist parents in setting up their own treatment programs. In such programs, discussed in detail in a manual edited by Maurice (1996), parents recruit paraprofessional therapists (often college students) to provide treatment for their children. The professional then trains the parents and therapists in ABA techniques and develops a treatment plan for the child. Subsequently, the professional conducts follow-up consultations to provide further training and update the treatment plan.

By delegating much of the responsibility for treatment to parents, professionals can increase the number of families they serve. By relying on paraprofessionals to implement the treatment, they can keep costs down. Given that parents and paraprofessionals can be highly effective in implementing ABA techniques (e.g., Anderson et al., 1987; Lovaas, 1987), parent-directed programs with paraprofessional therapists may substantially enhance children's functioning. Despite these potential advantages, however, it is essential to evaluate such programs carefully. Factors such as extensive demands on parents, infrequent training from consultants, reliance on therapists who may have little background in learning theory and ABA, and high staff turnover may reduce treatment effectiveness, relative to professionally administered treatment.

In the only published study on parent-directed, intensive ABA treatment to date, Sheinkopf and Siegal (1998) compared 11 preschoolers with PDD who were receiving this treatment to 11 similar children who were enrolled in classes in their local public schools. Twenty months after treatment onset, after receiving a mean of 27 h of treatment per week, the ABA group displayed much higher intellectual functioning than the comparison group (M IQ = 90 vs. 64), as well as fewer parent-reported symptoms of autism (M = 7.5 vs. 8.6). Though in need of replication by other investigators, these results yielded important evidence for

the effectiveness of parent-directed programs. However, as the investigators acknowledged, the study contained limitations. Of note, the investigators did not directly observe treatment and hence could not directly assess the quality of therapy or children's rate of progress at different points during the intervention. Moreover, they did not evaluate parents' reactions to the treatment.

The present study was designed to take a closer look at programs run by parents who requested consultation on one ABA program for preschoolers with PDD: the UCLA treatment model developed by Lovaas and colleagues (Smith & Lovaas, 1998). The study addressed 1) the progress made by 6 children with PDD at the beginning of treatment, 2) treatment quality, and 3) parents' impressions of the treatment. The investigation also included a follow-up assessment of children and families 2–3 years after treatment onset.

2. Method

2.1. Participants

2.1.1. Children

Six boys who were consecutive referrals and who met the following criteria participated: 1) diagnosis of autism or PDD Not Otherwise Specified according to DSM-III-R criteria by licensed psychologists or pediatricians at the Alta California Regional Center (Sacramento, CA); 2) residence in the catchment area for the Regional Center; and 3) chronological age (CA) under four years participated in the study. (A seventh child was considered a dropout because his family did not begin an ABA program after receiving the initial workshop.) The boys' mean chronological age at intake was 36 months (range 31–45). Based on procedures described in "Data Collection," two boys (Henry and William) were judged to be untestable on standardized measures of intelligence. The other four obtained a mean ratio IQ of 50 (range 45–60), as assessed by the Bayley Scales of Infant Development–II (Bayley, 1993). According to parents' report, all children lacked imaginary play and peer play, and they engaged in high rates of stereotyped or ritualistic behaviors. Two (Sam and Tom) occasionally used approximations of words to communicate, and Tom also pointed to objects. The remaining children were reported to have no expressive or receptive language.

2.1.2. Parents

Four of the six children resided in two-parent households, while the remaining two (Sam and William) lived in mother-only households. All parents had completed high school or high school equivalency examinations. Four of the six mothers and two of the four fathers had completed a bachelor's degree.

2.1.3. Therapists

Each child had 3–6 therapists ($M = 4$). All therapists were undergraduate students who worked as volunteers or for course credit at local universities, with

three exceptions (a grandparent and two family friends). Families recruited through fliers placed on bulletin boards at local universities, and through parents and other members of a local family organization called Families for Early Autism Treatment. None of the therapists had any previous experience in the UCLA treatment model.

2.2. *Design and procedure*

A multiple-baseline design across children was used to assess children's progress with treatment. Children were assigned to a baseline condition lasting 1 month, 3 months, or 5 months. The assignment was random, with the restriction that each baseline condition needed to contain two children. While in baseline, children received no treatment. Following baseline, parents and therapists attended a total of six one-day training workshops distributed over the course of three months. Each workshop took place in children's homes and lasted six hours. Two workshop days occurred during Week 1 of treatment (e.g., Monday and Wednesday). One additional workshop day occurred during each of Weeks 2, 3, 8, and 12. Subsequently, two-hour workshops took place monthly, and parents were welcome to seek services from other agencies if they wished.

Workshops were conducted by the second author, who, at the time of this study, was a doctoral candidate in psychology at UCLA with eight years of experience implementing and supervising intensive, early intervention for children based on the UCLA treatment model developed by Lovaas and colleagues. Training content was derived from Lovaas et al.'s (1981) treatment manual and associated videotapes (Lovaas & Leaf, 1981), with the modification that families were instructed not to implement physical aversives or loud verbal aversives. As detailed in the manual, the UCLA treatment is designed to progress gradually and systematically from relatively simple tasks, such as responding to basic requests made by an adult, to more complex skills, such as conversing and making friends with peers. It emphasizes the implementation of empirically supported teaching approaches developed by the many behavior analysts who have studied interventions for children with PDD. Early in treatment, therapists rely primarily on a one-to-one, discrete trial format, implemented in children's homes, so that they can provide highly individualized interventions that maximize children's successes. Children are kept out of school at this stage. Once they imitate nonverbal and verbal behaviors, speak in short phrases, cooperate with verbal requests from others, play appropriately with toys, and acquire self-care skills such as dressing and toileting (approximately one year after treatment onset, with large variation across children), the focus shifts to more naturalistic instruction in group settings such as classrooms for typically developing children.

Both children in each condition attended the same workshops, along with their parents and therapists. Time was divided equally between the children. During each day of training, 20-min lectures on behavior analytic teaching principles and procedures were alternated with 20–30 min sessions when the workshop leader, parents, and therapists provided treatment directly to the children. In these

training sessions, the workshop leader demonstrated specific programs or procedures, and then allowed the parents and therapists to take turns performing the same procedures with the children. The first workshop day focused on the use of basic ABA procedures such as reinforcement, extinction, and discrete trial training. Each participant was given hands-on experience in reducing tantrums, teaching simple receptive actions (e.g., “Sit down” and “Come here”), and teaching two or more nonverbal imitation tasks (e.g., waving and tapping a table). Day 2 focused on how to teach additional receptive actions and nonverbal imitation tasks, as well as match-to-sample tasks. Lectures centered on discrimination training and the use of Lovaas et al.’s (1981) manual to select and conduct new programs. Days 3 and 4 emphasized teaching verbal imitation, in addition to elaborating on the curricula introduced in Days 1 and 2. For those programs that children were not yet ready to begin (e.g., verbal imitation in children who were still learning nonverbal imitation), the workshop leader used role-plays to demonstrate teaching procedures. Days 5 and 6 of training were dedicated to critiquing parents’ and therapists’ techniques, and updating children’s instructional programs.

2.3. Data collection

2.3.1. Child measures

During baseline and the first five months of treatment, children were assessed once per month on the Early Learning Measure (ELM). Developed by Smith, Buch, Eikeseth, Lovaas, and colleagues at UCLA and available from the first author, the ELM consists of 40 unmastered tasks, including 10 receptive actions, 10 nonverbal imitation tasks, 10 verbal imitation tasks, and 10 expressive object labels. Unmastered tasks were selected during the first ELM administration in baseline; the same tasks were then repeated at all subsequent administrations. ELM sessions were conducted at the Alta California Regional Center by a case supervisor who had 2 years of experience providing and supervising treatment for children with autism at the UCLA Clinic. The supervisor was blind to the baseline conditions to which children had been assigned. Sessions were videotaped and scored by undergraduate students who were also blind to children’s assignment. To evaluate inter-observer reliability, 25% of the ELM administrations were scored by two independent observers.

Standardized testing at pretreatment and the 2–3 year follow-up included; 1) a full-scale IQ, obtained from the Wechsler Preschool and Primary Scales of Intelligence – Revised (WPPSI-R; Wechsler, 1989) or Wechsler Intelligence Scales for Children – Third Edition (WISC-III, Wechsler, 1993), as determined by the child’s CA, or (if the child did not achieve a basal on these tests) the Bayley Scales of Infant Development – Second Edition (Bayley-II, Bayley, 1993); 2) language development, as measured by the Reynell (1990) Developmental Language Scales; and 3) functioning in everyday settings, as gauged from the Vineland Adaptive Behavior Scales (Sparrow, Balla, and Cicchetti, 1984). A registered nurse conducted the pretreatment intelligence testing. The nurse had

been trained and certified in Bayley administration at the Child Development and Training Center at U.C. Berkeley, under the supervision of staff who contributed to the standardization of the instrument. A licensed clinical psychologist administered the pretreatment Reynell and Vineland. Both examiners worked at Alta California, where testing took place, and both had extensive experience in assessing children with PDD. All follow-up standardized tests were administered by the third author, who was a doctoral student blind to children's treatment histories. To establish the reliability of this examiner, she and the first author (a licensed psychologist with extensive experience assessing children with PDD) independently administered the Bayley to three children with autism who were not part of this study, and they obtained the same IQ for each.

2.4. Therapy measures

To assess the amount of therapy that children received, parents kept a log of the number of therapy hours per week. At follow-up, they were asked to give a retrospective report of therapy hours. To assess treatment quality, the parent and therapist who had conducted the most hours of therapy with their respective children were videotaped providing therapy three weeks into treatment, as well as three months into treatment. A comparison group of 12 therapists with three months of experience at the UCLA Clinic (approximately 60 h of therapy) was also videotaped. Videotaping consisted of five-minute samples of each therapist implementing current programs for his/her child. Observers scored the videotapes using time sampling (20 s observing, 10 s recording) and definitions developed by Koegel, Russo, and Rincover (1977) for correct discrete-trial techniques. Two independent observers scored 25% of sessions.

2.5. Parent measures

To measure parents' stress, parents completed the Parenting Stress Index (PSI) (Abidin, 1990) three months after treatment onset and at follow-up. (The PSI was added to the data collection after intakes had been completed; hence, intake PSI scores were unavailable.) At the 2–3 year follow-up, parents completed the Parent Satisfaction Questionnaire (PSQ), a 20-item written survey, with each item rated from 1 to 7, developed by the first author to assess parental perceptions of their children's progress and the services they received from the UCLA Clinic.

3. Results

3.1. Reliability

For the ELM and measure of therapy quality, inter-observer reliability was calculated as the percent of observation intervals in which observers agreed in

their scoring. Two scales in Koegel et al.'s measure of treatment quality (Shaping and Prompting) were dropped because of poor reliability. However, percent agreement for the remaining three scales (Discriminative Stimuli, Discrete Trials, and Consequences) and for the four ELM scales ranged from 95 to 100%.

3.2. *Child measures*

3.2.1. *First five months*

Fig. 1 presents children's rate of skill acquisition during the first five months of therapy, as assessed by the ELM. The figure contains lines for receptive actions, nonverbal imitation, verbal imitation, and expressive labels. As one can see, all children's baselines were flat and stable, with the exception of Tom's performance in nonverbal imitation during ELM Session 2. Tom's parents subsequently reported that, prior to this study, they had participated in a six-week parent-training program that specifically focused on teaching nonverbal imitation.

Fig. 1 reveals that, following treatment onset, 5 of the 6 children substantially increased their correct responding to receptive actions, nonverbal imitation, and verbal imitation, though the sixth child (Henry) did not show such improvement. Two children (Sam and Tom) also improved on expressive labels. However, both children's performance reached a maximum of only 30% correct, which occurred after 5 months of treatment.

3.2.2. *Long-term outcome*

Table 1 summarizes the results of intake and follow-up standardized testing for each of the 6 boys. Two (Tom and William) showed large increases on all tests (≥ 10 points), while one (Henry) showed declines. Two others (Sam and Vince) displayed stable scores on all tests. The results for the remaining participant were mixed: Dave's IQ was untestable at pretreatment and 58 at follow-up, but his other test scores were stable.

3.3. *Therapy measures*

During the first three months of therapy, children received a mean of 26.2 therapy hours per week (range 23–35 across children, $SD = 5.3$), according to parent logs. Dave continued to receive consultations from the second author for another three years, though he also received ABA consultations from an independent agency for six months out of this period. Dave's mother reported that he received 32 h per week of therapy. For the first year, this therapy took place entirely in the home. Subsequently, he entered school assisted by an aide and gradually increased his time in school from 10 h per week to 30 h per week over the next two years. Therapy time at home decreased as school time increased. Sam, Tom, and Vince received consultations from the second author during their first year of treatment, but then switched to ABA consultants from another agency. Their mothers all reported that the children averaged approximately 30 h

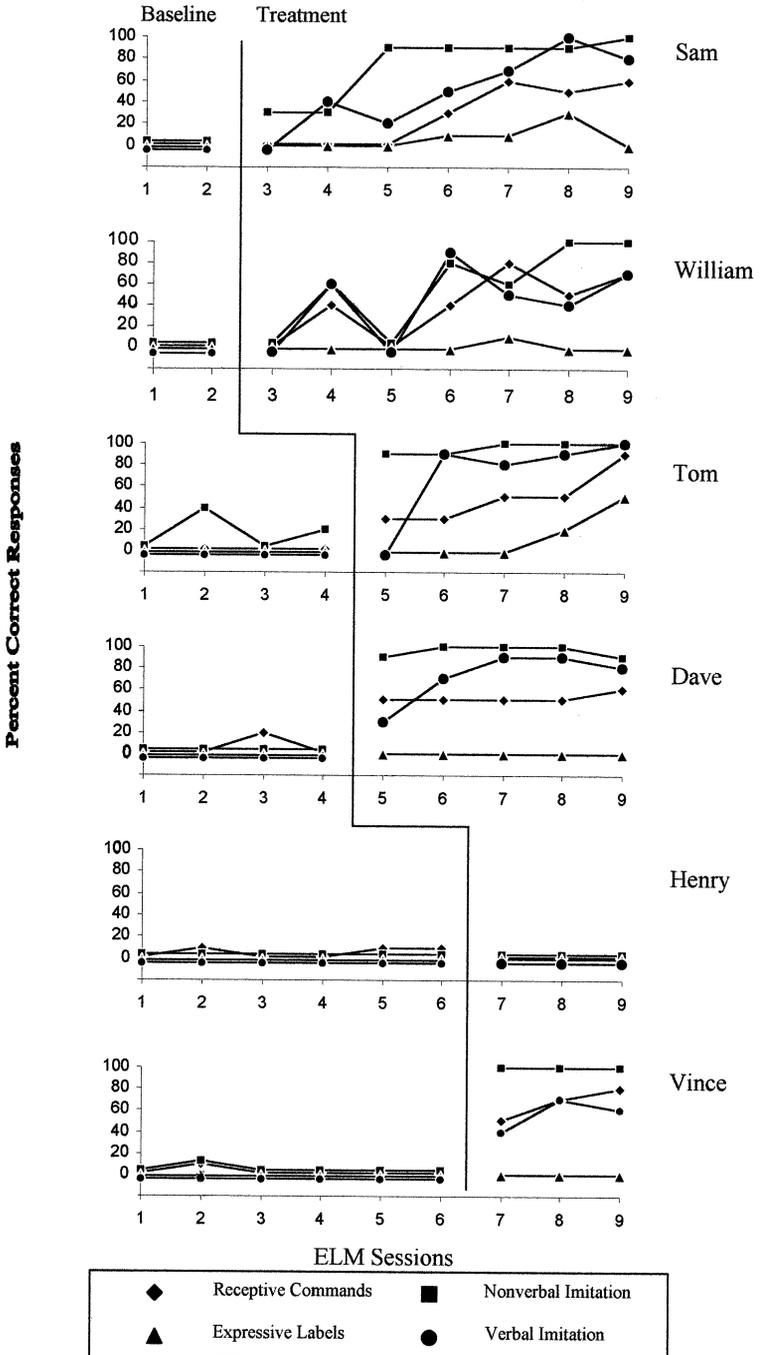


Fig. 1. Percent of correct responding to items on the Early Learning Measure (ELM) during baseline and after treatment onset.

Table 1
Demographic characteristics and intake and follow-up standardized testing

Child	CA	Diagnosis	Reynell			Vineland				
			IQ	Comp.	Exp.	Comm	DLS	Soc	Motor	Composite
Dave										
Intake	35	PDD	Unt	<34	<36	55	62	54	84	59
Follow-up			58	36	36	62	67	67	84	64
Henry										
Intake	45	Autism	45	<27	<33	48	51	51	53	47
Follow-up			30	<30	<30	<30	<30	<30	—	<30
Sam										
Intake	36	PDD	43	<33	<42	57	62	58	63	55
Follow-up			44	60	46	66	70	60	67	60
Tom										
Intake	35	Autism	51	<34	<43	54	59	54	76	56
Follow-up			79	67	117	92	90	75	—	80
Vince										
Intake	33	Autism	60	<36	<45	53	59	57	64	53
Follow-up			60	42	42	56	64	69	—	58
William										
Intake	31	Autism	Unt.	<39	<48	64	64	58	71	59
Follow-up			79	>69	>69	80	68	79	—	69

per week of services and had made gradual transitions from home to school, starting approximately one year into treatment. At follow-up, Dave, Sam, Tom, and Vince were all attending first or second grade classes for typically developing children and were all assisted in the classroom by an aide. Henry, however, ended ABA treatment after one year and was placed in a residential home one year later. William received two years of ABA treatment and was in a typical third grade class with an aide at follow-up.

Table 2 summarizes the data on treatment quality. The table reveals that the 12 therapists in parent-run programs used correct discrete-trial techniques most of the time when videotaped three weeks after treatment onset. Their rate of correct techniques was higher in the three-month assessment, though this increase was small and statistically nonsignificant. As Table 2 indicates, mean scores for the comparison group of therapists employed by the authors' clinic

Table 2
Percent of observation intervals during which therapists used correct one-to-one discrete trial procedures

Group	Discriminative stimuli (M[SD])	Discrete trials (M[SD])	Consequences (M[SD])
Parent-directed ($n = 12$)			
3 Weeks	96 (6)	74 (22)	75 (21)
3 Months	98 (4)	77 (21)	78 (19)
Comparison ($n = 12$)	100 (0)	97 (7)	97 (7)

exceeded those in the parent-directed group. Independent *t* tests indicated that this difference was statistically significant for the correct use of discrete trials, $t(22) = 3.15$, $p < .01$, and consequences, $t(22) = 3.10$, $p < .01$. Thus, while parents and therapists usually used correct techniques, they were less consistent than comparison therapists.

3.4. Parent measures

At three months into therapy, the children's mothers received a mean total stress score of 261 (SD = 35.7, range 195–293) on the PSI, which placed them at the 90th percentile for all parents completing this inventory. Their mean Child Domain Score was 121 (SD = 17.4, range 92–139), and their mean Parent Domain score was 140 (SD = 20.9, range 103–163), which corresponded to the 90th and 80th percentiles, respectively. At follow-up, PSI's were returned anonymously by mothers of 4 of the 6 children tested. For Total, Child Domain, and Parent Domain, respectively, the means were 206 (30th percentile, range 185–216), 95 (35th percentile, range 83–103), and 111 (25th percentile, range 100–113).

At follow-up, PSQ's were returned anonymously by mothers of 4 of the 6 children tested. All respondents rated their children as "greatly improved." All rated the workload associated with the treatment as "just right" for them and for their child. Further, all rated the stress on the child as "mild." Three mothers also rated the stress of the treatment on themselves as mild, though one rated it as "very stressful." All indicated that the treatment had positive effects on the family, bolstered their optimism about their child's future, and increased their confidence in handling their child's behavior problems.

4. Discussion

This study was intended to assess child, therapist, and parent variables in parent-run, home-based, behavior analytic treatment programs for 6 preschoolers with autism. Children averaged 26.2 h of this treatment during the first five months. Subsequently, 1 dropped out, while the remaining 5 continued to receive approximately the same amount of treatment for the next 2–3 years. There were four main findings: First, during the first five months of treatment, all of the children except Henry acquired new skills in the areas of receptive language, nonverbal imitation, and verbal imitation; 2 of these 5 (Sam and Tom) also acquired expressive labels. Second, at a follow-up conducted when the children were 5–8 years old, 2 children (Tom and William) showed substantially improved standardized test scores; 1 (Dave) improved on one of the three standardized tests though not on the other two; 2 (Sam and Vince) obtained scores that were essentially unchanged on all tests; and 1 (Henry) showed declines in test scores. Third, therapists in parent-run programs correctly implemented discrete trial procedures most of the time, but not as consistently as therapists

employed at the investigators' clinic. Finally, parents reported normal levels of stress during and after treatment, and parents whose children remained in treatment rated the treatment very positively at follow-up.

The study had several weaknesses, including small sample size, absence of pretreatment measures of parent stress, little information on the course of treatment after the first five months, and missing follow-up data. Also, parent measures were completed anonymously, which may have reduced demand characteristics but precluded correlating them with child measures. However, the study did contain a single-case experimental design to analyze the effects of treatment onset, and it incorporated a wider range of dependent measures than any previous investigation on early intervention for children with PDD or autism.

The use of multiple dependent measures revealed a potentially major limitation of parent-run programs. For children in the present study, this treatment yielded rapid skill acquisition at treatment onset, with high parent satisfaction. However, these benefits often did not lead to long-term developmental gains, as evidenced by increases in IQ and other test scores. Indeed, children's outcomes appeared less favorable than those previously reported for professionally run programs (e.g., Lovaas, 1987). The relatively low treatment quality that was observed may be one factor underlying this finding. Therapists may have achieved enough proficiency to teach children basic skills such as imitation, but not more advanced skills such as conversation and peer play. Similarly, they may have been able to promote skill acquisition, but not generalization and maintenance. Another factor may have been that all children switched consultants and/or reduced the frequency of workshops at some point during treatment. Such changes in service delivery may have been disruptive. Thus, more intensive, ongoing professional consultation may be needed in order to improve treatment quality.

Two other factors may also be important to consider. First, as a group, the children's pretreatment functioning (measured by standardized test scores) was lower than in any previous study on early intervention for PDD except Smith, Eikeseth, Klevstrand, & Lovaas (1997). Perhaps, therefore, children with higher pretreatment functioning would have tended to show more improvement at follow-up. Second, parents requested treatment based on the UCLA Treatment Model (Smith & Lovaas, 1998), but all children received fewer than the 40 h per week of intervention recommended by the developers of this model. (Against this possible factor, Sheinkopf & Siegal (1998) found large average IQ gains in their sample with a similar number of treatment hours, though they relied extensively on measures of nonverbal IQ, which may be more sensitive to change than the measures used in the present study.)

Overall, the present study suggests that parent-run, ABA early intervention programs may be less effective than professionally run programs but do bring about short-term gains for many children with PDD and autism, and long-term benefits for some. Further, parents report that this treatment is manageable for them, though some drop out. The study also underscores the need for multimodal,

ongoing assessment of parent-run programs to monitor treatment quality and evaluate whether gains made at treatment onset endure.

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