

Parents' Experiences of Home-Based Applied Behavior Analysis Programs for Young Children with Autism

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Abstract Although much research has documented the benefits to children with autism of early intensive behavioral intervention (EIBI), little has focused on the impact of EIBI on families. Using a semi-structured format, we interviewed 53 parents whose children had received 2 years of EIBI to obtain detailed first person accounts of the perceived benefits and pitfalls of running a home program, and the impact of EIBI on family life and support systems. In general, parents were positive about EIBI, its benefits for them, their child, and the broader family. Interviews also, however, revealed some of the more challenging aspects of managing home-based EIBI. The implications of these findings for more supportive interventions for families on home programs are discussed.

Keywords Early intensive behavioral intervention · Family impact

Research has shown that home-based early intensive behavioral intervention (EIBI) founded on the principles of applied behavior analysis (ABA) can produce dramatic improvements for young children with autism. This includes the development of an effective skills repertoire, the control of challenging behavior (e.g., self-injury),

successful integration into mainstream schools and for some, it is claimed, apparently normal levels of functioning (e.g., Anderson et al. 1987; Lovaas 1987; McEachin et al. 1993; Smith 1999). In a typical EIBI program, a team of trained therapists provide one-to-one home-based intervention for up to 40 h a week, often for several years. Consultants in behavior analysis regularly review child progress, tailor interventions to the child's strengths and needs and train therapists in instructional techniques (Smith et al. 2000b).

Researchers assessing the efficacy of EIBI have understandably focused on outcomes for the child with autism. There are, however, very few published data focusing on the impact of an intensive home-based intervention on the families of such children. This issue is of central importance because effective EIBI may depend critically on close family involvement (Green 1996). It is also important to consider the potential impact of having a child with autism on the functioning of the family. When compared with parents of children with no known disabilities, parents of children with autism have often been found to have more severe psychological problems. For example, mothers of children with autism have been shown to be at a higher risk for clinically significant levels of parenting stress than of those mothers of other children with developmental disabilities (Hastings et al. 2006). In a meta-analytic study, Singer (2006) also found that studies focusing on mothers of children with autism reported significantly larger effect sizes of depression differences than those focusing on intellectual disability or other disabilities. Thus, because parents of children with autism may already be at increased risk of stress and depression (see also, Gold 1993; Koegel et al. 1992), clinicians need to be aware of potential additional effects of engagement in EIBI.

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A few published studies focusing on the functioning of family members in the context of EIBI have reported parental stress outcomes as a part of their evaluation of EIBI. For example, Birnbrauer and Leach (1993) found that, after 2 years of a 20 h per week intervention program, nine mothers whose children were receiving EIBI reported less stress than a control group of five matched mothers who were not involved in an EIBI program. Similarly, Smith et al. (2000c), found no differences in ratings of stress when they compared mothers who had engaged in EIBI with another group who had received a parent-training intervention. Furthermore, longitudinal data from both of these studies showed that mothers became less stressed over two or more years of EIBI (see also Smith et al. 2000a). In a cross-sectional study, Hastings and Johnson (2001) reported that 130 mothers of young children with autism engaged in EIBI had similar levels of stress to mothers of children with autism in other research studies. Overall, these data suggest that parents of young children with autism engaged in EIBI programs are not at *increased* risk of stress or that they report *lower* levels of stress than comparable families.

Unfortunately, the studies reviewed have a number of limitations: some fail to incorporate appropriate control groups while almost all include only a restricted range of measures of family impact and focus exclusively on mothers. In a better controlled study, Remington et al. (2007) addressed these problems by reporting quantitatively on family impact using a broader range of psychometric measures taken at three time points (pre, 12 months, and 24 months) during the course of intervention. These included measures of parental mental health and positive perceptions about their child. Participants were parents (23 mothers and 16 fathers) of pre-school children with autism enrolled in a research project evaluating EIBI in the UK. The remaining 36 parents (21 mothers and 15 fathers) were a comparison sample that was not receiving EIBI. After 1 and 2 years of EIBI, parents' stress, anxiety and positive perceptions of their child were no different to those of the comparison group. Although there was an increased reporting of depressive symptoms in fathers (but not mothers) of children engaged in EIBI, paternal depression was low in the EIBI group at baseline, suggesting a regression to the mean effect.

Overall, Remington et al.'s (2007) data were consistent with earlier research in suggesting that EIBI created no additional burden for parents, but a more complex picture emerges from anecdotal reports from parents and some systematic data. For example, Cattell-Gordon and Cattell-Gordon (1998, p. 82), in describing their experiences of running a home-based EIBI program comment that there were "the more subtle but stressful problems of having one's home invaded for months at a time with team

members who came and went." Hastings and Johnson (2001) found that although program-related variables (e.g., child's age when the program started, length of time the child had been on the program, whether parents were also therapists for the child) did not predict parental stress, other psychological variables did. For example, adaptive coping strategies, informal social support, and beliefs in the efficacy of the interventions were associated with lower reported stress; conversely higher reported stress was associated with higher levels of autism symptomatology in the child receiving EIBI. Other potentially stressful aspects of running a program include recruiting and maintaining a suitable team of therapists, the financial burden on the family and disruption of family routines (Johnson and Hastings 2002; Maurice et al. 2001).

Some research has also focused on how siblings of a child with autism adjust when a high proportion of the family's financial and time resources are being directed into the EIBI program (Johnson and Hastings 2002). Although siblings may well appear to be at an increased risk of negative effects, Hastings (2003) found no evidence of additional psychological adjustment problems in comparison with normative samples.

Despite the clear advances in knowledge that these findings represent, several important issues, identified in the preceding discussion, remain. First, the research focus on EIBI has mostly been on child outcomes. There is still scant research on families' experience of EIBI. Second, although existing research suggests overall that parents and siblings are not negatively affected by involvement in EIBI, many behavioral practitioners report that some families do not adapt well to home-based EIBI. Finally, most research to date has used only a restricted range of quantitative measures of family impact and has concentrated mainly on mothers' experiences. The present study addressed these issues by interviewing both mothers and fathers of children with autism receiving EIBI to document their perspective on the impact of programs on their personal and family life. In addition to elucidating and enriching existing knowledge based on quantitative research, the qualitative data obtained may improve EIBI practitioners' sensitivity to the impact of their work on family life and thus contribute to improving its effectiveness.

Method

Participants

Fifty-three parents (32 mothers and 21 fathers) of children with autism were interviewed. Parents were not offered monetary payment for participation. The sample included 21 cohabiting couples. An additional four families had a

father at home who declined to participate in the research. For seven families, fathers were not living in the same home as the child with autism and did not participate. The interviews thus provided information on the family life of 32 children with autism (29 male, three female), aged between 54 and 77 months (mean = 65.8 months, SD = 5.6 months). All lived in the family home in the UK. Seventeen of the thirty-two children had no additional health problems. The most common complaint suffered by six children were gastro-intestinal problems, three children had skin conditions such as psoriasis and eczema. Other problems included dyspraxia and insomnia. Twenty seven children had at least one sibling living at home, aged between 2 and 156 months (mean 74.6 months, SD = 32.6 months).

At the time of the interviews, the EIBI programs had been running, on average for 25 months (SD = 3 months). Seventeen families were enrolled in University supervised EIBI programs provided by the Southampton Childhood Autism Program (SCaMP; Remington et al. 2007) and were funded through their local education service. The remaining 15 families ran an EIBI program with consultancy from a private service provider, paid for either by the parents themselves or their local education authorities.

Recruitment Procedure

Participants were recruited in several ways. First, 30 families involved in (or known to) the University of Southampton program were sent a letter inviting them to participate. Some received a University of Southampton managed service; others a service from private providers. Twenty four families responded, all but one agreed to be interviewed. Second, an advertisement seeking participants was posted on several UK ABA focused websites and in the newsletters of parent organizations. Nine families (15 parents) were recruited by advertisement.

The Interview Structure

To ensure that participants would talk freely, a semi-structured interview format was used. The content, prepared in advance, consisted of a series of open-ended questions intended to gain information on a variety of topic headings, often with alternative subsequent questions depending on the responses obtained. For example, suggestions for *probes* to encourage parents to expand on responses and *prompts* to suggest to the interviewee the range or set of responses expected from them. A proposed sequence to ask the questions was also prepared prior to interview, although this was sometimes subject to change during the course of the interview depending on the responses given.

After obtaining background and demographic information (e.g., who lived at home with the child, the number and age of siblings) the interview sought parents' accounts of their experiences of running EIBI programs. Discussion focused on the following four topics: (1) parents' perceptions of practical issues relating to their program (e.g., "Describe any practical benefits or difficulties associated with running an EIBI program in the home"), (2) the impact of EIBI on family life and support systems (e.g., "Tell me whether running the program affected how you got on with members of your family"), (3) the nature and level of parents' involvement in the program (e.g., "Describe your role in running the program"), and (4) any issues regarding parents' management of practical program-related matters (e.g., "What was your role in dealing with practical issues to do with the program?"). Finally, parents were given an open-ended opportunity to comment. A copy of the full interview protocol is available from the first author. Interviews ranged from about an hour to over an hour and a half.

Data Reduction and Coding

Following interview transcription, a content analysis procedure based on the fundamental stages recommended by Dey (1993) was used to identify a list of themes. Thus, the basic unit of data was the sentence and all units that related to the four topics listed above were grouped. Categories were created that described common themes within these general groupings. Next, these categories were combined or divided to create the best possible categorical organization of the data and category labels modified appropriately. The resulting categorical system, including the definitions associated with a category, formed the basis of the interview coding book (details of the codes appear under the "Results" section). Each interview transcript was then coded in terms of whether or not statements relating to the defined categories were present. Thus, each interviewee was characterized as either expressing or not expressing ideas relating to each category. All coding was carried out by the first author, from whom the codebook is available on request.

Reliability

To establish inter-rater reliability, another member of the research team coded 13 (25%) randomly selected interview transcripts (8 mothers and 5 fathers) using the codebook. The extent of agreement between the two coders was calculated using the list of codes for each interview and a simple percentage agreement index formula (agreements divided by agreements plus disagreements and multiplied by 100). An agreement was defined as when both raters coded a parent interview as containing a statement corresponding to a category, or when they both coded an

interview as containing no statements corresponding to a particular category. Overall inter-rater agreement across all categories was 87% (range, 83–100% for individual categories).

Procedure

The university ethics committee approved the study before the parents were interviewed. Prior to interview, parents received an information pack providing detailed information about the study and a consent form indicating that confidentiality and anonymity would be scrupulously maintained. When written consent had been obtained, the first author arranged a convenient time for the interview.

All interviews were conducted on the telephone and audio taped. The interviewer (the first author), explained that she was a research psychologist who had also worked as an EIBI program supervisor for several years. Confidentiality and anonymity was reiterated before and after the interview. Participants were also verbally debriefed and offered a written summary of the findings at the end of the study.

Results

The interview topics covered and the categories used to code each interview are shown in Tables 1–6. Excerpts from the interview transcripts are used to illustrate each of the categories, and the percentage of mothers ($n = 32$) and fathers ($n = 21$) who were coded into each category is listed. We will consider the results in relation to these categories.

In examining these data, one important question is whether or not mothers and fathers who are running the program have similar experiences. To address this question, we used a matched-groups design to examine data from the 21 couples who participated (e.g., each husband–wife pair). The purpose of the matched-groups design was to evaluate whether the pairs of cohabiting mothers and fathers had significantly different experiences from each other. Differences between the frequencies for each interview code for each mother–father pair were analyzed using McNemar’s test. Despite some differences evident from visual inspection of the data in Tables 1–6 which portray differences between all mothers and fathers (respectively, $n = 32$, $n = 21$), statistical analysis of each mother–father pair ($n = 21$) showed that, in general, these were not significant: mothers and fathers for the most part had similar perceptions about EIBI. In reviewing the results below, we will comment in the text only on those instances where the McNemar tests revealed parental beliefs were significantly different from each other.

Practical Benefits for the Family

Parents were asked to identify their perceived practical benefits and difficulties of running the EIBI program for all family members. The data revealed many benefits for family members. These responses are summarized in Table 1.

Practical Benefits for the Child with Autism

Every parent identified at least one practical benefit for the child with autism. All parents regarded their child’s progress in language and communication skills as a positive feature of the program. One father remarked, “Mark¹ didn’t speak; now he and his brother are blabbering between each other and conversing.” The vast majority of parents reported that their child’s social skills had improved. For example, taking turns, sharing, dealing with conflicts, following directions and asking for help were all cited as areas of improvement. One mother commented, “He now really loves to be with his sister and at bed time he goes into her bed now and hugs her so he is much more aware that they share.”

Approximately one third of parents commented that their child’s play skills had developed, in such areas as ball play, recreational games (e.g., tag, hide and seek) and independent play skills (e.g., puzzles, construction).

Practical Benefits for the Parents

Approximately three quarters of parents reported at least one practical benefit for themselves. Of the 21 couples interviewed, 86% of mothers reported additional support in the home as a positive feature of the program, whereas only 38% of fathers mentioned this ($p = .002$). Examples of support included that therapist’s helped with behavior problems (e.g., tantrumming and self-stimulation), feeding and toileting. They also helped by minimizing risk to the child.

Approximately two thirds of parents said that EIBI teaching released their time for other activities such as complete household chores and recreation. Thirty eight percent of mothers described increased free time as a positive feature of EIBI, whereas only 10% of fathers reported this consequence ($p = .03$).

Approximately one quarter of parents reported they had acquired a much wider social network, members of which understood their problems. Friendships developed with intervention team members (e.g., therapists, supervisors) or

¹ Names have been changed.

Table 1 Practical benefits for the family

Topic/category	% of mothers (<i>n</i> = 32)	% of fathers (<i>n</i> = 21)	Examples
Practical benefits for the child with autism	100	100	
Improved language and communication skills	100	100	“To start with he had no language; you couldn’t get him to do anything. Not only does he use language now but he uses it in the right context and names things. He frequently asks you what you are doing and there are times he talks more than the other kids around him.”
Improved social skills	84	79	“EIBI teaches children to interact with the world. Very early on [the child] was taught to wave and so now when you say ‘wave bye bye’ ...she at least produces a response in somebody else and this produces an interaction.”
Better play skills	26	43	“His play skills are so well developed now that he can play with anything.”
Became more used to being with people	19	10	“He has learned to let people into the house now and he is so friendly, as soon as he sees someone he says, “What’s your name?”
Practical benefits for the parents	86	67	
More support in the home	69	52	“We had a lot of problems with [the child] when the baby arrived and he found it very distressing. So with the program being at home they involved the baby in the teaching and this helped them to bond together.”
More free time when child with autism was in therapy	47	19	“There are times when [the child] is in his lessons and I can go to the gym! So there is the element that I get more free time.”
More socialization opportunities for parents	25	14	“One of the therapists has become a great friend; we get on very well together and still keep in touch.”
Parents could learn more about ABA	22	14	“You being there [at home], you see things, you pick things up and you know the kinds of things that the team are working on. And they can provide input, ‘have you thought about doing it this way? Maybe this will work.’”
Topic/category	% of mothers (<i>n</i> = 27)	% of fathers (<i>n</i> = 20)	Examples
Practical benefits for the siblings	78	75	
Sibling enjoyed involvement in therapy sessions	44	30	“He took part in some of the sessions which he thought was good fun.”
Sibling was able to learn about autism and ABA	22	30	“... [The sibling] has really benefited from the program. Now that she has started at school she goes round to all the other children and says “hey, excellent work”...You can tell from what she is actually reported as saying, it is what we have been telling her to say to her brother.”

Note: The main categorical labels (e.g., practical benefits for the child with autism) are described by the subcategories that follow (e.g., improved language and communication skills, improved social skills)

with other parents engaged on EIBI programs. Parents usually received positive support and useful advice from these friendships. Finally, nearly a quarter of parents reported that, because the program was run in the home, they learnt how to use effective behavior management techniques through observing therapists using them.

Practical Benefits for the Siblings

In those families with at least one typically developing child (mothers *N* = 27; fathers *N* = 20), over three quarters of parents reported at least one practical benefit for the sibling. Of these the two most commonly reported were

that the siblings enjoyed involvement in therapy sessions and that they were able to learn about autism and ABA, particularly through observing therapists modeling successful interaction styles (e.g., by simplifying language, getting attention before speaking).

Practical Difficulties for the Family

Parents’ comments also highlighted a number of areas where their experiences with EIBI increased the complexity of their personal and family life (see Table 2).

Difficulties with the Education Authority

Approximately three quarters of parents described difficulties with their Local Education Authority (LEA). Over

half of the parents interviewed reported that their LEA had been cautious about providing EIBI services, often because of a combination of cost and philosophical and practical concerns, and instead originally offered funding for alternative educational provision. One father explained:

As long as you wanted to put your child in a special needs school, and you wanted to do their way of things it was fine. If you wanted to do anything that was outside of this little box it was like ‘Oh no, we can’t let you do that’.

All families who had problems obtaining statutory funding entered into a lengthy dispute with their LEA, usually lasting for 6 months or more, during which they tried to persuade the LEA that EIBI could meet their child’s special educational needs.

Table 2 Practical difficulties for the parents

Topic/category	% of mothers (n = 32)	% of fathers (n = 21)	Examples
Difficulties with the LEA	78	67	
Difficult to obtain funding for EIBI program	59	48	“They told us right from the beginning that they would never fund an EIBI program for any child.”
LEA not at all knowledgeable about ABA	44	29	“They had no understanding at all about up to date research, they had heard horror stories about Lovaas [EIBI] in the sixties but didn’t know anything about current papers or initiatives and what could work.”
Difficulties with therapists	91	100	
Recruiting new therapists	56	57	“They [the service provider’s] don’t tell you the kind of person to look for...and things like not having a therapist that is only doing one session a week. I have found out things by trial and error but we could have done with more advice about it.”
Difficult finding the right person for the job	34	33	“I am sure she would have been a good teacher but not for a child with autism. She would read the notes and ask me what the notes mean and even when it was explained to her...it just wasn’t her cup of tea.”
Therapist unreliability	31	14	“She [the therapist] just couldn’t conduct herself in a professional fashion, she would cancel at the last minute and you could just tell that she was faking a cold.”
High therapist turnover	31	29	“Therapist turnover was a problem. I had a time when the program nearly collapsed, but I was determined to keep it going and eventually we found at least one person to work with him.”
Problems with therapist presence in the home	59	76	“Your home is never your own as there are always people trooping through it and in the most intimate way in that they come into the bedrooms.”
Administrative difficulties	47	33	“We used to spend all weekend taking photographs of locations. [The child] would master them in one session. So we used to spend hours just putting stuff together. I don’t think that side of it is made clear to families.”

Of those cases where the LEA continued to refuse program funding, 11 families (34%) found it necessary to seek support from a statutory Special Educational Needs Tribunal. Eight families (25%) were just a few days away from a tribunal when the LEA relented and offered to pay for the program, three families (9%) were subsequently funded by their LEA as a result of winning support from the educational tribunal (two full-time programs were funded, one part-time).

Of the private provision group, three families (20%) met the high costs of provision for a 2-year program themselves (at a cost of at least \$29,000 a year), ten families (66%) funded their program for a period of between of 6 and 12 months, and two families (13%) had a full-time program entirely funded by the LEA. Parents who paid for the program themselves spent their savings, remortgaged their house, or went into debt to finance it. Many parents (64%) from the private provision group commented that the dispute with the LEA and the financial burden of the EIBI program had been very stressful for them.

Approximately 40% of parents thought that their LEA was ignorant of EIBI. The most common criticism was that the LEA held outdated and incorrect views about EIBI. For example, one mother explained the views of her LEA: “In their brochure they said they could not condone distressing the child in the interest of long periods of drills....so they had the typical ‘you will be held in this chair and be forced to do this’ mentality”.

Difficulties with Therapists

Almost all parents reported at least one difficulty with their therapists. Therapist organization was particularly problematic, with just over a half of parents finding it difficult to recruit therapists. Some had few potential therapists nearby, others found it difficult to recruit individuals with the appropriate skills and teaching philosophy (e.g., educational background, commitment to use of reinforcement). High therapist turnover created additional difficulties for approximately one third of parents. Therapists were often undergraduates at nearby universities who left the program when their course finished, others reportedly stopped working because they did not believe there were opportunities for progression and career development in EIBI. In addition, approximately one quarter of parents reported instances of therapist unreliability (e.g., late arrival without notification, short working hours or failing to attend all team meetings).

Some parents also found it difficult to cope with therapist presence in the home, experiencing both problems with the therapist per se (e.g., some parents reported that therapists were too familiar with them or that they

left the house in disarray) or problems due to the structure of the program. Some felt that the increased emphasis of *natural environment teaching* on their program and the subsequent reduction in structured table-top work had resulted in reduced privacy for family members in private spaces such as bedrooms and that this was difficult for them. Approximately two thirds of parents reported that the presence of therapists reduced privacy and/or disrupted domestic routines. One mother commented how she always had to be in the house for the beginning and end of teaching sessions, “My life for the next two years was in three hour intervals, where I had a three hour interval to get out of the house, go somewhere and come back.”

Administrative Difficulties

Additional strains created by paperwork and teaching resources also featured prominently for almost a half the respondents. As one mother described, “It’s like running your own business and there is a lot of work, the accounts, sending off invoices to the LEA and all that sort of stuff which is very time consuming.”

Practical Difficulties for the Siblings and the Child with Autism

Parents’ descriptions of practical difficulties for the child with autism and for siblings are contained in Table 3.

Difficulties for the Siblings

Typically developing siblings reportedly experienced practical difficulties as a result of the EIBI program. Of the 27 families concerned, more than one third of respondents indicated that the sibling felt that he or she received less attention than the child with autism. One mother commented:

It was difficult for her [the sibling] to start with as she was used to being the centre of attention. Suddenly we had gangs of people coming round for [the other child’s] benefit and she did find it quite difficult.

Approximately one fifth of parents indicated that the sibling was routinely banned from entering some rooms when teaching was in progress.

Difficulties for the Child with Autism

Only around 30% of those interviewed mentioned practical difficulties for the child receiving EIBI. The most common concern was that the child missed socialization opportunities with peers through being educated at home. Other

Table 3 Practical difficulties for the siblings and the child with autism

Topic/category	% of mothers (<i>n</i> = 27)	% of fathers (<i>n</i> = 20)	Examples
Difficulties for the siblings	56	70	
Sibling didn't get as much attention as child with autism	34	40	"At the start he felt like he was being left out as he would see these people coming to the house giving [the child] a lot of attention and tickles and I think he looked at the program like [the child] was having a lot of fun."
Siblings having to stay out of the way when child was in therapy	25	10	"I have to say to [the siblings], please don't go upstairs and disturb [the child]...sometimes I'd be saying, 'leave [the child] alone he has to do his work.'"
Fewer trips/holidays for siblings	19	35	"You always had to be there at lunchtime because of the way the sessions are, so during the holidays I couldn't take the other children out for the day because I always had to be at home at lunchtime."
Difficulties for the child with autism	31	29	"He was not with other children and I still look back now and think I wonder if he should have gone one day at nursery...I didn't know how he would cope with being at home all day."

concerns included that the child had less time to exercise and that they became tired during teaching sessions.

Impact of EIBI on Family Relationships

Parents also described how EIBI program affected family relationships (see Table 4).

Parent–Child Relationship Improved

All parents remarked that their relationship with the child with autism had improved, particularly because of improved communication skills or increases in manifest affection. One mother explained, "She is much more communicative now, she really looks at you and is more huggy than she was before."

Sibling–Child Relationship Improved

For those families that included a typically developing sibling, over half of those interviewed commented that the sibling-child relationship had improved. The most common reason cited was that they were able to play together. One father reported, "She [the sibling] has a pretty normal little brother who she can play with now and they have fun together and do things together." Many parents also commented that teaching the child with autism how to play with their sibling had been a specific target on their EIBI program. For example, "Having [the sibling] involved in the therapy with him has really helped in the sense that he is now playing with her a lot more."

Parent–Sibling Relationship Improved

One third of parents reported that their relationship with the sibling had improved, particularly because they had more time to spend with the siblings when the child with autism was in therapy. One mother explained, "If I want to do something with [the sibling]...I can do that as long as I organize it, so it does give me that flexibility."

Parent–Sibling Relationship Deteriorated

Less than one fifth of parents felt that their relationship with the child's sibling had deteriorated, usually because (conversely to above) they had *fewer* opportunities to spend quality time with siblings. One mother remarked, "It [the program] meant I had less time for them [the siblings] and I think stress levels increased at times."

Parents' Relationship Deteriorated

Almost a third of parents interviewed reported that their relationship had deteriorated, usually because the couple did not spend enough time together. One mother remarked, "My husband runs the program and is always working on things for the program...it definitely affected our relationship". Conversely, however, some parents were disappointed that their partner was not more involved in the program. As one mother explained:

It did upset me that he wouldn't take too much of a part in the program that he wouldn't learn the signing

Table 4 Impact of EIBI on family relationships

Topic/category	% of mothers (n = 32)	% of fathers (n = 21)	Examples
Parent–child relationship improved	100	100	“I think he has a really great relationship with me his mother which I really don’t think he would have if he had stayed at school. I would have been the person who picked him up, took him home and put him to bed whereas I think it has helped for us to bond together.”
Child could communicate more	82	81	“We were able to communicate better. It is very easy to ignore a child who doesn’t talk. When he started he had no speech whatsoever, when he started speaking it was amazing.”
Child became more affectionate	31	24	“It is so nice when he learns something new...like just putting his arms around you and saying ‘hello’”
Sibling–child relationship improved	52	65	“Their relationship is much better now; they chat to one another now whereas before it was just [the sibling] speaking and nothing more...He has a brotherly relationship with [the child] which just wasn’t there before.”
Parent–sibling relationship improved	41	25	“Me and [the sibling] had lots of quality time...when [the child] was in therapy...I managed to enjoy him a lot more and we have perhaps got a very good bond from the amount of time we spent together.”
Parent–sibling relationship deteriorated	16	15	“She actually said to her teacher that she was jealous of her brother because mummy loves him more than me.”
Parents relationship deteriorated	31	24	“It put a strain on our marriage really. We haven’t had as much time for each other purely because I am tired because of all the one-to-one and the house is a mess in the evenings.”

and than he wouldn’t attempt to listen to me when I say this is the way we do this.

No parents interviewed explicitly mentioned that they believed their relationship with each other had improved as a result of the EIBI program.

Emotional Impact of EIBI

Parents also reported on the personal and emotional impact of EIBI. The main factors identified related to their expectations for the child with autism, and feelings of stress and levels of motivation throughout the program (see Table 5).

Emotional Responses Relating to Expectations for the Child

Parents were asked to describe their expectations for the child before undertaking EIBI. Just over two thirds expressed delight that after 2 years on the EIBI program, their initial expectations for their child had been either met

or exceeded. One father remarked, “As things have gone on I have been totally amazed with the things that Matthew has come out with...just things that a normal child would do.” The remaining parents, however, reported disappointment at their child’s progress, often describing a disparity between their initial expectation of normality after 2 years and their child’s actual progress.

Levels of Stress Throughout the Program

Just under a third of parents explained that they felt that their stress levels had declined over 2 years. Some had become less anxious about difficulties with the LEA and others more used to the demands of the program. The child’s progress also reportedly reduced parents’ feelings of stress. A quarter of parents reported that stress levels fluctuated depending on whether or not there were problems with the program. Thus, some reported stress when therapists left the program but not at other times. No parents reported that they felt their levels of stress had consistently increased throughout the program.

Table 5 Emotional impact of EIBI

Topic/category	% of mothers (<i>n</i> = 32)	% of fathers (<i>n</i> = 21)	Examples
Emotional responses relating to expectations for the child			
Feelings of delight when expectations for child were met or exceeded	66	72	“There was a feel good factor that my son was improving and radically to an extent that he would never have without this program.”
Feelings of disappointment when expectations for the child were not met	34	29	“When we started it with [the child] being two and a half, I thought by four and a half he would be coming out the other end a normal child.”
Levels of stress throughout program			
Less stressed towards the end of the program	32	29	“I think it has got easier because we have got used to it.”
Levels of stress fluctuated throughout program	22	29	“I am stressed now that it is coming to an end and he is going to school in September, but also when he wasn’t getting the hours he should have been I was very stressed about it, constantly having to chase people up...it has been very stressful.”
Levels of motivation throughout program			
Fully motivated throughout program	25	5	“I am probably a lot more relaxed now about the whole thing. I am still very positive about it and I don’t think that has changed because we will keep it going because it is the best for him”
Feelings of motivation fluctuated	28	29	“A couple of times I seriously thought of giving it up completely, it’s never been because of the progress he is making because he has always made good progress. But for me, sometimes I think I just don’t want to do this any more. I think it’s when you compare what you’re doing to what other people have-their normal life. But no, I’m carrying on.”
Less motivated towards the end of the program	25	33	“In the beginning you are very motivated particularly when you start to see results like your child talking. Further down the line two and a half years on, it becomes so much a part of your life it becomes part and parcel of life, so perhaps you don’t sit in on sessions as much.”

Levels of Motivation Throughout the Program

Of the 21 couples interviewed, 33% of mothers indicated that they remained well motivated throughout, compared to only 5% of fathers ($p = .03$). Just over a quarter of parents, however, reported constantly changing levels of enthusiasm. As one mother said, “My feelings of motivation fluctuate all the time. Sometimes I get very depressed about the whole thing. It doesn’t though make me want to change the fact that he is doing an EIBI program.” A similar number of parents felt that, after 2 years of EIBI they were less motivated than they had been at the beginning. Although none wanted to stop the program, they reported that their personal involvement had reduced (i.e., they did fewer hours of therapy, missed some team meetings, etc).

Overall Evaluation of EIBI

Although the interview data identified some practical and emotional difficulties of running the EIBI program, most

parents’ overall evaluation of EIBI remained markedly positive (see Table 6).

Whether EIBI was the Right Choice for the Child and the Family

Over three quarters of parents reported that, despite the difficulties, EIBI was *unequivocally* the right choice for all the family, particularly because of the child’s progress and its subsequent positive impact on the family. For example one mother explained:

Before we got EIBI we had a speech therapist who came up once a month, now what is once a month? If we hadn’t done EIBI we would still have a very difficult child, he would be in a special school not a normal one.

Another parent with two children with autism on programs commented, “To me nothing about doing EIBI has been any more difficult or affected my home life any more

Table 6 Overall evaluation of EIBI

Topic/category	% of mothers (<i>n</i> = 32)	% of fathers (<i>n</i> = 21)	Examples
Whether EIBI was the right choice for the child and the family			
EIBI was the right choice for child and family	75	90	“I had heard from ed psychs [Educational Psychologists] about how EIBI has such a negative impact on family life, but actually for me EIBI is what keeps me going. If I sat back and accepted autism I think that would have much more of a negative effect on my family life than feeling I am doing something positive to help my children.”
EIBI was the right choice for child but family life affected	13	10	“It was certainly the right thing for [the child], although it’s been hard on the family.”
Whether parents would recommend EIBI			
Would definitely recommend EIBI	59	71	“I would definitely recommend EIBI to other families. It just changes your life for the better and it changed [the child’s] life.”
Would recommend EIBI but would warn about negative impact on family life	19	29	“I would recommend EIBI to other families but also warn them it is hard work and it means disruption to your family life but if you feel you can cope with that you must go for it”

than it would do just having two children with autism anyway.” Only around 10% of parents reported that EIBI was the right choice for their child with autism, but not necessarily for other family members.

Whether Parents would Recommend EIBI to Others

Nearly two thirds of parents said that they would recommend EIBI to other families of children with autism. Most said they would not caution about any negative effects. One mum explained, “I would definitely recommend it [ABA] to other families. The benefits for [the child] far outweigh what we have been through.” Approximately one quarter of parents commented that although they would recommend EIBI to other families they would forewarn them about possible effects on family life.

Discussion

Despite a developing literature exploring the effects of engaging in EIBI on parents and typically developing siblings of children with autism, no published studies to date have examined parents’ accounts of their experiences. The present data provide an insight into the perceptions of parents who use EIBI, including its general effect on family life and support systems, their experiences with practical program-related issues, and the personal and emotional impact of running the program in the home. There were very few significant differences between the perceptions of mothers and fathers. In general, parents were positive about EIBI, its benefits for them, their child,

and the broader family. Additionally, however, they clarified some of the more challenging aspects of an intensive home-based early intervention program and described how these challenges may impact families. EIBI service providers typically focus their treatment efforts on the child with autism and are not necessarily mindful of the needs of the remainder of the family. In discussing the key findings of our research, we will focus on the results with the clearest implications for clinicians and EIBI service providers. Many of the issues raised are matters of best practice, but others may help to provide a different perspective for service providers. There are implications for the practical and emotional support of parents, and for other children in the family home.

Turning first to issues of practical support, the management issues relating to therapists were reported as stressful for many parents (cf. Cattell-Gordon and Cattell-Gordon 1998). EIBI service providers could assist parents in various ways to help alleviate these difficulties. For example, service providers could seek to establish networks for locating and recruiting students to be trained as therapists. Offering advice about how to recruit by providing carefully defined selection criteria would also help to improve recruitment efficiency, ensure better stability of the therapy team and thus greater treatment fidelity. Finally, senior staff could reduce the possibility of parents hiring unsuitable therapists by assisting with the interviewing process.

Other therapist-related problems included the frequent presence of therapists in the home and consequent lack of privacy. For example, parents sometimes found it intrusive when children were taught to request preferred items or

activities throughout the house, including in private spaces such as bedrooms. Service providers should ensure that therapy teams strive to maintain equilibrium between the most effective behavior change procedures and the least intrusion on the family (Lovaas 1996). Therapists should also routinely be familiarized—both verbally and in writing—with professional and ethical guidelines relating to such issues as punctuality, reliability, and respecting the family’s privacy and confidentiality.

Parents’ administrative duties, such as repeatedly creating new teaching materials, were also reported as stressful and consumed time that would otherwise be spent with their family. Service providers could help by offering more information about how to find resources or by establishing lending libraries for teaching materials related to specific tasks in the program curriculum. Similar solutions could be found for other common administrative problems, perhaps making use of computer technology to develop common resources (e.g., for timetabling or financial management).

In terms of support for siblings of children engaged in EIBI, parents identified many positive effects but also some areas of concern. Many service providers currently involve siblings in some therapy sessions, for example teaching them the skills they need to play with their brother or sister with autism (e.g., Celiberti 1993; Celiberti and Harris 1993). Older siblings may additionally benefit from attending support groups that provide them with an opportunity to talk about their experiences and perhaps find out more about autism and its impact on families (Lobato 1990; Harris and Glasberg 2003; Meyer and Vadasy 1994). Furthermore, siblings may find it easier to voice any uncomfortable feelings outside of the family, allowing other children in the same circumstances to affirm the normative nature of what they are experiencing.

Perhaps the most significant implication of the present research is the need directly to address the emotional well-being of parents of children on EIBI programs. Although, as a group, parents may not be at particular risk of increased distress (Hastings and Johnson 2001; Remington et al. 2007), there will be some families who will experience considerable strain as a result of engaging in EIBI. Some informal support may be offered by the therapists or more senior team members but service providers could be more proactive.

One key finding of our research was that over one third of mothers and a slightly smaller percentage of fathers were disappointed and upset by the limited progress made by their child, apparently in contrast to their expectation of eventual “normal” functioning. It is likely that their expectations originated with Lovaas’ 1987 research evaluation of EIBI, where 47% of children (nine) who received 2 years of intensive ABA (40 one-to-one hours per week)

were successfully mainstreamed among typical children in regular schools (see also Lovaas 2002).

It is important to note that all of the programs described in this study, used a *workshop* training and service delivery model where a behaviour consultant visits the family every 4–8 weeks to train the family and team to work with the child at home, as contrasted with the UCLA *clinic-based* training and supervision described in the original (1987) study. Lovaas (2002) expressed his concern about EIBI service providers who use the workshop-based training model citing his treatment results of 47% normal functioning (i.e., average levels of intelligence and satisfactory, unassisted performance in a class for typically developing children) He wrote that ‘We estimate that valid outcome data documenting normal functioning from such services, if completed and made available, would be less than 10 percent’ (Lovaas 2002, p. 397, see also Mudford et al. 2001 and Smith and Wynn 2002 for similar comments). This lower rate might reflect such factors as high staff turnover, less frequent supervision than that which occurs in clinic-based treatment (fewer expert consultations take place and program monitoring is not as intense), and the use of therapists and supervisors with less academic background in learning-based theory and research.

The expectation of eventual “normal” functioning is unrealistic and unfair to families. Service providers should therefore ascertain before parents start the program that they have an accurate and realistic understanding of treatment efficacy. Parents who are not provided with these explanations are likely to develop misconceptions about treatment which could cause unnecessary stress and disappointment.

There is evidence (Bristol and Schopler 1984) that a strong social support network, which provides emotional as well as practical guidance, can act as a buffer against stress, anxiety, and depression for some parents of children with autism. Service providers could foster social support in a number of ways, for example by establishing and evaluating the impact of parent support groups. Regular opportunities to talk together might help parents of children on EIBI programs to share practical skills and effective modes of coping. It may be comforting to receive guidance from others who have encountered and solved similar problems or who have the same goal. Other families may also help to provide respite care, enabling couples to spend time together away from the stresses of program management.

Under some circumstances it is possible that some parents could benefit from focused psychological treatment when potentially serious problems emerge. For example, one third of the parents interviewed for this study reported that their marital relationship had deteriorated since they implemented an EIBI program. Although

it is not clear that they blamed EIBI for these changes—or indeed whether this figure is above the base rate for all parents with a child with autism—these couples were nevertheless dealing with considerable stresses and strains (Hastings 2008). The demands of EIBI may exacerbate the situation, for example by reducing opportunities for intimacy, companionship, and privacy. As part of the overall service provision, senior EIBI staff need to be able to identify more serious family problems and respond to them sympathetically, perhaps by adjusting the program's demands. If a clear need for specialist treatment becomes apparent, such staff may be well placed to indicate with sensitivity the availability of appropriately qualified help from other professionals.

Some preventative strategies may also be called for. There is already some evidence that psycho-educational interventions may be useful for parents of children with autism (Bitsika and Sharpley 2000; Bristol et al. 1993) but there may be an additional factor that requires a more specific intervention approach for parents engaged in EIBI. Balazs (2005) has suggested that parents well-versed in ABA theory may find therapeutic interventions based on other models incompatible with their own therapeutic orientation. Therefore, an approach that draws heavily on a behavior analytic model may be worth exploring. Acceptance and Commitment Therapy (ACT; Hayes et al. 1999) is one such approach which seems particularly applicable to the psychological situation faced by parents engaged in EIBI. Briefly, ACT was created in part to treat those with chronic levels of distress that might have debilitating effects on functioning in multiple life domains. ACT emphasizes acceptance of unpleasant emotions, defusion from difficult thoughts, clarification of the client's personally held values and corresponding goals, and enhancement of the client's effectiveness in moving towards these values and goals. This collection of targets seen well suited to the parental stress caused by both having to adjust to the diagnosis of autism and running an EIBI program in the home.

ACT has already been shown to be a useful intervention for parents who have children with autism of school-going age (Blackledge and Hayes 2006). Results showed that ACT reduced parental depression and distress, helping parents to better adjust to the difficulties in raising a child diagnosed with autism. This suggests a line of future research exploring whether, in the pursuit of increased treatment fidelity and effectiveness, an ACT-based intervention for parents might be a useful adjunct to EIBI for the child with autism.

The present study is a rare example of exploratory research intended to investigate an area on which little information exists in the literature. Given its fundamental nature, the results of the research are not useful for

exploring relations between variables. It is also important to note that the data are descriptive only—reporting parents' experiences of EIBI rather than exploring outcomes for children that may or may not be attributable to the intervention. One potential shortcoming of the current study is that there are some sources of variability that may have confounded the results by contributing to family experiences independently of the putative effects of running an EIBI program per se. For example, the severity of the child's autism may have contributed to poorer family experiences.

In addition, various aspects of the program or the success of the program may have affected parents' experiences. For example, the child's progress reported by the families may have been related to their ratings of how stressful implementation had been. Furthermore, family experiences may also be related to the type of supervision or consultancy received. Some of the problems encountered by parents may, for example, have reflected idiosyncrasies of their particular EIBI program or service provider rather than problems with the general method of EIBI.

Our descriptive study was not designed to answer these questions. However, now that parents' experiences have been described in some detail future researchers could develop a survey instrument to enable the systematic collection of parents' perceptions about EIBI along with various demographic, child, family, and program-related variables. Such research would provide particularly useful information for service providers. Data about the experiences of parents who start an EIBI program but then stop before they have completed 2 years would also be of significant practical value. The parents interviewed in this study not only chose EIBI but continued it for a significant amount of time, even though they experienced stresses and difficulties. Subsequently, the perceptions of parents from this study may be more positive than those from the entire population of families who have tried EIBI. Future research would be useful that focuses on when parents give up on EIBI, why they do so, and the impact on themselves and their child with autism.

In conclusion, service providers of EIBI programs for children with autism currently restrict their treatment efforts to the child and are not always sufficiently sensitive to the needs of other family members. Our data suggest that, to ensure these needs are met, an expansion in the scope of provision would be beneficial. This could involve creating and evaluating interventions that provide more support for families on home programs. Targeted family support may in turn have a positive impact on outcomes for children with autism, contributing to the continued evolution and improvement of early intensive behavioral intervention.

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