How and Why do Parents Choose Early Intensive Behavioral Intervention for their Young Child with Autism?

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Abstract: Although the evidence of effectiveness of Early Intensive Behavioral Intervention (EIBI) for children with autism is growing, very little is known about the process parents go through in deciding to implement such a program. We interviewed 30 mothers whose children had been on an EIBI program to investigate more systematically how and why they chose EIBI. Typically mothers were informed about EIBI through other parents, books and the internet. Their expectations of treatment outcomes ranged from their child being cured of autism to no clear expectations. Some families had access to funding through their local educational department, some had to fund part or the whole program themselves, whereas some received funding after a dispute with their educational department.

In the decades following Lovaas’s (1987) seminal study of Early Intensive Behavioral Intervention (EIBI) for children with autism, a growing body of evidence has documented its positive effects as reported in a number of recent reviews and meta-analyses (Eikeseth, 2009; Eldevik et al., 2010; Eldevik et al., 2009; Reichow & Wolery, 2009; Rogers & Vismara, 2008; Virue’s-Ortega, 2010). These findings have been widely disseminated and many parents of children with autism worldwide have chosen to implement EIBI programs (Green et al., 2006). Interventions have been typically home-based, supervised by a behavior analysis professional and delivered by three to five therapists who work individually with the child for up to 40 hours per week.

Although much EIBI research has focused on measures of child outcome, a growing number of studies have explored the intervention process from a parental perspective. For example, Grindle, Kovshoff, Hastings, and Remington (2009), examined how parents perceive the impact of an EIBI program on family life. The positive effects parents mentioned included benefits to themselves (e.g., they received additional support from the therapists working with the child) and to the siblings of the child with autism (e.g., siblings enjoyed participation in teaching sessions and learned how better to interact with the child with autism). Parents also listed some negative impacts, such as problems with their local education departments, difficulties with recruiting and retaining therapists, reduced privacy and disruption to family life. Studies that have examined the psychological difficulties of parents and siblings of children with autism following home-based behavioral programs (Hastings, 2003; Hastings & Johnson, 2001; Remington et al., 2007) suggest no increased risk of problems in family members perhaps because the positive and negative impacts of involvement in these programs essentially cancel out (Remington, 2010).

The question of how parents arrive at the decision to adopt an EIBI approach for their child with autism has not been systematically investigated but the writing of individual parents provides some anecdotal evidence. For example Maurice, Mannion, Letso, and Perry (2001) invited three mothers of children with autism to share their experiences of accessing EIBI services for their children.
counts focused on two major areas of difficulty. The first involved the access to accurate information on potential interventions and their child's learning capacities. Mothers reported that at the time of diagnosis they were given no recommendations about possible interventions and that their enquiries about available educational services resulted in confusing suggestions about interventions that lacked clear scientific rationale (e.g. they could “try and see if it works,” p. 150). Moreover, mothers’ understanding of behavioral approaches was hindered by the technical language often used by behavior analysis professionals. The second major area of difficulty was in securing funding for EIBI programs and identifying service providers with adequate qualifications.

Only Green (2007) has attempted to examine the issue of parental choice of intervention more thoroughly, by interviewing a subsample of parents from a larger internet survey study conducted by Green et al. (2006). Parents were asked: (1) Where they had found information about the intervention they chose, and (2) What their expectations of outcomes were prior to its implementation. Of the 19 parents interviewed, 13 were currently using, or had used, an Applied Behavior Analysis (ABA) program. Of these, Green reported that parents’ sources of information about ABA were books and articles (46%), other parents (38%), and the internet (31%). Regarding parents’ anticipated treatment outcomes, 31% mentioned specific skills they expected their child to achieve (e.g., improved language), another 31% were not asked this question, while the remainder reported either having very high expectations (e.g., hoped for a cure), or no specific expectations.

Given the paucity of existing research data on the decision-making processes that lead parents to choose EIBI for their child, the aim of the present study was to conduct a more thorough exploration of: (1) The intervention options, if any, described to parents at the time of their child’s diagnosis; (2) Other interventions they tried prior to or during EIBI; (3) How parents first heard about EIBI and their initial impressions; (4) Their main reasons for choosing to implement the program; (5) Their understanding of EIBI and their initial expectations of this approach, and (6) How they accessed EIBI services and financial support.

Method

Participants

Thirty mothers who had participated in an earlier field effectiveness evaluation of EIBI (Remington et al., 2007), were invited to participate by letter. Twenty-three mothers from this sample agreed to be interviewed for the present research. Children of 17 of these mothers had received a service supervised by a University team that was provided free of charge to parents. The children of six of the mothers were receiving interventions from private service providers. An additional nine mothers were recruited via advertisements posted in UK ABA forums and in newsletters of parents’ organizations. The children of these nine mothers were also receiving supervision services from private service providers. Participants were not offered payment for participation.

Data from two of the 32 mothers were excluded from the present analysis, one as a result of recording failure, the other because of coding difficulties. Thus, 30 mothers of young children with autism participated, 16 receiving services from the University EIBI intervention team and 14 from a private service provider.

One of the participants had two children, each with a diagnosis of autism and both enrolled in EIBI programs. Thus, the mothers who participated parented 31 children with autism (28 male; 3 female) aged between 49 and 82 months at the time of the interviews (mean = 66.2 months, SD = 7 months). All of the children lived in their family home in the UK. For 25 of the 30 families the child with autism lived with both parents, whereas five children had a father living in a different home. Twenty six of the children had at least one sibling living at home. At the time mothers were interviewed, the EIBI programs had already been running on average for 25 months (SD = 3 months).

Interview Structure

A semi-structured interview format was used to encourage mothers to talk freely about their
experiences. The content, prepared in advance, consisted of a series of open-ended questions on a variety of topics. Topics included: (1) Interventions suggested to parents by the professional(s) who diagnosed the child (e.g., “Did anyone at this meeting discuss treatments with you?”); (2) Other treatments tried prior to or at the same time as EIBI and perceptions of their effects, (e.g., “Were there any educational or therapeutic treatments that you tried at all before ABA?”); (3) Their first contact with EIBI (e.g., “Can you describe how you first found out about ABA?” , “What was your reaction to it?”); (4) The reason(s) they decided to implement an EIBI program (e.g., “Why was it that you ended up going for ABA?”); (5) Mothers’ expectations regarding anticipated benefits (e.g., “Could you describe what your expectations were for [the child] before she/he started the program?”), and possible difficulties connected with the program (e.g., “Did you have any idea before starting ABA of any possible pitfalls associated with it?”); and finally, (6) How they accessed EIBI services once they had decided to do so (e.g., “Once you had decided on ABA, could you tell me how you went about accessing it?”).

This interview protocol was used flexibly. Often, depending on a response, prompts and/or probes were given to encourage respondents to provide additional details. Also, the sequence of questions was sometimes altered depending on the answers given. A copy of the full interview protocol is available from the corresponding author.

Prior to interview, participants received an information pack describing the aims of the study and a consent form. After consent was given, interviews were conducted by telephone and audio-recorded by the second author.

Data Reduction and Coding

After transcription of the taped interviews, a content analysis procedure based on the stages described by Dey (1993) was used: First, responses that related to the six topics listed earlier were grouped together. Second, categories that described similar responses within each of these six topic areas were created. Third, these categories were combined or divided so that the data were organized in the best possible way. A balance was achieved between the most parsimonious descriptions of mothers’ responses, and the use of categories that could be communicated clearly. Throughout the coding process, category labels were modified accordingly. A coding manual based on the final system of categories was written, and each interview transcript coded in full. Depending on content, every interview was coded as either containing or not containing statements corresponding to each category in the coding manual. Primary coding was carried out by the first author. A copy of the coding manual is available from the corresponding author upon request.

Reliability

To establish inter-rater reliability a second person coded eight (25%) randomly selected interview transcripts using the coding manual. Agreement between the two coders was calculated using the list of codes assigned to each interview and a simple percentage agreement index formula (agreements divided by the sum of agreements and disagreements multiplied by 100). An agreement was defined when both raters coded an interview as containing a statement corresponding to a particular 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 88% (range, 73% - 97% for individual categories reported in this paper).

Results

The topics of interest for the present analysis, the categories used to code material in each topic area and the percentage of mothers (n = 30) who were coded using each category are described below. All participants had the common experience of having committed to implementing an EIBI program for at least two years. One differentiating factor was the provider of EIBI services: children of 16 of the mothers had received University-supervised EIBI as a part of a research evaluation project and the remaining 14 received EIBI via a private service provider. When describing the results of the study, in most topic areas the
participating mothers are treated as a single group because there appeared to be no differences associated with the service provision model. However, for topic areas where the difference in service provision appeared to be related to findings, mothers’ views are reported separately for these sub-groups.

Information Given to Parents at the Time of Diagnosis

 Mothers were asked about information and recommendations for appropriate interventions given to them at the time of their child’s diagnosis. Fifteen of the 30 mothers reported that the professional (or team of professionals) who diagnosed their child offered no information or advice. According to one mother, “no-one ever said yes, there is ABA or Sonrise or anything; I had to go and do my own research.” Four mothers (13%) were informed that “nothing can be done” for their child with autism.

 When the diagnosing professionals mentioned interventions, the recommendations were: special school or nursery (30%), speech and language therapy (16%), ABA (16%), play therapy (10%), and Portage (10%; a home-visiting educational provision for preschool children with special needs in the UK). Eight mothers (27%) were already aware of ABA at the time of diagnosis and were actively seeking to enroll their child in a behavioral program.

Interventions Tried by Parents before or at the Same Time as EIBI

 Mothers were asked about other interventions they tried prior to or during implementation of the EIBI program. Most were educational or dietary in nature. More than two thirds (70%) had tried at least one educational intervention prior to EIBI. Speech and language therapy was the most common (40%), but others included the Picture Exchange Communication System (PECS) (23.4%), Portage (20%), special education nurseries (16.7%) and play therapy (13.3%).

 The majority of mothers who had tried an alternative educational intervention prior to EIBI said that they had not noticed any evidence of its effectiveness for their child (71.4%), although the remainder (28.6%) reported that implementing these intervention(s) had helped their child learn some skills. One third of participants remarked upon the lack of intensity of other educational intervention(s). According to one mother:

(The school) were very good actually and he started off using PECS at the nursery but, looking back, when you see how slow it was with the fact that he was only at nursery three days and having to work towards these targets with someone who wasn’t skilled, although she was great and really did go out of her way, so in that sense it was perfect at that time but if we had have carried on it wouldn’t have been sufficient. . . .

 Just over three quarters of participating mothers (76.6%) implemented a dietary intervention, either before starting the EIBI program or at some point during it. Of those mothers, 52.2% had tried a gluten and casein free diet, whereas 30.4% had tried a gluten free diet. One half of the mothers who used these types of dietary interventions reported that they saw some positive effects as a result of the diet. Perceived positive effects included sleep improvement (26.3%), improvements in the child’s physical health (21.1%), greater concentration (15.8%) and the child being calmer (15.8%). For example, one mother reported:

When I took him off dairy, the dark circles under his eyes disappeared overnight. The head sweats – he was always very sweaty and we could never figure out why – the head sweats disappeared overnight. He also never slept properly so from an early age I would go in to his room and he wasn’t sound asleep so he would be bolt upright in bed but he was a very sweet child so this was never really an issue with him. And then all of a sudden he started sleeping.

 A small percentage of mothers (15.8%) noticed the differences in the child’s behavior not so much when he/she was on the diet but when the foods were reintroduced. Regarding the pitfalls of dietary interventions, 26.3% mentioned that the child’s food variety was very restricted and 21.1% of mothers recounted that the child stood out from peers,
especially at parties, as a result of being on a restrictive diet.

Other dietary interventions involved the use of supplements. One third of mothers reported having tried supplements at some point (including fish oils, homeopathy medicines and vitamins) and one half of these participants reported the interventions to be effective. Thirty per cent of mothers who had tried supplements thought that the child seemed more able to learn as a result, two mothers had noticed some physical health improvement and one mother reported a positive change in her child’s behaviour (that after homeopathy treatment he became more affectionate). In terms of difficulties with supplements, 30% of the mothers who had used them remarked on the high cost of supplements and one reported that it was not easy to persuade the child to take them.

First Contact with EIBI

Mothers were asked about how they had first heard about EIBI and what their initial impression was. They were then asked what they did to enhance their understanding of the intervention prior to starting their child’s program. One of the participants was already familiar with EIBI at the time of the child’s diagnosis and was not asked the remainder of questions in this section of the interview.

As shown in Table 1, one third of mothers were initially informed about EIBI by another parent of a child with autism. Another third mentioned the internet or a book as their first source of information. One mother commented: “Really I found that it was the network of parents – friends of friends that really helped me out. . . . Really it was the internet and parents.” Four out of the thirty mothers received information about EIBI from a professional.

Approximately two thirds of mothers reported that their first impression of EIBI was a positive one (see Table 2). Almost half became “instant converts”; their reaction was an enthusiastic and very positive one. Five mothers (17.2%) reported thinking that EIBI was a logical, comprehensive intervention. Another five mothers (17.2%) reported an initially mixed reaction; they either felt skeptical about EIBI or they could not understand it. One mother said:

He (the paediatrician) didn’t describe it but got someone from the LEA to ring me and to be honest I didn’t have a clue what she was talking about! I couldn’t envisage what she was talking about and she came out to see me the week after and I still didn’t have a clue . . . it wasn’t until the training day that I understood a lot more.

A final five mothers reported a negative initial impression of EIBI. In most cases the reason they mentioned was the outdated information they had read involving the use of aversive techniques.

Table 3 summarizes how the mothers we interviewed acquired further knowledge about EIBI. After first hearing about EIBI, most mothers looked for more information before making a decision to start an intervention program for their child. The most common source was the internet followed by other parents of children with autism who were already implementing an EIBI program. Reading up on the subject with specialised books was reported by almost half of participants, many of whom read Catherine Maurice’s “Let me hear your voice.” Eleven mothers reported having visited an existing program.

Deciding to Implement an EIBI Program

In the next section of the interview, participants talked about the primary reason(s) behind their decision to implement an EIBI program and about the level of their understanding of EIBI/ABA at that time. They were also asked to describe their initial expectations regarding how the program
might have benefited their child and whether they were aware of any pitfalls associated with ABA interventions. There were some differences between the University and the private service provider group in these responses. Therefore, mothers’ responses are presented separately for these two sub-groups in Table 4.

The vast majority of mothers from both groups reported that their decision to start an EIBI program was influenced by both empirical and anecdotal evidence that it is an effective method of intervention. Awareness of effectiveness was based either on statistics they had read or on personal accounts from other families whose children with autism were already on EIBI programs. One mother reported:

Well, her son was very self contained and would lie on the floor and roll trains up and down and I think we saw him about two months after he had started and the change was just amazing so we sat and watched in disbelief really . . . We thought, god, well, there is this or there is special schools so we were obviously going to choose the one that had benefit, it was such an astonishing change in her son from the time that I had known him before to two months later, following simple instructions and stuff like that, so we decided practically there and then that yes, we would go for it.

**TABLE 2**

First Impression of EIBI

<table>
<thead>
<tr>
<th>Initial Impression</th>
<th>% of Mothers</th>
<th>Examples</th>
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</thead>
<tbody>
<tr>
<td>Very positive, enthusiastic</td>
<td>48.3</td>
<td>“Well what went through our minds before we knew about [University program] was when we had read this article in The Times about this intensive therapy and how the parents had to re-mortgage their house I said to [(husband)] lets go for this as it sounds absolutely fantastic.”</td>
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<tr>
<td>“ABA is a logical, sensible intervention”</td>
<td>17.2</td>
<td>“I thought this is a really positive approach. It seems to cover all the problems; in the home, out in the community, in schools. It’s a therapy that seems very workable, tailored to the child so very child specific and it doesn’t exactly nip autism in the bud because you can’t do that but it really helps the child to understand their world at an early age and helps them to take away a lot of the frustration and give them some kind of language even if it is just picture language and things like PECs . . . . I couldn’t see anything else that was so comprehensive.”</td>
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<tr>
<td>Skeptical, not sure, or did not understand ABA</td>
<td>17.2</td>
<td>“ . . . when [husband] described it to me as he did most of the research both me and my parents said does [the child] need that because he is quite mild and it seems an awful lot of work and effort . . .”</td>
</tr>
<tr>
<td>Negative</td>
<td>17.2</td>
<td>“ . . . one of things that you read is again dated and is put across like training a dog type thing and you think that is not what I want for my child.”</td>
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**TABLE 3**

Learning More about EIBI

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>% of Mothers</th>
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<tbody>
<tr>
<td>The internet</td>
<td>69</td>
<td></td>
</tr>
<tr>
<td>Parents of a child with autism doing an EIBI program</td>
<td>55.2</td>
<td></td>
</tr>
<tr>
<td>Books</td>
<td>48.3</td>
<td></td>
</tr>
<tr>
<td>Visited an existing EIBI program</td>
<td>37.9</td>
<td></td>
</tr>
<tr>
<td>EIBI professionals</td>
<td>34.5</td>
<td></td>
</tr>
<tr>
<td>Lectures / conferences</td>
<td>20.7</td>
<td></td>
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</tbody>
</table>
Other reasons mothers mentioned for choosing EIBI were that they could identify with the philosophy behind the intervention approach (36.7% of all mothers), and that EIBI offered hope for their child with autism (16.7% of all mothers). Six mothers (29%) mentioned that they chose EIBI because it was available to them at the time they were looking for possible interventions. These were mostly participants from the University-managed intervention project (see Table 4).

Approximately one half of the mothers (46.7%) reported that at the time they decided to start the child’s program they had a well-defined understanding of EIBI. Twelve mothers (40%) said they understood a little about EIBI whereas four (13.3%) admitted that at the time of decision they did not understand the method at all. There were no differences between the University and the private service provider group in this respect.

Participating mothers mentioned both general and specific expectations for their child with autism as a result of following an EIBI program. Thirteen mothers (43.3%) mentioned anticipating that their child would acquire some new skills and 20% that he/she would maximise his/her potential. Specific expectations included language improvement, mentioned by 17 mothers (56.7%) and the reduction of challenging behaviours (16.7% of mothers). Twelve of the participants (40%) reported they were hoping that EIBI would cure their child of autism, and that he/she would be indistinguishable from his/her peers. One mother said: “Well, we expected that he would be one of the 47% that recover from autism.”

TABLE 4
Reasons for Choosing ABA/EIBI for Both the University Provision and the Private Provision Groups

<table>
<thead>
<tr>
<th>Category</th>
<th>% of University Group (n = 16)</th>
<th>% of Private Group (n = 14)</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Evidence of effectiveness       | 81.3                         | 78.6                        | “...I thought ... that I want stuff which is out in the open where the data is out there and you can sort of see the success.”  
“I spoke to a couple of other parents in the area who were doing it and I phoned to speak to them and they told me themselves how their children had progressed so that just pushed us towards ABA.” |
| A logical intervention          | 18.8                         | 57.1                        | “To me an ABA program was logical, it kind of was working towards the academics and the development and the self-care, all the self-help skills etc. Just the whole thing of life skills and development.”
“I think it was the intensity of the support, the way it sounded so practical and logical. It wasn’t mumbo jumbo it was really clear understandable stuff.” |
| Available, let’s try it         | 31.3                         | 7.1                         | “I realised that two years one-to-one tuition for (the child) was something I could never afford myself and I thought well let’s put my prejudices to the side for one moment and let’s see what is on offer and it wasn’t easy to do because I had just bought in to all the negative stereotypes that are out there.” |
| Hope for a child with autism    | 25                            | 7.1                         | “That was probably the most helpful thing, seeing a programme and speaking to a parent and all of them had an injection of hope in to their lives from the despair and these are just people who have done ABA they haven’t elected all the other therapies so again that was a big part for us.” |
Enrollment in a mainstream school was anticipated by 11 mothers (36.7%). Twenty percent of mothers said they were not sure about what to expect. Finally, five mothers said that they tried not to have any expectations beforehand (See Table 5).

After talking about the benefits they had anticipated for the program, mothers were asked how much time they had expected the child would have to receive EIBI for those benefits to be realised. Five mothers were not asked this question because they had not reported any specific expectations as a result of the child being on the program. However, 48% of mothers who answered this question had expected that two years on the program would be enough for the child. One mother remarked: “I think, ignorantly, I hoped for a miracle cure after the two years and some of the stuff you read you think two years of this and then he will be absolutely fine.” Less than one third of mothers (28%) had some idea that the program might continue for more than two years: “I intended to test it for 6 months to see if he makes any progress at all. I was thinking 2 years, maybe 3.” Four mothers said they did not know for how long the child would have to be on the program and two mothers hoped that the improvements would be achieved in less than two years.

More than half of participants were aware that an intensive home program might be intrusive on family life. One mother said: “...people find it very hard having their house invaded every day by strangers but we were very willing to do that.” Worries about the financial burden associated with the approach and about siblings of the child with autism receiving less attention than their brother/sister were expressed by almost a quarter of participants. Other pitfalls mentioned by mothers were difficulties with the practical organization of the program, with finding therapists to work with the child, and worries that the child with autism would be isolated from peers. Some mothers reported fears

<table>
<thead>
<tr>
<th>Category</th>
<th>% of Mothers</th>
<th>Examples</th>
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</thead>
<tbody>
<tr>
<td>Language improvement</td>
<td>56.7</td>
<td>“I think my whole goal and aim for doing the programme was to achieve mainstream school for him and language as he was very limited with language when we started, just labels.”</td>
</tr>
<tr>
<td>The child would learn new skills</td>
<td>43.3</td>
<td>“My initial expectation was let’s just get him taught something.”</td>
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<tr>
<td>Cured, normal functioning</td>
<td>40</td>
<td>And then somebody gave me the book ‘Let me hear your voice’ which I took a while to get round to reading and then I thought “ooh I can cure my son!”</td>
</tr>
<tr>
<td>Mainstream school</td>
<td>36.7</td>
<td>“Well when you start ABA you look at the fantastic recovery figures that were published by [UCLA] which are now down to 10 or 15% but you hope you will be one of the lucky ones that will mainstream without support and that is what we hoped for and that is what we are still aiming for really.”</td>
</tr>
<tr>
<td>Child would maximize his/her potential</td>
<td>20</td>
<td>“...my aim wasn’t mainstream at all...but mine was just to get him to the best place that he could be.”</td>
</tr>
<tr>
<td>Did not know what to expect</td>
<td>16.7</td>
<td>“To be honest with you I really didn’t know what I was going to get.”</td>
</tr>
<tr>
<td>Tried not to have expectations</td>
<td>16.7</td>
<td>“I didn’t really want to have any expectations because you don’t want to be let down...”</td>
</tr>
<tr>
<td>Reduction of challenging behaviours</td>
<td>16.7</td>
<td>“And then but at the very least that he would learn something and his behaviour would be more manageable.”</td>
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</table>
TABLE 6
Anticipated Pitfalls Associated with EIBI

<table>
<thead>
<tr>
<th>Category</th>
<th>% of Mothers (n = 30)</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intrusion on family life</td>
<td>56.7</td>
<td>“Just that the house was going to be an open house but it didn’t worry me at all because if that was what I had to go through for him to improve I thought why not.”</td>
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<tr>
<td></td>
<td></td>
<td>“I didn’t think it was going to be quite as intrusive as it ended up being.”</td>
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<tr>
<td>Siblings receiving less attention</td>
<td>23.3</td>
<td>“We were concerned with our elder son and how it would affect him with people being in the house and all the attention being on (child with autism) and obviously we didn’t have as much time for him as we would have liked to – that was our main concern.”</td>
</tr>
<tr>
<td>High cost</td>
<td>23.3</td>
<td>“The downside would be the huge cost.”</td>
</tr>
<tr>
<td>Difficult to organize program</td>
<td>16.7</td>
<td>“The pitfalls, well, they told me straight away that they were having trouble getting and keeping therapists and trying to fund the programme and trying to get everything together.”</td>
</tr>
<tr>
<td>Child isolated</td>
<td>13.3</td>
<td>“People I have spoken to about it have said “oh that programme is so isolated” and also people don’t like some of the behavioural strategy but mainly the isolation.”</td>
</tr>
<tr>
<td>Use of aversives</td>
<td>13.3</td>
<td>“There was quite a lot of talk about aversive techniques being used in the past.”</td>
</tr>
<tr>
<td>Rigidity of program</td>
<td>13.3</td>
<td>“The only thing that people said was that it can produce little robots but I just thought I don’t care because I would rather have a talking robot than someone who you can’t get to at all. As it happens it is not like that at all.”</td>
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</tbody>
</table>

about aversive techniques being used or that the structure of the program would be too rigid. Anticipated pitfalls associated with EIBI are summarised in Table 6.

Almost three quarters of mothers (73.3%) expected to be involved in some tutoring of the child. Although the explicit agreement with the University service provider was that parents should do about 10 hours of tutoring per week, there was no difference between the University (75%) and the private service provider group (71.3%) in relation to this expectation. Forty percent of mothers expected to be involved in the general management of the program (e.g., recruiting therapists, preparing teaching materials, participating in team meetings, organising therapists’ timetables). More mothers from the private provision group (57.1%) expected to be involved in this way compared to the University group (25%). Finally, 33.3% of mothers said that they expected to be involved with generalizing the goals of the program outside of the formal teaching sessions.

Accessing EIBI Services

The next section of the interview covered how families accessed ABA services once they had decided to pursue an EIBI program for the child with autism. Table 7 shows how the EIBI programs were funded. There were differences here between the groups mainly because the University provider group families received funding from their local education department for at least part of the period of the program. More than two thirds of the University provider group were funded exclusively by their education department but this was the case for only 14% of the private service provider group. On the other hand, two thirds of the latter group started by funding the
program themselves and some months later received funding from their local education department. This was true of less than one fifth of the University provider group. Over 20% of the private service provider group funded the program themselves without any financial support from the educational department. Two families from the University provider group decided to continue to fund some hours of an EIBI program for their child after the end of the two-year project.

Table 8 shows mothers’ experiences of how they accessed an EIBI intervention. The responses were diverse and were again quite different for the University and other provider groups. More than half of the University provider participants were either offered the opportunity of an EIBI program by their education department or asked for funding and were accepted without difficulties. Two of the families from this group had moved house to another locality to have access to the University project. The rest of the University provider families and over a third of the private service provider group received funding after a long fight with their education department, which in some cases had included starting a legal process. Two families from the private service provider group won funding after going through a legal process. Of the three families who self-funded the whole program, one went through a legal process that was not successful, another did not attempt a legal process after their education department refused to support them, and the third did not approach the education department for funding.

Not all mothers who funded part or the whole program themselves offered detailed information on the sources of funding. Those who did reported using their savings, fundraising, receiving financial support from family members, and using volunteer therapists. Two participants remortgaged their houses to fund the EIBI program.

Forty percent of mothers reported that they would have implemented the EIBI program (or continued self-funding it) even if they had not received financial support from the local education department. “We would have remortgaged the house,” said one mother, and another: “We probably could have continued indefinitely – we would have had to borrow money but we would have done that I think.” Five mothers gave a negative reply to this question (i.e., they either would not have implemented the program or would not have continued with it), mainly for financial reasons.

**Family Members’ Reactions to EIBI**

Participants were asked whether their spouse/partner and their extended families supported their decision to implement the behavioral program. In 93.3% of cases the husband/partner agreed with the mother’s decision about the program. Just over three quarters of mothers (76.7%) reported receiving support from their parents, parents-in-law, siblings and other family members and friends.

**Discussion**

Although a large number of children with autism are receiving home-based EIBI programs in the UK and globally, very little is known about how their parents make the de-
cision to implement such a program. The present study provides systematic data on some UK parents’ experiences of this decision process. The findings highlight some of the main difficulties that parents may experience and have implications that can inform improved support for families in the future.

When parents begin to suspect a possible problem in their child’s development, it is usual for them to undergo a series of consultations with health professionals. Once a diagnosis of autism has been given it would be reasonable to expect that the next issue to be addressed would involve the course of action to be taken. That is, parents of children diagnosed with an autism spectrum condition, have the right to expect the diagnosing clinician to discuss evidence based treatment options with them. However, as the present data show, potential interventions may not be discussed at all during the diagnosis meeting. Additionally, despite the growing body of evidence for the effectiveness of behavioral interventions, the majority of parents were not informed and advised about EIBI by the senior diagnosing health professionals involved with

<table>
<thead>
<tr>
<th>Category</th>
<th>% of University Group (n = 16)</th>
<th>% of Private Group (n = 14)</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>LED funded program, no difficulties</td>
<td>56.2</td>
<td>28.6</td>
<td>“...we phoned them up and she said she would come out and see [the child] and she did and I was like please let me have this and it was so easy I think it was meant to be. I couldn’t believe that there weren’t more children queuing up for the two places I was shocked.”</td>
</tr>
<tr>
<td>Funding was offered after fight with LED</td>
<td>43.8</td>
<td>35.7</td>
<td>“...at 5.45pm on the night before Tribunal¹ I had a phone call from the LED to say “We’ve got a suggestion that you could join [the University provision project]” and I said “Well I did suggest that about 10 months ago!”</td>
</tr>
<tr>
<td>Tribunal – parents won</td>
<td>–</td>
<td>14.3</td>
<td>“We just went through the normal process which everyone does which is statementing² and then when you get your final statement you put in your papers for tribunal and you go to tribunal.”</td>
</tr>
<tr>
<td>Tribunal – parents lost</td>
<td>–</td>
<td>7.1</td>
<td>“...it is so difficult to prove at tribunal because the LED only has a duty of care to provide adequate education not the best. ...We have been to tribunal to get full funding for ABA and failed and it was because all the LED had to do was prove that they had an adequate alternative.”</td>
</tr>
<tr>
<td>Parents asked for funding and were refused</td>
<td>–</td>
<td>7.1</td>
<td>“I wrote to the Council who told me that I would have no chance but I wrote a letter, sent all the paperwork and sent letters and said that for any help we would be delighted but we just got a letter back saying that what the local authority provide for autistic children is more than adequate so they couldn’t help and that was basically it.”</td>
</tr>
<tr>
<td>Parents did not ask LED for funding</td>
<td>–</td>
<td>7.1</td>
<td>“No we didn’t (ask for funding). I was too tired and exhausted.”</td>
</tr>
</tbody>
</table>

¹ This is the legal process open to parents in relation to the education services received by the child.
² The procedure of obtaining a statement of special educational needs from the local education department.
their child. This lack of appropriate information about intervention for autism could result in time delays and unnecessary waste of resources as parents need to research information themselves and may initiate interventions with limited or no evidence of effectiveness. In addition, receiving a diagnosis of autism that is not accompanied by detailed advice and information on how to proceed, could work to intensify parents’ feelings of distress, especially when research has suggested that parents value advice on decisions regarding intervention approaches (Webster, Feiler, Webster, & Lovell, 2004).

We could find no data on diagnostic professionals’ perspectives on informing parents about intervention options, and we can only hypothesize about the reasons for this lack of guidance. For example, it is possible that among the different professional groups involved in diagnosing children with autism (child psychiatrists, pediatricians, psychologists, speech and language therapists, etc.) there is no clear consensus at present that EIBI is an approach with the necessary evidence base for effectiveness for children with autism. Alternatively, medical professionals might regard educational interventions to be outside their area of expertise.

In the absence of recommendations from diagnostic professionals, parents look for alternative sources of information about interventions. The majority of mothers we interviewed became aware of EIBI through other parents, the internet and books. They also reported that the main reason for choosing to implement the program was the evidence of its being an effective intervention (80% of mothers). An issue to be considered here is the accuracy of information about EIBI upon which families based their decisions and expectations. Although it is not possible to assess this accuracy, the fact that a significant percentage of mothers expected their child to have achieved normal functioning and a mainstream school placement after two years of intensive intervention could be an indication that the information they received was unrealistic or over-positive. Many mothers mentioned the results of the 1987 Lovaas study and the frequently reported finding of 47% of children achieving “normal functioning.” Maurice’s book “Let Me Hear Your Voice” (1993) described outcomes for two children with autism who were indistinguishable from peers after two years of EIBI and this was also mentioned as influential by a number of participants. Only one mother in our sample mentioned being familiar with a study that explored outcomes of children in workshop-based EIBI programs (Bibby, Eikeseth, Martin, Mudford, & Reeves, 2002) which showed smaller improvements than the Lovaas study and no attainment of “normal functioning.”

It is important that parents of children with autism are being provided with honest, authoritative and up-to-date information about issues such as treatment outcomes and duration and especially about outcomes in community-based research projects (e.g., Perry et al., 2008).

Another important theme emerging from the present data has to do with the difficulties parents who decide to implement EIBI face when accessing services and funding. Many parents reported a long dispute with their local education department as they sought financial support for the program. A significant percentage of families from the private provision group had to finance all or a portion of their child’s intervention themselves. It is quite possible that this experience more accurately reflects those of the average UK family who seeks to secure funding for their child’s program. Data from previous research with parents of children with autism in the UK has identified the attitude of educational authorities as a significant barrier to the implementation of EIBI (Johnson & Hastings, 2001).

It seems that the most important difficulty that parents of children with autism face during the period of choosing and starting an early intervention program for their child stems from the fact that links of communication and collaboration among the different professional groups who are involved in the process have not yet been established. There is little evidence of continuity of services between diagnosis, early intervention provision and then later integration into the school system. Parents often need to find the way through these major steps by themselves, and they might have to fight for an effective intervention for their child. This is an issue that has already been discussed and identified as cru-
sical in the literature on intervention provision for children with disabilities including autism (McCollum, 2002; Webster, Feiler, & Webster, 2003).

The present study has certain limitations. The fact that the interviews took place approximately two years after the beginning of the children’s programs might have had some impact upon the accuracy of mothers’ recollections about the processes involved in decision making. Also, it is difficult to assess the degree to which the sample of participants is representative of UK mothers whose children follow a home-based EIBI program. In spite of these limitations however, the study offers a valuable first insight into parents’ experiences as they seek to choose an effective intervention program for their young children with autism.

References


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