



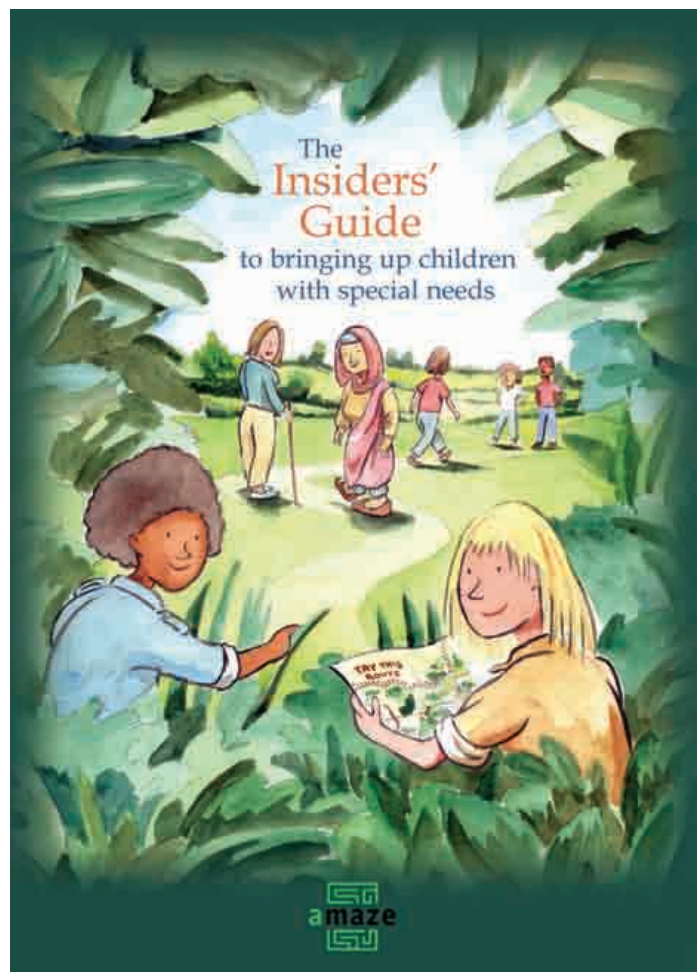
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Insiders' Guide ... to bringing up children with special needs: Evaluation findings of the Amaze parent support course

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Summary of key findings

What do we already know about this topic?

- Over the past decade, parent support courses have gained a very positive reputation in policy, practice and research. They are generally considered helpful by parents, and objective studies report that in many different situations such courses have a positive effect on parenting.
- Parents of children with special needs face particular challenges.
- There are hardly any support courses that specifically target parents of children with special needs.
- In children's services work with parents more widely there is a growing emphasis on parent-professional partnerships. Most parenting support courses however, are facilitated by professionals.

What does this project add?

- The Insiders' Guide parent support course is aimed specifically at parents of children with special needs.
- The course goes a long way to meeting their learning and support needs.
- It facilitated positive changes in parental confidence and competence (especially for those parents starting off feeling very unconfident).
- The course was oversubscribed, popular with parents (including parents who would not normally attend such courses), and had a very low drop out rate.
- The Insiders' Guide course is co-facilitated by parents and professionals.
- Course facilitators valued the experience and most felt that it improved their parenting and/or practice.
- The evaluation provides evidence to suggest that the parent-professional facilitator partnership model is effective.

What do we still need to find out?

- How the Insiders' Guide matches up when directly compared to other forms of parenting support.
- Whether or not the positive effect of the course is sustained over time.
- Whether a group of entirely unconfident parents would find the course helpful.



What aspects of the course would it be most worth taking away and copying in other contexts?

- Parent support course planners might usefully note that the combination of support, psychological reflection, information and education worked well.
- It is worth investing in the detail. Pre-visiting prospective course participants in their own homes prior to them signing up is particularly helpful for getting less confident parents along to the course. Providing nice refreshments, a pleasant environment and a take home gift were highly appreciated.
- The co-delivery model of the course (by a professional and a parent facilitator) was very effective and popular with participants and facilitators. It could be harnessed by children's services to meet policy and practice objectives of partnership working in other contexts.
- Intensive co-training of facilitators appears to be crucial in ensuring this success.

Why develop a parent support course for parents bringing up children with special needs?

- Families with a disabled child are more likely than other families to have a hard time. To mention just a few issues, they experience poverty (Prime Minister's Strategy Unit 2005), relationship breakdown (Beresford 1995; Higgins et al 2005), general health and mental health problems (Barlow et al 2006; Oelofsen and Richardson 2006), unsuitable housing and problems associated with employment such as finding suitable childcare and returning to work (Prime Minister's Strategy Unit 2005).
- Studies indicate that services may meet the immediate health care needs of disabled children but they are less able to meet broader social and emotional needs of the child and family (Abbott et al 2005; McGill et al 2006).
- How parents cope with the specific demands of caring for a child with special needs will be influenced by many factors. These include their internal, built in capacity to manage challenges; the external support and resources available to them; family support; their pattern of communication and problem sharing; their value and belief systems; and the extent of the adversity they face (Clarke et al 1989).
- While parents have diverse individual backgrounds, resources and preferences, studies have shown that they share in common a distinct set of experiences that set them apart from parents of children without disabilities (Gammon and Rose 1991; Russell 1991; Worthington 1994).



- Parenting support courses have proven their worth in helping parents manage the demands of family life (Scott 2003; Webster-Stratton 2006). There are many courses for mainstream parents and many for parents managing specific problems with their children such as behaviour (Scott and Sylva 2000), poor reading and youth offending (Dishion et al 1992). Specific courses for adoptive parents and foster carers also exist (Hart and Luckock 2004; Henderson and Sargent 2005) However, there are very few parent support courses devised for parents of children with disabilities and special needs (Orphan 2004; Positive Parenting 2004).
- Of those courses that do exist, even fewer actively involve parents in their design and delivery. This is despite the fact that partnership with parents is a growing feature of modern children's services, and occupational standards have been developed for working with them (Lifelong Learning UK 2005).
- Parent support courses for parents of children with special needs have not been rigorously evaluated.

So what was the point of this evaluation?

- The purpose of this study was to evaluate an innovative parent support course specifically designed for parents of children with special needs. Course modules were co-facilitated by parent trainers, who are themselves parents of children with disabilities or special needs, and professionals involved with supporting families with children with disabilities or special needs. The parent support course used a variety of learning methods and catered for different learning styles. Broadly speaking it conformed to a 'psycho-educational' model. This combines a focus of the psychology of parenting with explicit educational input. The course provided opportunities for parents to gain insight into their parenting dynamics, provided support, information and practical training.
- An evaluation was devised to capture the changes that the course was intended to promote.
- The main aims were to find out whether the parent support course is an effective way to deliver information and support that strengthens parental confidence and competence; whether the course increases parents' ability to work effectively with professionals and to find out whether it empowers parents to advocate for services on behalf of their children and families.



Who took part in the evaluation?

- Fifty-three parents attended the five separate courses. Forty-four of these were interviewed by questionnaire both before and after the support courses. Both the 'before' and 'after' questionnaire asked the same questions so we could track the impact of the course on parents. Twenty-five parents attended focus groups after the courses, and we undertook 5 individual interviews with a further 5 parents. Thirteen parents gave additional feedback when completing the second questionnaire. Four of the five parent facilitators and all 6 professional facilitators took part in a focus group. One of these professionals was also a parent of a child with special needs. All the facilitators kept written journals of their experiences which they made available to the evaluators.

Who came on the course?

- Demographic details are available for 50 of the course attendees. Four men attended the course with one not completing it. Sixty percent of the attendees were homemakers, 20% were from professional occupations and 20% were from low paid occupations. 16 or 30% lived in a regeneration area. Of the 50 parents, 42 were English/British. English was spoken in 45 of the households. One respondent did not give the language spoken at home. Approximately half of the parents were tenants and half owner occupiers. Thirty-three of the parents lived with a partner whilst thirteen lived alone. Four respondents did not give this information.



Does the course help parents access services on behalf of their children and families?

- Only a handful of parents (4) were confident about knowing where to go to get information and advice before the course. Of the rest, the evaluation shows a very marked increase in them knowing where to get help.
'The education system was the most important aspect...but left me hungry for more... We were told things that made life a lot easier. We have a clearer idea where to go now.'
- Before the course, quite a few parents already felt very confident about contacting professionals (14), and a smaller number felt fairly confident (10). Nevertheless, both numbers increased after the course – 17 and 22 respectively. And by the end of the course no parent was left feeling unskilled in this area.
'I think it enabled me to see the person I was having the meeting with in a different light. Instead of giving my power over to them I felt like I could actually deal with them a lot better. When I came out of there I was chuckling away...thinking "YES!"'
- Many parents (25) felt worried about asking for help at the beginning of the course. The course did not significantly affect this number, with 23 at the end still feeling worried. Despite this, the numbers of parents who became more confident about asking for things and felt more able to push for services and support increased from 28-36 and from 36-39 respectively.
'The course made me more confident about tackling things. I often back off from saying things. I now feel confident to ring people. I would probably have just left it before.'



Does the course improve parents' confidence?

- Before the course, most parents felt they could do things as well as other parents (38). Of those who didn't, the course clearly helped all but one of them. For the whole group, the only area where there was no change was in feeling that they had enough practical support.

'Most of the time I feel invisible because the focus is on our children's needs. In this group I feel visible. I am real.'

- Prior to the course, these parents were fairly self-contradictory about how confident they were. Most were satisfied with themselves; but on the other hand most of them also felt useless. In any case, all the figures improved after the course. The greatest improvement in feelings was in general self-confidence. By the end of the course more parents felt able to do things as well as most people and fewer wished they could have more respect for themselves.

'When you can have low esteem at times...you know when you are absolutely worn down and your child has not been well ...and everything seems to be going wrong. You can have self doubt after a few years...so it was nice to talk it through and you think, "yeah, we do a bloody good job".'

- Only 13 out of 44 parents came onto the course feeling that they had the support of other parents in their situation. This figure rose significantly after the course to 23. Over half of parents felt they left the course with more support from other parents. However, 21 still felt they did not have this type of support.

'I think for me what this group has meant to me is that I had felt very alone in my parenting to my children and all their special needs. So I have gained a lot from everyone in the group and I have also learned extra strategies.'



What did parents feel about parenting?

- Most parents (41 of the 44 who took part in the evaluation) felt confident about their parenting before the course, and all but one of the entire group (43) felt this at the end. So the course did manage to improve the confidence of the small minority who were unconfident.
- A similar effect can be seen with whether they felt they had a lot to be proud of in their parenting.
- At the end of the course all parents felt they handled their child or children well, with most feeling that beforehand anyway.

How did parents feel about the parent and professional working in partnership as facilitators?

- All parents endorsed the partnership model. In particular, course participants were unanimous in their enthusiasm for having a parent facilitator. The parents saw the parent-facilitator as 'one of them' and felt that her shared experiences and patience encouraged them to open up and express their emotions freely. Parents said that they were used to dealing with professionals who were unable to truly empathise with the difficulties and issues involved in raising a child with special needs. Therefore they welcomed the opportunity to work with a parent facilitator – 'someone from the inside'. They felt that their shared experiences provided the necessary link between parents and professionals and served to promote honest communication within the group. The parents praised the parent-facilitator's willingness to be open about her own experiences and emotions.
- Professional facilitators were welcomed, but only when paired up with a parent facilitator. Parents appreciated professionals' efforts to try hard to understand the common issues faced by parents of children with special needs. Experiencing professional facilitators in this way seemed to do much to bridge the gap between parents and professionals formed through previous experiences and reduce the differences in perspectives.
- Parents believed that the parent-professional facilitator model was an excellent idea that should be used again.
'I really liked the fact that they had a parent. We knew she had been there, done that. The workers knew what they were talking about but having a parent helps lead the discussion. She was really confident. You could connect with what she was saying most of the time.'



How did the parent and professional facilitators feel about working together?

- Both parents and professional facilitators expressed how much they valued working in partnership. They were keen to point out the numerous benefits for themselves of co-operation between professionals and parents. In particular, the “letting go” of preconceptions, the opportunities to gain insight into the experiences and feelings of others, the acquisition of new knowledge and skills, and the personal sense of reward were put forward as beneficial effects of the experience.
- They also reported that parents who had attended the workshop benefited from the co-delivery model. Parent and professional facilitators agreed that for parent participants the opportunities to share personal experiences with other parents and interact with professionals on a more equal basis was truly rewarding. It had, they felt, helped parents feel more in control of their situation.
- Feedback from parent-facilitators indicated that the workshop would not have worked as well without their experience and credibility as a parent of a special needs child. In particular, they felt that their unique insights enabled them to be sensitive to the emotions of other parents, challenge the perceptions and attitudes of the non-parent-facilitators and contributed to several of the modeling exercises. Their views are in line with participants' views on parent facilitators.
- Parent facilitators thought that the professional facilitators added a dimension of credibility to the course.
- Feedback from both parents and professionals suggests that co-facilitating the course had led to significant reflective practice.

‘I have really enjoyed working in my team and found it really useful facilitating with a parent. It has really opened my eyes to the different strengths we all have. I hope to continue working alongside/ with parents....Thank you for this experience. I have learnt a lot about the parents I work with daily and about myself. (Professional facilitator).’

‘I am pleased to note my own strengths and weaknesses in the facilitation role. Noticed things about myself, people skills, positive attitudes, assertiveness... This has been a really tough journey in lots of different ways (mainly time commitment and emotionally draining) but so far we have managed fantastically....(Parent facilitator).’



- The initial title of the project “Parents Doing It For Themselves” was considered inaccurate by some professionals as it undermined the strength of the parent and worker partnership and, it was felt, should be changed to reflect this innovation. Hence the Insiders' Guide title was chosen.
- Despite the considerable pressures involved in such participation, co-facilitators voiced their eagerness to take part in future workshops.
- Our data indicates that both parents and professional facilitators believed that the parent support course had been rewarding, empowering and insightful for themselves. They said it was a positive step towards promoting better working relationships between parents and professionals. It had helped and developed more effective and fulfilling strategies for coping with the demands of living with a child with ‘special needs’.

‘There could be so much to gain from a course like this one by anyone involved... (Parent facilitator)’

‘The course gave me the opportunity to have honest discussions with parents about their experiences of contacts with professionals...and also my own experiences of contacts with parents. It has given me a deeper understanding which I feel will help me further my communication skills with parents. And finally, it has also given me an increased sense of working in partnership with parents.’ (Professional facilitator)’

How did the course structure, content and delivery measure up?

- The pre-preparation of the course, including a home visit and accommodating parents' wishes into the design and delivery of the courses was greatly appreciated by participants. It contributed to the success of the course.
- The pleasant venue, nice refreshments and take home gift were little touches that meant a great deal to parents and contributed to the success of the course.
- In focus groups and interviews parents commented extremely favourably on the structure and content of the sessions. Only one parent was persistently critical of the course, (and parts of her constructive feedback have now been incorporated into the course design). A handful of others described some elements as ‘boring’. Reasons for this were given as: ‘loads of paperwork...only value was meeting up with other Mums’; ‘The (visiting) professional didn't have charisma and negotiating skills’; ‘One bit was a waste of time as my children don't have what they were talking about’. ‘People were bored with the (visiting) professionals’.



- Parents repeatedly stated that they found meeting other parents one of the best parts of the course.
 'I met other parents. I didn't put myself forward but listened to what other people say. In the past I didn't really bother because it meant socialising. There was no aspect that wasn't helpful. It made a difference having the parent. It was helpful talking to her. There was no problem being a man. I found it very helpful.'
- Of the parents of younger children, several particularly valued the educational information.
 'I really liked the educational bit – the statementing – it really prepared you for what is going to come and the difficulties. Understanding that the process takes time. Knowing what the norm is.'
- One course took place in a regeneration area. In this group, the practical guidance on how to fill out forms was especially welcomed. Just over half of the parents at the focus group (4 out of 7) spoke of earlier experiences reducing their self-confidence and leaving them feeling suspicious that the forms were intentionally confusing to discourage application. Several parents felt they needed practical, step-by-step guidance for claiming benefits and completing statements. The course clearly improved parents' confidence in claiming benefits.
 'I have a friend going on the next course and she will gain a lot from the benefits.'
- Parents generally felt that the exercises conducted during the sessions provided them with the opportunities to rehearse emotions and exchange ideas. They also helped foster a supportive environment between the parents and with the facilitators.
 'I think what you write down and put it up on the board...when people start seeing duplicates you realise that someone else feels the same. Someone else feels angry. Someone else doesn't feel appreciated.'
- The potential benefit of the course to non-primary carers such as the working parent or partner was also highlighted by one parent. He felt that the educational sessions and opportunities to talk with other parents had provided him with deeper insight into the experiences of his partner who stayed at home all day with their child.



- One of the positive aspects of the course was using the real life experiences of the participants as illustrations rather than case studies.
- Many parents felt that there was sometimes insufficient time to properly cover the issues raised in the sessions. This applied to both emotional exercises where more time could have been given to 'recover' and to information sessions where some parents felt overloaded.
- A number of parents found the emotional aspects of the course difficult, and a further few found them unnecessary.

'I don't like sharing my emotions. So to actually put it up was scary. But then, because there were duplicates up there it made me feel safe because it was alright to be normal, it's alright to feel hurt, it's alright to be frustrated because other people do. So I think it did work though it was scary.'

'I felt I'd dealt with the emotional side though some people on the course did benefit from the emotional stuff. For me there were too many emotional bits but that is maybe because I'd done some of it before. It is good for parents with a late diagnosis to have the emotional side. That would have been brilliant for me a couple of years ago. I was still trying to get to grips – even in denial.'

What can we conclude from the evaluation?

- In general terms there is evidence of greater personal confidence and self-esteem since attending the course for parents who felt more vulnerable beforehand.
- Parents were clear that the course provided more effective support than general support groups. This was partly attributed to the structure of the course and that course facilitators combined parental and professional experience. Most found great value in the support gained by the sharing of experiences with other parents in a similar situation. They spoke of their previous isolation in not knowing other parents.
- Sharing experiences has increased their confidence and self-esteem by finding out that other people have similar experiences or have tried similar strategies. They have also learned from others' experiences and strategies
- Our data suggests that the course helped parents feel less vulnerable about needing, and then asking for, support.
- Parents valued the information given to them, particularly about advice and support with benefits and education.
- The course increased parental confidence in working with professionals and they felt more empowered to advocate for services.



- The overwhelmingly positive feedback from parents indicates that the course has had a dramatic impact on the lives of many of those who attended. Most parents asked for occasional continuing support to maintain the impetus the course had given them for managing their caring responsibilities. All the groups expressed an interest in continuing to meet up. In the regeneration area a longer-term parent support group has taken off with parents from the Insiders' Guide Course co-running it. Another group of parents with children with ongoing health care needs is meeting and is being organised by the parents themselves.
- A significant outcome of the course has been the success in attracting and engaging families on benefits, on very low incomes and living in particularly disadvantaged circumstances. They made up a third of course participants.
- The findings suggest that there is value in repeating the Insiders' Guide parenting course.
- Our study adds considerable weight to the importance of including parents in the facilitation team. Indeed, it adds to the body of knowledge providing evidence for the positive impact of experiential, service user perspectives in supporting families (Milne 1999). And it provides evidence of one model for successful parent-professional partnerships in children's services.
- Finding professional facilitators who have good presentation skills and the capacity to empathise with parents of children with special needs is crucial to success.
- 'Visiting professionals' on parent support courses need to be particularly empathetic as it is difficult to create a rapport in a one-off session. The contrast between them and co-facilitators involved for a longer period can seem particularly marked.
- Given the complexities of partnership working, the 4 day training programme for co-facilitators is probably integral to the course's success.



Do we need to qualify these findings?

- Yes. There are some things that we didn't find out.
- Changes have been captured by both the questionnaires and focus group contributions. However, as we did not have 'a control group' to make comparisons with we cannot be absolutely certain that it was the courses that made a difference. And some researchers would say that even if we had a control group we still would never know for sure.
- Parents were given £10 per session to attend the course. This was a pilot course and the parents were 'guinea-pigs' so it was felt that their participation should be valued, and indeed rewarded in some way. This payment may have affected how many parents signed up for the course. However, it is unlikely to have had a significant impact on the evaluation aspects of the project, because parents were assured payment regardless of whether or not they took part in the questionnaires or focus groups.
- The course did raise feelings of confidence and competence in the group overall. But many of the parents on the course claimed to be fairly confident and competent in parenting before they started. (Just to complicate things further though, we need to note that some contradicted their own statements when different measures were compared). Future studies would need a more sensitive measure to better capture what is going on here.
- Precisely how effective the support course would be with a group of parents starting off from different baselines is unclear. It may be that if the course targeted less confident parents, it would have an even more dramatic effect. On the other hand, having some quite confident parents on the course may have had a positive effect on those who felt more vulnerable.
- The evaluation did not reveal the course to have had any negative effects. Controversially though, it may be that some parents were inappropriately confident about their parenting and that the course should have made them feel more self-critical.
- There were very few fathers involved as participants on the course and none as facilitators. How the courses would work with them is therefore as yet untested.



- The parent support course cost approximately £200 per parent (assuming 12 participants in a group), not taking into account pre-training costs. This is broadly in keeping with the cost of many other parent support courses, and certainly cheaper than some (e.g. Webster Stratton) assuming that they include a crèche, accessible venues, facilitator fees, two facilitators, pre-course visit and materials. The weight in favour of the Insiders' Guide Course over other parenting courses is that parents of children with special needs say they want something specific to their unique context. The parent-professional facilitator dynamic adds further clear value.
- We do not know for sure that if we spent £200 on one-to-one support for each of these parents (for example through investing in 5-10 hours of individual case work support or telephone help line advice) whether the same effect would be produced. However, given that most parents valued the group process, and had clearly learnt things through the process, it is unlikely that a one-to-one model would produce the same effects.
- Parents valued meeting professionals in a different context, and professional facilitators reported the benefits of learning more about the parent perspective for their regular work. However, we don't know whether the course has had a knock on effect and improved working relationships between parents and professionals in other settings.

What should happen next?

- Some longer-term research with parents who have attended the course would be beneficial to see if the changes have been sustained.
- A comparative study with other forms of parenting support would make us even more sure that this model is both effective and particularly good value for money.
- The co-delivery model of the course (by a professional and parent facilitator) was very effective and popular with participants and facilitators. This dovetails very well with the service user involvement agenda in health, social care and education (Beresford 2001). It also empowers individual parents and makes professionals more effective. Taking all this together suggests that the model should be replicated across children's services for other courses and training events beyond those targeted at parents of children with special needs. However, intensive co-training of facilitators (4 day programme) would seem to be crucial in ensuring this success.



About the evaluation project

- A method was devised that incorporated a questionnaire that was completed before the course and the same again after to capture changes. Focus groups were also set up for parents to give more in-depth feedback and comment on the value of the course to them.
- Fifty-three parents attended 5 courses and completed the pre-course questionnaire. Each of these was visited in their own homes by the course director prior to signing up for the course. Forty-four parents completed the post-course questionnaire and the comparisons between the 44 parents have been used in this evaluation. There were 5 focus groups of parents and a focus group for course facilitators. And interviews with a further 5 parents were completed. Parent and professional facilitators kept a written journal of their experiences.
- The aim of the questionnaire was to attempt to capture parents' perception of three areas of their experience of being the parent of a child or children with special needs. The three areas were:
 - o Parents' self-esteem and well-being
 - o Parents' experience of parenting
 - o Parents' perception of their relationships with professionals.
- As the questionnaire was intended to capture areas of experience of parenting children with special needs a search was made to find a questionnaire that had already been used in previous research. However, the parent course designed for this project is innovatory. So there were no examples that fitted the specific requirements of the evaluation. A base for the questionnaire was therefore devised from a composite of general self-esteem questions taken from the Rosenberg Self-Esteem Scale (Rosenberg 1965) and some parenting issues from the Parenting Stress Index (Abidin 1995). Other evaluation tools were considered such as those used with general parenting programmes such as the Webster-Stratton programme (www.theincredibleyears.com) but they did not cover issues that were specific to families of children with special needs.



- Three parents of children with special needs were consulted to ascertain what outcomes they would like from a parent support course. Their views were incorporated when designing the questions on each of the three areas. The issues raised by parents were:
 - o Wanting to feel better about the ability to parent a child with special needs; more confident and competent; less worried.
 - o Wanting to be better at dealing with professionals and managing contact with them.
 - o Wanting to feel stronger at pushing for services and support for their children.
 - o Wanting more strategies to manage certain situations.
 - o Wanting to feel less isolated.
- Three practitioners were consulted to ascertain what outcomes they would like from a parent support course. Those issues incorporated in the questionnaire were:
 - o Wanting to find out if running a course was an efficient way to support parents.
 - o Wanting to learn more about what matters to parents.
- Once the draft questionnaire was drawn up it was piloted with two parents of children with special needs. This led to refinements of how and what questions were used. The final questionnaire was then piloted with three prospective course participants. Focus group data was recorded and transcribed. Ethical approval for the study was obtained from the University of Brighton's research ethics committee.
- The information gathered from the evaluation has been analysed in a variety of ways. The data collected from the 'before' and 'after' questionnaires was analysed in a quantitative way. Numbers of parents answering a particular aspect of a question were counted and compared 'before' and 'after' the course.



- The information gathered from the focus groups and interviews was analysed mainly in a qualitative way. This is a more complex method of analysis as it requires interpretation rather than measurement. The questions which formed the main structure of focus groups and individual interviews were designed with the aim of finding out what was successful and what did not work so well for those attending the courses in order that the value of the courses could be assessed. However, the groups and interviews were semi-structured, which means that there was plenty of opportunity for parents and group facilitators to give their own views. For groups and interviews took the form of discussions rather than simply answering questions. The outcome was that we had information that we particularly wanted and additional information that parents and facilitators felt was important or relevant. The data collected was analysed by selecting themes that arose during discussions. Some of the themes arose from the questions that formed the structure of the discussions and some arose from the participants.



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Where can I get more information?

- For more information on parent support courses **locally** contact
Amaze
Community Base,
113 Queen's Road,
Brighton
BN1 3XG
Telephone 01273 772289
- For more information on parent support courses **nationally** contact
Parenting UK,
Unit 431 Highgate Studios,
53-79 Highgate Road London,
NW5 1TL
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