

Parental views about services for children attending schools for the emotionally and behaviourally disturbed (EBD): a qualitative analysis

T. Crawford and E. Simonoff

Department of Child and Adolescent Psychiatry, Guy's, King's and St. Thomas' Medical School and Institute of Psychiatry, King's College London, UK

Accepted for publication 18 July 2003

Abstract

Aim This study examines the views of parents of children attending schools for the emotionally and behaviourally disturbed (EBD). The study aims to gain an understanding of the journey through the educational system taken by these children and to explore their families' experience of services along the way.

Methods Thirty parents of 25 children attending primary and secondary EBD schools in three South London boroughs took part in focus group discussions. Parents were asked about their experiences of services, including educational, health and social services, as well as how they thought services should be improved.

Results Qualitative analysis identified a complex web of individual, professional and organizational factors which contributed to social exclusion of children with EBD problems and their families. These factors included children receiving inadequate education because of long periods of exclusion or inappropriate placements whilst waiting for a statement of special educational needs. Parents also felt personally socially excluded because of lack of childcare provision out of school hours. Many parents felt that their children did not fit into services and were constantly being passed on to other professionals. The analysis identified aspects of services that promote social inclusion and provide support to families, including acceptance of children into EBD schools, help from voluntary organizations and support from other parents with children with EBD problems. Parents particularly stressed the value of working in collaboration with professionals to achieve shared goals.

Conclusion EBD schools provide a valuable resource for parents. However parents often lack emotional and practical support in coping with their children's complex needs. Agencies need to improve communication and joint working to provide effective services for these families.

Keywords

special schools, consumer satisfaction, focus groups

Correspondence:
Professor Emily Simonoff,
MD, Institute of Psychiatry,
PO Box 85, Department of
Academic Child and
Adolescent Psychiatry,
De Crespigny Park, London
SE5 8AZ, UK
E-mail:
e.simonoff@iop.kcl.ac.uk

Introduction

Schools for the emotionally and behaviourally disturbed (EBD) are a local education authority (LEA) provision for children with special educa-

tional needs because of emotional and behavioural problems. The Department of Education (1994) stated that children with EBD have problems which are 'clearer and greater than sporadic naughtiness or moodiness and yet not so great as

to be classed as mental illness. EBD may show through withdrawn, depressive, aggressive or self-injurious tendencies. There may be one or many causes. Family environments or physical or sensory impairments may be associated... There is no absolute definition.' Place *et al.* (2000) found pupils in EBD schools had a range of disorders including attention deficit disorder, conduct disorder, oppositional defiant disorder, depression and anxiety whilst three quarters had a reading age of 2 years or more below their chronological age

LEAs have a statutory duty to identify and assess any child who has a special educational need. If, following an assessment, it is decided that special educational provision is necessary, the authority makes a statement of special educational needs for the child. This statement sets out the educational provision such as attendance at special school, which must be provided by the LEA. A child can only be placed in an EBD school once a statement has been completed, however, most children who have a statement of special educational need because of emotional and behavioural problems attend mainstream schools. There are 264 EBD schools in England with an average of 44 pupils aged 0–19 years, providing a total of approximately 11 616 places for children with EBD problems (Ofsted 2001). Thus only a tiny fraction of the 10% of children and adolescents with an impairing mental health disorder in the UK (Meltzer *et al.* 1999) are educated within an EBD school.

Children from EBD schools are a group at high risk of developing a wide range of different problems in the spheres of mental health, academic attainment and psychosocial functioning. They consequently have needs from a wide range of different services including education, mental health and social services. Lack of successful intervention is likely to lead to long-term psychosocial and economic adversity, psychiatric morbidity and high financial cost to society (Cooper 2001).

It is becoming increasingly acknowledged that patient views should be taken more seriously in planning services (Ruggeri 1994; Atkin *et al.* 1998; Perkins 2001; Sayce 2001). Meeting the complex needs of this vulnerable group is a major challenge for service planners and providers. This study

explores service provision from a parental perspective on the premise that families will be most aware of the barriers they face in getting services for their children and that parents can make a vital contribution to finding practical solutions. Furthermore, user participation in decision-making is likely to lead to increased satisfaction (Nelson *et al.* 1992).

Focus groups were used as a means of generating baseline information on parents' views about services. In this largely unexplored area of research, this methodology is most suited to tapping into beliefs held by families. It is hoped that this study can be used to inform future research of a more quantitative nature.

The research should be of interest to agencies involved in planning and providing services for children with special educational needs because of emotional and behavioural problems. These agencies include LEAs, health services [including child and adolescent mental health services (CAMHS) and community child health services], social services and voluntary organizations. Together these groups face the challenge of integrating services, through effective multiagency working, to enable families to access a range of services to meet the complex needs of these children. This study is also relevant to those interested in the needs of young people with complex mental health, educational and social needs.

Methods

The study took place in three London boroughs: Lambeth, Lewisham and Southwark. Within these boroughs there are five EBD schools and one school for children with mixed needs which have a total of 325 pupils (The Education Authorities Directory and Annual 2002). This population has high deprivation scores on the Townsend and Jarmen scales, ranking third out of 99 health authorities (CHI 2002).

The focus groups were part of a larger study assessing psychopathology in children attending the five EBD schools. This larger study consisted of a survey of all pupils in the schools using teacher, parent and child versions of the Strengths and Difficulties Questionnaire (Goodman *et al.* 2000) and in-depth interviews on a randomly selected sub-

Table 1. Location and composition of focus groups

School	A	B	C	D	E	Total
No. of parents	12	7	3	5*	4	30
No. of children†	10	5	3	4	3	25

*Includes one grandmother with parental responsibility and one stepfather.

†Children not present in focus group. Table shows number of children referred to by parents.

group of 40 participants, using the Child and Adolescent Psychiatric Assessment (CAPA) (Angold & Costello 2000).

This component of the study involves a qualitative analysis of focus group discussions with parents. The sample was drawn from two primary EBD schools, two secondary EBD schools and one school catering for youngsters 6–16 years old with mixed needs including those with EBD problems. One EBD school out of the six schools approached, declined to take part in the study. All parents from the five participating schools were invited to attend by letter from the head teacher. All those who attended received a £5 gift token. Thirty parents participated and three of these had also taken part in the individual interviews used in a different part of the study. One focus group took place at each of the five participating schools. See Table 1 for further details.

Focus groups

The framework for the focus groups is shown in Appendix 1. All participants completed a consent form before taking part. Each focus group lasted 1 h and was facilitated by T.C. and one other research team member. T.C. took the lead in asking questions, clarifying statements, encouraging participants to expand their answers and facilitating participation of all group members. The focus groups were tape-recorded and transcribed verbatim.

Analysis

Analysis of the five transcripts took the form of content analysis of the data (Riley 1990; Pope *et al.* 1999). Coding categories were based on the framework of questions asked in each focus

group, including good experiences, bad experiences/barriers and improvements for each of the services mentioned. Each text unit was assigned to the appropriate category using a grid format. All text units were assigned to the most appropriate category except those units that had no relevance to the themes. After T.C. completed this process with one transcript, E.S. analysed the transcript and verified the categories used and the assignment of data units to each category. Minor adjustments were made to the allocation of data units following this process. The process was then completed on the remaining four transcripts by T.C. Following further review, the initial categories were refined into subcategories to incorporate issues and themes identified both within and across categories.

Results

Characteristics of participants

Twenty-one mothers, seven fathers, one grandmother with parental responsibility, and one stepfather took part in the focus groups. In five cases, both parents of one child attended the focus group. The children of the participants had an age range of 6–17. Seven of the participants were black, two were Asian, and 21 were white.

A number of themes were identified, which are described below.

Impact on parents

Stigmatization and isolation

Parents felt isolated and marginalized by their children's problems. They repeatedly referred to the stigmatization associated with children with EBD problems, which they saw as greater for them than parents with physically disabled children.

They just see you as an outcast.

Having J. is like having a big stigma, like a big wart. I love him dearly, as you said every child should be treated as the person within, not what they are on the outside. In a sense that they are the second class citizens. That is how I felt to these people.

Feelings of blame

Participants often talked about feeling blamed. They felt that others, including professionals, thought it was their bad qualities as parents that had led to their child's problem.

They put it down to, 'The parents aren't strict enough, the parents don't do this'.

The battle with services

A recurrent theme was the need to minimize marginalization through 'fighting' services. Parents used combative metaphors and descriptions to describe their attempts to gain services for their children.

I fought for two years to get him statemented.

Support for parents

Many parents talked of needing support for themselves. They highlighted the personal stress involved in looking after their children. A number of ways support had been or could be given were identified, including providing parent groups, individual counselling for children or having regular telephone calls with teachers to discuss their children's progress.

More support to parents. They should understand what the parents go through.

The value of the shared experience

Participants felt that they particularly valued the experience of sharing their problems and getting advice from other parents of children with similar problems.

It's good for parents to come together. And the way you try and cope with your problem may be a different way to how I try to cope with my problem. So, I can sit down and listen to you when you say why don't you try this way.

Relief was expressed in response to hearing about other parents' experiences and in particular their difficulties in obtaining services. Some

parents had believed their difficulties resulted from personal inadequacies and were enormously relieved to hear about similar experiences from other group members. At the end of one focus group the participants asked the head teacher if they could use a room in the school to hold a regular informal support group for parents.

Experiences with professionals

The therapeutic alliance

An important theme was the reciprocity involved in effective communication with professionals. Parents valued an interactive relationship with professionals, which included elements of equality, valuing the parent's ideas and gaining a shared perspective.

(The psychologist was) . . . always asking me what I feel would be best . . . Sometimes slipping in a bit of advice there, now and again, but listening and when I came out of there I just felt like . . . something lifting off my shoulders . . . because I felt better in myself . . . each time I felt better about myself, my son started to feel happier.

Conversely many parents described the problem of professionals having their own agenda which was at odds with parents' expectations. One mother described her experiences of a parenting group:

We expected to come and share the views, talk between ourselves and then get on the phone and be able to say I've had a bad day today and how can we deal with it? But we didn't have no help like that. It was just two people coming in, they have been showing videos and talking about things that weren't really beneficial to us.

Acknowledgement and reassurance

A number of parents described their relief when professionals acknowledged that there was a problem with their children. However, some were distrustful of reassurance which was perceived to have

an ulterior motive. For instance, being told that their child would 'grow out of it' or that their problems were normal was often seen as a brush-off by professionals to save time or because they could not be bothered to help.

The child psychologist that we was under kept saying, 'Things will get better.' But it doesn't.

Reassurance was experienced as useful only when it came from a credible source such as a professional with whom the parent had a good relationship or another parent with a child with similar problems.

Negative aspects of experience with professionals

There were a variety of ways in which parents found professionals unhelpful. These have been grouped into the following six categories.

1 *Authoritarian professionals* Parents were dissatisfied with professionals whom they felt were belittling and judgemental.

It was almost like a power seating arrangement with a psychiatrist chap sitting with a window, natural light behind him and there was this darkened shadow and there's me and H (parent's son) at this end and they were just watching you. They didn't exercise any control and you think well, what do I do, is this what they want to happen? Do they want to see the child loose or do they . . . and you feel that you're being judged for not involving yourself and exercising some control but you just don't know who's running the show. You're left absolutely bewildered.

2 *Passing the buck* Many participants talked about their frustration about being passed on from one service to another. Professionals repeatedly told them that their children were not appropriate for their service. This experience of not fitting in and not being provided for often exacerbated parents' feelings of social exclusion.

You go and sit in the doctor's and it's all, 'Well, you know we'll pass you on to someone else', They pass you on, they pass you on. Pass the buck.

Interestingly, some parents talked about the value of voluntary services advising them to attend another service. This was seen as positive and helpful rather than 'passing the buck'.

3 *The empty promise* A few participants spoke about the exasperation they felt about being promised services that were then not delivered. Parents expressed anger towards the individuals who had misled them about service availability.

They give you all this, 'I'm going to do this and we'll do that', but they don't.

One parent stated that a professional told him which services he should have but explained they did not have the resources. Whilst this appeared disappointing, he felt that at least the professional was being clear.

4 *Denigrating other professionals* Professionals' disagreement about diagnosis, treatment and placements was viewed as a problem particularly when this involved undermining another discipline or agency.

One chap came in and spoke of (hospital) saying, 'I don't think you want to go there, they don't talk our language do they?' and he was actually slagging (hospital) off and saying, 'You come to our own special behavioural centre.' . . . and I thought, right, that's obviously turned the child further against the good advice (hospital) were giving, and they never, ever delivered on this clinic.

5 *Lack of training* Lack of experience and training in emotional and behavioural problems amongst staff was seen as a particular problem for mainstream teachers, but also for teachers in EBD schools, child minders and those running play schemes.

And there wasn't even a proper special needs helper* it was just like myself, I'd go in and

*Classroom assistant for children with special educational needs.

give a few hours, and that made me more angry because they promised to get a proper person in and they did not.

- 6 *Lack of continuity of staff* Frequent changes in staff was viewed as a problem across all services but caused particular concerns relative to health services. A parent described the consequences of their doctor leaving following which the parent had to adjust medication without medical advice over an extended period.

Experiences of organizations

Communication between services

Participants pointed out the problems in communication between services and stressed the need for better communication and sharing of information between services.

(The problem) was a lack of communication between the education department and the social services. No one knows what the other one was saying. So whatever letter was sent was just left in a tray.

A few parents specifically advocated bringing services to one site in order to improve communication. Interestingly none of the parents mentioned confidentiality as a concern when services shared information.

Attitudes to specific services

1 *Education*

EBD schools Parents generally felt that attending an EBD school had helped their child. Many described the positive effects of this environment on their child's behaviour, and development. They felt that EBD schools were less inclined to exclude children, had smaller classes and higher teacher–pupil ratios. They perceived that EBD schools had a greater understanding and tolerance for EBD problems. A number of parents commented on the extra support EBD schools gave to parents compared with mainstream schools. Interestingly most described feeling less stigmatized than when their child attended a mainstream provision.

They got time and one kid is not different from the other. They are all the same and treated the same. In the mainstream school, they just push you aside like you are nothing, whereas here they have the patience.

Mainstream schools The issue of lack of alternative educational provision following permanent exclusion was discussed with considerable concern. A parent whose child was out of school for nearly 2 years explained that her attempts to get her child back into school were unsuccessful until she involved the legal system. A further problem was repeated suspensions leading to children missing significant portions of education. Some parents felt angry that their children had been segregated within mainstream school, for instance, through being placed away from the rest of the class. A common theme was parents' frustration with the long, bureaucratic statementing process. Some parents reported waiting up to 5 years to obtain a statement of special educational needs.

And I don't agree that it should actually take that long to get statemented (statement of special educational needs) . . . you're roughly talking five years before he's been put into a school where he can actually develop.

- 2 *Social services* Parents spoke about their frustration with the lack of support they received from social services. There was a perception that social services would only provide help to parents who did not want assistance.

If I was hitting him or something then social services would come round straight away. But because I wanted help there and then no one just wanted to know.

- 3 *Health services* Parents complained of long waiting lists to receive help. This was particularly a problem for child and adolescent psychiatry services.

Half the time you're left just sitting on the shelf waiting for them to do something. You could be sitting there for months and months waiting to hear something and then

all of a sudden it's, 'Oh sorry, it's been put back because we have a backlog.'

Lack of speech and language therapy for children was repeatedly mentioned as a concern.

- 4 *Childcare services and after-school/holiday clubs* Many parents talked about the problems they had experienced in trying to get their children accepted by out-of-school activities groups. This prevented their children from enjoying the benefits of such clubs and prevented parents from having time for themselves.

Lack of childcare facilities for children with EBD problems prevented a number of mothers from working. Many parents felt that there should be child minders trained specifically in EBD problems. Difficulty in accessing childcare and out of school groups contributed to parents' feelings of social exclusion and marginalization.

There's no clubs or anybody you can go to for help because no one seems to be bothered. It's a behavioural problem, they just sort of like push it to the side, 'There's nothing we can do.' Sort of thing. So we don't really get any help.

They (Local Authority) gave me a list but none of them have expertise with special needs children or they don't really want to. I feel that (they) should do something about it, either training people up or make up a database. Or you start to think, 'What is the point of working?'

- 5 *Voluntary organizations* There was considerable enthusiasm expressed for voluntary agencies. Parents commented on the value of individual counselling for children offered by voluntary groups. A few parents also explained that their children were engaged with a voluntary service although they had refused to be seen in CAMHS. Other parents talked about the valuable support they had personally received from voluntary organizations either in parent groups or individually.

(The voluntary group had a) 'Big Brother' system in which they train people up and then they appoint them to certain children. So P. was lucky enough to get a big brother

called Mike who saw him once or twice a week. That has been quite a good, positive experience that P. has had him to look up to. Although he has big sisters, it is completely different because he is out of family. So that has helped a lot.

There was only one negative comment made about voluntary organizations during the focus groups.

Discussion

Whilst this study provides valuable insights into the experiences of parents of children attending EBD schools there are some important limitations. The sample is small and self-selected. Groups took place within schools and it is likely that parents who had a more positive relationship with the school were over-represented. Some parents may have been reluctant to share their experiences in a group setting because of concerns about confidentiality. The study took place at a point when children had been placed in EBD schools; their views might have been different at an earlier time. This research has not addressed the views of the pupils themselves or the professionals.

In common with other studies dealing with marginalized, excluded groups, this study has used a rather small sample, which may not be entirely representative of the study population. It is therefore important that the results are interpreted with caution. Whilst some parents views have been examined, this study does not reveal the prevalence of these views. Furthermore, parents who were not included in this sample may have expressed different or indeed contradictory views.

Support from other parents

Parents experienced stigmatization and isolation because of their child's EBD problems. The stigmatization of mental health problems is well recognized (Penn & Martin 1998; Gray 2002). However, there is less research about the experiences of parents of children with difficulties. This study suggests that parents felt alone and unsupported concerning their child's problems but were often reluctant to share their concerns because of fears of

being stigmatized and blamed. It is perhaps not surprising that parents talked so enthusiastically about gaining support from other parents of children with EBD problems. The unique position of other parents to give emotional support has also been reported in children with disabilities (Kerr & McIntosh 2000) and chronic illness (Pelletier *et al.* 1994; Sloper 1996). Peer support from other parents is also effectively utilized in parenting treatment programmes such as the Webster Stratton parenting groups (Scott *et al.* 2001).

The therapeutic alliance

This study reveals parents' feelings of powerlessness in the face of bureaucratic organizations and authoritarian professionals. Similar findings are reported in a study of parents' views of health service provision (Lynch & Kruzich 1986; McKay & Hensey 1990). Parents valued reciprocal relationships between themselves and professionals. They highlighted the importance of having a shared understanding of problems and common goals. This therapeutic alliance is well described in the literature (Bjorkman *et al.* 1995; Marinker 1997).

In common with the work by O'Hagan *et al.* (1984), families found voluntary organizations very helpful and approachable. This perhaps reflects parents' willingness to engage with groups that are less likely to be perceived as authoritarian and more likely to work in collaboration with parents. It may also be that parents have themselves elected to approach voluntary organizations, whilst they may have been required to work with a statutory organization. This could influence their attitude towards involvement.

Concerns regarding education

Parents were concerned with the long delays in their children receiving statements of special educational needs. This process should be completed within 6 months of the LEA receiving a request from parents, except in exceptional circumstances (Callias 2001). Under the *Special Educational Needs and Disabilities Act, 2001* (HMSO 2001), LEAs have a legal responsibility to arrange the special educa-

tional provision set out in the statement. If this provision is not given, parents can appeal to the Special Educational Needs Tribunal. A further concern was the perception of delays in finding alternative educational provision following permanent exclusion from school. Lack of speech and language therapy provision was a significant resource issue.

Childcare facilities

Parents experienced social exclusion because of lack of childcare facilities including child minders and out-of-school clubs for their children. This often prevented parents from working as they were unable to find services prepared to look after their children out-of-school hours. Lack of childcare facilities has also been a problem for families of children with severe physical disability (Sloper & Turner 1992) and suggests a widespread need for childcare provision with specific training and facilities for children with special needs.

Communication between professionals

Parents expressed concern about the lack of communication between services. They wanted improved communication and sharing of information between professionals. Numerous studies suggest the advantages of improved communication across services (Leaf *et al.* 1996). Some authors also advocate the introduction of a coordinator, or link worker, for children with special needs, working in partnership with parents and professionals from all involved agencies (Stallard & Lenton 1992; Wishart *et al.* 1993). This is an attractive model for children with EBD problems and merits future research.

Parents complained about professionals who denigrated other professionals. It is important that services not only share information but also respect and understand roles and responsibilities of different professional groups. Somewhat surprisingly, confidentiality was not raised as a concern amongst these parents. However, it is possible that parents with these concerns were unwilling to take part in focus groups held within the school.

Implications

Whilst some of the findings from this research are unique to children in EBD schools, many of the difficulties described are likely to overlap with families of other groups of children with complex mental health, educational and social problems. In particular, service providers should be aware of the need to support parents and communicate effectively across agencies.

Current government policy is focused on the inclusion of children with special educational needs within mainstream schools (Department for Education and Skills 2001). This study, in common with the work by Cooper (2001), suggests that, for some parents, EBD schools provide a valued alternative to mainstream education, promoting social inclusion for pupils and parents. Parents' preference for special schools over mainstream education has also been reported for children with learning difficulties (Male 1998). Future research should investigate the experiences of children with emotional and behavioural problems educated within mainstream schools.

Acknowledgements

The study was funded by the Health Action Zone for Lambeth, Southwark and Lewisham via a research grant to E.S. The authors would like to thank Richard Harding for his valuable advice on conducting focus groups, staff at the participating schools and all the parents who took part in the study.

References

- Angold, A. & Costello, E. (2000) The Child and Adolescent Psychiatric Assessment (CAPA). *Journal of the American Academy of Child and Adolescent Psychiatry*, 39, 39–48.
- Atkin, K., Ahmad, W. & Anionwu, E. (1998) Screening and counselling for sickle cell disorders and thalassaemia: the experience of parents and health professionals. *Social Science and Medicine*, 47, 1639–1651.
- Bjorkman, T., Hansson, L., Svensson, B. & Berglund, I. (1995) What is important in psychiatric outpatient care? Quality of care from the patient's perspective. *International Journal for Quality in Health Care*, 7, 355–362.
- Callias, M. (2001) Current and proposed special educational legislation. *Child Psychology and Psychiatry Review*, 6, 24–30.
- Commission for Health Improvement (CHI) (2002) *Report of a Clinical Governance Review at the Lewisham Hospital NHS Trust*. DoH Publications, London, UK.
- Cooper, P. (2001) *We Can Work it Out: What Works in Educating Pupils with Social, Emotional and Behavioural Difficulties Outside Mainstream Classrooms?* Barnados, Essex, UK.
- Department of Education (1994) *The Education of Children with Emotional and Behavioural Difficulties*. DfES Publications, London, UK.
- Department for Education and Skills (2001) *Inclusive Schooling Children with Special Educational Needs*. DfES Publications, London, UK.
- The Education Authorities Directory and Annual (2002) School Government Publishing Company Ltd., Surrey.
- Goodman, R., Ford, T., Simmons, H., Gatward, R. & Meltzer, H. (2000) Using the Strengths and Difficulties Questionnaire (SDQ) to screen for child psychiatric disorders in a community sample. *British Journal of Psychiatry*, 177, 534–539.
- Gray, A. (2002) Stigma in psychiatry. *Journal of the Royal Society of Medicine*, 95, 72–76.
- HMSO (2001) *Special Educational Needs and Disabilities Act*. The Stationary Office, London, UK. <http://www.hms.gov.uk>
- Kerr, S. & McIntosh (2000) Coping when a child has a disability. Exploring the impact of parent to parent support. *Child: Care Health and Development*, 26, 309–322.
- Leaf, P., Alegria, M., Cohen, P., Goodman, S., Horwitz, S., Hoven, C., Narrow, W., Vaden-Kiernan, M. & Reiger, D. (1996) Mental health service use in the community and schools: results from the four-community MECA study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35, 889–897.
- Lynch, M. & Kruzich, J. (1986) Needs assessment of the chronically mentally ill: practitioner and client perspectives. *Administration in Mental Health*, 13, 237–248.
- Male, D. (1998) Parents' views about special provision for their children with severe or profound and multiple learning difficulties. *Journal of Applied Research in Intellectual Disabilities*, 11, 129–145.
- Marinker, M. (1997) Writing prescriptions is easy. *British Medical Journal*, 314, 747.
- McKay, M. & Hensey, O. (1990) From the other side: parents' views of their early contacts with health professionals. *Child: Care Health and Development*, 16, 373–381.

- Meltzer, H., Gatward, R., Goodman, R. & Ford, T. (1999) *Mental Health of Children and Adolescents in Great Britain: Summary Report*. Department of Health, Scottish Executive and National Assembly for Wales. Office of National Statistics, London, UK.
- Nelson, D., Howard, V. & McLaughlin, T. (1992) Empowering parents to become advocates for their own children with disabilities. *International Journal of Special Education*, 7, 295–305.
- O'Hagan, F., Sandys, E. & Swanson, W. (1984) Educational provision, parental expectation and physical disability. *Child: Care Health and Development*, 10, 31–38.
- Office for Standards in Education (Ofsted) (2001) *Performance Assessment and National Contextual Data (PANDA) for Special Schools*. Ofsted Publications, London, UK. <http://www.ofsted.gov.uk>
- Pelletier, L., Godin, G., Lepage, L. & Dussault, G. (1994) Social support received by mothers of chronically ill children. *Child: Care Health and Development*, 20, 115–131.
- Penn, D. & Martin, J. (1998) The stigma of severe mental illness: some potential solutions for a recalcitrant problem. *Psychiatric Quarterly*, 69, 235–247.
- Perkins, R. (2001) What constitutes success? The relative priority of service users' and clinicians' views of mental health services. *British Journal of Psychiatry*, 179, 9–10.
- Place, M., Wilson, J., Martin, E. & Hulsmeier, J. (2000) The frequency of emotional and behavioural disturbance in an EBD school. *Child Psychology and Psychiatry Review*, 5, 76–80.
- Pope, C., Ziebland, S. & Mays, N. (1999) Analysing qualitative data. In: *Qualitative Research in Health Care*, 2nd edn (eds C. Pope & N. Mays), pp. 35–88. BMJ Books, London, UK.
- Riley, J. (1990) *Getting the Most from Your Data*. King's Fund, London, UK.
- Ruggeri, M. (1994) Patients' and relatives' satisfaction with psychiatric services: the state of the art of its measurement. *Society of Psychiatry Psychiatric Epidemiology*, 29, 212–227.
- Sayce, L. (2001) Social inclusion and mental health. *Psychiatric Bulletin*, 25, 121–123.
- Scott, S., Spender, Q., Doolan, M., Jacobs, B. & Aspland, H. (2001) Multicentre controlled trial of parenting groups for childhood antisocial behaviour in clinical practice. *British Medical Journal*, 323, 194–198.
- Sloper, P. (1996) Needs and responses of parents following the diagnosis of childhood cancer. *Child: Care, Health and Development*, 22, 187–202.
- Sloper, P. & Turner, S. (1992) Service needs of families of children with severe physical disability. *Child: Care Health and Development*, 18, 259–282.
- Stallard, P. & Lenton, S. (1992) How satisfied are parents of pre-school children who have special needs with the services they have received? A consumer survey. *Child: Care, Health and Development*, 18, 197–205.
- Wishart, J., Macleod, H. & Rowan, C. (1993) Parents' evaluations of pre-school services for children with Down syndrome in two Scottish regions. *Child: Care, Health and Development*, 19, 1–23.

Appendix 1

Focus Group Guide

Introduction

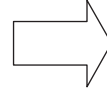
- Introduction of facilitators and project
- Consent and Confidentiality
Written consent forms / Tape recording
- Framework of discussion
- Ground rules
One person speaking at a time
Hearing everyone's views
No right or wrong answers, (I'm hear to learn from you)
Talk to each other not the researcher
- Introduction of each participant (first name only, first name and age of child)



Previous experience of services

- We are interested in your experiences of getting services to help with your child's emotional or behavioural problems.*
- *What services have you received?*
- *Were they useful/ unhelpful? In what way?*
- *How did you find out about them?*
- *Does any one else have a view about that?*
- *Has anyone else had a different experience?*

Probe about health, social services, education and voluntary services if not spontaneously mentioned



Barriers to receiving services

- *What made it harder to get services?*
- *What has discouraged you from getting services?*
- *What difficulties have you experienced in getting the services that you want?*



Improving services

- *What would make it easier for you to get the services you need for your child?*
- *What would you have liked professionals to have done differently in terms of getting services for your child?*
- *What would an ideal service for your child look like? (access, site, professionals involved, liaison etc)*
- *Would anyone like different services?*

* Asked in all focus groups.

Italicised probes were asked at the facilitator's discretion to provide additional information about each topic where information was not given spontaneously

Copyright of Child: Care, Health & Development is the property of Blackwell Publishing Limited and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.