

THE UNIVERSITY *of York*



An Evaluation of Specialist Mental Health Services for Deaf Children and Young People

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Chapter 1: Executive summary

1.1 Introduction

A lack of early intervention to support communication between children with moderate to profound hearing loss¹ and their families means that these children, especially those born to hearing parents, are likely to experience significant constraints in their ability to communicate and delayed language development. These increase risks for psychological, emotional, social and educational difficulties (du Feu and Ferguson, 2003). Furthermore, deaf children are more likely to experience physical, emotional and sexual abuse than their hearing peers (ADSS, 2002). The cause of the hearing impairment may also mean the co-occurrence of learning disabilities, physical and/or visual impairments (Roberts and Hindley, 1999). These factors also increase the risk for adjustment difficulties.

Despite this increased risk there is limited research on the prevalence of mental health problems among deaf children, and much of it is compromised by the use of measures which assume normative verbal and literacy development and were standardised using populations of hearing children (Bailey *et al.*, 2003). However, Hindley *et al.* (1994), using a screening instrument developed specifically for use with deaf children, reports an estimated overall prevalence of 43-50 per cent among deaf children aged 11 to 16 years, compared to a 25 per cent prevalence rate among hearing children. Also, a study in the US by Watt and Davis (1991), using revised forms of depression measures, found higher rates of depression among deaf compared to hearing junior high school students (mild depression: 40 per cent versus 17 per cent; moderate depression: 6 per cent versus 3 per cent).

Access to high quality, effective mental health services is a key standard of the Children's National Service Framework (Department of Health, 2004). There is evidence, however, that deaf children are not accessing mental health support. For example, a recent study found that only three out of thirty-two adolescents with DSM disorders had had contact with mental health services (van Gent *et al.*, 2007).

The relatively low incidence of hearing impairment (around 1 in 1,000 children aged 0-3 years, rising to 2 in every 1,000 children aged 9-16 years, have permanent moderate to profound hearing impairment, Fortnum *et al.*, 2001) and the specialist skills required to meet their needs mean that generic child and adolescent mental health services (CAMHS) are not able to provide an adequate service (Bailey *et al.*, 2003; NDCS, 2005).

¹ A hearing loss of 41dB or greater is likely to limit access to conversational speech (Roberts and Hindley, 1999). Moderate hearing loss: 41-70dB loss; severe: 71-95dB; profound: 96+ dB.

The three key areas of skill or expertise required to work with deaf children with mental health difficulties are: being able to meet their communication needs, having an understanding of deafness, and being knowledgeable in the interactions and relationships between mental health and deafness. It is for these reasons that generic CAMHS are not equipped to meet the mental health needs of deaf children.

Deaf children use a variety of languages and ways of communicating including British Sign Language² (BSL), Sign Supported English³ (SSE) and/or oral methods of communication (speech, lip-reading and the use of residual hearing). A child may use more than one method of communication and their BSL or SSE may be idiosyncratic. This complexity of communication issues means that deaf children's communication needs cannot be properly addressed through generic interpreting support. In addition, generic practitioners will not have an adequate understanding of deaf child development (language, social, emotional and cognitive), the impact of deafness on family dynamics and peer group relationships, and issues of cultural identity⁴.

The first specialist mental health service for deaf children and their families was established in London in 1991. The service began with outpatient and family therapy services, with an inpatient service being provided from 2000. The clinicians involved in the service were, however, conscious that a service based in London could not serve the whole of England and that the lack of services outside London created major inequities of access. The commissioners of the Inpatient Service (the National Specialist Commissioning Advisory Group) were equally cognisant of this problem and commissioned a pilot project to extend access to specialist out-patient mental health services for deaf children by establishing two 'satellite' services in York and Dudley (West Midlands).

The model on which the pilot services in Dudley and York were set up was that two staff in the London service (a psychiatrist and clinical psychologist) would be funded to provide expert advice to the new services and also offer the opportunity, where appropriate, for deaf children to be treated 'remotely' (primarily through the use of videoconferencing equipment though with occasional face to face sessions) by the clinical psychologist in London who was fluent in BSL. A key way in which contact between the London service and the two new services would be supported was the use of videoconferencing facilities (known as the telelink). The pilot project began in 2004.

² BSL is the sign language used in the UK, using movements of the hands, body, face and head. BSL is a complete language in its own right, having a structure and grammar totally different from English. As with a verbal language, children develop BSL skills over the course of time. Some children will be fluent whilst others will use BSL in a more limited way.

³ SSE is a form of English that additionally uses signs to convey meaning.

⁴ Most people who use BSL see themselves as belonging to a distinct linguistic cultural group and are part of the deaf community.

1.1.1 The research project

In 2005 the Department of Health commissioned the Social Policy Research Unit at the University of York to assess the impact and effectiveness of this pilot project.

The research project included:

- seeking users' and referrers' views on the impact of using a specialist mental health service;
- discovering children's, parents' and referrers' experiences of using a specialist mental health service;
- analysis of clinical outcome measures collected by the research project and from routine clinic data collected by the Dudley and York services;
- eliciting from all staff involved in the pilot project (i.e. the London-based staff and staff working in Dudley and York services) their experiences of developing the new services, delivering mental health services to deaf children and their families, and working for the service.

When the research project was originally conceived the view was that families using the London service would act as a comparator group who were receiving the well-established, 'gold standard' service. However, shortly after the research began the head of the London service and a number of other staff left the service. This resulted in the London service losing key sources of expertise and having to significantly contract the service it provided. The distinction between the London service as being a pool of expertise and the new satellite services being relatively unskilled and inexperienced was therefore lost. Thus the notion of using the London service as a comparator group was no longer appropriate. In consultation with the commissioners of the research and the research advisory group the decision was therefore taken to reframe the project so that it sought to evaluate, from the perspectives of referrers and users, all three specialist mental health services.

1.2 Research design and methods

There were a number of strands to the research project.

1. A 'before and after' study of a sub-sample of families using the specialist services. This involved interviews with children and parents around the time of their first appointment with the specialist service and then at discharge or six to eight months later (whichever occurred first). The interviews also involved the parents completing a standardised measure of child mental health (Strengths and Difficulties Questionnaire, Goodman, 1997). In addition, at the second interview, parents and children completed a questionnaire about their experiences as service users (Experiences of Service Questionnaire, Attride-Stirling, 2002).

2. Interviews with key referrers⁵ to inform the development of a questionnaire which was administered to all referrers to the specialist services.
3. Interviews with staff working in the two new specialist services on two occasions, 12 months apart. The two staff based in the London service but funded to support the new services were also interviewed.
4. Analysis of data (descriptive data on users and clinical outcomes) routinely collected by the new services.

Deaf researchers were recruited to work on the project on a sessional basis alongside the research team. They were involved in all aspects of the project – developing and refining tools to facilitate the interviews with the children, advising on the content of information sheets and consent forms, conducting fieldwork with any participant who requested a BSL interviewer, contributing to the data analysis and disseminating the project’s findings.

1.3 Reporting the findings

The different strands of work are reported in the chapters which follow. They typically take the form of papers which have been submitted to academic journals for publication. The location of findings pertinent to each of the research topics are shown in Table 1.1.

Table 1.1: Location of research findings by topic

<i>Research topic</i>	<i>Chapter</i>
The pilot services and their development	Chapter 2
The population using the pilot services	Chapter 3
Families experiences of accessing mental health support	Chapter 4
Using the service	
• Children’s views	Chapter 5
• Parents’ views	Chapter 6
• Referrers’ views	Chapter 7
Outcomes of the using the service	
• Children’s views	Chapter 5
• Parents’ views	Chapter 6
• Outcome data collected by the services	Chapter 3
• Referrer views	Chapter 7
Delivering the service	Chapter 2
Working for the service	Chapter 2

⁵ Key referrers were those who regularly referred to one of the specialist services.

The remainder of this chapter is devoted to providing an overview of the research findings. The appendices contain the research tools.

1.4 Overview of research findings

1.4.1 Developing the service

- The services evaluated were developed primarily by professionals who, at the outset, had relatively little expertise in the area, or were skilled or experienced in one area (for example, deafness, BSL or mental health) but had no skills or training in another. At the start of the pilot project, therefore, attention was centred on 'skilling-up' staff and accruing experience and expertise.
- Formalisation of certain practices (for example, developing an interpreting protocol) and working more innovatively (for example, using the telelink for clinical work, developing multi-media resources) appeared to happen once staff were more confident in their skills and abilities, and typically occurred in response to the needs of cases they were working with and/or situations or issues encountered delivering the service.
- The (initial) time-limited nature of the funding of these services and on-going insecurities with regard to future funding was seen by staff as impeding the development and evolution of the services because it threatened staff commitment to the service and skilled, experienced staff left the service. Time for clinical work also had to be diverted to developing bids and pursuing funding.
- The specialist services were developed within a model of a network of services (one pre-existing and two 'new' services). A key difficulty encountered in managing and communicating within the network was that staff in the three services worked on different days of the week. Staff believed it was important to ensure some overlap in the working days of staff within a service and across the three services. This would allow maximum benefit to be gained from the expertise and experiences of other members of the network, and to support the sense of belonging, both to a team and the network.

1.4.2 Families' use of generic CAMHS and other sources of mental health support

- Families participating in the research project had, typically, been living with their child's mental health problem for a number of years without any effective support. Less than half had accessed other services prior to accessing the specialist service, and less than a quarter had used generic CAMHS.

Information collected routinely by one of the services would suggest these figures are fairly representative of all families using the service. Thus just over a third of families using the York service had had previous contact with CAMHS.

- Half of the families who had used generic CAMHS had found the help provided useful but limited. In most cases CAMHS had provided support and advice to the parent as opposed to carrying out direct work with the child. Some parents felt this had been the appropriate approach, others found this unsatisfactory.
- Families who had not found generic CAMHS useful believed this was primarily due to a lack of expertise within the service, either in terms of working with deaf children or, more specifically, because of being unable to meet the child's communication needs.
- Almost three-quarters of referrers to the specialist service reported they did not refer deaf children and young people with mental health needs to other services.
- Nine out of ten referrers believed generic CAMHS were not equipped to meet the mental health needs of deaf children and young people.
- Routine referrers, especially those working in specialist schools, believed the service was vital for the children and young people they cared for and in its role of supporting them and their practice. They believed that without the service there would be an increase in school exclusions, admissions to the inpatient unit, an increased risk of children and young people being taken into care, and an increase in the number of deaf children and young people with long-term mental health problems.

1.4.3 Accessing the specialist service

- Parents were universally relieved about obtaining a referral to the specialist service. Over half the families believed their child should have received specialist help much earlier.
- None of the children represented in the research project had accessed the specialist service via a referral from generic CAMHS.
- Analysis of routine clinic data shows that most children are referred by schools as opposed to health or social services.
- Despite considerable difficulties some children who participated in the research project did not access the specialist service until they had moved from a mainstream school to one of the specialist deaf schools. This suggests that access to the service by children in mainstream education may be problematic.

Referrers to the service also believed these children were less likely to be receiving the mental health support they need.

1.4.4 Experiences as service users

- All the children who participated in the research liked their clinician. They valued the support and advice they were given and felt their clinician 'listened' to them. Referrers working in residential specialist schools noted that children and young people appeared to value the service highly and were confident about using the service.
- Children's responses to the Experience of Service Questionnaire (ESQ) also reveal very positive views about the service and their clinician(s). The large majority of children were confident their clinician understood them and had helped them. Almost all reported they could express their feelings and did not feel embarrassed doing so. They also felt properly involved in consultations when their parents were present.
- Parents participating in the research project also completed the ESQ and demonstrated equally positive views of the service. Almost all felt they were treated well by the service, were listened to and found it easy to talk to the child's clinician. Over 80 per cent believed their worries had been taken seriously and the help they had received was good. Similar proportions felt they worked in partnership with their child's clinician and would definitely recommend the service.
- Children who used BSL were generally happy with the way the service met their communication needs, though they felt that hearing clinicians could improve their signing skills. Those who were seeing a deaf clinician or family support worker particularly valued this relationship and the ease with which they were able to communicate with them.
- Referrers also reported that an area of *relative* weakness within the services was the ability of all team members to communicate with a child or young person using their preferred means of communication.
- One in three parents participating in the research project reported that getting to appointments was difficult. Referrers were also concerned about this issue and believed geographical distance acted as a barrier to families using and/or accessing the service.
- There are issues of geographical access to the service by parents of children attending residential schools some distance from the family home.

1.4.5 Using the telelink for direct clinical work

- Using the telelink for clinical purposes has been tentative and the protocol by which it is used has been developed carefully and in consultation with young people who have used it.
- A small proportion of children had used the telelink to allow them to have a clinical psychologist based in the London service who was fluent in BSL as their clinician. These telelink sessions were interspersed, less frequently, with face to face sessions.
- The way that the telelink afforded the opportunity to have a clinician who was fluent in BSL and was also deaf was valued by all the young people using the telelink.
- Only one of the young people who used the telelink found the technical difficulties (for example, the image 'freezing') which sometimes occurred problematic. Another found the ending of sessions difficult, which he ascribed to the remote nature of the interaction.
- The telelink was also being used for 'interim' sessions by clinicians working with children in some of the specialist schools. These supplemented regular face to face appointments and allowed the clinician to be responsive to the changing needs of a child and provide a higher level of support than would have otherwise been possible.
- Clinicians with experience of using the telelink also reported the young people who had used it were, almost universally, very positive about the technology. Some felt, the technology itself improved engagement and may allow some children to be more open about the difficulties they are experiencing. At the same time there were concerns about the lack of control the clinician had over how the times just before and after the sessions were managed by school staff.

1.4.6 Outcomes of using the specialist service

- Children who participated in the research believed the service was helping them. They reported positive changes with respect to at least one of their mental health difficulties which they felt was a result of using the service.
- Significant positive improvements in scores (either at discharge or during treatment) were found on clinician and parent completed measures of mental health (Child Global Assessment Scale and Strengths and Difficulties Questionnaire respectively) routinely collected by the services.
- Scores on a standardised measure of mental health (Strengths and Difficulties Questionnaire) completed by parents participating in the research project (at referral and 6-8 months into treatment) also provide evidence on the

effectiveness of the service. These typically showed significant improvements, with many children no longer scoring above the cut-off point for 'caseness'. The qualitative accounts of parents with regard to their child's outcomes support these findings.

- Three-quarters of referrers were satisfied with the outcomes for children and young people they had referred. It was acknowledged that some children and young people have complex difficulties which require prolonged input.
- Referrers to the service also reported positive outcomes for themselves from using the service. Two-third respondents reported contact with the service had changed their practice. Non-specialist referrers said it had increased their understanding of mental health and deafness. Routine referrers said the service reduced their levels of stress.
- Parents also valued the emotional support, information and advice gained from their child's use of the service.

1.4.7 Key features of the service

- Referrers and parents believed the key skills held by the teams which supported positive outcomes for the children using the service were the ability to meet the communication needs of children and an expertise in deafness and mental health. Referrers to the services rated the teams as being very skilled in these areas. The presence of deaf staff and understanding and sensitivity to deaf culture were also seen as important.
- In addition to the skills of the team, features of the service which referrers believed contributed to positive outcomes included: the ability of the service to accept referrals quickly, liaison between the team and school staff, the range of therapeutic interventions available, and a willingness to visit the child or young person for appointments.

1.4.8 Suggested improvements to the service

- Different practices with regard to confidentiality between health and education was sometimes seen by referrers as a barrier to effective liaison. Referrers suggested an information sharing protocol should be developed to overcome this difficulty.
- Children and parents wanted the services to get better about the way they provide information, both about the service in general and also their own use of the service. Staff working for the service acknowledged that this was an area they needed to work on.

- Some children were concerned about confidentiality and wanted to have written agreement on confidentiality with their clinician.
- Children who used BSL felt that all hearing clinicians should be skilled signers.

1.4.9 Developing specialist mental health services for deaf children

- A greater number of regional centres, higher levels of outreach work, and extending the use of and access to the telelink were suggested solutions by referrers the issue of geographical access. Parents also identified outreach clinics and home visits as ways of resolving the difficulties of geographical access faced by some families.
- Ensuring equity of access was a very strong theme in referrers' and staff's responses to the question about future developments of the service. As well as improving geographical access, they highlighted the need for equity with regard to funding of referrals, greater awareness of the service within mainstream services, and improving access (or widening the type of provision) for children with learning difficulties, complex needs and children in mainstream schools.
- Referrers also wanted the service to engage in more preventive work so that it became one of the key activities of the service. In addition, referrers felt that providing low-level post-discharge support to children and young people and their families and/or the referrer, and developing the consultancy role with specialist schools/units would be worthwhile avenues to explore when developing the service. Staff also felt it was important that there was a preventive strand to the work done by the service.
- Cascading of skills to generic CAMHS, school staff (special and mainstream) and other relevant professional groups was another key area which referrers wanted to see the service move into. Again, staff agreed that this should be a core strand of their work.

1.4.10 Delivering the service

- Families, referrers and staff working for the specialist service all reported that a shared expertise in mental health and deafness and an ability to meet the communication needs of a child are critical to providing a high quality and effective service.
- The telelink proved extremely important to the development of staff skills and expertise. It was seen as a highly effective and efficient way of meeting the supervision and peer support needs of staff.

- In terms of communication, practitioners have learnt that finding a way of communicating with a child can take time and that both parties need to be comfortable and confident with the chosen approach.
- The use of interpreters skilled in working in mental health settings and with working with children was seen as essential. Hearing practitioners tried to ensure they used the same interpreter when working with a family. However, the views of the deaf clinical psychologist differed on this issue. She preferred to alternate between two interpreters to prevent the interpreter inadvertently assume the role of the therapist in the eyes of the child or family.
- All hearing staff agreed that, although they used interpreters, they still needed be able to sign and many wanted to improve their signing skills.

1.5 Conclusions

This was a wide-ranging project seeking to research a number of different topics within the context of specialist mental health services for deaf children. At one level it was an evaluation of the services, in terms of outcomes and experiences as service users, from the perspectives of children, parents and referrers, supplemented by data routinely collected by the services. On another level was research into a particular model of configuring and supporting the development of highly specialist services. Finally, the research wanted to identify key components of good practice in terms of delivering mental health services to deaf children and their families and to document the experiences of staff working in the service.

With respect to the evaluative element of the research, there is consistent evidence from a number of sources on the effectiveness of the specialist services in addressing the mental health needs of deaf children. Children and parents are also, on the whole, very positive in their accounts as service users. The expertise of staff in mental health and deafness, their own abilities to communicate with a deaf child and the provision of skilled interpreting support were seen by all stakeholders to be key to the effectiveness of the service and the positive experiences reported by service users.

The research has also observed and charted the development of the two new 'pilot' services in Dudley and York. Developing the skills of the teams working in these services was challenging given the very limited access to expertise available to them. Having the opportunity to share expertise and experiences between staff working in the different services was seen as critical to this process and also to meeting ongoing supervision and peer support needs. The telelink was vital to this process.

The research has illuminated the way in which time was needed to develop skills and staff confidence. Refinements to the service, formalising procedures and processes and developing innovative ways of working only appeared to come into place once the service has been operating for a while and staff were confident in their own skills. It has also documented the ways in which funding insecurity stymies service development and innovation.

The use of technology (i.e. the telelink) to support interaction and communication, both between staff and between users and clinicians, was an interesting aspect of this research. It also presented another 'new' thing for staff to learn to use and, in terms of its use in clinical work, there was no precedent. Thus, not unexpectedly, staff were cautious about using it. However, on reflection, they note that some of that caution was based on their own inhibitions with the technology *per se* and were not necessarily shared by young people. Indeed, the technology itself was felt, in some cases, to support engagement and enable the young people to divulge their concerns and difficulties more freely. With time, experience and growing confidence in the technology the researchers observed increased and extended uses of the telelink for clinical work. Critical factors to staff confidence and belief in the usefulness of the telelink were its reliability and the quality of the images it produced.

The research also provides information on what needs to be in place in order to deliver an effective mental health service to deaf children and their families. For example, there is the essential requirement that all staff use BSL, and ideally to a relatively high level. At the same time, there will always been a need for high quality interpreting support. The presence of deaf staff on the team is also vital – both in terms of the ways they can, uniquely, provide support to children and families, but also in terms of the way they impact on staff's understanding and perceptions of deafness. Finally, expertise in mental health *and* deafness was seen as essential and a feature clearly separating the specialist service and generic CAMHS.

There are, of course, limitations to the research and these are detailed in the subsequent chapters. Many of these limitations also inform future research. Thus the absence of data from child-completed outcome measures is due to the fact that, at the moment, generic measures are not available in BSL nor have they been standardised for use with deaf children. There is a pressing need for such a measure. In addition, the constraints of the research were such that it was not possible to explore long-term outcomes or, in many cases, outcomes at discharge. Whilst good response rates from families about participating in the research were achieved for two of the samples, issues with regard to the way information about the research was presented was seen to have partly caused the poorer response rates from the service with high levels of use by families from minority ethnic groups and families where the parents are deaf. Clearly more research is needed to explore the experiences of families from minority groups in terms of mental health support. Finally, it has not been possible to compare the specialist services with generic

CAMHS. Given the very low levels of use of generic CAMHS by deaf children and their families it would be difficult to see how this could be achieved.

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Chapter 2: Developing and providing a specialist mental health service for deaf children and their families

2.1 Introduction

The first specialist mental health service for deaf children and young people in the UK was set up in London in 1991. It began as an outpatient service, with an inpatient service being provided from 2000. Referrals to the outpatient service are funded by Service Level Agreements (SLA) or Named Patient Service Agreements (NPSA).

In 2004 National Specialist Commissioning Advisory Group (NSCAG, now the National Commissioning Group (NCG)) of the Department of Health funded a pilot project (initially for three years but extended to five years) for two new services to be set up. The main purpose of project was to improve access to specialist mental health services for deaf children and young people. These two new services are located in Dudley (West Midlands) and York.

The Department of Health funded a research project to evaluate the pilot services. It included seeking user and referrer views on the impact of the services and experiences as users, analysis of clinical outcome measures and other data collected routinely by the services. In addition, it sought to chart the evolution of the new services and obtain practitioners' views and experiences of delivering mental health services to deaf children. This chapter reports the findings from this last aspect of the research.

2.1.1 The model for the pilot

The model on which the pilot services in Dudley and York were set up was that two staff in the London service (a psychiatrist and clinical psychologist) would be funded to provide expert advice to the new services and also offer the opportunity, where appropriate, for deaf children to be treated 'remotely' (primarily through the use of videoconferencing equipment though with occasional face to face sessions) by the clinical psychologist who was fluent in BSL. A key way in which contact between the London service and the two new services would be supported was the use of teleconferencing facilities (known as the telelink).

2.2 Methodology

Interviews with all staff working for the pilot services in Dudley and York and the two staff in London service were interviewed on two occasions, in mid 2006 (approximately two years after the pilot services began operating) and then just over a year later in 2007. Repeat interviews allowed the development of the teams and the services to be charted. Copies of the interview schedules are provided in Appendix 1.

2.3 Overview of the pilot services

2.3.1 The Dudley service

The Dudley service became operational in August 2004 and consisted of a consultant psychiatrist and a mental health nurse. In 2005 a play therapist and psychotherapist joined the team followed by a family support worker in early 2006. In late 2006 the mental health nurse left the team and this post has not been filled. In 2007 a clinical psychologist started working for the service. All team members are part-time and work for the service between a quarter and three days a week. The psychiatrist had been providing a service to deaf children and young people prior to the instigation of the pilot project, these were funded by NPSAs. He continues to provide this service to children living outside the geographical boundaries set by the pilot project on days not funded by NCG.

Referrals arrive mainly from three local specialist schools for deaf children, local social work teams and a consultant audiologist. The team occupies two offices within a health centre. Children can be seen at the clinic although staff members are involved in considerable outreach, particularly to schools. They spend one day every fortnight in one of the specialist schools and hold a session a month in the other two specialist schools. They also have monthly outreach clinics in two other locations in the West Midlands.

All the team have some level of signing skills. The only member of the team fluent in BSL is the family support worker.

2.3.2 The York service

The York service became operational in January 2004. At the time of the first interview with staff, in mid 2006, the team consisted of six members: two psychiatrists, a clinical psychologist, a community psychiatric nurse, a family support worker, and a social worker for the deaf who also acts as project manager. All staff

but two had been part of the team since the inception of the pilot. The two newer members were a CAMHS nurse who had been joined the team in 2005 and a family support worker who began working for the service at the beginning of 2006. In 2007 another clinical psychologist joined the team. Further changes in staffing have been a reduction in hours by one of the psychiatrists and the original clinical psychologist. All the team are part-time (between one and four days a week).

Children are referred by two local specialist schools for deaf children, general practitioners, teachers of the deaf, social work sensory impairment teams and other professionals working with deaf children and their families. They receive the majority of their referrals from the specialist schools and they provide consultancy and training to staff in these schools. Until 2008 the service shared a building with the generic CAMHS team. It is now housed in a purpose built building on the same site. Children attending the specialist schools tend to be seen in school. Others are seen at the clinic or at home.

All the team have some level of signing skills. The only member of the team fluent in BSL is the family support worker.

2.3.3 Management of cases

In both teams new referrals are assigned to a member of the team according to presenting need, expertise and available time. Joint working can occur with, for example, one clinician working with the child and the other working with the family. Where the child has a residential placement in a specialist school the parents, if deemed necessary or appropriate, travel to the school to attend appointments.

The different skills and professional backgrounds of staff in the two teams means there is some variation between teams in terms of the referrals accepted and interventions delivered (for example, the York team includes a social worker and so this team will taken on cases where child protection issues are a primary cause for referral).

There is a considerable range in the type and severity of mental health difficulties presented. Staff reported that, although a specialist service, both services accept less severe cases because of the absence of any other CAMHS provision which can meet the needs of deaf children and their families. Indeed a proportion of children referred would not be eligible for generic CAMHS support either on the grounds of the severity and/or the nature of the presenting problem. Chapter 3 provides more detailed descriptions of presenting clinical needs and interventions delivered.

2.4 Current levels of resources available to the services

When interviewed in 2007, staff working for one service felt the current level of resources enabled them to meet local levels of need. However, staff in the other service reported being understaffed and unable to properly meet the needs of children within their geographical boundaries. Some staff found this very stressful because they felt they were having to choose between providing a high quality service to a smaller number of children, thus leaving some families with no help or support, against providing a 'less than ideal' service (especially in terms of frequency of appointments) for a larger group. It also made engaging families more difficult when appointments were widely spaced. Staff were conscious that children and families could be disappointed with the level of support they receive and may have to wait longer to see positive changes in their child's mental health.

The lack of physical space (the service is co-located with other services and only has two dedicated offices) added to this service's difficulties. As well as increasing the size of the team, practitioners working for this service also felt the team needed to widen its multi-disciplinary nature by having a social worker, occupational therapist and psychiatric nurse on the team.

2.5 The evolution of the services

The accounts of clinicians working in both services revealed the way the services have been evolving since the instigation of the pilot.

Staff were first interviewed in mid 2006 when the services had been operating for around two years. At that stage, accounts from staff in both services suggested they were still in the process of 'bedding down' in terms of establishing roles with the teams. In addition, staff described the tremendous amount they had learnt in terms of mental health and deafness and working with and delivering mental health support to deaf children and young people. There was a sense of growing confidence amongst team members, indicated by the fact that individual staff who had no previous experience in the field were assuming sole responsibility for cases.

The interviews with staff conducted in Autumn 2007 revealed significant changes, both in terms of staff confidence and developments to the service, compared to the interviews conducted just over 12 months previously.

There was a clear sense of confidence amongst staff in their skills and knowledge with regard to working with deaf children and their families, a greater clarity in terms of the roles of each member of the team and the services' vision of what they were trying to achieve, and a greater sense of being part of a team. The appointment of

new staff (for example, psychologist, family support worker) which complemented and broadened the skills and approaches of the teams had, for both teams, made important contributions to the evolution and continued improvement of the services.

There was not, however, a sense of complacency. Even very experienced members of staff spoke about the way their understanding of issues associated with mental health and deafness in children and young people was continually being extended and refined. The teams were also exploring new ways of working as well as formalising their practices.

The previous year had also seen links being made with related organisations including providers of mental health services for deaf adults, D/deaf organisations, and other professional groups working with deaf children or in the field of mental health and deafness. Other markers of the growing maturity of the services was increased activity linked to disseminating the service and their own experiences and expertise to national and international audiences. One member of staff noted that the service had a role to play in generally raising the profile of deaf children and mental health issues.

2.6 Innovations

Interviews with the teams in the autumn of 2007 revealed that both teams had continued to develop ways of working and the services provided. These interviews also revealed the barriers to innovation experienced by the two new services.

2.6.1 Barriers to innovation

The time-limited nature of the funding of the Dudley and York services was seen by staff to have had two main ramifications, neither of which are conducive to developing a new service which is, internationally, at the forefront of its field. First, it had caused a considerable sense of insecurity within the teams and had resulted in the loss of skilled staff. Second, it meant time which could have been spent doing clinical work and developing the service had had to be used for work towards securing future funding.

More specifically, there appeared to be a difference in the extent to which each service had developed since staff were interviewed in 2006. The Dudley service had lost a key member of staff and had been understaffed for a considerable period. This had, inevitably, made high demands on remaining staff in terms meeting the needs of a large and geographically spread caseload. In addition, the fact that most newly appointed staff were (relatively) inexperienced meant that attention had, over

the past year, been focused on individual staff training and development as opposed to service-wide developments and innovations.

2.6.2 The Dudley service

Despite the difficulties described above the Dudley team had done extensive work with regard to exploring the possibility of family therapy, using the telelink to allow practitioners working for the London service to act as the reflective team. One member of the team had been funded to train in family therapy techniques and they were currently exploring using this approach with a newly referred family. [The York team was also exploring using the London team in this way to allow them to develop systemic ways of working with families.]

The Dudley team had also formalised their links with the local CAMHS team and had a regular slot in their meetings. Changes in staffing had also released funding to buy in management input from the general CAMHS manager. This not only provided management support but also served to partially integrate the service into general CAMHS in that area.

Time had also been given to establishing routines in the way the service was being delivered (for example, dates for outreach clinics fixed well in advance) and this had eased the administration of practical arrangements (for example, booking interpreters, rooms).

2.6.3 The York service

There were a number of ways in which York team had developed their practice and the services they provided. Generally, there had been a greater formalisation of practice compared to the Dudley team which appeared at least partly to be due to the fact that this service had more staff (many of whom who had worked for the service since its inception), felt adequately resourced and reported overall fewer pressures on staff time.

First, children typically now receive a communication assessment before they are assigned to a clinician. (In some cases it is clear the child does not require an assessment; for example, if they are very oral and do not use BSL at all). This assessment is carried out by the Family Support Worker who is also deaf. The purpose of the assessment is to identify the best ways of communicating with a child. This procedure was put in place because the clinicians had found some deaf children use a number of ways to communicate and it was taking time to identify the best way to communicate. In addition, there had been occasions when it would have

been helpful to have an interpreter present but the child had indicated they did not need an interpreter.

Second, the team had taken the decision to provide full team assessments and, at the time of our interviews, the team had trialled this approach with two cases. The assessments, based on a Swedish assessment model, take place on a single day and include: cognitive assessment, play-based assessment, communication assessment, taking a fully history, gaining the views of teachers, members of care staff, speech and language therapists, and parents.

Third, in response to the needs presented by cases being seen, the team was developing a number of support resources. Thus, a resource for children with Tourette's and their peers had been developed. This included a video for affected children which focused on coping strategies, and written material for peers providing information about the condition. This had been used with two children. Similarly a video resource for a child with sleep problems was also developed. This has subsequently been anonymised for use with future referrals. The clinicians feel that by developing resources in response to actual cases ensures the resources are relevant and meaningful. The team aims to continue to gradually built up these resources.

Fourth, the team are developing a deaf awareness programme for use with families. This is seen as being a resource for use as a preventive intervention. Fifth, with one case, the service has supported a generic CAMHS to provide mental health support to a deaf child. It was felt this had worked well. Finally, based on the issues encountered by staff and their cumulative experiences, policies with regard to working with interpreters, using the telelink and using mobile phones to allow users to contact the services or members of the team had been developed.

2.7 Managing the network

As reported earlier, the pilot project was conceived as two new services in Dudley and York working with the support of two NSCAG funded clinicians based in the London service. This formed the network.

A manager, based in the York service, was appointed to oversee the network. Some of the roles assumed by the manager included developing the training programme, organising network wide meetings, and leading on coordinating discussions between the teams with regard to the future of the service and leading on the preparation of bids for further funding.

Management of the network takes place through monthly meetings attended by two members of staff from each team (typically the clinical lead and the management lead). These meetings are either face to face or held using the telelink.

2.7.1 Difficulties experienced with managing the network

Staff were asked about their views of the management model and two key factors were identified which have made it difficult to manage the network. First, from the outset, there was a financial vulnerability due to the time-limited nature of the funding. This resulted in teams exploring options for local or alternative sources of funding which would ensure the continuance of the service should national funding be withdrawn. This diverted attention and commitment away from working on network level solutions to improve access to services nationally. Second, each team is accountable to their own local health Trusts and there are structural differences in the way the two teams sit within local structures.

A further consequence of this management structure has been a lack of management resources specifically for the Dudley service.

2.8 Meeting training and supervision needs

The Dudley and York services have found that generic training in therapeutic approaches and developments and basic British Sign Language (BSL) have been relatively easy to obtain or organise.

However, access to external sources of specialist training and supervision is very limited. This is because these services, along with London service, are at the forefront of mental health provision to deaf children in Europe. This has meant that the two teams, along with the NCG funded staff based in the London service, have used the skills, expertise and cumulative experiences existing within the teams to develop their specialist skills. Weekly or fortnightly telelink meetings and six-monthly day meetings have been vital to this process. In addition, staff in both services also said they had learnt a lot from having a deaf member of staff on the team.

For staff with no background in mental health, and thus requiring extensive training, a tension was reported between the need for time and funding for training against the often pressing need for the individual to be working with families. This difficulty was made more acute when staff were working part-time. In addition, some courses required certain levels of educational qualification which discriminated against individuals whose education had been impeded by poor schooling.

Interviewees identified further training needs and these depended, to some extent, on their professional role and background and the way individuals wanted to develop their skills. However, the desire to improve BSL skills was frequently mentioned and the lack of individuals with level 3 BSL was identified by some as a weakness in their service.

A number of interviewees mentioned that they felt that opportunities to draw on the skills and expertise held by staff working for the inpatient and outpatient London services had been very limited and would have been of great benefit.

2.8.1 Supervision

Supervision structures were, inevitably, relatively flat across the service. A key reason for this was the loss of, perhaps, the only UK expert in childhood deafness and mental health early on in the pilot. However, staff were happy with supervision arrangements. Within team supervision was taking place, as well as across team supervision by means of the telelink. In some instances staff were using or seeking external supervision with regard to one aspect of their work (for example, family therapy).

Staff working in the London services (inpatient and outpatient) were seen as a potential, but as yet virtually untapped, source of supervision and peer support. Staff working for the York and Dudley services wanted there to be greater cooperation and collaboration between all the specialist services providing mental health support to deaf children and young people.

2.8.2 Peer support

All staff noted the importance of professional group peer support in addition to supervision and training. Working in a small multi-disciplinary team means that each profession is, typically, only represented by one member of staff.

Where a professional group was represented in both services and/or the NCG funded London staff, the telelink enabled professional peer support arrangements to be set up. However, this model of support was not available to all staff (for example, mental health nurse, play therapist) because they were the sole representative of that professional group within the network. These professionals believed this left a gap in their support and professional development arrangements.

In addition, a peer support group for deaf staff also operates which is highly valued by the newer members of staff. Peer support from Deaf professionals working outside of the services is also used and felt to be important.

On a wider basis, some staff had attended mental health and deafness conferences in Europe which were useful in terms of knowledge gain and also for team-wide peer support.

2.8.3 Continuing professional development

The psychiatrists working for the service had modelled a programme of continuing professional development based on that used by other specialisms. This takes the form of biannual meetings conducted using the telelink.

2.9 The part-time nature of staffing and the service

None of the staff working for the York and Dudley teams, nor those based in the London service, work full-time for the service. The high level of outreach work (for example, school-based clinics) and the fact that staff do not all work the same days of the week has presented difficulties in working and management within and across the teams. It has resulted in some staff feeling isolated as well as reduced levels of contact between the teams. Some felt it also increased the time made to make and implement individual service and network wide decisions. In addition, it meant that formal mechanisms were needed to ensure all staff felt informed and involved in events, discussions and decision-making. One service had developed a procedure whereby everything was written down in a shared log book.

However, in terms of service delivery and patient care, it was not felt that part-time staff *per se* presented significant problems except it could make fixing appointments which suited families more difficult. In addition, one member of staff felt a protocol was required for managing days when there was no cover.

Staff who also worked in generic CAMHS noted the benefits of working in both settings. These included developing skills and keeping in touch with developments within mental health, cross-fertilisation of ideas, promoting the specialist service, increasing deaf awareness within generic CAMHS, maintaining a balanced perspective and keeping future career options open.

2.10 The constituency of the teams

2.10.1 Multidisciplinary teams

The multidisciplinary nature of the teams was seen to significantly improve the quality and range of services provided. At the same time, both teams had found that

time and attention needed to be paid to developing cohesiveness and shared goals within the team. As well as the alternative approaches used by different professionals to manage or treat a mental health difficulty, sources of difference between members of the team were also possible in terms of beliefs or attitudes about the mental health and deafness.

2.10.2 Having D/deaf staff on the team

Hearing staff identified a number of significant benefits to them as practitioners by having a member of staff on the team who was deaf. They reported it improved their signing skills and increased their deaf awareness and understanding of what it is like to have a hearing impairment.

However, there was a slight unease, in terms of the impression or 'message' it gave, that the deaf staff on the team only held junior positions. Staff working in both services said they would also like their team to include qualified clinicians who were also deaf. Barriers to achieving this reported by staff were the lack of deaf professionals working in mental health and the difficulties of providing training.

2.10.3 Family support workers

Both services employed deaf family support workers. The work carried out by these staff included befriending, teaching independence and life skills, developing the child's or parents' BSL skills and providing information to families. They always co-worked with a clinician.

Family support workers were seen by other staff as having a unique and important role to play in the way the service could support families. Namely, they make a 'connection' with deaf children and young people based on the shared experience of deafness. For children who used BSL, it meant they could communicate freely and directly with a member of the team. They also acted as positive role models for children and parents.

2.11 Managing communication

Ensuring the child used their preferred means of communication when using the service was seen as extremely important. Families are asked to provide information about the child's communication prior to referral. However, staff had discovered that identifying the best way for a child and clinician to communicate was not necessarily a simple process. They found it could take a few sessions to fully assess the child's

communication abilities and determine how the child and clinician would communicate with each other. Sometimes a degree of negotiation was necessary to ensure both the child and clinician were confident with their agreed way of communicating.

Deaf children may use a range of communication methods and they may vary in the method they choose to use depending on the context or setting. For example, some specialist deaf schools require children to communicate orally, yet within their peer group outside of formal lessons children may develop BSL skills. This has resulted in parents'/school staffs' reports of a child's preferred means of communication being different to that reported by the child themselves. In addition, a child may prefer a particular way of communicating (for example, BSL) but may not be sufficiently skilled in it to allow them to communicate adequately in a therapeutic session without, for example, interpreting support. Staff also reported that some children are reluctant to use interpreters because of confidentiality issues or because they perceive it carries an implicit signal that they have a hearing impairment (for example, children with cochlear implants or those with some residual hearing). Other children are not used to working with interpreters and thus impeding communication, and the development of the therapeutic relationship, between the child and his or her clinician.

2.11.1 Clinician's BSL skills

Where a child used BSL almost all hearing staff preferred to work with an interpreter. At the same time, all clinicians felt that having, at least, reasonable signing skills was very important for clinical work with deaf children and young people. The consensus was that all staff should have a minimum of basic sign language (level one) in order to be able to greet people at the door and put them at ease. The intermediate level (level two) was seen as sufficient for everyday conversation, whilst advanced BSL (level three) was essential for one to one clinical work. However, clinicians felt that even with level three some nuances may be lost and the use of interpreters is still necessary. All hearing clinicians expressed a desire to improve their signing skills. Across both services most hearing staff were at level two BSL with a couple of new staff at level one. When interviewed in 2007, one member of staff was working towards level three. Achieving level 3 BSL requires a high level of commitment in terms of attending training and practicing signing skills in between sessions.

2.11.2 Interpreters

Staff in both teams reported preferring to use the same interpreter when working with families. The York team had piloted having a dedicated team interpreter. This had worked extremely well and funding was being sought for a permanent interpreter

post to be established. Staff working for the Dudley service also believed such a post would be beneficial, allowing better support systems for the interpreter to be put in place.

Both teams used a small pool of interpreters who were, themselves, building up expertise in working in a child and adolescent mental health setting. Their expertise had developed mainly through experience rather than training (which is limited to interpreting in adult mental health settings) and the need to develop training for interpreters working in child and adolescent mental health settings was highlighted. One service had worked with their main interpreter to synthesise their learning and experiences of working with interpreters into a formal policy which covered the following points:

- where possible, to use the same interpreter with a family;
- a clinician can request an interpreter being present even if the child indicates they do not need one;
- the clinician and interpreter should meet before and after the session for briefing and de-briefing;
- the agreed timing of breaks for the interpreter should be adhered to;
- where necessary (for example long meetings or appointments, full reliance on BSL and high levels of BSL fluency) an additional interpreter should be used.

It was very important for clinicians to have confidence in their interpreter. A poor interpreter can be very distracting with the clinician's attention being diverted into monitoring the quality of the interpretation. It is possible to draw up an objective list of the desired qualities of an interpreter based on staff accounts:

- fully qualified;
- able to adjust register to work with children and young people with different levels of signing ability;
- are comfortable working with children;
- experience of working in mental health settings and understanding of 'technical' language.

There was, however, a clear sense that more subtle and subjective aspects of interpreting style and the interpreter's sensitivity to the therapeutic situation were also very important.

Hearing staff also observed that having access to high quality interpreters did not absolve them of the responsibility for developing their own signing skills. This was essential to being able to work effectively with the interpreter and being sure that the interpreter is working at the right pace and level for the child.

2.11.3 Clinical issues

A number of clinical issues were raised with regard to working with interpreters. Staff acknowledged that there was a potential for young people and families to engage with the interpreter instead of with themselves. An interpreter's non-verbal behaviours were important to preventing this happening. It was noted that young children may not be used to working with interpreters (for example, establishing eye contact with the interpreter and not the clinician when signing) therefore increasing the risk of the child engaging with the interpreter and not the clinician. Finally, the services had also learnt that confidentiality was an important issue when using interpreters. Interpreters may know a family socially or may have interpreted for them in different settings. It was therefore important that families were happy with the interpreter provided.

Staff also acknowledged that, in cases where a lot of depth work needed and the child or young person was a skilled signer, then using an interpreter is the second-best option to that child working directly with a deaf clinician. They acknowledged that the presence of an interpreter altered the dynamic of the therapeutic relationship and imposed an additional person on the young person.

Unlike hearing staff who tried to work with the same interpreter with a family, the clinician who was deaf preferred to alternate between two interpreters. There were two reasons for this. First, she believed that using the same interpreter could generate a false situation in which the interpreter becomes the therapist. Second, it removed the risk of 'bias' in interpretation. Parents who had had different interpreters reported to her that she 'sounded' different with different interpreters. This was ascribed to differences in vocabulary being used by the two interpreters. This clinician was also very careful in her choice of interpreter. She described the way she worked with interpreters as co-working, relying on them to provide her with relevant information about tone of voice (for example, indicating distress or anger). She therefore needed to feel entirely confident with them. Other deaf staff working for the service also reiterated the importance of high quality interpreters being available for them to use.

2.11.4 Resource issues

A number of factors contribute to the fact that working with a deaf child or young person will, typically, require more resources than working with those without a hearing impairment. As well as costs associated with providing interpreting support, there was a belief that it typically takes longer to work with a deaf child than a hearing child because of the time it can take for a clinician and child to establish an effective and acceptable way of communicating with each other and the need to work through an interpreter (because of the communication needs of the child and/or

clinician). Staff believed it was important, that this is understood and accounted for in future funding arrangements.

2.12 Using the telelink

At the outset of the pilot, videoconferencing equipment (known as the telelink) had been installed in all three services and in the specialist schools referring to the Dudley and York. It consists of a large screen (~1 x 1.5 metres) with a camera positioned on top. The focus of the camera is controlled directly or by using a remote control device. High speed telephone lines carry the signal. The reasons for installing this equipment was to facilitate three-way communication and support between the Dudley and York teams and the NCG funded clinicians based in the London service. Whilst the quality of the image is not sufficient to allow lip-reading, staff felt the quality and reliability of the link had improved considerably during 2006-2007.

2.12.1 Using the telelink for communication between teams/staff

The telelink has been used for a number of different purposes by the network including management meetings, strategic discussions about the future development of the service, clinical issues, case discussions and inter-team referrals. It has also been used for case discussions when a child has been admitted to the inpatient unit in London, especially at the assessment stage and planning the discharge and transfer back to the outpatient service.

Staff believed the telelink had played a significant role in training, peer support, managing the network and planning the future development of the service as well as being a tool by which therapy was delivered. If face to face meetings had been the only means of contact, funding and time constraints would have meant the frequency of contact between sites would have decreased significantly and would not have included all team members. At the same time, occasional face to face meetings attended by all members of teams were as vital to maintaining the relationship between the teams.

2.12.2 Practical issues

Staff had learnt how to optimise the quality of the telelink. This included using the telelink in a room with plain coloured walls, not sitting in front of windows, and arranging the chairs in a semicircle. In addition they had found that interaction was best if the number of people is restricted to two to three people at each 'end'.

However this has meant the teams have had to develop systems by which information arising from a meeting can then be shared with the rest of the team. Accommodating the communication needs of deaf staff has not presented any difficulties and the fact that the sessions need to be closely chaired may make these sessions easier for deaf staff than face to face meetings.

2.12.3 Using the telelink for direct clinical work with children

The telelink had been used for clinical work in two ways. First, nine young people have used it for clinical sessions with Dr Sara Rhys-Jones who is based in the London service. Dr Rhys-Jones is a clinical psychologist who is also deaf. The key driver to using the telelink in this way is that it allows the young person to communicate in their preferred way with their clinician without the presence of an interpreter. (None of the clinicians working for the York and Dudley service are fluent in BSL.) There was a concern that other positive consequences working with a deaf clinician (for example, exposure to a positive role model, an improved therapeutic relationship because of shared experiences of deafness) were sometimes being seen as the primary reason for referring a case to Dr Rhys-Jones and this risked inappropriate cases being referred.

Second, a couple of clinicians had started to use the telelink to provide additional support sessions for young people in between their regular, face to face appointments. Here, the driver behind the use of the telelink is that it is a very cost effective use of clinician time whilst allowing clinicians to be more responsive to fluctuating needs for support. To date, in all these cases the young people who have used the telelink have been attending specialist deaf schools where telelink equipment has been installed.

2.12.4 Developing practice

Using the telelink for clinical work was a highly innovative part of this pilot project. One member of staff described using the telelink for therapeutic work as 'an extremely steep learning curve'. As far as could be established, it had not been used in this way previously anywhere in the world.

At the start there was a certain degree of caution within the teams to using the telelink in this way. This was due to a number of factors including: early difficulties with the quality and reliability of the telelink (for example, the clarity of the image, 'freezing' or break down of the link); an unfamiliarity with the technology; the absence of a precedence in delivery therapy in this way to deaf children; and personal awkwardness experienced when using the telelink for professional

meetings. However, by 2007 both services were using the telelink for direct clinical work.

An increased confidence with using the telelink clinically was observed when staff were reinterviewed in 2007. This appeared to be grounded in: growing familiarity with it as a means of remote communication; improvements in quality and reliability of the link; the cumulative experience of using it for therapeutic purposes; the ease with which the young people learnt to use the equipment; young people's receptiveness and engagement with the technology; and positive clinical outcomes. This has also resulted in staff feeling more able to work creatively within a clinical session (for example, using flip charts for drawing exercises, role play and, simply, feeling able to move about the room). In addition, one service was exploring ways to extend its use to children with less advanced signing skills by using the family support worker to support the child and act as a relay interpreter during sessions with Sara Rhys-Jones.

2.12.5 The protocol for using the telelink for direct clinical work

A protocol for using the telelink, developed in consultation with young people who had used it, was drawn up by the teams quite early on and this has been reviewed and refined on the basis of on-going experiences. It includes the following:

- the young person's language skills and their ability to use the equipment must be assessed in a face to face meeting by the clinician who will be working with them;
- a named member of school staff must be available (but not present) during and after a session should the child require support;
- telelink sessions must be interspersed (at least once of every four sessions) with face to face appointments. This was seen as essential to the therapeutic relationship;
- where using the London-based deaf clinician was a possibility:
 - the presenting case must be appropriate and 'fit' with the clinical skills of the deaf clinician;
 - it must be the young person who decides whether they want to see a (local) hearing clinician (for face to face therapy) or the London clinician for, mainly, telelink sessions;
 - there is a written protocol between between the local (i.e. Dudley or York) service and the London-based clinician with regard to clinical responsibilities and the management of unexpected disclosures;
 - the York and Dudley services have a named telelink coordinator.

2.12.6 Concerns about how telelink sessions are organised

Clinicians expressed concern about the lack of control they have over the way schools inform or collect young people for their telelink sessions. Clinicians needed to be confident that this was handled sensitively and appropriately and that the young person was not attending 'under duress'. This required positive and cooperative relationships with the specialist schools.

2.12.7 Perceived benefits of the telelink for clinical work

Overall, clinicians who had used the telelink clinically reported that almost all of the young people had been very positive about using it, as long as face to face sessions also took place.

Staff identified a number of benefits to using the telelink for clinical work. It saved time and travel costs for them and the child/family. It allowed them to be more responsive to a child's support needs by providing short 'interim appointments' even though they were based some distance from the child. For young people fluent in BSL, it gave them the opportunity to see a clinical psychologist who was also fluent, thus removing the need for interpreting support; there was also the additional benefit of having a therapist who was also deaf.

Staff also felt that some children preferred the 'emotional distance' between themselves and their clinician afforded by the telelink, and found it easier to express themselves and divulge difficulties. Finally, staff felt that there was some kudos attached to the technology which supported engagement. It should be noted, however, that all but one of the young people who had used the telelink were boys and the only girl who had used it was more ambivalent. This might be a gender effect or merely reflect that not all young people will respond positively to this technology.

2.12.8 Future applications of the telelink

There was a consensus among all staff interviewed that the full potential of the telelink had not been fully explored. For example, it was felt that the London outpatient service should be enabled to use the telelink to support their work. In addition, there was a view that its use for other therapeutic approaches would continue to develop. For example, as reported earlier, both services were hoping to use the telelink for family therapy with clinicians based in the London service acting as the reflective team. There was a consensus that the strong and consistent belief in the value of the telelink, a growing confidence in using the technology, and the

improved visual and audio qualities of the link would all support the teams' desire to further exploit the opportunities provided by this technology.

2.13 Other service provision issues

2.13.1 Missing groups

Interviewees noted and were very concerned about the large gaps in provision across the country and also noted the total absence of any provision in Wales.

Geographical boundaries aside, it was deaf children attending mainstream schools who were identified as the key group whose mental health needs may remain unmet and who are not accessing the service. The reasons for this were, staff believed, two-fold. First, school staff may not be aware of the mental health needs of children with hearing impairments. Second, they are unaware of the existence of the specialist service. It was noted that even professionals with considerable experience of working with deaf children, unless specifically trained with regard to mental health issues, may not identify children needing mental health support. (For example, one interviewee recalled when the service was just beginning being told by one of the specialist schools that they thought just a couple of their pupils needed referring. What has happened in reality is that almost half the pupils have been referred.) .

Initially there had been a reluctance to advertise the services widely because of concerns about coping with demand alongside managing the instigation and development of the service. However, both services acknowledged that more needed to be done to publicise their service (providing they had the resources to manage the referrals received).

Some staff felt that the service needed to develop their provision to better meet the needs of children who used oral methods to communicate. When the services first began operating a lot of attention was given to ensuring BSL users could access the service. There was a feeling that this needed to be balanced by working on how therapy is delivered to oral children where issues of communication could be equally challenging.

2.13.2 Preventive work

The York service had undertaken some preventive work such as peer support groups for young people in the specialist schools and the local special school. These were regarded as positive developments to the service. A number of other different areas for preventive work were identified including awareness raising and

educating professionals working with deaf children, and parent/family support-type interventions.

Staff described a tension between meeting clinical need and engaging in preventive work, which is not typically undertaken by national specialist services. At the same time, they felt this was a role for the service and needed to be incorporated into planning the future shape of the service.

2.13.3 Working with schools and education professionals

Specialist schools were the main source of referrals to both services. Developing and maintaining collaborative relationships with these schools was viewed as being as very important. It ensured children attending these schools were referred at the appropriate time and, where appropriate, schools could play a positive role in supporting the way the service was working therapeutically with a child. Staff working for both services believed they had a role in developing awareness and understanding of mental health issues among staff working in the specialist schools.

In addition, the need to develop positive working relationships with other professionals in routine contact with deaf children was flagged up. Teachers of the deaf were seen as a key professional group who could play an important role in identifying deaf children in mainstream school in need of mental health support.

2.13.4 Information provision to families

An area for improvement or development identified by staff was information provision to families, including BSL versions of appointment letters as well as more general information about the service. There was a feeling that whilst the deaf community had embraced new technologies to facilitate communication this had not happened in the same way with the services.

2.14 Making the service a national service: a proposed model

All the staff strongly, even passionately, believed in the need for specialist mental health services for deaf children and young people. Indeed, it was this strong sense of belief which had meant they carried on working for the service during what has been a sustained period of insecurity and uncertainty with regard the future of the service.

Over the period of the research project the three services had been engaged in developing a model for a national service, and an application for funding based on this model will be submitted in mid 2008.

2.14.1 An overview of the proposed model

Clearly, a nationally funded service would address a key aspect of inequity of access; however, the model also needed to resolve further significant issues, namely:

- the need to greatly improve geographical access;
- the relatively low incidence of deafness meaning that:
 - the children requiring the service are nationally but thinly dispersed;
 - resources available for a national service are going to be relatively limited;
- there are now, and in the foreseeable future, insufficient numbers of skilled professionals to support a system of additional specialist centres based on the current model;
- a sizeable proportion of deaf children and young people attend specialist residential schools, thus creating 'pockets' of higher incidence.

The proposed model extends the current 'hub and spoke' model. The three existing services will act as hubs and each having with two/three outreach centres (spokes) embedded in local CAMHS services, thus creating a total of ten centres across England. In addition it proposes that telelink equipment will be installed in all specialist schools for deaf children and as well as the outreach centres.

The model addresses the workforce issue by proposing far more work more with generic CAMHS than has happened to date. This will allow skills to be cascaded in order that generic CAMHS can be supported to work with deaf children and young people themselves. This would 'free up' the specialist service to:

- work with those cases requiring specialist support or interventions;
- cascade their skills and expertise to professionals working with deaf children and young people;
- oversee, deliver or support the delivery of low level interventions and preventive work can be carried out by a wider range of staff;
- become more active in research and furthering knowledge and clinical understanding of mental health and deafness in children and young people.

2.15 Discussion and conclusions

This chapter has described the two pilot services set up to increase access to specialist mental health services for deaf children and their families. It has reported

on the development and evolution of the services and their practice over the first three or so years of their existence. This has been based on depth interviews with staff working in the two services and the two staff based in the pre-existing London service and supporting the new services. These interviews were conducted in 2006 and 2007.

Part of the chapter provides a description of the two pilot services and much of the remainder of this report is concerned with reporting users' and referrers' views and experiences of using these services. There are also, however, some interesting points to draw out in terms of what can be learnt about how 'new' services in highly specialist fields can be set up and developed.

An unusual aspect of these services is that, although they are specialist, some of their caseloads consist of children who are not presenting with complex difficulties or are not requiring highly specialised interventions. This is partly because of a strong multi-disciplinary approach and that the services were having to find their way in terms of eligibility criteria, but it is also because of the absence of any other sources of mental health support for these children. Two factors underlie the scarcity of mental health services for deaf children: meeting their communication needs and understanding deafness and the interplay between deafness and mental health. In addition, the scarcity of services also means that, again unusually, staff working for these services feel that preventive work should be a core activity.

The development of these specialist services can, in a sense, be viewed as the development of a specialism *and* the delivery of that speciality in the context of a deaf friendly, deaf aware service. Aside from the expertise held within the pre-existing service in London, which was unexpectedly limited by significant losses of staff at an early stage in lives of the pilot services, there was very little external sources of knowledge and expertise to draw on, either in the UK or further afield. In addition, staff new to the area were also having to learn to work with telehealth technology and many were also having to learn a new language.

Thus staff accounts of the development of the new services focused both on the acquisition of skills, experiences of working with the telelink, and the, often iterative, development of policies and practices which were grounded in the experiences of delivering the service.

The main factor contributing to the considerable progress made in developing a service 'from scratch' was the way teleconferencing equipment allowed staff from the three services to communicate at a frequency which would have been prohibitive (in terms of time and money) if face to face meetings had been the only option. The technology has also been used to deliver therapy, but only in a very small proportion of cases. This may partly be due to treating this aspect of the service as a 'higher level' achievement and early attention needing to be paid to more basic issues.

Furthermore, this aspect of the service was groundbreaking and also carried risks in terms to service users' well-being. It therefore needed to be developed with care. However, there was a sense from staff when they were re-interviewed in 2007 that they were keen to further explore the use of the telelink for therapeutic purposes.

It has also been possible to explore the factors which were perceived to have hindered the development of the services. Two key factors identified included understaffing or under-resourcing of a service and time-limited funding the loss of skilled staff (and therefore their expertise) and causing high level of insecurity which, particularly as the funding periods drew to close, could impact on levels of staff commitment.

Lessons have also been learnt in terms of the way a network of specialist services should be set up. First, it is important that staff working in the different services have at least some working days in common. Second, the management structure has to be such that it 'fits' or works with (disparate) local structures. Third, management time and resources are needed within each service as well as across the network. Fourth, the indispensable value of telehealth technology to facilitate access to expertise to support clinical work and to provide supervision and peer support.

The need for a sufficient period of time to develop, pilot, refine and 'bed down' practice and policies clearly emerged, especially in the context of these services where there was little pre-existing practice or expertise to draw on and most staff were having to acquire a range of new skills and knowledge either in mental health and/or deafness.

Ensuring a child is able to communicate in a way they are happy with and which allows the therapists to understand, as much as possible, the child's views and difficulties has proved a complex task. Staff have found it is not always possible to pre-determine, on the basis of parents' or teachers' reports, the way the child will want to communicate. The development of a communication assessment appears a promising solution in these instances.

Another interesting area concerns the use of interpreters, particularly the different views held by the hearing and deaf staff with regard to using the same interpreter for all appointments. This is clearly an area for further research, and this should include accessing the views of children and young people and interpreters, as well as those of parents and practitioners.

The presence of Deaf staff on the teams was highly valued by hearing staff in terms of their own understanding of deafness and their signing skills. It was also acknowledged that the roles played by the deaf family support workers was unique and could not be replaced by a hearing member of staff. Staff in both teams expressed the wish for more deaf staff, especially those with clinical qualifications,

because, for some children, it removed the need for an interpreter to be present. The lack of deaf professionals working in mental health and the barriers deaf people may face accessing training (where certain levels of academic qualifications are required) were seen as the main barriers to addressing this workforce issue.

Whilst staff believed there was good deaf awareness in the consulting room, it was interesting to find that this had not necessarily spread to all aspects of service delivery. Ways to ensure the service was 'deaf aware', some of which had already been implemented, suggested by staff included: reception staff should have basic signing skills, communication systems need to be in place (for example, minicom, email, text) so children and families can easily contact the service; and information provision needs to take account of the different levels of literacy of children and young people using the service, and BSL versions of written material should be produced. Again, there was a sense that refinements in these areas will take place as the services became more established.

The issue of deaf awareness also extends to having deaf staff on the team. Deaf staff gave examples of practices which they found valuable or supportive. These included: providing high quality interpreting support, staff being sensitive to communication/interpretation issues when chairing meetings or participating in discussions, using BSL whenever a deaf member of staff is present, and ensuring appropriate communication technologies have been installed.

The final point to make is that staff were very conscious that, in addition to addressing geographical and funding boundaries, the model for a future service needs to ensure that *all* children get access to the service if they need it. This would require a higher level of awareness raising and collaborative work among frontline education practitioners (especially teachers of the deaf) and among staff working in generic CAMHS. Furthermore, it was felt the staff would need to develop skills to work with all deaf children regardless of the way they communicate, whether or not they have additional impairments or disabilities and their cultural or ethnic background.

Chapter 3: Report on analysis of data routinely collected by the NSCAG funded services

3.1 Introduction

A pro-forma for routine collection of data by the two pilot services had been developed at the outset of the two services coming into operation (see Appendix 2). It consisted of the Paddington Complexity Scale and items about the child's schooling, the child's hearing impairment, socio-demographic information and the intervention provided by the service. In consultation with the two services, additional items were added by the research team including a checklist of presenting mental health difficulties and items on the outcome of closed cases, home postcode, number of sessions attended, and whether or not the inpatient service had been involved (Appendix 3).

The two pilot services were asked to provide the research team with all routinely collected data with regard to all NSCAG funded referrals since the inception of the pilot until mid-2007. The nature and completeness of the data available varied between the two services. The presence of the project manager in the York team and a larger and a more stable workforce are likely to have contributed to higher rates of completion of routine data by staff in that service.

Sufficiently complete data to allow statistical analysis available from both services include the number of children referred to the service, the mental health difficulties presented at referral, and home postcode. Data on numbers of children and their mental health difficulties is reported first, then more detailed data on the cases seen by the York team is described. Evidence on clinical outcomes for children using the two services is then reported. Finally, geographical information on users of these services and the London service is presented.

3.2 Measures used by the services

3.2.1 The Paddington Complexity Scale (PSC) (Yates *et al.*, 1999)

The PSC consists of 16 items covering: presenting condition(s), duration and severity of condition, the presence of chronic physical illness and learning disability, schooling, carers and their attitude to treatment, and contact with services. Responses are scored and a total score produced.

3.2.2 Outcome measures

The York and Dudley services use different measures for assessing clinical outcomes. The Dudley service uses the parent completed version of the Strengths and Difficulties Questionnaire and the York service uses the clinician completed Children's Global Assessment Scale.

3.2.3 Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) (see Appendix 4)

This is a 25 item questionnaire covering behaviour, emotions and social relationships (Appendix X). Child (11-18 years), teacher and parent versions exist. The items are equally divided between five sub-scales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behaviour. Responses to the emotional symptoms, conduct problems, hyperactivity/inattention and peer relationship problems subscales are summed to generate a total difficulties score. This score can also be used to define 'caseness' (normal, borderline, abnormal). There is also an 'Impact Supplement' which contains items on distress and social impairment which are summed to form an 'impact score'. It has adequate discriminative and predictive validity.

3.2.4 The Children's Global Assessment Scale (CGAS) (Schaffer *et al.*, 1983) (see Appendix 5)

This is a clinician completed scale consisting of 100 items which measures the impact of the child's mental health difficulty on the functioning of the child (Appendix 4). A score is used to assign a child to one of ten levels of functioning ranging from 'superior functioning' to 'needing 24 hour care and supervision'. It has acceptable discriminant validity and reliability (Schaffer *et al.*, 1983; Bird *et al.*, 1987).

3.2.5 Child completed outcome measures

Both services had explored using the child version of the SDQ. However, they found that a significant proportion of children experienced difficulties understanding the questions and clinicians found they were explaining (in spoken English, via an interpreter or directly using BSL) the meaning of some items thus invalidating the validity of the measure. The York service had explored developing a BSL version of the SDQ but it soon became apparent that a number of different versions would be needed to cater for the different levels of BSL among the children using the service. The resources required to develop and psychometrically test BSL versions were

significantly beyond the scope (and remit) of the service. It should also be noted that the SDQ has not been standardised for deaf children.

3.3 Findings

Numbers of children referred to the York and Dudley services: During the period 2004-mid 2007, 60 children had been referred to the Dudley service, of which 49 referrals were funded by NSCAG funding, and 66 children had been referred to the York service.

Mental health difficulties presented at referral: There was a high rate of completion (>96 per cent) of the checklist recording the difficulties presented by the children at referral, see Table 3.1.

Table 3.1: Mental health difficulties at referral

	<i>Dudley (n=47)</i>	<i>York (n=65)</i>
Behaviour issues	74%	69%
Family and communication issues	43%	51%
Emotional difficulties	49%	38%
Self-harm	11%	11%
Eating/sleeping difficulties	13%	17%
ADHD	32%	9%
Tourettes	4%	2%
Psychosis	0%	0%
Substance mis-use	0%	3%
Adjustment/post-abuse difficulties	4%	2%
Empathy skills deficits	0%	6%
Autistic spectrum disorders	21%	5%
Court reports	0%	0%
Other	28%	11%

For both services, the most frequently presenting difficulties were behaviour issues, family and communication issues and emotional difficulties. There are clear differences in the proportion of children being referred with ADHD and autistic spectrum disorders between the two services. The Dudley service had a greater number of referrals with children with these difficulties.

The majority of the children referred to the services presented with more than one difficulty, see Table 3.2.

Table 3.2: Number of presenting mental health difficulties per child

	<i>Dudley</i> <i>(n=47)</i>	<i>York</i> <i>(n=65)</i>
One difficulty	13%	28%
Two difficulties	21%	37%
Three difficulties	45%	22%
Four difficulties	21%	9%
Five or more difficulties	0%	5%

The figures in the table suggest differences in the complexity of the cases referred to the two services. However, this may be due to differences in the way the presenting difficulties checklist was completed (in particular, whether or not the ‘other’ category was used), and the fact there is some overlap between the difficulties listed on the checklist (for example, behaviour issues and autistic spectrum disorders). This apparent difference may therefore be spurious and without access to any corroborating evidence cannot be explored further and this data needs to be treated with caution.

3.4 A detailed look at the York Service

The York Service was able provide a greater range of information on the cases they had seen.

3.4.1 Clinical profile

Clinicians complete the Children’s Global Assessment Scale (CGAS) at referral, during treatment and at discharge. Table 3.3 reports CGAS scores at referral, these are represented in terms of the child’s level of functioning.

Table 3.3: CGAS level at referral

	<i>N</i> (%)
Superior functioning in all areas	0 (0%)
Good functioning in all areas	2 (3.9%)
No more than slight impairment in functioning in all areas	3 (5.9%)
Some difficulty in a single area but generally functioning pretty well	7 (10.6%)
Variable functioning with sporadic difficulties or symptoms in several but not all social areas	15 (29.4%)
Moderate degree of interference in functioning in most social areas or severe impairment of functioning in one area	15 (29.4%)
Major impairment of functioning in several areas and unable to function in one of these areas	8 (15.7%)
Unable to function in almost all areas	0 (0%)
Needs considerable supervision to prevent hurting other or self	1 (2.0%)
Needs constant supervision (24 hour care) due to severely aggressive or self-destructive or gross impairment in reality testing, communication, cognition, affect or personal hygiene	0 (0%)

Almost half the sample (47.1 per cent) experienced moderate or more severe impairment in functioning, with the majority of the remainder experiencing some difficulties or variability in functioning.

The Paddington Complexity Scale (PCS)

The Paddington Complexity Scale was also completed for each referral and provides information on the clinical profile of the children using the service.

Table 3.4: Primary psychiatric condition (n=65)

	<i>N</i> (%)
Conduct disorder (inc. mixed CED)	19 (29.7%)
Oppositional defiant disorder	16 (25%)
Sleep and feeding disorders (e)	5 (7.8%)
Anxiety disorders (OCD scores 3)	5 (7.8%)
Acute stress reaction/adjustment disorder	3 (4.7%)
Mood/affective disorders	3 (4.7%)
None	3 (4.7%)
Hyperkinetic disorder (or ADHD)	2 (3.1%)
Pervasive development disorder	2 (3.1%)
Eating disorders	1 (1.6%)
Schizophrenia	1 (1.6%)
Non-organic encopresis	0 (0%)
Somatoform disorders	0 (0%)
Other	4 (6.1%)

The most frequently reported primary psychiatric condition of children referred to the service was disruptive disorders, particularly conduct disorder (29.7 per cent) and oppositional defiant disorder (25 per cent), only two cases concerned ADHD. Emotional disorders (sleep and feeding, eating, mood and anxiety disorders) accounted for just under a fifth (22 per cent) of cases. A handful of cases were referred for acute stress reaction (n=3). One case was referred for an eating disorder and one for schizophrenia.

The great majority of children (83 per cent) had had the condition for more than six months.

Clinicians rated the severity of the condition. Nine cases (14 per cent) were rated as mild severity, 29 cases (44 per cent) as moderate severity, and 33 per cent as severe. None were rated as extremely severe. In addition to the primary psychiatric condition, a third of children (35 per cent) were reported to have a secondary psychiatric condition.

For over two-thirds of cases (68.8 per cent), the referral to York service was the first contact with mental health services.

The PCS also asks about the co-occurrence of chronic physical illness and learning disability, see Table 3.5.

Table 3.5: The co-occurrence of chronic physical illness and learning disability (n=64)

	<i>N</i>
Chronic physical illness	
None	56 (87.5%)
Present without brain involvement	1 (1.5%)
Present with brain involvement	7 (10.9%)
Learning disability	
None	34 (53.1%)
Specific	12 (18.8%)
Generalised – mild	5 (7.8%)
Generalised – moderate	10 (15.2%)
Generalised – severe	3 (4.5%)

In most cases (87.5 per cent) there was no co-occurrence of chronic physical illness, though in seven cases there was a co-occurring physical illness with brain involvement. Just under half the sample (46.9 per cent) had a learning disability, with almost one in five children having a moderate to severe learning disability.

The PCS collects information on the type of schooling and additional information was collected on the identity of the school, see Table 3.6.

Table 3.6: Schooling

<i>Type of school (PCS) (n=65)</i>	<i>N</i>
Ordinary	9 (13.8%)
Ordinary with special education provision	13 (20%)
Special school	39 (60%)
No school (excluded)	3 (4.6%)
Not applicable	1 (1.5%)
<i>Identity of school (n=62)</i>	
Specialist school for deaf children	38 (61.3%)
St Johns	25 (40.3%)
Doncaster	13 (19.7%)
Mainstream LEA school (York, North Yorkshire)	18 (27.7%)
LEA special school	1 (1.5%)
Other	5 (7.7%)

Almost two-thirds of children using the York service attended the local specialist schools for deaf children. The majority of other children were pupils in LEA schools in York and North Yorkshire, one of whom was attending a special school.

Just under a quarter of children (23.1 per cent) were not in contact with any other statutory service. Three out of ten (29.2 per cent) were also seeing a paediatrician. Education services were involved with over half of the cases (55.4 per cent), social work staff were working with over a third of cases (38.5 per cent). Just over one in ten children (12.3 per cent) were identified as being 'at risk' within the definition of the 1989 Children Act.

Referrers

Table 3.7 details the professional role of the referrer.

Table 3.7: Referrers to the York service (n=62)

	<i>N (%)</i>
School liaison officer in specialist school or unit for deaf children	30 (48.4%)
Teacher of the deaf	13 (20.9%)
Health professional	10 (16.1%)
Other education professional	1 (1.6%)
Social services	7 (11.3%)
Other	1 (1.6%)

Among children attending LEA schools (n=24), teachers of the deaf and health professionals were the most common referrers to YDCAF – each had referred nine children. Social services teams had referred five children.

Case complexity

Total scores on the PCS provides an indicator the complexity of cases seen by the York service. Scores ranged from two to 20, with a mean score of 11.14 (SD 4.48). This is a higher mean score than reported by other outpatient/day patient CAMHS (Yates *et al.*, 1999).

3.4.2 Socio-demographic profile

A greater number of boys (58.2 per cent) than girls (42 per cent) had been referred to the service. In line with the local population, almost all children were white (62/65). The youngest child referred was three years and the oldest 17 years. The mean age⁶ at referral was 11.14 years with most referrals (53 per cent) happening when the child was aged between 13 and 16 years. Comparing these figures to national data on age of referral to CAMHS (CORC, 2007) suggests children being referred to specialist deaf service are older than average, see Table 3.8.

⁶ Note data on age only available for 51/65 cases.

Table 3.8: Age at referral

	<i>York service</i>	<i>All CORC data*</i>
0-5 years	11.8%	20.8%
6-12 years	33.3%	55.3%
13-18 years	54.9%	23.8%

* This combined data from all CAMHS who are members of the CAMHS Outcome Research Consortium.

Hearing loss

Table 3.9: Level of hearing loss, use of hearing aids and occurrence of hearing loss

Level of hearing loss (n=62)	
Mild	3 (4.8%)
Moderate	5 (8.1%)
Severe	7 (11.3%)
Profound	42 (67.7%)
Hearing	5 (8.1%)
Use of hearing aids (n=57)	
Cochlear implant	11 (19.3%)
'Behind the ear' (BE) aids	38 (66.7%)
None	8 (14.0%)
Occurrence of hearing loss (n=53)	
Congenital	25 (47.2%)
Acquired	14 (26.4%)
Not known	14 (26.4%)

Over two-thirds of referrals had profound hearing loss. A small proportion of referrals (n=5) were either hearing siblings or hearing children of deaf parents. Data on use of hearing aids is less complete (86 per cent response rate), but indicates that the great majority of referrals were using BE aids, with one in five referrals having had a cochlear implant. Eight children (14 per cent) did not use a hearing aid. Information on when hearing loss occurred is also less complete (80.3 per cent response rate and 26.4 per cent 'not known') and but suggests that children who are born with hearing loss, as opposed to those with acquired hearing loss, are more prevalent among those referred to the service.

Visual impairment

Five children (7.6 per cent) referred to the service also had a significant visual impairment.

3.4.3 Parents' hearing

Eight out of ten children had hearing parents. Ten children (15.4 per cent) had parents who were deaf, and two had one deaf and one hearing parent.

Table 3.10: Parents' hearing (n=65)

Deaf	10 (15.4%)
Hearing	53 (81.5%)
Deaf and hearing	2 (3.1%)

3.4.4 Ways of communicating

Over a fifth of children used BSL to communicate, and just under a third used oral means of communication (for example, lipreading, speech and residual hearing). The majority of children referred to the service were using more than one method to communicate, for example, sign supported English.

Table 3.11: Ways of communicating (n=58)

BSL	13 (22.4%)
Oral	19 (32.7%)
More than one method	24 (41.3%)
Unclear, communication significantly impaired by ASD	2 (3.4%)

3.4.5 Interventions provided by YDCAF

Clinicians report the interventions provided to a child, these are summarised in Table 3.12.

Table 3.12: Interventions provided (n=62)

<i>Nature of intervention</i>	
Group work	7 (11.3%)
Individual work	30 (48.4%)
Family work/therapy	31 (50%)
Behaviour management	16 (25.1%)
Advice to school	16 (25.1%)
Medication prescribed	6 (9.8%)

Individual work and family therapy were the most commonly delivered interventions. In addition, behaviour management interventions and advice to school took place with a quarter of cases. Medication was used in less than one in ten cases. Just one child had only been referred to the service for an assessment.

In the majority of cases (72.1 per cent) more than one intervention took place. For example, individual and family work took place with 19 cases (30.6 per cent). Group work almost always took place alongside another intervention (n=6). Typically this was individual work (n=5), but was also co-occurred with family work (n=1). Advice to schools was provided alongside a range of interventions including delivering behaviour management interventions, individual and family work.

3.4.6 Use of the telelink

The telelink had been used by seven children (10.6 per cent) to link up with the deaf clinical psychologist based at the London service. The mean age of those using the telelink was significantly higher than those not using the telelink (14.3yrs versus 11.4yrs, $t=3.61$, $df=20.1$, $p<0.01$). There was no significant difference between mean scores on the PSC and level of functioning (as measure by the CGAS) between those using the telelink and those not using the telelink.

3.4.7 Staffing

The York team consists of two psychiatrists, a CAMHS community nurse, a social worker and a family support worker, all of whom are part-time. Data on staffing contains some ambiguities. The CAMHS community nurse was appointed after the start of the project and the family support worker post was vacant for a period. In addition, it is not clear from the data available whether multiple involvement was due to the needs of the child or for the purposes of training up new staff. Thus this section will be limited to reporting overall patterns in staff involvement in cases. In four out of ten cases more than one member of the team was involved. The psychiatrists and CAMHS community nurse were more likely to work alone with a family (58.8 per cent and 53.6 per cent of cases respectively) than the psychologist and social worker (33.3 per cent and 30.8 per cent of cases respectively). A psychiatrist was involved with almost two-thirds of cases (62.1 per cent). As would be expected the family support worker was always involved alongside another member of the team, and had worked with all other members of the team.

3.4.8 Closure of cases

Cases had been closed for thirty two children who had used the York service. Clinicians reported the outcomes of these cases, see Table 3.13.

Table 3.13: Closure of cases (closed cases only) (n=31)

	%
Did not opt in/did not attend any appointments	10%
Did not engage	16%
Child/family moved away	16%
Mutually agreed ending	58%

Over half of cases ended at a time mutually agreed by the clinician and family. One in ten referrals did not attend any appointments. Just over one in six families attended a few appointments but did not engage and ceased to attend. A similar proportion of cases were terminated prematurely because the child had moved away.

3.5 Clinical outcomes for children using the York service

Examination of CGAS scores at referral and discharge or into treatment provides evidence with regard to the outcomes for children using YDCAF.

3.5.1 Closed cases

By August 2007 32 cases had been closed. CGAS scores at referral and discharge were available for twenty of these children (62.5 per cent of potential sample). PCS scores, age at referral and gender of the children where outcomes data was not available were compared with the group where outcomes data was available and no significant differences were found between the two groups with respect to these variables.

The sign test for two related samples was used to compare children's level of functioning at referral and discharge. A significant change in CGAS scores was found ($p < 0.001$). In 15 cases (75 per cent) there was a positive change in level of functioning, in five cases there had been no change in CGAS functional classification. Table 3.14 shows the movement between CGAS levels of functioning.

Table 3.14: Closed cases: movement between CGAS levels of functioning (n=20)

<i>CGAS functioning classification</i>	
No change	5 (25%)
+ 1	6 (30%)
+ 2	5 (25%)
+ 3	2 (10%)
+ 4	1 (5%)
+ 5	1 (5%)

3.5.2 Open cases: interim outcomes

In August 2007 the service has 34 open cases. CGAS scores at referral and into treatment were available for 21 of these children (62 per cent of potential sample). These children had been using the York service for between six and 40 months. PCS scores, age at referral and gender of this group and was compared with those children where outcomes data was not available and no significant differences were found between the two groups with respect to these variables.

The sign test for two related samples was used to compare children's level of functioning at referral and into treatment. A significant change in CGAS scores was found ($p < 0.001$). In 18 cases (85.7 per cent) there was a positive change in level of functioning, and in five cases there had been no change in CGAS functional classification. Table 3.15 shows the movement between CGAS functioning categories.

Table 3.15: Open cases: movement between CGAS categories (n=21)

<i>CGAS functioning classification</i>	
No change	3 (14%)
+ 1	6 (28%)
+ 2	6 (28%)
+ 3	5 (24%)
+ 4	1 (5%)

3.6 Clinical outcomes for children using the Dudley service

The Dudley service used the parent completed Strengths and Difficulties Questionnaire to collect information on clinical outcomes.

In August 2006 the Dudley service distributed SDQs to all active cases where the child had been receiving treatment for at least six months (n=50). Forty completed questionnaires were returned (response rate=80 per cent). However, for 11 of these children no baseline SDQ was available reducing the sample size to 29 children (58 per cent of the potential sample). Data from the completed SDQs was passed to the research team. No data was available by which the response/non-response and complete data/missing data samples could be compared.

This sample was very heterogeneous in terms of the length of time the child had been using the service. Five children had been using the service for over two and a half years, suggesting complex and perhaps intractable mental health problems. Nine children had been using the service for less than a year with the remainder using the service between 15 months and two and a half years. It also needs to be remembered that this is data on interim outcomes– none of these children had been discharged. Changes in SDQ scores between referral and August 2006 were explored using a paired samples T-test, see Table 3.16.

Table 3.16: SDQ scores at referral and August 2006

	<i>At referral</i>	<i>August 2006</i>	
Emotional symptoms	4.37 (2.51)	3.34 (2.37)	t=1.74 (df 28) p=0.093
Conduct problems	5.68 (2.12)	4.57 (2.27)	t=2.42 (df 28) p<0.05
Hyperactivity	7.27 (2.04)	6.22 (2.43)	t=2.13 (df 28) p<0.05
Peer problems	3.72 (1.76)	4.44 (2.59)	t=-1.70 (df 28) p=0.099
Prosocial behaviour	5.53 (2.58)	6.00 (2.12)	t=-1.03 (df 28) p=0.312
Total difficulties score	20.98 (4.13)	18.59 (6.61)	t=1.715 (df 28) p=0.097
Impact score	5.86 (2.61)	2.60 (2.55)	t=7.45 (df 28) p<0.001

Though improved, the difference between Total Difficulties SDQ scores at referral and in August 2006 was not significant. However, significant differences in scores on the conduct problems scale, the hyperactivity scale and the Impact score were found.

SDQ scores can also be used to define caseness. Three categories are used: normal, borderline and abnormal. At referral, the SDQ scores for 24 out of the 29 children were abnormal, four were borderline and one was normal, see Table 3.17.

Table 3.17: Distribution of the sample according to caseness

	<i>At referral (n)</i>	<i>August 2006</i>
Normal	1	5
Borderline	4	4
Abnormal	24	20

When SDQs were completed in August 2006, eight children moved had in a positive direction (n=1 (borderline to normal); n=4 (abnormal to borderline); n=3 (abnormal to normal)). Three children had moved in a negative direction (borderline to abnormal), whilst the scores for the remainder led to no change in caseness banding (n=1 (normal); n=19 (abnormal)). The sign test for two related samples was used to compare differences in caseness at referral and in August 2006 and found these changes in caseness was not significant ($p=0.227$).

3.7 Geographical information

The distance parents and children were travelling to use the services was calculated using postcode information. The need to calculate both parent and child journeys was because many of the children were resident in a specialist school for deaf children which may well be some distance from the child's home. The Dudley and York services held clinics in their local specialist schools (as did the London service before the service had to reduce its level of provision) thus removing the need for the child to travel. However, parents did also attend at least some (if only the initial assessment) of these appointments. Table 3.18 shows the journey distances to appointments for parents and children.

Table 3.18: Distance travelled to appointments

	<i>Parent journey¹</i>			<i>Child journey²</i>		
	Min distance (km)	Max distance (km)	Mean distance (km)	Min distance (km)	Max distance (km)	Mean distance (km)
London (2004 onwards) (n=121) ³	6	395	41 (STD=53)	1	392	32 (STD=50)
Dudley (n=68)	2	267	41 (STD=53)	2	80	34 (STD=25)
York (n=34)	4	357	79 (STD=70)	2	107	63 (STD=28)

¹ Parent journey distance was calculated from home postcode to where service delivered (i.e. clinic, outreach clinic, residential school).

² Child journey distance was calculated from where child travelled (home, residential school) to where service delivered.

³ These figures should not be taken to indicate the number of children using the service. A proportion of postcodes from each services current and past caseload were inaccurate or not available.

These figures show the enormous range in the distance being travelled by parents to attend their child's appointments across all three services. The maximum distance being travelled by the children to the Dudley and York services is smaller compared to the London service. However, on average the journey distance for children and parents is greatest for families using the York service and is twice that of the average journey distance for those using the Dudley and London services.

However, as would be expected, whilst the pilot services have not reduced difficulties of geographical access for service users there is clear evidence that they have increased access to specialist mental health services *per se*. Postcode data was used to map the family homes of children using the service before and after the Dudley and York services became operational (see Appendix 6). Prior to these services being in place families using the London service were clustered around London with the odd 'pockets' of families located further afield. The map of family home location after the two pilot services came into place show a greater spread in the location of families accessing a specialist service with, as would be expected, concentrations around the York and Dudley areas though extending beyond these due to children using the service attending one of the residential schools local to Dudley or York.

3.8 Discussion

In this chapter data routinely collected by the services was presented. It consisted of descriptive data on the two services along with evidence with regard to clinical outcomes.

There were number of significant difficulties with this data set. First, one service had clearly struggled to maintain routine data collection, presenting considerable restrictions on the descriptive data available for analysis and the strength of the evidence with regard to clinical outcomes. Second, the services used different clinical measures which prevented any detailed analyses looking at differences in the populations using the two services. It also meant data could not be combined in order to explore overall clinical outcomes of using specialist mental health services, and to compare the profiles and outcomes of users of these services with other CAMHS. Finally, the Paddington Complexity Scale is not a widely used (the Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) appears to be preferred (CORC, 2007) and again opportunities to compare the presenting difficulties of these children against the wider population of CAMHS users was not possible.

Limited data was available which describes all the children who have used the service. It shows that over 100 children had used the two services during a period of around two and a half years. The (larger) service in York had accepted more referrals than the Dudley service. There are indications that, over that period, the children being referred differ between the two services. In particular, the Dudley service was seeing more children with ADHD and autistic spectrum disorders. One reason for this may be that the psychiatrist leading the Dudley service had, on a smaller scale, been providing a specialist mental health service for deaf children in the West Midlands before NSCAG funding came into place and may, therefore, have a wider pool of referrers including those working in learning difficulties.

It was possible to develop a more detailed picture of the children using the York service, along with describing the interventions being delivered and the way the staff team operated. It is worth noting that the majority of children had no previous contact with mental health services prior to their referral to the specialist service. This concurs with previously published evidence pointing to difficulties with access to mental health services (for example, Hindley, 2000; Du Feu and Fergusson, 2003; van Gent *et al.*, 2007) and from the findings of this research with regard to referrers' reluctance to use generic CAMHS and parents' difficulties accessing mental health support for their child (see Chapters 4 and 7).

The York dataset also included data on the closure of cases. This was an important issue on which to collect information given that attrition is a significant problem in

CAMHS. If moving away is included in the calculations, the treatment of 42 per cent of cases ended prematurely. This figure falls to one in four cases if it only includes those cases where the reason for premature termination was to do with difficulties engaging the child/family. This figure is lower than has been reported by other research (Kazdin and Mazurick, 1994; Kazdin *et al.*, 1993) and indicates the service was successful in engaging families. The particular features of this population both mitigates for and against engagement. The fact that many children were attending residential schools with clinicians visiting the school would seem to support regular attendance at appointments. However, parents were having travel, at times considerable distances, to attend these appointments. The high levels of family relationship difficulties within the group may work to either support engagement or make families less inclined to engage. Finally, among families where the child was not attending residential school, some still faced quite lengthy journeys to the clinic which could act as a barrier to attendance and/or engagement.

A second key issue to draw out of the data on premature termination of treatment concerns the families who move away from the location of the service. In these circumstances it is highly unlikely that access to another of the specialist services is possible. This would suggest that consideration needs to be given how the closure or transfer of these cases is managed to ensure mental health needs of these children continues to be met.

There are also implications to draw from the data on the age at referral. This is higher than is typically found within CAMHS (CORC, 2007). There are a number of possible reasons for this. It could be reflection of the difficulties deaf children have accessing services. It may also be because issues with respect to identity which may have implications for mental health are more likely to emerge during adolescence and, for young people facing moving on from a specialist residential school, may only become acute towards the end of their school life. Whilst this research cannot establish the underlying reasons for this higher than average age of referral it does serve to flag up the need for the specialist services to consider mechanisms by which young people make the transition to specialist adult mental health services.

A small group of children (7/66, 10 per cent) using the York service used the telelink to enable them to be treated by the deaf clinical psychologist based in the London service. This is perhaps a smaller proportion of users than had originally been conceived. Practitioners' views with respect to the use of the telelink therapeutically have been discussed in Chapter 2. It reveals a growing understanding in terms of the sort of children who are likely to benefit from receiving therapy in this way. There is also a sense that the potential of the telelink has not been fully developed but that this needs to happen alongside practitioners confidence and skills with using this medium. Children's accounts of using of the telelink, which are overwhelmingly positive, are fully described in Chapter 5.

Both teams provided data with regard to clinical outcomes. The data from the Dudley service needs to be treated with great caution for a number of reasons including: small sample size, data being available for just 58 per cent of the potential sample, the proportion of children with complex difficulties such as autistic spectrum disorders, and the considerable range in duration of treatment at the time when the clinical measures were completed for the second time. With this in mind, improvements in SDQ were found, particularly in terms of SDQ impact scores and the conduct problems and hyperactivity subscales. The data on clinical outcomes from the York service is more robust though the sizes of both open and closed cases samples, completeness of the data sets (around 62 per cent of the potential sample) means that these findings also need to be treated with caution. Findings from the analysis of both the closed and open cases suggest that improvements in functioning being achieved in the majority of cases. This limited evidence clearly needs to be considered alongside other data collected on outcomes by the project (see Chapters 5, 6 and, to a limited extent, 7).

The evidence with regard to geographical access highlights a specific issue faced by this service. That is, because many of its users attend residential schools, there is the issue of parental access to or involvement with the service when the school is at some distance from the family home. This presents particular challenges to the service given that difficulties with family relationships and communication are a very common presenting mental health difficulty at referral. Ways to support parent/family access or involvement in the service is an area which will need to be considered in any future development of the service.

A key implication from the findings of this aspect of the project concerns the routine collection of data. The Children's National Service Framework requires CAMHS to routinely audit and evaluate their work (Department of Health, 2004). Information on outcomes can contribute to the management of both individual cases and the overall service. It is also crucial to informing service development. The fact that mental health services for deaf children is a new area of specialism, with England at the forefront of service development, reiterates the importance of routine data collection to inform clinical practice and the future shape of services. In addition, routinely collected data could contribute to the relatively limited evidence on the mental health needs of deaf children. Furthermore, it could be used to establish the psychometric properties of generic mental health measures with respect to their use with deaf children.

Since this research project was conceived progress has been made in promoting audit and evaluation by CAMHS and aligning the measures used in those processes (Wolpert *et al.*, 2007). Recommendations from this research would be that collection of routine data should become core activity, and that the data collected is aligned with the CAMHS Outcome Research Consortium. Core measures agreed by this consortium are: SDQ (parent and child); the Commission for Health Improvement

(CHI) Experience of Service Questionnaire (parent and child version); and the CGAS. In addition, the HoNONSCA is recommended for services working in specialist settings. However, varying levels of English literacy and the need for BSL versions of these measures raises an important issue with regard to the use of the child completed measures. Translating and psychometric testing of translated versions of child-completed clinical measures would appear to be a priority in terms of future research.

3.9 References

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Chapter 4: Parents' experiences of accessing specialist mental health services for deaf children and young people⁷

4.1 Abstract

Deaf children are more likely to experience mental health problems than hearing children. Forty-one parents of children using a specialist mental health service for deaf children were interviewed about seeking help for their child and desired outcomes of using the specialist service. Just eight families had used generic CAMHS, all had found the service unsatisfactory. Many children had had mental health problems for a considerable period of time before accessing the specialist service. Parents were confident the specialist service could help their child. Improving access to specialist services is a pressing issue.

4.2 Introduction

Approximately 1.2 children in 1,000 are born with severe to profound hearing loss. Most deaf children (>90 per cent) are born to hearing parents who know little or nothing about deafness (Meadow-Orlans and Erting, 2000). Deaf children and young people⁸ often experience difficulties in communicating with their own families, with hearing peers, and in school. Communication problems, subsequent difficulties with peer relationships and family dynamics, and a high incidence of central nervous system damage are some of the main reasons why deaf children are approximately 1.5 times more likely to develop mental health problems than their hearing peers (Hindley, 1993). One study has estimated the prevalence of mental health problems (ranging from emotional and behavioural disorders to major mental illnesses) among deaf children and young people to be 40 per cent compared to 25 per cent among hearing children (Hindley, 1993). The Health Advisory Service (1998) report on deafness and mental health, *Forging New Channels*, estimates that the prevalence of disabling mental health problems in deaf children, requiring referral to a specialist mental health service for deaf children, is 3.4 per cent of the population.

Deaf children and their families require access to the same range of mental health services as their hearing counterparts. However, they have additional needs that ordinary mental health services cannot meet (Hindley, 1997). In particular generic mental health services are unlikely to have an adequate understanding of

⁷ A slightly modified version of this chapter has been submitted as a paper to an academic journal authored by Veronica Greco, Bryony Beresford and Sue Clarke.

⁸ For ease of reading, the term 'children' will be used in the remainder of the paper in place of 'children and young people'.

communication needs; deaf child language development; specific patterns of social, emotional, and cognitive development; issues of family dynamics and peer group relationships; and deaf culture (Kretschmer and Kretschmer, 1978; Conrad, 1979; Quigley and Paul, 1984).

Prior to 2004 the only specialist outpatient mental health service for deaf children in England was in London, presenting obvious difficulties with regard to access for most of the population. In 2004, in response to this situation, the National Specialist Commissioning Advisory Group (NSCAG) of the Department of Health set up, on a pilot basis, two further specialist teams in York and the West Midlands. The York and West Midlands teams are funded to provide a service to local specialist deaf schools and units and to children living within local Primary Care Trust (PCT) boundaries. The West Midlands service also accepts referrals from children living outside PCT boundaries and these are funded by Named Patient Service Agreements⁹ (NPSA). Funding of referrals to the London service is through Service Level Agreements¹⁰ (SLAs) and NPSAs. The teams are multidisciplinary and include psychiatrists, psychologists, social workers, mental health nurses and family support workers.

The research reported here concerns parent's experiences of seeking help for their child's mental health problems, the route by which they accessed the specialist mental health service, and their desired outcomes of using the service. This is part of a wider study which is evaluating the service.

4.3 Method

4.3.1 Procedure

Ethical approval for the research was obtained from the Multi-Centre Research Ethics Committee. All families referred to the specialist services between February 2006 and February 2007 received information about the research from their clinician. Families interested in participating completed a 'Contact Form' which was passed onto the research team who then contacted the family to arrange an interview (see Appendix 7 for recruitment materials). Written consent was obtained at the time of the interview. Interviews lasted approximately one hour and, with the participants' permission, were audio recorded. Parents who used British Sign Language (BSL) were interviewed by a deaf researcher and their interviews were, with permission, recorded using a digital camcorder.

⁹ Named Patient Service Agreements: Funding is agreed upon on a 'case by case' basis by the PCT.

¹⁰ Service Level Agreements: these are agreements between a provider (ie. the specialist service) and a commissioner (ie. the PCT) which determine the range and level of service to be provided and the fee.

4.3.2 Interview schedule

The interview covered the history of the child's mental health difficulties, experiences of mental health and other services used prior to the specialist service, the referral process, and desired outcomes for the child and family from using the service (see Appendix 8).

4.3.3 Sample

Forty-one parents participated, representing 38 families. The majority of participants were mothers, though in three families a joint interview with the mother and father was conducted. Three participants were legal guardians and there was one lone father. Three parents were from minority ethnic groups, and four participants were deaf.

The parents represented 40 children who were using the specialist service (in two families two children were using the specialist service). The average age of the children was 11 years (range 6-16 years). Twenty-two were males and the remainder were females. Ten children attended mainstream schools, six attended units attached to mainstream schools, 21 were in specialist schools for deaf children, and three were not currently attending school. All but three of the children were deaf. One young person was a hearing sibling and two were siblings with a deaf parent. At the time of the interview the majority of participants (n=32) had had one or two appointments with specialist service. The remainder had seen their clinician between three and five times.

4.3.4 Data analysis

Audio-recorded interviews were transcribed and for interviews recorded in BSL, a transcript in BSL gloss was produced¹¹. The data was analysed using the well-established Framework approach (Ritchie, Spencer & O'Connor, 2003). The transcripts were coded according to analytical categories comprising both *a priori* and emergent themes which had been generated by the researchers based on their readings of the transcripts. Two researchers separately coded a subset of ten interviews to check the clarity of the category definitions, consistency in the use of categories and thoroughness in coding the transcripts. Overall, there was a very high degree of agreement in the application of the framework by the two researchers. The data were summarised onto charts, one for each analytical category, each entry was accompanied by a reference to its location in a transcript.

¹¹ Glossing is a method of describing BSL signs. The meaning of the sign is written using an English word or words (Sutton-Spence and Woll, 1999).

While reading across a chart provided information about a particular participant, reading down a chart allowed comparisons to be made across the sample. Over-arching themes and were identified and conclusions drawn and verified by returning to the transcripts and through ongoing discussions within the research team.

4.4 Results

4.4.1 The mental health difficulties of children and young people

Parents described the types of difficulties experienced by children and young people. These are represented in Table 4.1.

Table 4.1: Children’s mental health difficulties as reported by parents

<i>Type of difficulty</i>	<i>Males (n)</i>	<i>Females (n)</i>	<i>Total</i>
Behaviour issues	13	6	19
Emotional difficulties	2	1	3
Self-harm	1	5	6
Eating/sleeping difficulties	2	5	7
ADHD	2	0	2
Psychosis	1	2	3
Adjustment/post-abuse difficulties	0	1	1
Learning difficulties	3	0	3
Autistic spectrum disorder	4	3	7
Other	1	4	5

NB. Most parents reported their child had more than one difficulty.

The most frequently reported problems were behavioural difficulties, typically aggressive or violent behaviours occurring at home and at school. Other problems included: self-harming, eating and sleep problems, autistic spectrum disorders, adjustment and emotional difficulties, and learning difficulties. Most children were reported to be experiencing more than one of these problems.

4.4.2 Impact of the mental health difficulty on the child

The majority of parents felt that their child’s peer relationships had been affected by their mental health problems. The children did not typically have many friends because of the behaviours or symptoms they displayed, for example tendencies to hurt or bully other children, autistic tendencies, hyperactive behaviour, or temper tantrums.

In addition, almost a third of parents said their child's behaviour had caused significant difficulties in school and three had been permanently excluded. Some felt their child's academic achievements had suffered because of their poor mental health. A small number of parents felt unaddressed learning difficulties had interfered with their child's education.

4.4.3 Impact of the mental health difficulty on parents

Parents also talked about the impact of their child's mental health problems on their own well-being. Parents of children with behaviour problems, autistic spectrum disorders or with a history of self harming reported living in a state of constant anxiety about what the child might do if left unsupervised. This constant requirement for supervision was stressful and left parents feeling drained and vulnerable:

It gets you on the edge, you know what I mean? You're just wary of things, you know, I mean when you go round and have to search, search your daughter's bedroom to make sure there's no sharp objects in her bedroom, well it's, you just don't do it ... just not a done thing is it really?
(Parent, 15 year old girl)

Some were concerned that, as their child got heavier, the likelihood of their doing significant harm to others increased. They also found it more and more difficult to contain any behavioural outbursts:

She can be extremely violent, she's threatened me with knives and things and tried to strangle me and bitten and punched ... the violence has been more the last three or four years.
(Parent, 13 year old girl)

Other sources of stress were worries about escalation of the mental health problems and some were concerned how, given their current needs, their child would achieve independence in the future.

In a few cases, these stresses had led to a 'breaking point' and some parents had started to suffer themselves from mental health problems and felt they were not coping any longer.

4.4.4 Impact of the mental health difficulty on siblings

Parents of children with emotional/behavioural problems or autistic spectrum disorders were most likely to report difficulties with relationships between siblings. Some siblings had witnessed and/or been at the brunt of aggressive or erratic behaviour and temper tantrums and this often resulted in siblings avoiding their

brother or sister. This had a wider impact on family life because families tended not to do activities together, preferring to keep siblings apart. A number of parents mentioned being conscious that siblings had taken a 'back seat' because of the deaf child's needs. One parent reported that her child had assumed some caring responsibilities, particularly supervising their deaf sibling when parents were not available. For some children, living with a deaf sibling with mental health difficulties had a significant impact on their own mental health. Indeed, siblings in two families were themselves using mental health services for this reason.

4.4.5 Families' stories of seeking help

Families typically described struggling to manage their child's mental health on their own for years without effective support. Not surprisingly, they described this period as being very stressful and feeling very isolated. Despite the sometimes quite severe symptoms described in the previous section, less than half of parents interviewed had used other services to help deal with their child's mental health problem prior to using the specialist service. Furthermore, less than a quarter had used generic mental health services.

Experiences of other support services

Generic CAMHS and social workers were the main sources of support prior to accessing the specialist service. However, only seventeen children had used these services.

Eight families had used generic CAMHS, and their experiences were mixed. Half found the input they had received on behaviour management strategies had been helpful but limited, becoming less effective as the child's problems increased in complexity or severity. Others felt the help provided by CAMHS had never been adequate primarily because the service was not equipped to deal directly with the deaf child. In some cases parents were openly told by CAMHS that they could be of limited or no help because they did not know enough about deaf children:

She decided she couldn't help him because he was deaf.
(Parent, 14 year old boy)

Typically, CAMHS had provided a service to the parent, as opposed to working directly with the child. In some instances this was due to the young age or because that was the most appropriate mode of intervention. However, in other cases, parents felt it was due to the professional's reluctance to work with their child because they lacked the skills and expertise to do so. Parents of children who used BSL found the communication needs of their child remained unaddressed: interpreters were not provided and none of the mental health professionals used BSL.

Nine families had used social services and most felt that social workers had been a support to their child (for example by teaching the children sign language, aiding transition to college), but that this support was limited. Two families had approached social services over a year prior to the interview but were still waiting for a response. They felt that the delay was due to the child's communication needs.

The route to the specialist service

The means by which families were referred to the specialist service varied. Nineteen children were referred by special schools, six by mainstream schools, four by social workers, four by audiologists, three by paediatricians, two by general practitioners, one by a CAMHS psychiatrist, and one parent self-referred.

The main route was, therefore, a referral from the child's school and typically, this was a specialist deaf school. This is to be expected given the funding arrangements and close working relationships between these schools and the specialist service. At the same time, it should be noted that seventeen of the children had been taken out of or excluded from mainstream schools and moved to specialist schools because of mental health issues. In these instances, the specialist school typically referred the child soon after. In other words, despite longstanding problems, it was only when the child moved into specialist education provision that specialist mental health services were accessed. However, this was not always a smooth or speedy process, especially where the child's difficulties were intermittent or the school felt they were making progress with the child. In these instances, parents had been frustrated, especially when the child's symptoms were still very problematic at home. Apart from the specialist schools, most of the other referrers had already used the specialist service.

The time between referral and the first appointment for most families was two or three months. However, three families had waited between two and three years for the funding for the referral to be agreed by the child's PCT.

The timing of the referral to the specialist service

Over half of parents believed their child should have received specialist help much earlier. Parents described how their child's difficulties had got progressively worse, and/or that their child had 'missed out' due to the lack of timely input from the specialist service. The quote below is from a parent whose had been diagnosed by the specialist service as having learning difficulty:

He's actually been diagnosed with learning disabilities and I were a bit annoyed that, you know, it weren't picked up sooner (...). But how many years has been wasted? How many years has gone by where they could have had that extra help in??..... to give _____ a nudge with his reading and his writing and maybe I wouldn't have been having half of problems.
(Parent, 16 year old boy)

Feelings about the referral

All parents expressed a sense of relief about their child being referred to the specialist service. They believed it meant their child would be receiving help from someone expert in mental health **and** deafness. None of the parents mentioned concerns about the stigma of their child using a mental health service. Accessing the service also reduced parents' sense of isolation in terms of feeling they were dealing with their child's difficulties by themselves:

I mean Dr (...) is charming and he's been lovely, you know, for, if, he's always said if there's any problems to phone and he, and he's spoken to me on the phone a couple of times, which I think is wonderful really. So I've always felt that there's somebody there if I, if I needed to speak to somebody he'd be available.

(Parent, 10 year old boy)

Furthermore, in contrast with most of their dealings to date with regard to their child's emotional well-being, almost all parents had great confidence in the service. (The misgivings raised concerned the perceived skills of the clinician and the desire to see the psychiatrist on the team instead.)

4.4.6 Desired outcomes of using the service

Desired outcomes for the child

Parents' desired outcomes for their children centred on resolving their child's difficulties or alleviating symptoms. For children with behaviour problems, parents did not want these behaviours to persist into adulthood and develop into harmful behaviour patterns that would not change. Parents hoped and expected the specialist services to reduce these behaviours, be it through therapy, medication or a combination of these:

We're going to find what we need, you know, in terms of (child)'s future, you know, so that she can grow up. I don't want her to carry on with this behaviour right through till she's an adult. I want it nipped in the bud now, I want her helped now. I want her to (...) get out of these behaviour patterns and, and that we'll get some strategies as to what we do.

(Parent, 13 year old girl)

Where there were emotional difficulties, parents wanted the service to help their child become more emotionally literate, and to express and channel their emotions more appropriately. Others hoped the service would support their child to have more confidence, greater self-awareness, and a more positive self-image. The presence of deaf staff on the specialist team was seen by some as offering an opportunity for the child to meet deaf adults who were positive role models. Finally, some parents were

hoping for improvements in social skills which would mean the child could manage themselves better in social situations and widen their circle of friends.

Parents' desired outcomes for themselves

Parents strongly expressed the need for information and advice from someone expert in mental health and deafness. They wanted to understand why their child might be having particular difficulties, and to have expert advice on how they could support and help their child:

I want to try and understand [her] mind..... why she thinks the things she does think. 'Cos she has got a thing about death and why does she think like that? (...) I'm hoping to try and find out why she's, if she isn't happy, why she is and, 'cos she's got a habit at the moment of self-harming herself and we'd like to get to the bottom of why she does that.
(Parent, 15 years old girl)

Some parents were specifically looking for a diagnosis or assessment of their child's abilities. They talked about the importance of having 'a label' for their child so that people would be more understanding and the child would receive additional support at school.

Finally, parents wanted the service to relieve their emotional distress. Having a clear explanation of their child's problem was one means by which this could be achieved. For example, one parent said they wanted to be reassured their child was not just 'naughty'. Others expressed the need to feel someone understood their child's needs and the situation their family was coping with. They also wanted to feel that someone was going to help them and their child:

Sometimes you're not even looking for an answer or anything, you just want to have a rant or just talk about it. But being able to talk about it to someone who actually understands, like having that sort of a conversation with, you know, people I work with who are younger and don't even have any kids or people who have kids who haven't got any issues or whatever it is, quite a different thing being able to talk to somebody who, you know, is a professional and has seen lots of different situations. It's almost comforting especially when they can come back and say 'well, you're not the only ones (...) this sort of thing does happen'. So it's reassuring to know that other people are experiencing the same kind of thing as well.
(Parent, 9 year old boy)

4.5 Discussion

This study explored parents' experiences of accessing mental health services for their deaf child. Whilst the parents interviewed had all eventually managed to access the specialist mental health service, for many this had been preceded by a

very difficult, and often prolonged, period of time without any effective support being provided. Parents described the impact of unresolved or untreated mental health problems on their child's schooling and peer relationships, on their own well-being, and the threat it had posed to sibling relationships and sibling well-being. The findings highlight the difficulties families with deaf children experience accessing *any* support with regard to their child's mental health needs, the (understandable) inadequacies of generic services, and the significant barriers and inequities of access to specialist mental health services that currently exist.

One of the barriers to access identified included lack of knowledge on the part of professionals working in generic services about the existence of the specialist service. Just one of the eight children who had used CAMHS had been referred on to the specialist service by CAMHS. Similarly, many parents described how their child's mental health needs had not been dealt with while attending mainstream school but had soon been addressed on arriving at a specialist school for deaf children. Whilst this does in part reflect issues of the geographical/funding boundaries of the specialist service, there may be other reasons why generic practitioners were not referring children to the specialist service such as a lack of awareness of the service and, due to a lack of expertise in deafness and mental health, not recognising that a child has a mental health problem.

The experiences of those who had accessed a generic service were, at best, mixed and provide strong support for the argument for specialist services. Any positive experiences of generic services were tempered by the sense that the level of support provided was limited either because of the complexity of their child's needs, a lack of expertise on deafness and mental health, or because the service was unable to meet their child's communication needs. In contrast, the research found that parents recognised the specialist service as holding the expertise their child required. Parents expressed relief at accessing a service which was expert in mental health and deafness, and which rid them of a sense of isolation and lack of support. The study also explored the outcomes parents wanted from the specialist service. As well as dealing with the presenting mental health issue, parents saw the service as means for them to access information, advice and emotional support. Their initial contacts with the service made them confident that these outcomes could be achieved. Repeat interviews with parents being conducted as part of the wider evaluation of the service will afford the opportunity to explore the extent to which these desired outcomes are met.

The findings of this research clearly point to the need to increase the availability of specialist mental health services for deaf children. Current limits on access (geographical and/or funding constraints) to the specialist service will mean that the experiences of living with, and trying to find help for, a deaf child with mental health problems described by parents in this study are being replicated across the country by families currently unable to access the specialist service. In addition, as was

found among a few of the families participating in this study, there will be some families who are experiencing considerable delays in access due to NPSA negotiations, and these delays may well be taking their toll on the well-being of the family. Aside from funding, the key issue to be addressed in terms of improving access and widening availability is identifying the most effective way of providing a specialist service to a low incidence, geographically dispersed population.

This research was limited to parents who had accessed and engaged with the specialist service. For a complete picture of the experiences families seeking help for their deaf child with mental health problems further research needs to be conducted with families who, as yet have not accessed services and, as importantly, who accessed the specialist service and then chose not to use it.

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Chapter 5: Deaf children and young people's experiences of using specialist mental health services¹²

5.1 Abstract

Deaf children have an increased prevalence of mental health problems compared to hearing children. Generic CAMHS do not have the skills or expertise to meet the mental needs of this group of children. Three teams in England provide specialist mental health services for deaf children. This research explored children's experiences of using these services. Twenty deaf children participated in the study. Overall children valued and benefited from the service. The expertise of the staff and the presence of deaf clinicians were key to these positive experiences.

5.2 Introduction

There is an increased prevalence of mental health problems among deaf children and young people¹³ (45-50 per cent) compared to hearing children (25 per cent) (Hindley and others, 1994). Difficulties with communication, problems with peer and family relationships, central nervous system damage and delays in accessing service are all thought to contribute to this higher level of prevalence (Hindley and others, 1994; du Feu and Fergusson, 2003). Deaf children are also more likely than hearing children to experience emotional, physical and sexual abuse and these experiences also increase risk of mental health problems (ADSS and others, 2002).

Nonetheless, the relatively low incidence of hearing impairment (about one in 1500 children is severely or profoundly deaf, Meadow-Orlans and Erting, 2000) and the specialist skills required to meet deaf children's needs mean that generic services may not be able to provide an adequate service (Bailey and Lauwerier, 2003; NDCS, 2005). This mirrors the wider picture of the health care experiences of deaf people (Harmer, 1999). In particular, generic child and adolescent mental health services (CAMHS) are unlikely to have the skills to meet the child's communication needs, and will not have an adequate understanding of deaf child development (language, social, emotional and cognitive), specific issues of family dynamics and peer relationships, and Deaf culture. As a result, specialist mental health services are necessary in order to meet the mental health needs of deaf children and their families.

¹² A slightly modified version of this chapter has been accepted for publication in *Children and Society*. It is authored by Veronica Greco, Bryony Beresford and Hilary Sutherland.

¹³ For ease of reading, the term 'children' will be used in the remainder of the paper in place of 'children and young people'.

Prior to 2004 the only specialist outpatient mental health service for deaf children in England was in London. In response to obvious inequities in access, the National Specialist Commissioning Advisory Group (Department of Health) funded, on a pilot basis in the first instance, two further specialist teams in York and the West Midlands (Dudley). These became operational in 2004. The York and West Midlands teams are funded to provide a service to local specialist deaf schools and units and to children living within local Primary Care Trust (PCT) boundaries. The West Midlands service also accepts referrals from children living outside PCT boundaries and these are funded by Named Patient Service Agreements¹⁴ (NPSA). Funding of referrals to the London service is through Service Level Agreements¹⁵ (SLAs) and NPSAs. All the teams are multidisciplinary and include psychiatrists, psychologists, social workers, mental health nurses and family support workers. At the time of the research, all had one deaf member of staff: family support workers in the York and West Midlands services, and a deaf clinical psychologist in the London team who was also funded part-time to work with users of the York and West Midlands teams. (For further information: [http://www.deaf-friendly.org.uk/Deaf Mental Health Factsheet.pdf](http://www.deaf-friendly.org.uk/Deaf%20Mental%20Health%20Factsheet.pdf)).

An innovative part of the service is the use of teleconferencing technology to allow children using the York and West Midlands services to have access to the deaf clinical psychologist based in the London service. In these instances, most of the therapeutic sessions are conducted via a videolink (or 'telelink') but are interspersed with face-to-face sessions when the psychologist travels to meet the child.

Traditionally, telemental health services are used to improve access to mental health services for people (including children) who reside in under serviced, sparsely populated areas, such parts of Australia and North America (Alberta Mental Health Board, 2002; Starling and others, 2003). With respect to deaf people, telehealth technology has been used to support deaf adult's access to sign language interpreters (Harmer, 1999; Hughes and others, 2004) and some services are also using it for therapeutic purposes (Smith and Allison, 1998; Harmer, 1999). The use of this technology for therapeutic purposes with deaf children is, however, highly innovative. Indeed, when the teams started developing this aspect of the service they could find no pre-existing guidelines about how to manage the delivery of therapy in this way (Wright and Rhys-Jones, 2005).

This paper reports one aspect of an evaluation of the service, namely the children's views and experiences of using the service. Other components of the evaluation include research with referrers, parents and service providers and findings pertaining

¹⁴ Named Patient Service Agreements: Funding is agreed upon on a 'case by case' basis by the PCT.

¹⁵ Service Level Agreements: these are agreements between a provider (i.e. the specialist service) and a commissioner (i.e. the PCT) which determine the range and level of service to be provided and the fee.

to these aspects are reported elsewhere (Beresford and others, 2007; Greco and others, 2007).

5.3 Methods

The study involved interviews with two samples of children. A small sample of young people was interviewed on one occasion specifically about their experiences of using the telelink (referred to as the 'telelink sample'). A larger sample of children was interviewed on two occasions (referred to as the 'main sample'). All the children were still using the service at the time of the second interview and this was not, therefore, a before and after study design. Rather it afforded the opportunity to explore on-going experiences and changes associated with using the specialist service. The first interview took place within the first two to three appointments (Time 1) and the second four to nine months later (Time 2). MREC approval for the research was obtained.

In line with good practice with respect to eliciting children's views about services, a variety of tools were used to facilitate the interviews and reduce reliance on communication and literacy skills (Worrall-Davies and Marino-Francis, 2007). In addition, two or more different approaches were used to explore key issues. For example, children's experiences of using the service were investigated through semi-structured interviewing and through completion of a questionnaire.

Managing communication issues

Participants chose whether to be interviewed by a deaf or hearing researcher, and the language they used (British Sign Language (BSL), English or Sign Supported English). BSL interviews were conducted by deaf researchers. The deaf researchers and members of the specialist teams advised the hearing researchers on issues with regard to language, literacy, communication and other D/deaf issues during the entire course of the research project. Throughout all the interviews great care was taken to ensure the child understood the meaning of the questions being asked.

5.3.1 Recruitment

Recruitment of the main sample

Recruitment of the children occurred alongside recruiting parents to a different aspect of the evaluation. All families referred to the specialist services over a 12 month period were given information leaflets (parent and child versions) by their clinician about the research (see Appendix 9 for child recruitment materials). Families interested in participating completed a 'Contact Form' which was passed onto the research team. Families were contacted and, if the parent agreed to participate, an interview arranged. The child's involvement was discussed and

finalised during that visit. Children under five years were not recruited, neither were those where the parent felt the child would not be able to participate either because of the level of learning difficulties or because of the severity of their mental health problems.

Children were sent a letter confirming the interview. The letter was written in simple English, illustrated with pictures including a photograph of the researcher (see Appendix 9). Interviews lasted approximately thirty minutes and took place either at the child's home or, if the child attended a specialist deaf school, at school.

Recruitment of the 'telelink sample'

At the time of the research six young people had been using the telelink for their appointments with the deaf clinician based at London service. All were invited to participate in the research using a recruitment process similar to that used for the 'main sample'.

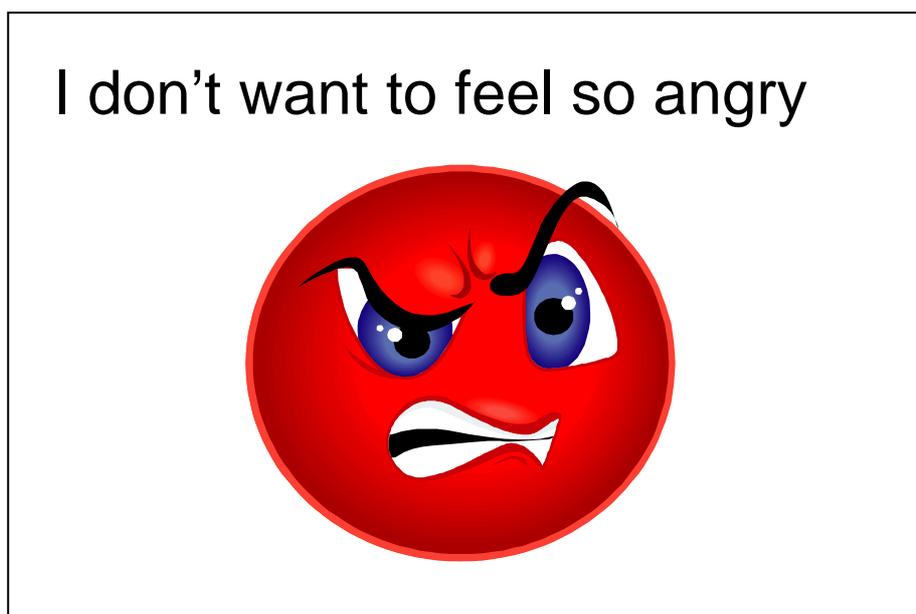
5.3.2 The interviews

Interviews with the 'main sample': Time 1 interviews

Consent was re-checked at the beginning of the interview and written consent obtained. The child was given cards which they could use to indicate they wanted the interview to end (red card) or to skip to the next question/topic (yellow card). Warm-up activities including drawing a map of 'people who help me', and some simple questions about their use of the specialist service (assisted by a series of photographs of the team) were used to start off the interview.

The interview explored the child's beliefs about why they were using the service and their initial experiences (see Appendix 10 for interview topic guide). In addition, a card sorting exercise was used to identify the child's desired outcomes of using the service. Nine pre-prepared cards (see Figure 5.1) covering a range of outcomes (see Table 5.2) were shown to the child. The child was asked to choose all those which were true for him/herself. Blank cards were used if the child identified an outcome not represented on the pre-prepared cards.

Figure 5.1: Examples of cards used in the desired outcomes exercise



Interviews with the 'main sample' : Time 2 interviews

The Time 2 interview covered any changes in the way the child had used the service, views about their clinician(s) and how he/she had helped them, and their experiences of managing communication (see Appendix 10 for the topic guide). Various activities were used to facilitate the interview such as giving the clinician marks out of ten, photographs of the team, and reviewing materials generated during the Time 1 interview. The interview also explored whether the child had experienced changes with respect to the desired outcomes identified during the Time 1 interview. Cards representing these changes were contained in a colourful booklet. Under

each card was a continuous line labelled at opposite ends with 'worse' and 'better', and with 'about the same' marked at the mid-line. Children were asked to mark the line to indicate how they felt at the time of the interview compared to how they felt when they started using the service. Finally, the child completed an amended version of the Commission for Health Improvement's (CHI) Experience of Service Questionnaire (ESQ).

The Experience of Service Questionnaire (amended) (see Appendix 11)

CHI developed a series of 12 item, self-completion questionnaires to help the clinical governance review process for mental health trusts in the UK (<http://www.healthcarecommission.org.uk/db/documents/04017625.pdf>). Various versions exist including one for children aged 9-11 years. On the advice of the deaf researchers working on the project, this questionnaire was used but adapted in the following ways: clinicians' names were used instead of the more generic wording 'people who saw you'; the wording of the items was simplified to better suit children who use English as a second language and to ensure consistency in situations where the researcher would be translating the items into BSL. In addition, one deaf-specific item was added and, in response to concerns raised in some Time 1 interviews, an item on confidentiality was included. The items contained in the modified version are listed in Table 5.3. The questionnaire uses a fixed response format and colourful 'smiley faces' were used to increase its visual appeal. Children who were seeing two clinicians (for example, psychiatrist and family support worker) completed a questionnaire for each clinician.

Managing different levels of ability

The topic guides were constructed to allow the researcher to pitch the interview at a level that was suitable to the child's cognitive, linguistic and literacy abilities. Visual materials used to facilitate the interviews. In addition, inclusion of the card sorting exercise (Time 1) and the amended ESQ (Time 2) in an interview was based on the researcher's judgement of the child's level of understanding. Thus the data collected reflected the various abilities of participants and their stories of using the service ranged from quite concrete and simple descriptions to more reflective and in depth accounts.

Interviews with the 'telelink sample'

Four young people were recruited expressly for the purpose of exploring their experiences of using the telelink (the 'telelink sample'). In these interviews the young people were asked about using the telelink, how it compared with face to face sessions, and perceived advantages and disadvantages of the telelink (see Appendix 12 for the topic guide). One of the young people in the 'main sample' was also using the telelink and this was covered using additional questions during the Time 2 interview.

5.3.3 The samples

The 'main sample' consisted of 20 children (see Table 5.1). All children deemed able to participate in the study by their parents consented to take part. The children were aged between seven and 16 years (mean = 12.2 years). Ten children chose to be interviewed in BSL by a deaf researcher with the other ten choosing an interview in English with a hearing researcher. Fourteen children were interviewed at Time 1 and Time 2. Due to delays in the recruitment process three additional children were recruited to the study after they had been using the service for a number of months, these children were interviewed once using a merged version of the Time 1 and Time 2 topic guides. A further three children were not interviewed at Time 2, one child had emigrated, one had been admitted for assessment to the inpatient unit in London, and one, for various reasons, had not had any appointments since the Time 1 interview.

Four (out of the six approached) young people were recruited to the 'telelink sample'. All were interviewed by a deaf researcher in BSL. Three were 16 years old and one was 15 years.

Table 5.1: The samples

	<i>Male</i>	<i>Female</i>	<i>Total</i>
Main sample			
T1 only	3	0	3
T1 and T2	7	7	14
Merged T1 and T2	2	1	3
Telelink sample	2	2	4
TOTAL	14	10	24

5.3.4 Data analysis

Interviews were either audio-recorded, recorded using a digital camcorder or by use of detailed field notes. Recorded interviews conducted in English were transcribed. For interviews conducted in BSL a transcript in BSL gloss¹⁶ was produced. Researchers also completed an 'interview record' which recorded the child's choice and categorization of cards on the desired outcomes. Raw data were coded according to analytical categories which had been generated by the researchers based on their readings of the transcripts. Two researchers separately coded a

¹⁶ Glossing is a method of describing BSL signs. The meaning of the sign is written using an English word or words (Sutton-Spence and Woll, 1999).

subset of ten interviews to check the clarity of the category definitions, consistency in the use of the categories and thoroughness in coding the transcripts. Overall, there was a very high level of agreement in the application of the framework by the researchers.

The data were summarized onto a series of charts which did not contain verbatim text but rather a synthesis accompanied by a reference to where it could be found in a transcript. Reading across a chart provided information about a particular participant, reading down a chart allowed comparisons to be made across the sample. Over-arching themes were identified and conclusions were drawn and verified by returning to the transcripts and through ongoing discussions within the research team (Ritchie and others, 2003).

5.4 Results

5.4.1 Where the children accessed the service

In the 'main sample', nine children (all of whom attended a specialist deaf school) met their clinician at school, three received visits at home, and five typically attended the clinic, two saw their clinician both at home and at clinic and for one the appointments took place both at school and at the clinic. All the 'telelink sample' had their appointments at school.

5.4.2 Communication

In the 'main sample', nine children chose to communicate with their clinician using BSL and, of these, three had an interpreter present during appointments. Nine children used English and communicated orally. Two children used English and BSL. All the 'telelink sample' communicated with their clinician using BSL.

5.4.3 Desired outcomes of using the service

Fifteen of the children and young people in the 'main sample' completed the card sorting exercise during the Time 1 interview with regard to the outcomes they wanted to achieve from using the service. Table 2 reports the frequency at which each desired outcome was identified by a child to be true for them. Outcomes of using the service most frequently identified by the participants included: not wanting to feel so sad, not wanting to feel so angry and/or wanting to get along better with friends. In addition, just under half of the children said they wanted their parents to feel better, to enjoy school more and/or to feel good about themselves. A third identified improving family relationships as a desired outcome. The children could also

nominate additional desired outcomes and these included: help with learning, not wanting to be bullied and help with eating.

Table 5.2: Desired outcomes of using the service

	<i>Children choosing card as a desired outcome (n)</i>
I don't want to feel so sad	9
I don't want to feel so angry	8
I want to get on better with my friends	8
I want mum and dad to feel better	7
I want to enjoy school more	7
I want to feel good about myself	7
I don't want to feel so worried	6
I want to get on better with my family	5
I don't want to get so upset when things are difficult	4
I want help with learning*	1
I don't want to be bullied*	1
I want help with my eating*	1

* These outcomes were identified in addition to the pre-prepared cards

All but one chose more than one desired outcome of using the specialist service. Over half the children (n=9) identified four or more different outcomes they wanted to achieve.

The extent to which changes had been achieved with respect to these desired outcomes was explored in the second interview which took place four to nine months into treatment (none had been discharged). Nine children completed this exercise and all but one said that things were better with regard to at least one of their desired outcomes. These children had identified a total of 38 desired outcomes at Time 1. At Time 2, 20 of these were reported to have improved since Time 1, and 13 were reported to be about the same. Five children reported things were worse with regard to one of their desired outcomes, however in all these cases they also reported that they felt there had been positive changes with regard to another of their desired outcomes.

5.4.4 Experience of using the service

Quantitative evidence

Evidence on children's experiences of using the service was gathered using the amended version of ESQ and through the interviews. Fifteen children completed the ESQ (five completed it twice because they were seeing to clinicians). Responses to the questionnaire are shown in Table 5.3. The items have been grouped into five

themes: confidence in the service, relationship with the clinician, child involvement, practical issues, and recommending the service.

Table 5.3: Responses to the experience of Service Questionnaire

	<i>All the time</i>	<i>Some- times</i>	<i>Never</i>	<i>Not sure</i>
Confidence in the clinician/service				
Do you think (...) understands about deaf children and young people?	12 (60%)	4 (20%)	2 (10%)	2 (10%)
Do you think (...) knows how to help you?	13 (65%)	3 (15%)	1 (5%)	3 (15%)
Has (...) helped you?	12 (60%)	4 (20%)	3 (15%)	1 (5%)
Relationship with the clinician				
Is it easy to tell (...) about how you feel?	11 (55%)	8 (40%)	0	1 (5%)
Can you talk to (...) without feeling embarrassed?	10 (50%)	8 (40%)	0	2 (10%)
Do you think (...) keeps private what you tell them?	12 (60%)	1 (5%)	1 (5%)	6 (30%)
Child involvement				
Did (...) explain how he/she was going to help you?	13 (65%)	4 (20%)	2 (10%)	1 (5%)
Does (...) pay attention to you or do they just talk to your mum and dad? (n=15*)	13 (86%)	1 (6%)	1 (6%)	0
Practical issues				
Are you happy with the time of the appointment when you usually see (...)?	14 (70%)	5 (25%)	1 (5%)	0
Do you like the room/building where you see (...)?	16 (80%)	3 (15%)	1 (5%)	0
	<i>Yes</i>	<i>No</i>	<i>Not sure</i>	
The place where my appointments are held is the best place	17 (85%)	3 (15%)	0	
Recommending the service				
If a friend needed the same sort of help you needed, do you think they should see someone like (...)?"	14 (70%)	2 (10%)	4 (20%)	

Overall, responses suggest that most children and young people held positive views about the service and their clinician. Specifically, most children were confident that the clinician could help them (80 per cent) and understood about deaf children and

young people (80 per cent). A similar proportion believed the clinician had helped them. In addition, at least some of the time, almost all reported feeling able to express how they were feeling to their clinician (95 per cent) and did not feel embarrassed about doing so (90 per cent). However, it should be noted that over a third (40 per cent) were unsure, or expressed concerns about, confidentiality.

In terms of involvement, the majority of children felt that, at least some of the time, the clinician had explained how they would help them (85 per cent) and almost all felt properly involved in consultations when their parents were also present (92 per cent). Given these very positive responses it is not surprising that over two-thirds of the sample believed the service would be of help to peers who were experiencing similar difficulties. Finally, on a more practical note, the children and young people were generally happy with the venue and timing of appointments.

Children's accounts of using the service

To supplement this quantitative evidence, analysis of the interview material provides further insight into the particular aspects of the specialist service which the children valued. These can be organised into four key themes: positive feelings about the clinician, feeling supported, being able to communicate, and deaf staff.

Positive feelings about the clinician

None of the children disliked their clinician. Reasons for liking their clinician was because he/she was 'nice', 'kind', 'funny', 'friendly', 'makes me laugh'. These positive feelings were reported regardless of whether the child or young person felt the clinician had helped them.

Feeling supported

Some children described the sense of support they felt from using the service. This stemmed from feeling that the clinician was helping them, was giving them attention and/or 'listening' to them. They also appreciated it when they were given practical help and advice on how to overcome their particular difficulties. For example, children mentioned receiving advice on how to be confident when talking to people, learning yoga techniques to relax, and writing diaries to help identify emotions. One child described how the clinician had taught her to walk out of the room if she felt her temper soaring. This had helped her feel calmer and she had stopped having temper tantrums before bed-time:

... before when it was bedtime, they would tell me to go to bed and I would lose my temper, always take it out on my mum (...) but now I have stopped doing this.
(Female, 13 years)

Communication

Children who were BSL users were happy that the service provided interpreters and signing clinicians to communicate with them. These children wanted their clinicians to be skilled at signing:

When I meet someone hearing, they don't know sign, they have no signing, how do we communicate? It's better to sign in BSL, it makes it easier to understand...
(Female, 14 years)

Deaf clinicians

Some children had sessions with both deaf and hearing clinicians and were able to compare their experiences. In all cases children talked about having a particularly good relationship with the deaf clinician because of being able to communicate easily through BSL and because the clinician also knew what it was like to be deaf. This young person is describing why he chose to see a deaf clinician using the telelink as opposed to face to face sessions with a hearing clinician:

I thought it would be a better relationship, we can talk things through, they can understand the situation (...) because this person will have similar experiences growing up and would know something about being deaf.¹⁷

5.4.5 Use of the telelink

In this section, findings from the interviews with the 'telelink sample' are reported along with the experiences of one young person in the 'main sample' who used the telelink for some of her appointments with her hearing clinician.

Most described feeling uncomfortable or self-conscious when they first started using the telelink but, except for one young person, they had quickly got used to the experience and felt at ease using it:

I like it. I thought it was fabulous, you know like MSN, which is small, but this is big.

At first I didn't think it would work, it feels flat, but then I realised it wasn't as bad as I thought it would be, it is all right, just the same like watching a telly really, but it can answer back. I feel OK about this, not at first but when I got used to it, it's OK.

Three young people explicitly mentioned that they had chosen to use the telelink because seeing a deaf clinician made communication easier and gave them a sense

¹⁷ To preserve anonymity of the very small 'telelink sample' age and gender details will not be reported.

of shared experience. They believed the telelink allowed more frequent sessions with the deaf clinician than if they were dependent on the clinician travelling to visit them.

Some felt communicating through the telelink was not as 'real' as a face to face encounter, and one felt nuances of body language could be lost. At the same time, whilst one of these young people was still ambivalent about the technology, the others were convinced of its value and felt it should be more widely available. However, a couple specifically mentioned valuing the face to face sessions which are interspersed, at less frequent intervals, with the telelink appointments. All but one of the young people reported that the screen sometimes 'froze' or was blurry but this only appeared to be seen as a significant difficulty for one young person. As well as this technical difficulty, two other concerns were raised. First, one young person described finding the close of the sessions difficult and described how saying goodbye on the screen 'doesn't feel finished'. Another was concerned about the confidentiality of the sessions and wanted to be confident that the sessions were private.

5.4.6 Concerns and complaints about the service

Whilst the overall picture obtained both from children's accounts of using the service is positive, a number of concerns or complaints about the using the service were described though it should be noted that less than half of the sample had anything negative to report. Most frequently mentioned problems were: not feeling informed about some aspect of using the service (for example, why they were using service, what would happen when they moved school), and difficulties with communication. With respect to the latter this included the signing expertise of the clinician and the clinician or interpreter using different signs to those used by the young person, or signing too quickly. Difficulties with communication were described as frustrating and confusing:

Sometimes the interpreter makes me a bit confused, and slow, makes it confusing, then (clinician) tells mum, mum tells me to help me understand, and only then I can answer ...
(Female, 14 years old)

There were also hints in a few of the young people's accounts of the way that attending sessions could be emotionally difficult because of the unpleasant or upsetting nature of the discussion. The end of a session could also be difficult, one child described the close of a session as 'strange' and feeling 'cut off'. Another found she was very emotional for the remainder of the day following an appointment.

A further concern related to confidentiality. A couple of children raised this as a significant concern and were worried that family and/or school staff would be told about what transpired during appointments. Using an explicit agreement about confidentiality was found to be a way of resolving this issue. Finally, the children did not like it when appointments were postponed.

5.5 Discussion

This study investigated deaf children experiences of using specialist mental health services and, whilst its remit was not to explore effectiveness, the extent to which children felt the service was helping them achieved their desired outcomes was explored. At the time of the second interview all but one of the children who had completed the desired outcomes exercise felt using the services had meant good changes in their lives and progress had been made to achieving one (or more) of their desired outcomes. Quantitative and qualitative evidence on children's experiences of using the service also paint a very positive picture. Four key themes emerged from the interviews which appeared to contribute to children's feelings about using the service.

First, all the children liked their clinician. This might seem a rather trite statement but, intuitively, it would seem very important that children 'like' their clinician if they are to engage with mental health services. However, it is interesting that this aspect of users' experiences of services is not typically included in evaluations of services (for example, Thorne, 1999). Yet it is clearly a very significant part of the user experience and, as has been shown in other fields, the nature of the user-professional relationship can be as, if not more important, than the help actually provided (for example, Beresford, 1999).

Second, children felt supported. As reported elsewhere (Greco and others, 2007) there is typically a considerable period of time between the onset of mental health problems and a child accessing the specialist service during which children receive little or inadequate support. Children's experiences of the specialist service contrasted with this experience: they felt 'listened to' and were confident the service would help them. Third, the service met their communication needs, either by the provision of skilled interpreters or having a clinician who could use BSL. Finally, children really valued the opportunity to work with a deaf clinician. Those who had experience of hearing and deaf clinicians described a qualitative difference in the nature of their relationships with the two professionals, with the relationship with the deaf professional being closer since it was based on the shared experience of being deaf and, for BSL users, communication was easier.

Having access to a deaf clinician was also the key advantage to using the telelink and outweighed technical difficulties which sometimes occurred and also the unease

associated with the unfamiliar nature of the interaction. As noted earlier, the development of the telelink service was carried out in the absence of any pre-existing guidelines. Based on initial experiences (including user feedback), occasional face-to-face sessions with the clinician were introduced and this practice was valued by the young people who participated in the research. Developing satisfactory ways to 'close' the sessions, minimising misunderstanding or miscommunication, and providing reassurance with regard to confidentiality would be further ways in which to refine service delivery.

Interestingly, the issues of confidentiality and 'closure' were also raised by the 'main sample' and improving users' experiences in these two areas, as well as being alert to increased emotional vulnerability resulting from a therapeutic session would improve users' experiences of this service.

One limitation of this study was that the sample does not represent all children referred to the service. In particular, it does not include children who did not engage with the service or those deemed by their parents as being unable to participate in the research. It may well be that these children's experiences of the service are different and it would be very useful to do further work to try to explore the experiences of these two groups.

In addition, it has not been possible to explore the effectiveness of the service. This was partly because of the constraints of the study period. However, a lack of standardised measures which have been validated with a population of deaf children is a significant barrier to any rigorous quantitative study of effectiveness (Bailey and Lauwerier, 2003). A further limitation of the study is its inability to assert whether specialist services are objectively better or worse than generic CAMHS. However, it is important to note that other components of this project have found that referrers and parents both strongly believe generic CAMHS are not appropriate for deaf children and also that very few deaf children use generic CAMHS (Beresford and others, 2007; Greco and others, 2007). In addition, it should be also be remembered that a clear finding from this study was the value placed by children on the expertise of the team and the presence of deaf staff neither of which would be found in generic CAMHS.

5.6 Conclusions

This study found that deaf children find specialist mental health services beneficial and have positive experiences of using the service. This is largely due to the skills and expertise of the staff. Whilst a relatively small part of current service provision, the use of telehealth technologies to allow access to a deaf clinician was highly valued and further research into this aspect of the service would be very worthwhile

given this has the potential to resolve, *in part*, the significant difficulties many deaf children experience accessing specialist mental health services.

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Chapter 6: Parents' evaluation of specialist mental health services for deaf children and their families¹⁸

6.1 Abstract

Deaf children are more likely to have mental health difficulties compared to their hearing peers. These needs are also more likely to remain unmet because generic CAMHS do not have the skills or expertise to work with these children. There are three specialist mental health services for deaf children in England. Thirty-six parents of children using these services were recruited to a study exploring effectiveness and user experiences. Parents were interviewed when their child started using the service (Time 1) and 6-8 months later (Time 2). As well as semi-structured interviews parents completed the Strengths and Difficulties Questionnaire (SDQ). At Time 2 the Experience of Service Questionnaire (ESQ) was also completed. A significant decrease in SDQ scores was found between Time 1 and Time 2, a finding corroborated by parents' descriptions of changes in their child's mental health. Parents believed clinicians' expertise in deafness and mental health and the service's ability to meet their child's communication needs were key factors contributing to these positive outcomes. Parents' reports and ESQ scores revealed high levels of satisfaction with the service. Implications of these findings in terms of the delivery of mental health services to deaf children and their families are discussed.

6.2 Introduction

Approximately 30 per cent of UK children have unmet mental health needs. Factors such as the sex of the child, socioeconomic status, ethnicity and type of mental health difficulty affect whether or not families seek and/or receive help (Meltzer, Gatward, Goodman, & Ford, 2000; Department of Health, 2004). Deaf children and adolescents are a population group who are more likely to have unmet mental health needs compared to other groups, such as their hearing peers (Hindley, 2000). For example, a recent study found that only three out of 32 deaf adolescents with DSM disorders had experienced contact with mental health services (van Gent, Goedhart, Hindley and Treffers, 2007).

At the same time, findings from research suggest that deaf children are at increased risk of developing mental health problems. More than 20 studies in the past 35 years have investigated the prevalence of mental health problems among deaf children and young people and it is estimated that incidence is 1.5-1.7 times higher

¹⁸ A slightly modified version of this chapter has been submitted as a paper for publication in an academic journal. It is authored by Veronica Greco, Bryony Beresford and Sue Clarke.

than among hearing children and adolescents (van Gent *et al.*, 2007). Reasons for this increased risk are: (i) delayed language development and constraints on their ability to communicate impact on these children's socio-emotional development, peer relationships, family dynamics and identity; (ii) there is a higher incidence of central nervous system damage among this population compared to hearing children and which may mean the co-occurrence of learning disabilities, physical and/or visual impairments; (iii) deaf children are more likely to experience physical, emotional and sexual abuse than their hearing peers; and (iv) delayed access to mental health services means mental health problems can become more severe or entrenched. (Hindley 1993; Marschark, 1993; Hindley, Hill, McGuigan and Kitson, 1994; Roberts and Hindley, 1999; Hindley, 2000; Association of Directors of Social Services, 2000; Du Feu and Fergusson, 2003).

Although deaf children and their families are entitled to the same range of mental health services as their hearing counterparts (Department of Health, 2004), they have additional needs that, because of the low incidence of deafness¹⁹ generic Child and Adolescent Mental Health services (CAMHS) will not have the skills or expertise to meet (Hindley, 1997; Du Feu and Fergusson, 2003; Department of Health, 2005; Hindley and Williams, 2005, Dent, 2007).

In terms of delivering mental health services, specialist knowledge about mental health *and* deafness is essential in order to understand the interaction between the two. Deafness may 'mask' other disorders such as autism or ADHD and untrained clinicians may be unable to distinguish between behaviours related to deafness and those caused by mental health difficulties. In addition, cultural aspects of deafness (viewing deafness as a label of cultural identity) must be taken into account in understanding and responding to a child presenting a mental health difficulty.

Knowledge of how to manage communication is also essential. For the non-specialist, this is a complex area. Deaf children use a variety of languages and ways of communicating, including British Sign Language²⁰ (BSL), Sign Supported English²¹ (SSE) and/or oral methods of communication (speech, lip-reading and the use of residual hearing). A child may use more than one method of communication, their BSL or SSE may be idiosyncratic and their signing skills may vary from having quite simple sign to being a very skilled signer. Because of the complexity of communication issues, deaf children's communication needs cannot be properly

¹⁹ 1 in 1,000 children aged 0-3 years and 2 in 1,000 children 9-16 years have permanent moderate to profound hearing impairment, Fortnum *et al.* (2001). Moderate hearing loss: 41-70dB loss; severe: 71-95dB; profound: 96+ dB A hearing loss of 41dB or greater is likely to limit access to conversational speech (Roberts and Hindley, 1999).

²⁰ BSL is the sign language used in the UK, using movements of the hands, body, face and head. BSL is a complete language in its own right, having a structure and grammar which is different from English. As with a verbal language, children develop BSL skills over the course of time. Some children will be fluent whilst others will use BSL in a more limited way.

²¹ SSE is a form of English that additionally uses signs to convey meaning.

addressed through interpreting support alone. Rather, optimal communication can be achieved when clinicians can sign, interpreters are trained or experienced in mental health interpreting, and clinicians are skilled in working in ways that do not rely heavily on spoken language (for example, through pictures, drawings, and other visual materials).

Before 2004 the only specialist outpatient mental health service for deaf children in England was in London, with referrals being funded through Service Level Agreements²² (SLAs) or Named Patient Service Agreements²³ (NPSAs). Whilst ostensibly a national service, its geographical location presented obvious difficulties with regard to access for most of the population. In response to this, in 2004, the National Specialist Commissioning Advisory Group (now known as the National Commissioning Group, NCG) of the Department of Health set up a pilot project of two further specialist teams in York and the West Midlands. These were funded to provide a service to local specialist deaf schools and units and to children living within local Primary Care Trust (PCT) boundaries. The West Midlands service also accepts referrals from children and young people who live outside PCT boundaries and these are funded by NPSAs.

All the teams are multidisciplinary and include psychiatrists, psychologists, social workers, mental health nurses and family support workers. Characteristics which define these specialist services are clinicians' experience in working with deaf children, specialist knowledge and expertise about mental health and deafness, deaf clinicians working in the teams, routine use of interpreters in skilled in working with deaf children in mental health settings, and all clinicians being able to use British Sign Language. In addition, when it is deemed appropriate, children from the York and Dudley teams are given the choice of using videoconferencing (known as the telelink) to conduct therapy with a deaf clinical psychologist from the London team, rather than seeing a local hearing clinician face to face. Professionals from the three teams also use the telelink for professional meetings (for example, case conferences, supervision and discussions of cross-service issues).

The teams were originally set up following a 'hub and spoke' model, with London, the most experienced team with the most staff and resources, acting as the hub, and York and Dudley, which were less experienced teams, acting as spokes. The London team was thus to play a part in training and supervising the other two services. However, as the younger teams gained experience and grew in size, the relationship between the three teams had changed into a 'network' of teams of equal status.

²² Service Level Agreements: Agreements between a provider (ie. the specialist service) and a commissioner (ie. the PCT) which determine the range and level of service to be provided and the fee.

²³ Named Patient Service Agreements: Funding is agreed upon on a 'case by case' basis by the PCT.

The National Service Framework for Mental Health (Department of Health, 1999) has emphasised that services should be led by the interests of consumers. This entails that users' views should be incorporated in the evaluation of outcomes (Perkins, 2001). This is reiterated in the CAMHS Standard for the Children's National Service Framework (Department of Health, 2004) which stipulates that the views of service users are 'systematically sought and incorporated into reviews of service provision' and that clinical audit includes users' views in relation to individual outcomes and service provision' (p13).

The research reported here forms part of a wider study which was commissioned by the Department of Health to explore stakeholders' (families, referrers, and clinicians) views of providing or using these three specialist mental health services. This paper specifically focuses on parents' reports of outcomes of using the service, and their views and experiences of using the service.

6.3 Methods

The research involved interviews with parents on two occasions – when their child first started using the service (Time 1) and then either at discharge or six to eight months into treatment (Time 2), whichever occurred first. The interviews involved a semi-structured interview and completion of a standardised measure of child mental health and, at the second interview, a 'user experience' questionnaire. The original design of the research had also included teacher and clinician completed child mental health measures. However, considerable difficulties outside of the control of research team were encountered with collecting these data and this aspect of the study was therefore abandoned. Ethical approval for the research was obtained from the Multi-Centre Research Ethics Committee.

6.3.1 Recruitment

Recruitment took place in the three services over the course of a 12 month period during 2006 and 2007. Families were sent information about the research with letters confirming their first appointment with the service. Two services then approached families about the research at the first or second appointment. The recruitment rates in these two services were 78 per cent and 75 per cent. The third service adopted a slightly different approach in that clinicians did not routinely discuss the research with all families during initial appointments. Here the recruitment rate was substantially lower (17 per cent).

Families expressing an interest in the research completed a form which gave permission for the research team to contact them. These were returned to the

research team who then made arrangements for the researcher to visit. The option of being interviewed by a deaf researcher who used BSL was provided. Written consent was obtained at the time of the interview. At the end of the Time 1 the researcher ascertained if the parent was willing to participate at Time 2. Separate written consent was obtained at Time 2. The interviews typically lasted around an hour and, with participants' permission, were audio-recorded. All interviews took place in parent's homes apart from one which took place at school.

6.3.2 Interview schedules

The Time 1 interview covered the history of the child's mental health difficulties, experiences of mental health and other services used prior to the specialist service, the referral process, expectations and desired outcomes for the child and family from using the service (see Appendix 8). Findings regarding parents' experiences of accessing the service are reported in Chapter 4. The Time 2 interview explored use of the service, views on whether the service had helped to achieve desired outcomes for the child/family, experiences and views about the clinician/s and service, difficulties experienced in using the service, and ways the service could be improved (see Appendix 13).

6.3.3 Measures

Parents were asked to complete the Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997) at Time 1 and Time 2 (see Appendix 4). In addition, at Time 2 parents were given the Experience of Service Questionnaire (ESQ, Commission for Health Improvement, 2002) to complete (see Appendix 14). Instead of completing the questionnaire at the time of the interview some parents chose to return the questionnaires to the research team by post. This meant that 100 per cent completion response rate was not achieved. The Strengths and Difficulties Questionnaire (SDQ) was completed by 28 parents at Time 1 (78 per cent) and 26 parents at Time 2 (72 per cent), with SDQ data at Time 1 and Time 2 collected for 22 children (63 per cent of the sample). Thirty parents (83 per cent) completed the Experience of Service Questionnaire (ESQ).

The Strengths and Difficulties Questionnaire (parent version) (SDQ-parent) (Goodman, 1997)

The SDQ is a behavioural screening questionnaire used to measure child mental health difficulties (3-16 year olds). The items are equally divided between five subscales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behaviour. Responses to the emotional symptoms, conduct problems, hyperactivity/inattention and peer relationship problems subscales are summed to generate a total difficulties score. This score

can be also be used to define 'caseness' (normal, borderline, abnormal). There is also an 'Impact Supplement' which contains items on distress and social impairment which are summed to form an 'impact score'.

The Experience of Service Questionnaire (ESQ, Attride-Stirling, 2002)

This is a 15-item self-completion questionnaire that assesses CAMHS users' views of services with respect to accessibility, humanity of care, organisation of care and environment. The questionnaire was developed by the Commission for Health Improvement (now the Health Care Commission) and was originally used as a measure for one-off audits of service delivery but CAMHS Outcome Research Consortium (CORC) recommends that it be used routinely in conjunction with other 'core measures' so that a family's experiences with the service can be linked to the child's difficulties and symptom reduction. Versions exist for parents/carers, children, and young people. It consists of 12 statements rated 1 ('Not True'), 2 ('Partly True') and 3 ('Certainly True') which explore respondents' experiences of using the service and three free-text response questions about what the respondent liked about the service, what they felt should improve, and any other comments. In this study, only the 12 fixed-response items were used as the semi-structured interview covered questions contained in the free-text section.

6.3.4 The sample

Thirty-six parents (representing 33 families) participated in both Time 1 and Time 2 interviews. A further six parents were interviewed at Time 1 only. Reasons for drop-out at Time 2 included parental mental health problems, emigration from the UK, the researchers being unable to establish contact at Time 2, or, with respect to one family, only having attended one appointment since the Time 1 interview. This paper reports findings from those who were interviewed on both occasions.

The majority of participants were mothers, although in two families a joint interview with the mother and father was conducted. Three participants were legal guardians and two interviews were conducted only with the father. Three parents were from minority ethnic backgrounds and three were deaf.

Parents represented 35 children who were users of the specialist services (in two families, two children were both using the service). The average age of the children was 10.74 years old (range 5-16). Twenty-one were males and the remaining were females. Eleven children attended mainstream schools, five attended units attached to mainstream schools, 16 were in specialist schools for deaf children and three were in special schools. One young person was a hearing sibling and two were siblings with a deaf parent. Only six children (17 per cent) had used generic CAMHS before using the specialist services and, among these, only one had been referred to the specialist service by a generic CAMHS.

At Time 2, 27 of the families were still using the service and six families were no longer using the service. Among the latter group, all had stopped using the service within the previous two months. One child had been discharged and the remainder had stopped using the service prematurely: two families had moved away from where the service was located, one child had been referred to the inpatient service, and one had chosen to stop using the service. Around half the families had seen the clinician between one and five times, and the remainder had had at least six appointments.

6.3.5 Data analysis

Qualitative data

Recordings of the interviews were transcribed. The transcripts were analysed using the well-established Framework approach (Ritchie, Spencer & O'Connor, 2003). The transcripts were coded according to analytical categories comprising both *a priori* and emergent themes which had been generated by the researchers based on their readings of the transcripts. Two researchers separately coded a subset of ten interviews to check the clarity of the category definitions, consistency in the use of categories and thoroughness in coding the transcripts. Overall, there was a very high degree of agreement in the application of the framework by the two researchers. The data were summarised onto charts, one for each analytical category and each entry was accompanied by a reference to its location in a transcript. While reading across a chart provided information about a particular participant, reading down a chart allowed comparisons to be made across the sample. Over-arching themes were identified and conclusions drawn and verified by returning to the transcripts and through ongoing discussions within the research team.

Questionnaire analysis

Frequencies and descriptive statistics were calculated for SDQ scores at baseline scores and Time 2. Then a Paired Samples T-Test was run to explore changes in SDQ scores between baseline and Time 2. SDQ scoring guidelines also include bandings which define 'caseness'. Frequencies were calculated and cases were grouped into the three categories of normal, borderline and abnormal (Goodman, 1999). The sign test for two related samples was used to compare differences in caseness at Time 1 and Time 2. Finally, frequencies were calculated for each item of the ESQ.

6.4 Results

6.4.1 Mental health difficulties of children and young people

Parents described the reasons why their children had been referred to the specialist service, see Table 6.1.

Table 6.1: Children’s mental health difficulties as reported by parents

<i>Type of difficulty</i>	<i>Males (n)</i>	<i>Females (n)</i>	<i>Total (n)</i>
Behaviour issues	12	4	16
Emotional difficulties	2	1	3
Self-harm	1	4	5
Eating/sleeping difficulties	2	5	7
ADHD	2	0	2
Psychosis	0	2	2
Adjustment/post-abuse difficulties	0	0	0
Learning difficulties	2	0	2
Autistic spectrum disorder	3	3	6
Other	1	4	5

NB. Most parents reported their child had more than one difficulty.

The most frequently reported difficulties were behavioural, with aggressive or violent behaviours occurring at home and at school. Other problems included self-harming, eating and sleep disorders, autistic spectrum disorders, adjustment and emotional difficulties, and learning difficulties. Parents reported that most children were experiencing more than one of these problems. Scores from the SDQ provide evidence on the severity of the children’s mental health difficulties, see Table 6.2.

Table 6.2: SDQ scores at Time 1

<i>Scores on scales</i>	<i>Mean score</i>		
SDQ Total Difficulties Score (n=28)	21.75 (SD 6.85)		
SDQ Impact Score (n=31)	5.06 (SD 2.73)		
Caseness	<i>Normal</i>	<i>Borderline</i>	<i>Abnormal</i>
SDQ ‘Caseness’ (n=28)	4 (14.3%)	3 (10.7%)	21 (75%)

The mean SDQ scores found in this sample were over twice as high as the national norms (Meltzer, Gatward, Goodman, & Ford, 2000). The mean score for total difficulties for this sample was 21.76 (SD 6.85) at Time1 compared to national norms (5-15 year olds) of 8.4 (SD 5.8). The impact score for this sample was 5.06 (SD 2.73) at Time 1 compared to the national norms of 0.4 (SD 1.1). When ‘caseness’

was calculated, scores for four children (14.3 per cent) were within the normal range, three (10.7 per cent) were classified as borderline, and 21 (75 per cent) as abnormal.

Review of desired outcomes of using the service

When children first started using the service, parents' desired outcomes for their child centred around obtaining a diagnosis (for example, autistic spectrum disorders, attention deficit and hyperactivity disorder), alleviating symptoms, and/or resolving their child's difficulties. By the time of the second interview, parents of 23 of the 35 children felt that the service had helped achieve these outcomes. Most of these reported their child had become calmer, their behaviour had improved and they had fewer tantrums. Others said their child was happier, had higher self-esteem, and was more confident. Parents who had desired that their child's eating, sleeping and/or toileting would improve reported positive changes in these areas. When a diagnosis had been obtained parents expressed relief and this had enabled them to request additional support from school:

For years school wouldn't recognise there was a problem. I wanted a diagnosis because I just felt that within the education system we had spent too long making excuses for behaviour and thinking it would improve. I needed a diagnosis so that I could go back to education people and say, 'Look, this is the problem - we do now need specialist support'.
(Parent of 10 year old)

Parents of a further seven children reported the service had not yet resulted in improvements for their child, either because they had had too few appointments or because of the intractable nature of their child's condition. However, the contact they had with the clinician and their experiences of the service so far meant these parents were hopeful that, with time, their child's difficulties would be resolved.

Parents of five children believed that their child's condition had not improved and were not confident that the service would be able to help them. This was either because parents judged the intervention or approach adopted by the clinician as inappropriate (for example, only offering medication) or ineffective (for example, by not offering alternative strategies or solutions to manage difficult behaviour to those already being used). Neither the service that was being used (that is, York, West Midlands, London) nor the nature of the child's difficulties appeared to be related to whether or not parents reported a lack of improvement in their child's mental health difficulty.

A different aspect of this research found that moving to a specialist school was often the factor that facilitated children's access to the specialist mental health service (Beresford & Greco, 2007). An issue raised by some of the parents of these children was the difficulty of teasing out the effects of using the specialist mental health service from the positive impact of their child changing school. However, positive outcomes were reported across the whole sample and not only among those who

had recently moved to specialist provision. Indeed, many parents, regardless of the sort of school their child attended, believed that liaison between the clinician and school facilitated the improvements they had observed in their child. Parents described how school staff supported and reinforced the therapeutic work being done by the clinicians. Likewise, clinicians provided training in behaviour management and supported requests for additional learning support:

I don't think we'd have been getting as much help from school if we hadn't been going to see (clinician) because it's made the school more aware of what's been going on and made them more involved.
(Parent of 12 year old).

In terms of their own needs, the majority of parents believed their child's clinician had provided them with information, advice and emotional support. These were the desired outcomes they previously had identified when their child first started using the service. Specifically, parents valued having someone they could contact for expert information and advice about their child. They were also reassured by the fact that they could telephone the clinician in between appointments for advice, and that the clinician understood how they felt, having worked with numerous other families with deaf children. Furthermore, when parents had witnessed an improvement in their child's condition there was a 'knock-on' positive effect on their own emotional well-being:

The important thing is that we know that the service is there, the people are available and whenever they want to contact us or we want to contact them we have this open door.
(Parent of 14 year old)

6.4.2 Quantitative data on outcomes

In addition to the qualitative data, changes in SDQ scores were investigated. Paired samples T-tests measured differences between SDQ scores at Time 1 and at Time 2, see Table 6.3.

Table 6.3: Paired samples T-tests on SDQ scores at Time 1 and Time 2 (n=22)

	<i>Mean score</i>	<i>SD</i>	<i>Mean score</i>	<i>SD</i>	
SDQ Total	21.64	7.05	18.77	7.17	t=2.495 (df 21) p=0.21
Difficulties Score					
SDQ Impact Score	5.23	2.37	3.86	2.96	t=2.806 (df 21) p=0.01

These data show that there was a significant decrease in mental health difficulties among the sample, both in terms of the Total Difficulties score ($t=2.495$, $df=21$, $p<.05$) and the Impact Score ($t=2.806$, $df=21$, $p<.01$). This improvement occurred notwithstanding the fact that treatment was still ongoing for the majority of the children at Time 2 ($n=29$).

In terms of SDQ ‘caseness’, at Time 2, six children fell into the normal banding, six children into the borderline banding and ten children into the abnormal banding, see Table 6.4. Significant changes in the ‘caseness’ banding of SDQ scores were found ($p=0.039$). Scores for eight children had changed in a positive direction, one child’s score had changed in a negative direction (normal to borderline), and the ‘caseness’ banding for the remainder ($n=13$) had not changed.

Table 6.4: SDQ ‘caseness’ at Time 1 and Time 2 (n=22)

	<i>Normal</i>	<i>Borderline</i>	<i>Abnormal</i>
SDQ “caseness” Time 1	3 (13.6%)	2 (9.1%)	17 (77.3%)
SDQ “caseness” Time 2	6 (11.5%)	6 (42.3%)	10 (46.2%)

6.4.3 Parents’ views about the service

In this section we examine parents’ views on the nature and quality of the service. The themes emerging from parents’ accounts which relate to the perceived quality of the service include: expertise in deafness and mental health, managing communication, the parent-clinician relationship, and the presence of deaf staff. Finally, we describe some of the practical issues parents encountered when using the service.

Expertise in deafness and mental health

The great majority of parents believed their child’s clinician was expert in mental health *and* deafness. This combination of expertise was seen as very important to ensuring their child’s difficulties were correctly diagnosed and managed. Parents who had previously used generic CAMHS ($n=6$) noted a marked contrast in the expertise of the specialist team compared to generic clinicians. Parents also appreciated that clinicians in the specialist service had worked with many deaf children and had extensive experience. It was the combination of specialist expertise and experience that made parents feel confident the service could help their child:

(Clinician) is there for deaf children... I mean I wouldn't want her to go with someone who doesn't understand a deaf child... they perceive the world different from an ordinary hearing child and knowing (clinician) specialises in the deaf world, it's good. He understands them.

(Parent of a 13 year old)

As referred to earlier, a small number of parents were not confident the service would be able to help their child and for some this was partly ascribed to their child being seen by one of the less experienced clinicians on the team.

Managing communication

Approximately half the children in the sample used oral methods to communicate (speech, lipreading, residual hearing). The remainder used Sign Supported English or British Sign Language. Parents of this latter group of children valued the fact that their child's clinician was able to sign, at least at a basic level. This was seen as critical to ensuring their child could develop a relationship with their clinician and that the child remained the focus of attention during sessions. In addition, the presence, where necessary, of interpreters at every appointment was seen to be very important and ensured that children could participate fully. Parents reported that the quality of the interpreting service was high. For example, interpreters were used to working in child mental health settings, services tended to ensure a child or family used the same interpreter, and parents were confident that confidentiality was maintained. Meeting their child's communication needs was considered to be a key feature setting this service apart from generic services:

Cos in the past if we've seen somebody they'd only just see me. With this one, (child) was actually sitting there and the interpreter was focused on him.

(Parent of 5 year old)

(Clinician) really engages with (child) and listens to (child) and the comments that (child) says afterwards at the end of the meetings like 'When can I see (clinician) again?'

(Parent of 13 year old)

Presence of deaf staff

Seven children were seeing a deaf member of staff, either a family support worker or a psychologist through the telelink. Parents of these children felt that having deaf staff on the team was a great asset to the service and that they offered something that hearing staff could not. Namely, they acted as deaf role models, they could share the experience of growing up as a deaf young person, and they were able to communicate without an interpreter:

He's kind of 'Oh, I love (clinician) because she's deaf like me and she's got fantastic signing'.

(Parent of a 9 year old)

The parent-clinician relationship

All parents, including those who did not report improvements in their child's condition, described having a positive relationship with their clinician. Clinicians had a relaxed attitude, were friendly, non-judgemental, and parents felt listened to and believed. In most cases, they were on first-name terms with their clinicians. It was the combination of professionals' having specialist expertise and yet being 'down to earth' and accessible that parents deemed to be a distinctive and highly valued feature of the service.

One of the ways shared decision-making occurred between the parent and the clinician was through parental involvement in the therapeutic sessions. This was generally decided between the parent and clinician. Almost all parents were happy with their level of involvement, although two parents felt they had not been sufficiently consulted.

Practical issues

The interviews also explored practical aspects of using the service such as travelling to appointments, information, and the physical environment where sessions took place. Just under half of parents reported practical difficulties using the service.

The largest area of concern centred on the distance between where the family lived and the place where the service was delivered, which was either service headquarters, an outreach clinic (for example, audiology department), or the specialist school attended by the child. Some children and/or their parents had to make long journeys which could be tiring and/or expensive. Those using public transport reported lengthy and/or complex journeys to get to the service and confusion over whether they were entitled to a refund of travel costs. Additional and related concerns to attending appointments were around organizing childcare, and taking time off work.

A small number of parents expressed concerns about information provision. This included: insufficient information about what the service offered; not feeling informed about how their child was progressing; and, on a more practical note, wanting more notice before appointments. Finally, a few parents considered the environment where sessions were held to be unsuitable, either not being child-friendly enough or insufficiently private. However, none of these parents attended sessions at the service's head-quarters, instead their child's appointments took place at school or at one of the local outreach clinics.

6.4.4 Experience of Service Questionnaire

The ESQ scores further investigated families' views about the service. Table 6.5 shows responses for each of the ESQ items.

Table 6.5: ESQ responses

	<i>Certainly true</i>	<i>Partly true</i>	<i>Not true</i>	<i>Don't know</i>	<i>Not applicable</i>
1. I feel that people who have seen my child listened to me	26 (86.7%)	4 (13.3%)	0	0	0
2. It was easy to talk to the people who have seen my child	26 (86.7%)	3 (10%)	1 (3.3%)	0	0
3. I was treated well by the people who have seen my child	28 (93.3%)	2 (6.7%)	0	0	0
4. My views and worries were taken seriously	25 (83.3%)	4 (13.3%)	1 (3.3%)	0	0
5. I feel the people here know how to help with the problem I came for	23 (76.7%)	4 (13.3%)	1 (0.3%)	2 (6.7%)	0
6. I have been given enough explanation about the help available here	23 (76.7%)	3 (10%)	4 (13.3%)	0	0
7. I feel that the people who have seen my child are working together to help with the problem	24 (80%)	3 (10%)	1 (3.3%)	2 (6.7%)	0
8. The facilities here are comfortable (e.g. waiting area)	20 (66.7%)	7 (23.3%)	0	3 (10%)	0
9. The appointments are usually at a convenient time (e.g. don't interfere with work, school)	16 (34.8%)	10 (21.7%)	4 (8.7%)	0	0
10. It is quite easy to get to the place where the appointments are	16 (53.3%)	6 (20%)	4 (13.3%)	0	4 (13.3%)
11. If a friend needed similar help, I would recommend that he or she come here	25 (83.3%)	2 (6.7%)	1 (3.3%)	2 (6.7%)	0
12. Overall, the help I have received here is good	25 (83.3%)	0	2 (6.7%)	3 (10%)	0

Responses to the ESQ support the findings from the interviews. Almost all parents (93 per cent) strongly believed they were treated well by the service and that they were listened to and found it easy to talk to their child's clinician (87 per cent). Over 80 per cent reported that their worries were always taken seriously and the help they had received was good. Similar proportions stated they certainly felt they were working together with the practitioner to help their child (80 per cent) and would definitely recommend the service (83 per cent). There was slightly less certainty about whether staff knew how to help their child (77 per cent), and over one in five parents (23 per cent) were not fully satisfied with the explanation given to them about the help their child was receiving. A third of parents reported experiencing difficulties getting to the place where appointments were held. Areas of greatest dissatisfaction concerned the waiting facilities (67 per cent were fully happy with this) and the timing of appointments (just under a third experienced difficulties with this).

Suggested improvements to the service

Twenty families offered suggestions about improvements to the service. First, a number of possible solutions to the practical difficulties of getting to appointments were put forward including home visits, telephone appointments, more outreach clinics, sessions after school hours, and improved parking facilities.

The second area concerned improving the information provided to families. Some parents wanted to know more about their child's progress. Other felt more information about the types of support the service can offer should be provided. Third, suggestions were made regarding the timing of service delivery. These included a shorter period of time passing between referral and the first appointment, assessments being performed more quickly, more frequent appointments, and keeping up appointments during school holidays.

A small number of parents suggested there needed to be greater awareness of the service among all families with a deaf child. Finally, one parent, who was deaf, felt that reception staff working at the services should receive training on communicating with deaf people.

6.5 Discussion

This paper describes parents' views on the effectiveness of, and experiences of using, a specialist mental health service for their deaf child.

Parents' descriptions of their child's problems were reflected in their high scores on the SDQ. The proportion of children above the cut-off point for 'caseness' indicates the severity and complexity their mental health problems for the majority of the sample. It is striking therefore, that only six of the children had previous contact with mental health services, in all cases their local CAMHS. In addition, only one of these children received their referral to the specialist service via CAMHS. These findings support the view that deaf children and young people are 'falling through the net' in terms of identifying and meeting their mental health needs. In addition, they indicate a lack of awareness of the specialist service among generic CAMHS.

The effectiveness of the service was investigated using parents' qualitative accounts and using a standardised measure of child and adolescent mental health. After 6-8 months of using the service, the majority of parents reported that their child's condition had improved and this was confirmed through significant reductions in scores on the Strengths and Difficulties Questionnaire. Furthermore, many children and young people no longer scored above the cut-off point for 'caseness'.

Parents talked about the aspects of the service which they felt had most helped their child. These included the clinicians' experience and specialist expertise both in mental health and deafness; being able to meet the child's communication needs; and the presence of deaf staff on the teams. Parents also valued the ways the service worked with the child's school to support improvements in the child's mental health, and the positive relationship they, as parents, had with their child's clinician. The importance placed on the specialist aspects of the service provides some explanation why families who had previously used generic CAMHS had found them unsatisfactory (see also Beresford and Greco, 2007). This also concurs with research with referrers conducted within this project where almost all stated that generic CAMHS are not equipped to meet the mental health needs of deaf children (Beresford and Greco, 2007). Taken together, these findings reinforce the view put forward that providing mental health services to deaf children involves much more than just providing interpreting support in a generic CAMHS setting (for example, Hindley, 1997; Bailey & Lauwerier, 2003; Du Feu & Fergusson, 2003; National Deaf Children's Society, 2005). Instead it requires specialist expertise with regard to deafness and mental health and having the skills and interpreting support to meet the child's communication needs. In addition, parents of children who had worked with a deaf member of staff believed this added a further, highly positive dimension to the service.

The findings also point to the need to improve geographical access to the service. The regional nature of the services meant that some parents found travelling to appointments difficult. For some, travel and distance was even more problematic because they were journeying to the residential school their child attended for appointments. As well as the issue of geographical access, it must also be remembered that, as described in the introduction, there are currently significant issues in terms of equity of access to these services with respect to funding of referrals. Very few primary care trusts (PCTs) have service level agreements (SLAs) with the London service, and the York and West Midlands services are currently only funded to provide a service to local PCTs. Thus families living outside of these boundaries face the double difficulty of getting funding for a referral (through an NPSA) and, if successful, having to travel to London or Dudley (West Midlands) for their appointments which typically will happen relatively frequently and over a considerable period of time.

These issues highlight the difficulty of providing a specialist service to a low-incidence, geographically dispersed population, a difficulty compounded with respect to this population by the dearth of professionals (including interpreters) with expertise in deafness and mental health and also the lack of deaf professionals working within the speciality (Department of Health, 2005). A possible solution would be to further develop the hub and spoke model used by these services to create additional 'satellite' services across the UK with the existing teams acting as a source of expertise in the development of the staff in the new satellite services. This is in line

with the support given to the notion of clinical networks as a means improving access to specialist services (Edwards, 2002; Department of Health, 2004). Teleconferencing could be an effective tool for the training and supervision of professionals (Smith and Alison, 2001). Telehealth may also be a means of allowing parents with children at residential schools to remotely 'attend' appointments. However, the authors could not find any reports of using this technology in this way and this would therefore need careful exploration.

There are a number of limitations to this study and these constrain the confidence which can be placed on the findings with respect to the effectiveness of the service. First, it was not possible within the constraints of the project to explore longer term outcomes (at discharge and post discharge, for instance). In addition, a proportion of participants did not complete the Time 2 interviews and it is possible that these families experiences and outcomes of using the service were different to those who participated at Time 1 and Time 2. The absence of clinician and teacher completed outcomes measures also needs to be taken into account when evaluating the strength of the evidence, as does the fact that SDQ scores at Times 1 and 2 were not available for all the sample. The inclusion of child completed clinical outcome measures would have also improved the design. However, none of the standardised measures of mental health have BSL versions or have norms for deaf children and young people and this option was not, therefore, available to the research team. Furthermore, the design did not include a comparison group, either, for instance, those waiting for treatment or those using generic CAMHS users (though given the difficulties accessing generic CAMHS already described, this latter design is probably unfeasible). Moreover, whilst recruitment rates from two sites were good, for a number of reasons (including a less proactive recruitment strategy) recruitment was difficult in the third site yielding a low recruitment rate. Whilst no differences were found between the services in terms of parents' accounts of their child's outcomes, practitioners believed a further reason for lower recruitment rates was the very high proportion of families from minority groups using the service who do not have English as their first language. This not only signals the need for any future research to ensure recruitment materials and strategies are accessible to all services users. It also highlights the fact that the views and experiences of families who chose not to participate in the research may be different to those in the sample. However, despite these limitations, this study does provide initial data on the effectiveness of specialist mental health services being provided to deaf children in England, and parents' experiences of using these services.

6.6 References

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Chapter 7: Referrers' use and views of specialist mental health services for deaf children and young people in England²⁴

7.1 Abstract

Deaf children are at greater risk of mental health problems than hearing children. Generic child and adolescent mental health services cannot be expected to have the expertise to work with these children. Three teams in England currently provide specialist mental health services to deaf children. The research sought to explore referrers' views of these specialist services. Interviews and a postal survey were used. Referrers were very satisfied with the service and identified the features of the service which supported positive outcomes for users. Access was, however, a significant problem. Referrers suggested developments to the service should incorporate preventive work and cascading of skills to other professional groups. Deaf children require services which are expert in deafness and mental health, and the findings suggest the specialist services are achieving this. Resolving issues of access and widening its remit are desirable ways forward in any future development of the service.

7.2 Introduction

A lack of early intervention to support communication between children with moderate to profound hearing loss²⁵ and their families means that these children, especially those born to hearing parents, are likely to experience significant constraints in their ability to communicate and delayed language development. These increase risks for psychological, emotional, social and educational difficulties (du Feu and Ferguson, 2003). Furthermore, deaf children are more likely to experience physical, emotional and sexual abuse than their hearing peers (ADSS, 2002). The cause of the hearing impairment may also mean the co-occurrence of learning disabilities, physical and/or visual impairments (Roberts and Hindley, 1999). These factors also increase the risk for adjustment difficulties. Despite this increased risk there is limited research on the prevalence of mental health problems among deaf children, and much of it is compromised by the use of measures which assume normative verbal and literacy development and were standardised using populations of hearing children (Bailey *et al.*, 2003). However, Hindley *et al.* (1994), using a screening instrument developed specifically for use

²⁴ A slightly modified version of this chapter has been submitted and accepted as paper for publication by the *Journal of Mental Health*.

²⁵ A hearing loss of 41dB or greater is likely to limit access to conversational speech (Roberts and Hindley, 1999). Moderate hearing loss: 41-70dB loss; severe: 71-95dB; profound: 96+ dB.

with deaf children, reports an estimated overall prevalence of 43 – 50 per cent among deaf children aged 11 to 16 years, compared to a 25 per cent prevalence rate among hearing children. Also, a study in the US by Watt and Davis (1991), using revised forms of depression measures, found higher rates of depression among deaf compared to hearing junior high school students (mild depression: 40 per cent versus 17 per cent; moderate depression: 6 per cent versus 3 per cent).

Access to high quality, effective mental health services is a key standard of the Children's National Service Framework (Department of Health, 2004). However, the relatively low incidence of hearing impairment (around 1 in 1000 children aged 0-3 years, rising to two in every 1,000 children aged 9-16 years, have permanent moderate to profound hearing impairment, Fortnum *et al.*, 2001) and the specialist skills required to meet their needs mean that generic child and adolescent mental health services (CAMHS) are not able to provide an adequate service (Bailey *et al.*, 2003; NDCS, 2005).

Deaf children use a variety of languages and ways of communicating including British Sign Language²⁶ (BSL), Sign Supported English²⁷ (SSE) and/or oral methods of communication (speech, lip-reading and the use of residual hearing). A child may use more than one method of communication and their BSL or SSE may be idiosyncratic. This complexity of communication issues means that deaf children's communication needs cannot be properly addressed through generic interpreting support. Furthermore, generic practitioners will not have an adequate understanding of deaf child development (language, social, emotional and cognitive), the impact of deafness on family dynamics and peer group relationships, and issues of cultural identity²⁸.

Specialist outpatient mental health services for deaf children in England are provided by three multi-disciplinary teams based in London (set up in 2000), York and the West Midlands (Dudley). The latter two teams (both part-time) were set up in 2004 to improve access to the service. Any deaf child can be referred, regardless of the way they communicate. BSL users form a greater proportion of those using the London service reflecting that, until quite recently, it used was restricted to BSL users. Data on current cases/recent discharges shows that, across the three teams, approximately 42 per cent of children use BSL, 30 per cent use SSE and 20 per cent use lipreading and speech (8 per cent missing data).

²⁶ BSL is the sign language used in the UK, using movements of the hands, body, face and head. BSL is a complete language in its own right, having a structure and grammar totally different from English. As with a verbal language, children develop BSL skills over the course of time. Some children will be fluent whilst others will use BSL in a more limited way.

²⁷ SSE is a form of English that additionally uses signs to convey meaning.

²⁸ Most people who use BSL see themselves as belonging to a distinct linguistic cultural group and are part of the deaf community.

The York and West Midlands teams are funded to provide a service to local specialist schools and units for deaf children²⁹ and to children living within local Primary Care Trust (PCT) boundaries. The West Midlands team accepts other referrals, funded by Named Patient Service Agreements³⁰ (NPSAs). Referrals to the London team are funded through Service Level Agreements³¹ and NPSAs.

Telelink (video-conferencing equipment) may be used for therapy and supporting contact between appointments for children attending some of the specialist schools. A clinical psychologist in the London team also works part-time for the other teams providing the option of using a deaf clinician to work with a child. In these situations the telelink is used, interspersed less frequently with face-to-face sessions. Telelink is also used for case conferences and supervision between the teams.

This paper reports on referrers' experiences of using this specialist service and is part of a larger evaluation incorporating user and provider views and experiences.

7.3 Method

Semi-structured interviews with routine referrers followed by a survey all referrers to the service since the instigation of the York and West Midlands teams were carried out. Ethical approval for the research was given by MREC.

7.3.1 The interviews

The interview covered: use and evaluation of the service, effects of the service on practice, and improving and developing the service. Interviews took place at the interviewees' places of work during winter 2006 and lasted between 40 and 90 minutes (see Appendix 15).

7.3.2 The survey instrument

The questionnaire consisted of a four-sided A4 booklet and covered: use of the service, skills of the team, satisfaction with outcomes, impact on own practice, and improving and developing the service (see Appendix 16). Fixed and free text response formats were used. The survey was administered during spring 2007.

²⁹ Referred to as 'specialist schools' for the remainder of this article.

³⁰ NPSA: funding is agreed upon on a case by case basis by the Primary Care Trust.

³¹ Service Level Agreements: agreements between a provider and a commissioner which determine the range and level of service to be provided and the fee.

7.3.3. Recruitment

The teams provided contact details of all referrers, specifying those who referred routinely (n=17). A sub-sample of routine referrers (n=11) was purposively selected to represent the different agencies/organisations referring to the service and their geographical spread. Letters were sent to this sub-sample inviting participation in the interview phase. All agreed to be interviewed. Seven interviewees worked in specialist schools, reflecting the fact that these schools are the main source of referrals, see Table 7.1.

Table 7.1 Interview sample

	<i>n</i>
Head/teacher: specialist school	7
Team member Local Education Authority specialist team	2
Social worker (sensory loss team)	1
Community paediatrician (audiology lead)	1

Following the interview phase, questionnaires were posted to all referrers (n=72). Reminders were sent two and four weeks after the initial mail-out. Five uncompleted questionnaires were returned (referrer no longer in post or family had not taken up the referral) reducing the sampling pool to 67. Forty-five completed questionnaires were returned (response rate=67 per cent). The response rate among routine referrers was higher (n=16/17; 94 per cent) than among one-off/occasional referrers (n=29/50; 58 per cent).

Respondents worked in specialist deaf education services (n=20), social work teams (specialist sensory impairment or generic) (n=7), local CAMHS (n=5), or were paediatricians (n=6), general practitioners (n=4), speech and language therapists (n=2) or mainstream teachers (n=1).

7.3.4 Analysis

With permission, all interviews were audio-recorded. The recording was used to make detailed notes of the interview. Thematic analysis of these notes (Ritchie and Lewis, 2003) was conducted by the research team to identify: the range of experiences of using the service, views on factors supporting and hindering positive outcomes, impacts on own practice, and ways in which the service could be improved and developed. The findings from the analysis were used to develop the

questionnaire and to provide qualitative data to complement the quantitative survey data.

Quantitative survey data was analysed using SPSS 14. Free text questionnaire responses were analysed using the thematic framework developed for the analysis of the interview material and included as part of the qualitative data set. Findings from the quantitative and qualitative data are both reported.

7.4 Findings

7.4.1 How referrers use the service

Routine and non-routine referrers used the service differently, particularly in terms of preventive work, advice and staff training, see Table 7.2. The most common reason for referral was for assessment and therapeutic work. (Funding restrictions will have meant some 'assessment only' referrals would, ideally, have also been for therapeutic work.)

Table 7.2 Ways in which referrers used the specialist service

	<i>Routine referrers (n=16) %</i>	<i>Non-routine referrers (n=29) %</i>
Assessment only	69	41
Assessment and therapeutic work	100	69
Preventive work with children and families	44	10
Advice re own/organisation's own practice	75	14
Staff training	44	3

Children were referred because of: family/peer relationship difficulties, emotional/behavioural problems, mental health problems, diagnosis of other conditions, child protection issues and for educational assessments.

7.4.2 The importance of being able to access a specialist service

The majority of respondents (74 per cent) did not refer to other services. Almost all (89 per cent) believed generic CAMHS were not equipped to meet the mental health needs of deaf children. Interviewees, especially those working in specialist schools, clearly expressed their need for a specialist mental health service and the likely negative consequences if the service did not exist. Exclusion from school, inpatient admission, increased risk of children being taken into care, and long-term mental

health problems were cited by referrers as likely consequences for the children had they not been able to access the service.

7.4.3 Outcomes for children

Three-quarters of respondents (76 per cent) were satisfied with the outcomes for children of using the service. At the same time interviewees noted that some children have complex problems which require prolonged input and may never fully be resolved.

A number of interviewees reported that, overall, the children were very positive about the service. Being able to communicate using BSL, having deaf support workers, knowing the team are skilled, and having appointments in school were features of the service which, interviewees believed, the children valued.

7.4.4 Key skills of the team

Referrers identified skills which distinguished the teams from generic mental health practitioners and were critical to the quality and efficacy of the service.

First was the ability of the clinician to communicate with the children who used BSL, either by using BSL themselves or by using skilled interpreters. Whilst interpreters may be available in generic services, a number of interviewees highlighted the need for interpreters to be skilled in mental health and working with deaf children.

Second, referrers highlighted the importance of being expert in deafness **and** mental health, and the interplay between the two, in order to properly assess and treat a child. Some reported negative outcomes (for example, inappropriate advice, inaccurate assessments) of using generic CAMHS, which, they believed, were the result of a lack of this combined expertise. Finally, understanding of deaf culture and the presence of deaf team members were considered important.

Survey responses showed that the teams were rated highly for all these areas of expertise, see Table 7.3. In addition, almost all respondents agreed that having deaf staff on the team was important.

Table 7.3 Referrer ratings of competencies of the teams

	<i>Respondents agreeing with statement</i>	
	n	%
Able to communicate with a child using their preferred method of communication (N=31)	26	84
Understand the cognitive and socio-emotional development of deaf children (N=32)	31	97
Understand of the way deafness may affect language/ communication development (N=32)	31	97
Understand the psychological/ psychiatric issues associated with deafness (N=32)	32	100
Understand Deaf culture (N=32)	32	100
The presence of deaf staff is an important feature of the service (N=37)	35	97

An area of weakness concerned the ability of all team members to communicate with a child using their preferred means of communication. In line with this, the need for higher levels of signing skills among *all* staff was one of the most frequently suggested areas for service improvement.

7.4.5 Key features of the service

Respondents also identified features of the service (or ways of working) which, they believed, supported positive outcomes. These opinions were based on good as well as less positive experiences.

First, the ability of the service to accept referrals quickly (initial appointments are typically offered within a few weeks) was valued, and comparisons made with delays experienced with referrals to local CAMHS. Referrers also reported the service was typically able to give more time and a greater depth of support to a child than a local CAMHS. This was seen as critical given the complexity of some cases and the time it can take for a child and clinician to identify the best way of communicating with each other.

Second, and a key theme among referrers working in specialist schools, was the importance of liaison between the team and school staff both during the assessment process and the therapeutic phase (for example, supporting implementation of behaviour management strategies).

Third, referrers valued the range of therapeutic approaches available: an important feature given the diversity of mental health need among referrals. Finally, a willingness, when appropriate, to see the child at home or school was seen to be important, allowing for assessments or therapy to happen in a familiar environment and relieving the child/family of having to travel. In some cases, referrers believed this also helped with engaging parents.

Table 7.4 shows how respondents felt the service performed with respect to these key features of the service. Overall it shows that referrers rated the service very positively.

Table 7.4 Performance of the service against key valued features

	<i>Respondents agreeing with statement</i>	
	n	%
The referral process		
Acceptable period of time between referral and assessment (N=43)	29	67
Liaison		
Referrers' expertise and knowledge valued (N=45)	31	69
Easy to contact staff (N=45)	37	82
Satisfied with the information provided about progress/outcomes (N=45)	26	58
Therapeutic diversity		
Satisfied with the range of therapies/interventions (N=33)	23	70
Team consists of an appropriate mix of professional groups (N=34)	31	91
Outreach/geographical access		
Service is flexible in terms of where children/families are seen (N=37)	23	62

The most frequently reported difficulties were liaison and the desire for more outreach-type provision. These issues also dominated responses to the question in the survey on service improvements. Respondents noted that demands on the teams could threaten liaison, causing, for example, fewer visits to schools. The part-time nature of the York and West Midlands teams was also seen to hinder liaison. Differences between health and education practitioners with regard to managing confidentiality was viewed as a potential source of tension and, some referrers felt, a barrier to liaison.

Other suggested improvements included: more frequent appointments; low level post-discharge support to children/families and/or referrers; and developing the consultancy role with specialist schools.

7.4.6 Geographical access

The introduction of the York and West Midlands teams has improved access for children in those areas. However, much of the country remains a great distance from any of the teams. Almost half the respondents (47 per cent) reported children/families found travelling to appointments difficult. Referrers believed this could undermine the benefits of attending the service. For example, one referrer described the difficulty of taking children with autistic spectrum disorders or severe behavioural problems by train to London for an appointment, which the child may find distressing, and then having to make the journey back to school.

7.4.7 Impact on referrers' practice

Two-thirds of respondents (67 per cent) reported that contact with the service had changed their practice. For non-specialist referrers, this centred on an increased understanding of mental health and deafness. In contrast, routine referrers described how the service reduced their levels of stress because they knew they could refer to, or seek advice from, the service.

7.4.8 Developing the service

Respondents were asked about future developments of the service. Equity of access emerged as a strong theme and concerned: funding, geographical access, awareness of the service by relevant professional groups, and access to the service by children with complex needs, significant learning difficulties or those in mainstream schools. In terms of geographical access, respondents suggested increasing the number of regional centres, higher levels of outreach work, and extending the use of the telelink. It was also noted that the teams needed to further develop their skills to work with particular groups (for example, those with complex needs).

Second, having preventive work as a significant aspect of the service was frequently mentioned. This included work with parents and/or children at different life stages/transitions and supporting children in mainstream schools.

Providing training and cascading skills to generic CAMHS, school staff (specialist and mainstream), and other professionals working with deaf children was the third suggested area of development. Finally, the provision of an emergency service was noted by a number of respondents working in specialist schools.

7.5 Discussion

This paper reports professionals' experiences of referring deaf children to a specialist mental health service. Overall, referrers were very satisfied with the service, and routine referrers believed not having access to the service would have a significant impact on the current and future well-being of children in their care, and on their ability to support and manage the children. Almost all respondents believed that generic CAMHS are not equipped to meet the mental health needs of deaf children.

Having the appropriate communication skills, an expertise in deafness *and* mental health, and the presence of deaf staff on the team were identified as key competencies of the specialist teams. Respondents were very satisfied with the teams' expertise. Referrers also identified ways of working which, they believed, supported positive outcomes. This included: a quick referral process, the duration and depth of the intervention, liaison between the referring agency and service, a multi-disciplinary approach, and a willingness to see the child in familiar, non-clinic settings. Again, referrers rated the services very positively against these indicators. Taken together these findings show the multi-faceted way in which the specialist service differs from generic CAMHS, and reinforces the view that providing mental health services to deaf children cannot just be about providing interpreting support in a generic CAMHS setting.

Access is the key issue to resolve in planning the future development of specialist mental health services for deaf children (Department of Health, 2005). This includes equity of access in terms of funding of referrals, geographical access, and access to the service by children with complex needs, significant learning difficulties and by those in mainstream education. Suggested solutions to geographical access included increasing the number of teams and the amount of outreach work, and extending the use of the telelink. These first two solutions carry significant funding and workforce implications. The workforce issue cannot be quickly resolved: it can take years to become fluent in BSL, and there is a dearth of Deaf people working in mental health (Department of Health, 2005). The use of telelink has been suggested previously with regard to improving access to services by deaf people (Department of Health, 2005). To date, the service has used telelink for therapeutic purposes in a limited way but there are indications that it can be a successful (and preferred) way of working (Wright and Rhys-Jones, 2005).

Clinical networks³² are a possible model for regional centres and have been used in other areas of health care where specialist expertise is scarce and access to

³² Clinical networks are "linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high quality clinically effective services". (Lugon, 2003, p1)

specialist services problematic (Edwards, 2002). Clinical networks also provide a structure by which specialist skills can be cascaded (Department of Health, 2004).

The Children Act (2004) may be a lever for improving access. The Act acknowledges that some children will require services which are not available locally and that pooled funding arrangements can be used to fund a referral to a specialist service. In addition, the Act notes that collaborative commissioning arrangements between Primary Care Trusts will be required for access to highly specialised services (for example Tier 4 mental health services), and this would support a model of more regional centres. Children's Trusts are, however, still in their infancy (University of East Anglia, 2007), and it is too early to know whether implementation of the Children Act (2004) will improve deaf children's access to specialist mental health services. What is important now is that Children's Trusts are aware of the specific needs of deaf children in order to facilitate referrals and to inform future commissioning decisions.

Referrers also suggested two additional roles for the specialist teams: preventive work and cascading skills. Interestingly, neither is typically seen as the responsibility of Tier 4 services. The need for this particular service to take on these tasks must, in part, be due to the absence of any other professional group or service with the skills or expertise to assume this role. Both should, in the long-term, reduce demand on the specialist service. The dilemma for now is how the service balances the pressing demands for individual therapeutic work against preventive and training activities.

Liaison was the most frequently reported source of dissatisfaction, appearing to stem from differences in practice between health and education professionals with regards to confidentiality. Greater clarity at the outset about information sharing may alleviate some frustrations. Another suggestion was that the teams developed information sharing and liaison protocols with its routine referrers. Cross-government guidance on information sharing (HM Government, 2006) could be used to inform changes in this area.

While this research achieved a good response rate, it is possible that non-respondents hold different views. In addition, referrers are just group of stakeholders whose views need to be incorporated into an evaluation of a service. However, the positive reports of the quality of the service, and participants' strong views on the necessity of such a service are important messages to those interested in developing similar services in other countries, and should also inform service developments in this country.

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