An evaluation of specialist mental health services for deaf children

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Deaf children are more likely than hearing children to experience mental health problems. The research reported here evaluated the three specialist mental health services for deaf children and their families currently operating in England. It found that:

- Only a minority of families had used generic Child and Adolescent Mental Health Services (CAMHS) prior to accessing the specialist service. All had found the support provided by generic CAMHS to be limited and, in many cases, unsatisfactory.
- Almost all practitioners referring families to the specialist services did not believe generic CAMHS could meet the mental health needs of deaf children.
- Children and parents were very positive about their experiences of using the specialist services. They were confident about the service being able to help them and reported good relationships with their clinicians.
- Children's and parents' own accounts of the impact of the service on the children's mental health difficulties, and changes in standardised measures of mental health, indicate that the specialist services resulted in positive outcomes for users.
- An ability to meet the child's communication needs and an expertise in deafness and mental health were seen to be the key factors behind these successful outcomes.
- There are indications that telehealth technologies can be used when working with deaf children with mental health needs. In addition, these technologies can allow access to training, supervision and peer support for staff working in the services which, otherwise, would have been far less accessible.

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Introduction

Deaf children are at increased risk for mental health difficulties compared with their hearing peers. Access to high quality, effective mental health services is a key standard of the Children's National Service Framework. There is evidence, however, that deaf children are not accessing mental health support and that generic CAMHS do not have the necessary skills or expertise, such as being able to meet a child's communication needs, and being knowledgeable about deafness and the relationship between mental health and deafness.

The first specialist mental health service for deaf children was established in London in 1991. In 2004, two further services (in the West Midlands and York) were funded to extend access. An innovative aspect of this network was the use of teleconferencing (known as the telelink) to facilitate case management and supervision between services, and to allow, where appropriate, children referred to the West Midlands and York services the opportunity to work with a clinical psychologist based in the London service who was fluent in British Sign Language (BSL).

Data collected by the research project, supplemented by information collected routinely by the clinics, were used to evaluate the services.

Findings

Previous use of mental health services

Families had, typically, been living with their child's mental health problem for a number of years. Less than a quarter had used generic CAMHS prior to accessing the specialist service. Of these families, half had found the help provided useful though limited. In most cases CAMHS had worked with the parent as opposed to the child. Some parents felt this was appropriate, others found this unsatisfactory. Families believed generic CAMHS lacked the expertise to work with deaf children.

Referrers' views of generic CAMHS

Almost three quarters of practitioners referring families to the specialist services reported they did not refer deaf children with mental health needs to any other service. Nine out of ten referrers believed generic CAMHS were not equipped to meet the mental health needs of deaf children.

Accessing the specialist service

Many families thought their child should have received specialist help much earlier. None of the children had accessed the specialist service via a referral from generic CAMHS. Many children had been referred soon after transferring from mainstream education to a specialist deaf school. Staff working for the services believed a lack of awareness among mainstream education practitioners of deafness and mental health issues and the specialist services acted as barriers to children accessing the services.

Experiences as service users

All the children felt their clinician 'listened' to them. Almost all were confident their clinician understood and could help them. They reported being able to express their feelings without feeling embarrassed. They also felt properly involved in consultations when their parents were present.

Parents were equally positive about the service. They felt listened to and believed their worries had been taken seriously. The great majority believed the help they had received was good. Most parents also reported feeling that they worked in partnership with the clinician.

Children who used BSL were generally happy with the way the service met their communication needs. Those who were seeing a deaf member of staff particularly valued this relationship and the ease with which they were able to communicate with them. However, an area of *relative* weakness within the services reported by children and referrers was the ability of *all* team members to communicate with a child using their preferred means of communication.

One in three parents 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 the service.

Outcomes

Children believed the service was helping them and reported positive changes with respect to at least one of their mental health difficulties. Significant positive improvements were found in scores (at discharge or after a period of treatment) on clinician and parent completed measures of mental health (Child Global Assessment Scale; Strengths and Difficulties Questionnaire). The qualitative accounts of parents with regard to their child's outcomes support these findings.

Referrers and parents believed the key skills held by the teams which supported positive outcomes were the ability to meet the child's communication needs and expertise in deafness and mental health. Referrers 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.

Other features of the service which referrers believed contributed to positive outcomes included: a speedy referral process; liaison between the service and school staff; the range of therapeutic interventions available; and the use of outreach clinics which removed the need for children to travel, possibly considerable distances, for appointments.

Using the telelink for direct clinical work

A small number of older children referred to the West Midlands and York services had used the telelink to allow them to have as their clinician the clinical psychologist based in the London service who was fluent in BSL. These telelink sessions were interspersed, less frequently, with face to face sessions.

Children's experiences of using the telelink were, on the whole, very positive. They valued the way it allowed them to have a clinician who was fluent in BSL and who was also deaf. However, one child found the technical difficulties (for example, image 'freezing') which sometimes occurred problematic. Another described the ending of sessions difficult, and this was ascribed to the remote nature of the interaction.

The telelink was also used to provide 'interim' sessions for children attending specialist schools for deaf children (where the telelink equipment had been installed). These supplemented face to face appointments and allowed the clinician provide a higher level of support than would have otherwise been possible. Clinicians believed the technology itself could improve engagement and allowed some children to be more open about the difficulties they were experiencing.

Other uses of the telelink

The telelink also 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.

Delivering the service

Families, referrers and staff all identified a shared expertise in mental health and deafness, and an ability to meet the communication needs of a child, as critical to providing a high quality and effective service. In terms of communication, practitioners learnt that finding a way of communicating with a child takes time and both parties need to be comfortable and confident with the chosen approach.

The use of interpreters skilled in working with children in mental health settings was seen as essential. All hearing staff agreed that, although they used interpreters, they still needed be able to sign and many wanted to improve their signing skills.

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 all identified as possible solutions to the issue of geographical access. Referrers and staff highlighted the need for equity with regard to funding of referrals, greater awareness of the service within mainstream services, and ensuring the service met the needs of children with learning difficulties and/or complex needs.

In terms of broadening the work of the service, referrers and staff believed that carrying out preventive work with children and families and cascading skills and expertise to practitioners working in generic CAMHS, schools (special and mainstream) and social care agencies should become core activities.

Implications

The findings from this project support the conclusions of previous research that generic CAMHS cannot typically meet the mental health needs of deaf children. It also provides evidence that the current specialist services are effective in working with deaf children with mental health difficulties.

The findings support the argument for the need to increase the number of specialist mental health services. The research also identified additional activities that such services should engage in, including preventive work and skilling up generic practitioners.

The presence of deaf staff on the teams was highly valued by the children. The dearth of deaf mental health practitioners has been noted in government reviews of services. Actions to support training in mental health by deaf people are needed to ensure there are, in the future, sufficient numbers of deaf people within the workforce.

An innovative aspect of the specialist services was the use of telehealth technology. Findings from the research would support continuing to develop its use within the service. The technology also played a central role in facilitating and enabling service development and staff support. This illustrates the potential of such technology to meet training, supervision and peer support needs in situations where services and/or expertise are rare and scattered.

Research Design and Methods

There were four strands to the research project.

- A 'before and after' study of a sub-sample of families (n=38) using the specialist services. This involved interviews with children (aged 6 to 16 years) and parents around the time of their first appointment and then at discharge or six to eight months later (whichever occurred first). On both occasions parents completed a standardised measure of child mental health (Strengths and Difficulties Questionnaire, Goodman, 1997). At the second interview, parents and children completed versions of the Experiences of Service Questionnaire (Attride-Stirling, 2002).
- Interviews with key referrers (n=11), and a survey of all referrers to the specialist services (n=45).
- Interviews with staff (n=14) on two occasions.
- Analysis of data (including clinical outcomes) routinely collected by the York and West Midlands services.

Deaf researchers were part of the research team and were involved in developing tools to facilitate the interviews with the children, advising on information sheets and consent forms, conducting fieldwork with participants who requested a BSL interviewer, contributing to the data analysis and disseminating the project's findings.

Further information

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