

# Addressing mental health needs of deaf children and their families: the National Deaf Child and Adolescent Mental Health Service

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**Summary** Rates of developmental delay, autism and mental illness in deaf children are higher than in hearing children. Early language acquisition (signed or spoken) is a protective factor against mental disorder. Deaf children and their families are often given conflicting messages and advice about their upbringing and many are unable to access generic child and adolescent mental health services (CAMHS). We describe the National Deaf CAMHS, a service that has been set up to answer the needs of this group of patients. It uses specialist intervention which incorporates some aspects of Deaf awareness to empower deaf children and reduce the burden of mental health problems that are likely to accompany them into and throughout their adulthood.

**Declaration of interest** None.

The prevalence of deafness in children varies according to which population is looked at, but approximates to around 2 in every 1000 children.<sup>1,2</sup> Deafness may be caused by sensorineural or conductive problems, or both, with a wide range of specific acquired causes, including *in utero* damage from drugs or infections, and many syndromic and non-syndromic genetic causes.<sup>3</sup> About 40% of deaf children experience mental health problems, compared with 25% of their hearing peers.<sup>4</sup> Behavioural and emotional problems in deaf children may be associated with low IQ and comorbid physical problems secondary to syndromic causes of deafness,<sup>4</sup> but are also linked to family, societal and cultural factors which interrupt parent–child communication and cause subsequent social and emotional delays and low self-esteem.<sup>5</sup> There is no reason why deafness should result in low intellectual performance, and given the right support deaf children can achieve the same educational outcomes as their hearing peers.<sup>6</sup>

Deaf children and their families often receive conflicting messages and advice about their upbringing and many are unable to access generic child and adolescent mental health services (CAMHS).<sup>7</sup> The National Deaf CAMHS was developed to improve access to services for children and families where deafness is involved. The purpose of National Deaf CAMHS is to ensure that deaf children are correctly diagnosed and supported and to minimise the risk of further complications.

### The development of National Deaf CAMHS

In recent years it became clear that too many deaf children were slipping through the net, unable to access generic CAMHS.<sup>7</sup> The result was too many people with untreated

mental health problems going into adulthood, by which point many had severely dysfunctional lives and were gravitating towards adult mental health services and other services such as secure forensic services.<sup>3</sup>

In the past decade a specialised branch of CAMHS aimed at deaf children and families has been developed nationwide. The National Deaf CAMH Service, known by families as the ‘national deaf children, young people and family service’, aims to provide high-quality mental health services integrating in-depth Deaf cultural knowledge and child mental health expertise. It also seeks to advance accessible services by working with generic CAMHS and up-skilling other professionals who support the emotional and psychological welfare of deaf children. It supports and encourages a culture of improved language acquisition for deaf children to prevent negative mental health outcomes.

There are now four main regional National Deaf CAMHS teams in England and one in-patient psychiatric facility for deaf children, commissioned by the National Specialist Commissioning Team, with regular dissemination of skills and data across the teams. The National Deaf CAMHS offers specialised consultation, assessment, interventions and advice. All clinicians and staff have Deaf awareness skills and are required to learn the British Sign Language. We may either work independently from generic CAMHS or jointly case-hold and train local teams to improve their Deaf awareness skills and management of deaf children. We offer a full range of multidisciplinary inputs including liaison with schools and other agencies, individual and family therapies, specialist autism assessment and medication prescribing. All the National Deaf CAMHS teams include professional deaf staff members and we fully embrace emerging information technologies to assist us in our work,

such as telelink conferencing, text message appointments and use of signed clinic letters on DVDs for our clients.

### The value of early and effective language acquisition: visual v. verbal?

Given that the society in general is oriented towards those who can hear, an expectation is placed on deaf children to acquire and use speech. There is robust evidence that delayed language acquisition in either modality increases the risk of mental health problems, and such delays occur in many deaf children.<sup>8</sup> Hearing parents with deaf children (90–95%) are less likely to encounter the world of deafness and as such are more likely to choose a predominantly oral approach to communication, despite the risk that this might result in a significantly delayed acquisition of language in the child.<sup>9</sup> In contrast, deaf children with deaf parents have natural access to sign language as their first language and subsequently have typical language acquisition patterns and fewer mental health problems.<sup>10</sup> The key appears to be establishing language development and good communication as early as possible. Significantly, not all deaf children are able to acquire spoken language successfully.<sup>11</sup> The advantage of sign language is that it uses a visuospatial modality that does not rely on a deaf child's ability to listen and to speak well. Various studies have concluded that sign languages are rich, living languages with grammar and syntax systems distinct from those used in spoken languages.<sup>12</sup> Previously, it was believed that signing would seriously hamper speech development but recent linguistic studies have shown that this is not the case. More recent studies have found that using sign language in fact promotes spoken language acquisition.<sup>13</sup>

Sign bilingualism has been seen as an attractive option for some families as this means making use of the two languages, the British Sign Language (BSL) and English.<sup>14</sup> One of the aims of sign bilingualism is to provide deaf children with access and exposure to sign language that would enable them to develop their second language skills in English, as modelled in the case of deaf children from deaf households.<sup>15</sup> As with hearing children in hearing families, deaf children need to be able to interact with other deaf adults and children, thus affording them the same kind of socio-emotional development that accompanies interaction with children of all ages and adults who are accepting of their deafness and their languages.<sup>16</sup>

However, sign bilingualism is not the most common educational approach to be used with deaf children. In the UK, only 6% are educated using the sign bilingual approach, whereas 79% are educated with a monolingual approach using auditory and oral methods.<sup>17</sup> As a result, our service, the National Deaf CAMHS, needs to be responsive to children with a wide range of communication experiences both within their families and in the education system.

### Language, theory of mind and autism

The value of human language goes beyond that of mere communication. Language is an essential part of our capacity for sentient consciousness and self-reflection.

Development of language has occurred side by side with theory of mind as a necessary tool for humans to describe to ourselves and others the complexities of our social environments. It has even been suggested that communication could be a mere secondary by-product of this more fundamental need for self-language.<sup>18</sup>

A lack of exposure to natural language and socialisation is believed to leave deaf children with poorer developed theory of mind. Hearing children consistently outperform deaf children in theory of mind tasks, with studies showing that deaf children are around 3 years behind their hearing peers.<sup>19</sup> One of the reasons for this is that deaf children do not have the same opportunity as hearing children to overhear family members' conversations which would enable them to have a better understanding of various actions and reasons as well as learning about other people's thoughts and emotions.

Another important point is that autism is about seven times more common in deaf children than in hearing children.<sup>20,21</sup> Social and emotional developmental delay affects early communication and can mimic some aspects of autism, which as a result may present as a misdiagnosis. Diagnosis is also complex because children with autism have been found to have a poorer theory of mind.<sup>22</sup> Furthermore, to diagnose autism in deaf children, clinicians use tools that have been designed with hearing children in mind. This may skew the diagnosis – deaf children do not have sufficient access to language exposure, which can cause a delay in theory of mind development, whereas for a child with autism the delays are a fundamental part of their disability.<sup>23</sup> Deaf children with deaf parents are found to have the same level of incidence as hearing children.<sup>5</sup> The paper suggested that this is not due to children's general language skills but their vocabulary skills and the ability to understand syntactic complements.

Critically, from a clinical point of view, the National Deaf CAMHS strives to help deaf children who present with language delay and theory of mind delay to reverse these impairments with focused and targeted clinical interventions. This is why accurate and early diagnosis of autism in deaf children is essential and why all UK's National Deaf CAMHS teams have well-established autism assessment clinics.

### Psychosocial and family interventions

The purpose of the National Deaf CAMHS is to support deaf children and their families with effective communication and focused psychosocial interventions which encourage normal development, reduce the risk of mental health problems and improve children's sense of inclusion and self-esteem. A lack of awareness of deaf children's different communications needs can lead to problems such as hearing parents being overprotective, intrusive, restrictive and controlling, which may subsequently interrupt healthy attachment.<sup>24</sup> However, the case for early intervention from statutory services to provide parents with support and education is not consistent throughout the UK, despite a common consensus for the need of early language acquisition.<sup>25</sup>

Other intervention programmes are also available. The National Deaf Children's Society provides a wide range of support for deaf children and their families, including information about education, local activities, family support, parent training and a network of local groups ([www.ndcs.org.uk](http://www.ndcs.org.uk)). They have developed a Healthy Minds resource to support emotional health and well-being for deaf children ([www.ndcs.org.uk/professional\\_support/news/healthy\\_minds.html](http://www.ndcs.org.uk/professional_support/news/healthy_minds.html)).

### Deaf Culture v. a cure for deafness

Many people do not consider deafness to be a disability and are staunchly opposed to medical models that frame it in such a way. 'Deaf Culture' (with a capital D) refers to the empowerment of deaf people and the recognition that they exist as a distinct social group.<sup>26</sup> Seeing that as many as 85% of deaf children are being educated in mainstream schools, there is a strong chance that they may have little or no exposure to other deaf children or adults. Although education in a mainstream environment allows deaf children to socialise with wider society, it can also restrict their opportunities to develop key interactions with other deaf children who they may feel naturally more able to relate to. There are anecdotes about deaf children growing up believing that when they reached adulthood they would be able to hear, as they had never seen a deaf adult. This illustrates how important it is for deaf children to have access to role models they can relate to. Offering the child an opportunity to explore and choose the extent to which they wish to be involved in Deaf Culture or not is an important part of the process of empowering them.

Despite the objections from some representatives of Deaf Culture, it is inevitable that medical science will continue to strive towards preventing causes of deafness and exploring treatments to reverse deafness where possible (<http://deafpositive.blogspot.com>). New technologies such as digital hearing aids, cochlear implants and genetic testing are available for those who wish to use them. What does not help is how cochlear implantation is sometimes being portrayed, with the implication that the implants cure deafness, which can be very misleading. A large amount of the work at National Deaf CAMHS concerns deaf children who wear hearing aids or cochlear implants and are placed in mainstream schools. At times, expectations raised by supportive technology can be unrealistic and can affect parents' expectations of their deaf children's communication competency. Children may also have unrealistic expectations for themselves, which may result in feelings of disappointment or low self-esteem.

It seems unlikely that deafness will ever be eradicated – and certainly not by the current level of technology. Therefore there will be a continued role for mental health services caring for children and families affected by deafness.

### Summary and conclusions

Deaf children are at greater risk of mental health problems than hearing children. Many things affect the likelihood of

problems but a major factor – and one which the National Deaf CAMHS is well positioned to tackle – is how the child, their family and the community respond to the child's deafness. Through taking small steps, educating colleagues and empowering deaf children we can implement simple measures that may drastically improve outcomes.

The National Deaf CAMHS operates in a highly specialised area of medicine but it is a globally cost-effective approach, aiming to reduce the massive cost and societal risks of deaf people with untreated mental illnesses, preventing forensic trajectories and high use of services in the future. Big hurdles remain for the continued development of National Deaf CAMHS. As the service is a relatively new facility for deaf children, there is still a lack of awareness about it among other professional agencies. The other issue is that there is a shortage of appropriately qualified deaf professionals working in this area, which makes recruitment challenging. When hearing professionals are recruited it takes time for them to learn about the specific needs of the deaf community and how to work effectively, using an interpreter, which might be a new experience for them. It might be that even the most experienced practitioner can feel de-skilled when first working with deaf people as they are used to methods of communication which are no longer effective with this group of patients. Most interpreters working with deaf adults may not be familiar with relaying information in a register and manner that fits in with the child's level of understanding. The National Deaf CAMHS must strive to recruit more appropriately qualified deaf professionals to work alongside the hearing staff members, and support new career pathways in addition to developing more appropriate diagnosis tools to meet the current challenges. The team needs to have a broad range of skills and experiences so that they can cater for the needs of the target group. Communication and education are crucial factors to prevent developmental delay and improve mental health outcomes for deaf children. Early identification of deafness and early intervention with any form of language is the key.

Parents and carers need good support and psycho-education with these decisions. Rather than being prescriptive, we aim to empower children and families to develop whatever appropriate communication skills best fit them at the time, with an acknowledgement that their needs may change as they develop. It is important to keep these goals in mind as the National Deaf CAMHS continues to grow as a specialist service, improving outcomes and accessibility for deaf children and teenagers.

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## References

- 1 Fortnum HM, Summerfield AQ, Marshall DH, Davis AC, Bamford JM. Prevalence of permanent childhood hearing impairment in the United Kingdom and implications for universal neonatal hearing screening: questionnaire based ascertainment study. *BMJ* 2001; **323**: 536–40.
- 2 Fortnum H, Davis A. Epidemiology of permanent childhood hearing impairment in Trent Region, 1985–1993. *Br J Audiol* 1997; **31**: 409–46.
- 3 Wright B. The cognitive and behavioral complications of deafness. In *The Cognitive and Behavioral Abnormalities of Pediatric Diseases* (eds R Nass, Y Frank): 544–62. Oxford University Press, 2011.
- 4 Department of Health. *Mental Health and Deafness: Towards Equity and Access*. Department of Health, 2005.
- 5 van Gent T, Goedhart AQ, Hindley PA, Treffers PD. Prevalence and correlates of psychopathology in a sample of deaf adolescents. *J Child Psychol Psychiatry* 2007; **48**: 950–8.
- 6 Yoshinga-Itano C. Factors predictive of successful outcome of deaf and hard of hearing children of hearing parents. Presented at the National Symposium on Infant Hearing, Denver, Colorado, USA. July, 1998.
- 7 Beresford B, Greco V, Clarke S, Sutherland H. *An Evaluation of Specialist Mental Health Services for Deaf Children and Young People*. Social Policy Research Unit, University of York, 2008.
- 8 Hindley PA, Hill PD, McGuigan S, Kitson N. Psychiatric disorder in deaf and hearing impaired children and young people: a prevalence study. *J Child Psychol Psychiatry* 1994; **35**: 917–34.
- 9 Lederberg AR, Everhart VS. Conversations between deaf children and their hearing mothers: pragmatic and dialogic characteristics. *J Deaf Stud Deaf Educ* 2000; **5**: 330–45.
- 10 Strong M. *Language Learning and Deafness*. Cambridge University Press, 2007.
- 11 Bishop DVM. Comprehension of English syntax by profoundly deaf children. *J Child Psychol Psychiatry* 1983; **24**: 415–34.
- 12 Sutton-Spence R, Woll B. *The Linguistics of British Sign Language: An Introduction*. Cambridge University Press, 1998.
- 13 Humphries T, Kushalnagar P, Mathur G, Napoli DJ, Padden C, Rathmann C, et al. Language acquisition for deaf children: reducing the harms of zero tolerance to the use of alternative approaches. *Harm Reduct J* 2012; **9**: 16.
- 14 Pickersgill M, Gregory S. *Sign Bilingualism – A Model*. Laser Publications, 1998.
- 15 Sutherland H. *Sign Bilingualism – Through the Eyes of a Child* (PhD dissertation). Department of Nursing, Midwifery and Social Care, University of Manchester, 2004.
- 16 Mahshie S. *Educating Deaf Children Bilingually*. Laurent Clerc National Deaf Education Center, 1995.
- 17 Pruvost E (2003) Making the Grade, <http://www.deafchildworldwide.info/document.rm?id=211>.
- 18 Gould SJ. Evolution: the pleasures of pluralism. *N Y Review Books* 1997; 26 June.
- 19 Lundy JEB. *Age and Language Skills of Deaf Children in Relation to Theory of Mind Development*. Oxford University Press, 2002.
- 20 Jure R, Rapin I, Tuchman RF. Hearing-impaired autistic children. *Dev Med Child Neurol* 1991; **33**: 1062–72.
- 21 Newschaffer CJ, Croen LA, Daniels J, Giarelli E, Grether JK, Levy SE, et al. The epidemiology of autism spectrum disorders. *Ann Rev Public Health* 2007; **28**: 235–58.
- 22 Baron-Cohen S, Tager-Flusberg H, Cohen DJ (eds) *Understanding Other Minds: Perspectives from Autism*. Oxford University Press, 1993.
- 23 Schick B, de Villiers J, de Villiers P, Hoffmeister B. Theory of mind: language and cognition in deaf children. *Asha Leader* 2002; 3 Dec.
- 24 Edwards L, Crocker S. *Psychological Processes in Deaf Children With Complex Needs: An Evidence-Based Practical Guide*. Jessica Kingsley Publishers, 2008.
- 25 Wallis D, Musselman C, MacKav S. Hearing mothers and their deaf children: the relationship between early, ongoing mode match and subsequent mental health functioning in adolescence. *J Deaf Stud Deaf Educ* 2004; **9**: 2–14.
- 26 Ladd P. *In Search of Deafness – Towards an Understanding of British Deaf Culture* (PhD dissertation). Centre for Deaf Studies, University of Bristol, 1998.