

Executive briefing on mental health services for deaf and hard of hearing people

Introduction

There are almost 9 million deaf and hard of hearing people in the United Kingdom (RNID 2005). It is estimated that up to 40% of deaf and hard of hearing people experience a mental health problem at some point in their lives – well over 3 million people – who are therefore likely to have contact with health and social services (Hindley 1994). Yet most deaf people seeking access to mental health care have to overcome considerable barriers to access services that meet their needs (NIMHE/DH, 2005). Many of these barriers are caused by lack of information and knowledge about deafness and its implications when assessing and treating mental health problems.

A significant minority of Deaf, deafblind, deaf and hard of hearing people experience mental ill health. They have considerably higher rates of common mental disorders, which for many of them is probably a consequence of being deaf in a hearing world. They have much greater difficulty getting the help they need and many, particularly those who perhaps are not perceived as problematic by others, get little or no help.

This executive briefing summarises the main issues. It is part of a joint project by the Mental Health Foundation and *Sign* to improve health and social care services for deaf people with mental health needs. The project aims to implement the additional measures called for in *Towards Equity and Access*, the Best Practice Guidance on mental health and deafness published in 2005 by the National Institute for Mental Health in England (NIMHE) and the Department of Health (DH). Initially this work focuses on England, but we believe the issues are equally relevant elsewhere in the UK. We therefore hope to make the information pack more widely available after this initial phase.

Terminology

This briefing follows the common convention of using the term Deaf with a capital D for people who are born Deaf or become deaf (or 'deafened') in early childhood. They communicate mainly through sign language and see themselves as part of the Deaf Community and Deaf Culture, which is a relatively close community – for example Deaf people often marry other Deaf people or have Deaf partners. They do not usually see themselves as having a disability.

Where deafness is used with a small d the term refers to the wider, all-inclusive deaf population, the majority of whom will use spoken language and its written form. This includes hard of hearing people and people who have become deaf in adulthood or in later life, many of whom also have considerable difficulties in communicating with hearing professionals.

Deafblind people who are born deaf or deafened in early childhood tend to identify with the Deaf Community, whereas the majority of deafblind people, who are deafened later in life, identify with the blind hearing community.

General statistics

Prevalence

About one in seven adults are deaf or hard of hearing. Between one and two people in a thousand of the general population are born Deaf or become deaf in early childhood in developed nations (Appendix 1 from ADSS et al, 2002). The UK Deaf Community that uses sign language is thought to number between 50,000 -75,000. Ninety per cent of deaf children have hearing parents. The deafblind population is thought to number about 23,000.

Deaf populations are geographically widely dispersed although there is a tendency to selective migration to larger conurbations. However the Royal National Institute for Deaf People (RNID) has estimated that in any given area in the UK there will be on average 6.6% of the population aged between 16 and 60 who are deaf or hard of hearing, rising to almost 47% of people aged between 61 and 80. Approximately 25% of the deaf population and 30% of deaf mental health service users have other disabilities. Ten per cent have more than one disability, such as a learning disability or communication disorder, in addition to 10% with clear neurological impairments such as epilepsy or cerebral palsy (Hamblin & Kitson, 1992).

The relationship between social disadvantage and deafness is under-researched but it is known, for example, that deaf adults are less likely to be employed and if they are employed it is less likely to be in professional or managerial positions (Bradshaw, 2002).

Children

The 10% of Deaf children who are born to Deaf parents do better academically, are more socially mature, and have more positive self-esteem than deaf children born to hearing parents (Health Advisory Service, 1996). Deaf children overall are more likely to experience emotional, physical and sexual abuse than hearing children (ADSS et al, 2002). They are vulnerable to delays in development, low academic achievement, behaviour difficulties and emotional distress as well as mental health problems.

Mental health statistics

There are very few studies of mental health problems among Deaf, deafblind, deaf and hard of hearing people. Most reports are based on mental health service usage statistics. This can lead to both over and under-reporting.

The degree of hearing impairment is not directly related to the likelihood or severity of mental health problems. Deafness can lead to a greater sense of identity and confidence within the Deaf Community. Those with partial deafness can have a less secure identity where they struggle to function in a hearing world. Increased use of signed communication in the family appears to be linked to a decrease in the prevalence of mental health problems (Hindley, 2000)

Severe mental illness

As with the general population, about half of deaf people diagnosed with schizophrenia remain significantly affected with ongoing or relapsing psychotic phenomena and behavioural change. Extrapolating from hearing populations (Office of Health Economics, 1989) about 300-600 deaf people in the UK will have been clinically diagnosed with schizophrenia in their lifetime and between 150-300 will have ongoing problems. There is some inconclusive evidence to suggest higher rates of symptoms such as paranoia and paranoid psychosis in those who acquire bilateral deafness in middle age, though not in old age or in the Deaf community. In the past specialist services for Deaf people suggested that bi-polar disorder (manic depression) was less common than in the population as a whole (Altshuler, 1971). This appears to be due to lower referral rates and difficulty in the diagnostic process, since these conditions are now commonly identified by specialist services for Deaf people (Kitson & Thacker, 2000).

Common mental disorders

Mild to moderate/common mental disorders have been rarely reported by mental health services for Deaf people, and depression is not commonly reported, though community studies in both deaf children and adults have showed high rates of prevalence approaching double that of hearing populations (Checinski, 1991; Hindley et al, 1994). In the early years of specialist Deaf Mental Health Services the low rate of referral for depression was assumed to be an indication of its prevalence. Over time and particularly as specialist Deaf mental health services have become more available and general awareness of deaf people's needs has improved, the rates of referral for depression have increased (Kitson & Thacker, 2000).

Behavioural disorders

Historically, Deaf people have had stereotyped personalities and behaviours ascribed to them (Altshuler, 1971; Misiaszek et al, 1985). On closer inspection it has become clear that many diagnoses are attributable to poorly expressed or received emotional expression. With appropriate diagnosis, their origin can often be understood on the same terms as have been recognised for years for hearing people and are not typical of Deaf people.

Behavioural disorders including personality disorders are at least twice as common in Deaf adults and children, with some studies suggesting rates of up to five times that found in the hearing population (Kyle & Griggs, 1996). Difficulties with impulse control are an aspect of personality that has been attributed to deafness (Altshuler, 1971; Altshuler, 1976; Vernon, 1978). Though these difficulties occur similarly among deprived hearing people, it is likely to be more common in deaf people due to the greater educational and environmental deprivation they experience in their developing years. An additional explanation is impulsivity as a result of minor brain damage, such as that caused by maternal rubella, which also causes congenital deafness. Over time the rates of referral for behavioural problems have decreased, probably due to improved general educational and environmental services for deaf people and better perinatal care.

Eating disorders

Though the prevalence and distribution of symptoms associated with eating disorders (eg. bingeing, body image distortion) among deaf people have been found by research to be similar to hearing populations (Hills et al, 1991), specialist Deaf Mental Health Services users have a lower prevalence possibly indicating reduced referral or detection.

Substance misuse

Evidence suggests that deaf people suffer drug and alcohol addictions to the same degree as hearing people (Issacs et al, 1979 ; Johnson & Lock 1978, Spikofski, 1992).

Suicide

We do not know how many deaf people self harm or commit suicide as this information is not collected, but we might hypothesise that some sub-groups in the population who experience other difficulties will at least be at higher risk.

Service provision issues

Service usage, including forensic services

These statistics repeatedly show a high level of unmet need as well as poor detection, probably due to the barriers faced by deaf people in accessing adequate mental health assessments and services at all levels.

Deaf people appear to be over represented in secure mental health facilities and in prisons. They also tend to be treated differently by the criminal justice system. It is not uncommon for deaf offenders to be let off or merely cautioned, arguably out of pity for their deafness, or avoidance of the burdensome procedures such as interpreters necessary to give a Deaf person full access. Some Deaf offenders are let off for escalating offences, until finally they commit serious offences and are imprisoned. Retrospective Deaf mental health service case note studies reveal high rates of offending behaviours (Young et al, 2001).

Providing appropriate services for low incidence groups

The trade-off between universal access and the need for specialist expertise for relatively sparsely spread populations in need of rare, but thorough, expertise or treatment is one of the major challenges for policy and practice in mental health services (Health Advisory Service, 1996).

Low incidence groups, such as deaf people, need a different form of service commissioning and provision to many other mental health service users. Regional commissioning or central funding would appear to make more sense, given the small numbers of deaf people at practice or PCT level. For PCTs to engage in meaningful commissioning for Deaf Mental Health Services there needs to be an appropriate level of awareness and good information at local level. Local needs assessment requires reliable information and knowledge of services.

This briefing and its accompanying papers, together with the NIMHE best practice guidance (NIMHE/ DH, 2005), represent a significant step in addressing the needs of this neglected group. When a deaf person presents with a mental health issue procedures and local resources should deal sensitively and knowledgeably with that person. Deaf patients have the same basic rights to treatment and to be understood as any other health service user. The information pack produced by *Sign* and the Mental Health Foundation highlights the minimum service adjustments that would support the provision of deaf-friendly services.

Working with deaf people generally takes longer than with hearing people, and gaining the extra expertise requires considerable commitment from staff. There are shortages of expert staff in all workforce categories. Because of this there is a widespread view that mental health services for deaf people are far from adequate and that progress needs to be made if people are not to be excluded from them. Those responsible for strategic decisions and service development need improved understanding of deafness, communication and the heterogeneous nature of the deaf population if basic rights are to be met.

Many of the basic steps are easy to implement and not unduly expensive for PCTs and providers.

Assessing deaf people

Mental health workers' chief tool in assessment, diagnosis and treatment is effective engagement and communication. Deaf, deafblind and hard of hearing people present a significant challenge except in the currently very rare circumstance where the mental health worker is fluent in BSL and its variants. In the case of deafblind and Deaf people mental health workers also need to be skilled in the adaptations of sign language or specific words necessary for communication. Even in situations where this is available it may be more complex because many Deaf, deafblind and hard of hearing people will have further difficulties with their communication due to other associated disabilities or limitations in their education or life experience.

A study by the RNID suggests usage of interpreters at GP and hospital appointments for Deaf people is less than 20%. (RNID, 2004) The practice of using family members, often children, as informal interpreters seems widespread, although we believe that this is wholly inappropriate in relation to most, if not all, mental health issues. More than 20% of deaf people left meetings with their GP unsure of what was wrong with them and more than 10% avoided attending the doctor because of communication problems. Effective communication and access to appropriate assistance with communication is key to improving access to all health services.

Assessing Deaf people who use sign language

Language is the key difference in assessing the mental health status of most Deaf people. To achieve accurate assessments, sign language's normal and abnormal form and meaning must be fully understood. An effective mental state examination is the result of observations usually made during the assessment interview. Without fluent communication the assessor will not be able to observe the form of thought (via communication) or the degree of congruence between emotions and behaviours and the explanation that the person is giving. The appropriateness of beliefs, behaviour and communication styles cannot be understood without understanding the person's culture – as already pointed out, there is an identifiable and unique culture within the Deaf community. While Deaf Culture does not affect beliefs particularly, it has a great impact on behaviour and communication styles. An example prone to misinterpretation by those not sufficiently aware is Deaf people's way of storytelling. The Deaf person will take on the emotional expression and attitudes of various characters in the story or background history. It is essential that the assessor can differentiate these from the Deaf person's own emotions and attitudes. In some therapies emotional interactions are key. Therapists who lack competence in understanding these different cues will be much more likely to misunderstand, leading to inaccurate or inappropriate interpretations and interventions. In addition to the complications of language and culture some people specifically use forms of sign language to refer to aspects of their mental health although these forms are used differently by other Deaf people. Furthermore, all mental health practitioners who see Deaf people should be aware of the causes of deafness as the potential cause of mental disorders in their own right.

Using carers' views as an input to the assessment

Deaf or hearing people, known as informants, can provide independent accounts of a deaf person's past and present behaviours and life history or assist a deaf person to overcome communication difficulties when feeling distressed. The majority of informants tend to be family members, yet less than 10% of deaf people have deaf immediate relatives and their hearing immediate relatives rarely have fluency in sign language. It is often the case that relatives of disabled people may have particular views or ways of behaving towards them, such as overprotection, denial or rejection of the person's disability. Informants for deaf people may therefore be unreliable on the basis of their own limited communication with the deaf person and their individual bias.

Mental Health Act 1983

Mental Health Act procedures must be operated in a fashion that respects deaf people's human rights as much as other people's human rights. The English and Welsh Codes of Practice to the Mental Health Act are key to the proper implementation of the Act and make a number of references to deaf people. Procedures should be 'in a suitable manner' (Mental Health Act 1983), 'taking into account any hearing or linguistic difficulties the patient may have' (Department of Health, 1987), 'wherever practicable recourse should be had to a trained interpreter', (Department of Health, 1993), and 'Deaf or hearing impaired patients may feel more confident with a friend or advocate who is deaf' (Department of Health, 1999). Staff need to take into account the risk of making assumptions based on a person's social and cultural background and the possibility of misunderstandings, which may be caused by medical/health conditions 'including deafness' (Department of Health, 1999 & 2005a). Mental Health Review tribunals recommend the use of Deaf Relay interpreters in addition to registered and qualified BSL interpreters to ensure full communication for people subject to the Act.

The Codes of Practice do not adequately deal with ongoing assessments, treatment or discharge for deaf people. It has been argued that all deaf patients detained under any mental health law should have their detention and treatment reviewed by a specialist psychiatrist for deaf people as soon as is practicable. It is equally important that specialist mental health workers for deaf people are involved in their aftercare to ensure proper planning for rehabilitation (Kitson & Thacker, 2000).

Social Care Needs

Deaf people need the same range of social care services as the general population. They may have mental health problems, physical illness, long-term disabilities, old age related problems or other family circumstances. Their hearing difficulties are considerably eased however by the provision of minor pieces of equipment such as text telephones, alerting systems, listening devices such as loop systems and baby alarms, etc. Provision is the responsibility of social services, and applies equally to adults, children and young people.

Given that deaf people often have a poor educational experience and may have limited literacy skills, many require assistance with daily living activities such as help in dealing with official letters and forms – a role sometimes filled by specialist social workers with deaf people or voluntary organisations. Accessible information is an important component of a deaf-friendly service. Advocates or interpreters may be required to accompany the deaf person to enable them to make the same choices as other service users.

Above all, deaf people benefit from deaf-aware service provision, where staff are welcoming, have effective communication skills, understand when to provide sign language interpreters or other language professionals to support communication, and know how to work with them.

What are the Mental Health Foundation and *Sign* doing?

The Mental Health Foundation and *Sign* have worked closely together over the last two years to develop a project that aims to raise awareness among health and social care providers in the statutory and voluntary sectors of the particular needs of deaf people with mental health problems. Both organisations recognise that NIMHE's *Towards Equity and Access* (NIMHE/DH, 2005) highlights best practice. The guidelines make recommendations to improve services to meet the mental health needs of deaf people. We welcome this report, but consider that some of these developments may take some time to become embedded in everyday practice. There are fundamental, basic standards of service accessibility that must be met for deaf people to experience an equitable service. Recently issued NHS guidance on ethnic monitoring also identifies the importance of ensuring appropriate communication methods are used when collecting information from people who are deaf or hard of hearing. We firmly believe that only by continuing to work together to help health and other social care organisations understand the importance of making firm commitments to addressing these issues will improvements come about. These guidelines therefore need to be implemented together with the basic steps outlined in our charter (included in our service provider pack).

The Mental Health Foundation and *Sign* recognise that for many service providers the constraints of limited resources, competing demands, and the relatively small numbers of deaf people with mental health problems who come to their attention may act as disincentives to make some of the changes recommended by *Towards Equity and Access*. However, it is vital for service providers and practitioners, as well as people who are using services and their unpaid carers, that information and guidance on core elements of deaf-friendly practices is available. This is particularly important given that most deaf people with mental health needs come into contact with generic health and social care services rather than specialist services. Our information and guidance therefore aims to strike a balance between what constitutes good practice in promoting mental well being and meeting the fundamental needs of deaf people.

We have developed a charter of basic rights to highlight the key issues for service providers and practitioners in promoting the mental well being and rights of deaf people, reducing barriers to services and helping deaf people with mental health problems get a better response from health and social care services. The charter, together with the supporting information provides a quick reference guide on how the barriers to services can be overcome, and some practical steps providers can take to make their services more inclusive. In giving a clear indication that they are adopting these minimum standards, organisations are not only enabling their services and staff to become more informed and better prepared, but they are also making a firm commitment to recognising and meeting the basic needs of this group.

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