

Primary care for deaf people with mental health problems

Jack Levine

There are approximately 10 million people who have some form of hearing loss in the UK, and this figure is estimated to rise to 14.5 million by 2030 (Action on Hearing Loss (AOHL), 2011a).

Taking into account the social determinants of mental ill health (World Health Organization (WHO), 2005; Marmot Review, 2010), it is not surprising that the prevalence of mental health problems among deaf people appears to be significantly higher than in the wider population (Sign and Mental Health Foundation (MHF), 2006a). Although exact rates are difficult to calculate owing to a lack of research on the topic (Sign and MHF, 2006b; Horne and Pennington, 2010), it is known that this population is exposed to more mental health risk factors. For example, deaf people are at a higher risk of experiencing social isolation and low self-worth, and are more likely to be victims of both abuse in childhood and domestic abuse in adulthood (AOHL, 2011b; SignHealth, 2012). Deaf people are also at an increased risk of underachieving educationally, and more likely to be unemployed (Royal National Institute for the Deaf (RNID), 2007; Fellingner et al, 2012).

Mental health problems in the deaf are often misdiagnosed or missed altogether because existing assessment scales are largely inappropriate as they were not designed or validated for deaf people and, without expertise, it is difficult for psychiatrists to discern language, cognitive, and behavioural issues inherent to hearing loss from those present in many common mental health disorders (Fellinger et al, 2012). As inpatients, deaf people experience psychiatric admissions that are approximately twice as long as the hearing population (Baines et al, 2010). Communication is integral to all mental health therapeutic interventions (Morrissey and Callaghan, 2011), and a central factor in mental health recovery (Onken et al, 2002). Deaf people find it harder to establish good communication with health professionals and, sadly, many of these communication issues arise from discrimination and practical obstacles faced within the healthcare system (Sign and MHF, 2006a).

There is strong evidence that good mental healthcare integration and provision within primary care can reduce the impact of mental illness on individuals, families, and whole communities (WHO, 2008; NHS Confederation, 2012). It

Abstract

There are approximately 10 million people in the UK who have some form of hearing loss, and the prevalence of mental health problems among deaf people appears to be significantly higher compared with the wider population. Deaf people find it harder to establish good relationships with health professionals and, sadly, many of the issues arise from discrimination and practical obstacles faced within the healthcare system. Some of these issues include a lack of awareness, funding, and prioritisation within the wider political and healthcare agenda. This article provides an overview of the background of hearing loss and mental ill health, policy and current access to mental health services for deaf people, what has changed and recommendations for the future.

Key words: Deaf ■ Mental health ■ Primary care ■ Policy ■ Disability

is clear therefore that improved access to primary care is a crucial first step if deaf people are to experience mental healthcare equity. Crucially, the *National Service Framework for Mental Health* (Department of Health (DH), 1999a) Standard Two, states that:

‘Any service user who contacts their primary healthcare team with a ... mental health problem should:

- **Have their mental health needs identified and assessed**
- **Be offered effective treatments ... referral[s], ... and care if they require it.’**

The literature contains guidance about classifications within the deaf community. Deaf with a capital ‘D’, refers to those deaf from or very soon after birth. These people generally identify with the Deaf community and Deaf culture and most use British Sign Language (BSL) as their first language. Deaf with small ‘d’ refers to the wider hard-of-hearing population, the majority of whom use spoken/written language. This population includes people who become deaf later in life (Sign and MHF, 2006a; Ladd 2003). Unless otherwise stated, this article will use a small ‘d’ to include the entire Deaf/deaf population as both groups experience comparable issues when accessing healthcare.

What issues do deaf people face when trying to access primary care services?

Mental Health and Deafness: Towards equity and access (DH, 2005) summarises what the issues facing deaf people trying

Jack Levine is Staff Nurse, Mildred Creak Unit, Great Ormond Street Hospital for Children, London

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to access primary care were at the time of its publication. Many deaf people found contacting their GP surgery difficult owing to an increasing reliance on telephone booking. Many reported finding it hard to explain their health problem to the doctor/nurse and were often left feeling unclear about their condition, medication or treatment instructions. Also, as most surgeries rely on 'name calling', appointments were very easily and frequently missed. There was widespread difficulty in obtaining BSL interpreters and, when available, there was a concerning 'reluctance' from some services to provide the funding (which was seen as discrimination by the deaf community when comparing provisions made for other minority language users (DH, 2005). Also of concern was evidence that approximately 15–30% of deaf people reported avoiding making appointments as a result of these difficulties (RNID, 2004).

Policy background and context

Elected in 1997 with a landslide majority, New Labour brought with it, among other policies, the promise of a 'Third Way in Mental Health' (Harrison, 2002). Over the next few years, this resulted in the publication of various mental health policy documents focused on modernisation, health promotion and, crucially, access to services; something which was desperately needed after years of underfunding and archaic psychiatric services (Rankin, 2004).

Arguably, more than ever before, there was a real opportunity for implementing change within deaf mental health services (Buse et al, 2005). Politically, the government was promising healthcare investment and reform, and appeared interested in the experiences of its disabled citizens (Carpenter, 2009). Disability equality had already been on the political agenda with the 1995 Disability Discrimination Act (DDA), and Labour continued this with the formation of the Disability Rights Commission (DRC) in 1999, aimed at reviewing the DDA and making amendment recommendations in 2002. In 1998, the Human Rights Act, targeting all forms of discrimination, was passed. Additionally, 2003 saw BSL recognised as an official minority language by the government (Rogers et al, 2012).

Economically, New Labour came into government during a period of 'boom' (Corry et al, 2011), allowing for substantially increased funding for mental health services (termed a 'modernisation fund' (Carpenter, 2009)). Socially, high-profile cases such as the Clunis enquiry, in which a mentally unwell man with significant risk-history murdered a stranger at a train station (Cold, 1994), put effective mental health care further up the public agenda. Finally, the 1990s and early 2000s saw rapid advances in the technology available to assist in the treatment of deaf mental health patients in primary care (DH, 2005).

It is therefore understandable that between 1997 and 2005, there were a number of government publications focused on the mental health and social care of the deaf. *A Service on the Edge* (DH, 1997) reported that, overall, the social services provision for deaf people was unsatisfactory. This was followed by *Stepping Away from the Edge* (DH, 1999b), a report making specific practical recommendations to improve services. The year 2000 saw the publication of an independent

inquiry (Merton Sutton and Wandsworth Health Authority et al, 2000) into the care and treatment of Daniel Joseph, a profoundly deaf young man with severe mental health problems, who was found guilty of manslaughter with diminished responsibility in 1998. The inquiry highlighted that there was no national strategy for the mental health of deaf people and, therefore, the needs of this population were not being adequately managed. In part a response to the inquiry, the consultation document, *A Sign of the Times—Modernising mental health services for people who are deaf* (DH, 2002) was produced. It looked at the standards contained in the National Service Framework and what the challenges would be to implement these for the Deaf/deaf community. Throughout the consultation, concerted efforts were made to liaise with voluntary organisations, deaf communities, and individual service users. The results confirmed a widespread dissatisfaction with mental health service provision for deaf people.

Mental Health and Deafness (DH, 2005) was published as a response to and summary of *A Sign of the Times* (DH, 2002). The document, amalgamating issues raised in the original consultation, was developed to address the inequalities in mental health care faced by deaf people. It made 26 recommendations and practical suggestions based on the National Service Framework for Mental Health about how services could become more responsive to the needs of deaf people (DH, 2005). Some of these focused specifically on primary care.

How far have we come?

Mental Health and Deafness (DH, 2005) had the potential to be the springboard for a wave of change in primary care that would benefit the deaf population. Looking at some of the recommendations made, and at the current wider policy context, this article will now examine some ways in which primary care services for deaf people with mental health difficulties in England have changed in the 8 years following the publication of *Mental Health and Deafness* (DH, 2005).

One recommendation made in *Mental Health and Deafness* was that BSL/English translation software already in development by the charity SignHealth be made available to primary care services. In 2007, the web-based programme, 'SignTranslate', which translates approximately 300 medical questions into BSL, was made available free of charge to all GP surgeries (Besant, 2008). Initially, it was only funded for 1 year; however, as a result of its ease of implementation and use, value for money, and the overall success of the system, it is still in use today (SignHealth, 2014).

Access to basic mental health assessments is another area where improvements have taken place. Rogers et al (2012) found good evidence for BSL versions of clinical self-report mental health assessment measures, commonly used in primary care. Further research and effective dissemination of results should help to increase clinician awareness and confidence using these scales. The work of Rogers et al (2002) forms part of a wider programme to make it easier for deaf people to access *Improving Access to Psychological Therapies* (IAPT) (DH, 2008). IAPT has shown good clinical outcomes and since its inception, has increasingly been seen (often

alongside medication) as the first-line primary care option for low-to-moderate mental health problems (Richards and Suckling, 2009). 'BSL Healthy Minds' (SignHealth, 2011a) was developed to grant deaf people access to IAPT services, and while it is not fully national yet, the future of IAPT for deaf people appears positive owing to continuing research, BSL fluent staff training, and increasingly available self-help materials (Flynn, 2012). It is relevant to note that the BSL Healthy Minds service and the SignTranslate programme have allowed organisations to fulfil the legal requirements of the Equality Act 2010, and this arguably is a key factor in ensuring continued funding for both.

Current circumstances and hope for the future

Two reports from the charity SignHealth (SignHealth, 2008; 2009) indicated that the access issues discussed in *Mental Health and Deafness* were as prevalent 3 years later, and deaf people continued to 'experience huge ... [primary] ... health inequalities' (SignHealth, 2009: 2). Unfortunately, this trend has continued, with research published in 2013 revealing evidence that the same practical problems faced by deaf people with mental health issues are still largely unmet, and the solutions are analogous to those recommended in *Mental Health and Deafness* (AOHL, 2013).

While it does not appear that mental health has fallen from the government agenda, it is arguable that opportunities have been missed in bringing about change in this area. The current coalition government mental health strategy *No Health Without Mental Health* (DH, 2011) contains only three mentions of deaf people, and these are very brief and generalised (British Society for Mental Health and Deafness (BSMHD), 2011). Additionally, there are no mentions or commitments to implement any of the specific improvement recommendations made in the numerous publications referred to in this article before and following *Mental Health and Deafness*.

No Health Without Mental Health has been mostly welcomed by major mental health charities. However, one recurrent note of caution revolves around the lack of tangible financial commitments, and that the strategy can only be successful if adequate funding is provided (MHE, 2011). It is arguable that despite still being on the public and political agenda, the 2008 financial crisis has been the 'nail in the coffin' for improving primary care mental health services. The government maintains that the NHS budget is 'ring-fenced', yet healthcare providers are being asked to do 'more with less', and spending in real terms on mental health has declined (Gregory et al, 2012; DH, 2013a). After adjusting for inflation, there has been a 1% decrease in mental health funding in 2011–12 (DH, 2013a) and 2012–13 (Brindle, 2013). The author feels it is sensible to predict that a small minority such as the deaf community will not see large financial guarantees to implement changes to improve their access to services.

The 2012 Health and Social Care Act represents the biggest reorganisation of the NHS since its inception (The King's Fund, 2012). SignHealth (2011b) has raised serious concerns that the reforms will have a negative impact on deaf people. The deaf community is small and geographically dispersed (Ayres, 2004). Therefore, there are concerns that with

more clinical commissioning groups (CCGs) than outgoing primary-care trusts, the deaf population will be seen as a less important group as a result of fewer numbers represented within each CCG. There are also concerns that deaf organisations will need to spend vast amounts of time forging



KEY POINTS

- People with hearing loss are more likely to experience a mental health problem in their lifetime
- In general, existing primary mental health services do not adequately serve the needs of the hearing loss population
- In the past decade, despite increased research and opportunities to bring about change, there has been little improvement to the access and provision of mental health services for those with hearing loss

new relationships with multiple CCGs, having spent years building strong relationships with their PCTs. The Health and Social Care Act states that services can be commissioned to 'any willing provider' (The King's Fund, 2011), and as CCGs have a less established management structure, there are concerns that deaf people could become stuck in the middle between commissioners and providers over who is responsible for making the 'reasonable adjustments' necessary to make services accessible (SignHealth, 2011b). One potential counterpoint is the prospect of deaf organisations and charities becoming those willing providers, something which has been done successfully with the SignTranslate programme. Arguably, the idea of third-sector providers in the current climate is one worth pursuing, as most charities are well practised in cost efficiency, and can be more adaptive and responsive without the constraints of NHS bureaucracy, not to mention more expertly focused on the population for which they are providing the service (King's Fund, 2013).

Future recommendations

Continued focus on individualised patient care

In setting the healthcare agenda, swings in public mood are important (Dattani, 2010), and in the wake of the Francis Report (Francis, 2013), individualised patient-centred care will be firmly part of all current and future healthcare policy discussions (Haq, 2013). Arguably, it often takes a scandal to effect change, and while deaf people are not directly implemented, the scope of the Francis Report is broad and all-encompassing. It may well be that the deaf community can use the public outcry to amplify their own voices.

Training deaf mental health nurses and therapists

Increased and continued training of mental health nurses and therapists is crucial to ensuring that deaf access to IAPT continues to grow (Weisberg, 2012). There is also good evidence for 'one-stop shops', where mental health services for the deaf are integrated into outpatient primary care (Fellinger et al, 2005). Potentially, there is a risk that deaf-specific primary care centres could be seen as an exclusion measure. This risk needs to be weighed up against the wider societal inclusion benefits (e.g. returning to work) which could result from deaf people having their mental health needs addressed quickly and effectively.

Conclusion

Specialist mental health services for the deaf, although essential, are associated with inequality. The deaf mental health service

in South-West London has anecdotally reported that many people discharged from the service choose to settle in the local area, and that this has led to the accelerated development of deaf accessible services in the area. Clearly expertise and awareness of deaf issues is a positive thing, however the risk is that specialist knowledge and access to care is likely to remain isolated in pockets and insufficient for the majority of deaf people in the country.

The United Nations (UN) Convention of the Rights of People with Disabilities (UN, 2008) clearly states that all disabled people deserve effective communication with public services. Only an approximate 75 000 people in the UK use BSL (AOHL, 2011a). Therefore, for the rest of the deaf population, arguably what is needed is a common-sense approach. Measures such as speaking slower and louder, making eye contact, and checking understanding could go a very long way towards improving deaf individuals' experiences in primary care (AOHL, 2013). Indeed, surely everybody would benefit from their doctors adopting these measures and the deaf community could seek to remind policy makers and health providers of these facts.

The *No Health Without Mental Health* implementation framework (Centre for Mental Health et al, 2012) clearly states how it intends to evaluate its success. However, for deaf people to be included in this evaluation, they have to first be included in the services being evaluated. One example of this evaluation is the 'Friends and Family Test' (FFT) (DH, 2013b), which will ask all patients on discharge whether they would recommend the service to loved ones. Before they can give an answer to the FFT, however, deaf service users first have to have heard the question.

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