In Leeds a unique, multi-agency partnership is pioneering new approaches to meeting the needs of Deaf people

Listening to Deaf people

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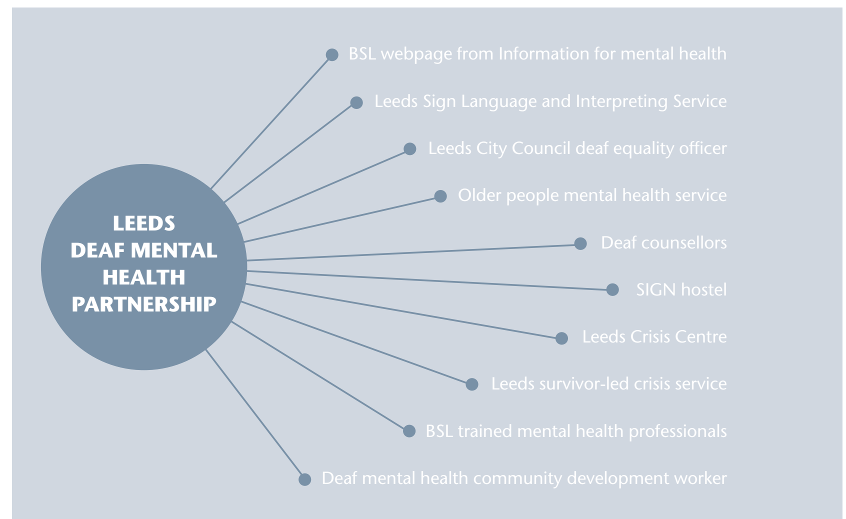
As the UK has grown in ethnic diversity, services have recognised a duty to work in more spoken languages. Services such as employment, education and public health are becoming more accessible for people who speak a language other than English. This exposes a disparity in accessibility for people from the Deaf community who use British Sign Language (BSL), which shows up strongly in mental health services.

The Department of Health report Towards Equity and Access[1] acknowledges that mental health services for Deaf people are far from adequate, and recommends action to address poor accessibility of mainstream services and lack of specialist provision. For the last 13 years, a group of organisations in Leeds has been working towards making local mental health services accessible to Deaf people, and making local Deaf services more accessible to people experiencing mental health problems. The Leeds Deaf Mental Health Partnership is made up of Deaf and hearing professionals from a range of health and social care services in the public and third sectors (see figure), with the common aim of providing holistic, integrated mental health services.

All the partnership's initiatives have been funded by the member organisations: they have made a commitment to effect change. Most organisations convince themselves that they have made services accessible by providing a minicom and assuming that the need has been met. Commitment means that organisations sign up to improving services by buying in training for staff and service users, incorporating the Deaf mental health agenda into their service plans, and investing in equipment such as flashing fire alarms and video intercoms. Some of the partners have trained mental health professionals who are native BSL users. The key to the success of the partnership is that each organisation has committed workers and a strong emphasis on partnership working. In addition, the range of partners offers different perspectives. The diversity represented at our meetings includes services working from a social model and those working from a medical model, which together create services that meet the needs of a diverse population.

Deaf culture

Ridgeway explains: 'The term "Deaf community" has demographic, linguistic, political, psychological and sociological dimensions. Britain's Deaf community shares characteristics that derive from common experiences, beliefs, values and norms – most importantly, the community bonds through a common language (BSL) and a shared culture.'[2] Ridgeway further observes that: 'Deaf people have developed a distinctive culture, viewing themselves as part of a linguistic and cultural minority, rather than as disabled.' →



→ Deaf people who use BSL may not be able to read material written in English: 'BSL is a visual-spatial language which has its own vocabulary and distinctive grammar and structure and bears no relation to spoken English.'[3] In Leeds the number of Deaf people who use BSL is difficult to estimate accurately. Prendergast[4] describes the difficulties in providing accurate statistics on a national level. This adds to a further problem in identifying accurate service need.

Deaf mental health

So why make an issue of mental health provision to the Deaf community? The mere fact of being Deaf does not lead to mental health problems. However, the prevalence of mental distress within the Deaf community is disproportionately high. Deaf people, as with other minority groups, commonly access mental health services via the criminal justice system, suggesting that no early intervention from the mental health services is provided. The Department of Health concludes from the evidence that:[5]

> 'Deaf adults share the overall prevalence for psychotic disorders but are more likely to be diagnosed as having a personality disorder, or behavioural or adjustment problems. This is probably a consequence of being Deaf in a hearing world, rather than an innate predisposition.
>
> 'Comorbidity is higher in Deaf people with mental health problems. They are more likely to have learning difficulties (though this may be more… a case of being disabled by the learning environment, rather than being learning disabled)…
>
> 'Deaf people are no less likely than hearing people to suffer from common mental health problems, like depression and anxiety states.'

The Deaf Mental Health Charter co-published by SIGN and the Mental Health Foundation[6] suggests that, although research in this area is limited, there is evidence that the prevalence of mental distress within the Deaf community is almost double the rate within the hearing community. The Charter goes on to hypothesise that the cause for the disproportionate figures may lie in discrimination and social exclusion.

Timmermanns[7] identified in 1989 that a hearing person's average stay in psychiatric hospital was 148 days, compared with 19.5 years for a Deaf person, even though Deaf people were no more likely to suffer schizophrenia or anxiety or depression than their hearing counterparts. It has also been suggested that, as the psychiatric diagnostic framework is written from a hearing perspective, Deaf people's mental distress may be commonly misdiagnosed.[6]

Historically, Deaf people in the UK have been marginalised and have faced discrimination. Attempts were made to 'normalise' Deaf children, who were forced to communicate in English in school and other situations, enforcing oralism. Many Deaf children were removed from the family environment and placed in boarding schools (sometimes as young as two years old), as this was felt to be best for the child and the family. Prendergast[4] explains that mistrust towards the hearing community is a common theme in working with Deaf people, and quotes Deaf people describing how they were forced to speak by hearing people, were denied an education, had their lives controlled by hearing people, and in some cases were abused by hearing people.

Ridgeway proposes that there is a significant correlation between achieving a positive Deaf identity and positive mental health. Where there is impoverished communication, negative attitudes and medicalisation of Deafness, Deaf people struggle to achieve a positive identity.[6] Prendergast through her research identified a theme of 'not being allowed to be Deaf'. One respondent described:

> '… pressure all though my life with people not accepting my Deafness, being under pressure to conform, to be normal, to be a normal person. Sometimes I just feel like I have no strength, no energy, nothing. That's why I became ill.'

The Leeds perspective

In the embryonic stages of the Leeds partnership, the topic of Deaf mental health was new. The usual approach is to present research and point to demand as a way of justifying new services. However in this area there was limited research and the community has historically been excluded, so the known demand was limited to a few isolated cases. As a group of interested professionals, the partnership had to argue the case for changing services to create a demand. At the time there were several service units in the UK working to a medical model, but nothing based on an integrated community model. The lack of existing models presented the exciting opportunity to pioneer the work. The partnership chose a framework to examine the points of access in the mental health system used by hearing people and match these to points that could be available for Deaf people. This identified three basic units in social services: a hostel, a day service and a crisis counselling service. Staff were trained in Deaf awareness and BSL, involving close working with Leeds Sign Language and Interpreting Service.

In 2001 the Leeds Deaf Mental Health Partnership held a mental health conference, with guest speakers from the Deaf community nationally. It was so successful that the partnership obtained funding to employ a researcher to explore the mental health needs and experiences of the Deaf community in Leeds, which led to the report Free Your Mind.[4]

Free Your Mind identified areas of strengths and weakness in Leeds, and used the social model of distress. Themes became apparent throughout the research:

> '… I know professionals try to help but maybe we should have someone who is experienced in mental distress or mental health, a specialist worker who can refer people to the right places... It could be a hearing or Deaf person as long as they can sign very well, then Deaf people will be attracted to talk to them and feel confident in going to.'

It described vividly the discrimination and stigma (within the hearing and Deaf communities) and lack of service

provision experienced by Deaf people with mental health problems in the area:

> 'Deaf people feel that they are second best stuck in a hearing world and that is something they have to accept in their everyday life.' (Deaf worker, specialist setting)

> 'I think every person I have worked with there has been a real issue of internal oppression. They have just taken on all that pressure and bad messages about themselves, and their expectations of themselves can be really low. Particularly for women I have worked with.' (Hearing worker, non-specialist setting)

> 'Deaf people don't want to be associated with being mad. Also, nothing is private or confidential and there is this absolute fear of having mental health problems and this coming out.' (Hearing worker, non-specialist setting)

It also explored the problems created by poor communication support, and their consequences:

> 'If you're in an environment where nobody can communicate with you in your preferred language, then you are going to become isolated, vulnerable, depressed etc.' (Hearing worker, specialist setting)

> 'Most information is impossible for a deaf person to read. There is jargon, terminology, sentence structure and Deaf people just can't access this generally.' (Deaf worker, non-specialist setting)

The report concluded: 'Deaf people who experience mental distress clearly have difficulties obtaining quality services in Leeds. They struggle to access the most basic support, and even to find ways in which they can communicate meaningfully with services providers. Deaf people have become accustomed to expecting little and therefore being grateful for the most basic support – this situation has to change.'

Services in Leeds

Leeds mental health services are becoming more accessible. A crisis centre has Deaf associate counsellors working with people experiencing acute crisis, and plans are in process to create a BSL counsellor post. In 2006 Information for Mental Health, with assistance from the Deaf Mental Health Partnership, launched a BSL website that explains mental health issues and services in a BSL format. Leeds has a SIGN hostel for deaf people with mental health issues. Leeds Sign Language and Interpreting Service has interpreters specialising in mental health.[8] Recently an older people's deaf mental health service came into existence, offering specialist provision for older people who use BSL.

Services are actively working towards change. This has entailed changing information leaflets and literature, training, environmental equipment, and reviewing the service overall. Resources for these initiatives come from individual organisations applying for grants and from the commitment of workers.

So how did we make it work? We suggest the success is down to enthusiastic committed professionals and service users, who buy into the philosophies of collaborative work rather than working in isolation. Leeds Deaf Centre has a diverse, energetic community that has worked with the generic mental health services to assist change. We meet regularly to share and disseminate good practice and information, and, more importantly, we want the good services citywide, to enable as much as choice as possible.

What next in Leeds?

As a result of the 26 recommendations in the Department of Health's Towards Equity and Access report, £2.5 million recurring funding was allocated nationally to PCTs to improve access to services for Deaf people. Leeds PCT, in collaboration with the Deaf Mental Health Partnership, created a part-time Deaf mental health community development worker post, initially for two years.

The rationale for the creation of a post, rather than allocating the funds to equipment or training, came from the recommendations in Free Your Mind. Community development work can be a highly effective approach. The resource is used to empower the community itself to define its needs, assert them and get them met. The Deaf community has rarely had a resource like this.

The Leeds-based voluntary sector mental health service provider Community Links is running the project, and a native BSL user was appointed in October 2006. The worker has been auditing existing provision in Leeds for Deaf people with mental health needs. There are plans to hold a conference later this year for people from the Deaf and hearing communities and stakeholders interested in changing services in Leeds. The vision for the project is that mainstream mental health services will change to become services for Deaf people, and that the Deaf community will be the force behind the change. ■

An electronic copy of Free your Mind is available free at:
www.commlinks.co.uk

For further information about initiatives in Leeds for Deaf people, visit:
www.commlinks.co.uk
www.yorkshire-bsl-interpreters.co.uk
www.mentalhealthleeds.info/
www.leedsdeafandblind.org.uk/services/services_lslis.asp
www.signcharity.org.uk

1 Department of Health. Towards equity and access. London: Department of Health, 2005.

2 Ridgeway SM. Deaf people and psychological health – some preliminary findings. *Deaf Worlds* 1997; 1, 13: 9–17.

3 Denmark JC. Deafness and mental health. London: Jessica Kingsley, 1994.

4 Prendergast Y. Free your mind. Leeds: Leeds Social Services, 2003.

5 Department of Health. A sign of the times: modernising mental health services for people who are deaf. London: Department of Health, 2002.

6 SIGN/Mental Health Foundation. Deaf mental health charter. London: SIGN/MHF, 2006.

7 Timmermanns L. Research project. European Society of Mental Health & Deafness. In: European Congress on Mental Health and Deafness. Proceedings. Utrecht, 1989.

8 Tuohy B. Working with interpreters using sign language. *Healthcare Counselling and Psychotherapy Journal* 2004; 1.