Developing networks to improve practice, policy, and education with Deaf communities

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This reflection explores my journey working with Deaf communities around improving mental health and learning how Deaf people are affected by health inequalities. It includes information on why Deaf people are at risk of mental health problems and how we can work together to improve mental health services particularly for Deaf people.

Introduction

I remember meeting a Deaf man on an adult acute inpatient unit in the 1990s, while attending a ward review as a Community Mental Health Nurse. At the meeting with a British Sign Language (BSL) interpreter, I thought three things then, and these thoughts have stayed with me:

i)   What is it like to be Deaf and have mental health needs that require inpatient treatment?

ii)   How will this man be able to communicate with staff on a day to day basis? (It was assumed that most staff were not deaf aware or BSL trained).

iii)   How will arrangements continue for booking BSL/English interpreters? (As most staff do not know how interpreter bookings work).

Twenty years later, I am aware that little has changed, being a Deaf inpatient in a mental health setting is still an incredibly difficult and isolating experience (unless you are in a specialist Deaf mental health service). Many mental health staff in various healthcare settings lack the skills to communicate with Deaf people or know how to book a BSL interpreter. Reflecting on

this experience two decades ago and early discussions with a range of health services and individuals in Wales confirmed that little is known by mental health staff about how best to work with Deaf people and that many changes are needed in our current health services.

Reflecting on my own journey as I have started to develop networks with Deaf individuals and communities in different parts of the UK, I have met with a range of influencers and stakeholders in health and social care about what needs to change to improve Deaf people's mental health. Deaf with a capital D, refers to people who identify as and are culturally Deaf; people with hearing loss are referred to with a lower-case d D/deaf is an all-inclusive ter.

Background

Over 11 million people in the UK are D/deaf or hard of hearing, with more than 151,000 people in the UK using a signed language (BSL). Deaf people are twice as likely to develop mental health problems than hearing people (Fellinger et.al., 2012) with the prevalence of mental health problems within D/deaf communities ranging from 30 to 60%. The incidence of mental health problems is due to higher levels of isolation, bullying and trauma, and lower levels of self-esteem are often linked to lower educational achievements and employment rates compared to hearing people. A higher incidence of mental health problems is evident in deaf children compared to hearing children too.

More than 90% of deaf children are born to hearing parents who have no previous experience of Deafness. This means that deaf children are often born into worlds with few D/deaf role models. Hearing families are reliant on advice and information from health professionals and are not always informed about the importance of early language development and ways they can help and communicate with their child from a very early age. Early communication is key, regardless of any later interventions and treatments. Deaf children of

D/deaf parents tend to fare better as they have access to communication, role models and immediate integration into Deaf communities.

Currently there is limited support for hearing families to learn signed language, which supports language development because of costs and availability. Small initiatives and community projects are welcome examples because there is a lack of state provision in this area. Families have been informed to wait for cochlear implants for their children, but the waiting occurs at a key time when children need to be immersed in language to support their overall development. Most deaf children begin life with inequalities stacked against them with abuse and discrimination being common experiences as they grow into adulthood, often resulting in a need for mental health support. Access into services for people with specific needs is often a significant challenge. While motivated people struggle to access help, those with previous poor healthcare experiences are often reluctant to approach services. The image above 'Burdens of mental health problems on deaf people' by Fellinger, a Psychiatrist who works with Deaf, Deafblind and people with Intellectual disabilities, shows the complexity of accessing services.
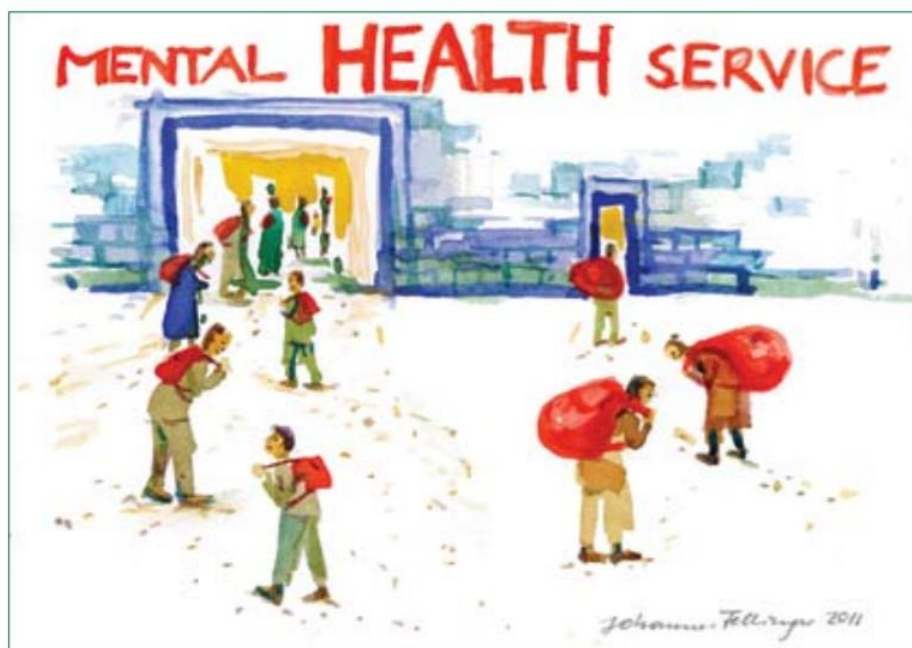
Figure: Burden of mental health problems on deaf people
The burden of mental health problems is symbolised by rucksacks, which everyone carries and from which they seek relief. The rucksacks of deaf people are bigger but the entrance to services is smaller, because accessibility is poor.

Drawing Fellinger from The Lancet (2012), reproduced with permission.

D/deaf people experience challenges in primary care settings with booking appointments, confusion around who organises interpreters, poor communication with receptionists, reliance on audio systems, short appointments, lack of D/deaf awareness, information that is not accessible, variable quality of interpreters, and reliance on family/friends to provide interpretation (Bown, 2020). These frustrations have existed for D/deaf people for decades resulting in a lack of confidence in health services, and often reliance on health information from family, friends and social media, with risks of increased anxiety, inaccurate information and missed diagnoses.

For the majority, routes into mental health services start through primary care. Generally mental health services are very stretched, but mostly GPs provided screening and initial suggestions to local primary mental health services or secondary services where needed. However, health literacy in Deaf communities is lower than in hearing populations, which

extends to mental health literacy too. Resulting in few D/deaf people knowing how to seek help for mental health problems and a reluctance to engage due to previous poor experiences in primary care. D/deaf people often attend primary care more than hearing people, and this is reportedly due to not having issues resolved. Engaging in medical appointments with staff who are unaware of' Deaf culture, trying to communicate solely through written notes, while discussing personal issues through an interpreter is often an experience many D/deaf people wish to avoid.

Increasing the number of Deaf health professionals

The pandemic has shown the public that a career in the helping professions is worth considering due to an increasing focus on mental health needs, and regular work given NHS's job vacancy rates. However, higher education providers have been slow to recruit people with disabilities to health professional programmes. Both employers and Higher Education Institutions could do more through positive action to encourage people from specific population groups sharing a protected characteristic who have: a) different needs, b) a past track record of being disadvantaged, c) a record of low participation.

Taking positive action might include providing work experience, mentoring or training. People who are D/deaf may not have considered a health service career. Careers officers may not be aware of reasonable adjustments that can be made. D/deaf people have experienced years of 'you won't be able to do that because you are D/deaf', when what is missing is a lack of positive D/deaf role models and good mentoring. Increasing the number of D/deaf psychologists, D/deaf nurses and D/deaf medics will certainly help to serve D/deaf populations better and raise awareness about issues that D/deaf people experience. The General Medical Council have published advice about equality and diversity requirements relevant for medical students who are D/deaf. The GMC (2015) advise on steps that can be taken to minimise any

differential access, experiences and outcomes and to remove any unlawful discrimination, and provide examples from case studies. Providing training on equality and diversity issues is strongly advocated. Many people are unaware of the availability of equipment, for example amplified stethoscopes for health professionals with hearing loss.

When there is a D/deaf professional in a team there are often increased discussions about how provisions can become accessible for a range of population groups. Although, there are discussions about meeting people's individual needs, yet many aspects of services including initial appointments, information leaflets, booking systems and early engagement still exclude many populations groups. Services who regularly involve service users in reviewing and improving their processes will have improved in this area, but change is slow. When people seek help, they often do not have further energies to raise awareness, to suggest change or to make a complaint. Health professionals themselves frequently think change will involve a cost, when it is usually the case of thinking and doing things differently that can make great improvements to how people experience services.

Deaf friendly tools for mental health practitioners to use with D/deaf service users

Knowing that D/deaf people require accessible services, assessment tools that are meaningful and contextual for D/deaf populations has been important for different age groups and mental health conditions. There are some excellent examples of mental health assessment resources available. Elsewhere in this edition, the Social Research with Deaf People (SORD) team at the University of Manchester resources have outlined their assessment tools with BSL versions including: the EQ-5D-5L BSL, PHQ-9 BSL; GAD-7 BSL and the Short Warwick and Edinburgh Mental Wellbeing Scale BSL (SWEMWBS BSL).

Prior to the development of D/deaf friendly assessment tools, mental health practitioners have relied on interpreters to be present, however this brings several challenges.

According to Morere et al (2019) when practitioners are working with a D/deaf person it is essential that specific information about the severity and aetiology of deafness is included. Records that incorporate an individual's language, communication mode and educational approach, history and setting are vital, as this provides important context, and will aid future care and treatment.

Few health professionals know how to work with a BSL interpreter whose role is essentially to facilitate communication between D/deaf and hearing people. Some interpreters have additional training, supervision and experience of working in mental health settings. Just having an interpreter to communicate assessment questions and responses is simply not sufficient, as it is Deaf culture and context that is so important. For example, clinicians usually seek to draw conclusions based on observations of behaviour, reports from others, and of course pay attention to what services users say and how they say it. Assessments generally include evidence of language dysfluency, of odd, unusual expressions of language, as they can indicate mental illness (Glickman, 2007). Mental health professionals need to determine whether language problems are due to mental illness, language deprivation, both, or other factors.

Practitioners who are experienced in working with people who are D/deaf know that simply using an interpreter, even one skilled in mental health interpreting, is not sufficient because there is a need to understand the impacts of deafness itself as well as potential cultural impacts on which assessment tools are used and how they may be administered (Glickman, 2007).

Improving practice through policies and guidelines

Many people are unaware that Deaf for Deaf services exist. For a D/deaf service user to meet with a D/deaf Psychologist, Counsellor or clinician can mean there is no need for an interpreter.

When discussing personal and traumatic issues, ideally there should be limited numbers present. D/deaf people very often say they would rather talk with a D/deaf worker. However, some can be unsure about confidentiality within D/deaf communities. The number of D/deaf clinicians in the UK is very low, and often D/deaf people find there is a long wait and referral process if they want to access Deaf for Deaf therapies.

The Joint Commissioning Panel for Mental Health together with SignHealth (2017), a leading Deaf charity, developed guidance for commissioners of primary care mental health services and state the need for Deaf people to have a clear care pathway that is equitable to the general population. Everyone who uses mental health services should have equitable access to effective interventions, and equitable experiences and outcomes (under the Equality Act 2010, Deaf people have protected characteristics).

Specific interest groups in the UK for particular population groups continue to meet regularly include people who work within Deaf Forensic Mental Health Services (Psychology led), and the Mental Health and Deafness International Nurse Specialist forum.

NHS contracts with care pathways exist in England for Deaf adults and also for deaf children (NHS England, 2013a; NHS England, 2013b) which state the need for Specialised Mental Health Services for Deaf people to include inpatient, outpatient and community services. The specialised service is provided to D/deaf service users who have significant mental health difficulties and have been unable to access culturally appropriate assessment and treatment services. These specialised mental health people are provided for D/deaf people in England, Northern Ireland and Scotland, but not in Wales.

Deaf awareness training for all

There is a considerable need for health professionals to have D/deaf awareness training, which is best delivered by people who are D/deaf themselves. Healthcare Trusts and Health Boards

occasionally provide basic information, and university programmes may include content on working with D/deaf people, but this is usually ad-hoc. Increasing the number of D/deaf professionals who work in health and care settings will have a positive impact in raising awareness of D/deaf issues as well as providing role models which are often lacking for deaf young people as they consider career options.

Wales, Scotland and Northern Ireland governments were prompt in providing BSL interpreters at their Government Covid 19 briefings unlike England. A #WhereIsTheInterpreter campaign resulted from Deaf communities with the Government subsequently taken to court (the focus on scientific briefings held in Downing Street which came without BSL interpretation). Campaigners have made the language more visible at a government level (O'Dell, 2021).

In 2019, I began a scoping exercise in Wales exploring mental health service provision for D/deaf people. It became apparent that services had little knowledge about the needs of D/deaf people and that the drive for lobbying came strongly from Deaf charities. The All Wales Deaf Mental Health & Well-Being Group is comprised of Deaf and hearing professionals have produced a report about the inequalities of D/deaf people's mental health provision and is about to start a dialogue with Welsh Government to make a case for change, as Wales has no mental health provision for D/deaf people. However, the tenacity and resilience displayed in D/deaf communities is remarkable because D/deaf people have always had to fight to be heard.

Conclusions

Too often population groups are disadvantaged by health and information inequalities. If awareness raising was prioritised during practitioner education there would be a greater awareness of the risks that Deaf communities experience. An increasing focus on improving

D/deaf people's mental health, on positive D/deaf role models and on Deaf awareness for all will significantly improve the overall health of D/deaf people. **2,372 words**

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