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Barriers to Mental Health Care Experienced by the Deaf Community in North Wales.

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The Deaf¹ community should have equitable access to health care as a group of people with protected characteristics. Wales has never provided specialist Mental Health Services for Deaf people. Access to mental health care for deaf people in general is problematic, but it is particularly difficult for the Deaf group of BSL users, for the obvious reason that very few GPs, primary care and secondary care mental health professionals are able to assess and provide interventions in BSL. Similarly, levels of deaf awareness are extremely variable across both primary and secondary care. Anticipated communication problems prevent many Deaf people consulting their GP, and when they do their mental health problem may not be recognised or they may not be referred for counselling or treatment. Educational and awareness-raising programs about mental health problems are usually not available to the Deaf community as they are not in BSL, leading to delays in recognising problems, seeking help and receiving prompt treatment. However, in 2010 the Welsh Government issued guidance to Health Boards with the instruction to develop local solutions for the provision of such services and the Betsi Cadwaladr University Health Board became the first Health Board to support such a development in 2011 by appointing a small team consisting of a Consultant Psychiatrist, Social Worker and a Nurse. The mental health needs of the Deaf community in Wales have received little academic attention. Robinson & colleagues (2003) explored the emotional & mental health needs of children & young people with hearing loss (in North Wales) and identified befriending, peer support and access to counselling services as important factors in promoting a Deaf identity and developing resilience. Inadequate access to health services in general, including GPs and Hospitals, have been reported in Wales (British Deaf Association, 2013; Crimond, 2012), reflecting wider UK concerns about health inequalities in the Deaf population (Alexander et al, 2012; Edmond et al, 2015).

There is a consensus that Deaf people have a heightened vulnerability for developing mental health problems - a lifetime prevalence of 40% is often quoted - while also facing a range of barriers to receiving adequate and appropriate treatments (Fellinger et al, 2012). The higher incidence of mental health problems has been attributed to two main factors: (1) some forms of deafness are caused by damage to the brain before or after birth which might give rise to other difficulties (e.g. meningitis) and (2) deafness for many people is associated with social exclusion and reduced educational and employment opportunities - the links with this and mental health status are well known and documented (DoH, 2005) – and has been identified as a contributing factor in social defeat, increasing the risk for schizophrenia (Govenden et al, 2014). Barriers to access to mental health care include not only the obvious communication problems and shortage of interpreters but also a lack of knowledge of available services

¹ It is the convention to distinguish between the 'Deaf' (British Sign Language users with a distinctive culture) and the 'deaf' (people with a range of hearing loss). The term 'Deaf community' defines a group of people not by their hearing loss but rather by their distinct way of life (Ladd, 1988), with its own language (BSL), traditions, history, values and norms of behaviour (Higgins, 1980). See Sheikh, Leeson and Walker (2012) for an excellent and accessible guide to working with the Deaf community in the UK.

among Deaf people. Checinski (1991) found a low take up of mental health services within the Deaf community and estimated that 90% of the Deaf population's mental health needs remain unserved. It has also been noted that the expression and understanding of mental illness among Deaf people is thought to be unique, reflecting cultural and linguistic characteristics of the community (Thacker, 1991), compounded by hearing professionals' limited appreciation of the Deaf cultural experience of mental health (Griggs, 2004).

Taken together, these issues risk impeding a Deaf person's progress on the pathway to mental health services. Using Goldberg and Huxley's (1980, 1992) early pathway model for mental health services, it is possible to see the potential difficulties faced by a Deaf person trying to navigate mental health systems and how she or he can be disadvantaged at each of the four filters described in the model (figure 1). The first filter, 'illness behaviour', represents the decision of an individual to consult his or her GP; the second filter is the ability of the GP to detect a mental health problem; the third filter is the decision of the GP to refer to mental health services and the final filter is the decision to admit to hospital. This model provides a useful framework for considering how Deaf people obtain access to mental health services and how their needs are assessed. For a Deaf person these filters are even less permeable and often constitute barriers rather than open pathways. If the Deaf person passes through the filters, access to the full range of culturally appropriate interventions (particularly psychological therapy) is likely to be extremely restricted due to the uneven and unequal distribution of services across the UK. Research into the permeability of these filters for Deaf people has been recommended (Connolly, Rose & Austen, 2006).

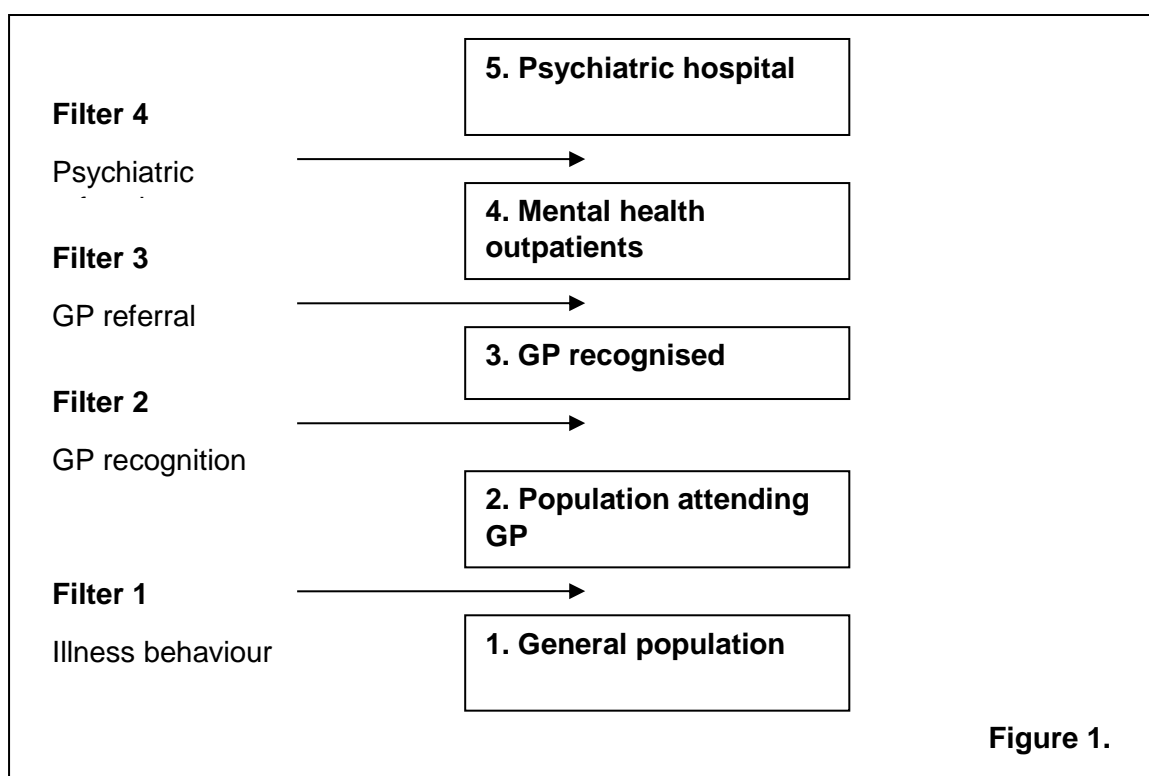


Figure 1.

The framing of the research question for this study placed the experiences of Deaf people at its centre. By asking 'how accessible are mental health services to Deaf people?', the study focused on the person and not the *condition* of deafness, inherent in a question like 'how does deafness interfere with accessibility?' In this sense, the study was concerned with the subjective experience of being Deaf rather than the impact of deafness (Young & Hunt, 2011). The study aimed to describe the Deaf community's experiences of mental health problems

and its preferences regarding a local mental health service in North Wales. The principal intended outcome of the research was to inform the development of a culturally relevant and acceptable pathway into mental health services for Deaf people in North Wales. The research was a small-scale qualitative study exploring the Deaf community's awareness and understanding of the concept of 'mental health problem', ways in which that community seeks help for mental health problems and its experience of mental health service provision. The research set out to interview representatives from three distinct groups: the Deaf community; current users of Community Mental Health Teams and General Practitioners.

Social research with Deaf People.

Conducting research with Deaf people raises a number of epistemological, methodological and ethical issues that are briefly discussed here in relation to the present study. Young and Temple (2014) argue that the epistemological position of the researcher within the research needs to be explicitly described and state that '...researchers and participants are involved in a creative process of *producing reality/realities* rather than reflecting them' (Young & Temple, 2014, p. 39). This perspective on the research process demands that the researcher's input into the production of realities is described in terms of the social, political and personal influences guiding the researcher's choice of study and methodology as well as her or his epistemological orientation. Essential to Young and Temple's position is the notion that knowledge creation cannot be divorced from social and political forces: 'Our epistemological position is that there is no objective truth in the sense of a truth that is independent of who is doing the research' (Young & Temple, 2014, p. 181). In this spirit, therefore, and following the position outlined by Young and Temple (2014, p. 134), we briefly reflect on our positions as researchers in this study.

The first author (DR) is a hearing person with Deaf parents, or CODA (Child of Deaf Adults). He was therefore brought up in a BSL-using household with parents who are members of a local Deaf community (not in North Wales) and is therefore competent in BSL (Signature Level 3) and familiar with Deaf culture through experience and naturalistic exposure. He is also a Mental Health Nurse working with the Deaf community being studied. The second author (HF) was employed as a Research Officer for the study with the primary role of recruiting and interviewing participants. She is a Deaf professional with a cochlear implant and is a member of the Deaf community being studied. The third author (CR) supervised the study and is a hearing person with no BSL competence, but with an academic interest in mental health and society. The three authors naturally have different experiences of Deafness and sign language and occupy different socio-cultural positions in relation to the Deaf community. We are aware of the issues raised by this; for example, the nature of the Deaf researcher's status as insider/outsider in this study and the problematic role of the hearing researchers' interpretation of Deaf participants' signed language (for a discussion see Temple & Young, 2004). We acknowledge that these issues may have affected the validity of this study and we would like to return to them in another paper.

Pollard (1992, 2002) discusses ethics in cross-cultural research, including anonymity, confidentiality and the status of the 'host' community as a participant in its own right and argues that the host community – in this case the Deaf community – should be viewed as a collective entity with the same rights to protection as individual participants, such as rights to information, consent and freedom from harm. In addition, he proposes a number of ethical guidelines for cross-cultural research, including concordance of the research agenda with the host's interests and needs and the stipulation that the research must benefit the host community in ways that are recognised and valued by the host (Pollard, 2002). Given the well-documented

problems experienced by Deaf people in accessing appropriate mental health care, we are confident that this research fits Pollard's guidelines.

Design and procedure.

The study received Ethical approval from the North Wales Research Ethics Committee. Taking a narrative approach to data collection and analysis the study sought participation from members of the Deaf community, current Deaf users of Community Mental Health Teams and General Practitioners, in order to:

1. Explore the challenges facing Deaf people with mental health problems as perceived by the Deaf community.
2. Describe the experiences of Deaf people who have used mental health services in North Wales.
3. Explore the experiences of General Practitioners when identifying and assessing the mental health needs of Deaf people in North Wales.

This was an exploratory study and the maximum sample size was deliberately set at nine. The adult Deaf community in North Wales is small and was considered likely to be difficult to recruit from. It was anticipated that the interviews would generate a rich and detailed dataset, in BSL, and it was expected that this would be an additional challenge for the analysis.

Participants were recruited from the Deaf community by the Deaf Research Officer, following meetings at Deaf events and forums and through personal contacts. Current and previous users of mental health services were invited to participate by their care coordinators and the Specialist Nurse for Deaf Mental Health. General Practitioners were contacted by email with details of the research. All interviews with Deaf participants were carried out by the Deaf Research Officer using a semi-structured interview schedule. Interviews were filmed and the recordings transferred to a secure computer for analysis.

We used a thematic analysis approach, identifying patterns across the qualitative data. BSL issues relating to clarification and nuance were explored with the Deaf researcher. The analysis identified ideas and provisional categories, moving onto broader and more abstract themes. Further work focused on comparing and contrasting emergent themes and their significance for the deaf community and service development.

Results.

All General Practitioners were contacted, but there were no responses. Four members of the Deaf community (2 male, 2 female) and one service user (female) were interviewed. Six themes were identified: the meaning of 'mental health'; the role of interpreters in mental health care; the role of Doctors; the role of the Deaf Community; the nature of treatment and help and what Deaf people need.

The meaning of 'mental health'.

Each Deaf person interviewed discussed 'mental health' in terms of both maintaining wellbeing and the possible reasons for developing mental health problems. Both dimensions were connected to the experience of being Deaf: for example, good mental health was considered to be dependent upon having knowledge and understanding of the hearing world (being able to navigate through the hearing world) and Deaf people were described as more prone to

mental health problems than hearing people because of communication issues. Being resilient, persevering and strong were seen as qualities that maintained emotional wellbeing - one participant's motto was 'never give up'. Good mental health comes with a positive Deaf identity and the ability to be assertive and express yourself as an equal in BSL; an oral education, on the other hand, was identified by one participant as increasing the risk of mental health problems. Similarly, attending a residential school for the Deaf was seen as a protective factor, as it enabled people to be connected and reduced isolation; although one participant described the shock of entering the hearing world after residential school: 'in school I was at the top, in the hearing world I was at the bottom'. Participants also referred to their own or others' experiences of over-protective or over-controlling parents who 'spoiled' the Deaf child by creating dependency or limited the child's day to day learning by responding to questions with answers like 'don't worry' and 'I'll explain later'. These kinds of experiences were seen as potential causes of mental health problems later in life. In these ways, the participants construed mental health in terms of coping with the hearing world (in contrast to the hearing world's assumption that the Deaf person is struggling to cope with deafness).

The role of interpreters in mental health care.

The role of interpreters was discussed in relation to consultations with both GPs and mental health workers. In general terms, using family members as interpreters was problematic, although one participant said that she was very comfortable with her hearing partner acting as a communicator with her GP. A common experience was the tendency for family members to provide clearly abbreviated summaries of GPs' information, with responses like 'I'll tell you when we get home' when asked for more detail. Some participants said they would not trust interpreters to maintain confidentiality regarding mental health issues and were concerned that with a small pool of interpreters in North Wales it would be awkward to use the same interpreter for both sensitive mental health appointments and other more practical tasks. Meeting the interpreter at social functions was also seen as potentially embarrassing and stigmatising. Interpreters from outside the area were preferred for mental health interventions. One participant suggested that even an interpreter could misinterpret vital communication in the context of extreme emotional distress or illness and recommended that Deaf relay workers should be included in such sessions (a Deaf BSL user who is able to ensure that all communication is accurate and pitched at the right level for the Deaf service user).

The role of Doctors.

There was agreement that GPs are not sufficiently 'deaf aware' and two participants described particularly negative experiences where they were made to 'feel small' and treated as if they were 'stupid', with little or no information shared by the Doctor. This was summed up by one participant as 'Hello, how are you? Take these tablets'. Another participant described a GP abruptly ending the consultation by standing up, without any warning. A 'Deaf GP would be wonderful!', was one participant's comment.

The role of the Deaf community.

The participants expressed mixed views on the Deaf community's attitudes towards mental health problems, ranging from acceptance to rejection: 'in Deaf clubs, most people will want to keep away from people with mental health problems, no patience with them' while, on the other hand, 'being with Deaf is like getting a fix, recharged batteries'. It was noted that the Deaf community is very small and enjoys gossip, hence the observation that 'Deaf are very secretive, keep problems to themselves, appear happy on the surface', pointing to a strategy adopted by some Deaf people who might be experiencing mental health issues. This reflected

a view held by one participant that it is better not to engage with a person in distress, 'don't go too deep, will make things worse'.

The nature of treatment and help.

Most of the participants said that they knew little about the range of treatments they could expect from a mental health service when directly asked, although some discussed counselling in relation to other questions. One participant referred to visiting a psychiatric hospital and described staff wearing white coats who appeared 'to know everything'. The same person perceived hospitals to be like prisons, where people were treated with injections and the 'electric chair'. Another participant said that treatment involves being 'taken away for two or three months'. A third participant had been referred to SignHealth (a third sector organisation providing psychological therapy in BSL) and commented that they 'didn't look professional' and 'didn't help, signing didn't match' (a discrepancy in signing register between client and therapist). One participant expressed doubt that a Deaf counsellor could be competent as they might not 'stick to the point, wander off the subject'. This participant knew a Deaf counsellor who has 'problems himself'.

What Deaf people need.

Recommendations from participants fell into three categories: action within the Deaf community; action by the third sector and system-wide action to provide easy access to skilled psychological therapy. At the community level, it was said that more Deaf groups were needed to maintain social connections and promote Deaf pride and mutual support. Examples were groups for expectant mothers, new parents and mother and toddler groups. This related to a need for Deaf people to support others in talking about problems rather than sweeping them under the carpet. The third sector was criticised for being too focused on acquired deafness when it should be facilitating more opportunities for Deaf people to meet and help to organise befriending networks. According to one participant, it is difficult to complain about services due to fears about possible consequences. This participant indicated that this was due to a third sector monopoly locally, creating dependency in some Deaf people. At the system level, including statutory and third sector organisations, delays in receiving help need to be eliminated and information about mental health issues, including how to seek help, needs to be delivered to the Deaf community. Counselling should be provided; one participant was anxious that a Deaf counsellor couldn't be trusted while another said that 'the hearing don't have a clue, must be deaf' and a third was equally adamant that a Deaf person should 'go straight to Deaf counsellor'. The option of a hearing therapist with an interpreter was seen as barely acceptable and only if the therapist had received deaf awareness training. Systems in Wales should match those in England, said one participant.

Discussion.

This was a very small sample of the North Wales Deaf community. The sample cannot be considered to be representative as it is based on selection by the Deaf researcher. The Deaf community can be viewed as a hard-to-reach group and this research did not attempt to penetrate the hardest to reach members of this group (for example, those who are not well-connected with the community, do not use Deaf social networks or are marginalised within an already marginalised group). The failure to recruit GP participants has restricted the scope of the findings from the research, which are necessarily one-dimensional and reflect only the Deaf view of access to mental health care. These limitations mean that the conclusions drawn from the research need to be cautious and subject to further scrutiny.

However, the themes that have been identified here do suggest potential ways to overcome barriers faced by Deaf people in accessing mental health care and reflect findings from other

studies in the area of Deaf wellbeing, for example in the work by Griggs (2004). The role of coping in a hearing world has emerged as both a source of stress and a determinant of poor mental health as well as a characteristic of positive emotional and psychological wellbeing. Issues relating to interpreting, effective communication with health professionals and information deficits have also been raised in a recent community survey of Deaf people (Baker et al, 2014). In their survey of 43 Deaf people, the Nottinghamshire Deaf Wellbeing Group (Baker et al, 2014) found that only 33% of those interviewed used an interpreter when seeing a GP and 19% admitted that they did not fully understand the treatment given to them by the GP. The North Wales study and the study by Sheppard and Badger (2010) into depression among Deaf adults point to fears about familiarity with interpreters and confidentiality and this may explain the reported low use of interpreters in GP consultations. The Nottinghamshire group found that willingness to use specialist mental health services was questionable, with 42% saying that they would not seek help from the specialist Deaf mental health service. The authors suggest that this could be due to the absence of serious mental health problems requiring secondary care, a preference for BSL counselling and a lack of understanding of services and how to access them: 'Many Deaf people said that they are unsure what services are available to them. They also discussed how they could find out more, and want to be able to make decisions about what is best, but they continuously struggle to find out information to help them make those decisions' (Baker et al, 2014, p. 10). This sentiment is echoed in the North Wales sample, confirming that help-seeking behaviour can be inhibited by both lack of information about the type of help available and structural barriers in services providing that help. Recent work by the London Assembly Health Committee (2017) has also identified this issue, adding that it is compounded by 'the lack of a shared mental health vocabulary between health professionals and disabled or Deaf service users. Contributors to our investigation told us that it can be difficult for some disabled and Deaf people to recognise the symptoms of depression or anxiety and to articulate them to people who could offer support. So it is vital that information on how to recognise mental ill health is made more widely available' (p. 14).

Exploring the lived experience of depression among Deaf adults, Sheppard and Badger (2010) identify themes of 'Reaching out' and 'Deaf-belonging' in the narratives of participants. Reaching out for help is difficult for some because of concerns about interpreter confidentiality and stigma while a sense of Deaf-belonging provided 'the greatest moderator for depressive symptoms' (Sheppard & Badger, 2010, p. 788). Again, these are themes that are evident in the North Wales study, underlining the need for an approach to mental health care and wellbeing that is adapted to the cultural and linguistic needs of Deaf people.

Conclusion

The barriers that have been described by the participants are both internal to the Deaf community and its members and external to health service providers. Internally, the research points to 'fund of information deficits' (Pollard& Barnett, 2009) regarding mental health and to stigmatising attitudes in the Deaf community that may inhibit help-seeking behaviour and mutual support (Steinberg et al, 1998). Additionally, there is evidence for a lack of faith in the ability of providers, both health professionals and interpreters, to act in a safe, confidential and competent manner. There is also expressed concern that the Deaf community itself is not an entirely safe space in which to explore mental health issues for its members. Taken together, these factors suggest that mental health services need to actively engage with the Deaf community and the third sector, perhaps using a co-production model, to develop a strategy to improve mental health literacy and refine the meaning of 'coping' for Deaf people. The Deaf community in North Wales is very small in number but its members are very well connected and keen to engage with mental health services. What is needed is a model that promotes

emotional well-being, on a continuum from self-help to group and individual interventions across North Wales, making best use of practitioners who are either Deaf or skilled BSL users from the 3rd and private sectors. There is a vital role for Deaf advocates, professionals and role models in this process of education and stigma reduction for both the Deaf community and hearing service providers.

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