Cyflwynwyd yr ymateb i ymgynghoriad y <u>Pwyllgor Iechyd a Gofal Cymdeithasol</u> ar <u>anghydraddoldebau iechyd meddwl</u>

This response was submitted to the <u>Health and Social Care</u> <u>Committee</u> consultation on <u>mental health inequalities</u>

**MHI 17** 

Ymateb gan: | Response from: All Wales Deaf Mental Health and Well-Being Group



# Response to Senedd Mental health inequalities consultation

From: All Wales Deaf Mental Health and Well-being group

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#### Context of submission

The context of our submission is Deaf British Sign Language users in Wales, as that is the focus of the All Wales Deaf Mental Health and Well-being Group. We are also aware that d/Deaf Cochlear implant users and hearing aid users experience similar mental health inequalities in Wales.

## Deaf people are disproportionately affected by poor mental health in Wales

40% of Deaf people experience mental health problems, which is twice that of individuals in hearing populations (Fellinger et al., 2012). There are around 575,000 deaf and hard of hearing people living in Wales (Action on Hearing Loss, 2016), and this includes over 4000 people who use British Sign Language (BSL) (Shank & Foltz, 2019).

The reasons why Deaf people are disproportionately affected by poor mental health include a range of factors. Deaf children, particularly those born to hearing parents, are disadvantaged from birth as they do not have access to the same education and health opportunities as their hearing peers (Hermann et al, 2014; Murray et al, 2019). Potentially hearing parents might have had no experience of a visual language (i.e. BSL) nor have they had any contact with Deaf role models. If parents and siblings cannot use BSL, children are isolated, and families struggle with communication (Collinson, 2017). Equally deaf children in education settings, including residential schools, may have experienced abuse and not been able to communicate this to their families.

There is little support or resource for the Deaf child's family to learn BSL (Bowen & Holton, 2020). The skills and knowledge that people develop in their own culture is limited (Young & Hunt, 2011) as deaf children do not have the opportunity to incidental learning opportunities, to ask questions and pick up news, information or social capital which extends into education (Listman, Rogers & Hauser, 2011).

The incidence of mental health problems for deaf children and Deaf adults 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 (Terry, 2021).

As over 2500 children in Wales are Deaf, around 1000 children in Wales will likely be at risk of mental health problems in the future (Wright, 2020). Currently there are no established links between Deaf Child and Adolescent Mental Health Services (CAMHS) in Wales and Deaf CAMHS services in the UK, as there are between

hearing CAMHS services with Wales and other hearing CAMHS service in other UK areas.

Deaf people regularly experience isolation, discrimination, and stress daily (Bone, 2019) which contributes to experiences of anxiety and depression. Current health services rely heavily on audio provision from reception entry systems, telephone screening, and audio interventions. These examples apply to primary and secondary services generally, again indicating to Deaf people that services are full of barriers (Royal College of Psychiatrists, 2017).

Deaf people often experience limited access to healthcare, variations in access to education, negative societal attitudes and reduced opportunities regarding work and leisure (Lesch et al., 2019; Dreyzehner & Goldberg, 2019). Deaf people in Wales have reported poor experiences with health services generally, often leading to them avoiding contact with health services due to poor past experiences, which also leads to poorer mental health experiences.

Many Deaf people are not recorded as being Deaf in their primary care records. If they are then referred to other health services, specific details that may impact on their health service experience are frequently not passed on and therefore unknown.

The coronavirus pandemic has forced many people into poverty, unemployment and mental health crisis with the exclusions faced by Deaf BSL users even more stark (Redfern & Baker, 2020).

Wales is the only UK country that does not provide a clear pathway or service to meet the needs of Deaf people experiencing poor mental health (British Society for Mental Health & Deafness, 2020).

#### Barriers to accessing mental health services for Deaf people in Wales

There is no Deaf specialist mental health service in Wales. Deaf people have difficulty accessing mental health services, and health services more widely that are available to the hearing population for reasons described below.

In terms of health services broadly, in 2019 Public Health Wales commissioned a report to explore health behaviours and barriers experienced by Deaf people in Wales and reported that access to health services is a major problem and Deaf people often avoid contact with health services due to poor past experiences (Shank & Foltz, 2019). In 2010 the Welsh Government commissioned the Royal National Institute for Deaf People to investigate the inclusion barriers faced by Deaf and hard of hearing people in Wales. 84% of Deaf respondents highlighted that it was hard to use health services because there was limited provision for Deaf people to use services in Wales particularly health services.

New patient forms at General Practitioner (GP) surgeries often do not ask about hearing, so if people attend for a screening appointment this information may be recorded but is rarely collated on health databases or central systems. Many GP surgeries do not know local arrangements for booking BSL/English interpreters to enable Deaf people to engage in meaningful discussions at health appointments.

Mental health professionals, and indeed all health professionals, seldom have Deaf awareness training during their professional education, few have any British Sign Language knowledge, and few also know how to book and confirm BSL/English interpreters for appointments and treatment sessions. Equally few BSL/English interpreters have had mental health training. Few mental health clinicians know how to assess a Deaf person's mental health and are not aware of important contexts and differences or available tools that help and are culturally relevant (Rogers et al., 2016). There are validated BSL mental health assessment tools, but few clinicians in Wales can use them. Scoring is not the same on generic assessments, as there are cultural and linguistic differences, so there is a need for adaptation and the use of appropriate tools.

A lack of experience and awareness of engaging with Deaf people with mental health problems means there is virtually no accessible help in primary, secondary or tertiary mental health services in Wales for Deaf people; and certainly little access to specialist services like for people with eating disorders or perinatal services.

Wales has very few Deaf mental health clinicians. Deaf for Deaf services are available, but this depends on knowledge about these, and about funding arrangements and outcomes. Sadly, there have been examples of Deaf people being referred for services that are not accessible or appropriate for them, for example mindfulness courses where Deaf people have been asked to 'close their eyes and listen'.

Despite having recognised BSL as a language in its own right (National Assembly for Wales, 2006), there is a shortage of BSL/English interpreters across the UK (Department of Work & Pensions, 2017). On the National Register of

Communication Professionals working with Deaf and Deafblind people, only 48 individuals are registered as resident in Wales with 6 at training level, which is below the target of 64 set (Welsh Government, 2019a). Equally few staff understand the context of booking a qualified and registered interpreter (Association of Sign Language Interpreters, 2021).

A 2020 Freedom of Information request (FoI) suggests that Deaf people are required to ask for information in an accessible format, like an information leaflet in BSL, unlike that of Welsh speakers who are afforded an active offer.

People want to access local services and so clinicians do not have broad experience of working with d/Deaf people. Frequently there is an assumption that d/Deaf people can lipread or read standard written information when this is rarely the case.

There are barriers to involvement in improving services, as d/Deaf people cannot easily take part in discussions, consultations and active involvement as they are seldom offered an accessible option, even responding to this consultation there has been no active offer by Welsh Government. There was mention of sending a video, but no mention of BSL or the provision of how a deaf person might put forward their views.

Please note when consultations about equalities are publicised, there needs to be adequate time for people to have the information in their preferred format and then to respond. The same is true for all marginalised communities. There is an assumption about reading levels, language and how people engage. In order to get information out to Deaf communities about any consultation, time and resource needs to be considered to ensure information is accessible to Deaf people, and then support individuals and groups in order to encourage people to take part.

Deaf people persistently battle to access mental health services, with limited provision for Deaf people in Wales. South Wales has no specialised Deaf mental health network, and the service in North Wales reported by Reader, Foulkes and Robinson (2017) has now dissolved. Mostly Deaf patients requiring in-patient care are referred to England, at great distance from their families and social networks, and at significant financial cost to the health service.

### How Welsh Government policy does not recognise or address Deaf people's mental health needs

Policy is often developed in isolation with little cross-over and a lack of joined up thinking. For example, there is little link between the All Wales Standards for Accessible Communication with Together for Mental Health (Welsh Government, 2019b). The Standards for Accessible Communication need to be monitored and revisited as Health Boards are simply not rising to the challenge to meet them at all. There is mention of people with sensory loss in Together for Mental Health with an acknowledgment of increased risk of mental health problems but no plan as to intervention or implementation.

Together for Mental Health includes a focus on helping people at risk of mental health problems including those vulnerable groups and with protected characteristics under the Equality Acts on (Chapters 1 and 2), but the strategy goes no further. The comprehensive mental health needs of Deaf in Wales are not fully recognised.

We appreciate that policy aims need to be broad, but unless specific objectives are identified and then evaluated then little change occurs. There has been mention that the All Wales Standard for Accessible Communication will be evaluated in each individual Health Board in Wales, if this is the case then shortfalls can start to be addressed. Changes to the way we communicate with Deaf people has a significant affect on their mental health because this would immediately start to improvement Deaf people's engagement with health services and start to reduce anxieties and frustrations.

The gap that exists for Deaf people in Wales regarding mental health provision is slowly receiving increasing recognition, mostly through the efforts of our group and through Deaf charities.

Key stakeholder mental health organisations recognise the increased risk that exists for Deaf people (Centre for Mental Health, 2020), but the Welsh Government has not recognised the risk or provided support to Deaf communities so far. Due to these mental health inequalities, the All Wales Deaf Mental Health and Well-Being Group launched their report *Deaf People Wales: Hidden Inequality* in 2021 and awaits further dialogue and action from Welsh Government (Terry et al., 2021).

The new Wolfson Centre for Young People's Mental Health is a welcome addition to Wales research and improvement community in Wales, however so far there is no mention of any accessible events, nor how they will engage with young people from minority backgrounds, who are at most risk of mental health problems.

Whilst data linkage is increasingly being used to increase knowledge about population health, there are further challenges in this area. Following liaison about a number of potential projects with both the Secure Anonymised Information Linkage (SAIL) Databank, based at Swansea University, and with Digital Health and Care Wales, it is apparent that our current systems in Wales are not able to provide accurate information about the number of Deaf people, or the number of Deaf people

with mental health problems. The NHS Wales Informatics Services agree this to be the case.

We note that there is a consultation on the mental health workforce plan out currently led by Health Education and Improvement Wales (HEIW). Improving the knowledge, skills and Deaf awareness that our health and care workforce have in Wales will make a significant difference to Deaf people's mental health. In Wales we have over 9000 health professional students in Wales currently undertaking their education to become the next generation of nurses, doctors, and allied health professionals. Welsh universities are in a prime position to positively influence the way students are taught about how to work with people who are Deaf. There needs to be greater joined up working between government and providers. The public has few reassurances that consultation groups liaise and work collaboratively as they should.

### Further action needed to improve outcomes for Deaf people's mental health in Wales

Our *Deaf People Wales* report highlighted the following key recommendations which are built on research conducted in Wales, the UK and from existing evidence.

- Increase health and care workers' knowledge of basic BSL and how to book Sign Language BSL/English interpreters
- Primary care staff to have increased knowledge of available mental health services for Deaf patients and to signpost
- Direct referrals for Deaf patients to access NHS funded Deaf counselling services.
- Basic training around Deaf issues for all health and care workers
- An accessible helpline and signposting service would direct individuals, families and workers to timely advice
- Monitoring effectiveness of Health Boards' delivery of All Wales Accessible information standards
- Improve access to information for BSL users by adopting same rights as Welsh speakers to services
- Re-establish links between Child and Adolescent Services (CAMHS) in Wales with Deaf CAMHS in England

Whilst there has been increased use of online interpreter provision, this is not recommended for mental health appointments, because it is important to book an appropriately trained, qualified, and registered interpreter who conducts a face to face appointment. The lack of qualified interpreters leads to unsatisfactory (and sometimes dangerous) situations in the healthcare sector, particularly mental health, and context can be misconstrued.

Policy for workforce development needs to include interpreters and translators given the accessible communication standards and that Welsh Government has not yet achieved its aim of 64 qualified interpreters.

Failing to ensure the BSL/English or BSL/Welsh interpreting cost and service provision at 3rd party commissioning results in delays to access and further delays to treatment. It is imperative that language costs are planned for at the outset.

There are four main providers of interpreting services for Deaf people in Wales and they provide services to facilitate communication between Deaf and hearing people Arrangements for booking BSL/English interpreters are patchy and not always known to Deaf people. Frequently health staff are unaware of how booking systems work and do not know how to help. Online interpreting can be an alternative, but uptake in Wales remains low due to procedural and technical issues.

Many workers, organisations and departments will not have considered the mental health needs of deaf communities before, which is why d/Deaf people with mental health problems are a hidden population. Although there is an increased risk of poor mental health, psychiatrists and mental health practitioners may not see the number of Deaf people due to people's reluctance to engage in services.

#### Summary

In terms of the triple barrier mentioned by the Centre for Mental Health, Deaf people certainly are i) disproportionately at risk of poor mental health ii) as a group with poor mental health, Deaf people have great difficulty accessing services and iii) when or if Deaf people have received mental health support, outcomes have been poorer as services are absent, not provided in an accessible way, not with information in an accessible format, and there is no Deaf mental health service for people in Wales.

The All Wales Deaf Mental Health and Well-being Group collaborated with Deaf and hearing professionals to compile the report *Deaf People Wales: Hidden Inequality*, which was launched at the Cross-Party Group on Deaf Issues in October 2021. BBC Wales covered the report with members of Deaf communities discussing their frustrations as the lack of mental health services in Wales on 8<sup>th</sup> December 2021.

On 14<sup>th</sup> January 2022, AM Mark Isherwood's Senedd debate provided an overview of the health inequalities experienced by Deaf people in Wales in relation to mental health service provision. These mental health inequalities have been experienced by Deaf people in Wales for far too long.

These inequalities for Deaf people existed before the COVID-19 pandemic, but the pandemic has made them worse.

In summary, the All Wales Deaf Mental Health and Well-Being Group are keen to continue a dialogue with the Welsh Government about the issues raised in this consultation response. It is essential that progress is made towards immediate and short-term solutions, as well as effective long- term provision to improve mental health pathways for Deaf people in Wales.

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