

Deaf People Wales: Hidden Inequality

This report has been compiled in collaboration with:











June 2021

Deaf People Wales: Hidden Inequality

Suggested citation:

Terry, J., Redfern, P., Bond, J., Fowler-Powe, M., Booth, C. (2021). *Deaf People Wales: Hidden Inequality*. All Wales Deaf Mental Health & Well-Being Group. June 2021.

Affiliations:

The All Wales Deaf Mental Health and Well-being Group task and finish group are collectively: Julia Terry (Swansea University), Paul Redfern (BSMHD), Jacqui Bond, Michelle Fowler-Powe (British Deaf Association) and Cath Booth (Royal National Institute for Deaf People), and are authors of this report.

About this report

This report outlines the situation for Deaf people in Wales who experience mental health problems and the present position regarding health service provision. The purpose of this report is to raise awareness within the Welsh Government and other relevant stakeholders to achieve positive outcomes for Deaf people because they experience a high number of mental health and physical health inequalities. This report highlights a number of concerns and includes case studies and suggested solutions to improve Deaf people's mental health. Wales is the only UK country without a specialised Deaf mental health service.

In recent consultations and calls for evidence (Centre for Mental Health, 2020; Mental Health Reform, 2015) Deaf people's mental health was highlighted as an area of need in Wales that has been overlooked. Increasing evidence shows that there is a clear need for action to improve Deaf people's mental health in Wales by understanding the issues, investing in, and providing relevant and accessible services. The Centre for Mental Health (p20, 2020) recognises that Deaf people are a Group who experience major inequalities around mental health, and that 40% of Deaf people will experience a mental health problem; double that of the general population.

During the past 12 months there has been an increase in mental health literacy and support in Wales through the British Society for Mental Health & Deafness' Hear Deaf Mental Health project, mostly delivered by the third sector through grant funding (Community fund – formerly Big Lottery), and these initiatives are highlighted in this report.

The case studies and quotes are based on real-life stories and experiences, with identifying features removed and anonymised.

A Group of Deaf and hearing professionals collaborated during 2020 and 2021 to review previous and current support of mental health initiatives for Deaf people in Wales, and their names and organisations are listed on the Acknowledgements page.

What this report is not:

This document does not report on the prevalence of mental health difficulties in Wales for Deaf people because currently there is no funding or resource provision to access the statistical evidence available.

Resources:

This document has been produced through goodwill and co-operation of individuals and organisations involved, without commission or funding.

©2021 Swansea University material contained in this document may be reproduced under the terms of the Open Government Licence (OGL). www.nationalarchives.gov.uk/doc/open-government-licence/version/3/ provided it is done so accurately and is not used in a misleading context. Acknowledgement to Swansea University to be stated www.swansea.ac.uk

Contents

About this report	2
Definitions of Deafness	3
Executive summary	
Introduction	7
Background	8
Examining the evidence	13
A UK map of Deaf mental health service provision	19
Ambitions and solutions for Welsh Government	21
Conclusion	22
References	23
Acknowledgements	27
Appendix One: Deaf charities supporting people re COVID 1	928
Appendix Two: Progress - All Wales Deaf MH & Well-being (3roup29
Appendix Three: Case studies	31
Appendix Four: Specialist Mental Health provision in Englar	າd35

Definitions of Deafness

People with profound hearing loss are described as Deaf using an upper case 'D' in Deaf to define people who use British Sign Language and identify as members of the Deaf community.

When deafness is referred to with a lower case 'd', this refers to hearing loss. This report focuses specifically on the needs of Deaf British Sign Language users.

Executive summary

This report outlines the situation for Deaf people in Wales who experience mental health problems and the present position regarding health service provision. The aim is to raise awareness within the Welsh Government and other relevant stakeholders to recommend ways to improve mental health outcomes for Deaf people in Wales.

The All Wales Deaf Mental Health and Well-being Group collaborated with Deaf and hearing professionals to compile this report to provide an overview of the health inequalities experienced by Deaf people in Wales in relation to mental health service provision. A literature search was conducted, then data gathered from case studies from Deaf people and British Sign Language (BSL)/English interpreters, evaluations of mental health promotion initiatives involving Deaf people, statistics from Sign Language interpreting agencies, and information from UK specialist Deaf mental health services.

The report was produced as **40% of Deaf people experience mental health problems, which is twice that of individuals in hearing populations** (Fellinger et al., 2012).

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).

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).

This report draws attention to the following findings:

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).

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).

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.

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. 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.

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).

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.

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).

There is little support or resource for the Deaf child's family to learn BSL (Welsh Government, 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).

Deaf people regularly experience isolation, discrimination, and stress daily (Bone, 2019) which contributes to experiences of anxiety and depression.

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.

The Secure Anonymised Information Linkage (SAIL) Databank, based at Swansea University, reports our 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 support this view.

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.

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.

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.

The following recommendations based on this report's findings will make significant improvements to the positive mental health of Deaf people in Wales:

Key recommendations:

- ➤ 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
- Deaf patients can directly go to 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 with Deaf CAMHS

In summary, the All Wales Deaf Mental Health and Well-Being Group are keen to start a dialogue with the Welsh Government about the issues raised in this report. 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.

Introduction

The aim of this report is to inform stakeholders about Deaf British Sign Language (BSL) users attempting to access mental health services in Wales both before and during the coronavirus outbreak. Equity of access to mental health services for Deaf BSL users is vital if mental health services are to overcome the discrimination that prevents first language British Sign Language users from accessing support and therapeutic help in their language of need. As the coronavirus storm continues to unleash strong currents sweeping many people into poverty, unemployment and mental health crisis, the exclusions faced by Deaf BSL users have never been more evident.

Within the context of Covid 19 a number of individuals and organisations have highlighted the impact of the pandemic on the general population's health. Deaf communities would benefit from a targeted approach (see Appendix One) given the difficulties they experience accessing GPs, primary care, community support and the need for face-to-face communication, compounded by the disproportionate effect of covered face masks which limit communication and prevent Deaf people accessing information in person.

The All Wales Deaf Mental Health and Well-being Group have collaborated with Deaf and hearing professionals and Deaf service users to compile this report, which seeks to provide an overview of the health inequalities experienced by Deaf people in Wales in relation to mental health service provision. Deaf people have double the risk of experiencing a mental health problem than individuals in hearing populations. This report highlights reasons for this increased risk, examines evidence about populations and interpreting provision; and provides a map pinpointing Deaf mental health services in other parts of the UK. The final element of this report highlights solutions in line with Welsh Government policy. These solutions are selected by Deaf people themselves and will help to improve their mental health and overall well-being (Appendix Two).

The Welsh Government is committed to promoting equality of opportunity in all aspects of Welsh life including race, language, religion, disability, age, sex, gender reassignment and sexual orientation.

We must meet the specific duties, which are set out in the Equality Act 2010 (Statutory Duties), and the (Wales) Regulations 2011 to ensure people with protected characteristics are treated in an equitable way.

Background

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). It is reported that 40% of Deaf people experience mental health issues during their lifetime, which is twice that of the general population (Fellinger et al., 2012). The mental health needs of Deaf people are significant in our communities (Cabral et al., 2013; Reader et al., 2017), but the actual prevalence of mental health difficulties for Deaf people in Wales remains unknown.

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). These often result in Deaf people experiencing inequalities, and not sharing an equal status to hearing people. If a Deaf person experiences high levels of discrimination, feels marginalised and has low self-esteem, they are likely to have lower levels of psychological well-being than the general population (Rogers, Ferguson-Coleman & Young, 2018).

Deaf BSL users and information about them, is often not recorded. There are assumptions that Deaf people have acquired some spoken language to lipread or read written notes and this is not always the case. Coding and information recording is based on workers' understanding, and there is no current robust way of capturing people's preferred language. Many Deaf people are not recorded as being Deaf in their primary care records. If they then are referred to other health services, specific details that may impact on their health service experience are frequently not passed on and are therefore unknown.

According to SignHealth (2013), who conducted the largest health survey of Deaf people, there has been no real national attempt to address the health of Deaf people. Health and care providers should be making reasonable adjustments for Deaf individuals, such as offering communication support. Many Deaf people have low expectations of healthcare because of previous poor experiences. Deaf people would be more empowered if they were aware of how to raise concerns and complaints, but current systems do not allow them to engage in these processes due to a lack of equity of access to complaints systems. Although the Welsh Government (National Assembly for Wales, 2006) provided advice for public services to be delivered in BSL, very little has been implemented.,

In 2010 the Welsh Government commissioned the Royal National Institute for Deaf People (2010) to investigate the inclusion barriers faced by Deaf and hard of hearing people in Wales. 84% of respondents highlighted that being Deaf made it harder to use services in Wales, and 96% of those stating that health services were the most difficult to use. Reasons for difficulties using services were that few people know how to communicate with Deaf people. Deaf people noted that there was frequently an absence of information in a relevant format, due to the use of audio systems, and limited information in BSL.

Having recognised BSL as a language in its own right (National Assembly for Wales, 2006), a BSL Futures initiative with £2.7million from the Welsh Assembly Government and the European Union aimed to increase the number of professional BSL/English interpreters in Wales to a target of 64. Unfortunately, this has not been reached, there are currently only 48 registered BSL/English interpreters resident in Wales and 6 at training level on the National Register of Communication Professionals working with Deaf and Deafblind people (NRCPD), so interpreter provision remains insufficient for Deaf people's needs. BSL/English interpreters may travel from England but may not have the local knowledge – in terms of both sign variation (similar to local dialect and idioms) and locality.

A 2020 freedom of information request (responses from 19 Welsh local authorities) suggests that Deaf people are required to ask for information in an accessible format. Due to its status in law, Welsh speakers are afforded an active offer, and BSL users would also benefit from a similar offer. The freedom of information responses advise that staff would explain relevant information, examples requested were consented to share information and financial charging, by staff members or BSL/English interpreters, but only one authority advised that there could be a delay in arranging an interpreter. The nature of a visual spatial language means that specific access requirements are not always factored into the practicality of provision unlike via the telephone for spoken language BSL/English interpreters.

In February 2021 a motion for a BSL Bill was passed by the Welsh Parliament, which signifies change, as in Wales, BSL currently lacks the legal status that Welsh has been afforded. In Scotland, the BSL (Scotland) Act came into force in 2015 requiring authorities to develop BSL plans as to how this will promote and raise awareness of the language. Wales has led the way in having BSL/English interpreters present at First Minister's Questions time in the Senedd. The production of BSL summaries by the British Deaf Association (BDA), by Deaf people for Deaf people, of Ministers' coronavirus statements have been viewed positively. RNID's care and support team, who are mostly Deaf themselves, then share these summaries with the 80 Deaf people they currently support in Wales.

Deaf children, particularly those born to hearing parents, are disadvantaged from birth. A Deaf child may be the parents' first experience of profound or severe deafness requiring a change to their means of communication. If parents and siblings cannot use BSL, children can be isolated, and families struggle with communication. Language acquisition in the first five years of life is essential, and this is the most important time in a child's life for their parents or carers to learn BSL (Bowen & Holtom, 2020; Cormier et al., 2012; Kuhl, 2010). People are language deprived if they do not have access to BSL. There is little support or resource for the Deaf child's family to learn BSL (Welsh Government, 2020), so language development is difficult from the start. The fund of knowledge (Young & Hunt, 2011) is limited as deaf children do not have the opportunity to overhear conversations, ask questions and pick up news, information or social capital. This extends into education and the workplace where there is limited communication. The equality of opportunities for Deaf people is absent. Many Deaf people are not aware that they can act on the problems they experience.

Without the essential building blocks for language and knowledge Deaf people are significantly disadvantaged. The chances of a Deaf person having a traumatic experience are then higher than the general population. Following a traumatic experience such as abuse or bullying, the

usual supports that would help are often not available to Deaf people. Traumas would likely include sexual abuse, as Deaf people experience higher rates of abuse than hearing populations (Wakeland et al., 2018). Deaf children may not be able to communicate adequately with their parents about feelings, are unlikely to have received information in an accessible language and are unlikely to have peers they can talk to. These barriers increase the likelihood of isolation and make the development of mental health problems more likely.

People who live in Wales who are Deaf and have learning disabilities do not receive relevant mental health treatment and support because professionals in the field of learning disabilities do not understand their Deafness and use of BSL. However, people from Deaf or signing families have language acquisition advantages, as they can be bi-lingual and enjoy the same or better life outcomes and opportunities compared to hearing people.

Many primary care providers, such as GPs, are not aware of services that are provided for Deaf people by Deaf people. Deaf direct counselling means that trained counsellors, who are Deaf themselves and understand Deaf culture, provide a counselling service directly to Deaf people. Services provided by Deaf people for Deaf people are extremely effective because individuals know they can focus on the problem they are seeking help about, and not have to worry about communication or the helping professional lacking awareness about Deaf culture (see Appendix Three). Having BSL/English interpreters helps but is not the solution. Deaf culture-led services are required. Employing Deaf professionals will significantly change services from remaining as hearing-led.

Currently in Wales for Deaf people to be referred for Deaf counselling patients are required to visit their GP, at which point they are often in a fragile and vulnerable position and can then request a referral for Deaf counselling (presuming they are aware the provision exists). Many Deaf people have no relationship with their GP, and GPs frequently do not appreciate the issues Deaf people experience (British Deaf Association, 2014), which make applications for Deaf counselling very difficult, as the process has to be initiated by GPs.

"I have been on a hearing Mindfulness course, but it was ridiculous – the instructor just could not comprehend or adjust the training to the Deaf mind or my identity.

She kept insisting on me closing my eyes and 'listen' even though I told her I am Deaf. Having my eyes closed in that situation made me very anxious."

Many of the factors that keep people well so they can enjoy good mental health like employment (Modini et al, 2016), access to education (Araya et al., 2003), and supportive social networks (Thoits, 2011) are different for, and often denied to Deaf people. Deaf people regularly experience isolation, discrimination, and stress daily (Bone, 2019) which contributes to experiences of anxiety and depression, with many Deaf people facing barriers in getting supports they need.

A report was commissioned for the Council for Social Care Inspection (Wales) to address the role of specialist social workers with Deaf people (Young & Hunt, 2009), which examined the relationship between advocacy services and social work services for Deaf people, and what training is required to support the specialist contribution. Clear evidence for the specialist social work role was identified, as they promote the autonomy and empowerment of Deaf people, with Deaf advocacy making a significant contribution. However, social workers that provide a language concordant service are fewer in number than in 2009. Interpreter numbers have increased, although availability in a timely manner can be problematic. When booking, agencies recommend arranging two weeks in advance as a minimum. Some BSL/English interpreters have a specialist skillset and may be more in demand for assessments, such as mental health or court work. While some local authorities have maintained a specialist social worker with Deaf People role, others have been unable to replace with cultural or linguistic knowledge. There is no equivalent role within health. Given the low incidence and dispersal of deafness in the population, it is unlikely that individual health and social care professionals will work with a large enough group of Deaf people to develop cultural competence and knowledge of specialist services. Social workers have been part of the support network advising colleagues in health and social care of the need for BSL/English interpreters and of specialist mental health provision that can be accessed.

"BSL users can expect a good service to have BSL as an integral consideration when organising meetings and events"

Welsh Assembly Government (2006)
Delivering services in BSL: Advice for public

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. As there is no local provision in Wales, when Deaf people are discharged from any open, secure or medium secure units in England to their home area, there are no mental health support services in BSL to respond in a timely manner.

Deaf people may remain on a local mental health ward with often very limited access to communication, if fortunate, interventions may be facilitated by an interpreter, such as when being assessed by a doctor. Alternatively, if funding is agreed (and usually after significant delay) they may be placed in a specialist mental health unit in Manchester (if from North Wales) or Birmingham (if from South Wales), with follow up from these units on discharge. It can be difficult to facilitate contact with family and friends at this distance and is of significant financial cost to local health boards.

However, there are opportunities for early intervention and health promotion, and this report includes recommendations that would significantly improve mental health outcomes for Deaf people in Wales.

Deaf people who live in Wales need an in-patient mental health assessment that is culturally and linguistically appropriate. Assessments in Wales are problematic due to lack of knowledge in local teams, delays, and lack of awareness regarding the commissioning of specialist services. Treatments usually require placement in a National Deaf Mental Health Service in Birmingham or Manchester, following individual patient funding requests.

Examining the evidence

Examining evidence provides the context and informed perspectives on specific health issues of population groups. It must be acknowledged that there are situations where evidence simply is not available to be obtained. In terms of Deaf people, few are registered as Deaf people who use BSL in clinical data in health care settings such as GP surgeries (Young et al., 2017). Clinical data does not routinely include information about patients whose first language might be BSL and therefore need BSL/English interpreters, lip speakers or note takers to assist the parties during appointments. After liaison with the Secure Anonymised Information Linkage (SAIL) Databank, based at Swansea University, it is apparent that our 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 agreed this information is simply not accessible.

A lack of evidence raises questions as to whether there are marginalised communities (that is Deaf communities) whose needs are consistently ignored and forgotten. It is important to recognise that current data does not give an accurate picture about Deaf people's needs at all as they are simply not recorded. The 2021 Census approach will have much more up to date information, as a strategic approach has been taken to work with Deaf Hubs in Wales to better support Sign Language users (or Deaf people) to participate in the Census. In previous years Census information assumed audiences were mainly hearing with assumptions about individuals' reading levels, leading to a lack of Census participation by Deaf people. However, it will be some months before the new Census information becomes available

New patient forms at GP surgeries often do not ask about Deafness and preferred language. If people subsequently attend for a screening appointment this information may be recorded but is often not 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. If a record of a person's language used is recorded, this would indicate whether a person prefers to use spoken or a signed language (Young et al., 2017).

Poor access to health services in general is a constant challenge for Deaf people. SignHealth (2016) reported following their survey that 70% of Deaf people who had wanted to access their GP did not attempt an appointment knowing there would be no interpreter (SignHealth, 2016). Even the booking of health appointments in Wales usually requires the use of audio systems such as telephone, with little choice of alternative systems of engagement. According to a Public Health Wales commissioned report, often Deaf people find they must go to a GP surgery in person just to book an appointment (Shank & Foltz, 2019).

The Welsh Government's (2019c) vision is that everyone in Wales should have longer healthier and happier lives, are able to remain active and independent, in their own homes for as long as possible, promoting a 'wellness' system that aims to support and anticipate health needs, with the whole system approach an equitable one. The 'Together for Mental Health' delivery plan acknowledges the need to develop good mental health and resilience for all individuals and that this will result in a more socially just Wales as health and other inequalities will be addressed

(Welsh Government, 2012, 2019c). However, it is not sufficient to assume that new systems will be equitable as little information is currently available in BSL format.

Equally more needs to be done in relation to preventative work to ensure that there is provision available for deaf children and their families (Rogers, 2013). Health information resources that health professionals know about, need to be readily available in relevant formats, so they can then readily signpost Deaf people towards them and they can access the health information they need.

Around 40% of Deaf people experience mental health problems. As over 2500 children in Wales are Deaf, this means that around 1000 children in Wales will certainly be at risk of mental health problems in the future. Currently there is little provision to meet their needs, and no established links with Deaf Child and Adolescent Mental Health Services (CAMHS) in other areas of the UK (see Appendix Four). When comparing deaf children and hearing children, deaf children will have significantly more mental health problems. There are ten National Deaf CAMHS centres in the UK, and none in Wales. Concerns have been raised about CAMHS clinicians in Wales and their lack of Deaf awareness (National Deaf Children's Society, 2014).

Anecdotally there is an increase in Wales in suicide by people who are Deaf, although specific details were not available from the Coroners' Offices and often data about Deafness is not recorded.

The problem about the incidence of mental health problems for Deaf people is that issues are only known to people affected by these issues, and the champions and organisations who work closely with Deaf people. Certainly, the voices of Deaf communities are not apparent, and individuals are being significantly disadvantaged by a lack of mental health pathways, and access to health services generally.

Deaf children in Wales and education

Each area of the UK completes an annual report for the Consortium for Research in Deaf Education (CRIDE). In 2019 the CRIDE report for Wales reported the following about educational provision for deaf children in Wales:

Summary of key findings

- Services reported that there are at least 2,486 deaf children in Wales; a reported decrease of 5% over the past year.
- 80% of school-aged deaf children attend mainstream schools (where there is no specialist provision).
 9% attend mainstream schools with resource provisions, whilst 10% attend special schools not specifically for deaf children.
 1% were home educated.
- 28% of deaf children are recorded as having an additional special educational need.

There were 66 full time equivalent Teachers of the Deaf posts in Wales, with 45% of these over the age of 50, and likely to retire within the next 10 to 15 years. Many services reported difficulties extracting data about deaf children in their area (CRIDE, 2019).

The 2020 CRIDE report involved a shorter survey and responses were lower due to the pandemic, with only half of the local authority areas responding to the survey. The 2020 report noted a lack of suitably qualified Teachers of the Deaf and difficulties in recruiting to specialist posts. A lack of intervention to support emotional development for deaf children was also highlighted, and too little targeted support for parents of deaf children. These findings suggest that the lower educational achievements of deaf children compared to their hearing peers will continue, with associated higher unemployment and increased mental health issues (Herman et al., 2014; Wright, 2020).

Deaf people and interpreter provision in Wales

People who are Deaf and communicate using BSL require a BSL/English interpreter who is a language professional registered with the National Registers of Communication Professionals working with Deaf and Deafblind People (NRCPD) to facilitate communication between Deaf and hearing people. Sign Language BSL/English interpreters are qualified professionals and are part of a national register, subscribing to quality, governance and professional procedures and monitoring (Association of Sign Language BSL/English interpreters, 2021; Webb & Best, 2020). If Deaf people require an interpreter at a health or social care appointment, it is essential that they have access to one, preferably with discussion about choice beforehand. It is important that BSL/English interpreters are high quality and appropriate to appointments in terms of adaptability and gender, according to the type of appointment and patient choice (NHS England, 2018). However, 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.

There are four main providers of interpreting services for Deaf people in Wales: the Wales Council for Deaf People (WCDP), the Welsh Interpreting and Translation Service (WITS) and the Royal Institute for Deaf People Cymru (RNID Cymru), who operate predominantly in the South; and the Centre of Sign Sight and Sound (CoS), which works mostly in the North.

The table below shows the bookings by these organisations over the past two years, to show need and uptake. Figures include bookings for BSL/English interpreters and occasional bookings for lip speakers and note takers. (Figures do not include direct bookings with interpreters working outside agencies).

Table 1: Interpreter bookings in Wales during 2019-20 and 2020-21

Interpreting agency	Bookings 2019-20	Bookings 2020-21
Centre of Sign Sight and	135	76
Sound		
Royal National Institute	176	8
for Deaf People Cymru		
Wales Council for Deaf	1415	524
People		
Welsh Interpreting and	2585	850
Translation Service		
Total	4311	1458 *

^{*} The Covid 19 pandemic has impacted on society in many ways, particularly the engagement of patients with services. Many appointments are only held face to face if essential, which explains why there is a drop-in interpreting bookings, as so few organisations and services have been open for Deaf people to engage with, and patients have also been reticent about seeking help.

The CoS in North Wales provide in-house BSL/English interpreters. In 2019-2020 they provided 135 appointments all of which were face to face. Between April 2020 to February 2021 they made provision for 76 appointments, 6 of which were conducted remotely and 70 face to face.

During 2019/20, 176 interpreter bookings were conducted through RNID Cymru for a mix of housing, social services, focus groups, banking and work support needs, but not for health appointments. The fall in bookings for 2020-21 is explained by the pandemic.

Interpreting bookings with the WCDP for 2020-2021 were 524, which included bookings for four Welsh health boards in South Wales, County Council and Career related appointments and 524 for the 2020-21 period.

Provision from WITS is for health appointments in the main, as well as for local authorities and occasionally with the Police. They keep figures as whether interpreting appointments are face to face or remote, with 78% of their 2020-21 bookings remote engagements due to the pandemic.

Martin, an Advocate with no BSL or Deaf awareness had made little progress in conversations with one of the patients, Ben, on the ward who was Deaf.

However, after Deaf Mental Health First Aid training he knew to ensure an interpreter was arranged, then when an interpreter came in, within an hour there was a plan in place, despite a three-month admission which had been extremely challenging for Ben, with little information about what was happening.

Support for Sign Language BSL/English interpreters is limited as it is in context of Association of Sign Language Interpreters (ASLI) membership. Whilst supervision and mentoring are available through ASLI, resources are opt-in, meaning some interpreters do not have this input. BSL/English interpreters are indirectly exposed to trauma and have to listen to traumatic stories and then retell this information without having the time or space to process as an individual. There is an unmet training need for BSL/English interpreters who are often working in assistance to helping professionals. BSL/English interpreters must work to a code of conduct but have not received training to help them to deal effectively with the interface between their Deaf client's trauma, and the interfaces involved in service provision.

Case study (2006) - Cardiff, Vale and Cwm Taf Health Board employment of a full-time (fully qualified) interpreter increased the request and provision of BSL interpretation at all health appointments – GP, hospital, dentist and optician. This approach is not for everyone, as individual choice remains important.

Sign Language interpreting: face to face, remote and using family members

Deaf people report that they prefer face to face interpretation because 50% of communication can be lost through a webcam (British Deaf Association, 2017). Mental health assessments particularly require a face to face Sign Language interpreter in the room, in order that accurate context is communicated and understood by all those present. It remains commonplace that hearing children interpret for their Deaf parents, which places an inappropriate burden on them (Klimentova et al, 2017). Deaf people continue to report having to resort to family members to interpret for them at health appointments, which can be inappropriate, and have legal and ethical implications. BSL/English interpreters are registered and have to adhere to a Code of Conduct (NRCPD, 2010), in terms of ensuring a confidential service. Many health appointments still take place with professionals resorting to writing notes, which does not equate to Deaf people having an informed choice about their care and treatment.

Deaf people are at a higher risk of sexual abuse due to lack of equity of access with minimal accessible routes for complaint (Taylor et al., 2015). Sexual abuse cases frequently involve family members who are hearing or people of authority within education and religious settings who are hearing. When a Deaf person has been abused by a hearing person, it is understandable that they would not want to try interpreted counselling with a hearing person. Also, Deaf people know that BSL/English interpreters move in the same circles as Deaf people, so would prefer to communicate with a trained Deaf professional from the start of their treatment. The problem is when Deaf people have been battling with lack of accessibility and a lack of understanding from service providers; confronted with the prospect of interpreted counselling, they often do not want this form of service, and can subsequently disengage from the process. Even if Deaf- for-Deaf services are available, often Deaf people are not made aware of them.

Frequently Deaf people report having limited information about how BSL/English interpreters might be booked. Hospital switchboard operators now conduct booking procedures direct, but often the detail required as to whether an interpreter is actually available and has accepted the booking is not known until the actual appointment time. This can leave Deaf people facing the dilemma as to whether they proceed with medical treatment without information or wait further weeks for a re-booking when an interpreter can be present. Suggestions have been made about a national (a Once4Wales) interpreting service, which could have benefits, improve equity, and simplify booking practices.

When face to face interpreting is not available, remote or online interpreting can be a second option. While the introduction of using digital technology to increase interpreting arrangements at healthcare appointments certainly has potential, wider systems have yet to catch up in terms of availability of devices, service level agreements and information sharing. New digital technologies are being explored with *Interpreter Now* and *Interpreter Online* available in some parts of Wales. For example, in a primary care or unscheduled care setting patients can bring a device with internet access and login into these services that connect to remote BSL/English interpreters who use video in real time to translate between patients and workers. The service requires a licence and annual fee payable by GP surgeries, and uptake of these services is low in Wales.

A UK map of Deaf mental health service provision

In 2017 the Royal College of Psychiatrists produced guidance for commissioners about primary care mental health services for Deaf people, which stress Deaf people's unique life experiences, a need for improved interpretation services and access to them, and clear pathways and strategies for mental health interventions and treatments.

Due to their unique life experiences, Deaf people require different primary mental health care. Commissioners should commission appropriate cultural and linguistic provisions when planning services for Deaf people.

Below each UK country and their current mental health service provision for Deaf people is presented.

England

There are special NHS mental health services for adult Deaf people, as well as deaf children. Three main centres in England with in-patient units for adults are located in Manchester, Birmingham, and London, with further specialised community services in Bristol, Yorkshire and Northumberland.

National Deaf Child and Adolescent Mental Health Services (CAMHS) are available in London, Leeds, Manchester, in the North East, North West and East of England, and in Somerset. They operate under a national Deaf CAMHS network (for further details see Appendix Four).

An advice service is operated at South West London and St Georges NHS Trust to its catchment service area in England. This includes a mental health support line with a Sign Live video relay service for people who are Deaf. The 24/7 support service provides a useful link for individuals, families and workers.

Deaf people are over-represented in secure mental health settings and over-represented in prison populations (Kelly, 2017; British Deaf Association, 2017; McCulloch, 2012; Gahir et al, 2011). Rampton Hospital has a Deaf unit, and the John Denmark Unit in Manchester now has a small secure step-down facility for Deaf people who are on a programme to increase their independence.

Scotland

The Scottish Deaf mental health service was established in 2012. Starting from an outreach clinic in Manchester, a proposal was put to the Scottish Government to establish such services, with recurrent funding now established. The national service is hosted by NHS Lothian and works across Scotland as a consultancy and liaison service that provides specialist support and organises regional clinics across Scotland to assess and treat Deaf adults and provide Deaf awareness training for mental health professionals. One Scottish university, Robert Gordon, provides a placement with Deaf people for all nursing and midwifery students to raise awareness about Deaf issues.

Northern Ireland

The Northern Ireland Mental Health and Deafness Service provides assessment and care for profoundly Deaf adults with complex mental health needs. The team provide regional outreach

clinics, home visits and liaison. Additionally, consultation and training are offered to staff working with Deaf clients. Deaf signers with mental health difficulties are their core group, but the service also sees anyone referred whose deafness is significant to them. The service is also involved in promoting access to all mental health services for all clients and in the strategic development of services for Deaf service users.

Wales

None of the above services in other UK countries exist in Wales.

In 2006 a proposal was submitted to Welsh Government from the British Society for Mental Health and Deafness, for a national specialised Deaf mental health network in Wales, but there was no positive outcome from this. Further work presented at a BSMHD meeting in 2008 involved a discussion of potential service models. The Welsh Government (2006) supported a BSL Futures project to train people who wished to become BSL/English interpreters and supported Deaf tutors in Wales to train them. While the increase in the number of BSL/English interpreters was welcome, not all would choose or be able to interpret in mental health settings. Until the current arrangements of catchment area, with North Wales patients going to John Denmark Unit and South Wales patients going to Jasmine Unit, there was a satellite outreach service in South Wales from the John Denmark Unit. This service existed as an occasional satellite outreach, but was little known, and ceased over twenty years ago. The service in North Wales stopped in 2018.

A support and information service would be useful for workers in GP surgeries and Community Mental Health Teams, which are locally based and unlikely to build an expertise in Deaf mental health issues.

Commissioners need to ensure that
Deaf people have a clear care
pathway that is equitable to the
general population
(Royal College of Psychiatrists, 2017)

Ambitions and solutions for Welsh Government

The Welsh Government has in various documents and communications set out its ambitions in terms of improving mental health services in Wales. The list below states some of these ambitions, with solutions provided that would equip Deaf people and workers to meet these aims.

<u>Ambitions</u>	Solutions
Progress towards Primary Care Clusters so professionals can make direct referrals	All primary care staff need to know what is available to support a Deaf person's primary care journey
	Primary care staff can refer directly to Deaf for Deaf counselling services
A core aim of A Healthier Wales is to support and develop the workforce to deliver services that populations need	Strategy to ensure basic Deaf awareness training for all health and care workers (e.g. an All Wales Deaf Awareness Passport)
	Effective monitoring of adherence to Wales Accessible Information Standards
	Increase workers' knowledge of basic BSL and how to book BSL/English interpreters
Right of Welsh speaking citizens to have access to information and services in Welsh (active offer)	Improve access to information for BSL users by adopting the same strategy
Local authorities record individual's preferred means of communication, although only required for people who access services	All health and care providers to ensure accurate record keeping of individuals' preferred language
Increased commissioning for mental health support from voluntary and third sector	At commissioning stage BSL provision must be costed and included, so Deaf people's needs are always met
Welsh Government directs health boards to establish a lead for Deaf CAMHS and referral route to services	Need to increase Deaf awareness training for all CAMHS staff and awareness of Deaf CAMHS services in England, as well as establish a lead in Wales for Deaf CAMHS
Welsh Government want people to have timely access to Primary Care and Specialist services	Access to prompt specialist consultants and advice with commissioning arrangements in place to facilitate this, avoiding long delays
A More Equal Wales focuses on reducing inequalities not perpetuating them	Increasing the number of Deaf health professionals in Wales and supporting routes into health professional education. Sharing opportunities to Deaf communities, and increasing Deaf role models to inspire future generations

Conclusion

This report has highlighted the inequalities in mental health provision for Deaf people in Wales. Reasons for these inequalities include persistent inequity of access to information about health issues and health services generally, with little health information available in accessible formats. There is a paucity of information about mental health, what helps to achieve positive mental health, and about what help might be available to improve mental health when problems arise for Deaf people.

These barriers are coupled with the fact that health professionals lack understanding about Deafness, need basic BSL skills and must know how to book and ensure BSL/English interpreters are present at health appointments for people who require them. Wales has previously made good progress in training people for the interpreting profession, however, with Deaf people requiring them to participate in the public and private sphere, there are limits on the numbers of skilled, experienced BSL/English interpreters for those presenting with mental health problems when required in a timely manner.

The lack of equity of access to health services and the barriers from health professionals contribute significantly to Deaf people developing mental health problems. Additionally, many Deaf people have experienced problems during early life with little family support for language development, resulting in lower educational attainment and higher unemployment than hearing people. These are all major factors in the development and likelihood of mental health problems developing and are some of the very reasons why Deaf people are twice as likely to experience mental health problems as hearing people.

Currently we cannot change the reporting and collecting of clinical data, but together we can start to explore the type of services and mental health interventions that Deaf people need. There is an appetite for developing services in Welsh communities that includes professionals working alongside Deaf people – both as providers and patients. A funded specialist helpline for health and care workers, individuals and families would go some way towards positive change in the immediate term, in the absence of a specialist local service.

Wales remains the only UK country to have no provision for Deaf people who experience mental health problems whether the need requires information, mental health education, mental health assessment or active intervention, like talking therapies or in-patient care. Wales is currently not able to meet Deaf people's mental health needs and Deaf communities continue to be disenfranchised.

There is scope for significant change and increased partnership working with Deaf communities, who are keen to work with stakeholders. The All Wales Deaf Mental Health & Well-being Group are keen to start a dialogue with key stakeholders in Welsh Government to explore ways to improve Deaf people's mental health in Wales.

References

Action on Hearing Loss. (2015). Hearing matters. Retrieved from: https://www.actiononhearingloss.org.uk/about-us/our-research-and-evidence/research-reports/hearing-matters-report/ (Accessed 29 Nov 2019)

Araya, R., Lewis, G., Rojas, G., & Fritsch, R. (2003). Education and income: which is more important for mental health?. *Journal of Epidemiology & Community Health*, *57*(7), 501-505.

Association of Sign Language Interpreters (2021). What is ASLI? https://asli.org.uk/about/

Bone, T.A. (2019). No one is listening: Members of the Deaf community share their depression narratives, Social Work in Mental Health, 17:1, 1-22, DOI:10.1080/15332985.2018.1498045

Bowen, R, Holtom D, (2020). Independent Review of BSL Provision for Adults in Wales. Cardiff: Welsh Government, GSR report number 4/2020. Available at: https://gov.wales/independent-review-british-sign-language-bsl-provisionadults-wales

British Deaf Associtaion (2014). Report on Access to Health Services for Older Deaf People in England and Wales. https://bda.org.uk/wp-

content/uploads/2017/03/BDA_EDDJ_Report_On_Access_to_Health_Services_2014.pdf

British Deaf Association (2017). Report on NHS BSL/English interpreting provision within health settings in Scotland. https://bda.org.uk/wp-

content/uploads/2017/03/NHS_interpreter_Website.pdf

British Deaf Association (2017b). Throw away the key? How Britain's prisons don't rehabilitate Deaf people. https://bda.org.uk/wp-content/uploads/2017/03/BDA-Deaf-Prisoners-Report-2016.pdf

British Society for Mental Health & Deafness (2006). Mental Health Services for Deaf People in Wales. Unpublished report presented to National Assembly for Wales

British Society for Mental Health & Deafness (2020). Mental Health Services for Deaf People. https://bsmhd.org.uk/wp-content/uploads/2020/05/Mental-Health-Services-UK.pdf

Cabral, L., Muhr, K., Savageau, J. (2013). Perspectives of people who are Deaf and hard of hearing on mental health, recovery, and peer support. *Community Ment Health J* (2013) 49:649–657

Centre for Mental Health (2020). Commission for Equality in Mental Health: Mental health for all? The final report of the Commission for Equality in Mental Health.

https://www.centreformentalhealth.org.uk/sites/default/files/publication/download/CentreforMH_Commission_FinalReport.pdf

Collinson, S. (2017). Early years language and development in deaf children. https://www.ndcs.org.uk/media/2568/natsip_paper_synthesis_of_key_findings.pdf

Cormier, K., Schembri, A., Vinson, D., & Orfanidou, E. 2012. First language acquisition differs from second language acquisition in prelingually Deaf signers: Evidence from sensitivity to grammaticality judgement in British Sign Language. Cognition, 124(1), 50-65.

Consortium for Research in Deaf Education (2019). 2019 report for Wales: CRIDE report on 2018/19 survey on educational provision for deaf children in Wales. https://www.ndcs.org.uk/media/6041/cride-2019-wales-report-final-english.pdf

Department of Work & Pensions (2017). Market review of British Sign Language and communications provision for people who are deaf or have hearing loss. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/630960/government-response-market-review-of-bsl-and-communications-provision-for-people-who-are-deaf-or-have-hearing-loss.pdf

Dreyzehner, J., & Goldberg, K. A. (2019). Depression in Deaf and Hard of Hearing Youth. *Child And Adolescent Psychiatric Clinics Of North America*, 28(3), 411-419. doi:10.1016/j.chc.2019.02.011

Fellinger, J., Holzinger, D., Pollard, R. (2012). Mental health of Deaf people. *The Lancet*, Vol 379 March 17, p1037-1044

Gahir, M., O'Rourke, S., Monteiro, B., & Reed, R. (2011). The unmet needs of deaf prisoners: A survey of prisons in England and Wales. *International Journal on Mental Health and Deafness*, 1(1).

Health Technology Wales (2019). Topic exploration report: Deaf mental health services: Interpreter on Wheels/Interpreter Now. http://www.healthtechnology.wales/wp-content/uploads/2019/08/TER073-Interpreter-on-Wheels.pdf

Herman, R., Roy, P., & Kyle, F. E. (2014). Reading, dyslexia and oral deaf children: From research to practice. https://openaccess.city.ac.uk/id/eprint/3225/1/

Kelly, L. (2017). Silent punishment: the experiences of Deaf prisoners (Doctoral dissertation, University of Central Lancashire).

Klimentová, E., Dočekal, V., & Hynková, K. (2017). Hearing children of deaf parents—a new social work client group?. *European Journal of Social Work*, *20*(6), 846-857.

Kuhl, P. K. 2010. Brain mechanisms in early language acquisition. Neuron, 67(5), 713-727

Lesch, H., Burcher, K., Wharton, T., Chapple, R., & Chapple, K. (2019). Barriers to healthcare services and supports for signing Deaf older adults. *Rehabilitation Psychology*, *64*(2), 237-244. doi:10.1037/rep0000252

Listman, J. D., Rogers, K. D., & Hauser, P. C. (2011). Rethinking deaf adolescents' resilience: Why cultural capital matters. *Risk and resilience: Adaptation in the context of being deaf*, 279-298.

McCulloch, D. (2012) Not hearing us: an exploration of the experience of deaf prisoners in English and Welsh prisons. http://oro.open.ac.uk/42456/1/Not_hearing_us.pdf

Mental Health Reform (2015). Briefing note: Mental health services and supports for people who are Deaf September 2015 Retrieved from: https://www.mentalhealthreform.ie/wp-content/uploads/2018/05/Briefing-note-on-mental-health-services-for-deaf-people_-September-2015.pdf

Modini, M., Joyce, S., Mykletun, A., Christensen, H., Bryant, R. A., Mitchell, P. B., & Harvey, S. B. (2016). The mental health benefits of employment: Results of a systematic metareview. *Australasian Psychiatry*, *24*(4), 331-336.

Murray, J. J., Hall, W. C., & Snoddon, K. (2019). Education and health of children with hearing loss: the necessity of signed languages. *Bulletin of the World Health Organization*, *97*(10), 711.

National Assembly for Wales (2006). Delivering Services in BSL: Advice for Public Services. Equality of Opportunity committee. Retrieved from:

http://www.assembly.wales/Committee%20Documents/EOC(2)%2005-

06%20Paper%201%20%20Annex%201-14062006-

22088/n00000000000000000000000045431-English.pdf.

National Deaf Children's Society (2014). NDCS Cymru response to the National Assembly for Wales's Health and Social Care Committee's post-legislative scrutiny of the Mental Health (Wales) Measure 2010. https://senedd.assembly.wales/documents/s31156/MHM%2003%20-%20National%20Deaf%20Childrens%20Society.pdf

National Registers of Communication Professionals working with Deaf and Deafblind people (2010). Code of Conduct for Communication Professionals. Retrieved from: https://www.nrcpd.org.uk/documents/misc/code_of_conduct_for_communication_professionals.pdf

NHS England (2018). Guidance for commissioners: Interpreting and Translation Services in Primary Care. https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2019/04/guidance-v61-published-310818.pdf

Reader, D., Foulkes, H., Robinson, C. (2017). Investigating barriers to mental health care experienced by the Deaf community in North Wales. *Mental Health Nursing*. June/July 2017, p14-19

Redfern, P., Baker, K. (2020). Impact of Covid-19 on Deaf people with additional problems. *Social Work.* 14 July 2020. https://sw2020covid19.group.shef.ac.uk/2020/07/14/impact-of-covid-19-on-deaf-people-with-additional-problems/

Rogers, K. D. (2013). Deaf people and mental well-being: Exploring and measuring mental well-being in British Sign Language (PhD). University of Manchester.

Rogers, K. D., Ferguson-Coleman, E., & Young, A. (2018). Challenges of Realising Patient-Centred Outcomes for Deaf Patients. *The Patient - Patient-Centered Outcomes Research*, 11(1), 9-16. doi:10.1007/s40271-017-0260-x

Royal College of Psychiatrists (2017). Guidance for commissioners of primary care mental health services for Deaf people. Retrieved from: https://www.jcpmh.info/wp-content/uploads/jcpmh-Deaf-guide.pdf

Royal National Institute for the Deaf Cymru (2010) RNID Cymru study into the inclusion barriers facing people who are deaf or hard of hearing in Wales. Funded by the Welsh Assembly Government's New Ideas Fund February 2010

Shank, C., Foltz, A. (2019). *Health and Wellbeing for Deaf Communities in Wales: Scoping for a Wales-Wide Survey.* Retrieved from

https://research.bangor.ac.uk/portal/files/26546430/PHW_Health_and_Wellbeing_for_Deaf_Communities_in_Wales_Report_ENG.pdf

SignHealth (2013). Research into the health of deaf people. Retrieved from: https://signhealth.org.uk/wp-content/uploads/2014/03/SignHealth-Deaf-Health-Survey-Report.pdf

Signhealth, (2016). Sick of it: how the health service is failing Deaf people. Retrieved from: http://www.signhealth.org.uk/health-information/sick-of-it-report/sick-of-it-in-english/

Taylor, J., Cameron, A., Jones, C., Franklin, A., Stalker, K., & Fry, D. (2015). Deaf and disabled children talking about child protection: research into children's experiences of the child

protection system.

https://strathprints.strath.ac.uk/52256/1/Taylor_etal_NSPCC2015_deaf_and_disabled_children_talking_about_child_protection.pdf

Thoits, P. A. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of health and social behavior*, *52*(2), 145-161.

Wakeland, E., Austen, S., & Rose, J. (2018). What is the prevalence of abuse in the deaf/hard of hearing population? *The Journal of Forensic Psychiatry & Psychology*, *29*(3), 434-454.

Webb, S., Best, B. (2020) "The Most Important Cog in the System: A Case for Legislative Change to Drive Professionalisation," *Journal of Interpretation*: Vol. 28: Iss. 1, Article 6.

Welsh Government (2019a). Delivering in British Sign Language: advice for public services. https://gov.wales/sites/default/files/publications/2019-05/delivering-in-british-sign-language-advice-for-public-services.pdf

Welsh Government (2019b). A Healthier Wales: our plan for Health and Social Care. Retrieved from: https://gov.wales/sites/default/files/publications/2019-10/a-healthier-wales-action-plan.pdf

Welsh Government (2019c). Together for Mental health delivery plan 2019-2022. Consultation Document. Retrieved from: https://gov.wales/sites/default/files/consultations/2019-07/together-for-mental-health-delivery-plan-consultation-document.pdf.

Wright, B. (2020). Mental health in Deaf children. The Bridge. https://www.acamh.org/app/uploads/2020/05/RD_The_Bridge_May_20.pdf#page=8

Young, A., Hunt, R. (2009). The role, contribution and training requirements of specialist social workers with d/Deaf people. (Commission for Social Care Inspection, Wales). Commission for Social Care Inspection.

Young, A., & Hunt, R. (2011). *Research with d/Deaf People*. (1 ed.) (Methods Reviews). National Institute for Health Research. http://eprints.lse.ac.uk/id/eprint/41800

Young A, Rogers K, Davies L, Pilling M, Lovell K, Pilling S, et al. (2017). Evaluating the effectiveness and cost-effectiveness of British Sign Language Improving Access to Psychological Therapies: an exploratory study. Health Services and Delivery Research 2017;5(24)

Acknowledgements

Thanks are due to the following people who have been instrumental in helping with this report:

Paul Redfern, General Secretary, British Society for Mental Health & Deafness

Cath Booth, Head of Service Wales and South West Community Services, Royal National Institute for the Deaf

Roger Hewitt, Consultant to Hear Deaf Mental Health in Wales project & Ex General Secretary, British Society for Mental Health & Deafness

Michelle Fowler-Powe, Advocacy Co-ordinator, British Deaf Association

Helen Green, Public Health Wales

Dr Julia Terry, Associate Professor, Swansea University

Stephanie Woodcock, Centre of Sign, Sight & Sound

Dr Katherine Rogers, NIHR Post-Doctoral Research Fellow, Manchester University and Chair of British Society for Mental Health & Deafness

Daisy Cole, Independent Consultant

Jacqui Bond, Former local authority social worker with Deaf People

Dr Rob Wilks, Senior Lecturer, University of South Wales

Dr Sara Rhys-Jones, Highly Specialist Clinical Psychologist, Bridgend Community Support Team

Julie Doyle, RSLI, MASLI, Qualified and Registered BSL/English interpreter, mentor and trainer. Teacher at SignWorld iBSL

Anne Silman BA (Hons), Bevan Commission Exemplar, Betsi Cadwaladr University Health Board

Ceri Harris, Equality, Diversity and Inclusion Specialist, Aneurin Bevan University Health Board

Appendix One: Deaf charities supporting people re COVID 19

British Deaf Association have provided summaries of all the Welsh Government COVID briefings within a short turnaround. While a BSL interpreter is present for briefings, there is no interpreter for the discussion and unpacking of announcements in newsrooms or political shows.

In March 2020, SignHealth established the practice of covering the cost for remote BSL/English interpreting access for Deaf people in England. However, in Wales the British Deaf Association has worked to ensure local BSL/English interpreters for local people accessing local services is ongoing and continued to be paid within existing arrangements. This has involved Welsh interpreting agencies working in collaboration, to provide local online BSL/English interpreters at all health appointments for Deaf BSL users during these unprecedented times. Between them they are able to cater access and provide a service 24/7. Additionally, Welsh NHS Health Boards recognise these systems and have valid contracts in place. Regular BSL videos are disseminated to the Welsh Deaf community via social media to keep them all updated on how to continue to receive accessible health care.

RNID Care and Support services have continued to provide essential support to more than 80 people who are Deaf in Wales during the pandemic- providing support with practical matters such as assisting people to access food, medication, money, their GP or health professional, as well as providing vital opportunities for people to talk about their physical, mental and emotional well-being with someone who can communicate in BSL / their own language and who is aware of and fully understands their cultural needs as well as their language and communication needs.

BSMHD produced two leaflets for health and social care providers during Covid 19.

Each year BSMHD support Welsh Health Boards and their Deaf awareness week activities.

Appendix Two: Progress - All Wales Deaf MH & Well-being Group

And other initiatives in Wales that support Deaf people.

The All Wales Deaf Mental Health and Well-Being Group have been working to improve mental health services for Deaf people for many years. During this time, they have progressed several initiatives including those listed below:

The Health Technology Wales' (HTW) topic call in 2019 on non-medical technologies provided an opportunity to suggest technologies that could improve health and social care in Wales, and a submission was sent in March 2019 regarding remote digital interpreting services for Deaf people. This submission was raised to topic exploration status (HTW, 2019) to inform discussions on new topics raised by HTW, however it was deemed there was insufficient evidence on which to base a health technology assessment at the present time.

Responses to the Welsh Government's Together for Mental Health consultation open during August 2019 were made by members of the All Wales Deaf Mental Health & Well-being Group to highlight specifically the needs of Deaf people in Wales. It is not known whether the consultation documents were available in BSL format at the time to allow Deaf people to participate. The eventual **Together for Mental Health publication made no mention of mental health service provision for Deaf people.**

The All Wales Deaf Mental Health & Well-Being Group is aware of the All Wales Accessible Standards for Sensory Loss, and that at least **four Local Health Boards in Wales have signed the British Deaf Association's BSL charter.** However, the Accessible Standards have no legal power, which limits their scope.

Due to the lack of mental health provision in Wales, the British Society for Mental Health & Deafness, in partnership with CoS, the BDA and the RNID successfully applied for funding, with their project "Hear Deaf Mental Health in Wales" - awarded £224,155 by the Community Fund (previously the Big Lottery); the aims of the project were to:

- a) Raise awareness in Wales of the barriers that Deaf people with mental health issues face
- b) Make Mental Health First Aid (MHFA) courses accessible to the wider Deaf community through adaptions to the course and with Deaf accredited Instructors. At least nine courses have been delivered nationally with 120 people trained.
- c) Support Deaf people with or facing mental health issues by signposting or to understand and explore self-help strategies on a Peer-to-Peer basis

Along with partners; the BDA, the RNID and the CoS, as well as Mental Health First Aid (Wales) Training in Mind has enabled the BSMHD to carry out a programme of courses, information dissemination, advocacy support and practical workshops.

In line with the grant aims, nine Mental Health First Aid (MHFA) courses in Wales have now been delivered to over 120 people with the successful recruitment and training of four

Deaf MHFA Instructors. This training commenced in March 2018 and has a sustainable model, as trainers will continue to provide these courses predominantly to Deaf communities in Wales.

This, along with newly recruited Peer Deaf Mental Health Advocates aim to help spread the word in the Deaf community on the importance of early intervention and support and leave a lasting legacy for Deaf mental health in Wales (see case studies).

ACTivate your life through medium of BSL - ACTivate your life is a self-management program based on Acceptance and commitment therapy, a psychological intervention developed by Dr Neil Frude. In Wales, Frude is currently working with RNID and a group of Deaf people in a steering group on an accessible version of the ACTivate Your Life course. This involves not only changes in content, to incorporate particularly relevant examples (as the bespoke versions relates to cancer, stroke, prisoners and university students), but also delivery through the medium of BSL, which is radically different from English in terms of its structure. This project is due to reach completion in 2021 and has been funded by the British Society for Mental Health and Deafness and Public Health wales. RNID (formerly Action on Hearing Loss) are in the process of developing ACTivate your life as a BSL resource which will be provided free of charge, although filming has currently paused due to the Covid 19 pandemic.

Over 40 Deaf people have participated in Deaf Mindfulness programmes:

"I have been on a hearing Mindfulness but it was ridiculous – the instructor just could not comprehend or adjust the training to the Deaf mind/identity. She kept insisting on me closing my eyes and 'listen' even though I told her I am Deaf. Having my eyes closed in that situation is anxious for me. This retreat has given me understanding, access to what is mindfulness, and realisation that I too now need to ask for help."

"A massive hugs and thank you for lovely couple of days of mindfulness. Have enjoyed so much and great to be with all DEAF and their needs. Have to say is powerful few days."

"Where I work they do have Mindfulness, mental Wellbeing but it was so jargon ridden that I got nothing out of it. Even with the Interpreter, it didn't make sense. It went right over my head, I came here [to Mental Health First Aid], the tutors could sign – it was so smooth, I learned so much about myself and I did cry. This was so right for me – this is where I learned so much."

"The doctor told me that I have PTSD but I didn't know how to self-care, I really, really need that. So many Deaf people have so many different things, we do need help for all those conditions – where is the funding??"

Appendix Three: Case studies

All case studies have been anonymised and are based on people's experiences in Wales, some details have been revised so they are GDPR compliant, and do not contain personal data.

Case studies from British Society for Mental Health & Deafness

- 1. I'm Clifford and I'm 55. I get depressed because I can't get information or services. One example was I tried to communicate with the mobile phone shop and they wouldn't help. Same with service delivery people, also PIP I couldn't talk with them. I got an iPad but I couldn't understand how to use this. The Peer Deaf Mental Health Advocate (PDMHA) has helped me with this and I'm now making decisions for myself. I'm also starting to realise that there are some positive things. But it's hard and I do get down very easily when I have trouble with them who are supposed to help me.
- 2. My name is Brian and I'm 35 years old. I lived in England but then I split up with my partner and came back to Wales. I felt really depressed and thought about killing myself. Then I met with a Peer Deaf Mental Health Advocate (PDMHA) who suggested I go to my GP and I went. My GP referred me to the Mental Health team. I've also applied for a place to live near my family with support from the PDMHA. I'm taking my medicine and have visits from the Mental Health team. I've found a job and have challenged the benefits people as they did it wrong. The PDMHA has helped me with that as well. I now write every day in my diary to help me manage my feelings.
- 3. My name is Felicia and I'm 40. All my life I've kept things to myself. Other people see me as a strong woman so I have no-one to talk with. It doesn't matter who they are, they could be Deaf or hearing, I still don't talk with them. When I met with the PDMHA I realised I could talk with her which helped me to relax and I now know we all need help sometimes, even me. I'm thinking of asking Deaf4Deaf for counselling now.
- 4. I'm Simone and I'm 50. I was so upset about the PIP assessment, I felt so anxious. I didn't want my family or friends to come with me, but I accepted the PDMHA coming with me. I found it very helpful to sit down and go through before the PIP meeting to make sure I said what I wanted to say. Also I didn't know how to use an interpreter, but now I know. The PIP assessment went on forever, but that was good because the PDMHA reminded me of what I wanted to say. Sometimes the interpreter would sign something to me and I couldn't understand so the PDMHA signed it again so I could understand, she used my language. I was so grateful I told the PDMHA: if you had not been there, I would not have been able to answer all those questions especially with my wellbeing." The PDMHA was Deaf herself and I found that to be so helpful.
- 5. Andrew in early 30s said "I have depression I get emotional and frustrated which leads to anxiety. I try to do things like meditation and yoga for my well-being so I can continue a normal life. I've realised it is important to be able to talk about these things. It's ok to ask

for help. You may think they don't want to talk with you but that's not true, they are waiting for you to approach them and they will listen to you.

It obviously depends on who. Some might be judgemental or give you the wrong advice. It needs to be someone who can understand, empathy, support, encouragement, and reassure about what's bothering you such as frustration, a family problem, relationships, feeling down, depression, having a bad day, problem with work, lost jobs, financial problem, and many more. Also, allow yourself to cry as this is nothing to be ashamed of. Don't think "because I am a man and I should man-up as this means I am not allowed to cry". I cried yesterday after my counselling session which helped me to release my emotions. I then had a hot bath for half a hour with a face mask on as "self-care". It was lovely and relaxing and I needed it. I try to think positive during the day because we only live once and it is important we carry on our lives and survive despite our struggles".

- 6. I'm Philip, I'm 30, over the last 18months, I have had peer support from time to time and found having someone to talk to about certain things that were going on in my life helpful especially from another Deaf BSL user. One example was helping me set up Deaf4Deaf online. I recently finished counselling from D4D, which was funded by NHS, and am now waiting for the next lot of counselling with the same counsellor. I was worried that the time gap in 'waiting' for the next phase would affect my MH. I spoke to my regular PDMHA and she suggested that I have a weekly hourly structured chat via online to another PDMHA for the time being. This was set up and having someone to talk to online every week at my home has reduced my anxiety. My counselling sessions have been deferred for a few more months and without my peer support I know I would have become very ill, with anxiety and anger issues. Hopefully in time I will be able to leave my safe space at home and re-integrate with the Deaf community."
- 7. My name is Farouk and I'm 28. Life is so difficult; I get so confused. The PDMHA and I talked a lot and I started to know what I need to do. I became more confident and I felt more in control of my own life. I decided that I would post on Facebook and tell all my friends that I cry. It's ok to cry. It's ok for men to cry and struggle and its ok for men to talk about them. I haven't seen my PDMHA for six months I feel good about my life and I'm doing ok.

The seven individuals describe above are all real-life case studies of people who live in Wales.

Case studies from BSL/English interpreters

Malcom, an interpreter said that when an interpreter is called for a mental health assessment, first of all, it's usually short notice. That's the nature of the work. Not much can be done about that if we are using freelance BSL/English interpreters (in house BSL/English interpreters for services brings its own challenges too) but it does add a few problems: 1) BSL/English interpreters are notoriously unavailable at short notice, 2) the ones that are available might not be the most suitable people to be interpreting the assessment, 3) the client's interpreter of choice is unlikely to be available (if they are ever asked).

When booked, (normally via an agency) information is usually scarce. Sometimes, no name is given, often the form will simply say "mental health assignment" and NEVER are we given any background information. Depending on the experience/confidence of the interpreter, it is up to us to find the relevant information. Some BSL/English interpreters don't think of this, some think of it but don't know how/where to get the information, some of us try and fail to get the information.

Once you are into a mental health assessment, very often, the professionals you're working with, have no idea how to work with the interpreter. Very often, they've never met a Deaf patient before either. The assessments themselves are often unsuitable. I mean that from a language and cultural point of view. So, take a simple memory test - questions like 'Do you know what day it is today?' 'Do you know the name of the hospital you're in?' 'Which newspaper do you read?' 'Remember the name of these four flowers ...'. That sort of question/task can throw people. They're seemingly innocuous to most of us, but for a lot of Deaf people that that can cause a problem anyway and therefore skew the results.

Val, an interpreter, had been sat in a meeting with mental health staff, on a ward, with a Deaf person and an interpreter. Mary, the Deaf patient didn't like the interpreter and I am not sure if this is because the staff didn't explain her role, prior to my involvement. When the interpreter started to sign, he turned to me and said he wasn't going to watch her. I had to explain that the interpreter was signing what the mental health ward staff were saying. It wasn't her view, but the clinical view of staff. After that she was willing to watch her. Other Deaf people experience similar lack of explanations. Direct access with someone who can sign (social worker or advocate) is really useful.

It's really important that the interpreter is seen as a part of the team and not just a communication tool. The cross-cultural knowledge they can share with the team could be vital. It's also important that they establish with the Mental Health team how they are going to/want to work.

The interpreter also needs to bear in mind appropriate language for the Deaf person in front of them. Age, background, ethnicity, gender, education, etc will affect how a person is signing and if they are in a mental health assessment then they are already likely to be experiencing some difficulty. BSL/English interpreters need to adjust their language to match the client and never expect it to be the other way around.

When an appointment is finished, who knows how effective the communication has been. 99% of the time, the only person in the room who knows both languages being used is the interpreter. There is much need for more monitoring of arrangements. Equally there are virtually no resources for training and supervision for BSL/English interpreters who are indirectly exposed to trauma and also have to listen to traumatic stories and then retell them without having the time or space to process as an individual. There is an unmet training need for BSL/English interpreters who are often working in assistance to helping professionals; have to work to a code of conduct and may not have received training to help them to deal effectively with this interface.

<u>Case studies from carers and those attending Mental Health First Aid (MHFA) Courses with</u> <u>British Society for Mental Health and Deafness</u>

The British Society for Mental Health & Deafness, in partnership with MHFA Wales and employing Deaf instructors, have run nine Mental Health First Aid courses to 120 people including Deaf people, carers and professionals, e.g. BSL/English interpreters, social workers for Deaf people etc. The aim was to provide Deaf participants with culturally and linguistically appropriate information on mental health. The impact made was life changing for those attending, as it enabled them to manage their own mental health alongside encouraging their family members and peers to take positive action on mental health and wellbeing. Information has affected people's mental health, and the fact that they have used the knowledge gained from the accessible courses has enabled individuals to examine their own mental health issues.

A Deaf mother, Maria aged 62, realised that her son's behaviour was due to escalating mental health issues, which had not yet been recognised. She was able to persuade her son to visit a GP and he was then seen promptly. Maria told BSMHD "My son's mental health would have only deteriorated further if I had not attended the BSMHD [Mental Health First Aid] course about understanding mental health problems.

An Interpreter, Maxine, attended the MHFA course after an intensive few days of interpreting at funerals (one of which involved a Deaf young person who ended their own life, with many Deaf mourners present). She realised she had kept her 'professional face on' and became very depressed. She was able to talk about her experiences with a fellow Interpreter and Mental Health First Aider. It is important to remember that any issues with Deaf people where interpreting can be very intense are likely to have a ripple effect on others.

Appendix Four: Specialist Mental Health provision in England

Specialised mental health services for Deaf people include inpatient, outpatient and community services. The specialised services are provided to Deaf service users who have significant mental health difficulties and have been unable to access culturally appropriate assessment and treatment services or have not responded to treatments or require inpatient admission for assessment.

The services provide expertise in the assessment, treatment and recovery of people who are Deaf, likely to use British Sign language and have a serious mental health problem.

Provider:	Contact details:
Avon and Wiltshire Mental Health Partnership:	Avon and Wiltshire Mental Health Partnership NHS Trust Petherton Resource Centre Petherton Road Hengrove Bristol BS14 9BP www.awp.nhs.uk email: awp.SpecialisedDeafService@nhs.net
Birmingham and Solihull Mental Health NHS Foundation Trust	The Barberry National Deaf service - Jasmine suite 25 Vincent Drive Edgbaston Birmingham B15 2SG Ward telephone numbers: • Voice phone: 0121 301 2460/2497 • Minicom (text phone): 0121 301 2497 • Fax: 0121 301 2451 • Video phone Barberry reception: 0121 301 2002
Deaf4Deaf Counselling	Deaf4Deaf House, Pembroke Avenue, Hersham, Walton-on-Thames, KT12 4NT Telephone 07539 877357 & Text 07736 835445 Email: simon.lloyd@Deaf4Deaf.com Deaf4Deaf Limited Company Number 10070652
Greater Manchester Mental Health NHS Foundation Trust	John Denmark Unit Greater Manchester Mental Health NHS Foundation Trust Trust Headquaters Bury New Road Prestwich M25 3BL Tel: 0161 358 0570 Fax: 0161 772 3401 Email: jdu@gmmh.nhs.uk

South West London and St George's Mental

Health NHS

Inpatient services (Bluebell Ward) Morrison (Building 9, entrance 3)

Springfield Hospital, 61 Glenburnie Road,

Tooting

Trust

London SW17 7DJ Tel: 020 3513 4640 Fax: 020 3513 4643 Mobile: 07789 501 491

Email: adultDeafinpatientservicebluebell@swlstg.nhs.uk

Deaf Adult Community Team (DACT)

Newton (Building 2 entrance 1),

Springfield Hospital, 61 Glenburnie Road,

Tooting,

London, SW17 7DJ Tel: 0203 513 4646 Text: 0203 513 4677 Fax: 0203 513 5629 SMS: 07766 257 846

Email: Deafadultservices@swlstg-tr.nhs.uk

National Deaf Child Corner House National Deaf CAMHS

Newton (Building 5, entrance 5)

Adolescent Mental Health Services (CAMHS) Springfield Hospital, 61 Glenburnie Road, London SW17 7DJ Tel: 020 3513 6860 Fax: 020 3513 6689 Text: 020 3513 6909 SMS: 07595 414 692

Email: cornerhouse@swlstg.nhs.uk

National Deaf CAMHS - London

Springfield Hospital, 61 Glenburnie Road, London SW17 7DJ Tel: 0203 513 6925 Text: 020 3513 6950 Fax: 020 3513 6461 SMS: 07879 420 453

Email: ndcamhs@swlstg.nhs.uk

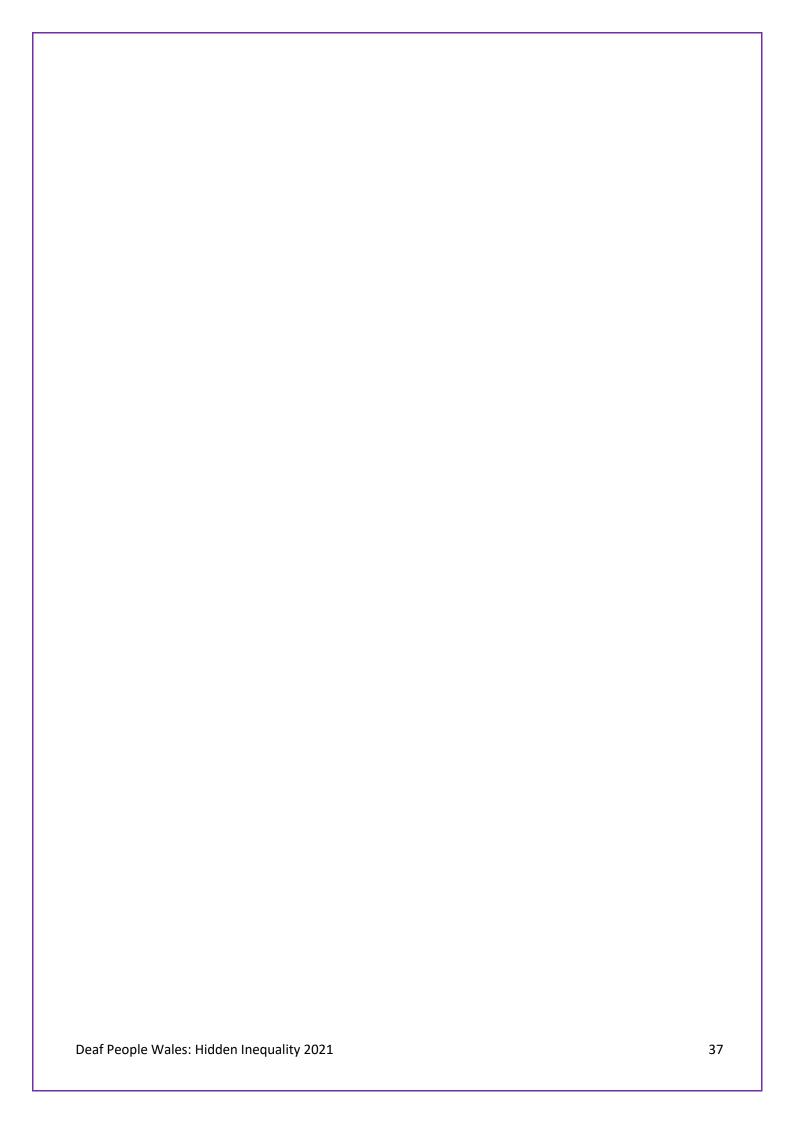
And more in North, South and East England

National High Secure Deaf Service Assessment, treatment and rehabilitation for Deaf male patients who have a range of conditions including mental illness, and/or personality disorder, and/or a learning disability.

Main Switchboard: 01777 248 321

Adele Fox

Head of Clinical Operations Telephone: <u>01777 247299</u> Email: <u>adele.fox@nottshc.nhs.uk</u>



All Wales Deaf Mental Health and Well-being Group

The All Wales Deaf Mental Health and Well-being Group came together in 2018. The Group comprised professionals working in the charity and public sector who were concerned that the current arrangements of sending Deaf people with psychosis to establishments in England were not addressing the full range of needs within the Welsh Deaf community. The Group deliberated for some time as to how best we could raise the issue of finding a Welsh solution to the incidence of mental health amongst Deaf people in Wales. It was agreed to set up a sub-group to compile a report to raise awareness of the issue. This report is the outcome. The full All Wales Deaf Mental Health and Well-Being Group will reconvene, and looks forward to working collaboratively with stakeholders to find the best ways of addressing and improving the mental health of Deaf people in Wales with a Welsh approach.