

# Joint Commissioning Panel for Mental Health

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## Guidance for commissioners of primary care mental health services for deaf people

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| Practical<br>mental health<br>commissioning |  |
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In this guide 'deaf' with a lower case 'd' refers to deaf people who are spoken language users. Deaf people who use British Sign Language (BSL) are conventionally referred to using upper case 'D' ('Deaf'). This acknowledges the historical and cultural traditions of this distinct population in the UK, in the same way as we would write French or Polish and not 'french' or 'polish' in reference to members of those communities. We adopt this convention in these guidelines.

## Ten key messages for commissioners

- 1 Deaf people find it difficult to access healthcare, face communication barriers and, as a consequence, have poorer mental and physical health than the rest of the population.
- 2 Everyone who uses mental health services should have equitable access to effective interventions, and equitable experiences and outcomes. Under the Equality Act 2010 Deaf people are included as having 'protected characteristics'.
- 3 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.
- 4 Psychological therapy in British Sign Language (BSL) is as cost effective, if not more so, than a hearing therapist using a BSL/English interpreter.
- 5 Deaf people should be able to choose to receive primary care psychological therapy services in BSL directly from a BSL practitioner, without needing a sign language interpreter, if that is their choice.
- 6 A comprehensive commissioning strategy is required to enable an appropriate BSL psychological therapy service to be available.
- 7 Commissioners need to ensure that Deaf people have a clear care pathway that is equitable to the general population.
- 8 Commissioners need to include Deaf professionals in their workforce planning strategy.
- 9 Deaf people need to be involved with the ongoing development of Deaf primary care mental health services.
- 10 Where services are commissioned that require sign language interpretation, commissioners must ensure the provision of interpreters is of a high standard, as highlighted in NHS England's *Principles for High Quality Interpreting and Translation Services in Primary Care 2016* and forthcoming NHS England guidelines for the commissioning of interpreting and translation services.

# Introduction

The Joint Commissioning Panel for Mental Health (JCP-MH) ([www.jcpmh.info](http://www.jcpmh.info)) is a collaboration co-chaired by the Royal College of General Practitioners and the Royal College of Psychiatrists. The JCP-MH brings together leading organisations and individuals with an interest in commissioning for mental health and learning disabilities. These include:

- People with experience of mental health problems and their carers
- Department of Health
- Association of Directors of Adult Social Services
- NHS Confederation
- Mind
- Rethink Mental Illness
- National Survivor User Network
- National Involvement Partnership
- Royal College of Nursing
- Afiya Trust
- British Psychological Society
- Mental Health Providers Forum
- New Savoy Partnership
- Representation from Specialised Commissioning
- Healthcare Financial Management Association.

The JCP-MH has two primary aims:

- to bring together people with experience of mental health problems, carers, health professionals, commissioners, managers and others to work towards values-based commissioning.
- to integrate scientific evidence, the experience and viewpoints of people with mental health problems and carers, and innovative service evaluations in order to produce the best possible advice on commissioning the design and delivery of high quality mental health, learning disabilities, and public mental health and wellbeing services.

The JCP-MH:

- provides practical guidance and a developing framework for mental health commissioning.
- will support commissioners of public mental health to deliver the best possible outcomes for community health and wellbeing.
- has published a series of short guides describing 'what good looks like' in various mental health service settings<sup>1-9</sup>.

**SignHealth** is a charity dedicated to making sure Deaf people receive the same sort of access as 'hearing people' to healthcare and health information. The charity has a range of projects, services and campaigns, all aimed at improving the health of deaf people.

## WHO IS THIS GUIDE FOR?

This guide should be of value to:

- Clinical Commissioning Groups (CCGs) and local authorities who should be informed by the principles highlighted in this guide.
- Health and Wellbeing Boards (HWBs).
- Service providers across primary, secondary and tertiary services.

## HOW WILL THIS GUIDE HELP YOU?

This guide has been written by a group with expertise and experience in the mental health of Deaf people, including Deaf and hearing professionals and academic researchers, in consultation with Deaf patients and carers. The content is evidence-based and includes guidelines deemed to be best practice by expert consensus where the formal evidence-base may be lacking.

By the end of this guide, readers should:

- be more familiar with the particular needs of Deaf people who have mental health problems, including issues of access, developmental difference, language and culture.
- understand what effective primary care mental health services for Deaf people should look like.
- be aware of the range of services and interventions that should be on offer.
- understand how those interventions can contribute to achieving recovery outcomes and make improvements in public mental health and wellbeing.

# What are primary care mental health services for people who are Deaf?

## Deaf or deaf?

The term 'deaf' with a lower case 'd' is conventionally used to refer to deaf people who are spoken language users. Deaf people who use British Sign Language (BSL) are conventionally referred to using upper case 'D' ('Deaf') in the same way as we would write French or Polish and not 'french' or 'polish' in reference to members of those communities. We adopt this convention in these guidelines.

## WHAT IS DEAFNESS?

**From a physiological perspective,** deafness is an impairment of an individual's ability to hear.

**From a cultural-linguistic perspective,** to be 'Deaf' is not associated primarily with having an impairment in hearing. It is instead a marker of identity based on language use and acknowledges the historical and cultural traditions of a distinct population in the UK<sup>10</sup>.

It is also a means of distinguishing culturally Deaf people who use BSL from the much larger populations of 'deaf' people who might be spoken language users, who lose their hearing as a result of aging, or experience a 'hearing impairment'<sup>11</sup>. The term 'Deaf community' is used to refer to people whose first or preferred language is BSL.

However, the Deaf community is not limited to those whose first language is BSL. For example, deaf people who grew up with an oral form of communication, hearing people with Deaf parents for example, may be part of the community and regard themselves as culturally Deaf.

## Age-related deafness, and deafness in adulthood arising from illness or accident

involves considerable psycho-social and communicative adjustment from a state of hearing, to one of hearing loss. Most (6.3 million) of the 10 million people in the UK with some type of deafness are of retirement age, the vast majority of whom will have lost their hearing as part of the ageing process<sup>12</sup>.

These guidelines do not specifically address the needs of people with age-related hearing loss; however in the context of mental health, this specific population has particular needs given the increasing evidence of the association between age-related hearing loss and dementia<sup>13</sup>.

## DEAFNESS FROM BIRTH OR IN EARLY CHILDHOOD

The vast majority of deaf children are 'oral' deaf – they have been born into families where their parents are hearing and communicate with their children in spoken language. These children are also educated in spoken language. Not all will continue to use spoken language in adulthood and it is not uncommon for deaf people to start to sign in young adulthood and to explore what is termed as their 'Deaf identity' through contact with other signing people and the Deaf community<sup>14,15</sup>.

**Deaf children growing up in families where the spoken language is not English** face additionally complex linguistic challenges. Consequently, amongst those Deaf adults who use BSL as their first, preferred or strongest language, there are highly variable degrees of fluency and bilingual ability (in spoken/written/signed language[s]).

**Deaf children from Deaf families** will usually acquire BSL as their first language but may struggle with a spoken/written language.

## BRITISH SIGN LANGUAGE

**BSL** is not a visual version of English; it does not follow English word order and has a totally different grammatical structure<sup>16</sup>. BSL has been formally recognised by the Government as an indigenous language of the UK<sup>17</sup>. In 2015 the Scottish Parliament passed the BSL (Scotland) Act 2015 conferring legal rights and duties towards BSL users in Scotland.

## POOR LITERACY AND THE SOCIO-ECONOMIC EFFECTS

Poor literacy in the spoken/written majority language remains a problem worldwide amongst Deaf young people and adults<sup>18</sup>. Deaf people's educational attainment, measured at first school leaving age, remains lower than the national average. Department of Education figures from 2015 in England show that only 36.3% of Deaf children in England have left secondary school having achieved national GCSE benchmarks, compared to 65.3% of hearing children<sup>19</sup>. Poor literacy and educational attainment has knock-on socio-economic effects with Deaf people experiencing higher levels of unemployment and under-employment than the general working age population<sup>20</sup>.

These complex early linguistic environments and adult language profiles have consequences for cognitive and social development. **Gaps in world and social knowledge** (the 'fund of information' or 'fund of knowledge') are common<sup>21</sup>.

## What are primary care mental health services for people who are Deaf? (continued)

### WHAT ARE THE SPECIFIC DIFFICULTIES FACED BY DEAF PEOPLE IN ACCESSING AND USING PRIMARY MENTAL HEALTH CARE SERVICES?

#### Language barriers:

- **The written word:** low levels of literacy in a written language mean that health related and self-help information; online gateways to service access; and screening, diagnostic and self assessment material within therapy are fundamentally inaccessible and/or unreliable in the case of Deaf service users. For example, some Improving Access to Psychological Therapies (IAPT) services require a patient to complete several online assessments at the point of self-referral in order to be considered for therapy in the first instance.
- **The spoken word:** For the vast majority of Deaf people this guide refers to, spoken language is either inaccessible, only partially accessible or not the preferred medium in which to conduct therapy. Understanding an individual's linguistic strengths and matching their linguistic requirements is fundamental to effective service delivery.

It should be noted that these barriers apply for access to all healthcare services, not just mental health.

**Lack of specialist understanding:** While the provision of a sign language interpreter to facilitate language access may seem to achieve inclusiveness, mental health services are likely to be far less effective without an awareness of the atypical circumstances of individuals' early development and the adult consequences of being Deaf in a predominantly hearing world.

#### Incomplete cultural-linguistic adaptation:

Deaf people who use BSL are a cultural-linguistic group. Therefore, the requirements for effective adaptation of one therapeutic approach from one culture (e.g. hearing English people) to another (Deaf BSL users) should not be underestimated. For example, recent research has demonstrated that the clinical cut offs for caseness in the use of standard instruments<sup>22</sup> to measure anxiety and depression (even when reliable and validity checked BSL versions are used) is different for a Deaf population, as it might be for any cultural group. This means that screening and assessment tools should be used differently with Deaf BSL users to ensure accuracy of initial assessment and recovery. Therefore, BSL accessibility without cultural competence does not make a service accessible or effective.

### WHAT ARE THE NEEDS OF DEAF PEOPLE FROM PRIMARY CARE MENTAL HEALTH SERVICES?

Deaf people, in particular sign language users, are a population with increased vulnerability to mental health problems compared to the general population. It is difficult to determine the prevalence of mental health problems within the Deaf community; however, the range appears to vary between 30% and 60%<sup>23-27</sup>. Deaf people therefore have a significant need for effective mental health services that match their complex language profile and cultural-linguistic identity.

Deaf people in general are a hard-to-reach group as they are geographically dispersed and live in low numbers per area. As such, mainstream services are often unaware of the Deaf population in their locality and therefore lack an understanding of how to meet their needs. Deaf people risk being marginalised by society unless steps are taken to address this.

The specific challenges faced by Deaf people also create different needs in relation to mental health and treatment compared to the hearing population:

Therapy with Deaf people can take significantly longer than with hearing people. Therefore Deaf people will find the standard intervention times too restrictive to have much effect.

In addition to the language adaptation, any psychological work with Deaf people has to take into account cultural background, differences in experiences and the potential for significant deficits in their knowledge base and emotional vocabulary.

Standard psychological measures may not provide an accurate enough reading of a Deaf person's wellbeing. Without measures validated in the Deaf population, it is possible that some Deaf people will be inappropriately assessed. As a result, vital clues to their mental state, home/work circumstances might not be picked up which could lead to poor recovery or, at worst, suicidal ideation (thoughts) which are not recognised and therefore not acted upon. The University of Manchester has translated and validated the Outcome Measures used for IAPT (PHQ9, GAD7 and WSAS)<sup>28,29</sup> into BSL to address this need.

Deaf children have many risk factors which make them vulnerable to abuse. Research on abuse of disabled children (including Deaf children) shows that they are significantly more likely to experience all forms of abuse (sexual, physical, neglect) than non-disabled and hearing children<sup>30,31</sup>. There are therefore a large number of Deaf adults living with a history of childhood abuse today.

It is acknowledged that Deaf adults are more vulnerable to adult abuse, including financial abuse, as a result of inappropriately dependent and exploitative relationships<sup>32</sup>.

# Why are primary care mental health services for Deaf people important to commissioners?

High quality commissioning will ensure more Deaf people can self-refer for psychological therapies and receive treatment in a timely and equitable way, without being delayed by the need for Individual Funding Requests (one third of which are rejected).

The current fragmentation of commissioning does not provide equal access to primary care psychological therapy for Deaf people and, as such, population-based commissioning needs to become a priority. Given the relatively small numbers of Deaf people in each CCG area neighbouring CCGs will need to combine their 'services for Deaf people' budgets.

Improved management of mental illness in primary care will also reduce inappropriate admissions of Deaf people to non-specialist secondary care where miscommunication, misdiagnosis and incorrect treatment can put them at risk of avoidable harm. It will also reduce unnecessary admissions to specialist tertiary care where presenting problems could have easily been resolved in primary care. Both of these delay care and recovery and are an inappropriate use of costly and limited resources.

## LEGAL OBLIGATIONS

Commissioners and providers of health and social care services have a legal duty to offer services that are accessible and appropriate to all sectors of the community, irrespective of disability or culture. Current legislation including the Equality Act 2010<sup>33</sup> and Human Rights Act 1998<sup>34</sup>, mean that public bodies, including the NHS, should provide services that are both non-discriminatory and actively promote equality, and respect the needs of hard-to-reach and minority communities.

Deaf people are included under the Equality Act 2010 as a population with 'protected characteristics'. Therefore, there is a public sector duty to ensure that the provision and character of a service does not directly or indirectly create inequalities of access to treatment.

It is therefore necessary that commissioners understand the reasons a Deaf person may experience unequal treatment, and commission services that reduce these inequalities.

Deaf people who use BSL constitute an officially recognised minority cultural group in the UK. Therefore the commissioning of primary mental health care services must acknowledge and be sensitive to Deaf people's cultural needs in line with the Health and Social Care Act 2012<sup>35</sup> and The Care Act 2015<sup>36</sup>.

NHS England's Accessible Information Standard (SC11605 Accessible Information) directs and defines a specific consistent approach to identifying, recording, flagging, sharing and meeting the information and communication needs of patients, carers and parents, where those needs relate to a disability, impairment or sensory loss. All information provided about primary mental health services for Deaf people and communication with Deaf people must conform to the standard<sup>37</sup>.

## MEETING THE DIFFERING NEEDS OF DEAF PEOPLE

Deaf people are not a homogenous group and have a wide range of needs, characteristics and requirements. In order to fulfil their role, commissioners must understand the needs and difficulties of Deaf people to commission appropriate services.

Standard hearing services present significant access barriers to Deaf people. The common practice of requiring telephone contact to a single point of access is clearly not accessible to Deaf people. Therefore, if Commissioners do not take into account the specific needs of Deaf people they will not be able to commission appropriate services.

Working with Deaf people requires clinical, cultural and linguistic expertise to understand and address the specific challenges and needs of Deaf people. Commissioners need to ensure they commission services that understand and address these needs meaningfully in order for Deaf people to benefit from interventions.

## Why are primary care mental health services for Deaf people important to commissioners? (continued)

### **COST EFFECTIVENESS**

Commissioners need to ensure they provide services that have a high performance rate in relation to the service user and patient satisfaction, risk management and good recovery rates. Although national specialist commissioning arrangements for Deaf people exist in tertiary care, they do not at the primary or secondary care levels. Commissioners should make local decisions about meeting Deaf people's primary mental health care needs and associated funding arrangements.

Commissioning standard services with the addition of an interpreter is no more cost-effective than commissioning specialist services provided by BSL practitioners and should not be used as a default commissioning arrangement. A current National Institute for Health Research (NIHR) funded research study indicates that if interpreter costs incur no additional payment, then BSL-IAPT would be considered more cost effective if it achieves reliable recovery in 12% more cases than standard IAPT<sup>38</sup>.

### **CHOICE FOR EVERY DEAF SERVICE USER**

The 'right to choose your service'<sup>39</sup> is not currently available for Deaf patients in some regions. Good commissioning needs to ensure that this 'right' is available for every Deaf person. It may be assumed that to offer a choice would impact greatly on recovery as the Deaf patient would feel confident that they are in the right place with the right practitioner and therefore work through their issues in a timely manner.

### **ETHICAL AND INCLUSIVE COMMISSIONING**

Commissioning must be ethical and just. In order to achieve this aim, commissioners require a good and detailed understanding of how their local communities experience and understand mental health care. Values-based commissioning (VbC) will help achieve this, as it aims to ensure that whatever is commissioned is driven by, supported, and owned by patients and carers. Commissioners should therefore engage with Deaf communities and Deaf organisations to gather adequate understanding of the needs of Deaf people and what would be appropriate in terms of services that would provide safety, respect and dignity to promote choice and independence.



# What do we know about the current provision of primary care mental health services for Deaf people?

Deaf people face many of the same mental health care challenges as those experienced by hearing people. However, research has shown that Deaf people have more adverse experiences and negative outcomes within mental health care compared to the hearing population.

## INEQUITABLE CARE

Health outcomes for Deaf people are worse than those for hearing people<sup>40,41</sup>. This is due to a number of factors, including variable provision of accessible services.

Deaf people are excluded from many forms of mental health primary care. GPs simply do not provide the same direct support that they provide to hearing patients who are experiencing mental health problems. For example, regular mental health 'check ups' do not take place, and simple but important questions about the patient's mental health are not asked during physical health checks, as they would be for hearing people. This probing is more difficult with a Deaf patient, even with communication support in place.

## ACCESSING APPROPRIATE CARE

Many Deaf people avoid their GP because of communication difficulties. UK-based research has consistently demonstrated that Deaf people access GP services more infrequently and much later in the progression of a problem than the general population. Issues include barriers to appointments, doubt over communication support (such as whether a qualified interpreter would be provided), lack of understanding of Deaf people's perspectives by GPs and lack of health related information in BSL<sup>40,41</sup>.

In some regions in England, access to psychological therapy for a Deaf person requires a referral from their GP. However this is not necessarily the case for hearing patients. This means that, rather than being facilitators, GPs might act as barriers to psychological therapy for Deaf people.

## GENERAL HEALTH ACCESS ISSUES

In England, mental health care is delivered in a stepped care model. This aims to provide care in the least restrictive manner and by the service best placed to meet an individual's needs. For hearing people this means that the lower levels of intervention are easiest to access, with self-referral at the lowest level.

Deaf people do not have the same access to the stepped care model that hearing people do. They cannot self-refer, for example. The majority of the barriers to accessing care are at the lowest levels of the stepped care model. The highest levels of intervention, such as secondary and tertiary services, are provided by more accessible specialist Deaf mental health services.

Deaf people are therefore not being offered the least restrictive nor more preventative option. This is because Deaf people are a hard-to-reach minority group and as such it is unlikely that there will be a sufficient BSL population to make it cost effective for a CCG to set up a local primary care mental health service contract with a specialist provider<sup>42</sup>. However, this access varies across England – there are some regions where CCGs have a block contract and a Service Level Agreement (SLA) in place or are committed to Individual Funding Requests (IFRs) without needing to go to a funding panel.

## PROVISION OF ACCESSIBLE INFORMATION

Deaf people face a number of challenges obtaining accessible information about their health. This results in a low level of knowledge about health among the Deaf population<sup>43</sup> leading to lower levels of self-identification of problems and self-care.

When Deaf people do attempt to obtain help they often face the challenge of using a telephone 'single point of access' service to arrange an appointment, which is not accessible for a Deaf person. The low level of English literacy in the Deaf population also means that appointment letters may be misunderstood and self-directed learning and homework resources may be incomprehensible. This means that even if a Deaf person is referred to a service, they may not be able to access it or benefit from the intervention.

## What do we know about the current provision of primary care mental health services for Deaf people? (continued)

### BOX 1

#### How might psychological therapy with a BSL Interpreter alter the therapeutic experience?

Referring a Deaf person to a hearing IAPT service with a BSL/English interpreter may appear to be appropriate as 'reasonable adjustments'<sup>36,43</sup> have been made. However, although there are variables that determine the success in terms of recovery in any therapeutic relationship, the addition of a BSL interpreter increases the number of variables and may cause stress or anxiety for both the Deaf patient and the hearing therapist.

- A** The therapist may not be experienced in working with Deaf people and may not be aware of the adaptations required, such as addressing any 'fund of information' deficits. They may be culturally dependent on the interpreter if they lack experience of working with Deaf people or in BSL. This can significantly affect risk assessment and therapeutic work.
- B** There is a limited number of fully registered and qualified interpreters who have the skills to work with a mental health clinician, across the UK. This may result in a different interpreter being booked from one session to the next, which creates inconsistencies.
- C** In addition, as the pool of interpreters is small and interpreters often socialise with Deaf people, the Deaf person may know the interpreter and as such this could impact on trust being developed within the therapeutic relationship and therefore increase anxiety.
- D** The gender or other characteristics of the interpreter could influence the dynamic of the therapeutic relationship and outcomes of treatment.
- E** The Deaf person is relying on the abilities of both the interpreter and therapist.
- F** The three-way communication may be stilted, with multiple risks for misunderstanding and less opportunities for the person to ask questions and engage with the process effectively.
- G** If the interpreter is unable to attend the session or there is a problem with availability, the session has to be cancelled. The therapist may not have access to the translated and validated outcome measures and as such the completion of a written PHQ9 and GAD7 may result in an inaccurate score.

It should also be noted that the interpreter will need to meet with the therapist both before the session and afterwards. This will incur additional costs.

Nevertheless, there are some Deaf people who choose to access psychological therapies through an interpreter. In such cases, it is good practice to ensure that the same interpreter is booked for all sessions and appropriate support provided such as supervision or debriefing potentially complex sessions<sup>44</sup>.

### BOX 2

#### Psychological Therapy with a BSL therapist in a specialist Deaf primary care psychological therapy service

For cultural and linguistic Deaf people, often their preferred option is to see a therapist who is fluent in sign language<sup>45,46,47</sup>. This may be different for oral communicators. Deaf people are not a homogenous group and the Deaf person will be best placed to know the best way to communicate with them.

The Deaf person will receive an assessment with a Deaf or hearing (BSL fluent) therapist who has experience of working with Deaf people and the adaptations needed to undertake therapeutic work. This ensures that the Deaf person is able to fully explore their issue(s) and consider all the available treatment options that would best suit their needs, taking into consideration availability in their region.

A specialist service is also able to offer additional support to the Deaf community in terms of psycho-educational and wellbeing groups. Information is provided in sign language<sup>48</sup>, using BSL resources. This will enable a Deaf person to understand and develop confidence to take responsibility for their own personal development which in turn will empower the individual to go on to lead a more fulfilling life, including improved relationships at home and in the workplace.

## SECONDARY AND TERTIARY DEAF MENTAL HEALTH SERVICES

### Mental health and deafness inpatient services

There are three National Centres for Mental Health and Deafness in England providing services to Deaf people in the UK and the Republic of Ireland. The units are tertiary services offering assessment, treatment and management of complex psychiatric, behavioural and psychological problems for Deaf adults. Each unit provides inpatient, community, psychological therapies and outpatient services. They are staffed by multi-disciplinary teams of both Deaf and hearing staff who use BSL to communicate. The units aim to work in partnership with care coordinators from the patient's locality from admission to discharge.

#### The current Deaf inpatient services are:

- **London** – Bluebell Ward, Springfield University Hospital (a tertiary service which is NHS funded and covers the south of UK), South West London and St George's Mental Health Trust
- **Birmingham** – Jasmine Suite, the Barberry at Birmingham and Solihull Mental Health NHS Foundation Trust
- **Manchester** – The John Denmark Unit, Greater Manchester West NHS Foundation Trust.

The three specialist units mentioned above are NHS England funded.

### Mental health and deafness community-based services

Deaf community-based services offer assessment and treatment for Deaf adults experiencing a wide range of complex mental health issues.

Tertiary level community services often cover wide areas, and so cannot provide care co-ordination at a local level. They therefore require the involvement of local secondary care Community Mental Health Teams (CMHTs) for this.

The role of the Secondary and Tertiary Mental Health and Deafness services goes beyond clinical assessment and management; it includes educating, advising and supporting the mainstream professionals. It may also involve working in partnership to support the validity of assessment and treatment of Deaf people<sup>49</sup>.

#### The current Deaf community services are:

- **Birmingham** – Jasmine Suite, The Barberry
- **Manchester** – John Denmark Unit (JDU)
- **London and the South of England** – Deaf Adult Community Team (DACT), Springfield University Hospital
- **North East** – North East Mental Health and Deafness Service
- **South Yorkshire** – South Yorkshire Service for Deaf People with Mental Health Needs
- **Nottinghamshire** – Nottingham Mental Health and Deafness Team
- **Bristol** – Avon & Wiltshire Partnership Specialised Deaf Service.

## OTHER TERTIARY DEAF MENTAL HEALTH SERVICES

In addition to these services, there are tertiary specialist Deaf CAMHS services and Forensic Deaf Services funded by NHS England Specialised Services.

### National Deaf CAMHS

- **North** – Manchester, Newcastle and York
- **South** – Cambridge, London and Taunton
- **Central England** – Dudley, Nottingham and Oxford.

### Deaf Forensic Services

- **National High Secure Deaf Service** – High Security, Rampton Hospital, Retford. This is an NHS unit.
- **Fairbairn Ward** – Medium Security, St. Andrew's Healthcare, Northampton. This is an independent sector unit.
- **St. Mary's Hospital** – Medium Security, St. George's Healthcare, Warrington. This is an independent sector unit.
- **Cygnets Hospital** – Low Security male and Medium Security female (this is the only Deaf female secure provision in the UK), Cygnets, Bury. This is an independent sector unit.
- **All Saints Hospital** – Low security and locked rehabilitation, St. George's Healthcare, Oldham. This is an independent sector unit.

# What should good primary mental health care services for Deaf people look like

Deaf people are not uniform in their communication needs and preferences. There is a wide range of different forms of communication and cultural attitudes that are indicative of the Deaf community, including combinations of spoken and signed language. Therefore, it cannot be assumed that a particular way of meeting one Deaf person's needs will be the same as another and, as such, an initial assessment by a practitioner who is able to quickly define the linguistic and cultural needs of that individual should be sought and funded.

There are 12 principles that should guide the commissioning of primary mental health care services for Deaf people:

- 1 Primary care mental health services must meet the clinical needs of Deaf people in order to deliver equitable care.
- 2 Primary mental health care services must meet the linguistic needs of Deaf people to engage in therapeutic services using their strongest and preferred language, which is likely to be British Sign Language (BSL). For example, psychological measures need to be adapted to provide an accurate reading of a Deaf person's wellbeing.
- 3 The promotion of mental health awareness within the Deaf community should form part of a comprehensive local commissioning strategy for this group of service users. In addition to the general provision of accessible information and communication, the strategy must include preventative measures, including the introduction of self-help techniques in BSL for low mood, for example, as well as access to self-management materials that are tailored to Deaf people's needs.
- 4 Self referral to mental health services must be accessible to Deaf people through email and SMS (not just by telephone) and Video Relay Service. Telephone access is not adequate.
- 5 Primary care mental health services must acknowledge and be sensitive to Deaf people's cultural needs in line with the Health and Social Care Act 2012<sup>35</sup> and The Care Act 2015<sup>36</sup>.
- 6 Deaf people should be able to choose to receive primary mental health care services in BSL directly from a BSL practitioner, without needing a sign language interpreter, if they prefer. Regular services delivered with the addition of a sign language interpreter should not be regarded as the default provision<sup>38</sup>, but as one available option within the spectrum of linguistically accessible, culturally sensitive provision.
- 7 Where services are commissioned that require sign language interpretation, commissioners must ensure the provision of interpreters is of a high standard, as highlighted in NHS England's *Principles for High Quality Interpreting and Translation Services in Primary Care 2016* and forthcoming NHS England guidelines for the commissioning of interpreting and translation services.
- 8 Communication support must also conform to the NHS England Accessible Information Standard (AIS)<sup>37</sup>, as must all information provided about primary mental health services for Deaf people. The AIS recommends that "a mental health trust may wish to stipulate in relevant contracts/ include in their policy that only interpreters with experience in mental health settings should or must be used, either generally or in particular circumstances".

- 9 Deaf people need a clear care pathway to access care, equitable to that received by hearing people. Commissioning arrangements and the care pathway must encompass all levels of the stepped care model in primary care and facilitate both step-up and step-down referral, as well as referral to voluntary sector providers and secondary care where appropriate. Local commissioners must ensure timely access to services that is not impeded by professionals' lack of knowledge about available and appropriate provision in BSL.
- 10 Deaf people need sustainable services. In the absence of nationally agreed specialist commissioning arrangements, effective commissioning for Deaf people requires a locally agreed financial model. It should enable smooth access to specialist primary mental health care services, designed to meet the requirements of Deaf patients, regardless of whether the service is delivered through a specialist service provider or through an enhanced local provider service.
- 11 Deaf people need to be able contribute to primary mental health care services by communicating their views and experiences. They should be consulted on the effectiveness of local arrangements in order to ensure high quality services on an ongoing basis.
- 12 Deaf people need evidence-based, effective interventions. There is a growing evidence base for the effectiveness of primary mental health care services for Deaf people but only when specific conditions of quality service delivery are met. Commissioning decisions should reflect this evidence base, acknowledging where evidence for one model of provision over another is unknown or uncertain, as well as adopting aspects of provision where the evidence is strong.

## GOOD PRACTICE MODELS IN PRIMARY CARE

### BSL Healthy Minds (BSLHM)

- A specialist service with a national remit which can be commissioned on a locality basis through a block contract or on an individual basis through the Individual Funding Request IFR process. The service has trained 15 Deaf Psychological Wellbeing Practitioners (PWP) through an accredited standard IAPT low intensity training course which was adapted to deliver and assess in BSL. Also, three counsellors have been trained to provide CfD (Counselling for Depression).

Alongside seeing clients within GP surgeries, much of BSLHM's work is focused on promoting positive mental wellbeing to the Deaf community, and Deaf Awareness to non-specialist mental health services to help them offer the best service they can to Deaf patients. This can also raise awareness of appropriate services in their area that they can refer onto if necessary.

The BSLHM team has been instrumental in working with the University of Manchester to translate and validate the routine outcome measures (PHQ9, GAD7 & WSA-S). The team has also worked with the Northumberland, Tyne and Wear NHS Foundation Trust on the translation of 'Guided Self Help Materials' Deaf people can watch. The materials enable Deaf people to work through a series of exercises without needing to be referred into a psychological therapy service. The focus of BSLHM's work is prevention and the aim is to support Deaf people to help themselves and to become more empowered.

Members of the team frequently post short clips on social media which provide explanations about feeling low, what counselling is, and how they can receive help. These clips also help engage the Deaf community, particularly service users, by inviting suggestions for other topics.

An adapted, visual version of the usual Patient Experience Questionnaire is used to obtain feedback at the end of the treatment.

BSLHM is compliant with NICE guidelines and follows the IAPT model and, as such, reports the Minimum Data Set on a monthly basis through NHS Digital and has completed the Information Governance Toolkit as a Level 2 Business partner.

The team has full meetings every two months. Therapists from around the country meet at a central location and Psychological Wellbeing Practitioners (PWP) receive weekly case management supervision and fortnightly clinical supervision with qualified Deaf supervisors, either face-to-face or via video conferencing, in line with the IAPT model. The counsellors meet with their supervisors on a monthly basis as per the BACP Ethical Framework<sup>50</sup>.

The areas that are contracted on an annual basis can meet the IAPT waiting time targets. However, delays can be caused by CCGs who need to apply for IFRs: some Deaf people can wait up to 10 months for funding to be approved which has an impact on the service's waiting time outcomes. Additionally, there are some areas that do not fund the service which does not enable the Deaf person to have a choice of where they would like to access or receive treatment. However, once the person is in the system and is being seen by a practitioner the recovery process begins and the Deaf patient can see the benefit of the treatment they have undertaken.

## What should good primary mental health care services for Deaf people look like? (continued)

**The Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH)** employs a specialist Deaf PWP within their standard IAPT provision. The service has been promoted widely within the geographical area, through Deaf community networks, to stimulate self-referrals and direct patients to GP services. The PWP is currently based at a drop-in clinic known as 'Talking Shop', which Doncaster patients can access. The PWP travels to meet patients in their own localities, including Rotherham, Scunthorpe and small towns within the RDaSH catchment area, and often provides therapy within the local GP practice/community clinics in order to maximise convenience and reduce potential barriers. If the Deaf client knows the Deaf PWP through social connections in the small Deaf community and does not feel comfortable, or chooses not to see a Deaf PWP, they can be seen within the standard service with a BSL interpreter.

The standardised assessments used in IAPT are used in their BSL validated versions with Deaf clients who are BSL users. A crucial part of the specialist practitioner's work concerns the promotion of self-help and strategies to enable Deaf people to manage mental health difficulties in everyday life. In promoting self-help strategies, it is important to do this direct in BSL and also tune in to the Deaf person's preferred mode of understanding.

The PWP has become a trusted professional amongst the Deaf community and a vital resource for primary mental health care practitioners and wider services who have little knowledge of Deaf people or experience in meeting their needs. There is liaison with relevant providers at all levels within the stepped care model which provides support, advice and information, as well as referrals where they are appropriate for the individual client. The local commissioning model provides continuous funding for this post and provides money for additional requirements, such as interpreting and translation services. This ensures a quick referral process and a clear care pathway for Deaf clients.

RDaSH recognises the challenges described above and as such is developing a specialist team consisting of a Deaf PWP from primary care and a Community Psychiatric Nurse (CPN) for Deaf people from secondary care. They are taking a strategic lead on improving support and best practice to the benefit of BSL users accessing mental health services across the region.

### **Psychology and Psychotherapies Team, Adult Deaf Services – based at Springfield Hospital with satellite clinics in Maidstone, Canterbury and Bromley**

The service comprises a clinical psychologist, a psychotherapist and a counselling psychologist, two of whom are Deaf, and all of whom are fluent in BSL. Evidence-based therapies are provided including Cognitive Behavioural Therapy (CBT), Counselling for Depression (CfD), and Cognitive Analytic Therapy (CAT) and psychodynamic psychotherapy. The standard outcome measures used in IAPT services are also used here (PHQ-9, GAD-7, WSAS). Clients are given the choice of using the BSL or written English version of the measures. In addition, session-by-session progress is monitored using the Feedback Informed Treatment (FIT) system.

Access to the service is via clinics at Springfield Hospital in southwest London, and at Bromley, Maidstone and Canterbury (Kent), with other satellite clinics being considered depending on the pattern of referrals and funding agreements.

Originally the service was funded by block contracts with Primary Care Trusts (PCTs), and for many years accepted self-referrals. Since the establishment of CCGs, referrals have been accepted with funding sought by IFR from individual CCGs and referrals must now come via GPs.

# Supporting the delivery of the *Five Year Forward View for Mental Health*

The *Five Year Forward View for Mental Health* (FYFVMH)<sup>51</sup> sets out the steps that need to be taken to transform NHS mental health care. It has a particular focus on tackling inequalities at local and national levels for those who are disproportionately affected by mental health problems, including those who already face discrimination. Commissioning that invests in the provision of effective and appropriate mental health services for Deaf people will support the delivery of the *Five Year Forward View for Mental Health*.

The national strategy sets out three priority actions. However, neither these actions nor the recommendations make specific reference to Deaf people (aside from the broad commitments to people with protected characteristics and disabilities).

Additional and supplementary actions – as outlined in this guide – are therefore necessary if the national strategy is to positively impact on the current care experience of Deaf people.

## **GETTING THE FOUNDATIONS RIGHT: COMMISSIONING FOR PREVENTION AND QUALITY CARE**

Commissioning effective primary and secondary services for Deaf people, in addition to tertiary services, will help prevent mental health problems from escalating. Commissioning services in BSL, directly from a BSL practitioner, will provide appropriate and effective care as well as choice for Deaf people.

## **GOOD QUALITY CARE FOR ALL SEVEN DAYS A WEEK**

Establishing a clear care pathway for Deaf people will enable increased and timely access to integrated evidence-based psychological therapies (FYFVMH recommendations 13 and 14).

Commissioning high quality services for Deaf people could prevent deaths by suicide and reduce the risk of poor physical health and premature mortality by achieving improved mental wellbeing and mitigating the adverse effects of psychiatric treatment and institutional care (FYFVMH recommendation 19).

It will also reduce the relatively high number of Deaf people who avoid mental health services because of poor access and negative experiences. Greater choice and control for individuals regarding their care and treatment will be enabled which will reduce the inevitable increase in stress and anxiety experienced by BSL users as they wait for funding decisions, as well as reducing delays in treatment.

## **INNOVATION AND RESEARCH TO DRIVE CHANGE NOW AND IN THE FUTURE**

Commissioning support to develop innovative resources, including digital/online therapy services that meet the communication and cultural needs of Deaf people, will ensure that access to psychological therapies in BSL is achieved and delivered in an appropriate and timely manner. This will also provide greater accessibility and choice to Deaf people (FYFVMH recommendation 28).

Digital technology is a new mode of working within mental health settings and needs to be evaluated to ensure that it delivers effective interventions for the Deaf community and value for money for the NHS. Digital access does not replace existing face-to-face therapy. It simply offers a choice of therapy.

## **STRENGTHENING THE WORKFORCE**

It is necessary to retain the current specialist BSL workforce and to provide them with access to continuing professional development (CPD) training. The specialists also need to be able to further develop their skills and expertise through programmes like High Intensity Therapy, Counselling for Depression, supervision qualifications and other appropriate interventions. To enable this to happen, recruitment is required to sustain a Psychological Wellbeing Practitioner workforce as current therapists progress with their career development.

Deaf awareness training for all staff, and the provision of BSL interpreters, will help support and equip professionals to provide high quality mental health care. Deaf awareness and specialist supervision will also improve the wellbeing and inclusion of Deaf staff if they are working within a mainstream workplace (FYFVMH recommendations 33 and 35).

## Supporting the delivery of the *Five Year Forward View for Mental Health* (continued)

### **A TRANSPARENCY AND DATA REVOLUTION**

To enable commissioners to understand the impact of funding a specialist service for their Deaf population, data on common mental health problems needs to be available.

The reporting of all activity for BSL users at primary care level needs to be available through NHS Digital (previously HSCIC). Currently, this is an issue because data on Deaf people is not easily accessed within the system, due to small patient numbers. This needs to be addressed to support funding applications for psychological therapy in BSL and enable local commissioners to understand the value of the work being undertaken by specialist services in primary care.

### **INCENTIVES, LEVERS AND PAYMENT**

Sustainable services that enable smooth access to primary mental health care services for Deaf people will match payment models that incentivise quick access, high quality care and good outcomes and will help to reduce avoidable crises. Recent evidence<sup>38</sup> highlights that commissioners should not assume that providing a BSL interpreter within a standard IAPT service will be cost effective compared with a practitioner fluent in BSL. Other considerations, such as linguistic and cultural matching, therapeutic alliance and patient preference, need to be addressed.

### **FAIR REGULATION AND INSPECTION**

Although psychological therapies are not regulated or inspected by the Care Quality Commission (CQC) unless provided within secondary care, it is best practice to have robust governance in place. Therefore, the Information Governance Toolkit needs to be valid and available for inspection by commissioners on request. This will ensure transparency and help commissioners who are considering funding a psychological therapy service in BSL to know that it is of a high quality and committed to delivering an ethical and professional service.

### **LEADERSHIP INSIDE THE NHS AND ACROSS GOVERNMENT**

The Deaf community is an under-served minority group and as such the population number in each CCG is very small compared to the hearing population. Joint working and co-operation between CCGs with collaborative commissioning needs to be considered in the absence of a nationally commissioned service.



# Expert Reference Group Members

## Lead author

### Celia Hulme

Project and Service Management Lead,  
BSL Healthy Minds from SignHealth

The input from members of the  
Expert Reference Group is gratefully  
acknowledged.

## Expert Reference Group

### Dr Andrew Alexander

Medical Director, SignHealth

### Dr Libby Barnardo

Clinical Psychologist, South West London  
and St Georges Mental Health Trust

### Dr Alex Hamilton

Consultant Forensic Psychiatrist,  
St Andrews, Northampton

### Masood Khan

Policy Analyst, Royal College  
of Psychiatrists

### Dr Philip Matthews

Consultant Psychiatrist, Northumberland  
Tyne and Wear NHS Foundation Trust

### Melissa Mostyn

Service User

### Dr Omar Nasiruddin

Consultant Psychiatrist,  
South West London and St Georges  
Mental Health Trust

### Joyce Pennington

Clinical Nurse Specialist, Northumberland  
Tyne and Wear NHS Foundation Trust

### Helen Phillips

Senior Policy Administrator,  
Royal College of Psychiatrists

### Dr Sarah Powell

Clinical Psychologist, BSL Healthy Minds  
from SignHealth

### Susan Ramsdale

Principal Lecturer, University  
of Central Lancashire

### Peter Shaw

IAPT Psychological Wellbeing Practitioner,  
Rotherham Doncaster and South Humber  
NHS Foundation Trust

### Paul Stemman

Head of Policy and Communications,  
SignHealth

### Esther Rose Thomas

BSL/English Interpreter, Association of  
Sign Language Interpreters (ASLI)

### Hazel Wilcock

Clinical Strategic Lead, BSL Healthy Minds  
from SignHealth

### Professor Alys Young

Professor of Social Work Education and  
Research, Director of SORD, University of  
Manchester

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# Joint Commissioning Panel for Mental Health

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