

Report into mental health services for deaf people in Birmingham and the Black Country

Commissioned by: Birmingham East and North PCT
Birmingham South PCT
Dudley PCT
Heart of Birmingham Teaching PCT
Sandwell PCT
Solihull Care Trust
Walsall Teaching PCT
Wolverhampton PCT

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Executive Summary

This report was commissioned by eight of the PCTs in the West Midlands. The PCTs were responding to the publication of the Department of Health's *Towards Equity and Access* report, which examined mental health services for deaf people.

The PCTs' mental health commissioners wanted a better understanding of what services currently exist, where the gaps in service provision are and what steps could be taken to improve services.

There was a wish to look at the whole spectrum of deaf people, including sign language users, lip readers, etc. While their needs are essentially the same (to understand and be understood), the service responses obviously have to differ.

The report is meant as a working document, and will hopefully be just another step towards improving mental health services. We found evidence of some very good service provision and the area is fortunate to have the National Deaf Mental Health Service (NDMHS) located in Birmingham. In addition there are many other services that support deaf people with mental health problems – perhaps reflecting a high concentration of deaf people in the area.

However, there are many areas for improvement. These applied to existing services and to gaps in services.

A lack of overall strategy within the region has led to services being developed in isolation and haphazardly. There is no overall vision for the services as a whole. Commissioners have been involved with the specialist unit (NDMHS), but this has normally been in relation to individual people rather than in a strategic role.

Similarly, there is no forum available to look at the bigger picture that includes social care, employment and the wider range of health services. This situation reflects the fact that PCTs are working with small populations. It is difficult to develop services for such a small group within one PCT area, and it is necessary to work with colleagues from neighbouring PCTs.

It is for this reason that the report's main recommendation is the establishment of a regional group that co-ordinates service development for deaf people with mental health problems. This recommendation follows national commissioning guidance and is essential if other developments are to be pursued.

Other recommendations are directed at possible service developments that may follow from such a group being established. They are offered in an attempt to generate debate and focus attention on good practice and experience from elsewhere.

Further recommendations focus on simple steps that could be taken by individual PCTs to improve their services for deaf people. Some of these stretch beyond the confines of mental health. However, their benefit would be felt by all deaf people and would probably enhance the wellbeing of deaf people generally. Steps to improve the physical health of deaf people will also have a positive effect on their mental health.

Introduction

This report was commissioned by eight of the West Midlands PCTs through pooling the small amount of 'TEA' money they each received in 2006/7. This was funding that followed publication of the Department of Health's guidance, *Mental health and deafness: Towards Equity & Access*. Here in Birmingham & the Black Country the commissioners decided to conduct a systematic review of the needs of the local population and the services that currently exist for deaf people with mental health problems.

Sign and BID Services with Deaf People were selected to carry out the work. *Sign* is the leading national deaf charity with expertise in mental health. BID has a very large presence in Birmingham, and also provides services to deaf people who have mental health problems. BID also works closely with the National Deaf Mental Health Service.

It was agreed by BID, *Sign* and the PCTs that deaf people should be asked about their needs and the services they use. Deaf people would have a major say in how their needs should be met in future and what they felt would be appropriate services to develop. It is all too easy to presume what people may want, and then wonder why people are not using a new service.

The report condenses a lot of information, much of it gathered from forums of deaf people, and from informal conversations with NHS staff. We did not want to create a massive tome that people were afraid to read and sat on a bookcase gathering dust. The report is succinct and addresses the real issues. We hope it will be a report that generates action.

It is worth remembering why the report *Towards Equity and Access* came about, and why mental health services for deaf people deserve attention. Daniel Joseph, a young Deaf man, killed Carla Thompson in 1998. The subsequent inquiry into his care highlighted some of the difficulties of providing mental health services for deaf people. The inquiry recommended a review of service provision, which culminated in the publication of *Towards Equity and Access*. Many of the issues raised by the inquiry have yet to be properly addressed.

The other important point to remember is that deaf people are far more likely to experience mental health problems than the population in general. It is estimated that between 40 to 50% of deaf people will experience a mental health problem at some point in their life – compared to 25% among the hearing population. Depression is particularly common, probably as a result of isolation. This increased prevalence means that mental health services are vitally important for many deaf people.

That is why the commissioning of this report is so welcome.

How to use the report

The report can be used in a variety of ways. It contains the background evidence of what services exist now and where the gaps are. It also includes recommendations for future action. This information is broken down, where it can, on a PCT level.

It is hoped that the report will form the foundation for further pieces of work. Most of the recommendations are for clearly defined action – rather than woolly sentiments that do not translate into action. Many seek to establish a sound framework from which future services can grow. This is perhaps more important than whether particular service developments are followed.

An overview of the *Towards Equity and Access* recommendations is provided, with an indication of how PCTs are meeting them. It must be remembered that the remit of the *Towards Equity and Access* report expanded to all health services, while this report still largely focuses on mental health services.

The report should also stimulate discussion. Although it focuses closely on mental health services for deaf people, the report has ramifications elsewhere. It can form a starting point for a debate with the Deaf community. It should also be useful for other services within the PCTs – as people who are deaf access all parts of the NHS.

A note about language, deafness and Deaf culture

We are aware that language has reinforced discrimination for many years. It is also constantly evolving, so the terms used today may be seen as inappropriate in years to come.

At the current time, there is a reasonable consensus about what language to use with regard to deafness and mental health.

A large number of people are deaf. Indeed, it is estimated that one-in-seven people are deaf. We use the word “deaf” (with a small “d”) to refer to all deaf people. They may have been deaf from birth or deafened later in life. This includes people who are heard of hearing.

Many deaf people regard themselves as part of the “Deaf community”. These people are referred to as “Deaf” (with a capital “D”). These are usually people who were born deaf, or became deaf pre-lingually. Almost all will use British Sign Language (BSL) as their first language. They will also see the community as a linguistic minority and not regard themselves as disabled. The Deaf community is seen as a cultural group, bound together by shared experiences and views. However it is hard to make generalisations as there are bound to be exceptions.

British Sign Language has a long history. There are regional variations within BSL just as there are with English. There is a broad north/south divide, with local variations throughout (akin to dialects). This means that even the signs for numbers (6, 7, 8, etc.) vary.

It is also worth mentioning that for pre-lingually deaf people, English is an unheard additional language. It also has a different structure to BSL. While many deaf people have excellent written English skills, many more have a low level of written English. Research suggests that 95% of profoundly deaf school leavers have a reading age of nine.¹ While this would mean most deaf person could be able to read a tabloid, it masks many difficulties. For instance, metaphors and analogies can often cause confusion. This means that simply writing things in English does not overcome the access barrier for many deaf people. Health information is often written for a reading age that exceeds nine.²

Some deaf people use Sign Supported English (SSE). This uses many BSL signs, but tends to follow English sentence construction and grammar. SSE is often used by deaf people who had an oral education (were taught in English).

A note should also be made about Makaton. Makaton is not a language. It borrows signs from sign languages, but is a system that supports the spoken word. It is used with people who have communication, language or learning disabilities. So, a sign for “sit” may be used to reinforce the word “sit”. Some BSL users complain that comparisons with Makaton belittle their rich language.

¹ Conrad, R (1979) *The Deaf School Child*. London: Harper & Row. Depending on the measure used, you would expect the majority of 16-year-olds to have a reading age of 16.

² According to Prof. Boulos from the University of Bath, the NHS Direct website requires a reading age of 16.8.

A note about cochlear implants is also worth making. This is an issue of great controversy within the Deaf community. A cochlear implant involves major surgery. The external part looks much like a hearing aid and picks up sounds. It then passes them to the internal part, which sends electronic signals to the hearing part of the brain (which makes the brain 'think' it is hearing a sound).

It is still too early to say what the affect of implants will be. But, they are not appropriate for all deaf people. They only increase the awareness of some sounds – it is not like flicking a switch and suddenly being able to hear. Implants are **not** a 'cure' for deafness. Many deaf people have had implants and later got rid of them. Sometimes this is because they do not work, or work well enough. On other occasions it is because they still feel excluded by the hearing society and would rather stay a member of the Deaf community.

There are concerns that some children with cochlear implants may, at a later date, dismiss the implants (especially if the benefit is marginal). By that time, they could have missed opportunities to learn BSL and to benefit from traditional methods of deaf education. They will also be faced with identity issues, now feeling isolated from both the hearing and deaf worlds. This is bound to be a subject of much debate in the future, and will have a bearing on future health issues.

It should also be remembered that many people who have gradually lost their hearing may deny that they are deaf. Unwilling to admit it to themselves, people can become very sensitive and do not like being questioned about how well they can hear.

In addition to the deaf population there is also a sizeable group of people who are deafblind (24,000 in the UK). Again, this term covers a wide range of people. Some will have been born both deaf and blind. Some will have been born deaf but progressively lost their sight. The preferred method of communication varies from person to person. A person who was deaf and used BSL, but then lost their sight, will probably still use BSL (often by tactile communication to follow the movements). Some deafblind people will use 'deafblind manual' communication which is similar to words being spelled out letter-by-letter using BSL.³

Deaf people with Ushers Syndrome have deteriorating vision. Sometimes the vision is limited on the periphery. For other people, the vision deteriorates in the centre. These differences require different strategies to communicate. For a deaf person vision is crucial to communicate. To lose sight can be very difficult to cope with.

The field of mental health is also fraught with issues of language. Again, there is much debate about what terms should be used. We use the following terms in this report: "mental health problems", "poor mental health", and "experience of mental distress". We accept that not all people with poor mental health see their "problems" as problems. However, for now, it seems an acceptable description.

We know from work elsewhere that the stigma of poor mental health can be very severe within the Deaf community.⁴

³ When an interpreter is needed it is best to ask the person what their preferences are and whether they can recommend someone. Agencies that provide qualified English/BSL interpreters should be used. If they cannot provide anyone they will be well placed to know where a suitable interpreter can be found.

⁴ *Sign* staff frequently attempt to support deaf people with mental health problems so they can join Deaf community social events. They often encounter misconceptions and suspicion.

In both cases (deafness and mental health) we have followed the social model of disability. While this may not be a perfect model, it is certainly useful when considering services as it turns problems on their head. So, for example, the barriers faced by a deaf person do not arise because the deaf person cannot hear. The barriers arise because society has been unable (or unwilling) to learn how to communicate with deaf people.

As a test of the model, if everyone could communicate in BSL there would be no communication barriers for deaf BSL signers. This gets away from seeing the person's "impairment" as disabling. Instead, the environment and attitudes around them are disabling. The social model can be contrasted with the medical model, which sees deafness as an impairment that needs to be fixed or improved. Here the focus shifts to biological functioning rather than accepting the person as they are.

Aims of project

The aims of the project were specified in the tender document:

"You will be expected to complete a needs and gap analysis for each PCT against the specific identified mental health recommendations in *Mental Health & Deafness: Towards Equity and Access* national policy guidance. You will also be expected to engage with deaf communities and other range of stakeholders."

The Commissioners' Steering Group also provided a steer regarding the type of report they wanted. Commissioners wanted a document that they could work with. They were also unflinching in their willingness to have examples of poor practice highlighted.

The project has tried to include the views of a range of deaf people; across the age groups and from different ethnic backgrounds. The report should be seen as the start of a wider project. It will be a useful benchmark of what exists now, and how future progress can be measured.

Methodology and epidemiology

There were three stages to the project.

Desktop mapping – this involved finding out what services existed, the local epidemiology, the local NHS structures, etc.

Primary research – the main component for this stage was the Forums of deaf people. These engaged deaf people in each PCT area with facilitators who themselves were deaf and fluent sign language users. There is a high level of stigma about mental health problems in the Deaf Community so the participants were given free reign to express their views on health services generally. This was felt to be more likely to attract people. However, the meeting facilitators were then able to steer the questioning to areas of mental health, while gathering useful general information.

Feedback from each meeting was collated and analysed. Information was also collected on the age profile and ethnicity of participants. This engagement with deaf people was crucial.

Some practice managers and clinicians were also asked about aspects of their service. An e-mail survey was carried out in Walsall. Although not scientific, this gave a useful snapshot. The survey asked basic questions about whether there were deaf people registered at the practice, whether a contract for interpreting was in place, etc.

Specific research – this focused on what were seen as the important areas of service development. It was important to get an understanding of what had been tried elsewhere, what the particular local problems were and what the opportunities might be.

Population estimates

The number of deaf people with mental health problems is hard to estimate. The NHS patient database is the Patient Administration Systems (PAS) but not all record whether a patient is deaf. There are also varying degrees and types of deafness. Similarly, mental health is often not recorded explicitly.

The following table is a very crude estimate. Table 1 is based on the current prevalence of deafness among new born babies, not all of whom will grow up to sign. It is assumed that 1-in-1,000 people are BSL users⁵ but prevalence rates of deafness was higher in the past. This would probably raise the incidence of BSL users in the total population.

TABLE 1 – ESTIMATES OF DEAF POPULATION IN 2007

	Total population	Hearing impaired population (14.3%)	Deafblind population ⁶	Disability Living Allowance (DLA) awards due to deafness	Culturally Deaf BSL users	Culturally Deaf population with a mental health problem (40% of pop.) ⁷
BEN	391812	56029	157	253	392	157
HoB	243294	34791	97	157	243	97
B'ham South	341003	48763	136	220	341	136
Sandwell	282904	19941	113	197	283	113
Dudley	305155	22789	122	183	305	122
Wolverhampton	236582	26045	94	155	236	94
Walsall	253499	29766	101	184	253	101
Solihull	199517	34018	80	88	200	80
Total	2254744	38878	900	1437	2254	901

⁵ The National Study of Hearing was reported in Davis, A (Ed) *Hearing in Adults* (Whurr, 1995). This showed that 1-in-1000 babies are born with moderate hearing loss in both ears. In addition some children will lose their hearing, so the figure increases to 1.65-in-1000 children aged under-nine. Not all will necessarily become BSL signers, so I have used a 1-in-1000 estimate.

⁶ This is based on there being 24,000 deafblind people in the UK, assuming a total population of 60 million.

⁷ See section below on mental health and deafness.

The Disability Living Allowance figures are obviously going to reflect only a proportion of the profoundly deaf population. There has been no research to suggest what proportion this may represent.

The population of PCTs in the Birmingham and Black Country represents 3.95% of the population of England, Scotland and Wales. There are approximately 75,000 BSL users in these countries. This equates to 2,961 BSL users across the Birmingham and Black Country PCT areas.

Both of these estimates are likely to under-represent the case locally because the Deaf population is not uniformly spread across the country. It is believed there are more than average numbers of deaf people residing in Wolverhampton and Birmingham. This is based on observations as there is no data to analyse. Birmingham probably has a higher than average population because of having deaf schools and being a big city. Wolverhampton has an accessible University and is popular for deaf social events e.g. 5-a-side national football tournaments, DeafFest, etc.

All of this guesswork highlights the need for public health officials to try and capture some accurate data. It is hoped the 2011 census will be a more useful tool as people might be asked about their language, and there are other initiatives (such as the collection of sensory data on the Council Tax application form in Lewisham) that could help. As PAS systems develop, it should be possible for public health departments to arrive at a more accurate figure.

Just as population figures are hard to come by, detailed demographic data is limited. One survey, from Manchester University, revealed that 18.8% of deaf children being supported (by education services for under-5s) were from families with an ethnic minority background. Two-thirds of this total had an Asian background. It would be dangerous to make too much of this figure.⁸ Birmingham may, therefore, have a significant population of deaf people from BME communities.

Similarly, figures relating to other indicators such as social deprivation just do not exist. We know, anecdotally, that many deaf people find it very difficult to enter the job market and are – consequently – living on low incomes. Many young deaf people have stayed at home with their families longer than their peers. If pushed to generalise then it would be safe to say that deaf people are more likely to be social excluded than average, and find themselves in a lower socio-economic group. Where this is the case, it is really a symptom of not being able to access education and employment. Life chances are therefore severely reduced for many.

There is also a sizeable deaf refugee and asylum seeker population. This group may well have an increased incidence of mental health problems because of experiences in their country of origin (though this is based purely on anecdotal evidence mainly in London). Again numbers are impossible to provide.

⁸ “Teachers’ perspectives on support for under fives in families of ethnic minority origin,” Susan Turner & Wendy Lynas, *Deafness and Education International* 2(3), 2000.

Mental health and deafness

The prevalence of mental health problems among deaf people is one area that has been researched. The research has normally been conducted by committed clinicians and its extent is still minimal compared to health research in general.

In broad terms, the research tells us that:

- Deaf people are just as likely to experience schizophrenia as hearing people;
- 40% of deaf people are likely to experience a mental health problem, as compared to 25% of hearing people. This is mainly due to a higher incidence of depression; and

It is probable that this increased incidence is caused by deaf people's experiences: isolation, lack of opportunities (especially employment), attachment to parents, poor self-esteem as they are "impaired", etc.) Further research is needed to collate what is known and record it systematically.

Current service provision

It will surprise many to know that the West Midlands area has, *potentially*, the best mental health services for deaf people anywhere in the country. Unfortunately, this research suggests that the full potential is not yet being met.

National Deaf Mental Health Service (Denmark House)

As part of Birmingham & Solihull Mental Health Trust, the National Deaf Mental Health Service (NDMHS) is one of only four NHS services in the country that specialises in working with deaf people experiencing mental distress.⁹

The service offers inpatient assessment and admission, outpatient clinics and a Day Centre (at Denis Shilston House). It was not the job of this report to assess the quality of this service, but it is widely respected within its field.

The service has the following staffing:

Team manager	1	Consultant psychiatrist	2
Senior House Officer	1	Senior practitioner/ASW	1
Senior occupational therapist	1	Community Psychiatric Nurse	3.2
Day service manager	1	Day services staff nurse	2

⁹ The other services are part of South West London & St George's Mental Health Trust, Bolton, Salford & Trafford Mental Health Trust and Nottinghamshire Healthcare Trust (Rampton Hospital).

Acting ward manager	1	Staff nurses	6
Nursing assistants	5.5	Communication officer	1.5
Clinical psychologist	1	Psychologist	0.4
Research assistant	0.4	Social worker	1
Social Work Assistant	1	Occupational therapist	1
Administration/secretaries	3	Ward clerk	1

Follow-up work is carried out in the community for local people (and many who come from further away).

The service is a tertiary service, and this creates tensions that will be addressed elsewhere in the report. Referrals are taken from across the region, and beyond. People from Wales and Northern Ireland have been admitted in the past.

Dudley Deaf Child & Adolescent Mental Health Service (CAMHS)

Until recently, there was only one service for deaf children in the country (in South West London). However, two new deaf CAMH Services were established with funding from the National Specialised Commissioning Advisory Group (NSCAG). One of these was in York, the other in Dudley.

The Dudley Deaf Service is embedded in the mainstream Dudley CAMHS service. It is a valuable resource for deaf schools in the region: Royal School for the Deaf (Derby), Longwill School (Birmingham), and Braidwood School (Birmingham). The team is part-time, but able to offer traditional Tier 2 and Tier 3¹⁰ CAMHS interventions in BSL. The team is supported by the London service, and makes use of tele-links (so that people can communicate in BSL remotely).

The service to pupils of the three schools is paid for by NSCAG. There is also NSCAG funding to provide the service to deaf children from Dudley and Wolverhampton. In these areas referrals can be accepted from a wide range of sources, e.g. social workers, paediatricians, etc.

The Service will accept referrals from other parts of the West Midlands. However, individual funding has to be agreed by the referring PCT, and this can sometimes cause difficulties.

Across the country, the transition between CAMH services and Adult services has caused many problems. The Dudley Deaf Service works with young people up until school leaving age. This can mean there is a gap for some young deaf people, who are not yet 'eligible' for Adult services in areas where Adult services start at 18. The Dudley Deaf Service continue to see a young person if they are already engaged prior to leaving school. However, they cannot take new referrals of young people who

¹⁰ See *Together We Stand*, Health Advisory Service for details of the tiered model.

have left school. The Service is not currently resourced for 16-18 provision in all locations.¹¹

The West Midlands Specialist Services Agency should be addressing the commissioning of the Dudley Deaf Service. It is recommended that local CAMHS commissioners explore care pathways to ensure that no gaps exist in service provision. A pan-regional solution to commissioning the service is strongly supported. If young deaf people do not get an effective local intervention, then the consequences (and future costs) are likely to escalate dramatically.¹²

Tarragon Gardens

This is an RNID-managed four-bed house for deaf people with enduring mental health problems and challenging behaviour, based in Northfield, Birmingham. This is supported housing accommodation with 1:1 staffing. The unit is staffed 24hrs a day. Placements tend to be long-term. Although residents do move, the project offers a home for life, which naturally restricts throughput.

Mulberry House

The RNID also run a residential care home for deaf people with mental health problems in Walsall. This six-bed unit provides 24/7 support in a signing environment.

A one-bed 'move on' placement is also run by the RNID in Walsall.

BID Services with Deaf people – residential services

BID provide a number of residential services to deaf people with additional needs, which can include mental health problems. Services range from staffed homes, to supported living (funded through Supporting People). This means there are different solutions available when support is needed.

Referral tends to be through social services and are suitable for people who may have less severe mental health problems. For instance, support might be provided for a deaf person who is isolated or lacks independent living skills.

Supporting People

The Supporting People scheme also funds five placements in Sandwell, which are run by the RNID. The PCT is involved in this scheme, which is for deaf people with additional needs. This provides support at the lower-end of the spectrum.

¹¹ The *Children's National Service Framework* says that CAMH services should provide for 16- and 17-year-olds.

¹² Scott S, Knapp M, Henderson J and Maughan B (2001) *The cost of social exclusion: antisocial children grown up*. British Medical Journal 323, 191-195
Mental Health Foundation, *Bright Futures*, Mental Health Foundation, 1999
Dinah Morley and Peter Wilson, *Child and Adolescent Mental Health: Its Importance and How to Commission a Comprehensive Service*, Young Minds 2001

It is very positive that there are supported living schemes available in the West Midlands area. However, there are problems and these are discussed later in this report.

Advocacy for deaf people experiencing mental health problems

The Birmingham Citizens Advocacy service, located in Southside Business Centre in Balsall Heath, partners people who are experiencing mental health problems. One of their services is a specialist advocacy service working with deaf people. The advocate (who is Deaf) is based in the BCA team, but has close links with the service at Denmark House.

The advocate visits Denmark House every fortnight and is able to partner any people that may want support. The mental health system can be bewildering for many, and the important role an advocate can play is well recognised. What makes this service particularly good is that the service is not limited to in-patients. Indeed, the service is for any deaf person with a mental health problem, but 'inreaches' to the NDMHS. This has immense benefits for people in Birmingham who can continue to receive support on discharge.

Birmingham East & North (BEN) PCT pays for one worker under a Service Level Agreement with this service for advocacy for deaf people with mental health problems across the whole of Birmingham.

There is also a Deaf advocate in Sandwell, who works for deafPlus. However, they work with all deaf people, not just those with mental health problems.

Primary Care Mental Health Worker

Birmingham East & North PCT used to fund a dedicated BSL signing primary care mental health worker but the worker left as she did not get enough referrals. BEN PCT maintains a substantial team of Gateway and primary care mental health workers attached to GPs across the whole patch. In future it might again be possible to require one of the team to be fluent in BSL as a resource for the whole PCT but not seeing exclusively deaf people.

Support, Time and Recovery (STR) Workers

"STR workers are people who come from different walks of life with different backgrounds including volunteers and existing and former service users who have the ability to listen to people without judging them. STR workers are able to help service users to have an ordinary life assisting them with their everyday, practical needs in whatever setting they find themselves to facilitate recovery." Mental Health Policy Implementation Guide: support, time and recovery workers, DH (March, 2003)

STR workers are active in the Birmingham and Black Country area. It is not believed that any are deaf or can sign. However, the *Towards Equity and Access* report does highlight the STR model as a way of recruiting deaf people into mental health services. It would also go some way to meeting the wishes expressed in the forums (see later).

STR workers may also be well placed to assist in the assessment of the needs of carers.

Carer Support Services

The Birmingham Carers' Centre is a one-stop shop in a prominent location in the City Centre. A Minicom is in place and BSL interpreters are available. The Centre provides information for carers on a wide range of issues.

All PCTs commission support services for people caring for those with mental health problems. HOB has two BSL-trained carers support workers who link with deaf carers.

Interpreting Services

All PCTs in the project area have contracts in place for interpreting. Although not directly related to mental health, this is an important step. The *Report of the Independent Inquiry into the Treatment and Care of Daniel Joseph* stressed the importance of good quality interpreting. The *Report of the Independent Inquiry into the Care and Treatment of Sarwat Al-Assaf* highlighted the issue even more starkly.

What was particularly relevant in that report was that an interpreting contract was in place, but staff were unaware of it, or when it operated. Research for this report suggests the same is true in Birmingham and the Black Country. Some staff are unsure whether there is a contract. Others think they have no access to a BSL interpreter.

Case study

A young deaf woman went to an Accident and Emergency Department as she had a crisis following a relationship breakdown and was feeling very depressed. She had self-harmed and taken an overdose.

At the hospital the doctor wanted to assess her but there was no interpreter. The nurse told her that they could only use interpreters for pre-arranged appointments and if there was an emergency she would have to ask her manager to agree for them to book an interpreter.

The woman had arrived at the hospital at one o'clock in the morning. Eventually an interpreter arrived at 3.30 pm but was only able to stay for half an hour and there was no time for the doctor to explain what he had decided. She was then discharged from hospital unaware of what would happen afterwards.

Improvements to existing services

On the surface, it would seem that the West Midlands is well served with resources for deaf people experiencing mental health problems. Indeed, the picture is much better than in some parts of the country.

The existing services appear to do an excellent job. However, in addition to gaps in services, improvements could be made that would enhance what exists.

Carers' services

The relatively small numbers involved mean that a targeted support group is unlikely to be successful. This means that more emphasis should be given to supporting people to access existing groups and services.

It is disappointing that carers' services are not better used by deaf carers. It is quite common for deaf people to not attempt to access a service because they think there will be lots of difficulties organizing access (i.e. the deaf person normally has to explain why they cannot access the services, and what the person could do to make it accessible. This unusual request normally means service providers have to do lots of checking with other people to see whether they are meant to provide interpreters (or whatever may be required). This can often be quite a battle for the deaf person, so many understandably decide to not try).

This points to a need for a community-based 'resource' that can be accessed with any number of deaf-related queries. This links with a gap indicated below.

Support needs are at their most intense during a first episode of mental illness when the carer does not know the system or have confidence in recovery. Clinicians need to be confident that the carers' service they might refer someone to will be appropriate and accessible.

If the Birmingham Carers' Centre has a minicom and access to interpreters, then this should be actively promoted. Even if take-up is still low, it is important that the Deaf community feels services are being made accessible. That recognition alone can be of great benefit.

It has been suggested that a 'mystery shopper' tests the service to see whether it is truly accessible. This is an excellent idea and would be a valuable exercise for each PCT to undertake. The results would suggest what further action might be necessary.

Hearing carers of deaf people have access to mainstream support services. The support service is unlikely to have any direct experience of deafness, but this does not pose a barrier.

Support, Time and Recovery services

A key concern of local deaf people was the lack of deaf staff in the health service. STR services seem to be an ideal opportunity to address this. Engagement by a deaf STR worker (or at least fluent signing STR) would be far more effective. A lot of the boundaries and suspicion would be immediately demolished.

However, careful consideration needs to be given to how such a position would be managed. It would seem to fit most neatly with the NDMHS, providing support for people whilst in Denmark House and after discharge.

Post-discharge support has been highlighted as an important area of concern. However, we cannot be sure that a STR worker would be the best solution. The NDMHS may need someone with clinical skills who is able to undertake more responsibility. Both commissioners and the NDMHS should examine whether there is a role for STR workers.

Interpreting services

It appears that the Birmingham PCTs have a contract with Birmingham Integrated Language and Communication Service (BILCS). This contract fills in gaps they might have with their main interpreting contract. BILCS then sub-contract BSL interpreting to BID's interpreting agency.

Unfortunately, many staff seem unaware of BILCS and of how to access a BSL interpreter.

Similarly, in Walsall and Sandwell contracts are in place but there seems to be confusion among practice managers. Some were very clear about the contract and the procedure for booking an interpreter. But nearly half of those who responded to a survey either did not know how to book an interpreter or were unsure. This is likely to be a picture repeated elsewhere.

Case study

A deaf expectant mother was feeling unwell. The doctor took some blood tests, and she thought he said the tests would prove whether the baby had spina bifida. She worried for the next month before her father-in-law translated and she found out they were standard tests. Her baby was born healthy.

Having done the difficult part of agreeing an interpreting contract, it seems wasted if all staff are not then made well aware that the service exists. This could be the start of a wider process that educates staff about deaf patient experiences.

There also seems to be a particular issue with interpreting in Solihull. We have not gone into the detail of this, but it appears to centre around Solihull patients who do not have a Birmingham postcode. It seems that this was a wider interpreting/funding issue, rather than being specific to BSL.

There appears to be a mixed response from PCTs on the issue of Deaf Awareness and Communication Tactics training courses. There were signs that all PCTs were planning to put courses in place. But, when BID approached South Birmingham, Solihull, Sandwell, BEN and HoB PCTs, only HoB and BEN PCTs followed this up. In Sandwell, deaf awareness and other relevant training is provided by the Local Authority: this training is open to NHS staff also.

It is recommended that all Training Departments offer Deaf Awareness and Communication Tactics courses, and are encouraged to actively promote them.

National Deaf Mental Health Service — Denmark House

Provider issues

Anecdotal evidence suggests that if a deaf person presents displaying an obvious mental health problem, they are referred to Denmark House. It is, possibly, seen as a given that the patient should come under their care.

This assumption is understandable. Very few clinicians are experienced in working with deaf people who have a mental health problem. If there is a specialist unit nearby then why not refer there?

Case study

A deaf woman had been ill for some years but had not been referred to Denmark House. She had a relapse and was admitted to her local hospital and then transferred to Denmark House.

During her admission staff at Denmark House worked closely with local professionals to agree an appropriate package of support ready for discharge. They also explained about the importance of booking qualified sign language interpreters to ensure professionals could fully understand the service user.

A while later Denmark House visited the woman again. They noticed her mental health had deteriorated and she was showing signs of increased paranoid ideas with some evidence of risk to others. Local professionals had been visiting her without an interpreter and so had not understood her and missed the symptoms of her increasing paranoid ideas.

Unfortunately, there is a mismatch between people's expectations and the reality. Denmark House does not offer an emergency service. This point is a crucial. The *Report of the Independent Inquiry Team into the Care and Treatment of Daniel Joseph*¹³ highlighted this same issue. Colleagues in mainstream mental health services wrongly assumed that the specialist service operated in a similar fashion and could offer an emergency admission. One of the key recommendations from the Inquiry was for the Deaf Service to make it clear that emergency admissions could not be offered.

Admission to Denmark House normally follows a community assessment and discussion within the referral team (suitability, case mix, etc.). This naturally takes time, and also presupposes some involvement from local mental health services.

The staff at Denmark House admitted that the experience varied depending on the referring clinician. Some were happy to see the patient as "theirs" but wanted the expert input. However, in many cases there appears to be a keenness to pass responsibility over as quickly as possible.

While this could be viewed as just bureaucratic wrangling, the affect on the patient is important. It denies many deaf people access to pioneering early intervention, crisis resolution and home treatment services. Deaf people's treatment options are narrowed to either seeing their GP every few months, or being admitted to hospital. A whole range of intermediate interventions is missing. This picture appears consistent throughout the

Birmingham and Black Country area.

¹³ [Report of the Independent Inquiry into the Treatment and Care of Daniel Joseph](http://www.deafinfo.org.uk/policy/daniel_joseph2.html), Merton, Sutton and Wandsworth HA & Lambeth, Southwark and Lewisham HA (September 2000), http://www.deafinfo.org.uk/policy/daniel_joseph2.html

A similar problem exists for in-patients at Denmark House. Ideally, the staff like to work with local mental health services so they are involved in the treatment and prepared for when the patient is discharged. Unfortunately, many local teams seem unwilling to accept that the patient is their responsibility. This can lead to admissions that are longer than necessary. It also suggests that the post-discharge care is less likely to be as comprehensive (thus raising the chances of readmission).

It is recommended that clear referral criteria and protocols are established, circulated and endorsed. This will require the involvement of commissioners across Birmingham and the Black Country, and the Birmingham and Solihull Mental Health Trust. The protocols must make clear what is expected of both mainstream mental health services and the NDMHS throughout the care pathway.

Funding

Another difficulty arises with the funding of admissions (and, indeed, outpatient work). There is anecdotal evidence that some PCTs are unwilling for people to be admitted to Denmark House because of the cost. They would rather the patient remained on a normal in-patient ward, perhaps with some interpreting input.

There are occasions when this might be the best course of action, but this needs to be dictated by clinical need – not financial constraints. There is also an important question of patient choice. Some deaf people may prefer to stay on a local ward rather than go to Denmark House, particularly if they are worried about their admission becoming common knowledge. Likewise, many deaf people, particularly when experiencing distress, will find a deaf environment calming and reduces their anxiety.

This highlights a wider commissioning issue.

Commissioning

Denmark House has 'contracts' with a number of PCTs in the West Midlands.¹⁴ At present, Birmingham East & North (BEN), Heart of Birmingham (HoB) and Birmingham South have joint discussions before agreeing a block contract that is split between them. This is set to change to cost and volume contracting.

Solihull and Walsall also have cost and volume contracts, but most PCTs pay on a cost per case basis.

There are numerous difficulties with such an approach:

Patient

When block or cost-and-volume contracts are not in place, there can be delays for the patients as funding approval needs to be sought and agreed.

Commissioners

¹⁴ Including: Birmingham East & North, Heart of Birmingham, South Birmingham, Solihull, Sandwell, Worcestershire, North Warwickshire, South Warwickshire, Wolverhampton, Walsall, Dudley, South Staffordshire, Gloucestershire and Trentcom LSCG.

For each PCT there is a balance to be struck in the commissioning of low volume services between ensuring adequate services are available at a reasonable cost and paying for services that are not used by the local population.

Cost-per-case funding can be more expensive but is a better use of resources if likely referrals are low as block contracting can be wasteful. There is some risk for a PCT if referrals rise above predicted levels in a year.

Unfortunately, because of issues of low volume and cost-per-case purchasing, as well as a lack of cross-authority commissioning, it is harder for commissioners to address issues of outcome, quality measures, and service developments. In the case of deaf services, this has resulted in fragmented commissioning with nobody really taking ownership of a service like the National Deaf Mental Health Service.

This is well recognised and mental health services for deaf people are one of 35 'conditions' on the Department of Health's National Definition Set for specialised commissioning. That means they require different commissioning to normal services because of their low planning populations. Guidance from 2003 encouraged Health Authorities to work together to jointly commission such services¹⁵. Unfortunately, this failed to happen for many of the conditions.

The Specialised Commissioning Groups (SCGs) recommended by Sir David Carter are only just beginning to take shape and set their agendas¹⁶. However, mental health services for deaf people will certainly feature strongly, and the Department of Health is funding a three-year project on specialised commissioning that focuses on mental health services for deaf people.

The Service

It is harder for a service to create a business plan when it cannot guarantee its annual income and service developments are less likely in a climate of uncertainty. Clinicians at the Service have a clear idea about what they would like to change and what they would like to develop. But, because there is no overall strategy or agreed outcomes to work to, these ideas are less likely to develop.

It would also be wrong for the service to have no involvement from commissioners. The service would benefit from having a relationship that brings commissioners concerns, ideas and recommendations to the fore.

Indeed, clarity around what the service is expected to provide would help and commissioners should agree to a detailed service specification if required. There are clear signs from the NDMHS that they would welcome this, and they are beginning to take an active role in bringing this about. We get the impression that the Service has not felt confident about thinking strategically because there has been no-one to do this with. A forum for commissioners and the Service would be an important step forward. The Service needs to build far stronger links with commissioners to create a joint vision that everyone can work towards.

¹⁵ [Guidance on commissioning specialised services](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4081718), DH (2003)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4081718

¹⁶ Sir David Carter, *Review of Commissioning Arrangements for Specialised Services*, DH(2006)

Service gaps

Commissioners of mental health services for deaf people are in an unenviable position. It is a low incidence group of people, and the move to PCTs made the absolute numbers in each locality even smaller. Deafness and mental health can both be seen as hidden disabilities, and people rarely demand a service.

Deaf people need access to exactly the same services as hearing people. But delivery of these services often has to be adapted to meet their communication and cultural needs. Although it might be tempting to say, "we will provide an interpreter" that is often not enough. Seeing the Deaf community as another cultural group is important. Different methods of service delivery and outreach are common for BME groups, but not thought of for deaf people.

Primary care

It is estimated that over 90% of people with mental health problems are cared for within primary care but there is little evidence of whether this is the case for deaf people.

Some deaf people are unlikely to have contact with their GP. For those that do, a somatised presentation is less likely to lead to the GP identifying a mental health problem. GPs are highly skilled at picking-up signs of emotional problems, but may feel a lot less confident on probing or pursuing a deaf patient.

In other cases, a GP may identify a mental health problem but feel out of their depth because the patient is deaf. This can often lead to premature referral to the NDMHS, or other mental health services.

It was hoped that the Deaf Forums would have shown examples of deaf people who had sought mental health support from their GP. However, this was not the case although participants were happy to share other personal experiences of mental health.

More detailed research is needed to establish the patterns of whether and how deaf people with mental health problems seek support from primary care, and what the outcomes of any contact are.

What is easier to assert is that services to support deaf people in primary care are limited. In theory, practices that offer counselling could extend this to a deaf person. However, the chances of engagement are low. This will depend partly on the deafness. For a BSL-user they will need not only confidence in the counsellor but also in the interpreter (who would need to be suitably qualified and have experience in mental health). The counsellor would also need knowledge of Deaf culture and identity. Competent counsellors work from the individual's own experiences rather than generalisations but this background knowledge forms an important context.

This is not to say that primary care counselling services should not be available for deaf people. Quite the opposite. But, it must be recognised that use of such services is likely to be low, not because of need, but because of other factors.

Many hearing people do not realise that they can see a counsellor at their primary care practice (or be referred to a counsellor from there). It is perhaps unsurprising that almost all deaf people were similarly unaware.

A primary care mental health worker who could sign was appointed in Birmingham but left because of a lack of referrals and the service has not been replaced.

Mental health

There was no evidence of any mental health promotion work with the Deaf community despite being Standard One of the National Service Framework for Mental Health. However, health promotion is particularly relevant for deaf people who do not have the same access to 'incidental' health promotion messages that might be picked up from the TV, radio or newspapers.

A project was run in Birmingham last year with Department of Health funding. This targeted vulnerable deaf people and brought them together for two 'Healthy Deaf Days'. Deaf people were able to attend workshops on different aspects of health. This proved popular and successful. It also demonstrated just how much basic information had been missed by this group of people. The key to engaging these people was the events being Deaf-led, with all the presenters being deaf.

It is therefore recommended that consideration be given to a generic Health Promotion Officer working across the region who would include mental health promotion. This person would ideally be Deaf and could work directly with local deaf people, with the backing of health resources and support.

Precisely because of the stigma surrounding mental health, anybody trying to do just mental health promotion work would find it a very hard task. There is also plenty of evidence of poor physical health among deaf people, primarily caused by lack of information and lifestyle issues which may justify a more generic remit.

Supported housing

Although supported housing is an area that might not be directly relevant, there is an important link with health. Currently, many people have admissions longer than is necessary because it is difficult to find appropriate accommodation. People are faced with living further away from their home area than they might like – cutting them off from local support and family. Inappropriate placements also increase the chance of relapse and readmission.

In the past year, one patient from Denmark House was refused admission at a care home because the home said they would not be able to communicate with him. Another patient is now in a care home for Muslim men where one member of staff happens to sign.

There are a few housing placements for deaf people with mental health problems within the region. The housing that does exist tends to be used for long-term placements and is consequently 'blocked'. There is also not a full range of 'solutions'

Case study

An older deaf man who had long term mental health problems was admitted to Denmark House for treatment. It took two years for his mental health to improve. He then had to wait another two years for an appropriate placement to become available before he could be discharged.

available within the Birmingham and Black Country area.

There needs to be a clear social care/housing/health pathway for people being discharged from Denmark House. This pathway must include a range of options and levels to address a person's needs during recovery.

An urgent audit of current local authority placements, and Denmark House discharges is recommended. This should provide a better idea of the scale of the problem and the type of needs that have to be met. Due to the long timescales involved in the development of housing, this should happen as soon possible and be included in local mental health strategies.

Supported housing need not be registered care (which is now very difficult to establish). There are plenty of alternative models that have been successfully developed. However, without joint action between local authorities (and health services) new schemes are unlikely to develop. Consideration also needs to be given to supported housing for older deaf people (with no mental health problem). There is currently no provision. Elsewhere in the country there are generic homes for older people that include a cluster for older Deaf people, e.g. four of the 30 units are allocated to deaf people. This allows them to benefit from the support offered to other old people, whilst not feeling isolated as the only Deaf person.

Expertise in community health services

There is very little expertise within local primary and specialist community health services. This is stark in comparison with the wealth of expertise held at NDMHS.

Poor local knowledge means mental health problems are probably going unnoticed for a long time. And, when problems are identified this is likely to be at a far later stage (and so more entrenched). When mental health problems are identified then referral to NDMHS often takes place, rather than support in the community. There is nobody in primary care or mental health services who can work with deaf people who may be experiencing mental health problems, and later refer to NDMHS or elsewhere if necessary.

A Primary Mental Health Worker/Gateway Worker may well help fill this gap. The roles of Primary Mental Health Workers vary from place to place. Similarly Gateway Workers have differing roles. What we have in mind here fits neither role perfectly, but we have used the term Primary Mental Health Worker (PMHW) for convenience.

The PMHW would be able to offer direct clinical work (ideally co-working with colleagues), such as short courses of Cognitive Behavioural Therapy (CBT). Having a PMHW that was deaf or could sign would be particularly valuable in engaging a deaf patient at the early stages of assessment or treatment.

This direct work would be combined with a consultative role – they would be able to offer advice and information to colleagues throughout primary care and local mental health services. They would also be able to signpost and work with secondary services to ensure appropriate access.

This would mean local services would be able to offer a better service – they would be less likely to feel deskilled when working with a deaf person. It would also mean that people would get access to the most appropriate services as the PMHW could signpost these for colleagues.

Because of the different service configurations, it is unclear how best such a post could fit with local teams. The experience of East Birmingham suggests it would need to be carefully planned and managed. The postholder would probably have to work across PCT areas, or work with hearing as well as deaf clients. It would be best if they could be part of a wider team doing a similar role, so that expertise is cross-fertilized and the worker is less isolated.

Such a role is probably best restricted to mental health alone. Broadening it would probably cause too many organisational problems and the mental health remit would be diluted. Mental health services face more difficulties working with a deaf person than generic health services – largely because communication and interaction are so central to diagnosis and treatment/support. In contrast a deaf health promotion worker within the region could probably target physical and mental health problems.

It would be recommended that were a Primary Mental Health Worker appointed they do not automatically take case responsibility. Having seen other services respond to deaf people, there is a tendency to 'dump' responsibility on to whoever can sign or knows the most about deaf people. This is understandable, but would undermine the role. The PMHW should support fellow clinicians in their work, rather than take sole responsibility.

Early Intervention Services

The NHS Plan (2000) and Policy Implementation Guide (2001) detailed the case for Early Intervention services. In many places these have been embraced and there are signs of success. Unfortunately, nothing of its kind exists for deaf people.

A crucial component of Early Intervention (EI) is early detection of symptoms. A PMHW post would go quite some way to addressing this. They would have the necessary skills and experience to help colleagues identify people possibly experiencing the early stages of psychosis.

Clearly, the number of deaf people experiencing psychosis for the first time in Birmingham and the Black Country does not justify a dedicated team. This is an example of where mainstream services must be made to work differently. EI services must accept deaf people. This is not easy for services that are many-faceted and focus on different aspects of a person's life. A patient may have involvement with a number of people in the team.

The local EI service would, undoubtedly, have to draw on expertise from the NDMHS. There would probably need to be involvement from many other agencies as well. However, I think the NDMHS would welcome the opportunity to provide advice and support to the EI service. Staff at the EI service would become more skilled as a result, and better prepared to support future deaf people.

Healthy Living Centre and Enhanced Practice

The *Towards Equity and Access* report suggested that a deaf Healthy Living Centre be piloted. Despite a great deal of effort, plans for a Centre in London collapsed in 2006. This demonstrated the challenge of partnership working between numerous PCTs and the voluntary sector.

Case study

“My doctor sent a letter about 24hr appointments. I explained we are deaf and she said I could fax 24hrs before. I faxed and they faxed back. They are really helpful. I go in the surgery and sit down and our names come up on screen and tells us the room and when we get in there we use pen and paper. I use the same doctor for confidence.” Deaf patient

The Deaf Forums addressed this question and found no overwhelming support for the idea. From a service development standpoint, there is a danger that a Centre removes deaf people from the mainstream. By their very nature, primary care services are meant to see everyone. They should be capable of providing a service for non-English speakers, for wheelchair users, and for deaf people.

Enhanced Practices, also suggested in the *Towards Equity and Access* report, are an alternative. An Enhanced Practice is an

ordinary practice that is more skilled than normal in a particular health issue and is financially rewarded for providing the agreed service. All staff in the practice would need to be trained in Deaf Awareness and have communication skills, and be committed to working with deaf people. The Deaf Forums did not find universal support for the proposal.

However, it is recommended that PCTs do try to identify whether there are any practices that might have an interest in developing an enhanced service for deaf people. Such practices offer an excellent way for commissioners to experiment and learn from deaf people. These lessons can then be shared across the PCT, and beyond. There are many initiatives that could be trialled at such Enhanced Practices, e.g. text message communication. For some PCTs, evidence from such trials may make it easier to implement PCT-wide changes. It also means there are ‘champions’ within primary care who can help convince others of the benefits.

Are the *Towards Equity and Access* recommendations being met?

The following table covers the 26 recommendations contained in the *Towards Equity and Access* report. It must be remembered that the *Towards Equity and Access* report shifted its focus from mental health services to generic health services. Therefore, many of the recommendations are not directly relevant for mental health commissioners.

	Recommendation	Have PCTs addressed?
1	That consideration should be given to conducting local Needs Assessments of the mental health of Deaf people.	Met through this report.
2	Primary Care and Hospital Trusts are asked to include Deaf awareness training in their training and development curricula for all front line staff. Local voluntary groups and local authority social services departments are likely to be able to provide the appropriate expertise.	The response from PCTs has been variable. Some have now taken advantage of free training. Walsall has a relationship with the Walsall Deaf People's Centre to provide training. However, it is not clear how well courses are promoted within Trusts.
3	A telemedicine pilot should be established between one of the specialist providers and a suitable remote site to explore whether further developments of this kind can be justified.	National development.
4	That the BSL/English translation software developed by SIGN is made available to primary and secondary care as speedily as possible.	Sandwell PCT has bought a licence. Solihull, Wolverhampton, Walsall, HoB, BEN, and Dudley PCTs all used the software during its free trial.
5	Area Child Protection Committees should review local procedures, policies and training programmes to ensure that the needs of Deaf children are recognised and can be met.	Not applicable, but could be raised with Local Authorities with Social Services Responsibilities.
6	There should be links developed between the National Deaf Service for Children and local CAHMS Teams for advice and consultation.	The Dudley Deaf CAMH Service is a pilot project. PCTs need to be clear about potential gaps (16–18-year-olds), and support regional commissioning of the service.
7	The use of video-links for this purpose	See above.

	should be piloted and proposals for roll-out of this facility developed should this prove useful.	
8	That Local Implementation Teams and CAHMS development teams make arrangements to access the data held by Local Authorities on Deafblind people as a starting point in considering how they might meet the needs of this group.	Not yet undertaken. Accessing the information in isolation is unlikely to lead to any service developments.
9	That the specialist services consider how they wish to manage referrals of Deafblind individuals in future and what additional expertise or specialisation is required	National agenda.
10	That consideration should be given to conducting a needs assessment of Deafblind people alongside any undertaken for Deaf people.	Met. Included in this exercise.
11	Every primary care facility should have a minicom and a service agreement with a translation service which includes BSL.	Only one minicom found. However, all PCTs have a contract in place for BSL interpreting.
12	Consideration be given to the potential role of Gateway Workers in assisting Deaf people with a mental health problem to the service most likely to be of assistance at that time.	Met. Considered within this report. This needs to be pursued within PCTs.
13	That a proposal for a Healthy Living Centre pilot be developed in one or two areas initially.	National/regional agenda. Considered within this report.
14	Primary Care Trusts consider whether there is a practice within their boundaries who could develop a special interest in the needs of Deaf people.	For consideration at the next stage by individual PCTs.
15	That specialist CPNs are recruited to those parts of the country with the greatest need for an enhanced service.	CPN support does exist in the area (from NDMHS) – although its commissioning needs evaluating.
16	That consideration is given to replicating the Deaf Enhanced Support Team model.	Considered in this report.
17	That the pattern of referrals, lengths of stay and eventual disposal of service users at Mayflower Hospital is carefully monitored with a view to establishing whether there is a firm case for a further medium secure unit.	Not applicable.

18	Mental Health Trusts involved in Prison Inreach should seek to identify Deaf prisoners with mental health problems and seek specialist advice on their management. Alternatively, if it were possible at some stage for the Prison Service to designate one prison as having a distinct role in managing Deaf prisoners, specialist inreach could be considered.	BID currently runs the Deaf Prison Project. Birmingham & Solihull Mental Health Trust's Inreach Service should make contact with the Project to see how the mental health needs of deaf prisoners can be met.
19	That local Needs Assessments take account of the number of Deaf elders who may require residential care.	Local authority duty, but mentioned in this report.
20	Those responsible for planning carer support should be aware of the need to consider those carers who may have particular needs.	Some evidence from Birmingham but little elsewhere.
21	In any needs assessment, attention needs to be paid to the implications of cultural and ethnic diversity	Covered within this report. For this to happen 'on the ground' then a lot more training and support will be needed for staff in primary care and mental health services.
22	In considering how to meet their aspirations for race equality, NHS bodies need to be aware of groups with particular access needs.	
23	Staff working in mental health settings should be encouraged to learn BSL and those in specialist services to acquire a fluency that would allow them to carry out their professional functions.	Some mainstream mental health staff have been learning basic BSL, but this remains a small proportion. Staff at Denmark House encouraged to reach appropriate fluency.
24	Attention should be given to means of increasing the number of Deaf people employed in mental health services at all levels. Support, Time and Recovery Workers (DH, 2003) may provide a model of how this could be done relatively quickly.	Covered in this report. Commissioners need to consider following discussions with NDMHS.
25	Consideration needs to be given to the best mechanisms for increasing the pool of skilled interpreters. This may also need to encompass the employment status of such individuals. This will need to involve a number of agencies.	National/regional agenda.
26	The feasibility of developing specialist training in mental health for interpreters should be explored by the specialist providers.	National/regional agenda.

What do local deaf people think?

The views from the Deaf Forums held in each PCT area have been used throughout this report. It is worth noting some of the feedback from these forums.

The forums served as a very useful reminder that there is a huge variety among deaf people. The range of ages, ethnic backgrounds, communication methods and views is enormous. This diversity is something that should be celebrated. However, it also makes service development more difficult. There is not a 'one size fits all' solution. For instance, at the Deaf Forums some deaf people wanted a palantypist (someone who transcribes what is being signed or spoken and displays it on a screen). Others wanted BSL interpreters, others wanted to sit near the front where they could lipread. This gives an indication of the range of communication methods used.

People were asked about how they would like to be able to contact their GP practice. Even on such a straightforward question as this, there was much disagreement and a range of preferred methods, from videophone to SMS (Short Message Service, also known as "texting", used on mobile phones).

The facilitators raised many questions specific to mental health and always got a variety of responses.

Many thought that access to a Deaf counsellor would be good. Others said they would prefer a hearing counsellor with an interpreter (mainly because of fears over confidentiality).¹⁷

Likewise with a Healthy Living Centre. Some thought this would be fantastic and they would be prepared to travel a substantial distance. Others said they would not travel far, and quite liked their local GP practice. Here, BSL users tended to be more in favour of a Healthy Living Centre than others.

Issues of privacy were raised again with the proposal for an enhanced practice. While some supported the idea, others felt that they would not be able to go to the doctors without other people knowing about it.

Proposals for a 'Gateway Worker' were more universally supported. However, participants had very clear ideas about what type of person the Gateway Worker should be.

It would be easy to portray the participants as suspicious and pessimistic. There was no end of complaints about how they had been treated by various parts of the NHS. However, it must be remembered that many deaf people have had very bad experiences, or know of other deaf people who have.

Any developments that are made, must be done with deaf people. This needs to be more than token involvement – many deaf people do not forget being invited to a

¹⁷ There is a perception within the Deaf community that "word gets around" and it is hard to keep anything private.

meeting and finding no interpreter. Only with active involvement will suspicions abate and barriers come down.

The attitude of staff is clearly important. Deaf patients want to feel welcomed by NHS staff. If staff have received training then they can approach a deaf patient with a more positive attitude, and this will be recognised and appreciated by the deaf person.

Recommendations

Actions that should be taken

1. A regional group needs to be established that will take responsibility for mental health services for deaf people. It should consider the whole patient pathway, and not be limited to purchasing in-patient beds. The group should be a sub-group of the Specialised Commissioning Group (SCG). There must be deaf representation on this group. This representation needs to be carefully chosen and should try to reflect the diversity within the deaf population (and be more than just one person).
2. A new contracting system should be established between the above group and the National Deaf Mental Health Service (Denmark House). This should be designed to give security to the specialist service and better value and quality for commissioners.
3. A formal care pathway needs to be agreed upon by commissioners, local mental health services and the NDMHS. It is unacceptable that local services should try to shirk their responsibility. Clinicians at all levels need very clear protocols and guidance that they can refer to.
4. The protocol and guidance needs to be supported by a referral system that can monitor how well mainstream mental health services and NDMHS work together along the pathway.
5. While the care pathway is being agreed, local mental health services need to be reminded that NDMHS is not an emergency service, and given details of the referral procedure.
6. Local authority sensory services should also be involved in the regional group. Many social workers are very engaged with the local Deaf community and have more specialist expertise than health staff.
7. Every PCT facility should be sent a poster detailing the procedure for accessing a BSL interpreter.

8. That the Deaf Rights Charter, written by *Sign* and the Mental Health Foundation, is endorsed by Trusts.¹⁸
9. Local CAMH Services establish a formal link and care pathway with Dudley's specialist team, and any 'gaps' around the transitional age are addressed.
10. All PCTs offer Deaf Awareness and Communication Tactics courses and actively promote them. Commissioners should check with Training Departments that courses are available, as there was some confusion in this area.
11. All PCTs survey their practices to see whether there are any that may be interested in becoming "enhanced practices" (trailblazing deaf-friendly practices).
12. PCTs conduct informal 'mystery shopper' exercises to see how accessible particular services are.

Recommended developments for the new structure to consider

13. A Primary Mental Health Worker/Gateway Worker post be established as a pilot project. This post should cover more than one PCT area. The postholder would have two main roles: a) some case co-working, especially in the early stages of a case to ensure engagement, b) an advice and education role, providing support and information to colleagues in primary care and local mental health services.
14. A regional housing strategy is written and fed into the appropriate local and regional housing authorities. This should be supplemented by an audit of placements from Denmark House and elsewhere.
15. Mental health commissioners engage with colleagues to explore the potential for a Health Promotion Officer across the region. This would probably be the whole of the West Midlands rather than the eight PCTs involved in this project.
16. Consideration be given to whether a Support, Time and Recovery post could be developed.

NB While the purpose of this report was to produce recommendations pertinent to the BBC SHA area, these recommendations should not be seen as an exhaustive list and local action will, of course, be reflective of local issues.

¹⁸ See www.signcharity.org.uk or www.mentalhealth.org.uk .

Next steps

As the recommendations make clear, establishing a robust commissioning structure is seen as the most important priority. Support for this work can be provided by the Department of Health funded project on commissioning of specialised services.

The NDMHS will be involved in this work at a national level and it would be great to see the West Midlands trailblazing this work.

We hope that one trust will offer to take the lead on this. Without a senior person to drive things forward, mental health services for deaf people is likely so slip down the agenda again.

We had hoped to establish a Reference Group during this project – consisting of deaf people who had attended the forums and expressed a desire to contribute further. Because some of the forums were delayed this was not possible. However, the PCTs do now have a group of people willing to be involved. This should be capitalized upon and used as soon as possible. If such a group could be established on a more formal footing then it could feed into the proposed regional group (which will hopefully involve service users).

Conclusion

The PCTs involved in this project have shown a degree of vision in combining to commission this work. Our research has shown that the area does have a good foundation from which to build from. However, it suffers from not having been designed strategically, and there being no group overseeing the bigger picture.

Having the NDMHS in the area is a huge potential benefit. However, the full potential of this is not being realised.

It should be remembered that the *Towards Equity and Access* report brought with it additional funding for each PCT from the Department of Health. However, in a sense, that funding is a red-herring. The funding is **not** meant to be the only money spent on mental health services for deaf people. Trusts are already meant to be providing services that are appropriate for deaf people. The funding was given in recognition of how far behind services are nationally, and was intended to stimulate action.

Many of the steps that can be taken to improve services are very cheap or cost neutral. More than anything else, the commitment that brought this report about needs to continue.

If a proper commissioning structure is put in place, then we are confident that mental health services for deaf people will expand and improve. More importantly, deaf people with mental health problems will no longer be sidelined and can start to play an active role in their own health.