

## National Institute for Mental Health in England



# **Mental Health and Deafness**

Towards Equity and Access

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Towards Equity and Access

**Best Practice Guidance** 

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## **Foreword**

The Government is committed to improving mental health services for everyone and to reduce social exclusion wherever possible.

One group of people who need special attention are those who are Deaf and who are susceptible to mental ill health. It would appear that early influences, both biological and environmental, can impact on the development of children and communication barriers can impede, at every stage, an individual's access to health promotion and care.

These same barriers also make it more difficult for a Deaf individual to access education and employment as well as enjoying the range of leisure and social activities that most people take for granted. This can give rise to isolation and exclusion, important influences on the development of mental ill health.

This document shows how mental health services for Deaf people can be improved using the template of the National Service Framework for Mental Health as a starting point. It provides practical examples of how access to services can be made easier and it brings into focus the needs of a group of people whose access to services have, for too long, been fraught with difficulty.

I feel sure that the implementation of the recommendations in this document will do much to improve the lives of Deaf people that might otherwise have been diminished by their experience of mental health difficulties.

Rosie Winterton

Minister of State for Health.

# Introduction

In July 2002, the Department of Health launched a consultation document entitled *Sign of the Times*. It was focussed on Deaf¹ people who used sign language (predominantly British Sign Language) and considered how well their mental health needs were being met. The standards in the *National Service Framework for Mental Health*² were used as a template.

The consultation, due to end in November 2002, was extended well into 2003. This allowed the many voluntary groups who wished to contribute an opportunity to do so. A large number of meetings were held throughout the country and local organisations worked extremely hard to engage their Deaf communities and service users in the process. The voluntary organisations involved in deaf issues and the providers of specialist services played a major role in the consultation, ensuring a high participation rate by the people most affected by the proposals.

In addition, a version of the consultation document in British Sign Language (BSL) was produced in video format and 200 copies were distributed to enable Deaf people who were not comfortable with written English to take a full part in the process.

The response to the consultation document<sup>3</sup> was positive and enthusiastic. Many welcomed a focus on what they perceived to be a neglected area and service providers, advocates and users worked closely together to produce a considerable number of well-considered responses. Some responses came from a number of organisations working together and others were summaries of a group discussion, so it was not possible to know how many people were involved in the process. A list of respondents is provided as Appendix C.

There was a widespread view that the level and organisation of mental health services for Deaf people was far from adequate and that progress needed to be made if people were not to feel excluded from

<sup>1</sup> We will use the convention 'Deaf' for those who are born Deaf and see themselves as part of a Deaf community and 'deaf' for those who have acquired deafness and mainly use oral means of communication

<sup>2</sup> Department of Health, 1999 (http://www.dh.gov.uk)

<sup>3</sup> http://www.nimhe.org.uk/downloads/signoftimes.pdf

services. The words "equity" and "access" were used many times and it seemed right to reflect this in the title of this summary of the consultation.

Since the publication of the consultation document, the government has recognised BSL as a language in its own right as well as announcing £1 million investment to support initiatives to help Deaf people use sign language in more settings than currently. This has been warmly welcomed by Deaf people, many of whom have long campaigned on this matter. The government has also committed an additional £2.5 million to help the National Health Service implement the recommendations contained in this guidance. Together, these two initiatives could do much to allow Deaf people to feel more included in society.

The purpose of this document is threefold.

- to build on the ideas put forward in the original consultation (itself the result of discussions with a wide range of interested parties);
- reflect on the feedback provided during the consultation and to report on progress that has been made since.
- provide advice on ways to promote mental health and improve services for people who are Deaf.

It also takes into account the recommendations made in the Independent Inquiry into the care and treatment of Sarwat Al-Assaf<sup>4</sup>. This report pointed to the difficulties encountered in obtaining an interpreter in times of crisis and to the need to be able to obtain advice and support from specialist services when required. These concerns reflect and reinforce the views expressed in the consultation and are reflected in this document.

#### **Deafness and Culture**

Most people think of Deafness as a disability. That view is often shared by those who acquire deafness through illness or injury. However, many people who are born Deaf and who communicate mainly through sign language see themselves as part of a distinct community with a common language and cultural heritage. Sign language should not be seen as a degraded form of any spoken language. Rather, it is a fully formed language in its own right - readily capable of drama, comedy, poetry and the most evolved forms of prose. It should be remembered, also, that many users of sign language will view English, including written English, as, at best, a second language. It needs also to be born in mind that the vast majority of Deaf school leavers will only reach a reading age of nine. Written communication of complex issues will, therefore, often be insufficient.

### Mental Health and Deafness

There is a link between mental ill health and deafness. Estimates in children suggest a prevalence of mental health problems of 40% in Deaf children compared to 25% in their hearing counterparts. In adults, a number of studies from different countries have indicated a significantly higher level of mental ill health. Alcohol problems are frequently mentioned, although much of the evidence for this is anecdotal.

This link is not entirely surprising. Firstly, some forms of deafness are caused by damage to the brain before birth. It would be remarkable if this did not, on some occasions at least, give rise to other difficulties. Secondly, Deafness for many people is associated with social exclusion and reduced educational and employment opportunities. The links with this and mental health status are well known and documented, most recently in the report from the Social Exclusion Unit Mental Health and Social Exclusion<sup>5</sup>.

The precise figures can be, and are, debated but there is no doubt that there is a higher incidence of mental health problems among Deaf people when compared to the hearing population. This has a clear implication for mental health services and it needs to be remembered that working with Deaf people takes considerably longer than with hearing individuals, so the necessary investment in services can be commensurately greater.

There is a need to establish the true extent of need on a local basis to inform planning and provision. This will best be done by local collaborations between health and social services who share a responsibility for this group of people. Given the size of the population, there may be economies in carrying this out over a fairly large area, such as the size of a Strategic Health Authority.

#### Recommendation

That consideration should be given to conducting local Needs Assessments of the mental health of Deaf people.

#### **Deaf Awareness**

Many health service staff have little awareness of the particular needs of Deaf people and the culture they inhabit. This is not to make a criticism, but reflects the smallish population that they are likely to encounter during their working lives. The government has given a clear commitment to reducing inequalities and to improve access to effective health and social care services for everyone (*National Standards, Local Action – Health and Social Care Standards and Planning Framework, 2004*)<sup>6</sup>. The introduction of Deaf awareness training (which currently happens in some health settings) would go some way to achieving this.

## Good practice: Example A

Mental Health services in Newcastle have had a rolling programme of Deaf Awareness Training since 1999. Uptake has been good from staff within the Trust and the course is also open to local primary care services. Based on this success, Deaf Awareness Training has now been built into the curriculum for student nurses.

This form of training seems essential if front line staff in primary and secondary care are to be able to respond appropriately and sensitively to the needs of Deaf people who need to use their services.

NHS organisations will also be mindful of their responsibilities relating to the Disability Discrimination Act to take all reasonable measures to make their services available to everyone, regardless of disability. It may well be practical to combine Deaf Awareness training with training initiatives to support compliance with the Act.

There is a positive role for voluntary organisations to contribute to this training and the major charities are keen to be involved and to provide advice about appropriate approaches and trainers. The role of service users can be key. They have, after all, the first hand experience of service access and can be valuable "experts by experience".

#### Recommendation

Primary Care and Hospital Trusts 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.

### **Communication Technology**

In recent years, Deaf people have benefited from advances in information technology. The wider availability of email, chat rooms and web sites have helped Deaf people to remain in touch with each other and the wider population. Minicoms and textphones are now routinely used (although less so than they could be in health care).

Two other developments are worthy of further consideration. Telemedicine is now commonly used to provide access to remote populations and to connect satellite services such as Minor Accident Units to better resourced centres. There could well be a role for this in allowing Deaf people and local service providers' access to specialist centres for consultation and advice.

The other, very recent, innovation is some work done by the charity SIGN. They have developed software which will interface with family doctor systems and which will translate questions and advice into BSL. Given the shortage of interpreters referred to above, this could have a significant impact on access to primary care in a much shorter time span than would training additional interpreters.

#### Recommendation

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.

#### Recommendation

That the BSL/English translation software developed by SIGN is made available to primary and secondary care services as speedily as possible.

#### Children

Many respondents to the consultation highlighted the needs of children. We all know that the start people make in life determines much of what comes after. Sadly, the topic of the early years of Deaf children has been the subject of extremely polarised views. These, at times, seem to have hampered informed debate. The issue has centred on whether it is preferable for a Deaf child to learn oral communication to enable integration into a predominantly hearing world or whether to emphasise signing which, in the right environment, can produce much more effective communication among those who share signing language.

There is evidence that some children who achieve good hearing gain through cochlear implantation or hearing aids can progress well in an auditory environment. Equally, there is convincing evidence that those who do not achieve a good result from these interventions will do much better educationally in a signing environment.

Putting the needs of the child first and helping parents make a well-informed choice is the most important issue and good practice should derive from that principle. The understandable wishes of hearing parents (the overwhelming majority of parents of deaf children) to achieve "normalisation" needs to be balanced by the evidence that, for many children, a signing environment will afford an enhanced prospects of educational and employment opportunity.

The recent popularity of teaching simple sign language to hearing infants seems to bear out the notion that signing is a language that can be readily acquired, even before any speech would be expected.

Parents need to be supported through what, for many, will be a very difficult time and will need family centred support, information and education.

Deaf children seem particularly vulnerable to abuse, particularly those with more severe communication difficulties or in poorly communicating environments. They need the same degree of safety as hearing children.

When Deaf children need specialised care, there is only one in-patient service nationally (South West London & St. George's Trust) and a shortage of outpatient services. There is a scarcity of expertise in local Child and Adolescent Mental Health Services who are, in any case, often feeling over-stretched.

Services should be better co-ordinated between agencies when a child is identified as having hearing loss. Education services are routinely notified in many areas but social care services tend only to become involved when a problem arises. Social Services could make a significant contribution to the early input offered to the family. This, in turn, could have long-term benefits for the mental heath of the child. There may also be an important role for the voluntary sector in providing advice and advocacy and access to the training packages they have developed.

#### Recommendations

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.

There should be links developed between the National Deaf Service for Children and local CAHMS Teams for advice and consultation.

The use of video-links for this purpose should be piloted and proposals for roll-out of this facility developed should this prove useful.

#### Deafblind

During consultation, a number of themes concerning people who are blind as well as Deaf emerged. It is clear that Deafblind is an umbrella term that covers a number of different groups. The group with the greatest affinity to the Deaf community are those born both deaf and blind, but others acquire one sensory impairment later than the other and have different communication skills and needs.

This is a very small (just over 20,000) population and widely dispersed. Very little is known about mental health problems and treatment in this group although some do access the specialist Deaf services. People who are born deafblind may exhibit unusual behaviour, including self harm and destructiveness, in an attempt to communicate.

The Department of Health issued guidance in 2001<sup>7</sup>, requiring Local Authorities to identify and make contact with Deafblind people and to ensure that they are assessed by an appropriately trained individual. A key part of this guidance was the need to ensure that all key parties, including social care, health, education, the voluntary sector and parents are involved in the early intervention for children essential for their physical and emotional wellbeing.

Local Implementation Teams and CAHMS development teams will wish to take into account the needs of Deaf and Deafblind individuals in fulfilling their responsibilities towards vulnerable groups when reviewing their plans.

#### Recommendations

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.

That the specialist services consider how they wish to manage referrals of Deafblind individuals in future and what additional expertise or specialisation is required.

That consideration be given to conducting a needs assessment of Deafblind people alongside any undertaken for Deaf people.

## **Primary Care**

A common question was – "why are you focussing on Deaf people and mental health; we have problems going to the GP for any reason?" Of course, the consultation was specifically about Deaf people and mental health and it would not have been practicable to widen the remit. However, it is impossible to disentangle the issues around access to mental health consultations from other GP visits.

Respondents recognized that it is impracticable for every general practice and the staff associated to provide a comprehensive service to Deaf people. However, there was consensus that it was reasonable to expect some minimum requirements.

It is hoped that Deaf people missing their turn or appointment because the only prompt was their name being called out are isolated examples but, more worrying, is evidence that Deaf people come away with very little understanding of the advice given.

A common frustration was a difficulty in obtaining interpreters and a reported reluctance from some services to fund them when available. A contrast was made with the facilities made available to other minority language users and it was hard to for Deaf people to see this as other than discrimination. The use of family members as informal interpreters was widely resented by those who responded to the consultation.

There are resources available to primary care and much that can be done for little cost. A combined voice and text telephone to allow Deaf people to make contact costs around £200, a visual call system about £550 and a one day Deaf/disability awareness training about £300.

Locally, expertise can be found in social service and education departments of local authorities. There is also an information pack for general practice produced jointly by the Doctor Patient Partnership and the Royal National Institute for the Deaf<sup>®</sup>.

Reference should also be made to *Guidance on Developing local* communication Support Services and Strategies<sup>9</sup>, which contains a detailed account of the policy and legislative framework, an analysis of existing provision and recommendations for commissioners.

Another main theme to emerge was that of the desirability of "one-stop-shops" or Healthy Living Centres which would serve a wide geography and provide a wide range of services, including general health services and health promotion. Other suggested functions include:

- access to social care, education and benefits advice
- co-ordination point for interpreters
- a base for advocacy
- a source of Deaf awareness training
- resources for parents
- BSL classes
- Video-conferencing

There are developments in Scotland and Northern Ireland along these lines and there are established services in Austria and France.

## Good practice: Example B

About 700 Deaf people get a service from Deaf connections, based in the Gorbals area of Glasgow. As well as providing communication training and deaf awareness, the centre acts as an information centre for health issues and enables Deaf people to access health care as well as enabling educational opportunities.

Another idea was to ask each Primary Care Trust to encourage one practice to take a special interest in their local Deaf population.

The importance of access to primary care services cannot be overemphasised. This is where the vast majority of mental health problems are managed and treated and is the gateway to more specialist services. This is particularly important in conditions where it is known that early intervention reduces the likelihood of long-term disability or where suffering could be reduced.

Similarly, we know that most general public health messages are not picked up by people with mental health problems. It will inevitably be much harder for people who are also Deaf and, besides making material as accessible as possible, it needs to be borne in mind that messages may need to be reinforced.

#### Recommendations

Every primary care facility should have a minicom and a service agreement with a translation service that includes BSL.

Consideration should be given to the potential role of Gateway Workers in guiding Deaf people with a mental health problem to the service most likely to be of assistance at that time.

That a proposal for a Healthy Living Centre pilot be developed in one or two areas initially.

Primary Care Trusts should consider whether there is a practice within their boundaries who could develop a special interest in the needs of Deaf people.

## **Secondary and Tertiary Care**

The five secondary care providers worked closely together throughout the consultation process and this has been helpful in developing closer working relationships. They are:

- South Birmingham Mental Health NHS Trust (Denmark House)
- Mayflower Hospitals Ltd (Independent Sector Medium Secure Care)
- South West London & St. George's Mental Health NHS Trust (Springfield Hospital)
- Nottinghamshire Healthcare NHS Trust Rampton Hospital (High Secure Care)
- Bolton, Salford & Trafford Mental Health Partnership (John Denmark Unit)

This closer working has greatly enhanced the capacity of these services to provide an integrated approach. However, difficulties remain in the provision of secondary and tertiary care and these focus around the relationship between local and specialist providers. Unless Deaf service users live in Birmingham, Manchester or London, the main responsibility for their care rests with a local team who are unlikely to have either significant experience of working with Deaf people or the necessary communication skills.

Emergencies do occur in mental health and it is clearly impossible for a clinical team based in, say, London to respond to the immediate needs of someone in, for example, Cornwall. The dilemma is how best to support these local teams and how staff in a number of settings who encounter emergencies and urgent situations can best be helped.

Ideally, the development of an expanded network of specialist services, strategically placed to meet the most pressing problems of geography, would be the way forward. However, even if the resources were available to fund such an enhanced service, it is difficult to see how they could be staffed (see section on Workforce).

Ongoing support for any individual through the Care Programme Approach should be provided locally. The tertiary services are able to provide advice and consultation as well as admission when necessary but cannot assume long-term responsibility for an individual living outside their immediate catchment areas.

One model, which has been employed successfully in some parts of the country, is to have a Community Psychiatric Nurse (CPN) working with Deaf people across the area of a Mental Health Trust. They provide local assessments of need and support both local and specialist services in working with individuals. They are linked to, and receive clinical support from, one of the specialist services.

## Good practice: Example C

In Newcastle and in Nottingham, a dedicated Community Psychiatric Nurse for Deaf people maintains a caseload and acts as a source of advice to other health professionals. Although they would say that they do not represent a solution to access to mental health care for Deaf people, their facilitation is greatly appreciated by the people they see. Both maintain close contact with one of the specialist centres for clinical support.

Another model, based around a specialist centre, is the Deaf Enhanced Support Team<sup>10</sup>. This is an Assertive Community Treatment service for Deaf people in London, based at St. George's Hospital, which provides

support to Deaf people in the community as well as those being treated in local hearing impaired inpatient units. Evaluation of this project is encouraging and it is a good example of standard practice being sensitively adapted for use with a population with special access needs.

#### Recommendation

That specialist CPNs are recruited to those parts of the country with the greatest need for an enhanced service.

That consideration is given to replicating the Deaf Enhanced Support Team model.

#### **Forensic Services**

Deaf people with mental health problems appear to come to the attention of criminal justice agencies at a greater rate than would be expected. They are over represented in secure mental health settings and are thought to be over represented in the prison population. However, no figures are kept by the courts or prisons which would allow greater certainty about this. Clinicians in the specialist services all report seeing a high proportion of people who have had contact with police and the courts. Given this, it seems inevitably that some Deaf people with mental health problems will require care in some degree of security. It has been a source of concern for some time that Deaf people are:

- Held in a higher degree of security than necessary. Rampton hospital
  has provided a service for a small number for some time and it is
  important that those who are suitable can move on to a medium
  secure, signing, environment.
- Contained in prisons because of a lack of a suitable health facility.
- Refused admission to specialist services because of the risk they pose.

Recently, Mayflower Hospitals Ltd have developed a medium secure unit specifically for Deaf people in Bury, Lancashire. This has begun to fill the previously existing gap in provision at this level. It has been argued by service providers that this should be complemented by a comparable facility in the South of England. This may be desirable in the longer run. However, we need to be cautious about the risk of over-providing secure facilities.

We also need to be clear about the long-term need for care in high security and to plan with Rampton Hospital how that need is to be met, taking into account that appropriate communication is a prerequisite for a therapeutic environment.

#### Recommendation

That the pattern of referrals, lengths of stay and eventual disposal of service users at Mayflower Hospital are carefully monitored with a view to establishing whether there is a firm case for a further unit.

## **Commissioning of Specialist Services**

Mental Health and Deafness is defined as a specialist service in the national definition set and, therefore, one that should be commissioned through consortia arrangements representing an appropriate population size. In some parts of the country, such consortia are well established while in others they have been slower to develop.

It is important that each part of the country has a plan for meeting the mental health needs of its' Deaf population and appropriate commissioning arrangements in place.

## **Prisoners and the Criminal Justice System**

The plight of Deaf prisoners was highlighted by some respondents. They argued that special provision should be made for their needs and their inability to access rehabilitation programmes means that they can, in effect, serve longer sentences than hearing prisoners. They can also miss out on basic amenities like hot water if this is announced only verbally.

There are estimated to be around 100 Deaf prisoners at any one time but there is no systematic recording of this by the Prison Service. It is not known how many have a mental health problem. They are dispersed throughout the prison system and that makes it more difficult, in the context of the many other pressures on the system, to make any special provision.

There are also issues at other stages in the Criminal Justice System, through arrest to trial and conviction about ensuring the individual understands the procedures and their rights.

#### Recommendation

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.

## **Older People**

Deaf people, like everyone else, may need residential care when they get older and become frail. Most now go into residential or nursing care where their needs are not distinguished from those with acquired hearing loss. Understandably, staff do not differentiate between Deaf elders and those whose deafness has come later in life, despite the fact that they will have very different communication needs.

There are 24 nursing home places nationally for Deaf people and it is likely that this represents significant under-provision.

#### Recommendation

That local Needs Assessments take account of the number of Deaf elders who may require residential care.

#### **Carers**

We heard from a number of carers of Deaf people with mental health problems who raised a number of issues. One was about the amount of support they themselves needed and received. Some of this support was available from local networks around Deaf Clubs and voluntary organisations.

However, it needs to be remembered that such carers do have a right to have their needs assessed and that there may well be a role for the new Carer Support Workers in these circumstances. *Developing services for carers and families of people with mental illness*<sup>11</sup> sets out the way in which mental health services should recognise and support carers and engage them positively in treatment.

Another issue was an uncertainty about where to turn in times of crisis and this is exacerbated by the reality that many Deaf people are likely to receive mental health care further away from their homes than hearing people.

To some extent, this is an inevitable consequence of services being specialised and there is always trade-off between access and expertise.

This does place a burden on carers in terms of travel. The establishment of a network of specialist CPNs (see above) may assist in alleviating this problem by allowing fewer and briefer admissions to distant specialist providers.

#### Recommendation

Those responsible for planning carer support should be aware of the need to consider those carers who may have particular needs.

#### **Ethnic Minorities**

There can be particular issues for Deaf people within ethnic minority populations. These relate to cultural sensitivities and to multilingualism within families that can make it more difficult for an individual to function within an effective communicating environment. This is a significantly under-researched area and would helpfully feature in an over-arching needs assessment of the Deaf and Deafblind populations.

In addition, it is well documented that people from ethnic minorities in general have significant difficulty in accessing and feeling appropriately supported by mental health services (Delivering Race Equality: A Framework for Action)<sup>12</sup>.

#### Recommendation

In any needs assessment, attention needs to be paid to the implications of cultural and ethnic diversity

In considering how to meet their aspirations for race equality, NHS bodies need to be aware of groups with particular access needs.

### **Education and Employment**

A large number of Deaf children, particularly those educated in a predominantly oral tradition who do not achieve sufficient benefit through hearing aids or cochlear implantation, do not emerge from schooling with the skills needed to compete in the job market. Similarly, their route into further education will be effectively blocked.

When this is combined with the need for additional help with communication, which is patchily available, access to education and employment is severely hampered.

The need for child-centred early education has been touched on above. Similarly, there needs to be greater emphasis on communication support in primary, secondary and further education and employment, geared to the needs of the individual, if we are to avoid the level of social exclusion which has such a negative impact on the mental health of Deaf people.

#### Workforce Issues

Within mental health services, it is striking how few staff are working with Deaf people and how vulnerable services are to departures. This applies to all the main professions in mental health. There are very few professionals with signing skills sufficient to equip them to carry out their work in BSL and there are retention issues for this group.

It is also striking how few Deaf people are employed in these services and this presumably relates to the access to education and employment issues mentioned above. This is an important issue, not simply because of the increased opportunity for Deaf people but because of the need for positive role models for Deaf people in general, who too often assume that a Deaf professional is, in fact, a hearing person.

Another issue raised was the amount of "out of role" activity. Social Workers and Community Psychiatric Nurses both reported accompanying clients to general practice consultations and acting as interpreters. This is wasteful of scarce resources although understandable in the circumstances and no criticism is intended of the dedicated staff involved.

A number of respondents pointed to the additional training required to achieve an appropriate fluency in sign language and suggested that financial incentives would encourage recruitment and retention.

There are encouraging signs as well. A course in Psychiatric Nursing at Salford University for Deaf students seems well established and there are plans to develop similar courses elsewhere.

#### Recommendation

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.

#### Recommendation

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)<sup>13</sup> may provide a model of how this could be done relatively quickly.

### **Interpreters**

Many respondents raised the issue of interpreters. There are only 168 Members of the Register of Sign Language Interpreters in the UK. Whilst there are others with skills, this is the basis on which people are engaged to work in criminal courts and this should provide a benchmark for health care.

The practice of using family members, often children, as informal interpreters seems both widespread and unjustifiable in health care and particularly so in mental health.

Interpreters fund their own training and the vast majority work on a freelance basis and/or through an agency. There are a few accredited higher education courses (Bristol, Wolverhampton and Central Lancashire Universities are prominent) in Deaf studies but not all include the skills necessary to work as an interpreter.

The shortage of interpreters is a serious barrier to access to all levels of health care (and other services) for Deaf people and respondents to the consultation repeatedly stressed that this needed to be overcome before matters would improve. However, this is a complex issue and certainly not under the control of the NHS.

There is the additional issue of a lack of specialist training for those interpreters who wished to work with mental health clients.

#### Recommendation

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.

The feasibility of developing specialist training should be explored by the specialist providers.

## Conclusion

The recommendations in this guidance are wide-ranging and cross a number of organisational boundaries. We would, however, be failing to effectively tackle the issue of Mental Health and Deafness were we to shirk that complexity.

This is also a long-term issue. There are few areas in which very rapid progress can be made and considerable co-ordination will be required if progress is to be made consistently for the whole population.

There is considerable commitment among the main stakeholders for progress to be made in an area that is widely held to have been neglected for some time. This commitment needs to be built upon and the skills and expertise that were evident in the rich response to the consultation harnessed to make a real difference to the mental health of our Deaf population.

In Appendix A, we will consider how implementation of this guidance would move us towards compliance with the National Service Framework for Mental Health, our original template for Sign of the Times.

## **APPENDIX A**

#### The National Service Framework

Sign of the Times used the National Service Framework for Mental Health<sup>14</sup> as a template against which to measure how well the mental health needs of Deaf people were being met. This section examines how the recommendations contained in this guidance so contribute to meeting the seven standards in the framework and considers what else might be done.

#### Standard One

#### Health and Social Services should:

- Promote mental health for all, working with individuals and communities
- Combat discrimination against individuals and groups with mental health problems, and promote their social inclusion.

There are a number of themes in standard one that were reflected in the consultation. The early identification of Deafness is given prominence and, given what is known about the impact of early years on later development, this seems appropriate. Preventing abuse of Deaf children is also important in promoting future mental health.

The whole document could be seen as promoting social inclusion and diminishing discrimination and the emphasis on employment and education has a clear link with health promotion.

#### Standard Two

Any service user who contacts their primary health care team with a common mental health problem should:

- Have their mental health needs identified and assessed
- Be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it.

The main issue raised here was access and communication. Clearly, this standard cannot be achieved in the absence of a communicating environment and the issue of interpreters is clearly important. The software developed by Sign may prove to be very valuable, given the shortage of interpreters and their inability generally to respond to urgent requests. The issue of access to treatment is a difficult one, given the level of BSL expertise required to deliver "talking" therapies and this is why the specialist centres have a tradition of dealing with a very wide range of problems.

#### **Standard Three**

Any individual with a common mental health problem should:

- Be able to make contact round the clock with the local services necessary to meet their needs and receive adequate care
- Be able to use NHS Direct, as it develops, for first-level advice and referral on to specialist helplines or to local services.

The first part of this standard can only be met by care plans which detail how the communication issue is to be resolved and this will depend on local resources and ingenuity. NHS Direct will be made available to Deaf people and this could play a highly significant part in reducing access difficulties.

#### **Standard Four**

All mental health service users on CPA should

- Receive care which optimises engagement, anticipates or prevents a crisis, and reduces risk
- Have a copy of a written care plan.

There is no reason why Deaf people should not expect this standard to be met.

#### Standard Five

Each service user who is assessed as requiring a period of care away from their home should have:

- Timely access to an appropriate hospital bed or alternative bed or place, which is:
  - in the least restrictive environment consistent with the need to protect them and the public
  - as close to home as possible

The first part of this is an imperative. The development of medium secure services by Mayflower Hospitals was an important step in allowing people to move from high security into a communicating environment. It will be important to ensure that people do not remain longer in this level of security than their needs demand. Unfortunately, for many Deaf people, "as close to home as possible" will mean whichever of London, Birmingham or Manchester is most accessible or the alternative of an environment where communication is problematic. It will not be easy to remedy this situation. It simply isn't feasible to consider further specialist services because of skilled work force restraints. The best prospect of improvement lies with developing a network of specialist community psychiatric nurses to help reduce admissions and in encouraging more mental health staff to acquire some BSL fluency.

#### Standard Six

All individuals who provide regular and substantial care for a person on CPA should:

- Have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis
- Have their own written care plan which is given to them and implemented in discussion with them

This should, of course, apply to carers of Deaf people whose special needs should be taken into account as well as to Deaf carers of hearing service users.

#### **Standard Seven**

Local health and social care communities should prevent suicides by:

- Implementing the first six standards
- Support local prison staff in preventing suicides among prisoners
- Ensure that staff are competent to assess the risk of suicide among individuals at greatest risk
- Develop local systems for suicide audit to learn lessons and take any necessary action

We simply do not know how many Deaf people take their own lives. This is not systematically recorded in death certificates or elsewhere. There is reason to believe, however, because of the evidence of higher rates of mental distress and adjustment problems in this population that there may well be an issue. Deaf prisoners may be particularly at risk.

Implementation of the guidance in this document will go some way towards improving the situation. Better community support, access to specialist care and improved provision in prisons should all contribute to a reduction in the risk of suicide.

# **Appendix B**

## **Summary of Recommendations**

- 1. That consideration should be given to conducting local Needs Assessments of the mental health of Deaf people.
- 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.
- 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.
- 4. That the BSL/English translation software developed by SIGN is made available to primary and secondary care as speedily as possible.
- 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.
- 6. There should be links developed between the National Deaf Service for Children and local CAHMS Teams for advice and consultation.
- 7. The use of video-links for this purpose 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.
- That the specialist services consider how they wish to manage referrals of Deafblind individuals in future and what additional expertise or specialisation is required
- 10. That consideration should be given to conducting a needs assessment of Deafblind people alongside any undertaken for Deaf people.
- 11. Every primary care facility should have a minicom and a service agreement with a translation service which includes BSL.
- 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.
- 13. That a proposal for a Healthy Living Centre pilot be developed in one or two areas initially.
- 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.
- 15. That specialist CPNs are recruited to those parts of the country with the greatest need for an enhanced service.
- 16. That consideration is given to replicating the Deaf Enhanced Support Team model.
- 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.

- 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.
- 19. That local Needs Assessments take account of the number of Deaf elders who may require residential care.
- 20. Those responsible for planning carer support should be aware of the need to consider those carers who may have particular needs.
- 21. In any needs assessment, attention needs to be paid to the implications of cultural and ethnic diversity
- 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.
- 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.
- 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.
- 27. The feasibility of developing specialist training in mental health for interpreters should be explored by the specialist providers.

# **APPENDIX C**

## **Acknowledgements**

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Mr Glen Berry, Assistant Director of Mental Health Ashton, Leigh and Wigan Primary Care Trust

## References

- 2. National Service Framework for Mental Health, Department of Health, 1999 (www.dh.gov.uk)
- 3. Sign of the Times Department of Health, 2003 (www.nimhe.org.uk/downloads/signoftimes.pdf)
- 4. Independent Inquiry into the Care and Treatment of Sarwat Al-Assaf, Gelding Primary Care Trust 2004, (www.nottingham.nhs.uk/EasySite/lib/serveDocument.asp? doc=1590&pgid=2536)
- 5. Mental Health and Social Exclusion, HMSO, 2004 (www.socialexclusion.gov.uk)
- 6. National Standards, Local Action Health and Social Care Standards and Planning Framework, Department of Health, 2004 (www.dh.gov.uk)
- 7. LAC(2001)8 Social Care for Deafblind Children and Adults, Department of Health 2001 (www.dh.gov.uk)
- 8. Are you sure your patients hear what you have to say?, Doctor Patient Partnership, 2000 (www.dpp.org.uk)
- 9. Guidance on Developing Local communication Support Services and Strategies, Department of Health, 2004 (www.dh.gov.uk)
- 10. Assertive Community Treatment with Deaf People, Forest Books, 2004 (www.forestbooks.com)
- 11. Developing services for carers and families of people with mental illness, Department of Health, 2002 (www.dh.gov.uk)

- 12. Delivering Race Equality: A Framework for Action, Department of Health, 2003 (www.dh.gov.uk)
- 13. Support, Time and Recovery Workers, Department of Health, 2003 (www.dh.gov.uk)

## **Suggestion for Further Reading**

Deafness in Mind, Austen and Crocker, Whurr, 2004 (www.whurr.co.uk)

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