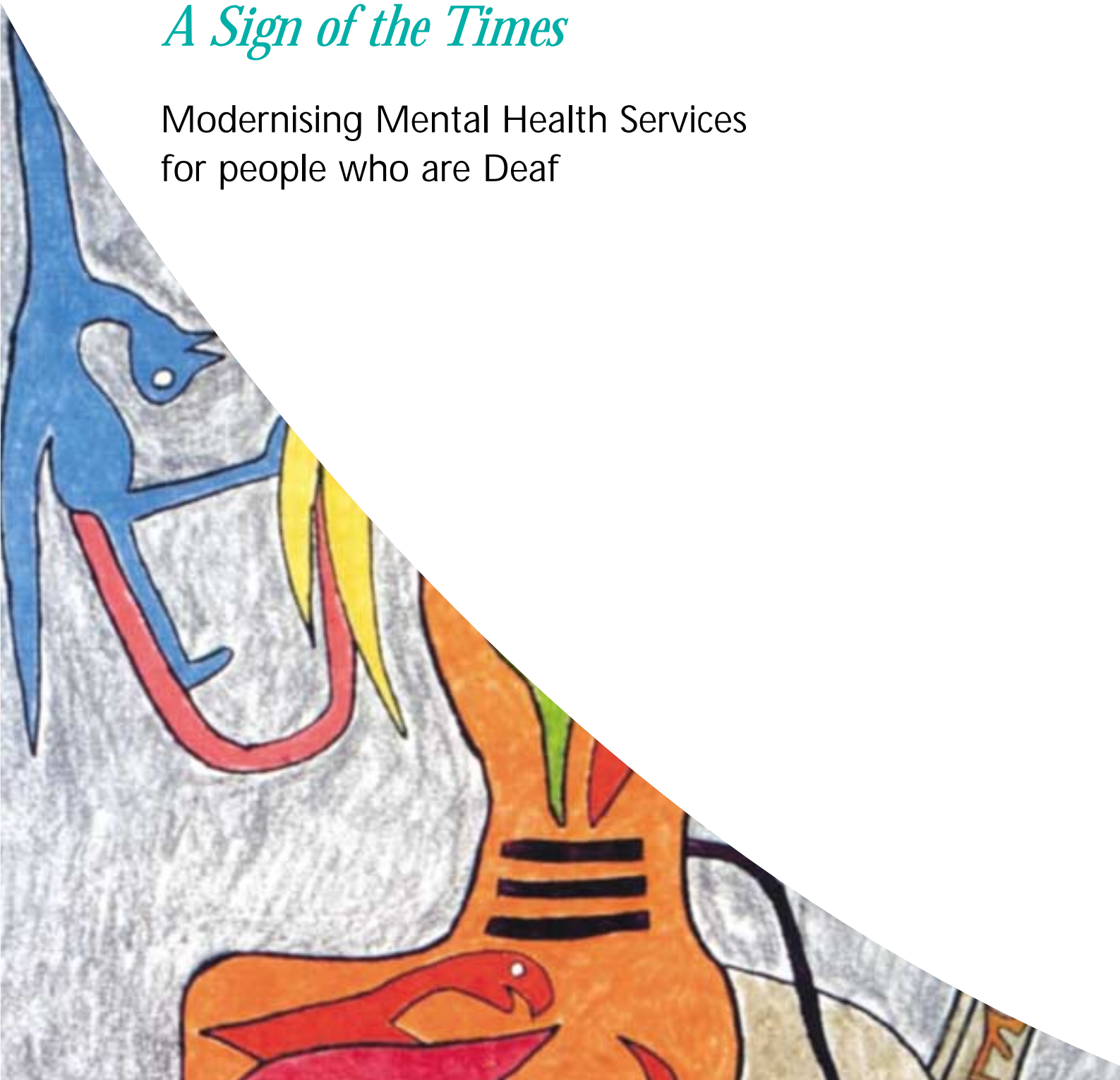


A Sign of the Times

Modernising Mental Health Services
for people who are Deaf





The Gift by John Roberts

My life so far has been quite diverse; I have travelled, been a family person, homeless and I am currently using the Creativity Centre. The Centre saved my life, changed my world and gave me the opportunity to express myself in various ways including painting, which I sometimes enjoy.

This artwork has been reproduced with the kind permission of Reflections.

Reflections is the publication supporting the promotion of 'Art Works in Mental Health', a new project that aims to encourage creativity in people who have been affected by mental illness and to promote understanding. We are launching a search for such art to showcase in a variety of ways, including a series of national exhibitions, for non profit purposes.

Entry is open to anyone who has experienced mental illness themselves or has been affected by the mental illness of someone they care about.

You can use a wide variety of media such as painting, drawing, photography, writing, sculpture, pottery and ceramics. Full details are in the application pack. If you are interested, or you know someone who might be, please contact 0870 609 0034, or log on to www.artworksinmentalhealth.co.uk

Art Works in Mental Health is sponsored by Pfizer Ltd and collaborating organisations involved in the project are Breakthrough, Coventry Healthcare NHS Trust, Depression Alliance, NSF, The Northern Centre for Mental Health, South London and Maudsley NHS Trust, PriMHE (Primary care Mental Health Education) and Priority Healthcare Wearside.

The Department of Health wishes to acknowledge the major contribution of the Sainsbury Centre for Mental Health in partnership with Alcohol Concern and Dr Alison Lowe (Barnet, Enfield and Haringey Mental Health Trust) to the production of this guidance, and the whole of the Dual Diagnosis Steering Group in overseeing it.

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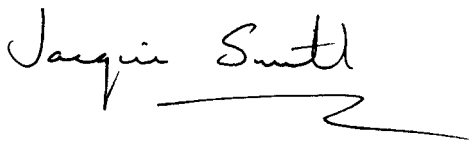
Foreword

Most Deaf people live full and rewarding lives. However, the minority who are affected by mental ill-health all too often find it difficult to get the help they need, when they need it, and in the way they need it.

This consultation document, which has been prepared with the help of Deaf people and those skilled in working with them, sets out some proposals aimed at making a significant difference to the lives of Deaf people with mental health problems.

This government has made it clear that it regards equal access to health care for everyone a priority. For mental health, in particular, the National Service Framework sets out clear standards that are applicable to all. This document uses these standards to examine how services to Deaf people can be improved.

I feel sure that the publication of this document is the beginning of a process which will produce improvements in service to a part of our population who have previously been overlooked.

A handwritten signature in black ink that reads "Jacqui Smith". The signature is written in a cursive style with a long, sweeping underline that extends to the right.

Jacqui Smith
Minister of State for Health

Executive Summary

Part I of *A Sign of the Times* explains that it is a Department of Health consultation document. It is about the development of a national strategy for mental health services in England for people of all ages who are Deaf (i.e. whose primary means of communication is British Sign Language) or Deafblind.

Part II describes some of the key issues. The Deaf population is believed to number 50,000 to 75,000. Mental health problems occur more frequently in Deaf children compared to hearing children. Deaf adults appear to suffer the same rates of psychoses as the general population, but higher rates of common mental health problems and complex problems.

Deaf and deafblind people experience great difficulty in getting access to health and social care services, and those with mental health problems are no exception. A small number of highly specialised mental health services for Deaf people have developed through the dedication of clinicians in various places rather than through any overall strategy. They are unable to provide a comprehensive service close to home for everyone.

Part III describes the *National Service Framework for Mental Health*, which sets out seven standards that people with mental health problems should be able to expect. While this only applies to adults of working age, we have used this as a template for all age groups, including children.

These standards relate to mental health promotion; primary care and access to services; services for people with severe mental illness; caring about carers, and the prevention of suicide, including the needs of prisoners.

A Sign of the Times examines the particular challenges faced in delivering these standards to the Deaf community, and identifies some solutions that have emerged from an initial limited consultation with key stakeholders. Each standard raises specific issues, but there are some recurring themes:

- That Deaf people (of all ages) and their carers are disadvantaged when trying to access mental health services.
- That the need for communication support and respect for the cultural diversity of the Deaf community (described conventionally as Deaf awareness) is fundamental to improving their mental health.
- That providing effective mental health services to the Deaf community is more costly than for mainstream services.
- That, when mentally ill, a Deaf person is likely to find a fluent signing environment the most therapeutic
- That service planning is hampered by a lack of knowledge concerning the demographics of the Deaf community nationally (including the numbers in prison and the extent of mental health needs), and the lack of a solid evidence base for specialised clinical interventions.
- That the capacity for service development is limited.

Part IV sets out for consultation some proposals for service development.

It is proposed that Primary Care Trusts and social care services work within their Local Implementation Teams to develop plans to meet the needs of their adult Deaf community. These could include:

- availability of appropriate communication support;
- general training in deaf awareness for front-line staff in primary care and prisons;
- training for some members of primary care teams in the recognition of mental health problems in Deaf people;
- establishing links and protocols with secondary care mental health services;
- establishing links with local CAMHS development plans/agencies.

It is proposed that Local Implementation Teams and others (e.g. those producing a CAMHS development strategy or Children's Services Plan) responsible for mental health promotion recognise the Deaf community as a "vulnerable group" requiring specific consideration.

It is proposed that care and treatment for Deaf people with mental health problems is based on an approach involving:

- local primary care and mental health services (including social services and education where appropriate);
- highly specialised services at centres of expertise;
- some intermediate services between the two.

Two broad options are put forward for intermediate level services, which respondents are invited to appraise. Both are intended to take account of the interface between primary, intermediate and highly specialised services, and both are intended to ensure the effective operation of the Care Programme Approach, the cornerstone of modern adult mental health care.

Option 1

Local mental health provider trusts develop services to meet the needs of their Deaf community within the context of their LIT and local CAMHS development strategies.

Option 2

The three existing specialised Deaf services develop comprehensive multi-agency and multi-professional community services all over the country, and provide care co-ordination for all patients in their care.

Whichever option is supported for the intermediate services, the highly specialised services should develop their expertise and capacity to work with Deaf children and young people across the country.

It is also proposed that the three specialised adult services agree catchment areas across the UK, with a degree of flexibility to allow patients to benefit from particular clinical expertise; provide consultation and training to other services; and develop a national forensic strategy.

It is recommended that further research be undertaken on the needs of Deaf people in prisons and young offender institutions with mental health problems.

Responses are invited on all of these proposals, and views are sought on which of the two options for provision of the intermediate tier of service is preferable.

Part I: Introduction

Aims

A Sign of the Times is a Department of Health consultation document about the development of a national strategy for mental health services (both health and social care) for people in England who are Deaf or Deafblind. It aims to:

- Promote the development of services, which will ensure that Deaf and Deafblind people can benefit equitably from current mental health policy.
- Acknowledge the challenge and complexity of this aspiration.
- Make practical suggestions for meeting this challenge.
- Contribute to future policy development concerning the delivery of health and social services to people of all ages who are Deaf or Deafblind.

Scope

The Government's ten-year strategy for adults of working age in England is set out in the National Service Framework for Mental Health, which gives seven standards that people with mental health problems should expect. More specific targets for the next three years are given in the NHS Plan. The National Service Framework for Older People also contains mental health standards, while the needs of children and young people will be considered in the forthcoming National Service Framework for Children which will include Child and Adolescent Mental Health Services.

Health and social care providers should be expected to ensure that their services are working towards meeting these standards for everyone, including people with disabilities, in line with their statutory obligations under the Disability Discrimination Act. This includes the vast majority of deaf people, mainly older people whose hearing impairment has developed later in life, but whose main method of communication is still speech.

A Sign of the Times concerns the smaller group of people, *of all ages*, known as the 'Deaf community' for whom sign language is their first language (Grant 2000).

The convention (Woodward 1972) of using "Deaf" for this cultural and linguistic community and "deaf" for those with hearing loss who use oral methods of communication will be followed in this document. Unless otherwise stated, references to Deaf people should be assumed to include Deafblind people as well.

Background

One impetus for *A Sign of the Times* grew out of the Report of the Independent Inquiry into the Care and Treatment of Daniel Joseph (2000), a profoundly Deaf young man, who suffered from a severe mental illness. On July 20th 1998, Mr. Joseph was found guilty of the manslaughter of his landlady on the grounds of diminished responsibility. The Inquiry team observed that there was no national strategy for mental health for Deaf people, and recommended that their needs should be given higher priority. The Department of Health's response included a commitment to consult key stakeholders on the development of a national strategy.

This document has been produced through consultation with a wide range of professionals working in specialised services for Deaf people and in mainstream mental health services, voluntary organisations, service users, and higher education.

Consultation has also taken place through visits to services, meetings with a large 'stakeholder' group, with professional teams and with individuals and through telephone contact. We believe, therefore, that the issues identified and the proposals in this document are based on good advice.

It is now time to consult more widely.

Part II: Issues

How many people are Deaf?

The precise size of the Deaf community is unknown. Indeed, providing an accurate estimate of the numbers of deaf people (covering the whole range of deafness) is '*notoriously difficult*' (Ahmad *et al* 1998).

The Royal National Institute for Deaf People estimate that there are over eight million people in the UK with hearing loss, most often associated with ageing and that the first and preferred language of over approximately 75,000 Deaf people in Britain is British Sign Language (BSL).

The Health Advisory Service in *Forging New Channels* (BSMHD, 1998) estimated that there are 50,000 people in the UK whose preferred language is BSL.

The uniqueness of the Deaf community

The term 'Deaf community' has demographic, linguistic, political, psychological and sociological dimensions. Britain's Deaf community shares characteristics born from common experiences, beliefs, values and norms. Most importantly, the community bonds through a common language (BSL) and a shared culture. Ridgeway and Monteiro suggest that the degree to which a Deaf person participates in the Deaf community depends upon:

- The age at onset of their deafness.
- The degree of deafness that they experience.
- The age at which the diagnosis of deafness is made and the effectiveness of the counselling and support that parents and carers are given.
- The type of education that the Deaf person receives. That is, whether their schooling was/is based on oral/aural methods or BSL.
- Their ethnic background.
- Their exposure to, and identification with, the Deaf community.

Some people with dual sensory impairment will identify themselves with the Deaf community (particularly people who are Deaf who have become blind) whilst others will regard themselves as having a deafblind identity.

Whilst recognising that the Deaf community share a language and a culture, we should be wary of assuming that their cultural identity, needs and aspirations are homogeneous. Diversity of ethnicity, age, gender, sexual orientation, ability and disability, impact on this community, as on any other. For example, sign language variations have been developed by Black-Deaf people and gay-Deaf people (Corker 1994).

Members of this community, like any other, encounter mental health problems. Because of the difference in language, coupled with a lack of deaf awareness, Deaf people can be misdiagnosed and wrongly treated (Ridgeway, 1997).

People with dual sensory impairment (also known as deafblindness) are also no less likely to suffer from mental health problems. Lewin-Leigh (2000) points out that such people face enormous difficulties in communication, mobility and in accessing information.

It is important to note that Deaf people with mental health problems share much in common with their hearing counterparts. They require access to the same range of effective mental health services, provided by the same range of agencies and professionals, as conveniently located as possible. This is of critical importance to people with dual sensory impairment as they encounter great difficulty with mobility.

Given that the provision of effective care is fundamentally underpinned by the need to communicate, people who are Deaf present a unique challenge to a mental health service primarily organised on the basis of hearing. The application of mental health policy to this group requires explicit consideration if we are to meet the challenge of providing them with an effective and equitable service.

Good practice guidance based on the Disability Discrimination Act (Department of Health 1999b) makes it clear that services have to take *'reasonable steps'* to enable and facilitate the use of services by disabled people. We must ensure that mental health care, wherever it is provided, lives up to these values in relation to the Deaf community. The Disability Discrimination Act makes it clear that services should *"provide a reasonable alternative method of making the service in question available to disabled persons"*. The Act actually uses the example of providing a sign language interpreter (Section 21,4).

The unique needs of Deaf people using mental health services share much in common with the routine difficulties experienced by Deaf people using the whole range of public services. The Social Services Inspectorate (1997) investigated services in eight local authorities for people who were Deaf and hard of hearing. They concluded that only one of these services was generally satisfactory. A recent study by the RNID found that 22% of patients who were deaf or hard of hearing left a meeting with their doctor unsure of what was wrong with them and 12% actually avoided going to the doctor because of communication difficulties.

Similarly, a small study conducted by Naish and Clark (1996) demonstrated poor communication between General Practitioners and Deaf patients. Mostly, the Deaf participants in their study did not make this a matter of complaint, despite their negative experiences. Chan (2000) makes a similar observation, noting that the Deaf patients involved in his audit of mental health assessment had a *'grateful attitude'*.

We cannot take this gratitude and lack of complaint as a reason for not improving services.

The relationship between deafness and mental health

People who are Deaf are at high risk of social exclusion. Grant (2000) argues that it is only when Deaf people have access to communication support and to Deaf awareness that they can be socially included in a world organised on the basis of hearing. Social exclusion amongst the Deaf community affects both their mental health and their access into appropriate mental health services.

An exploratory study by Ridgeway (1997) showed a significant relationship between having a Deaf identity and psychological health. Positive self-esteem, shown by psychologists to be an important factor in maintaining mental health, can be much harder to develop when socially excluded. Ridgeway's study found high numbers of Deaf people in the community suffering from psychological distress.

A report by Sign (1998) sets out a number of *'Pathways to mental ill-health'*. These included developmental delays, caused by the language and communication difficulties experienced by Deaf children and young people. A late diagnosis of significant hearing impairment in children means that they lose out at critical stages in their development.

The majority of Deaf children are born to hearing parents who will, initially at least, feel ill equipped to cope. *Forging New Channels* (BSMHD, 1998) notes that Deaf children who are born to Deaf parents (that is, 5%–10% of Deaf children) do better academically, are more socially mature and have more positive self esteem than Deaf children born to hearing parents. Deaf parents are in a better position to provide a communicative environment, to act as positive role models and to enable their child's access into the Deaf community.

Given the positive relationship between employment and psychological well being (Department of Health 1999a), it is of concern that there is some evidence to suggest that Deaf people are more likely to be unemployed, particularly Deaf women. They are less likely to be employed within the professional and management sphere (Dye *et al.* 2000). The difficulties that Deaf people experience in accessing professional education in the social and health care field fits with this pattern and means that mental health services encounter problems in recruiting a group of people vital to high quality provision (Klein and Kitson, 2000).

The prevalence of mental health problems in children and young people who are Deaf

Deaf children are more vulnerable to mental health problems than hearing children. Disentangling the reasons for this is complex but Hindley (2000) suggests there are both medical and cultural reasons. The cultural perspective is to do with the developmental issues discussed above – their increased vulnerability is primarily a consequence of being Deaf in a hearing world. Hay (1999), for example, notes that children are less likely to suffer from mental health problems if they have good communication skills and do not experience social adversity. Deaf children are also at increased risk of physical, emotional and sexual abuse (Sullivan *et al.*, 2000).

From the medical perspective, Deaf children are at greater risk of additional impairments such as learning difficulties, multi-sensory impairment and central nervous system disorders. People with multiple disabilities require painstaking assessment of their needs. Some children with a learning disability who have attracted a label of 'challenging behaviour' have later been found to have multi-sensory impairment.

Taking into account the whole range of mental health problems, Hindley (1993) estimates a prevalence of 40% in Deaf children compared to 25% in hearing children. This calculation is supported by the Health Advisory Service report (BMHSD, 1998).

The prevalence of mental health problems in adults who are Deaf

Assessing the mental health of Deaf people is a huge challenge to psychiatric practice based primarily on a hearing population. Indeed, Kitson (2000) argues that the scientific base of such assessment is still in its infancy. Given this difficulty and the fact that the majority of studies considering prevalence have been conducted in psychiatric populations, estimates are unlikely to be accurate. However, agreement over trends in prevalence has been established. *Forging New Channels* (BMHSD, 1998) states that:

Deaf adults share the overall prevalence rate for psychotic disorders but are more likely to be diagnosed as having a personality disorder, or behavioural or adjustment problems. This is probably a consequence of being Deaf in a hearing world, rather than an innate predisposition.

Co-morbidity is higher in Deaf people with mental health problems. They are more likely to have learning difficulties (though this may be more a feature of limited educational opportunity – a case of being disabled by the learning environment, rather than being learning disabled) and organic syndromes.

Deaf people are no less likely than hearing people to suffer from common mental health problems, like depression and anxiety states.

Current mental health services for the Deaf community

Providing mental health services to people who are Deaf requires highly specialist knowledge and skills. Specialised services, provided by multi-professional and multi-agency teams, have developed in England. These services also treat patients referred from Scotland, Wales and Northern Ireland. There has been some development of locally based services, including a range of supported residential care, counselling, advocacy and social opportunities.

Innovative partnerships between the voluntary and statutory sectors have created positive, vibrant services.

This current provision relies heavily on a small community of dedicated, expert staff and many service developments have occurred as a consequence of enormous individual and organisational effort. To a large extent, highly specialised mental health services for people who are Deaf have developed, at a national level in an *ad hoc* fashion.

There are also an unknown number of Deaf patients being treated within primary care settings for common mental health problems and within hearing mental health services. Eight patients are currently being treated in conditions of high security at Rampton Hospital. Although not formally designated and commissioned as a specialised Deaf service, staff at Rampton have developed a specialised service for their Deaf patients, including the employment of Deaf staff and BSL interpreters skilled in mental health issues.

Previous studies and reports have examined the needs of this client group and have made recommendations for service development. This body of work has influenced individual organisations and has effectively fuelled debate between interested parties. It provides an excellent resource and foundation for this consultation paper. However, it should be acknowledged that the evidence base for clinical work with this client group is patchy. Evidence is, on the whole, transferred from research conducted on the hearing population. Whether or not the whole range of these interventions is '*Deaf sensitive*' remains an important area for future research. There exists however, a wealth of '*practice based evidence*' within Deaf services.

Unlike services provided for the hearing population, adult mental health services for Deaf people are, on the whole, generic. The highly specialised services care for people ranging from those with forensic needs, to those with difficulties around substance misuse, to those requiring care for severe neurological problems. The national in-patient service for children, young people and their families, in common with other Child and Adolescent Mental Health Services (CAMHS) treats the whole range of mental health problems across a wide developmental spectrum.

Services for Deaf children face particular challenges to service development given the smaller overall base of CAMHS. The specialised Deaf services are faced with complex and ever present service interface issues, which are more demanding than those faced by local mental health services. Liaising with multiple agencies and supporting local services over the whole of the UK is a resource intensive activity. The brief case example (see box) illustrates these issues.

Luke, a pre-lingually deaf seven year old from Brighton, was referred to the National Child and Family Service by his local social worker, who was concerned that his behaviour had changed. Previously known to be a cheerful and contented little boy, who enjoyed school, he had lately become withdrawn and occasionally aggressive, Luke and his family were invited to an initial assessment meeting with the psychiatrist, psychologist and a BSL interpreter. Following this meeting, it was agreed that a fuller picture was required. Arrangements were made to observe Luke at school and to discuss him with his teachers. It was also agreed that the team needed to liaise with his social worker and GP concerning his developmental and health record and to begin to put in place a treatment plan in partnership with his family. These arrangements necessitated substantial travelling and close liaison between professional staff previously unknown to each other.

The challenge of service development

Developing mental health services for the Deaf community in keeping with current mental health policy is undoubtedly challenging and will require sustained efforts.

The pioneering work of John Denmark, who led the development of the first specialist unit in Preston, has been followed by practitioners dedicated to this disadvantaged client group. They have spotted service gaps and filled them where possible, innovated new ways of working therapeutically with Deaf people, developed training, liaison and consultation and created research opportunities. Employing Deaf people has been an important feature of service development. Expertise has flourished.

Forging New Channels (BSMHD, 1998) found that the service users were satisfied with the care they had received and that they reported that effective communication between them and staff was of the utmost importance.

By taking advantage of the consultation and training opportunities offered by the Deaf services, some local mental health services and non-statutory organisations have developed local expertise but this local enthusiasm has been patchy. The highly specialised services have attempted to offer a more local and accessible service to Deaf patients by developing community services and satellite outpatient clinics across the UK.

The Specialist Children's Deaf Service, in keeping with national CAMHS trends, has orientated itself towards empowering local child mental health services through co-working with education and social care providers, consultation, training and effective liaison.

The development of adult Deaf services has followed a different path from local mental health services. The latter have increasingly fragmented into services for smaller groups. For example, services for older people, dementia services, services for those with eating disorders, assertive outreach teams and forensic. By providing highly specialised services based (for good reasons) on Deafness as a primary organisational category, the Deaf services have bucked this trend. This has many practical consequences, not least that the highly specialised services do not have smooth access arrangements to appropriate facilities for a very diverse range of mental health problems. For example, (see Box) patients who most need the highly specialised services are sometimes unable to benefit from it.

A Deaf patient who was acutely psychotic and behaviourally disturbed would benefit, from both a clinical and therapeutic perspective, from being in a specialised Deaf service. However, the specialised services are not currently commissioned or resourced to provide intensive care. The next best solution would be for the patient to be treated in a psychiatric intensive care unit near the specialised service, with the latter providing an in-reach service until the patient was settled enough to be cared for in their open unit. However, the locally based intensive care unit has no beds available.

A similar point has been made concerning the availability of crisis services to Deaf patients by the Daniel Joseph inquiry team (2000). All in all, this does not look like the health service envisaged in the NHS Plan (Department of Health 2000); a health service designed around the needs of the patient.

The concentration of expertise within the Deaf services clearly has ramifications for developing local and national services. The very few local services that exist so far have been 'grown' from the specialised services. Recruitment and retention of staff is already an acute problem. Training hearing staff in BSL and Deaf awareness is resource intensive. Recruitment and retention of staff is a particularly crucial issue and Deaf services are vulnerable to any depletion and their capacity for service development is thus limited.

In the longer term, making mental health services more consistently accessible and appropriate for the Deaf community may well reveal a largely hidden need for such services. This phenomenon, common when health services become more 'user friendly', may pose a particular challenge to developing services for people who are Deaf. Specialised Deaf services may be further driven to provide services for those suffering from common mental health problems – people who would not usually meet the criteria for mental health services beyond the level of primary care.

To summarise, the key challenge for creating a national strategy is to develop local and specialised services in a way that strengthens both components, rather than one being at the expense of the other. In part 3, ways of meeting this challenge will be examined by considering the standards set by the *National Service Framework for Mental Health* and the needs of the Deaf community.

Part III: The National Service Framework for Mental Health – Meeting the Standards for the Deaf Community

While it was designed solely for adults of working age, we will use the standards in the *National Service Framework* as a template in relation to Deaf people of all ages, and as a way of looking systematically at their needs and possible ways of meeting these needs.

Standard 1: Mental Health Promotion

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.**

The challenge of meeting this standard for the Deaf community

People who are Deaf and who have mental health problems face discrimination and social exclusion.

Deaf children, young people and their families need:

- information and education to increase public understanding of their situation;
- a more enlightened approach from the media when reporting issues related to mental health and Deafness;
- an awareness among relevant primary care staff (e.g. Health Visitors; GPs) to provide early identification;
- sensitive support around the time of initial diagnosis of Deafness. As Hindley (2000) points out, *“Most parents assume that their children will grow up and talk”*. Parents may be shocked or suffer a grief reaction, which may diminish their ability to support a vulnerable child. Family centred support, information and education, will be health promoting in this context;
- supportive opportunities, which maximise the family’s ability to communicate with their Deaf child. Parents of Deaf children are rarely encouraged to learn BSL when their child is young – communication difficulties and delayed language development are the norm in this country (Hindley, 2000);
- multi-agency child and family centred assessment and on-going support concerning their communication and educational requirements. Deaf children are vulnerable to: *“low academic achievement, delays in some cognitive and social-cognitive processes, as well as higher rates of social maladaptation and psychological distress and disorder”*. Greenberg (2000) provides persuasive evidence that educational innovation with Deaf children and their families can counteract these problems through ‘developmentally timed preventive programming’;
- all agencies involved with Deaf children and young people to be aware of their vulnerability to abuse and neglect.

Deaf adults encounter communication barriers to their access to mental health promotion resources. This difficulty cuts across all health issues, not just those we consider under the heading of 'mental health'. For example, a Deaf woman may have breast cancer and will have less opportunity to gain psychological support through mainstream services. Deaf adults may benefit from health education, effectively communicated, regarding such matters as post-natal depression, alcohol and drug use and coping with stress and bereavement.

People with dual sensory impairment, who are particularly vulnerable to social exclusion, require access to effective support and counselling which is sensitive to their individual and changing needs over their life span.

The social exclusion of Deaf adults is also a consequence of their difficulties in accessing further and higher education, professional education and in gaining employment. Although the educational levels of Deaf people have improved over the last half-century, it still does not match that of the hearing community (Meadow-Orlans and Erting, 2000 & Dye *et al*, 2000).

Deaf people in prison are likely to experience enormous difficulty in having their mental health needs assessed and met. It is probable that communication problems in this setting will generate mental distress and add to that present prior to imprisonment. Not only is the prison health service unlikely to be in a position to carry out mental health assessment, the mental health service local to the prison will probably be in the same position.

Older Deaf people may find themselves to be particularly socially isolated (as a consequence of bereavement perhaps) especially if they become frail and less mobile in old age. As many more of their contemporaries develop hearing impairment as a consequence of ageing, there is a greater risk that their unique needs may not be recognised by social care and health services.

Ways forward suggested through the initial consultation exercise

The initial consultation exercise revealed some consistent themes regarding mental health promotion. Many of the suggestions concerned issues and initiatives that have already taken place but have been limited by resources. The themes included:

- The crucial necessity of the early identification of sensory difficulties. Twenty areas in England are to pilot universal neo-natal hearing screening (Department of Health, 2001c).
- The critical importance of early intervention aimed at preventing the 'social legacy' of being Deaf in a hearing world, which increases vulnerability to mental health problems.
- The need for a dialogue between educational, social and health services concerning the needs of Deaf children and the impact that educational opportunities have on their mental health.
- The importance of getting Deaf people onto the mental health agenda, so that their needs are considered alongside other groups.
- Support for, and acknowledgement of, the work of voluntary organisations that promote mental health amongst Deaf people.
- The need for health and social services to gather information about their local Deaf community in order that they can initiate effective social and health care.
- The sponsorship of Deaf awareness amongst those whose role primarily concerns health promotion. These will include public health nurses, school nurses and practice nurses.
- Outreach into local Deaf communities in order to promote mental health with resources that can communicate effectively. An example would be the availability of mental health promotion resources in BSL.

- The need to open up educational access to Deaf people, including their access into professional education. The nursing project to train Deaf people to become Registered Mental Nurses at Salford University was seen as an example of the way forward.
- Training more BSL interpreters was considered essential if mental health promotion initiatives were to be delivered.
- Public education and media campaigns.

Standards 2 and 3: Primary Care and Access to Services:

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

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

Any individual with a common mental health problem should:

- **Be able to make contact around 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 onto specialised help lines or to local services.**

The challenge of meeting this standard for the Deaf community

Delivering these standards to the Deaf community is very difficult because of a lack of Deaf awareness and appropriate communication support. Without the ability to communicate, recognising and assessing common mental health problems is difficult, if not impossible, and provision of treatment and care is impeded.

It has been suggested that GPs have significant difficulty identifying the mental health needs of children. This is made worse by variations in local provision of mental health services for children and adolescents.

Primary care workers who are usually in a good position to recognise mental health problems in older people (District Nurses, for example) are less likely to be able to do so with Deaf elders. The issue of identification, and therefore the ability to treat effectively, is most crucial when a Deaf person is acutely distressed or ill and in need of a rapid response.

These barriers have worrying implications for mental health treatment priorities. For example, the opportunity for early intervention in psychosis is reduced, and suffering from depression may be unnecessarily protracted. Children may become further socially excluded and increasingly vulnerable to mental ill health. The lack of mental health care at this level may mean that patients are treated away from their own home by highly specialised services. This reduces their access to their families and personal social networks, at a time when this is of crucial importance.

Ongoing small scale projects aimed at improving access to primary care may have positive local impact, but without appropriate research and development opportunities to co-ordinate and disseminate good practice, their scope for driving up standards overall remains limited.

Ways forward suggested through the initial consultation exercise

Local services need to be developed. Primary care workers would benefit from training in Deaf awareness. An information pack for GP's has been produced by the Doctor Patient partnership and the RNID (web.ukonline.co.uk/hearing.concern). This aims to improve health service access.

It was recommended that all GP practices/Primary Care centres should have a minicom and an established relationship with an interpreting service.

Innovations in the use of technology were suggested. These included assessment using BSL relay interpretation, consultation through the use of video-conferencing facilities and the use of information technology for both Deaf people and service providers. Telemedicine for mental health care has been used successfully in geographically remote places for hearing people and it may hold some promise for the Deaf community.

Three initiatives coming out of the *NHS Plan* (Department of Health, 2000a) were thought to offer promise. The employment of 1000 new graduate primary care mental health workers could include some with a special interest in Deaf people (ideally Deaf graduates). The same case is made for the 500 community mental health staff that will be working with primary care teams as gateway workers. The development of "one stop" primary care centres could include provision for people who are Deaf.

It was suggested that a "one stop" service could be designed to meet all the social and health care needs of Deaf people at a regional level.

Inevitably, discussion of service provision at primary health care level involved careful consideration of the interface between primary care, local mental health service care and highly specialised service provision.

Local expertise in relation to Deaf children is unfortunately rather scarce, but may be found in Social Service Departments and in Education Departments. The increasingly effective links between health and social care could therefore be especially beneficial to the Deaf community.

Two examples of specialist community mental health nurses who were locally based were investigated. Both these nurses, despite different service models, manage to 'straddle' service boundaries and provide a local mental health service to Deaf people. A case example is given (see box).

Jean, who is Deaf, is married and has two hearing children. She suffers from a mood disorder and experiences difficulty in managing anger. She has been admitted to a Deaf service during periods of crisis, and has been followed up by a psychiatrist who can use BSL. Two years ago she was referred to the locally based Community Mental Health nurse (CMHN) for the Deaf

The CMHN has co-ordinated a care programme for Jean and her family in collaboration with the specialised Deaf service and the local Social Worker for the Deaf. The care programme includes crisis planning, and Jean has been able to access local crisis services. During this period, Jean has also received help from the Disabled Employment Advisor and the local welfare rights officer. She now has a better relationship with her GP and a better appreciation of the impact of her mood disorder on her children.

The care programme has been very successful. Jean has had no further hospital admissions, is taking her medication as prescribed, and has improved her coping strategies. Jean's family feel safer now, and Jean is planning to enter a retraining scheme and get back to work.

Standards 4 and 5: Effective Services for People with Severe Mental Illness

All mental health service users on the Care Programme Approach should:

- **receive care which optimises engagement, anticipates or prevents a crisis, and reduces risk;**
- **have a copy of a written care plan which:**
 - **includes the action to be taken in a crisis by the service user, their carer and their care co-ordinator**
 - **advises their GP how they should respond if the service user needs additional help**
 - **is regularly reviewed by their care co-ordinator;**
- **be able to access services 24 hours a day, 365 days a year.**

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;**
- **a copy of a written after care plan agreed on discharge which sets out the care and rehabilitation to be provided, identifies the care co-ordinator and specifies the action to be taken in a crisis.**

The challenge of meeting this standard for the Deaf community

Ordinarily, the delivery of the care programme approach (CPA) works from the assumption that appropriate services are available locally. For Deaf patients, the current situation is inequitable. The nearer a Deaf adult patient lives to one of the three specialist centres, the more access they can have to the full range of multi-professional facilities. Deaf patients incur more personal inconvenience and travel costs in their efforts to receive the services that they need. Patients with dual sensory impairment may be particularly disadvantaged because of mobility difficulties. Two case examples from one of the Deaf services will illuminate these issues. (See boxes)

Doreen, a 75 year old profoundly Deaf woman who is widowed, is now living in a local authority “hearing” residential home. She has moderately severe dementia. She is often agitated and suspicious of the other residents and occasionally this has led to aggression towards them

The highly specialised Deaf services have assessed Doreen and have concluded that she would benefit from locally delivered anxiety and behavioural management; from medication, from careful and regular monitoring; and from the opportunity to communicate effectively. Doreen has refused the offer to move to another residential home where there are other Deaf residents because her daughter and the only friend with whom she is still in contact live nearby.

Mary has been profoundly Deaf from birth. She is 45 years old, married and has grown up children.

Mary has a long standing anxiety disorder and is agoraphobic. She has depended heavily on her children for escorting her on outings from home, but they are now leaving to begin their independent lives. Of late, Mary has begun to rely more on her own elderly mother, who is quite frail.

A specialised Deaf service assessment has concluded that Mary would benefit from a home-based cognitive behavioural therapy programme. Unfortunately Mary lives 150 miles from the nearest Deaf service.

In order to attempt to fill these gaps, some outreach facilities have been developed to provide outpatient clinics in various centres around the UK. New patients can be assessed and follow up care provided. The geographical location of this outpatient provision has evolved from the three specialist centres, rather than being nationally agreed.

The Deaf services cannot provide 24 hour access, nor are they in a good position to take on care co-ordination responsibility. Regular patient reviews are more difficult to achieve and the effectiveness of the interface between local and specialised mental health services is reported as extremely variable.

Vulnerable patients, who require intensive care in the community if they are to remain independent, present particular challenges. Given the right local service infrastructure, mainstream services can manage hearing patients at home. Deaf patients, on the other hand, are more likely to end up in residential services.

Written care plans may not be appropriate for a BSL user, and mainstream service developments such as early intervention, assertive outreach teams, crisis resolution teams, women only accommodation and psychiatric intensive care remain largely inaccessible to the Deaf community.

Whilst some of the themes raised above also relate to the care of Deaf children and young people, there are also some clear differences. A national in-patient facility for Deaf children has recently opened in London. Given such specialised needs, there has to be a balance struck between providing a sufficient 'critical mass' of expertise, with the requirement to provide a service which is as close to home as possible.

A national service has recently been proposed *National Outpatient Mental Health Service for Deaf Children and Young People* (NOPS) and an application made to the National Specialist Commissioning Advisory Group. It has the goal of improving access for Deaf children and young people to effective local services across the country and providing specialised intervention where necessary. Further work will be needed to examine how this fits with services that are currently commissioned at a regional level.

For a Deaf person, a signing environment, where effective communication can take place, will nearly always be the most therapeutic option available. Employing Deaf staff and hearing staff who can use BSL and using interpreters with mental health expertise makes this possible. Providing this kind of service in local mental health care is currently impossible. It was reported that recruitment and retention of such staff is an acute issue across all disciplines. Succession planning, particularly for specialist Consultant Psychiatrists, is also a critical issue. 'Ordinary' human resource issues, like occasional staff sickness, can threaten service delivery in a substantial way.

Deaf patients detained under the Mental Health Act (1983) are disadvantaged with regard to their legal rights for information. Whilst leaflets concerning such matters as rights of appeal to the Mental Health Review Tribunal are available in many written languages, there is no BSL equivalent. However, the Mental Health Act (1983) *'Code of Practice'* has been revised to include the needs of Deaf people. It makes clear recommendations concerning the use of BSL interpreters and the training of Approved Social Workers in Deaf Awareness. The Code suggests that: *'Deaf or hearing impaired patients may feel more confident with a friend or advocate who is also Deaf or hearing impaired'*. (Jones 1999).

The *Review of Health and Social Service for Mentally Disordered Offenders and Others Requiring Similar Services* (Department of Health 1993) examined the needs of Deaf and hearing impaired people. They noted (1993:76) that such people:

"...can be at a major disadvantage at the time of arrest, in court proceedings, in prison or in hospital"

Deaf people requiring forensic services are disadvantaged because no specialised forensic services have been formally commissioned. A specialised service is, informally, provided at Rampton Hospital and has been since 1987 (Department of Health, 1993). Currently detained under conditions of high security, the Deaf patients do not have access to less restrictive facilities. Making the 'leap' from high security to an open ward is usually impossible for this group of patients and there is no NHS medium secure facility available although an independent provider opened in 2002 in Bury. Similarly, mentally disordered offenders who require intensive care or high dependency provision are extremely unlikely to be placed in a signing and, therefore, therapeutic environment.

A study by Young *et al* (2001) examined forensic referrals of British Sign Language users to the three specialist Deaf centres from 1968. The cases of 389 patients were identified and investigated across a number of variables, including their sex and offending history. They found that the referral rate had risen steadily since the mid-1980s. The data were also used to estimate the need for a specialist medium secure facility by applying specific criteria to the cases. The authors concluded that nearly two thirds of their patient sample could have benefited from a medium secure unit.

Generally, Deaf people experience longer admissions to hospital. This is reported to be for two reasons. Firstly, because assessment may be particularly difficult, and secondly, because of a lack of appropriate community facilities.

Some specialist residential care is provided in the non-statutory sector. Sign, for example, provide supported housing, which aims to enable their tenants to live as independently as possible. This is not a cheap option and it was reported that on occasions Care Managers opted for less expensive, but less therapeutic, arrangements. Creating and sustaining such projects is hampered by the funding complexities of 'cross border' arrangements necessary for this specialised, low incidence group. The RNID provide nursing home care for older Deaf adults in Southern England. Older people who are Deaf and who require residential and nursing care will also have their needs most effectively met in a signing environment.

Ways forward suggested through the initial consultation exercise

Suggestions for developing of local services included:

- Making use of financial incentives to encourage local professionals in all disciplines to develop a special interest in Deaf people.
- Encouraging local Trusts (either individually or jointly) to bid for Nurse Consultant posts to develop local initiatives.

- The creation of local community mental health nursing posts for Deaf people, either through local Trust employment, or as 'outposts' from the specialist centres.
- Inclusion of Deaf awareness in the education of all mental health professionals.
- Encouraging more training of BSL interpreters by offering incentives.
- Ensuring that local services accept their responsibilities for the care of Deaf patients.

Suggestions for national service developments included:

- Effective co-ordination of the three adult highly specialised services to consider such matters as their catchment areas, cross medical cover and the development of more highly specialised services, such as forensic care.
- Development of existing specialist services to provide nation wide access to outpatient services for Deaf children and young people.
- Development of a forensic service with national coverage for Deaf patients, which, ideally, could offer flexible levels of security.
- Commissioning of 'emergency beds' (including the provision of psychiatric intensive care) within the specialist centres to enable a response to be made to a crisis situation.
- Enabling the specialist centres to provide more effective 'in-reach' to other services to cater for Deaf patients.
- Making use of financial incentives, flexible working and part-time posts to improve recruitment and retention, and considering the special skills required to work with Deaf patients in relation to wider workforce planning.
- Reviewing and improving funding systems for residential care, in collaboration with social care agencies.
- Supporting the development of specialised advocacy schemes. The RNID, for example, are appointing volunteers as advocates who can make an important contribution to care planning.

Standard 6: Caring about Carers

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.**

The challenge of meeting this standard for the Deaf community

The barriers to providing services to Deaf people with mental health problems, inevitably impact on their carers. The potential number of agencies involved can create even more difficulty. Also, carers may not be able to communicate effectively with 'their' service user and education about mental illness and patient care may be needed.

Carers visiting service users in national facilities may have to travel long distances and consequently incur extra expense and inconvenience. Setting up care planning meetings and reviews may be difficult.

Organisations set up to support carers within their own locality may have little awareness of the needs of Deaf people and their culture. Carers may find themselves more ‘expert’ than those advocating for them.

It is important to note that mainstream services may encounter Deaf carers of hearing patients during the course of their work towards meeting this standard.

Ways forward suggested through the initial consultation exercise

It seemed to be implicit in the views expressed during the consultation exercise that improving services for Deaf patients would concomitantly improve matters for their carers.

The use of the CPA process for adults, especially the new guidance on emergency contacts for carers, could be especially useful in providing appropriately skilled responses.

Services for Deaf children and young people, like their hearing counterparts, assume and make provision for the involvement of carers. More convenient access to outpatient services would be experienced as supportive by parents and come closer to meeting their needs. Non-statutory organisations (for example, the National Deaf Children’s Society) have a vital role to play in supporting the carers of children and young people in both educational and health care settings.

Standard 7: Preventing Suicide

Local health and social care communities should prevent suicides by implementing standards 1–7 and:

- **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.**

The challenge of meeting this standard for the Deaf community

Difficulty in meeting the standards of the National Service Framework for the Deaf community has a critical impact in urgent mental health situations. Assessing suicide risk, for example, requires a sophisticated level of communication, which is rarely available to the Deaf community.

The precise number of Deaf prisoners with mental health problems in the UK is unknown. It is suggested that there are between 63 and 100 Deaf prisoners in England and Wales at any one time (Young *et al* 2000). Dispersed around the UK, there are practical difficulties for mental health services providing ‘in reach’ to Deaf prisoners in attempting to meet this standard. Not least, as Young *et al* (2000) point out:

“There remains a great deal of research to be carried out in order to do the most simple thing – to describe adequately this population and to provide appropriate and targeted responses to its needs.”

Ways forward suggested through the initial consultation exercise

Improving standards of mental health care for the Deaf community should result in more effective risk assessment and risk management overall. Clearer lines of responsibility for individual patients would

decrease their chances of falling “through the net”. By timely access to appropriate services, it is anticipated that crises may be averted.

The development of a specialised forensic service for Deaf people, it was suggested, could seed initiatives for in-reach to Deaf prisoners with mental health problems and would improve the assessment and treatment of those presenting a risk to others.

Rationalising the placement of Deaf prisoners could also facilitate effective in-reach, though it would conflict with other responsibilities of the Prison Service such as locating prisoners close to home and meeting security and sentence requirements.

Summary

Part III of this consultation paper has considered two main issues in relation to the National Service Framework for mental health: – the challenges in meeting these standards for the Deaf community and ways forward to meet these challenges suggested through the initial consultation exercise. Clearly each standard raises specific issues but some persistent themes are revealed:

- The importance of deaf-awareness to aid early diagnosis.
- The scarcity of an appropriately skilled workforce.
- Deaf people (of all ages) and their carers are disadvantaged when trying to access mental health services.
- The need for communication support and respect for the cultural diversity of the Deaf community (described conventionally as ‘Deaf awareness’) is fundamental to improving their mental health.
- Providing effective mental health services to the Deaf community is more costly than for mainstream services.
- A Deaf person is likely to find a fluent signing environment the most therapeutic and beneficial for their recovery.
- Service development is hampered by a lack of knowledge concerning the demographics of the Deaf community and the lack of a solid evidence base for specialised clinical interventions.
- The capacity for rapid service development is limited by many of the above points.

Part IV of this consultation paper sets out options for the development of a national strategy for service development.

Part IV: Proposals for Service Development

The Vision

The principal ambition of a national strategy for Deaf people must be to promote their mental health through the delivery of the highest quality services. By placing the Deaf person “centre stage” we can imagine the kinds of services that we would like to see in the future. These would:

- prevent the process of social exclusion that makes Deaf people more vulnerable to mental health problems;
- ensure that those who do have difficulties receive the best possible care and treatment.

The Way Forward

Mental Health Promotion

Recommendations at local level

Local Implementation Teams, and those responsible for children’s services and older adult services, should consider and respond to the needs of their Deaf community as a ‘vulnerable group’ when reviewing and further developing their National Service Frameworks implementation plans. As advised by the National Service Framework, they should develop programmes “to build resilience in vulnerable children”. LITs could prepare/co-ordinate this work by considering the issues laid out below.

Local population review

The Mental Health Policy Implementation Guide (Department of Health 2001b) recommends that local health economies need to review their population in relation to its cultural diversity and vulnerable groups, as a pre-requisite for planning services. The unique needs of the Deaf community should be considered during this review process.

The early diagnosis of sensory difficulties

The early diagnosis of sensory difficulties, made in a sensitive and supportive environment, will enable rapid access to effective assessment and intervention.

The availability of good and effective family support

This is aimed at enabling families with a Deaf child to promote optimal health and development for their child. This could include support and information around initial diagnosis, early planning around the child’s communication needs and the family’s opportunity to develop their communication skills. Authorities will need to decide who is best placed to lead and to provide this support. They could, for example, build on current Local Authority arrangements, or look to other initiatives such as ‘Sure Start’ and local ‘positive parenting’ projects. The non-statutory sector could be enabled to develop independent information and advocacy systems.

Promoting child centred education

This is aimed at maximising each Deaf child's opportunity for educational development based on a careful assessment of his/her needs.

Child Protection

Deaf children's particular vulnerability to abuse in all its forms should be highlighted with the intention of ensuring their right to be protected. Safeguards for Deaf children should be the same as for non-Deaf children. Particular attention should be given to promoting a high level of awareness of the risks to Deaf children, to promoting high standards of practice, and to strengthening the capacity of children and their parents to protect children. (See paragraphs 6.27 to 6.29 in *Working Together to Safeguard Children* (Department of Health 1999))

Area Child Protection Committees have an important role in safeguarding Deaf children through:

- Raising awareness among children, families and services.
- Identifying inter-agency training needs, and meeting them in ways which encourage the pooling of expertise between those with knowledge about deafness and those with knowledge and skills in child protection.
- Ensuring that local policies and procedures for children meet the needs of Deaf children.

Promoting mental health in Deaf adults

This could involve considering the needs of Deaf people in relation to employment practices and occupational health standards and encouraging educational providers to find ways of making education fully accessible to people who are Deaf.

Those developing mental health promotion initiatives need to take account of the communication needs of Deaf people.

Non statutory organisations that campaign on behalf of, and support, people with mental health problems should ensure that they include the needs of Deaf people.

It is recommended that the non-statutory organisations that represent the needs of Deaf people develop formal processes of co-operation and liaison in order that they can co-ordinate and disseminate good practice initiatives.

British Sign Language Interpreters

The *Mental Health Policy Implementation Guide* (Department of Health, 2001b) advises that the training and availability of interpreters, and the training that health staff have received in working with interpreters should all be scrutinised by Local Implementation Teams.

Recommendations at national level

It is recommended that national organisations concerned with developing mental health promotion materials should consider the unique communication needs of the Deaf community. This includes:

- The Department of Health and the Mental Health Act Commission regarding information concerning patients' rights under the Mental Health Act (1983).

- The Royal Colleges.
- Non-statutory organisations.
- NHS Direct, advertising the availability of services by Minicom.

The Care and Treatment of Deaf People with Mental Health Problems

The Vision

- That national standards of mental health care apply equitably to people who are Deaf.
- That the Deaf community can conveniently access mental health services that are communicatively and therapeutically appropriate to their needs.
- That Deaf people can play a leading role in the provision of such mental health services.

The Way Forward

The Health Advisory Service report *Forging New Channels* (BSMHD, 1998) recommended a strategic framework for commissioning and delivering specialised services based on a four-tier model of service provision for both children and adults.

This proposed, in brief, that Tier 1 would involve the development of 'local services', including primary health care and local mental health services, aimed at improving recognition and earlier intervention. Tier 2 would concern 'augmented local services'. This envisaged links between local mental health services and the specialist centres, with the latter providing consultation, training and information to the former. At Tier 1 and Tier 2, responsibility for individual patient management would remain with the local service. Tier 3, 'dispersed services provided by the very specialised services' suggested the consolidation and formalisation of current outpatient and community services provided by the three centres. At Tier 3, the specialised services would take lead responsibility for patient management, at times offering co-ordinated care with the local service. Tier 4, 'Specialised services provided at the centres of special expertise' – concerned a continuation of the current specialised in-patient and day patient services provided by the three specialist centres.

The initial consultation process revealed that some stakeholders agreed that this was a useful framework to revisit in the light of current policy, whereas others were of the view that a different approach was required. This consultation document therefore draws on an approach involving:

- local primary care services;
- highly specialised services at centres of expertise;
- some intermediate services between the two.

Two options for the arrangements for the intermediate level services have been identified, and views on these would be particularly welcomed.

Development of Primary Mental Health Care

All options require development of primary care services.

Primary Care Trusts, in co-operation with social care services, should develop plans to meet the mental health needs of their Deaf community.

They will find it helpful to refer to the guidance offered to the Local Authority in *Best Practice Standards: Social Services for Deaf and hard of hearing people* (RNID, 1999), *Standards for Services for Adults who are Deafblind or have a Dual Sensory Impairment* (Sense, 2000) and *Standards First: Standards for Deaf Children* (RNID, 2002).

These plans should be incorporated into their National Service Framework Local Implementation Plan and could be considered under the following headings:

The availability of appropriate communication support

This includes communication support of human and mechanical means and the ability to use them. This could include the setting of local milestones. For example, that each GP practice/local health centre has a text phone within one year and that an appropriate number of trained BSL interpreters are accessible within the locality.

Training in Deaf Awareness

Ensuring that Primary Health Care staff, including reception staff and prison health staff, are sensitive to the cultural and communication needs of people who are Deaf.

Promoting the recognition of mental health problems in people who are Deaf

This could be achieved through education and training of the Primary care workforce, targetted on key personnel.

Establish links and protocols with social services and NHS mental health services

This could be initially aimed at developing clarity about roles and responsibilities and smooth systems of referral, particularly in urgent circumstances. As more integrated health and social care systems evolve into Care Trusts, more innovative solutions could be found.

Establish new projects

New projects could be established using investment set out in the NHS Plan (2000a). For example, by supporting the training of a Deaf graduate to be a primary mental health worker or by developing a 'critical mass' of BSL fluent staff in a 'one stop shop'.

Development of Intermediate Level Services

Two options have been suggested for the provision of services intermediate between primary care and the specialised services. Both take into account the interface between primary, secondary and highly specialised services and could ensure the effective operation of the Care Programme Approach.

Option One

Development of services by local mental health providers

All NHS Trusts providing mental health services and the corresponding Local Authorities should develop plans to meet the mental health needs of their Deaf community. These plans should be incorporated into the National Service Framework Local Implementation Plan and the CAHMS development strategies and could be considered under the following headings:

Training in Deaf Awareness

Ensuring that key mental health care staff, including reception staff, are sensitive to the cultural and communication needs of people who are Deaf.

The availability of appropriate communication support

This includes human and mechanical means of communication support and the ability to use them. This could include the setting of local milestones. For example, that a minimum of two staff per trust should be trained in BSL and that an appropriate number of mental health competent interpreters are accessible within the locality.

Ensuring the cultural competence of early intervention, assertive outreach teams and crisis services, including the needs of Deaf people

This can be effected through the current development of new mental health services (Department of Health, 2000a).

Developing local expertise in the assessment and treatment of mental health problems in people who are Deaf

Multi-agency mental health service providers could create/redesign posts for mental health staff with a special interest in Deaf people. Current systems for financial incentives could be exploited, including sessional schemes for Consultant Psychiatrists, Therapist Consultant posts and Nurse Consultant posts. Depending upon the location and the size of the Trust's catchment area, these posts could be wholly or partly devoted to the Deaf community, or could be 'shared' between contiguous trusts.

Developing a plan for meeting the special needs of Deaf in-patients

The National Service Framework requires services to consider the needs of 'minority groups' for hospital care. There may be occasions when a local mental health service has to provide in-patient care for a Deaf patient. The local plan would need to identify such matters as the appropriate budget for mental health interpreter fees and links with the local Deaf community.

Developing links with non-statutory organisations

Such links could be aimed at exploring local options for advocacy systems, for supported residential care and leisure and social facilities in appropriately communicating environments.

Establishing links and protocols with the appropriate tertiary Deaf mental health service

These arrangements could be aimed at ensuring smooth systems of referral particularly in urgent circumstances, effective discharge planning and in clarifying case responsibility.

Option Two

Developing the specialist Deaf centres to provide the equivalent of local, secondary mental health care nationally

This option emphasises the highly specialised therapeutic expertise required in caring for Deaf people with mental health problems. From this perspective, it is argued that effective assessment and comprehensive service provision requires much more than communication support and Deaf awareness because Deaf people express and experience mental illness in a unique way.

This model could bring highly specialised expertise, appropriately communicated, to the individual service user and give them access to the whole infrastructure of specialised services (inevitably within geographical limits) including, for example, psychotherapy, occupational therapy, clinical psychology and counselling.

This model would require the highly specialist Deaf centres to co-ordinate and develop their services under the following categories:

Developing comprehensive, multi-agency and multi-professional community services

Co-ordinating the development of service specifications and interface protocols, including those with secure units and prisons, to ensure that local services develop equitably across England.

The existing outreach/outpatient and family services could be used as a foundation for this development.

Providing care co-ordination under CPA for all patients in their care

Agreeing national management and leadership arrangements to take forward and 'performance manage' this agenda

Development of the Highly Specialised Deaf Services

Services for Deaf children and young people

Deaf children and young people require mental health (including social and education) services, which are:

- as geographically accessible and comprehensive as possible;
- integrated with other services (for example, with education and community paediatrics);
- sensitive to their evolving developmental need and that can effectively communicate with them and their families.

It is recommended that the current specialised outpatient mental health service network be further developed for children and young people, in order to provide expertise to:

- support local provision of mental health care for Deaf and hearing impaired children and adolescents by providing a support, advice, training and consultancy service to local CAMHS across the country;
- advise on appropriate care pathways for the very small number of children requiring inpatient assessment and treatment;
- help identify the most effective interventions for Deaf children and disseminate this knowledge nationally;

- work with adult Deaf services to ensure that there is a smooth transition of care arrangements into adulthood;
- develop partnerships nationally with other agencies that work with Deaf children especially education.

Services for Deaf adults (including older people)

It is recommended that the three specialised Deaf services for adults:

- agree flexible arrangements across the UK for in-patient, day patient and outpatient services to allow Deaf patients to benefit from particular clinical expertise;
- are commissioned to provide intensive services to the most severely mentally ill Deaf patients and to those who need the expertise of a highly specialised service. This should include in-patient care, the provision of 'emergency' beds, day care and out-patient care;
- provide consultation and training to other services and further develop effective links with local mental health services within their established catchment areas. This should include 'in-reach' to Deaf patients being cared for in other services and help for local service development. The specialised Deaf services should work together to avoid unplanned wide variation in the type of consultation offered;
- develop clinical specialisms in co-operation with mainstream services, including:

Open and low secure services

The specialised Deaf services should work together to audit their national provision and, if necessary, develop plans for providing further clinical specialisms for Deaf patients. These plans could include, for example, services for Deaf people with substance misuse problems, learning disability or eating disorders. Such plans could be developed in co-operation with mainstream services in order to maximise the expertise available to Deaf patients.

Medium secure and forensic services

It is recommended that the three specialist providers and the forensic commissioners, together with Rampton Hospital and Mayflower Hospitals staff, work together to agree a detailed proposal for developing a national forensic strategy for Deaf patients.

High secure services

It should be formally acknowledged that Rampton Hospital provides a specialised Deaf service in conditions of high security. Links between the high security service and the new national forensic service should, as a first priority, consider the appropriate exit strategy for those currently detained under conditions of high security who could move to lesser security.

Services for Deaf prisoners with mental health problems

It is recommended that research is undertaken to identify the number of prisoners who are Deaf and their mental health needs, utilising needs assessments being carried out by individual prisons. The best way of providing inreach support to Deaf prisoners needs to be explored. This would enable more effective health care and more effective sentence planning.

Securing the Delivery of Mental Health Services for Deaf People

Securing the delivery of services at local level is or soon will be the responsibility of Primary Care Trusts.

It is recommended that they should:

- Set standards for access to services within service level agreements with GP practices and community providers.
- Ensure service level agreements are in place with suitable providers for translation facilities.
- Make links with Local Authority arrangements with a view to establishing joint commissioning.

Specialised care for Deaf adults and older people with mental health problems, including secure care, is currently the responsibility of Regional Specialist Commissioning Groups. Implementation of *Shifting the Balance of Power* in the NHS (Department of Health 2001d) will involve the establishment of alternative commissioning arrangements for a range of specialised services. The special needs of Deaf people will need to be considered in this context.

Any views on the appropriate future commissioning arrangements for the range of services needed by Deaf people with a mental health problem would be welcome.

Consideration of Deaf people with mental health problems needs to be included in the national underpinning programmes of the MH National Service Framework and the NSF for Older People. The needs of deaf children and adolescents should be considered within the emerging national guidance for these services.

Resources

The proposals put forward in this document are mainly about inclusiveness. They argue that a disadvantaged group should receive the same degree of access to health care as any other member of the population. Where good practice exists, many of the recommendations contained in this document will already be in place. Primary Care Trusts and mental health services are asked to consider whether their arrangements for Deaf people need to be strengthened to meet the standards set out in this document and to implement these through better use of existing resources.

Whatever option is decided for the delivery of services at the intermediate tier, those responsible for specialised mental health commissioning will need to review their investments to ensure that improvements can be delivered.

It is recognised that forensic services for people with mental health problems would be a significant and necessary investment and consideration is being given to the provision of central support for this purpose.

Workforce planning, education and training

Initiatives should include the challenges:

- To employ more Deaf people in health and social care.
- To increase professional training opportunities for Deaf people.
- To recruit and retain staff to offer specialised services.
- To map current specialist workers with the deaf in relevant services.

- To encourage local mental health communities to include specialised services for the Deaf in their local directories.
- To influence the development of a greater number of BSL interpreters to be available to health services. Regional educational confederations could be influential in the training of interpreters in co-operation with their professional organisation.
- To encourage training in Deaf awareness across mental health professions in all agencies (education; health; social services; probation) in pre-registration and CPD education and training.

Research and Development

Initiatives are badly needed to underpin the development of mental health services for the Deaf. It is important that prevalence studies are undertaken to identify the numbers of Deaf people and their mental health needs, especially within the prison and young offender settings. It is recommended that the NHS R&D programme supports research in the speciality, particularly in the areas of the effectiveness of early diagnosis in preventing mental illness in deaf children; risk assessment/management tools and processes; incidence of suicide and 'near-misses'; service user involvement and advocacy. It has been noted that enabling Deaf people to participate in consultation is 'far from easy' and that it requires sustained multi-method approaches (British Deaf Association).

Deaf patients, because of their unique method of communication, have enormous difficulty in 'being heard' – it is crucial to meeting the standards of the national service framework that they are.

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A Sign of the Times

Modernising Mental Health Services for People who are Deaf

Comments from: _____
(Your name)

Organisation: _____
(if applicable)

Address: _____

Perspective _____
(e.g. CPN, carer, GP, service user etc. – as many as are applicable)

1. Overall

Is there anything in this document which is factually wrong? If so, what is it and what should be said instead?

2. Part II

Does it miss out important issues for Deaf or Deafblind people. If so, what are they?

3. Part III

For each of the standards in the National Service Framework, are there additional challenges we have missed out? Are there other good ideas we could have put in?

Standard 1 – Mental health promotion

Standard 2+3 – Primary care and access to services

Standards 4+5 – Services for people with severe mental illness

Standard 6 – Caring for Carers

Standard 7 – Suicide prevention

4. Part IV – Service Development

Have you any comments on the proposals for:

Mental Health Promotion

Primary Care Services

Intermediate Services

Do you have a specific preference as between Option 1 and Option 2? YES NO

If YES, which do you prefer? OPTION 1 OPTION 2

Why?

Specialised services

Commissioning

Underpinning Programmes

Can you suggest any examples of good practice in provision of mental health services to the Deaf community which should be publicised?

Is there anything else you would like to add?
(please use additional sheets if you need to).

Please return by _____

to
Bob McDonald, Policy Adviser, Mental Health Services,
Room 302a, Wellington House, 133–155 Waterloo Road, London SE1 8UG.
by 25th October, 2002 please



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