Deaf mental health services

A guide to commissioning

Written by the North East Commissioning Team for Learning Disabilities & Mental Health and SignHealth

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Acknowledgments

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Introduction

This document is designed to assist commissioners who have responsibility for mental health services for deaf[1] people. It examines the current commissioning landscape and makes recommendations for the future. The information and examples provided should give commissioners a basic understanding of the issues faced in commissioning Deaf mental health services.

This guidance arises from a Department of Health-funded project. The three-year project is attempting to ensure that specialised commissioning of Deaf mental health services takes place, and does so effectively. In recent years very few Primary Care Trusts (PCTs) have collectively commissioned Deaf mental health services. However, the Carter Review of specialised commissioning gave rise to an opportunity to raise the profile of Deaf mental health services. The DH funding for the project was to make sure this opportunity was taken and commissioning structures were firmly embedded.

The project is a partnership of commissioners, specialist providers and the voluntary sector. A group of "Business Change Managers" works on the project. These are managers from the specialist providers and commissioners from the North East. A "Sponsoring Group" oversees the project and is comprised of Chief Executives of the specialist trusts, Specialised Commissioning Group (SCG) mental health commissioners, and representatives from SignHealth (a charity working in the field of Deaf health). The Sponsoring Group asked for this report to be produced.

It is only with decent commissioning structures in place that we can expect quality services to thrive. The project is addressing issues such as workforce, equity of access throughout the country, service

[1] The word 'deaf' with a small 'd' is used to refer to the full range of deaf people, including deafened and hard of hearing. 'Deaf' with a capital 'D' refers to Deaf people who at part of the Deaf community and see themselves as a linguistic and cultural minority. A lot of Deaf people were Deaf from birth or at an early age.

models and provision, potential costs and savings. Deaf people should expect to get the same standard of care as hearing people do. Currently, few receive an equitable service.

Focus is given to England. However, it would be a mistake to see England in isolation. Many of the Deaf people seen by the current services are from Wales and Scotland. Developments in England affect them, and developments in those two countries have an impact on English services.

This document is not a service specification. Because Deaf mental health services are not being commissioned by the National Commissioning Group (NCG) we can only make recommendations which we hope will be adopted by all regions. This will, hopefully, go some way to producing a 'national service' which is provided and commissioned regionally.

Background

The current landscape consists of three NHS psychiatric in-patient units (with associated community and some sub-speciality services), private providers (mainly focusing on forensic services), special provision within Rampton High Secure Hospital, and 'random' (both NHS and other provider) community initiatives. The three main services provide in-patient assessment and treatment for Deaf people with severe or complex mental health problems. Additionally, the services also provide out-patient services. Unfortunately, deaf people get very different services depending on where they live in the country. This inequality can only be addressed by regional commissioners making informed strategic decisions.

In the past there was supra-regional funding available for these units. Unfortunately, with the creation of PCTs the commissioning picture worsened. Because of the small planning populations involved, the needs of Deaf people with mental health problems simply fell off the agenda of most PCTs. There were not enough people presenting with a mental health problem, or demanding a service, within these smaller areas. However, mental health services for deaf people was recognised as being "specialised" and the 'condition' was included in the National Definition Set. This meant that PCTs should have collectively commissioned services, although few did.[2]

The Carter Review looked at the commissioning of specialised services. It recognised that for many specialised services commissioning was hit-or-miss. New arrangements were proposed which were broadly accepted by Lord Warner.

Unlike many 'specialised conditions' there are not major pressures which encourage commissioners to address the area: there are no 'drug interests', there is not a large body of consultants demanding action.

Precisely because of this lack of pressure, people working in the area were keen that deaf mental health services did not slip off the agenda again. That is the aim of this project. The project has the support of the National Specialised Commissioning Group (NSCG), the specialist providers, senior DH directors, and Deaf groups. The project provides commissioners with an excellent opportunity to

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[2] Department of Health, *Guidance on commissioning specialised services*, 2003

establish a quality commissioning framework which can last for years to come. Guidance from Carter and the *Operating Framework* means that SCGs must commission Deaf mental health services – it is not an option. This project hopes to ensure that the commissioning is done well.

Who is this guidance for?

The project has been running for a year. What is already clear is that different regions are interpreting Carter differently, and will adopt their own ways of commissioning. We are clear that SCGs need to be responsible for commissioning Deaf mental health services. This guidance, therefore, is intended for commissioners of mental health services in the SCGs. However, because some Deaf mental health services may be commissioned more locally, the guidance will also be useful for PCT commissioners. This regional–local relationship is discussed below.

What needs to be commissioned?

This is a question that will probably be addressed more fully by the current National Definition Set review. Commissioners from the North East are leading this work for NSCG. However, this project is convinced that a full care pathway needs to be commissioned. The same logic that dictates in-patient beds need to be commissioned collectively also applies to every other point of the care pathway. This is something which differentiates Deaf mental health services from some of the other specialised services (on the National Definition Set). For many of those services, a full pathway already exists. What they require is a specialised procedure before the patient returns to perfectly adequate 'normal' care.

With Deaf mental health services the situation is different. As things stand today, mainstream staff are ill-equipped to deal with Deaf patients at any point along the pathway. The planning population at each of these stages remains small. Patients cannot seamlessly transfer into a specialist in-patient unit and then be discharged back to competent local care. That is why specialised commissioning needs to address the full pathway.

In our opinion this does not mean creating a pathway that runs parallel but separate from mainstream services. Instead it involves commissioning mainstream mental health services to provide the same service they do normally but in a more flexible way.

Traditionally, most commissioners have focused on in-patient services. This is understandable as in-patient placements can be costly. In some regions there has also been commissioning of 'secondary' mental health services.

Unfortunately, there has – to date – not been much commissioning of 'primary' mental health services. This is understandable for a number of reasons. The specialist units are able to offer a tertiary service which commissioners anywhere can purchase. But, away from the three main centres, commissioners have no easy way of accessing specialist primary services as there are none locally to buy 'off the peg'.

This imbalance goes against the prevailing move to put more emphasis on primary care services. It is estimated that (among the hearing population) 90% of mental health problems are dealt with at a

GP practice level[3]. This part of the care pathway is missing for Deaf people: which means they either get no primary care service, or they get referred to a specialist psychiatric service far earlier than would be expected (and then, sometimes, have funding refused). This is unacceptable as far as patient care is concerned, and uneconomic as well.

Commissioning the full care pathway makes sound sense. Patients would receive a far better level of care, and problems could be addressed at an earlier stage thus preventing deterioration and subsequent secondary or tertiary contact. The challenge for commissioners is to commission a service which cannot be created overnight. The expertise to deliver a service simply does not currently exist within most local mental health trusts or PCTs. Building this capacity will be vital. The existing three services have an important role to play in this. Regions need to draw upon the skills and knowledge contained in these services. This could be through training, supervision, secondment, mentoring and advice – as well as provision of direct services such as outpatient clinics.

The rest of this document crudely divides the care pathway into primary, secondary and in-patient care. We accept that this is not ideal and should not dictate how services are configured. However, the distinction does have advantages when looking at services geographically, as will become clear.

A commissioning framework

Before looking at service provision, attention needs to be given to the commissioning framework. We are very clear that quality services cannot thrive without quality commissioning. The National Specialised Commissioning Group has said that Deaf mental health services will not be commissioned nationally. This is a shame as we feel there is a strong case for a national approach. We hope that SCGs will be able to deliver a 'national' service by working closely together. The introduction of SCGs is the perfect opportunity to establish commissioning structures which will provide excellent Deaf services for years to come.

The review of the Specialised Services National Definition Set (SSNDS) may provide some clarity about what services need to be commissioned collectively for Deaf people experiencing a mental health problem. If this is not addressed in the review, then we believe the NCG needs to provide a guideline for SCGs. It would seem that the NCG/SCGs need to chose an option from both (1) and (2) below.

1) A) SCGs assume responsibility for all tertiary and secondary Deaf mental health services and directly commission these;

1) B) SCGs assume responsibility for all tertiary and secondary Deaf mental health services but delegate responsibility for some of these;

1) C) SCGs only commission tertiary services.

[3] The Sainsbury Centre for Mental Health & NHS Alliance, *Primary Concerns*, 2002

2) A) SCGs assume responsibility for primary care services and commission these directly;

2) B) SCGs just commission secondary and tertiary services and have no involvement in PCTs commissioning of primary care services;

2) C) SCGs assume responsibility for primary care services but delegate the commission to PCTs or groups of PCTs; or

2) D) SCGs do not take responsibility for primary care services, but play a role in assisting PCTs to commission these services.

If there is no national guideline agreed, then we suggest that each SCG address the question and is clear about where responsibilities lie. The Carter report was insistent that commissioning became more transparent and this is just the sort of grey area that could cause difficulties if not grasped at an early stage. The authors of this report are convinced that SCGs should directly commission secondary services and play an active role in primary care commissioning (even it is decided they should not receive that responsibility from PCTs). The document is written on that basis, but can, largely, be applied whichever options are selected.

Recommendation: Each SCG forms a Working Group to establish the commissioning of mental health services for Deaf people.

Recommendation: The NCG, or the SCG Mental Health Commissioners collectively, decide the extent and nature of SCG and PCT involvement in the commissioning of mental health services for Deaf people.

SCG commissioning

SCGs should be able to commission in-patient services without too much difficulty (but see supra-regional section below). Preliminary work by the Specialised Commissioning team and the Working Group can be supported by this project. Commissioning services for the rest of the care pathway will be more complicated and will depend, partly, on the location of each region.

SCGs may decide to divide their regions into sub-regions. Although this makes planning populations smaller it recognises that geography plays a factor. For instance, in the South West it may be felt that a 'central' secondary Deaf team would not be viable because of the time spent travelling. Sub-regional solutions would, though, be possible and could still work together at a regional level, e.g. sharing supervision, support, experience, etc.

What is important is that the SCG retains overall responsibility. If services are failing a Deaf population somewhere then there should be no question about who needs to address the problem. If commissioning is delegated then there still needs to be overview from the SCG and SHA.

Supra-regional SCG commissioning

Deaf mental health services have a small planning population, even when compared to other 'conditions' on the National Definition Set. There is a strong case for SCGs working together to

commission in-patient services. The three specialised units have reasonably ‘natural’ catchments.[4] It is in the interests of SCGs that they work together with other SCGs who are commissioning the same service. In this way commissioning can be more coherent and unified.

For in-patient services, we recommend that ‘host’ regions (those that have a specialised unit on their patch) take a lead for neighbouring SCGs. This may not always be possible, in which case SCGs should decide where lead ‘responsibility’ should lie. Contracting could still remain at an SCG level, but intelligence would be shared between SCGs. There would be a number of benefits to this arrangement:

- A clearer system and relationships for the providers (dealing with one commissioner not many);
- Specialist expertise would develop within one commissioning team;
- Trends or concerns could be more easily identified and addressed as they would no longer be seen in isolation;
- The provider could work to a clearer plan, rather then trying to meet the possibly contradictory demands of commissioners.

A lead SCG would seem viable in the North West and London, where both SCGs have experience and are currently engaged in an active commissioning process. The West Midlands, sadly, has no recent history of consortium or specialised commissioning for Deaf mental health services. This is something that needs to be urgently addressed as it places the service under undue strain and makes the service vulnerable.

The modernisation at the JDU in Manchester was done by the Trust and the North West SCG working in partnership, and was very effective. While the modernisation was extremely welcome, in an ideal world it would have been done in partnership with other regions (and Scotland and Wales): unfortunately no structures existed to allow this to happen. Indeed, the NW Specialised Commissioning Team is now supporting the JDU in their contact with other regions. This shares expertise from the North West and ensures commissioning is ‘joined-up’. Our aim elsewhere must be to have formal structures in place to facilitate this.

Lead SCG	Main in-patient provider	Regions covered
London SCG	Old Church	London, South East Coastal, South Central, East of England
To be decided	Birmingham Service	West Midlands, East Midlands
North West SCG	John Denmark Unit	North West, North East, Yorkshire & The Humber

[4] The South West region does not fall naturally into any of the patches. This is addressed later.

Individual PCTs contracting or reaching named patient agreements

Individual PCTs having in-patient contracts is no longer an option. The SCGs clearly have responsibility for commissioning. They could, theoretically, delegate this back to PCTs but they would have to be very confident that each PCT was commissioning a service. It is likely that the Healthcare Commission will be putting specialised commissioning under scrutiny. The Operating Framework has stated that:

> 3.11 As a result of the Carter Review, the 10 Specialised Commissioning Groups (SCGs) were created to drive up the quality of specialised services, and prevent wasteful or even unsafe duplication of services. For that reason, we expect SCGs to create pooled budgets and to commission the majority of specialised services on their patch this year, extending this to all specialised services in 2009/10. This year, at least half of specialised services commissioned on each patch should be designated, in order to guarantee patient safety and ensure that scarce skills are used effectively. This must be done with a regard to published competition principles and rules. (*Operating Framework 2008-09*, DH)

We also understand that the World Class Commissioning (WCC) competencies will also be applied to SCGs and this should strengthen their position as bodies which have clear roles and responsibilities.

Scotland and Wales

As mentioned above, the three specialised services stretch beyond England. Indeed, a proportion of in-patient activity at the JDU is from Scotland. There are moves in Scotland to develop services within the country, and this will undoubtedly have an impact on services in England. Following the review of Health Commission Wales, there is also a hope that Deaf mental health services will now be commissioned by Wales. **Just as SCGs in England need to co-operate to commission effectively, we recommend that steps are taken to include Scotland and Wales in the commissioning framework. A structure of host/lead SCGs would make this easier.**

Considerations

Whatever method of commissioning is adopted there are some practices that should be adopted by all. This is something that will be addressed in a forthcoming document on standards in Deaf mental health services. However, considerations are likely to include:

User involvement

Commissioning should not take place without meaningful user involvement. Community services offer more scope for user involvement but there is no reason why users cannot be involved in the in-patient commissioning process. This can sometimes involve a lot of effort preparing participants and making them feel their input is important. The charity SignHealth, working with the UK Council on Deafness, can, through this project, facilitate and help SCGs engage with Deaf people and groups.

The London Consortium has, in the past, had very strong involvement from the voluntary sector. Also in London, a Patient & Public Involvement audit tool is being used. This could provide useful

lessons for other regions. The London service also holds Open Days which are useful events for commissioners and others to learn more about the service. Commissioners and providers also recently met with members of the Deaf community to describe their work.

Exchange of information, especially relating to workforce

Information sharing has not always worked well for Deaf services. It is important that everyone involved with these services has easy access to useful, up-to-date information. This means developments in one part of the country must also be shared nationwide. This will assist the commissioning process and help providers develop services in an informed way.

There is now a well established Clinical Governance group which brings together people working in the field of Deaf mental health. This is an important body for sharing information and should be supported. A similar forum that involves commissioners would have value.

Particularly important will be the sharing of workforce information. If a key member of staff is leaving a team, then this is an issue for commissioners. They need to be aware that this could have a knock-on affect on the service. If staff shortages emerge then this is something that needs to be tackled by commissioners and providers together.

Longer-term investment and planning

Current commissioning arrangements in some areas do not provide much security for the three services. This makes long-term planning more difficult. Designation should go some way towards providing security, but more thought needs to be given to long-term planning. Commissioners need to be asking questions for the future, for example: is the composition of the Deaf community changing, what impact are cochlear implants having, could videophones be used for out-patient clinics, etc.

In-patient services

The three in-patient services provide a similar service to a core group of patients – Deaf people with a severe or complex mental health problem. Many patients are detained under the Mental Health Act, and most are sign language users. Beyond this commonality, there is difference. The London service, for example, may admit people who Manchester might not (e.g. Deaf people with a learning disability). There are also major differences in the ways the units operate – from referral procedures to Care Programme Approach (CPA) responsibility.

Having three specialist in-patient units across the country is *probably* the right number. Unfortunately, because there is no public health data available, it is impossible to know what the 'right' level of activity should be.[5] In London the number of admissions has recently risen, while in Manchester and Birmingham there has been a decrease in the past few years. Whether this is a long-term trend is hard to know. In Manchester there were a number of long-term patients who have

[5] If guidance in the new Mental Health Act Code of Practice (4.106) is followed, then mainstream hearing health services should contact one of the specialist units when they have contact with a Deaf patient. This may lead to a more accurate picture of where Deaf people are accessing services.

been discharged and this has affected occupancy levels. A growth in appropriate secondary care may decrease admissions, but could conversely generate an increased 'demand' for admissions.

Creating more in-patient services would reduce levels of activity and dissolve the specialist skills. We would worry that any extension would expose all the units to clinical risk – 'throughput' would mean staff did not gain sufficient experience to practice safely or effectively. The growth of private sector provision in the field of Deaf mental health has already posed serious challenges in terms of the workforce and sustainability.

If our recommendations are followed and SCGs work in partnership, then hopefully future demand and provision can be monitored. Commissioning the in-patient services is relatively straightforward. The need is the same for all SCGs and there are only three services to choose from.

Old Church, London

A large proportion of their activity comes from the London region. A consortium of London PCTs collectively commission in-patient and out-patient services. Most admissions are from the South and South East but do extend nationwide. Deaf people can refer themselves to the service.

Birmingham Service (formerly Denmark House)

There is no collective commissioning here. A handful of PCTs have individual contracts with the service. Most admissions are from the East and West Midlands. Historically, the 'catchment' area was larger, extending into the South West – an area also covered by Old Church.

John Denmark Unit (JDU), Greater Manchester

There were a lot of long-stay patients on the unit. However, following a modernisation programme most of these have moved on. The Specialised Commissioning Group (SCG) collectively commissions a service for two-thirds of the region (soon to extend to the whole region). While the unit has a good commissioning relationship with the North West SCG, most of its in-patient activity comes from outside the region. As with Old Church, admissions do come from across England but in this case are mainly concentrated in the north and Scotland.

Demand

We would like to be able to tell commissioners what level of demand they can expect from their region. Unfortunately, this is not easy. Some areas have a stronger tradition of using the specialist services. Others would *appear* to have no Deaf people in need of admission. What we do know is that in London and the North West, Deaf people are more likely to be able to access a service – probably because of better historical links and patterns. We can also be fairly certain that in areas where there are few admissions to the specialised services, there are probably Deaf people being missed. We know that Deaf people are being admitted to hearing wards, and some are not receiving any service at all.

We also know that the incidence of mental health problems is far higher in the Deaf population (probably 40% compared to 25%). The incidence of schizophrenia is probably similar (approximately 1 in 1,000). We can, then, make an educated guess as to the number of Deaf people in each region who are likely to experience a mental health problem and experience schizophrenia. These figures

will not be reliable enough to plan an in-patient activity level. But they will alert commissioners as to the likely number of Deaf people who are probably not ‘on their radar’ and yet should be.

Estimates are contained in the Table Two. It is worth noting that, other than the in the NE, we are unaware of any health trust which could reliably provide data on the number of Deaf people in their area – or have attempted to gather the data. In the twenty-first century this is alarming. It leaves commissioners planning services without even knowing what their ‘planning population’ is. We recommend that SCGs involve public health colleagues in the commissioning. If they are unable to provide data then they may want to look at how they can gather data in the future.

Table One. The current in-patient arrangements for each region

Region	Commissioning arrangements for in-patient admission
North East	Currently no block contract, although this is being examined as part of the SCG’s major review of deaf services.
North West	The SCG has a cost-and-volume contract with the JDU.
Yorkshire & Humberside	No regional arrangement in place.
East Midlands	No regional arrangement in place, but SCG is examining provision with Denmark House as part of its review.
West Midlands	No regional arrangement in place.
East of England	No regional arrangement in place.
South East Coastal	No regional arrangement in place.
London	A consortium of London PCTs had a block contract with Old Church, but this has now moved to a cost-and-volume contract. As well as tolerances, this uses a three-year rolling average. The Service Level Agreement (SLA) is for a ‘package’ of services that includes in the in-patient service.
South Central	No regional arrangement in place.
South West	No regional arrangement in place.

Secondary care

The Business Change Managers[6] involved with this project have discussed secondary care on numerous occasions. There was a growing recognition that solutions would have to vary depending on geography. We firmly believe that Deaf people should get the same level of care wherever they live in the country – but fully recognise that how that level of care is delivered will vary from place-to-place.

We already have differences in the model of secondary care used by the three specialist centres. In London the service operates an 'open access' policy which means patients can self-refer. However, in the North West, the specialist service takes referrals from mainstream mental health services. In London there is a Deaf Enhances Support Team (DEST). This team works with people on an enhanced CPA, which the team take responsibility for. They retain links to the local Community Mental Health Team (CMHT). London's Community Team does not take CPA responsibility and supports local CMHTs. In the North West there are clear procedures and protocols that maintain a patient is the responsibility of the local hearing mental health service. The JDU's role is to support and assist mainstream services. [7]

London and the North West already have strong commissioning structures and will continue to develop their services. For the rest of the country it is worthwhile seeing what currently exists.

Examples

North West, Birmingham and London

These areas are well placed to use their supra-regional service. For example, in the North West the JDU's community team provides support for secondary care services across most of the region. In that geographic area they can offer a quick response and know many of their clients well. The team is able to take advantage of being part of a wider Deaf service: support is available from colleagues on the in-patient unit, there are more economies of scale, cross fertilisation is possible, career development is easier, continuity of care, etc. The JDU is developing a system of 'zones' across the north with different services available in each zone.

Currently, all staff in secondary teams work for the same trust as their in-patient colleagues. However, this need not necessarily be the case. A key role for some of these teams is to work with local mental health services. Being employed by another trust, and possibly being based a long way away from the patient/local team, may not always be ideal. This will depend on exactly what role commissioners and providers agree for secondary care.

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[6] The Business Change Managers' group consists of managers/directors from the three specialised services, commissioners from the NE and a manager from SignHealth.

[7] The JDU's recent work on CPA has been praised in national guidance. For details of their protocol contact the service.

In these three regions commissioners are obviously fortunate to have existing services.

Nottingham and Newcastle

Examples of secondary care exist in Nottinghamshire and Newcastle. These are both areas outside of 'host' regions. In both cases Community Psychiatric Nurses (CPNs) are employed who have specialist knowledge and experience of Deaf mental health.

The Nottinghamshire service has recently expanded. The CPNs have a clear framework which allows them to network with mainstream mental health colleagues. They are able to assess Deaf patients and work with those that need a service. This is usually done in partnership with local mental health and support services, using a Stepped Care Approach. This is the approach we would recommend, with specialist staff either leading or co-working cases. In this way, a Deaf person is getting the same support, from the same services as a hearing person would – but crucially with the additional input of someone with the necessary specialist knowledge.

Indeed, we see a key component of the role as being training and support for mainstream colleagues. One CPN is not able to replicate the entire multi-disciplinary team. However, by working with mainstream colleagues the end result can be the same.

The CPNs in Nottinghamshire provide a service across the county. This makes it a very local solution, which could be replicated across the rest of the region. This would bring with it benefits: less isolation, better workforce development, improved skills mix, etc.[8]

Nottinghamshire has a population of approximately 1.06m and is covered by 2.0 WTE CPNs. If this ratio were followed elsewhere it would suggest one specialist per 530,000 of the total population. The addition of a second CPN in Nottinghamshire is recent. Allowing one specialist per million would be a rough rule of thumb and starting point. Nottinghamshire is probably a typical county in terms of Deaf population.

The example of Nottinghamshire is very helpful. However, we know that simply employing CPNs with the required skills (even if there was a large supply) is not the answer. Some CPNs have experienced isolation and have not had co-working relationships with mainstream colleagues. Indeed, there has been a tendency to 'dump' patients on the CPN. Therefore, commissioners and local trusts need to be very clear about the model and protocols that underpin it. The CPN (or other specialist) needs to be located in a mental health team so they have access to support. They should aim to assist colleagues in their own team and beyond, rather than take responsibility for all Deaf patients.

The 'virtual team'

This is an approach being pioneered in the North East. The SCG is currently reviewing the full care

[8] The CPNs in Nottinghamshire have the advantage of being employed by the same trust that operates Rampton Hospital. Therefore, they have colleagues in the Deaf Unit at Rampton.

pathway for Deaf people with mental health problems. They are committed to providing an end-to-end solution rather than just addressing parts of the pathway in isolation.

They currently have a CPN who has been working in part of the region for some time. This has probably reduced the number of in-patient admissions, although this is obviously hard to prove. Alongside the CPN, the region is building a 'virtual team'. This will be a multidisciplinary team of people working in mainstream mental health services. However, they are studying on a new Deaf mental health course being run by Northumberland University. This will give them some of the specialist Deaf skills they need. When a Deaf person presents somewhere in the region, the virtual team will be able to act. This means it is possible to develop a full team, without the risk of low activity: if activity is low then staff continue with their 'day job' in mainstream hearing health services. This makes it an economic solution for the trusts involved.

It is still early days for the virtual team, with staff only recently being identified and starting their training. However, it could prove an interesting model for other regions to consider.

Communication

It is vitally important that there are good channels of communication between specialist providers and mainstream secondary care. Regardless of which model is adopted, it is this communication which will probably make the most difference. All three specialist services have recently been addressing this issue. In some cases, training is offered to CMHTs which helps to promote the service and makes clinicians aware. The Business Change Managers will be pooling their experiences of using different approaches. This will help to share good practice and make sure communication is embedded in all services.

The 'vision'

Commissioners have options and plenty of scope for flexibility. **We recommend each region employ specialists who form the nucleus of a Deaf service.** They should assist and support mainstream colleagues and can be embedded throughout the region. The exact role can be determined locally, but there should be recognition of the need for: training colleagues, working from within a mental health team, the balance between having an individual caseload and working *with* colleagues.

These workers should be linked to their nearest specialist service (London, Birmingham, Manchester) for additional support. In this way, the wealth of expertise across the country is easily available, as required, for any Deaf person regardless of where they live. This must, surely, be our goal. Such a system would not be expensive and is more about establishing the necessary structures, systems and relationships. It is just a question of using existing 'resources' more efficiently; something most commissioners can wholeheartedly support.

Once a region has a 'team' (which may just be two or three CPNs or clinical psychologists), this can then begin to be augmented. In the North East this will be through a 'virtual team' but elsewhere it could be more informal. A consultant or an occupational therapist may have an interest in Deaf mental health and want to develop their knowledge and skills. With the right support and training

this then adds to the 'resource' that the 'team' can draw on; and provides improved care for Deaf people.

Table Two

Region	Population	Approximate Deaf population[9]	Approximate number of secondary care WTEs[10] required	Number of Deaf people experiencing a mental health problem[11]
North East	2,545,073	2,845	2.5	1,138
North West	6,827,170	7,495	6.8	2,998
Yorkshire & Humberside	5,038,849	8,145	5	3,258
East Midlands	4,279,707	4,005	4.3	1,602
West Midlands	5,334,006	7,585	5.3	3,034
East of England	5,491,293	3,900	5.5	1,560
South East Coastal	4,187,941	5,575	4.2	2,230
London	7,428,590	7,805	7.4	3,122
South Central	3,922,301	2,930	3.9	1,172
South West	5,038,200	4,195	5	1,678

[9] Estimates of the Deaf population are fraught with danger. This table uses the number of people registered as Deaf with a local authority contained in: Information Centre, *The number of people registered Deaf or Hard of Hearing year ending 31st March 2007, in England*. However, not all Deaf people will be registered. The local authority figures confirm the old approximation of 1 person in 1,000 being Deaf. However, evidence from the baby hearing screening programme suggests 2.6 children per 1,000 are deaf. While this will include children with moderate deafness it justifies the 1:1,000 being a minimum. There will always be larger numbers in regions with urban conglomerations.

[10] Whole Time Equivalents, e.g. two part-time clinicians may count as one full-time WTE. Follows Nottinghamshire's earlier ratio of 1 CPN for every 1 million people.

[11] Based on 40% of the Deaf population experiencing a mental health problem. This compares to 25% of the hearing population.

Sub-specialisms

We talk of Deaf people with a mental health problem, but obviously there is great diversity within this. For instance, a Deaf person may also have a substance use problem or autism. In such cases it is important that Deaf specialists are able to support mainstream services. So, the substance misuse team may be working with a Deaf client, but will need advice and support from a Deaf service. There should be a presumption that the Deaf person receives a service from the same team they would if they were hearing. Deaf services and teams then provide the specialist input to support this.

Primary care services

Why should SCGs think about primary care services? This is not the usual stuff of specialised commissioning. However, we think that it would be a mistake to concentrate on tertiary and secondary services in isolation. Such a focus comes from thinking in terms of institutions from the top down. We need to shift the focus back to the Deaf person experiencing a mental health problem. The review of the National Definition Set may clarify what needs to be commissioned, but we recommend that the full care pathway is addressed by the SCG.

By refocusing on the Deaf person we realise that any mental health service they receive is a 'specialised service'. Indeed, this fits well with "a model of flexible personalised care that is part of mainstream healthcare"[12]. It must also be remembered that there is considerable overlap between primary and secondary services.[13]

Comparison with Child & Adolescent Mental Health Services (CAMHS) may be helpful. SCGs may commission Tier 4 services (in-patient services) and not need to give much thought to Tiers 1-3. That is because Tiers 1-3 already exist and a young person discharged from Tier 4 joins the much larger 'planning population' of Tier 3. For a Deaf person, Tiers 1-3 do not exist and when they leave Tier 4 they are still part of a small specialised 'planning population'.

It would be a mistake to say that PCTs already commission primary care mental health services for the whole population so Deaf people are included. Commissioners and providers need to be clear about how their services are adjusted and adapted to be accessible and suitable for Deaf people. All PCTs will have Deaf people in their area who require a mental health service and can plan proactively. Many PCTs now commission primary care services to be delivered differently to people of non-Christian faiths and from different ethnic backgrounds. The same principle applies to the Deaf population. The difficulty is that the Deaf population is diverse and dispersed. Therefore, PCTs need to work together to provide the solutions – which reinforces the argument of SCGs playing an important role.

So what is needed at primary care level? As with secondary care, we believe it is largely a case of making existing 'resources' more efficient. We already have people working in the NHS who are used to giving excellent care to a wide range of people. We need to build on this and extend that care to Deaf people.

Training and support

Staff need access to training in deaf awareness and communication tactics. A quite basic course

[12] Prof Mayur Lakhani CBE, *No patient left behind: how can we ensure world class primary care for black and minority ethnic people?*, DH, 2008

[13] Commissioners should be aware of the guidance contained in *Mental Health and Deafness; towards equity and access*, DH, 2003. This was published in response to a homicide inquiry and makes 26 recommendations for health services.

lasting a few hours can bring about a huge change in practice. Clinicians (and receptionists) usually realise there are plenty of small adjustments they can make to their working practices which can have a huge impact. This makes the Deaf patient's pathway far less stressful and frightening.

As well as training for primary care staff, there should be a clear system of support for professionals who are working with a Deaf person. For example, if a GP has concerns regarding the mental health of a hearing patient they are able to make contact with colleagues within primary mental health services (such as a Gateway Worker) or the Community Mental Health Team (CMHT) and have a general discussion as to the best course of action. However, if their patient is Deaf this is not possible. It would be beneficial to be able to explore a way forward with a colleague who has the specialist skills. This could be a practitioner who works at primary care level in the region or from a specialist Deaf worker (e.g. CPN). The necessary expertise may already exist elsewhere in the same trust but it is a question of putting a system in place so that the connections are made. In Nottinghamshire, increasing use is being made of Gateway Workers supporting primary care staff, and one worker is now to receive sign language tuition.

Improved systems would give Deaf patients access to the same services as hearing patients. It would also mean that staff at all levels felt competent and confident to offer services knowing that there is the opportunity to request and receive support when appropriate.

Psychological therapies

Psychological therapies are an important part of secondary care, but are also increasingly common in primary care. Over the last 15 years there has been a big growth in psychological therapies for hearing patients. Many GP surgeries now have an in-house practitioner working within the Primary Health Care Team (PHCT). Clinicians from various disciplines are also applying techniques adopted from psychological therapies.

The Department of Health is investing £170m in the "Improving Access to Psychological Therapies" (IAPT) programme over the next three years. This will see a dramatic rise in the number of people available to work with patients using Cognitive Behavioural Therapy (CBT) as the main approach.

Unfortunately, most Deaf patients will be unable to access this treatment as practitioners will not be Deaf-aware, have British Sign Language (BSL) skills, or know about Deaf mental health.

Clearly, communication is imperative if a psychological therapy is to be successful – along with an awareness of the individual's culture and an understanding of their frame of reference.

In an ideal world both the client and therapist communicate in the same language (BSL) and have the opportunity to engage with each other on a deeper level than might be achievable using an interpreter. However, the lack of trained therapists who can sign means this is not always going to be achievable.

In the absence of a signing therapist a BSL interpreter needs to be used. It is important that a fully qualified and experienced interpreter is used. Involving an interpreter may make it harder to develop a therapeutic alliance between the therapist and client. The therapist receives a lot of subtle information from the client by body language and eye contact and *vice versa*. If the client is looking

at the interpreter it is impossible to look at the therapist and if the therapist is looking at the client who is looking at the interpreter again it is difficult to ascertain the nuances of the communication. Transference and counter-transference are important dynamics within the therapy and very difficult to work with if a third person is in the room (interpreter) and very much a part of the process. The interpreter and therapist need to be aware of the dynamics involved to make the most of the sessions.

Recent research suggests that using an interpreter can be effective if sessions are well planned. *Guidelines for psychologists working with interpreters in health settings* (Tribe & Thompson) provides valuable information on how therapists can approach their work if using an interpreter.[14]

The specialist service in London has a Psychological Therapies team, which works across primary and secondary care, and has a range of therapists. They are also actively involved in training therapists (e.g. deaf art psychotherapist, deaf clinical psychologist). The Birmingham Service also offers a range of psychological therapies, including CBT, psychodynamic and integrative psychotherapy. SignHealth Counselling (formerly managed by the British Deaf Association) provide counsellors throughout the UK. However, there are gaps in parts of the country where there are no therapists with the necessary skills.

As stated earlier, many GP surgeries now offer psychological therapies. A therapist may see up to five patients a day within one practice. For therapists working with Deaf clients this is not the case. A therapist may travel up to three hours to see a client for 50 minutes, and then travel another two hours to see another client before travelling home for another three hours. This obviously raises funding issues, which arise directly from it being a specialised service. There are, then, clinical and operating issues that SCGs need to consider by looking at the problem strategically. The workforce issue needs to be addressed along with establishing protocols for Trusts to work with.

We recommend that commissioners consider the following steps:

- That IAPT funding is used to train deaf people and fluent signers to be psychological therapists within low and high intensity;
- That IAPT funding is used to train existing specialist staff to be able to offer psychological therapies; and
- That the SCG commissions psychological therapies as part of the care pathway. If the SCG is unwilling to commission a region-wide service, then it must ensure that local commissioning is in place which specifically addresses the issue of Deaf access. The SCG should assume a performance monitoring role in this instance.

It will be important that 'new' therapists are not isolated. Ideally they will be linked to the specialist workers mentioned in the section on secondary care.

[14] Many thanks to the JDU for the reference.

From local to regional and back again

Discussion of therapy raises an important question as to *where* Deaf primary mental health commissioning should take place. We have said that SCGs should be involved in the full care pathway, including primary care. However, we recognise that PCTs have very different approaches to mental health at a primary care level. A region-wide solution may not fit all PCTs.

We are keen for Deaf people to have an equitable service. So, in PCT A, a Deaf person will follow the same system as a hearing person – with necessary adjustments along the way. In PCT B, a Deaf person would follow the local procedure, again suitably adjusted. While the arrangements in areas A and B may be very different, both Deaf people should be getting the same level of service.

We do not want separate systems that operate outside of mainstream primary care. We want mainstream systems that flexibly respond to Deaf people. The question of how this is best commissioned has already been raised. If there are a variety of primary care systems, then it could be that commissioning will have to take place at that local level – though, hopefully, with some regional oversight and co-ordination to improve quality and efficiency.

We also recommend all PCTs introduce a system for recording the number of Deaf people who require some form of mental health service. This need be nothing more than one administrator agreeing for all practices in the area to contact them with the name and details of any Deaf people who need mental health input. The administrator does not need to act on this, but a better picture of needs and demand begins to emerge. This information will be useful for commissioners in the future.

Workforce

When looked at nationally, the current workforce situation is dire. There is no national or regional planning. Some excellent staff have drifted into Deaf mental health by chance, e.g. after encountering a Deaf person in mainstream services. Unfortunately, most mainstream staff (even in the specialist trusts) get little exposure to Deaf services.

In some specialist units a large proportion of the team is approaching retirement (though not in London). This could lead to a huge loss of experience. Services are also very vulnerable to staff loss. For example, if a consultant leaves the service this can be very destabilizing. Recruitment and training of a new consultant is far from easy. Who will the new consultant learn from? When a consultant psychiatrist left Old Church it took years to appoint a replacement. Denmark House has experienced a similar problem. This is why workforce planning is crucial.

Unfortunately, specialist staff often get no recognition of their increased skills, e.g. BSL. Where this happens there is no incentive for staff to develop BSL and it is sometimes difficult for trusts to retain staff who have developed the appropriate skills. Greater Manchester West Trust is reviewing its payscales and hopes to introduce a financial incentive for staff that learn and work in BSL.

Elsewhere, vast swathes of the country have no staff with specialist Deaf mental health skills – or, at least if they do, they are not employed to use them. This means capacity must be planned and built in a sustainable way.

We are making two, basic, workforce recommendations:

1) In areas that already have a specialist service, commissioners should undertake a review with the Service of current workforce issues, vulnerabilities, and recruitment and retention policies. This review should be followed by a plan that seeks to ensure workforce stability.

2) In areas where there is no specialist Deaf service, commissioners should investigate with local providers what specialist skills may already exist, and what interest there may be in developing these skills, e.g. there may be an Occupational Therapist (OT) who signs fluently and would welcome the chance to work with more Deaf people.

Support, Time and Recovery Workers

There are many reasons why Deaf services should adopt the Recovery Model. However, even if we were to make such a recommendation there are too many factors involved which would make this impractical: provider trusts may not support the philosophy, and its development really needs to come from the grassroots rather than being 'imposed'.

However, there is a special case for Deaf services employing Support, Time and Recovery (STR) workers. The national Mental Health Care Group Workforce Team has espoused the benefits of STR workers and their role.

> "One of the many concerns that service users have is that very few staff working in mental health services have the time to spend with them to talk about their needs, what they want from services and how to put their life back on track. Service users say professional and other staff always seem too busy to support them in the way they want. Service users value the whole-person, whole-life support which they can receive from workers with a specific remit to take a flexible approach based on their individual needs." *Mental Health Policy Implementation Guide: support, time and recovery workers*, DH, 2003

Deaf people struggle to get time with mainstream hearing staff – largely because the clinician cannot sign. Interpreters may be used for 'formal' assessments and meetings, but we know that interpreters are often not booked for day-to-day contact. This can only serve to hinder recovery and exacerbate any feelings of distress.

Deaf STR workers could be of huge value to mainstream hearing services. We recommend that regions augment their 'teams' with additional staff. **STR workers would be an excellent addition by providing a strong link for the Deaf person.** The STR worker would, hopefully, be far more aware of Deaf culture and the Deaf community. This would make them better able to support recovery, as well as bringing unique knowledge and skills to mental health teams.

Key Recommendations

1	The NCG/SCGs decide which commissioning bodies commission which parts of the care pathway. The authors' preference is for 1b & 2c or 2d. (see page 6)
2	Regions co-operate to commission in-patient services – sharing intelligence, auditing together, etc. One SCG could take the lead for this on behalf of its neighbours. This should involve liaison with Scottish and Welsh commissioners.
3	Commissioners in each region need to decide which supra-regional service they partner with – or whether the region divides, with different areas being attached to different units.
4	Regions establish specialists in Deaf mental health. These staff (e.g. CPNs) can advise primary care, work in partnership with mainstream secondary care, and link to their supra-regional service. This network of workers thus provides expertise across the country.
5	SCGs work with PCTs and mental health trusts to examine how local specialists (above) can the augmented. A 'virtual team' is one option. Localised solutions will be possible once the 'core' is in place.
6	SCGs work with their SHA and local trusts in a co-ordinated approach so that the Improving Access to Psychological Therapies programme recognises the needs of Deaf people requiring a therapist.

Conclusions

This report only scratches the surface of commissioning mental health services for deaf people. The best thing for commissioners to do is to visit one of the specialist units. It's only by seeing the actual 'work' that you can get a sense of what the differences and challenges are.

There has never been a better opportunity to establish a framework for commissioning Deaf mental health services. We hope that this report will be a starting point for the debate that is needed. The Deaf commissioning project still has eighteen months to go. We urge all fellow commissioners to use the project to the maximum effect.

Commissioning need not be difficult. Deaf mental health services are not 'new'. We know what the challenges are. We also have a reasonable idea of what can work. All that is needed is the will to make things happen.

This report has not touched upon the standards that should be expected. This will be addressed in a subsequent report. Commissioners will be able to use that to determine whether the services they commission are 'fit for purpose'.

We urge commissioners to address Deaf mental health services now. There are existing services which can be built on. If too much time is lost then this may not be the case.

Appendix One – a possible funding model for specialist in-patient units

As has been explained in the report, all services are currently commissioned using fairly standard purchasing tools and contracts. If standard contracts are used then commissioners must recognise that they may need to be implemented differently for specialised services. For example, when considering tolerances on a cost-and-volume contract, the units are less able to cope with shortfalls in activity and have higher integral costs, e.g. interpreters. As commissioning will be done though SCGs we are confident that commissioners will understand these issues well.

For the meantime we suggest that commissioners have a cost-and-volume contract on a three-year rolling average. This should share the risk among PCTs and provide some protection for providers.

However, we hope that with SCGs working together they will be prepared to explore more radical options. Such options should provide greater stability for the in-patient services to guarantee their protection from activity fluctuations. Obviously if demand were to fall then commissioners would have to consider whether a service remains. But this should be based on the need for the service, rather than a service being hit by two years of low activity, or some other external factor. Designation of services will, hopefully, offer some degree of protection.

Appendix Two – starting from scratch

This section is intended for commissioners and providers who have no specialist Deaf service and want to start taking simple steps towards establishing a service. Most of them are largely cost-neutral and can be implemented differently according to local circumstances. These steps could be taken before any specialist workers are appointed.

Numbers

Most commissioners want to know how many Deaf people there might be with a mental health problem. Patient record systems are not very good at recording this information. As a simple first step, clinicians should be required to log Deaf patient contact onto a central system. This does not need to be an administrative headache. If each trust had one person responsible for keeping the log, then clinicians could simply send an e-mail saying that an episode of care has started with a Deaf person presenting with whatever it might be. The trust then begins to get a better idea of how many people it is dealing with, what they are presenting with, and who has been involved.

We also suggest that commissioners contact their local Social Services Sensory team(s). Social Workers tend to have a far better overview of where Deaf people are and what their needs might be. There is often a great deal of expertise being missed here, and Social Services should be involved in commissioning as much as possible.

Hidden talents

As recommended in the report, trusts should discover what skills may already exist within the workforce. BSL courses are popular and some staff are bound to already have a basic level. Finding out what you have does not cost anything and makes it easier to determine where you are starting from. In the North East we had some extensive Deaf knowledge among existing staff that we were unaware of and was not being utilized.

Interpreting

All trusts should have a contract in place for providing BSL interpreters. However, it is worth checking that a contract does exist and that it specifies that interpreters must be qualified and registered. We often find that BSL interpreting is sub-contracted and the interpreters used may only have Level 2 signing. More information on interpreting can be found at www.cacdp.org.uk and www.asli.org.uk . Also refer to the new Mental Health Act Code of Practice.

An even bigger obstacle is that staff are unaware that there is a contract for BSL interpreters. This is an issue which arose in the Sarwat Al-Assaf homicide Inquiry. All staff (clinicians and administrators) should be regularly reminded of the contract and the booking procedure. Again, this costs nothing.

Establish a link with local Deaf people

The Disability Equality Duty requires health trusts to consult and engage with disabled and Deaf patients. In our experience, very few have made contact with Deaf groups. You may decide that all CMHTs must have a textphone (minicom), only to discover that more Deaf people would rather use SMS. Involving Deaf people need not cost anything, could save money, and will go some way to satisfying the Disability Equality Duty.

Appendix Three – why mental health services for Deaf people are 'special'

Most specialised commissioners will probably be aware of why mental health services for Deaf people are considered a 'specialised service'. This section provides a brief explanation for those that are new to the field.

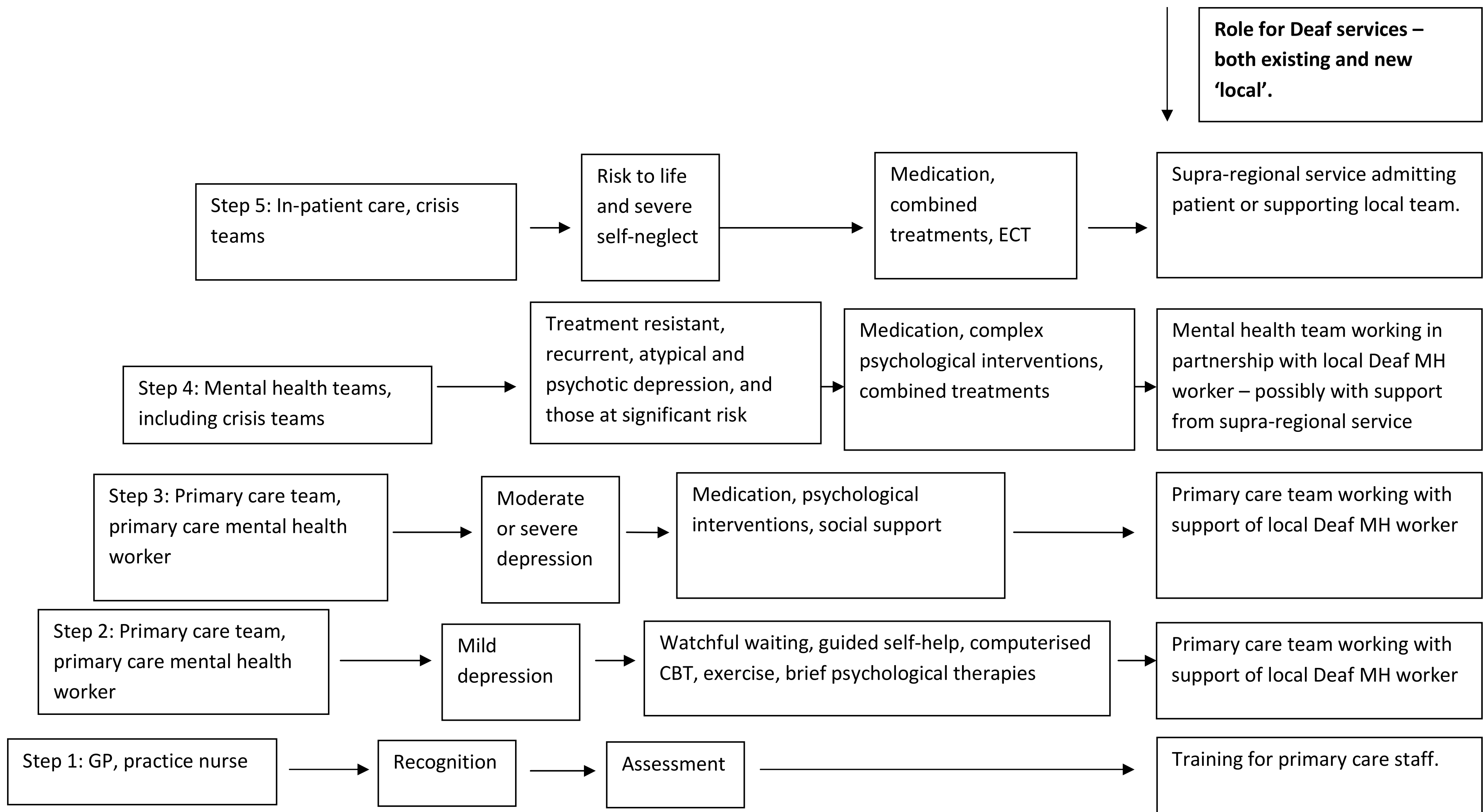
In commissioning terms, mental health services for Deaf people have a small planning population. This means it is fruitless for each PCT to try and commission a service separately. Indeed, for some Deaf mental health services, commissioning needs to be supra-regional.

But why just mental health, why not physical health? The simple answer is communication. In mental health communication is vital. If you break your leg and see a doctor there is some communication but, for the most part, the doctor is quite clear what the problem is and what needs to be done. Communication makes the process smoother (and more pleasant) but does not normally affect the treatment.

With mental health, communication is far more central. A clinician needs to be able to understand what a patient is signing and put that in a cultural context. Treatment can depend on establishing a strong therapeutic relationship. This is obviously very difficult if people are not communicating in the same language.

In addition to the communication, there are also cultural issues which specialist clinicians will be aware of. For example, if a Deaf person came up behind you and touched you on the shoulder to get your attention this may seem 'odd' to a hearing professional but quite normal for a Deaf specialist. Similarly, an experienced clinician will spot differences in signing that would be lost with straight interpreting, e.g. how is the signing delivered.

Appendix Four – possible stepped care approach (based on NICE clinical guidance)



Fragment from a possible pathway

Deaf person visits GP	GP has had basic Deaf Awareness training and is able to make the most of the appointment by using an interpreter, and allowing more time for the consultation. Discusses referral to CMHT.
Deaf person assessed by CMHT	Referral from GP highlights that the person is Deaf. CMHT contact Deaf CPN who works in a neighbouring CMHT. CPN joins the CMHT for the assessment.
Deaf person offered programme of support	CMHT happy to provide a service with support and advice from the Deaf CPN.
Clinical psychology assessment indicated	Deaf CPN contacts Deaf clinical psychologist who works elsewhere in the region. Specialist clinical psychologist joins local clinical psychologist for assessment.
CMHT refer to supra-regional service for in-patient assessment	Deaf CPN has good links with the supra-regional service and this makes the short admission far easier to arrange. Patient is quickly assessed and returns home.

Appendix Five – the Sponsoring Group

The Sponsoring Group oversees the work of the Deaf mental health services commissioning project. The following people are members of the Group or invited to meetings:

Beverley Humphries	Chief Executive	Greater Manchester West Mental Health Trust
Peter Houghton	Chief Executive	St. George's & South West London Mental Health Trust
Sue Turner	Chief Executive	Birmingham & Solihull Mental Health Trust
Mary Kearney	Commissioner Manager – Specialist Mental Health	Richmond & Twickenham PCT (representing London Specialised Commissioning team)
Carole Jobbins	Director of Mental Health Commissioning	North West Specialised Commissioning team
Mary-Ann Doyle	Director of Mental Health Commissioning	West Midlands Specialised Commissioning team
Rosemary Granger	Director of Mental Health Commissioning	North East Commissioning Team for Learning Disabilities & Mental Health (hosted by County Durham PCT)
Matthew James	Lead for Commissioning Model Development	Director of Mental Health Commissioning North East Commissioning Team for Learning Disabilities & Mental Health (hosted by County Durham PCT)
Steve Powell	Chief Executive	SignHealth
Dr Nick Kitson	Consultant Psychiatrist	Cornwall Partnership Trust
Ann Bristow	Director of Sensory Services	Association of Directors of Social Services (ADSS)
Paul Farrell	Commissioning Manager	East Midlands Specialised Commissioning team

Carole Theobald	Director of Mental Health Commissioning	East of England Specialised Commissioning Team
Bruce Dickey	Operational Director for Specialist Services	Northumberland, Tyne & Wear NHS Trust
Bob McDonald	Senior Adviser	Department of Health