The Valued People Project: Report of a strategic review of educational commissioning and workforce planning in learning disabilities.

Bob Gates.
October 2009.
## Executive Summary

### 1 BACKGROUND

1.1 Background to the ‘VPP’  
1.1 Defining learning disability  
1.2 Incidence and prevalence of learning disability  
1.3 Demographic changes and challenges for the wider health economy  
1.4 Health issues and people with learning disabilities  
1.5 Service configurations and workforce issues  
1.6 Summary

### 2 LEARNING DISABILITY SERVICES

2.1 The landscape of South Central SHA  
2.2 Types of learning disability services  
2.3 The learning disability workforce - overview  
2.4 Challenges facing NHS specialist learning disability services  
2.5 Challenges facing NHS mainstream services  
2.6 Summary

### 3 THE VALUED PEOPLE PROJECT

3.1 Working methods  
3.2 The Steering Group  
3.3 The Reference Groups  
3.4 The postal questionnaire of ‘Local Partnership Boards’  
3.5 Summary
4 THE LEARNING DISABILITY WORKFORCE
4.1 Training 40
4.2 The current student profile 41
4.3 Employment 42
4.4 The current specialist learning disability NHS workforce 44
4.5 Challenges for the wider NHS workforce 48
4.6 Summary 49

5 A NEW WORKFORCE FOR THE FUTURE
5.1 New roles and new challenges for the 21st Century 51
5.2 A new model for education commissioning 53
5.3 A Regional Academy - A Centre of Regional excellence 53
5.4 Modernising learning disability nurse education 54
5.5 A need for a new practitioner 55
5.6 Summary 57

6 RECOMMENDATIONS 59
7 REFERENCES 60
8 APPENDICES 63
EXECUTIVE SUMMARY

The ‘Valued People Project’ commenced in May 2008 and has been undertaken as a consequence of an initial meeting of regional key stakeholders who had articulated concerns regarding education commissioning of pre-registration learning disability nursing, and concerns for the specialist learning disability health workforce more generally. A subsequence of that meeting was an articulation of an urgent need to undertake a strategic review of the educational commissioning process of, and attend to workforce planning issues in, learning disabilities in South Central SHA. This was because of the scale and cumulative effect of changes to education, workforce, professional regulation and central health and social care policy that has affected people with learning disabilities and the services and personnel that support them. This strategic review has been undertaken to;

- map the range and extent of services and service providers across South Central SHA,
- establish an evidence base that will support a strategic approach to future educational commissioning in learning disability,
- establish how learning disability staff are deployed [with the possibility of the development of a new learning disability practitioner for health and social care],
- articulate a flexible learning and development framework that supports the career framework for staff who work with individuals with learning disabilities,
- develop an educational model that will ensure that all education programmes commissioned by SCSHA will have incorporated key competencies related to caring for individuals with learning disabilities,
- develop a communication strategy to inform services and practitioners of ongoing work and outcomes.

The project has adopted a structured multi-method approach to systematically generate robust evidence using a number of data sources to inform education commissioning and plan future workforce requirements. These data sources have included; postal questionnaire survey, semi-structured interviews, focus groups and analysis of relevant literature and policy documentation, and desk top research. The project has been overseen by an expert strategic steering group, and has also been informed by reference groups, comprising people with learning disabilities, parents and family carers, commissioners of services and education, service managers from health and social care as well as third sector, learning disability practitioners, and academic staff from Higher Education Institutions and students from Higher and Further Education Institutions, ensuring that there has been the widest possible consultation with key stakeholders.

This report is submitted with the full support of a range of stakeholders, and as such provides South Central SHA with a unique expert evaluation for the future strategic direction of education commissioning and leadership for workforce issues in specialist learning disability services, as well as the wider workforce of the NHS. The steering group recommends that South Central SHA should;

- develop a recruitment strategy to significantly increase the number of entrants to pre-registration learning disability nursing, and that this strategy be aligned to the modernising nursing careers work currently being undertaken at the DOH,
- provide a specific career advice facility for existing learning disability staff within the NHS and those wishing to join, and or move into other sectors,
• provide ‘high visibility’ clinical leadership for specialist NHS Learning Disability NHS staff who are experiencing unprecedented changes to their roles and contexts of service delivery,

• commission a ‘learning resource’ immediately for the wider NHS workforce but specifically for all ‘front line’ NHS staff to better understand the needs of people with learning disabilities.

• monitor the education, training and outcomes in improved services of NHS staff in respect of; learning disability awareness, communicating with people with learning disabilities, Human Rights, Disability Discrimination, Capacity to Consent, as well as best interest decision making and making reasonable adjustments, using the expertise of people with learning disabilities and or their families as well as specialist learning disability NHS staff.

• inform the existing HEIs currently holding pre-registration learning disability nursing commissions within their contracts of its intention not to renew the existing contractual arrangements,

• develop a specification for a competitive tendering process for a new ‘model of learning disability education commissioning’, based on the development of a South Central SHA resource of excellence1 for all pre and post registration specialist health learning disability education. Such a resource will be based on a commercial model of education delivery, with research and consultancy capacity and will be based on an academic partnership model between key stakeholders.

• ensure that educational commissioning decisions for pre-registration learning disability nursing in the future are better informed by contemporary key stakeholders, and that in the short term the numbers commissioned annually should be maintained at a ‘steady state’ and should not fall below ~ 60 students.

• require the ‘Valued People Projects’ brief, remit and plan be revisited and strengthened for a ‘next stage’ project proposal and that this should be submitted alongside the final report to the South Central SHA Board by the end of 2009, for new work streams to commence from January 2010.

Bob Gates, and the Steering Group of the Valued People Project
October 2009

1 A working title might be the South Central Academy in Learning Disability. [SCALD]
1 BACKGROUND

This section presents the background to the Valued People Project; it offers definitions of learning disability, and explores some of the implications of the incidence and prevalence of learning disabilities, and points to the demographic changes that are occurring in this population. It outlines the significant health burden that some people with learning disabilities face, and introduces some of the impacts these issues will have on specialist and mainstream services as well as the NHS workforce. The educational implications of these impacts for South Central SHA will be further explored in depth in subsequent sections of this report.

1.1 Background to the ‘VPP’

The ‘Valued People Project’ commenced in May 2008 and has been undertaken as a consequence of an initial meeting of regional key stakeholders who had articulated concerns regarding education commissioning of pre-registration learning disability nursing, and concerns for the specialist learning disability health workforce more generally. A subsequence of that meeting was an articulation of an urgent need to undertake a strategic review of the educational commissioning process of, and attend to workforce planning issues in, learning disabilities in South Central SHA. This was because of the scale and cumulative effect of changes to education, workforce, professional regulation and central health and social care policy that has affected people with learning disabilities and the services and personnel that support them. This strategic review has undertaken to:

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academic staff from Further and Higher Education Institutions ensuring that there has been the widest possible consultation with key stakeholders (NHS Workforce Review Team 2007).

1.2 Defining learning disability

Use of the term ‘learning disability’ is relatively new in the UK. In the past other terms have been used such as ‘mental handicap’ but these have now been replaced because they were seen as unacceptable, and in many cases derogatory in nature. It should be noted that some people with learning disabilities prefer the term ‘learning difficulties’ to be used, but for the purposes of this report learning disability has been adopted as its usage is common and relatively well shared in meaning. Generally speaking in the UK the term learning disability is now widely used, and this is accepted to mean:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with,
- a reduced ability to cope independently (impaired social functioning) and,
- which started before adulthood, with a lasting effect on development. (DOH 2001: 14)

Historically learning disability has been divided into a number of categories that were intended to reflect its nature and extent. These tended to range from ‘borderline’ through to ‘mild’ ‘moderate’ and severe to ‘profound’, generally these have been based on measured intelligence.

This represents one understanding of learning disability, the medical model, but there are others for example the social model. The medical model uses the World Health Organization classification system that uses the degree of disability (‘retardation’) according to how far an individual Intelligence Quotient [IQ] is from the normal distribution of IQ for the general population. Using this system, an individual who consistently scores more than 2 Standard Deviations (SD) below the mean on an IQ test, that is, a measured IQ of <70, is said to have learning disabilities. Individuals whose IQ is 50–69 are generally identified as having mild learning disability (F70); those with an IQ of 71–84 are said to be on the borderline of intellectual functioning; moderate learning disability (F71) is identified when the IQ is 35–49; the term ‘severe mental retardation’ (F72) is reserved for people whose IQ is 20–34; finally, the term ‘profound mental retardation’ (F73) refers to those with an IQ of <20.

Many now view learning disability in different ways, and this has important implications for strategic planning for personnel from health and social care to ensure that language chosen and used is shared in meaning. For example, some approaches are now based on a model of learning disability that sees it as an interaction between the person, the support they receive and the environment they are located in. See figure.1.1
**Basic Abilities**
- Processing, remembering,
- thinking through, learning,
- deciding and communicating

**Support**
- What support is needed to cope with everyday life?

**Environment**

What environment helps the person to cope with their Disabilities and what opportunities need to be provided?

**Figure 1.1** After: American Association for Mental Retardation, (2002) Mental Retardation, definition, classification and systems of support. 10th Ed. AAMR. Washington.

Assessment of the degree of learning disability will identify the level of support a person needs as well as the kind of environment and opportunities that they need (American Association for Mental Retardation, 2002). There is a system for categorising the amount of support people need on 4 levels;

- **Intermittent** - this is time limited support at key times in life such as loss of key relationships or transition.
- **Limited** - consistent need of support for specific tasks such as employment training but still time limited.
- **Extensive** - Regular long term direct support in at least one setting.
- **Pervasive** - Constant support high intensity support across all settings.

Having identified the type of support required this is then further informed by an assessment of the kind of environment a person needs, along with the opportunities important for them to lead healthy and personally meaningful lives. The next section moves on to discuss issues of incidence and prevalence of learning disabilities relevant to this project and the business of South Central SHA.

### 1.2 Incidence and prevalence of learning disability

Calculating the incidence of learning disabilities is difficult because there is no way of detecting the vast majority of those infants who have learning disabilities at birth. Therefore, to arrive at any estimate one has to use cumulative incidence and this has been calculated at 8yrs of age as 4.9 children with severe and 4.3 for mild learning disabilities.
disabilities per 1000 live births. It is only the obvious manifestations of learning disabilities that can be detected at birth for example, Down’s syndrome, and for these conditions it is possible to calculate incidence.

It is more usual, therefore, to refer to the prevalence of learning disability, because where there is no obvious physical manifestation at birth, diagnosis must be delayed in order to await significant developmental delay, along with other manifestations to diagnose learning disabilities; therefore, for this project it is more helpful to consider prevalence. Prevalence is concerned with an estimation of the number of people with a condition, disorder or disease as a proportion of the general population. If IQ is used as an indicator of learning disability, then it can be calculated that 2 - 3% of the population is likely to have an IQ <70. However, calculating prevalence is yet again problematic this is because a large proportion of the people with such an estimated IQ may only occasionally or never come into contact with caring agencies, consequently it is more common to refer to ‘administrative prevalence’; this is the number of people who are provided with some form of service from caring agencies. Emerson, et al, (2001) drawing on extensive epidemiological data, have confirmed the estimation of prevalence for severe learning disabilities. They state it to be somewhere in the region of 3 - 4/1000 of the general population. In the UK it has been further calculated that, of those with severe learning disabilities approximately 30% of these will present with multiple disabilities, including physical and, or, sensory impairments, or disability as well as behavioural difficulties. However, the prevalence rate given for the learning disabled population referred to as having mild learning disabilities is much more imprecise (Emerson et al, 2001). It is estimated that it might be 25 - 30 people/1000 of the general population.

Based on these estimates it can be assumed that there are some 230,000 - 350,000 persons with severe learning disabilities, and possibly 580,000 - 1,750,000 persons with mild learning disabilities in the UK. There is a slight imbalance in the ratio of males to females in people with both mild and severe learning disabilities, with males having slightly higher prevalence rates. Also there is some evidence of slightly higher prevalence rates among some ethnic groups, and this includes Black Groups in the USA, and South Asian Groups in the UK (Emerson et al, 2001).

And further that based upon these universally agreed prevalence rates for learning disabilities it is likely that within the geographical area of South Central SHA there are some ~ 16, 000 people with severe learning disabilities, ~ a third of this group about 5, 000 people will have multiple disabilities; physical and, or, sensory impairments, or disability as well as challenging behaviour. A further ~ 120, 000 will have mild learning disabilities. Therefore a total of ~ 136, 000 people with learning disabilities reside within the counties comprising South Central SHA, and of particular interest to the Health Authority should be the predicted growth in prevalence in learning disabilities, along with the changing complexity of need that some people with learning disabilities will present with, and these are discussed in the next section.
1.3 Demographic changes and challenges for the wider health economy

There is now a sufficient evidence base to conclude that because of health advances, the number of children with profound learning disabilities and associated complex needs are now surviving into adulthood, and this number is predicted to grow (DOH, 2001, Emerson, 2009). This in effect means that not only is the prevalence of learning disabilities increasing, but that these people will present, in the immediate to near future, many complex challenges both to services and the workforce supporting them; both specialist and mainstream. Some recent studies are showing unprecedented increases in the number of people with learning disabilities along with complexity of health and social care need. For example, a recent study in Sheffield (Parrott, Tilley and Wols tenholme, 2008) has pointed to a 25% increase in the number of people with a learning disability, and the number of children and young people with profound and multiple learning disabilities has increased by nearly 120%. A more recent and wider epidemiological estimate has been undertaken, and this has calculated that during the period 2009 - 2026 there will be an annual increase of 1.8% in the numbers of adults with profound and multiple learning disabilities. This would mean for an average area in England, with a population of 250,000, that the number of adults with profound and multiple disabilities will increase from ~78 in 2009 to ~105 in 202, and that the number of young people becoming adults in any given year will rise from ~ 3 in 2009 to ~ 5 in 2026 (Emerson, 2009).

Further it has previously been estimated that between 2001 and 2021 there will be a:

- ‘10% increase in the number of adults with learning disabilities known to services.
- 36% increase in the number of adults with learning disabilities aged 60+ who are known to services.
- 14% increase in the total number of adults with learning disabilities in England.
- 38% increase in the total number of adults with learning disabilities aged 60+ in England.’ (Emerson and Hatton, 2004)

In addition to the above, this increase in prevalence of people with learning disabilities can also be accounted for by an increase in young people from South Asian minority ethnic communities (Emerson and Hatton, 2008). Another contributing factor to this increase can be apportioned partly to the reduced mortality in the older age group which inevitably will lead to an increase in the ‘older’ population of people with learning disabilities. With this growing population of older people with learning disabilities will be people with increased risk of early onset dementia such as those with Down syndrome.

1.4 Health issues and people with learning disabilities

People with learning disabilities are 58 times more likely to die before the age of 50 than that of the general population; some of these deaths are avoidable (Michael, 2008). Up to one third of people with learning disabilities have epilepsy - 20 times greater than that of the general population, up to one third will have an associated
physical disability - commonly Cerebral Palsy - with attendant health challenges that includes; postural deformities, hip dislocation, chest infections; Dysphagia, gastro-oesophageal reflux, constipation and incontinence. Mental ill health is also more common in both adults and children and co-morbid conditions such as Autistic Spectrum Disorder and Attention Deficit Hyperactivity Disorder are more common. But by way of contrast we know, for example, that people with learning disabilities have a higher uptake of medical and dental services, but a lower uptake of surgical specialities, similar overall rates of admission, but shorter stays. People with learning disabilities and diabetes have fewer measurements of BMI compared with the general population, those who have strokes had fewer blood pressure checks, and cervical screening and mammography are less likely to be undertaken. Finally, people with learning disabilities are less likely to be given pain relief, and people with learning disabilities are less likely to receive palliative care (Michael, 2008).

There is irrevocable evidence that people with learning disabilities have higher levels of health need than that of the general population, many of which are unmet. As if to underline the scale of this difference the Department of Health has now developed ‘The Learning Disability Health Needs Annual Evidence Update’ that provides evidence summaries and bibliographies of published research for some of the key health issues concerning people with learning disabilities that includes; cancer, challenging behaviour, coronary heart disease, epilepsy, respiratory illness and visual impairment. In addition they acknowledge that some people with learning disabilities do not seek out support from the healthcare system unaided, and that healthcare issues can remain undiagnosed or untreated and as a consequence they have recently updated good practice guidance on Health Action Planning and Health Facilitation.

A recent review of research literature concerning access to secondary health care for people with learning disabilities has identified that that a range of factors influence the experience of NHS care for people with learning disabilities. These include amongst others, the carers role, attitudes, and knowledge and communication style of health staff as well as issues surrounding the physical environment (Backer, 2009). Clearly, as will pointed out in section 2.5 much needs to be done in relation to developing the wider NHS workforce if the vision of South Central SHA; ‘Improving health and alleviating the causes of poor health for the benefits of patients, the public and taxpayer alike in Berkshire, Buckinghamshire, Oxfordshire, Hampshire and the Isle of Wight’; is to be realised for people with learning disabilities.

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2 [www.library.nhs.uk/learningdisabilities](http://www.library.nhs.uk/learningdisabilities)

3 [http://valuingpeople.gov.uk/dynamic/valuingpeople142.jsp](http://valuingpeople.gov.uk/dynamic/valuingpeople142.jsp)
1.5 Service considerations and workforce issues

It is known that people with learning disabilities experience of mainstream health services is not acceptable (DRC, 2006, Mencap, 2007, Michael Report 2008, Parliamentary and Health Ombudsmen, 2009); making it essential for the future commissioning of all health education to incorporate ‘key competencies’ in caring for this vulnerable group of people. In addition the current and future workforce, whether health or social care staff, supporting people with profound learning disabilities and complex needs will need to be competent in; breathing and airways management, managing eating problems, managing epilepsy, mobility issues, and pressure care management and continence issues. These coupled with new demands on services that will occur as a result of the Bradley Report (2009), who has recommended the development of criminal justice liaison teams and a teaching role for specialist learning disability teams, and an expansion of responsibility for PCTs to now include health care whilst in police care as well as prison health care, will all make additional and significant demands on the specialist NHS learning disability workforce. It is worth noting that different types of mainstream services report on difficulties in meeting the needs of this client group for example in Mental Health (Gibson, 2009), Acute District General Hospitals, (Backer, 2009), Children’s services (Avis and Reardon, 2008), Community services - for people who engage in anti-social or offending behaviour (Wheeler et al 2009), and particularly those with profound and multiple learning disabilities (Dawkins, 2009).

It seems likely that issues around accessing health and health challenges, challenging behaviour, forensic issues, mental health problems, Autistic Spectrum Disorder [ASD] as well as people with very complex health and social care needs will continue to challenge the NHS and the wider health and social care economy.

1.6 Summary

To summarise the increase in prevalence of, and the associated changes to complexity of need of some people with learning disabilities, and the unprecedented demands that this will make on both health and social care services means that South Central SHA needs to urgently address not only the specialist NHS learning disability workforce, but also staff in the wider NHS workforce.

Therefore, and because of the now complex landscape of service provision, to be outlined in the next section, South Central SHA will need to proactively collaborate with all its partners in health and social care to ensure that the NHS specialist learning disability workforce is modernised and skilled, and has sufficient capacity to meet the needs of people with learning disabilities who will continue to use specialist NHS services. Also, the wider NHS health staff will need to be adequately prepared to meet the needs of people with learning disabilities in all NHS care settings, and that they are aware of, and are able to make reasonable adjustments for their inclusion, ensuring that their rights are upheld, and that they are not discriminated against because of their disability. And in particular specialist learning disability NHS service provision and the specialist learning disability workforce will need to be able to accommodate the significance of and implications of both the personalisation agenda and personal budgets for health and social care.
2 LEARNING DISABILITY SERVICES WITHIN SOUTH CENTRAL

In this section the landscape of South Central SHA is presented along with a descriptor of learning disability services and providers, an estimation of the numbers of people with learning disabilities within the geographical area, and issues around the workforce both in specialist learning disability services and mainstream services are explored.

2.1 The landscape of South Central Strategic Health Authority

NHS South Central covers the counties of Berkshire, Buckinghamshire, Oxfordshire, Hampshire and the Isle of Wight. It runs from Banbury and Milton Keynes at its northern edge down to the Isle of Wight in the south (See Figure 2.1). There are twenty four NHS organisations in the South Central region that provide healthcare to around four million people across 10,000 sq km. The total budget of NHS South Central is £5bn, and this is used to provide primary and secondary healthcare services to the public. Helping to achieve this are more than 88,000 staff who work throughout the local NHS -approximately 5% of the working population - making the NHS one of the largest employers in the South Central area.

Figure 2.1 Constituent Counties of South Central strategic Health Authority

Within the counties comprising South Central SHA lays a complex landscape of service provision for people with learning disabilities. In section 1 of this report it was shown that it is likely that there are ~16,000 people with severe learning disabilities, ~ a third of this group ~ 5,000 people will present with multiple disabilities; physical and, or, sensory impairments, or disability as well as challenging behaviour. A further ~ 120,000 will have mild learning disabilities. Excluding out of county provision most of these people, ~ 136,000, will reside within the counties of South Central SHA, and all of these people are entitled to the same aspiration held by South Central SHA that of; ‘Improving health and alleviating the causes of poor health for the benefits of patients, the public and taxpayer alike in Berkshire, Buckinghamshire, Oxfordshire, Hampshire and the Isle of Wight’; but we know that they are not (Michael 2008, Parliamentary and Health Ombudsmen, 2009). To address this a number of interrelated projects have been commissioned by the
Health Authority, and these include this project ‘The Valued People Project’, along with the Quality, Equity and Disability \[QEDS\] Programme that incorporates three projects; Care of people with learning disability in the acute care setting, learning disability NHS Provision and community based services. These three interlinked projects share a common purpose - to improve the experiences of people with learning disabilities as they interact with the statutory organisations, but particularly that of health, that provide care and support or services to them.

2.2 Types of learning disability services

Despite the final closure of the last long-stay learning disability hospital in England, some NHS residential care provision, known as ‘residential campuses’, has remained (Mair, 2009). Generally speaking this type of provision retains nursing and medical staff, and therapists, and provides a specialist focus of care. This type of residential provision, when compared with others such as, village communities and dispersed housing schemes, has failed to uniformly demonstrate quality service, and there appears to be no easy answer to explain why. In England since the publication of ‘Valuing People’ (DOH, 2001) there has been a sustained move away from NHS dominated residential service provision, and this range of services has all but been replaced with an array of service providers and provision. Services comprise care homes, independent living, supported living, as well as people with intellectual disabilities living in their own homes and family homes, employment schemes and day service configurations [many of the latter are currently being ‘modernised’]. However, there remain larger service configurations, and very specialist settings, such as treatment and assessment services and challenging behaviour units, as well as specialist health or social care settings, such as homes for older people and hospices providing care for children with life limiting conditions, or respite services for children with complex health or social care needs. There are also very complex service arrangements that involve a range of agencies that includes; the statutory sectors [NHS and Local Authorities], private and an independent sector along with the voluntary sectors - the latter also includes the provision of intentional communities. Excluding the NHS and private health care there are a number of establishments that provide services to people with learning disabilities. And as can be seen in figure 2.1 it is the case that the voluntary sector is a significant provider of services for adults with learning disabilities than in other areas, such as care for older people.

<table>
<thead>
<tr>
<th>Establishment type</th>
<th>Any adult services</th>
<th>Adults with learning disabilities</th>
<th>All NMDS-SC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statutory local authority</td>
<td>9%</td>
<td>9%</td>
<td>15%</td>
</tr>
<tr>
<td>Private sector</td>
<td>48%</td>
<td>45%</td>
<td>58%</td>
</tr>
<tr>
<td>Voluntary or third sector</td>
<td>37%</td>
<td>41%</td>
<td>22%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
<td>6%</td>
<td>4%</td>
</tr>
<tr>
<td>Not recorded</td>
<td>&lt;1%</td>
<td>&lt;1%</td>
<td>1%</td>
</tr>
<tr>
<td><strong>Base (all establishments)</strong></td>
<td>7,518</td>
<td>3,412</td>
<td>24,130</td>
</tr>
</tbody>
</table>

Figure 2.1 Establishments providing social care. From Skills for Care – (NMDS - SC briefing issue 10 - Adults with learning disabilities, 2009)
Specifically concerning current service provision in the geographical boundaries of South Central SHA this essentially comprises a single speciality learning disability NHS Trust, Mental Health Trusts and a range of private, voluntary and not for profit national and local providers of health and social care. In general terms NHS services for people with learning disabilities has become increasingly more ‘specialised’, and now almost exclusively provides services to meet the needs of people with;

- behaviour that challenges [DOH - The Mansell Report 2007] or who have,
- mental health needs or,
- Autistic Spectrum of Disorders or,
- forensic backgrounds [DOH - The Bradley Report 2009], or finally those with,
- profound and, or, complex learning disabilities [Emerson, 2009].

Over the last year the ‘VPP’ has commenced a scoping exercise documenting the range and extent of service provision and providers across the region. It was initially thought that this might be a relatively straight forward exercise using a range of sources such as the National Minimum Data Set (Skills for Care [SfC]), or Commissioners of services lists of providers, or the newly constructed Care Quality Commission [CQC] data base, but it has been found that often these data bases are often incomplete and, or, conflate learning disabilities with a range of other services, often making it difficult to extrapolate specific learning disabilities services and service users, and the skills of the workforce in supporting the wide range of needs of people with learning disabilities. A general overview of the main types of social care provision is provided in a recent publication from SfC is provided at Figure 2.2.

Concerning the overall and specific types of services provided within South Central SHA that have been identified, these are presented in tabular format in appendix 8.14. In order to generate this data the CQC web-site was accessed then the ‘Find a Care Service’ tab was selected. Next ‘Social Care’ was selected and then the following filters were added; ‘Learning Disability’ and the ‘Local Authority’ [in the case of Berkshire this had to be accessed six times one for each of the Unitary Authorities]. From all of the service providers and services offered results have been collapsed into social care homes, and social care homes with nursing, and then these are further sub-divided into Learning Disability, Learning Disability and Physical Disability, or Learning Disability and Dementia, and Old age. The same procedure was adopted for independent hospitals, although once again, the procedure was made problematic, as they are all classified as ‘mental health’. In reference to these independent hospitals five were returned in each of the Counties in South Central SHA. However, on closer examination of those returned, it was found that a number of them were either outside of the named county, outside the geographical boundary of South Central SHA, or were duplicated elsewhere; therefore these have been excluded from the tables. Finally, also incorporated in appendix 8.14 are the NHS specialist LD providers along with the services they provide.

Although not exhaustive and clearly, as with any data base, this information will have a ‘short shelf life’, nonetheless it does provide a comprehensive overview of learning disability services, and service providers within the geographical area of South
Central SHA, and does meet one of the original aims of this project Viz ‘map the range and extent of services and service providers across South Central SHA’. Also it will be possible for this data to be further developed following publication of this report, and therefore it will be made electronically available through the Authorities shared drive, to the South Central SHAs’ ‘Quality, Equity and Disability Programme’ consultancy managers.

<table>
<thead>
<tr>
<th>Main service group</th>
<th>Any adults services</th>
<th>Adults with learning disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care home without nursing or care only</td>
<td>49%</td>
<td>56%</td>
</tr>
<tr>
<td>Any other adult residential care service</td>
<td>17%</td>
<td>16%</td>
</tr>
<tr>
<td>Domiciliary care or home care</td>
<td>9%</td>
<td>12%</td>
</tr>
<tr>
<td>Any day services</td>
<td>6%</td>
<td>5%</td>
</tr>
<tr>
<td>Any adult community care service</td>
<td>8%</td>
<td>5%</td>
</tr>
<tr>
<td>Care home with nursing</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Any other adult domiciliary care service</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
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Figure 2.2 Main service provision in social care. From Skills for Care – (NMDS - SC briefing issue 10 - Adults with learning disabilities, 2009)

2.3 The Learning Disability Workforce - Overview

The majority of those who work with, and or support individuals with learning disabilities are non-professional staff who may possess a range of qualifications specific to their role for example National Vocational Qualifications at levels 2 or 3. Some who are in managerial or supervisory positions will have attained a National Vocational Qualification at level 4, this being the minimum requirement to be a Registered Care Home Manager with the Commission for Social Care Inspection, now the Care Quality Commission (CQC).

Following publication in England of the White Paper for learning disability, ‘Valuing People’ (DOH, 2001) a new vocationally based qualification the ‘Learning Disability Award Framework’ [LDAF] was developed specifically to address workforce issues; this was largely in response to estimates that only 25% of the social care workforce had any form of qualification (TOPPS, 1999). Whether this new award has addressed workforce issues in learning disability services is not known, as there has been no independent scrutiny of either the development of social or health care workforce issues in leaning disabilities - indeed it was this absence of scrutiny that prompted the VPP so that South Central SHA was better placed to make strategically informed decisions about workforce planning that might positively impact on the health and well being of this group of people.

Notwithstanding this a recent publication from SfC does provide some useful data concerning the social care workforce for adults with learning disabilities (NMDS - SC briefing issue 10 - adults with learning disabilities, 2009). Their data suggests that

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4 This is now the Learning Disability Induction Award - LDIA (Skills for Care, 2008).
this workforce has more men, better pay and they are more likely to hold to relevant qualifications when compared with NMDS-SC overall workforce data. Establishments are more likely to be from the voluntary sector and have lower turn over rates although they have higher vacancy rates 4.5% compared with 2.6% in services for older people - suggesting that attracting staff into this area of care provision is potentially problematic. Some of the assertions contained within this document however, do require further secondary and independent analysis as original data descriptors are not present, so whereas as an example it talks of this workforce being better qualified - we do not what qualifications these are nor when they were obtained.

Workforce, specifically the social care workforce, remains a high priority (Valuing People: Now, 2009) with new knowledge sets being developed by Skills for Care, however, whether these will provide sufficient knowledge, skills and competence to respond to the complexity of need for some people with learning disabilities is not known, although anecdotal evidence obtained during the field work of this report suggests not [see section 3.4]. Within the recently published Valuing People Now (2009) it was disappointing to note that little attention was paid to workforce issues, and no mention at all was made of the specialist NHS learning disability workforce. Interestingly though a recent written response to the NHS Workforce Review Team - Assessment of Workforce Priorities Summer 2009 by members of the Valuing People Team has identified a number of workforce issues of concern and these included;

1. ‘We welcome the reference in the context section of the document to Valuing People Now and a Life Like any Other?, there a number of other recent documents that should have been added including Six Lives: the provision of public services to people with learning disabilities (the Ombudsman Report 2009), Key action for making Valuing People Now happen locally and regionally – PCT and SHAs 2009 -2012 (DH 2009) and subsequent letters to SHA leads and LA and PCT CEO on health issues. We are very concerned and disappointed that there is no further mention of the workforce implications of providing high quality healthcare to people with learning disabilities and family carers in any other part of the document. It is essential to add these to the priorities to be able to fully comply with the Ombudsman’s requirements of the NHS.

2. That the DH guidance on the role of the learning disability nurse is full considered in the review of both pre and post registration nurse training. There is a real concern that in the future there will be insufficient trained and qualified specialist professionals to meet the needs of people with learning disabilities in both primary and secondary healthcare.

3. That in the future clear career pathways are identified with the necessary fit for purpose qualifications and course available for non professional and professional workers who support people with learning disabilities

4. That a stronger emphasis is placed on all frontline NHS primary care workers e.g. midwives, health visitors, A and E staff, OT etc having human rights and disability awareness training in particular learning disability awareness training delivered by people with learning disabilities and family carers
5. We are concerned that poor practices at all levels of the NHS workforce that were identified in the Healthcare Commission investigations and audits in 2006 and 2007 and in the joint reviews of 2008, have not been fully addressed. These workforce issues include a lack of competence in governance, commissioning, clinical leadership, first line managers etc.

6. In many parts of the country people with learning disabilities and family carers say that access to specialist NHS staff such as speech and language therapists, occupational therapists, clinical psychologists is very limited. This should be investigated and the necessary measures taken to ensure this is addressed. The population of people with learning disabilities will increase over the next 20 years and this needs to be factored into all planning arrangements.’ (Carmichael, Poynter, Mycock, and Barcham, 2009)

Concerning item 3 of this response it is both interesting and important to note the ongoing work in this area by Skills for Care where a range of web pages has been developed for people considering a career in social care, as well as those already working in social care. The web pages depict the career development opportunities there are, and use both text and video to explain, ‘what is social care?’, ‘starting in social care’ and ‘developing your career’. Under ‘developing your career’ there is an interactive career pathways matrix. This enables the enquirer to match their social care interests against job ‘levels’ to identify roles that they could move into, and to find out the kinds of qualifications needed for those roles. Skills for Health are also exploring the feasibility of undertaking a scoping exercise in learning disability to establish whether there is need to undertake work concerning career pathways in health for learning disability. Clearly, any work stream at South Central SHA to arise out of this report [see recommendations 1 and 2] should acknowledge this ongoing work, as well as that of the Programme Director for modernising nursing careers at the DOH, and ensure that a collaborative approach with Skills for Care and Health and the DOH be adopted to build on the excellent work already undertaken.

Workforce issues will continue to be crucial to the successful implementation of ‘Valuing Peoples’ (DOH, 2001) original intention of ensuring that this group of people are an integral part of the;

‘NHS Plan to a person-centred health service which challenges discrimination on all grounds [that] will improve health care for people with learning disabilities. Good health is an essential prerequisite for achieving independence, choice and inclusion.’ (DOH, 2001, 59-69).

It should, therefore, be of concern that such little attention is seemingly being paid to the development of the NHS workforce more generally, but particularly that of the specialist NHS learning disability workforce, given that the latter have been the subject of much criticism, and for a number of years, and clearly represent a

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6 http://www.skillsforcare.org.uk/careerpathways/
workforce that has not been modernised and or developed universally to meet the needs of people with learning disabilities.

2.4 Challenges facing NHS specialist learning disability services

Recent investigations into specialist learning disability NHS provision have clearly shown a need to modernise the educational preparation and ongoing educational development of those providing specialist support for people with learning disabilities. For example the report on standards of care for people with learning disabilities at Merton and Sutton NHS trust; found that people with learning disabilities were fed too quickly to enjoy their food at mealtimes, some people only had a few hours activity a week, care plans were only available for a minority of people, there was evidence of poor communication with people with learning disabilities, as well as unsatisfactory environments with inadequate access, poor furnishings and insufficient space (Health Care Commission, 2007). Or that of the Cornwall enquiry that investigated over 64 incidents of abuse over a five year period to October 2005. Here it was found that all patients were abused but two were targeted frequently. Some of the worst abuse occurred outside the hospital, in houses where up to 4 people lived with support from NHS carers. The inspectors said that more than two thirds of the houses placed unacceptable restrictions on their residents (Health Care Commission and CSCI, 2006). And as if to reinforce this the Health Care Commission for Healthcare Audit and Inspection (2007) in A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England. It made a number of recommendations identifying a need for better procedures for safeguarding vulnerable adults; improved care planning; better commissioning of specialist services; a need for a strong performance framework and internal and external scrutiny; staff training and strong leadership including at Board level. Finally, the findings of a recent parliamentary joint select committee of MPs and Peers has noted its disappointment at the continued abuse of people with learning disabilities and, ‘that it continues ten years after the Human Rights Act 1998’. In their published report they noted recent cases of abuse, neglect and ill treatment of people with learning disabilities. They were shocked that witnesses called reported that some staff simply did not recognise that what they were doing was wrong. The report made it startlingly clear ‘that the aspirations of ‘Valuing People’ fall short of the reality on the ground’. They reported on an emergent pattern of neglect, abuse, discrimination and indifference. The report called for a culture change and human rights led approach to address the continuing abuse of human rights of people with learning disabilities (House of Lords House of Commons Joint Committee on Human Rights, 2008).

Along with challenges for specialist health and social care providers of learning disability services, mainstream health care both primary and secondary (Backer, 2009) also have to address how they are providing equitable services for people with learning disabilities these are now further explored. Clearly, this section has highlighted the need to address the specialist as well as the mainstream NHS workforce.

2.5 Challenges facing NHS mainstream services

This section further explores some of the tensions and challenges facing the NHS in providing an equitable service to people with learning disabilities. An inevitable
consequence of governments’ agenda of social inclusion and cessation of providing long term specialist LD residential services will be that new demands will be on mainstream services. And there is now irrefutable evidence that people with learning disabilities experience of mainstream health services is not acceptable (DRC, 2006, Mencap, 2007, Michael Report 2008); making it essential for the future commissioning of all health education to incorporate ‘key competencies’ in caring for this vulnerable group of people. This has already been addressed by the ‘VPP’, though a separate but interrelated work stream undertaken for NESC which has responded to and addressed the Michael reports first recommendation;

"Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training."

In December in 2008 Lesley Sheldon, Head of Education Commissioning NHS Education South Central wrote to all HEIs that held contracts with NESC asking them to respond to their;

‘commissioning managers by January 31 2009 with a short report highlighting how their undergraduate programmes reflect competence based mandatory training in Learning Disabilities. This report should also indicate detail of the extent of service user and their carer’s involvement in curriculum development and implementation as well as how they contribute to the student’s experience. This report will be discussed as part of the contract management meeting due to occur after Jan 31st 2009.’

A number of responses were submitted as a consequence of this request from the HEIs that varied considerably in terms of; level of detail [4 paragraphs to 12 pages], position of person making the response [Senior Lecturer - Dean], level of clarity [many of the responses did not address the 2 questions asked], speed of response [January 2009 - March 2009], comprehensiveness of responders [a significant number of institutions did not reply]. Finally, often very different responses were given by the same Institution but for different programmes of study. Many of the responses reported to there being little explicit competence based training other than in the LD programmes. There was evidence of enormous variation in response as to whether all students have input on Disability Discrimination Act, Mental Capacity Act and safeguarding children and adults. Some branch programmes in nursing pointed to a complete absence of either theory or practice concerning learning disability. There was a general trend in programmes that do cover learning disability issues to focus on the ‘medical model’ of understanding learning disability, rather than people with learning disabilities needs and, or, expectations of the NHS, and health care professionals. Some responses provided detailed and extensive syllabus content related to ‘input’ on learning disability. There was very little evidence of involvement of people with learning disabilities and, or, their carers in either curriculum development and or implementation. Common features from nearly all responses were statements accompanied by promissory notes - with seemingly little attention to detail. Some programmes were quite clear that they did not involve people with learning disabilities.

As the Michael Report (2008) has acknowledged in relation to healthcare, and as this exercise also identified, in relation to education, some good practice does exist, but that in both cases this good practice is isolated - it was the exception rather than the
rule. The responses, of those that actually made a response, indicated a failure to make a distinction between the nature of competencies in caring of people with learning disabilities, as opposed to outlining theoretical coverage, and this was matched with a self reported failure to properly engage people with learning disabilities and, or, their carers in the design and implementation of programmes of education.

NESC having undertaken this work with its HEI partners to understand how they were addressing this issue has now instigated a number of actions to address any perceived short comings. Two short term actions have been identified and these are to be achieved by Spring 2010 and these will require South Central SHAs HEIs to ensure that competence based training in learning disabilities is an integral part of all their undergraduate health care programmes, and that they must ensure the involvement of people with learning disabilities and, or, their carer’s in curriculum development and implementation. And finally one long term action has to be achieved that requires South Central SHAs commissioning education managers to seek documentary corroborative evidence to demonstrate adherence to these requirements at their next contract monitoring. Additionally the project lead from the ‘Valued People Project’ at South Central SHA has been asked to advise on the construction of ‘generic’ competencies for the Nursing and Midwifery Council for the UK, to better prepare the future nursing workforce located in mainstream services, to ensure that they receive human rights and disability awareness training, and in particular learning disability awareness training delivered by people with learning disabilities and family carers. Indeed, as identified by members of the Valuing People Team in their response to the NHS workforce review team they said, ‘That a stronger emphasis is placed on all frontline NHS primary care workers e.g. midwives, health visitors, A and E staff, OT etc having human rights and disability awareness training in particular learning disability awareness training delivered by people with learning disabilities and family carers’. (Carmichael et al 2009).

Clearly, this and the preceding sub-sections have highlighted the need to address both the specialist and mainstream NHS workforce, in respect of education and training issues in learning disabilities.

2.6 Summary

Temporally we are located in a paradigm shift of service ideologies away from a past where the NHS dominated the provision of residential services for people with learning disabilities, to a complex landscape of service provision. This has resulted in most NHS campuses now being closed (DOH, 2008), and this means that many people with learning disabilities are now being supported by social care staff, who may not adequately understand the disproportionate health burden that some people with learning disabilities carry. Subsequently these social care staff are often not adequately prepared to understand the health challenges that people with learning disabilities face; and as a consequence they are increasingly looking to specialist services such as Community Learning Disability Teams (CTLDs) for advice and support.

Notwithstanding this some people with learning disabilities will continue to be supported by specialist NHS services and a specialist NHS learning disability
workforce, and **all** people with learning disabilities will, regardless of these specialist services, continue to need to access the wider NHS and when they do so they are entitled to expect to receive care and support from a workforce that will treat them as equal citizens. In the case of the latter there has to be a workforce that is competent in communicating with people with learning disabilities, and their families, and carers and, able to deliver equitable care that can accommodate reasonable adjustments, and address capacity to consent as well human rights issues.

Notwithstanding this some people with learning disabilities may need additional support and help, and it is here once again that those with specialist knowledge and skills in learning disability will increasingly be needed to support mainstream services in providing additional care and support to this service user group. In addition the specialist workforce have to modernise both their practice and their knowledge base and embrace a human rights led approach to their practice and be prepared to further develop clinical practice with strong clinical supervision and governance that will counter all neglect, abuse, discrimination and indifference making these an artefact of the past.
3 THE VALUED PEOPLE PROJECT, WORKING METHODS AND FINDINGS

In this section working methods employed, along with details of the steering and reference groups are given, and a content analysis of data from reference groups and semi-structured interviews are presented. This is alongside results from the postal survey of the Local Partnership Boards. This section will synthesise overall themes from all of the different data generated through the different approaches adopted in the ‘VPP’ before progressing to section 4 to present a detailed overview of the NHS specialist learning disability workforce in South Central SHA.

3.1 Working methods

Whereas the work reported here has not been undertaken as a research project, in the conventional sense, nonetheless it has been conducted using a systematic and structured approach that offers both valid and reliable data to inform a consensual and strategic approach to achieving the overarching aims of this project. In general terms the project has been conducted using the principles of ‘Prince 2’ (Office of Government and Commerce, 2005) throughout the sponsor for this project has been Katherine Fenton, Director of Clinical Standards - South Central SHA. The project has adopted a structured multi-method approach to generate robust evidence that combines postal questionnaire survey, semi-structured interviews, reference groups and analysis of relevant literature and policy documentation (Fox, Martin and Green, 2007) (see Figure 3.1) that has sought to ensure that there has been the widest possible consultation with key stakeholders (NHS Workforce Review Team 2007, NHS South Central SHA, 2008)).

These different approaches have been used to best address the aims of this project and have effectively run from May 2008 until November 2009. In general terms this ‘multiple methods’ approach (Creswell, 2003; Tashakkori and Teddlie, 2003) has been adopted as it provides opportunity to;

- enhance the validity of the projects findings through providing corroboration from different methods (triangulation),
- illustrate, clarify and amplify the meaning of constructs or relationships in both specialist and mainstream health and social care settings,
- gain further understanding of the complexity of issues; in this context a complex arena of statutory, private and independent and voluntary sectors and an equally complex workforce and finally,
- enhance the practical and theoretical insights into the issues that this project seeks to address.

A timetable was constructed and approved by the Steering Group that sought to undertake the project over a two year period which was divided into three phases. The first of these incorporated the appointment of a Project Leader, the development of a detailed project plan. The establishment of a Steering Group, to undertake an analysis of available literature and policy documentation, the development of reference Groups, to instigate a communication strategy and to hold the first steering group meeting to report on the first phase of the project to the steering group by

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7 This document advocates engagement with all providers of health and social care to ensure a supply of trained staff.
December 2008. Next, phase 2, was the consultative body of the work for the project, and this included the development, piloting of field work that was undertaken from January 2009 to July 2009. This phase also included the development of interview schedules and conducting semi structured interviews with commissioners of services and managers. During this time trigger questions were developed and focus groups were conducted with people with learning disabilities, family carers and practitioners, as well as representatives from HEIs.

![Diagram](image)

**Figure 3.1** A multi-method approach combining postal questionnaire survey, semi-structured interviews, focus groups and analysis of relevant literature and policy documentation.

Also during this phase the development and distribution of postal questionnaires for Local Partnership Boards was undertaken⁸. Finally, the project lead continued with

⁸ This part of the project was led by Vicky Thew from Southampton PCT, a postal questionnaire was sent to all Local Partnership Boards, as of the 17 August 2009 no responses have been made.
the refinement and update of an analysis of available literature and policy documentation. It was envisaged that this would be followed by an analysis of phase 2 data during August 2009 to October 2009 leading to the completion of phase 2 with an interim report with draft recommendations. The third and final phase was to run until May 2010 but the work of the project has been completed several months ahead of schedule.

Throughout both phases the ‘VPP’ has sought the views of key stakeholders locally, regionally and nationally. Locally this has included workforce planning colleagues, clinicians’ managers and self advocacy groups. Regionally all of the reference groups were well subscribed, and collectively to date has involved in excess of 200 people. Nationally, the project has been informed by four other Regional projects that are of a similar nature - these are Yorkshire and Humber, West and East Midlands and North West Strategic Health Authorities. Significant links have been made with Lesley Barcham - seconded from the British Institute for Learning Disabilities to the Department Of Health to lead on workforce issues. Additionally, links have also been made with Yvonne Cox recently appointed to the NHS Confederation to lead on improving the health care for people with learning disabilities. Links have also been made with Skills for Care, Skills for Health and numerous learning disability providers. Continuous contact has been sustained with the Nursing and Midwifery Council.

The work of the project has been presented to the national learning disability workforce group of the Valuing People Support Team at a meeting in March 2009, and at numerous presentations, conferences and workshops. Also the project has been used and presented to the Chief Nursing Officers meeting for England in the ‘Good Practice in Learning Disability Nursing’ project group. And the project is now informing an ongoing project at the DOH which is constructing a national ‘picture’ of the learning disability nursing workforce.

The next two sub section outlines details of the ‘Steering Group’ and ‘Reference Groups’. The latter is present with a content analysis of the data generated from the reference groups and the semi structured interviews conducted with them.

### 3.2 The Steering Group

The steering group comprised a multi-agency, inter-professional group of regional leaders from learning disability services, both statutory and private, Commissioners of services from Local Authorities, Skills for Health and Skills for Care, the Regional Lead for the Valuing People Support Team, a parent and user of services, along with workforce planning expertise [full details of membership can be found in appendix 8.12]. Terms of reference were drawn up, and a role profile for members developed, and both were subsequently approved by the steering group, these can be found in appendix 8.6. Katherine Fenton agreed to act as sponsor for the VPP, and is a Board Member of the Health Authority. The steering group met bi-monthly to act as a strategic Steering Group for the ‘Valued People Project’ to ensure that the project lead discharged his responsibility for developing a report that would provide a consensus as to future education commissioning for the learning disability workforce. The Steering Group also ensured that the project considered all matters related to workforce and education commissioning issues in learning disabilities, and
that it reflected service requirements, as well expectations held by people with learning disabilities and their families. The Steering Group helped to ensure that representatives from all key stakeholders were engaged with the project. The Steering Group also agreed to endorse and formally approve the final report and recommendations of the VPP to the Health Authorities Board.

### 3.3 The reference Groups

This project has been informed by a number of reference groups; comprising people with learning disabilities, parents and family carers, commissioners of services and education, service managers from health and social care as well as third sector, learning disability practitioners, and academic staff from Higher Education Institutions and students from Further as well as Higher Education establishments. All of the reference groups were conducted between January and June 2009. Some of the reference groups were conducted as focus groups, typically comprising three sequential meetings of at least two hours duration, where a number of trigger questions relevant to the projects overall aims were discussed. Notes were taken at each meeting and shared with the group at subsequent meetings where a post validity check was undertaken, however it should be noted that this was not possible for the last meeting of each of the groups. After all of the reference group meetings for each of the separate ‘key stakeholders’ were completed, transcripts were then content analysed to elicit the major themes of discussion and concern for each separate group. The parent reference groups were undertaken as single events over a number of months each event lasting from forty minutes to one and a half hours. Content analysis was undertaken in the same way as with the other reference groups. Separate semi-structured interviews were undertaken with commissioners of services, and these were conducted ‘face to face’, where themes were explored that were comparable to the trigger questions used for the other reference groups. Finally two separate meetings were arranged for the student groups where they engaged in ‘open’ discussion about their experiences, knowledge and or background in learning disabilities.

The content analysis for each of the reference groups are presented next. This is followed by a sub-section that briefly reports on the findings from the questionnaires distributed to the Local Learning Disability Partnership Boards, and then all of these data are synthesised in the summary to close this section, before workforce issues are presented and discussed in more detail in the penultimate section [4] of this report.

#### The Self Advocates

The self advocate group comprised a number of people with learning disabilities from Oxford, Berkshire and the Isle of Wight, although those on the Isle of Wight were met separately. Members of this group were contacted through supporters of self advocacy groups. At the initial, and each subsequent, meeting the purpose of the project was explained and informed consent was sought for involvement in the

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9 See appendix 8.13 for a list of members for each of the reference groups.

10 See appendix 8.4 for an example of the trigger questions used for the reference groups.
project, and participants were regularly reminded that they could withdraw form the project at any time. An easy to read consent form was developed, and each member had this explained to them and signed or marked this form to acknowledge their agreement to participate (Appendix 8.7). The group was facilitated by Dr Steve McNally from the Ridgeway Partnership NHS Trust.

**Summary of discussion/s**

**The right kind of person** - The self advocates identified that it was important that they knew that they could trust the people who cared for, and or supported them, and insisted that they had to have ‘police checks’. They pointed to the personal characteristics of care staff as being very important, and these characteristics included; having a good personality, and good attitudes. Participants were clear that they wanted their carers to have nursing experience, and to be competent in moving and positioning. Also they thought it important that care staff understood the importance of knowing about infections and food hygiene. Direct payments were discussed and people felt that employing their own support workers was a good thing, but they would be looking for someone who was caring and understanding. Participants talked about a need for a directory of support workers to look at, so that they could choose who would support or care for them. They also felt that in the future care staff should be able to assess their needs accurately. Finally, it was felt important that carers or supporters should have good communication skills, especially listening.

**Health staff** - Participants talked of the need for a hospital friend - someone who would look out for them whilst in hospital. They felt that all doctors and nurses should have training about learning disabilities. Someone made the point, rather poignantly, that *If you care for people you should care for all people properly no matter what.* Participants discussed the importance of health care professionals understanding of, and being able to, caring for people with learning disabilities, and these included; occupational therapists, doctors, nurses, support staff, dentists, dietician, chiropodist, speech therapist and physiotherapist. In particular participants felt that ‘adult’ nurses would be more useful if they had more training in learning disability. All participants talked of poor communication between health professionals and people with learning disabilities, and that this should be improved. Concerning doctors, particularly GPs, it was felt that at least one doctor in each surgery should have training in learning disability.

**Some things worry us** - Participants pointed to a number of issues that caused them distress, and these included things like; forgetting things, medication, needles, consent forms and allergies. All participants pointed out that Casualty and Accident and Emergency Departments were very frightening. Here more than anywhere they pointed to things being rushed, and that often they couldn’t read or understand information given to them. Often they felt that staff didn’t contact relatives or get the support they needed. Participants spoke about being very worried about pain. Also ambulances were reported to be very worrying, and people pointed out that paramedics often talked to parents and carers and not to the person with learning disabilities. Participants talked of a need for staff to engage in ‘experiential’ training in what it is like to use an ‘Evac’ chair, or to lay down in an ambulance when it is moving, as one person said, ‘*I didn’t feel safe, very noisy and made me feel dizzy.*’ Some participants felt that when people with learning disabilities make a 999 call...
they should say that they have special needs. All participants referred to being very nervous about staying in hospital, and also found it difficult to answer all of the questions especially about medication.

Specialist NHS staff - Self advocate’s spoke of the need for staff who really understood learning disabilities. It was felt that more learning disability nurses should specialise as sexual health advisors [male and female]. It was felt that there was a definite need for more challenging behaviour specialist nurses. They pointed to the need for someone who could assess their needs accurately and someone who would specialise in injections and blood tests. Participants felt that there should be a range of professionals and support staff to assist people with learning disabilities.

Making things better - Participants felt that to make things better in Casualty [Accident and Emergency] there should be a separate waiting place for people with learning disabilities, and that staff should have easy to read information, and use symbols and pictures for people who can’t read, and that staff used far to many abbreviations, and that staff should call someone to support them if they don’t understand someone with learning disabilities. It was felt that everybody should be valued, and this meant that other staff such as porters, care assistants, surgeons, doctors, chiropodists, dentists and opticians should all have training in learning disability for their everyday work. Occupational therapists, speech and language therapists, psychologists, dieticians need some awareness, it was also felt to be important to make sure that receptionists are also aware of their needs. It was said that everyone with learning disability should have an advocate if they want one and staff should not speak down to them and that carers should not take over.
The Parents and Family Carers

The parent reference groups were undertaken as single events over a number of months with each event lasting from forty minutes to one and a half hours. The parents came from Berkshire, Hampshire, Oxfordshire and the Isle of Wight.

Summary of discussion/s

Its hard being a parent - Parents in all groups consistently pointed to the difficulties of being a parent of a child with learning disabilities. Not because of the child [in some cases adults] with learning disabilities per se, but because of the lack of support from services and the inconsistent levels of support they received. Parents and carers reported;

‘There is definitely a lack of support for parents’.

‘NHS services are a bit hit and miss. Joan’s daughter had a bad experience with the NHS dentist in Basingstoke and also Basingstoke hospital; there was limited understanding and no dedicated support for LD. When she was in Winchester hospital, the treatment was much better probably due to the dentist having a better understanding. Different hospitals/services have different levels of care by the people providing the services – how can this be addressed?’

‘Services are so fragmented it is difficult to imagine how it would be possible to create a seamless service’.

The need for specialists and special services - Many of the parents pointed to a need for specialist services, and felt that these staff had a ‘better understanding and could accommodate’ their needs and that of their siblings, and that this enhanced their experience with the NHS - parents and carers reported;

‘Elderly and learning disability should not be lumped together as they have varying needs. When learning disability clients get elderly they are often put in elderly care homes where staff are not trained for learning disability’.

‘Independence can be whittled away through lack of support’.

‘All hospitals need a dedicated person to oversee approaches/practices for learning disability’.

‘Obviously we need a lot more of these people [learning disability nurses] they are the people who understand the most’

The need for education and training - Parents in all groups were very clear of the need for improved education and training, especially for health care professionals who did not have a back ground in learning disabilities. Although there was a view expressed that even those that did need to be more knowledgeable about children with learning disabilities, and not just adults. Comments included;

‘Professionals in all backgrounds need an understanding of learning disability.’

‘There should be more feedback and communications with acute services to promote their knowledge of learning disabilities.’
'They might be trained in many things they might be well trained and well meaning but red tape keeps getting in their way.’

‘Different hospitals have different standards. There appears no awareness of learning disability a lack of learning disability training, doctors under pressure to meet Accident and Emergency targets.’

‘Learning disability nurses need to have knowledge of children’s learning disability services’.

‘ASD poses real challenges and we need to develop people with specialist knowledge and skills’.

Some parents reported that they would prefer to see practitioners with a university education, and that central to all roles was the need to be able to communicate effectively. Others pointed to their potential role in education and training a role advocated by the Michael Report (2008), and one now formally monitored by NESC in relation to Higher Education providers who have contracts with South Central SHA;

‘Us as parents we could train people….who have experience… this is another area that could be looked into’.

Poor communication - As with the self advocacy reference group - parents and carers reported on the numerous occasions when bad communication had a deleterious effect on their experience within the NHS. Some examples of this include comments such as;

‘My daughter has a phobia of hospitals, I phoned A&E and explained the situation and received an assurance that she would be taken into a side room and seen right away. On arrival she was put into the main reception and had to wait 2 hours. The information is not being passed on.’

‘There should be more feedback and communication with acute services to promote their knowledge of learning disabilities’.

‘Information is so inconsistent’

‘Breaking the news about learning disabilities was awful they just told me that it was a translocation and basically said goodbye,

Poor services and misplaced practice - The parent and carer group often spoke about poor services, and what would appear to have been misplaced and or poorly informed practice. This should be a cause of real concern for South Central SHA as the views expressed mirror, in many respects, parental accounts expressed in Mencaps Report ‘Treat me right’ published over five years ago (Mencap, 2004).

‘The Dr refused to give local anaesthetic for stitches - due to Aspergers - he said he couldn’t feel pain. How can this be addressed’?
'We tried to pursue our complaint though PALs but they didn’t understand'.

'If I am with Paul – when the Dr is asking me - I have to say he is here'!

It all falls apart when they are out of the education system; I have to say the dental treatment was pretty awful until we got some one who specialised in dental work for people with learning disabilities'.

'They [health care staff in non specialist learning disability services] are frightened by people with learning disabilities'.

A sense of frustration, and of fighting for everything was felt acutely by some parents and this has been articulated many times in the literature (see for example, Maxwell and Barr, 2003), a recent and very personal account was published by one of the parents in this reference group (Burton, 2008). Again comments expressed included;

‘You have to fight for everything – it’s always us having to fight’.

‘You keep meeting new people all the time but nothing changes’.

Some things are good and when they are they make all the difference - Parents did point to some examples of good practice but it has to be said that these were scarce, nonetheless examples included;

‘My GP was fantastic if the hospital talked in jargon then he would tell me that he would explain.’

‘When people listen things do work better not just for the person involved but everyone’

‘The learning disability nurse was wonderful’.

‘The wellbeing team at the sports centre is really helpful’.

The central message from these parents is that they want to be listened to and supported. They want professionals to communicate effectively with them, and between each other, and they want these same health care professionals to value and treat their loved ones with respect and dignity. In addition they are clear that all health care professionals need not only training about people with learning disabilities, but also to change their attitude toward them. Specialist healthcare care professionals were valued, although often it was not individual professional groups that were identified, rather it was the person that helped them the most.

The Practitioners

This group comprised a number of clinicians from a range of different professional backgrounds and care settings, and from Oxfordshire, Hampshire, Buckinghamshire Berkshire and the Isle of Wight.
Summary of discussion/s

Practice issues - Clinicians spoke of a need for learning disability nursing to focus on nursing, **start with the person what are their needs - and to identify what learning disability nursing can offer**. It was felt that clinicians need to be very clear about their role as a learning disability nurse; **it is a clear ‘health’ role**. Continuing health care assessment was seen as an emerging theme for learning disability nursing to address. Four areas of relevance to the NHS, and particularly of relevance to learning disability nursing were adults and children with severe/profound learning disabilities and with additional complex needs, Specialist Treatment and Assessment Services [Challenging behaviour, Forensics, Mental Health, Autistic Spectrum Disorder], Health Action Planning and Facilitation [Primary and Secondary Care] and Community Learning Disability Nurse - with generic and specialist roles. People on the Autistic Spectrum of Disorders were discussed at length, as it was felt that **learning disability nurses were the only qualified health care practitioner offering those who needed it support**.

Career issues - It was felt that some, perhaps the majority, of learning disability nurses were working in a ‘social care’ dominated settings/environments. However, clinicians felt that there was still a need for a specialist learning disability workforce, but that at present being a learning disability nurse represented an uncertain career choice, and that career progression and advancement was problematic. It was felt that there was a need for specialist nurses, and there was also support for the continued need for consultant nurses; although as participants pointed out at the time of conducting this work there are only two consultant nurses in South Central SHA. There was discussion about the relationship of learning disabilities nurses located in Community Teams for Learning Disabilities and Primary Care Trusts - especially as Local Authorities assumed all commissioning responsibility, and it was reported that joint working [integrated teams] were seen as beneficial but also as problematic.

Education - There was strong support for a regional centre for learning disability nursing education. Colleagues also expressed a view that joint training programmes were not being supported - **where were all those qualifying going - mostly into social work?** There was also considerable discussion concerning continuing professional development in the private sector and who would pay for this. Notwithstanding this sector those in the NHS reported difficulties in obtaining learning disability specific courses, and questioned their use as a means to career progression.

Leadership - Colleagues identified a need for an advocate for the profession as well as the client group. A point was repeatedly made that as the number of learning disability nurses continues to contracts that South Central SHA should facilitate networking opportunities for sharing best practice and professional issues, and offer clinical leadership and strategic direction. Clinicians made the point that learning disability nurses interface with many different groups, they offer a sound value base, and were very flexible in the way they work – they felt that there was a need to market this. Colleagues identified the development of new posts such as ‘vulnerable adult’ posts in Hampshire, learning disability nurses were reported to be working in CAMHS teams in Southampton, the New Forest and Portsmouth and in a range of liaison posts located in district general hospitals across the region.
Managers of services

This group comprised a range of senior service managers from the NHS and the private sector, and from a range of different services that included; specialist ‘inpatient’ treatment and assessment services, private hospital, day services, community and respite services for children with learning disabilities, as well as a social care provider for adults with learning disabilities.

Summary of discussion/s

Matching education with service provision - Managers felt that it was problematic that they all had very different models of service provision; NHS, Private and a range of other providers of services for people with learning disabilities, and from children and young people to adults and older people with learning disabilities. This they felt represented a ‘challenge in design for any programme for professional preparation’. Some felt that they ‘have ended up with staff that they would not necessarily want’, and that this made the provision of good services difficult. Participants felt that there was a clear need to focus on the health care needs of people with learning disabilities. There was a universal view that there should be ‘modules in learning disability in all professional health programmes of study’. There was a view and strong lobbying against the existing preceptorship period of six months which was perceived as insufficient.

A new practitioner - There was some discussion of moving away from a nurse - centric practitioner, and this led to detailed discussion on an Associate Practitioner in learning disability services. ‘We are not talking about a nursing qualification but there is a need for a new kind of practitioner’. There was general support for the development of a health Associate Practitioner in learning disability, although some concerns were expressed that such posts might lead to ‘a dilution of qualified practitioners’. It was thought that training all staff together was important, and that there were many new opportunities for education around transition working. Participants felt that more attention should be paid to the ‘unqualified workforce’.

Out with old and in with the new - A consistent theme expressed by managers was one of general dissatisfaction with the current HEI provision, and a sense that current students were ‘not adequately prepared for practice’. There was a view that individual Trusts and or organisations did not have a relationship with the HEIs, as this was mediated through NHS Education South Central [NESC]. It was strongly felt that any new education provision/preparation should promote ‘work based learning much more so than is at present’, also that there should be a move back to some of the basic elements of nursing - such as physical measurements and good interaction skills with clients. There was a view that placement experiences should not be constrained to ‘term time’ only. Some managers expressed concerns over cultural issues with ‘over-seas students’ - these related to communication and perceived differences in how to work and interact with people with learning disabilities. There was considerable discussion concerning the quality of the placement experiences, and these were felt to be of variable quality and relevance [especially in social care] – placement experiences were seen as critical to the preparation of a practitioner. It was felt that the ‘private sector was under used, and that they had a range of excellent resources that were not being fully exploited in the preparation of current learning disability nursing students’.

NESC

31
Students from Higher Education and Further Education

This group comprised 25 BTEC [National Diploma in Health and Social Care] students from Newbury College of Further Education, and one cohort of 10 pre-registration learning disability nursing students from Southampton University. Both groups engaged in ‘open’ discussion about their experiences, knowledge and or background in learning disabilities. All agreed to take part in the project, and all contributed to discussions and presented as students very committed to their programmes of study, and as such presented themselves as ambassadors for the two educational institutions involved in this element of the project.

Summary of discussion/s

For the Higher Education group a morning was spent engaging in ‘open’ discussion about the experiences of learning disability and the background of students present. All agreed to take part in the interview, and all contributed and presented as a group of very committed individuals. It was interesting to note that most although not all had family members affected by learning disabilities, and or knew someone with learning disability. This was felt to be a strong motivating factor for some in joining the branch programme. All were convinced of the need for a specialist learning disability nurse, and pointed to many examples, both anecdotally, and from reports and literature, that supported this assertion. They pointed to what they believed was a ‘state where services were in transition’ and of ‘feeling very unsure about the future especially about the prospects for employment.’ They could clearly see a need for community nurses, but from their experience they were not sure what their central role was. They pointed to disparity between social policy, and what goes on at ‘ground level’. Practice placements were talked about a lot, and whereas they were broadly supportive of the ‘hub and spoke’ model being used at Southampton University they had some reservations. Students pointed to the need to really ‘promote learning disability nursing and working in learning disability as a very rewarding career’.

Concerning the Further Education group of students all 25 were female; approximately half were first year students, and the remaining half were second years. The group was asked to split into four groups to undertake some group work around their knowledge and exposure of, and to learning disability, and learning disability as career option. All reported a lack of career information about learning disability nursing, and yet approximately a third in each group was at least interested in exploring learning disability nursing as a career. All of the students had heard of nursing as a career, approximately half had heard about mental health nursing, a quarter had heard about children’s nursing whereas only a handful, three, had heard about learning disability nursing. Most of the students had some experience of learning disability, and seemingly understood the difference between learning disability and learning difficulties and mental health. Because of course design 1st years did not get learning disability experience until their 2nd year so knowledge about and contact with people with learning disabilities for them was dependent upon their personal pre-course experiences. All reported a lack of career information about learning disability nursing, and yet approximately a third in each group was at least interested in exploring learning disability nursing as a career. All reported a need for ‘better awareness training about learning disability’ and no one wanted to work with people with learning disabilities without ‘training’. Of those with experience of learning disability - this was gained from workshops, day centres, and the most
commonly cited people with learning disabilities known to them were those with Down syndrome, and people with Autistic Spectrum Disorder, and some were aware of people with learning disability attending the college itself.

**HE Academic Staff**

This group comprised a range of academic staff from the five universities that hold commissions for pre-registration learning disability nursing within their existing contracts with South Central SHA. Much of the discussion by this reference group was dominated by pre-registration learning disability nurse education. This would seem entirely reasonable given that this is the primary function that these individuals and their respective institutions are engaged with in relation to learning disability.

**Summary of discussion**

**Critical mass** - There was considerable discussion on ‘critical mass’, and what constituted a critical mass in terms of student numbers commissioned, and the numbers of academic staff present within an institution that could support an undergraduate programme in learning disability nursing. This led to discussion about not only service workforce issues but also workforce issues related to the academic staff in HEIs for learning disability, and what was described as ‘a pending retirement time bomb’. Academic staff referred to a variable number of lecturers and students in learning disability at the HEIs, and these numbers were not always straightforward to ascertain as some lecturers had wider remits, and in the case of Thames Valley University it holds pre-registration commissions with two SHAs, this could lead to a conflation of numbers. Colleagues pointed out that where there were higher numbers of learning disability lecturers this was only maintained because of their ‘input into other parts of the programme’ typically the Common Foundation Programme.

**Nursing and Social Work** - There was some discussion concerning the future of the joint Social Work and Nursing programmes. Generally, those present felt them not to be particularly relevant any more. Participants felt Social Work and Learning Disability Nursing had moved on considerably since the inception of joint programmes, and that additionally now it was not possible at post qualifying level to maintain two registrations. Participants felt that there was little support from employers for these programmes of study, although they acknowledged that they were popular with students, and typically HEIs offering such programmes had little problem in securing sufficient applications to run viable courses.

**Being relevant to the NHS** - It was felt that learning disability nursing needed to ensure that it was more relevant to the NHS, and if anything needed a much ‘stronger emphasis on those ‘health’ roles that were likely to be retained in some form within the NHS or in private health’. One participant pointed out that their main provider, because of campus closures, would require very few learning disability nurses, and that the main recipient of their ‘product’ would be a local large private hospital.

**Reviews and commissions** - There was considerable discussion about the Nursing and Midwifery Council [NMC], and the ongoing review of pre-registration nursing education and this led to discussion about the decision to continue with four fields of practice. In addition to the NMCs review it was also noted that the Prime Minister had established a commission for nursing, colleagues wondered ‘how this will fit in
with the NMCs review’. Colleagues also discussed the ongoing challenges and relevance posed by the NMCs ‘Essential Skills Cluster’, and this was discussed in relation to how different institutions dealt with this issue, alongside challenges posed by new demands for sign off mentors. A number of these factors led to a general sense being expressed that this made it difficult to truly predict the course for learning disability nursing, as it as felt that the ‘simmering argument about generic and specialist nursing’ was still progressing in the background.

A new practitioner - There was some discussion of the need for an Associate Practitioner in learning disability [not just for nursing] one colleague reported on a Foundation Degree in Health and Social Care at Oxford Brookes University. There was discussion about the ‘big’ decision/s that were still needed in relation to the type of workforce needed”. Examples of other educational programmes for the learning disability workforce from other countries such as Austria and the Netherlands were explored, and the model of education used in such preparation, for example, social pedagogy; but it was noted similar tensions are still found as in the UK for those people with learning disabilities with specific health challenges and or complex needs.

Lack of post qualifying education - There was discussion about the ‘lamentable lack of post qualifying learning disability educational provision in the region’. One participant pointed to ‘a flexible work based post qualifying framework at one HEI’, and other examples of similar schemes at other HEIs were also given. This led participants to explore the development of a Regional Academy - Regional Resource Centre – where there would be sufficient infrastructure and resource to respond to a wider agenda than participants felt at present able to do. This was generally viewed as a positive step and was supported by all participants.

Commissioners of Services

This group comprised three commissioners of learning disability services that included both adults and children. Each participant agreed to take part in a structured interview that took between fifty minutes and one and a half hours, interviews were conducted on the Isle of Wight and in Hampshire, and on one occasion a lead for work force development also took part in the interview.

Summary of discussion/s

Responding to changing needs - Commissioners were well aware of the changing demography of people with learning disabilities and that this would necessarily impact on the workforce of services commissioned. Examples of the changing needs of people with learning disabilities included;

‘Growing population of children with complex needs, people with ASD and challenging behaviour present real challenges to commissioners, also a growing number of children with life limiting conditions.’

‘I believe we need to improve the number of services in CAMHS also the number of learning disability nurses we have a project steering group locally that is looking at that.’

‘Transitional issues are really difficult and we need people to work in transitional roles.’

NESC

INFORMING INSPIRING IMPROVING

34
Commissioners were also very clear as to the kinds of services that particularly learning disability nurses could provide for example;

‘There are very few children’s learning disability nurses, and some have very complex health care needs’.

‘There is one learning disability children’s team in Winchester but it covers an enormous geographical patch. The kinds of areas that parents are looking for professional support and guidance in includes; sleep management, epilepsy, challenging behaviour, manual handling, tube feeding and this is a really strong case to have learning disability nurses.’

**Education** - As with the clinicians and managers, commissioners voiced strong support for the need for education and particularly at post qualifying level. In particular participants spoke of the need for interdisciplinary learning but they also pointed to the need for a strong professional focus.

‘There is a tremendous need for CPD areas around professional advocacy independent assessment and independent reports joint post graduate and interdisciplinary.’

‘It is important for them to have a career pathway and a professional identity’.

‘People need to think differently and much more flexibly’.

‘I wonder whether there is a need for a joint mental health and learning disability nursing qualification’.

**A clear role for specialist learning disability NHS staff** - The commissioners were able to identify very clear areas where specialist NHS learning disability services were needed and these related to both direct and indirect areas of practice. Given the complexity of need it is unlikely that any single professional group, or agency, would be fully ‘equipped’ and competent to deal with all of the areas identified, so in their view it seemed imperative to sustain and nurture the skill and knowledge base within learning disability services, and especially so in the CTLDs. Some of the areas articulated were;

‘People can’t get access to general services and they need help with this’.

‘Social care staff will need help and training by professional staff in understanding the complex health needs of people with profound learning disabilities and complex needs we’ve had our fingers burnt by people who cant really provide the level of support they say they will.’

‘Health Action Plans should be put together by health professionals.’

‘The person who got the attention of the GP was the learning disability nurse’.

In summary commissioners of services were very supportive of the need for a specialist NHS LD workforce. They were able to identify very clear areas of practice where their expertise was needed and identify the deleterious effect on the health and well being of people with learning disabilities were their expertise not available. They were also very clear that some of this expertise would be needed to support and train social care staff through education and training to support people with learning disabilities with complex needs in the future.
3.4 The postal questionnaire of ‘Local Partnership Boards’

This part of the project was undertaken by Vicky Thew from Southampton PCT, as part of an MSc being undertaken at Kings College, University in London. A postal questionnaire survey was developed comprising a 17 item document on 4 sides of A4 [see appendix 8.11]. Each of the questions posed used a ‘yes/ no’ response or a Likert rating scale. In the case of the latter typically respondents were asked to choose to what extent they agreed with a statement from ‘strongly’ to ‘Not at all.’ Most questions also sought additional text to clarify and amplify respondent’s answers. Questions were developed, and later refined after critical review, so as not to be ambiguous. Completion time of the questionnaire averaged at 15 minutes under test conditions - this was thought not too onerous for anyone completing it.

The questionnaire was divided into three sections General, Health and Social Workforce questions. They were designed to offer a portrayal as to the level of workforce activity, planning and associated outcomes of the Local Learning Disability Partnership Boards in the geographical area of South Central SHA. The questionnaires were posted to the Chairs of the 13 Learning Disability Partnership Boards located within the geographical area of South Central SHA, accompanied by a letter of introduction and explanation.

The first postal questionnaire resulted in a nil response, and so that was followed by a second request, and this had to be followed up by an additional and personal reminder from the Valuing People Support team lead for the South East at a Partnership Board Leads meeting in early September 2009 in order to obtain a response. This timely intervention resulted in the submission of N = 4 partially/completed questionnaires [N = 4 (31%) response] being returned.

The first question sought to identify whether the Learning Disability Partnership Boards had developed a workforce and training plan and if they did who had it been developed with [Question 2]. Of the returned questionnaires 2 of the 4 [50%] indicated that they did not have a workforce and training plan. In relation to questions 3 and 4 that sought to ‘identify the number of times each year workforce or training planning had been on the agenda of the Partnership Board’ since Valuing People (2001) and Valuing People now (2009) responses varied from N=3 to N=0 with the most common being N=0.

Perhaps not surprisingly 2 of the 4 returned questionnaires when asked ‘How strongly do you agree that workforce planning is a priority for the partnership board’ had answered ‘not very’. Difficult to understand is that the remaining 2 felt ‘Fairly strongly’ that workforce planning and training had been a priority – even though it had hardly featured on their agendas.

Concerning question 6, that sought to identify whether they, had a lead for workforce planning N=3 stated they did not, whereas the fourth questionnaire answered in such a way as to make it unclear whether they did or did not.

Questions 7 through 10 sought to identify specific training and workforce planning around the health care workforce. Responses to these questions were variable. Concerning whether training and workforce planning for health professionals for all organisations including the independent sector has been addressed - N=3 responded positively with GP training being identified in 2 of the 3 responses. Only N=2 responses could identify any outcomes or achievements in relation to Local
Learning Disability Partnership Board planning in this area. Concerning involvement of people with learning disabilities in training and workforce matters for health staff all responded although responses were variable from being involved in recruitment, delivering courses to trying to identify how they would be involved and identifying what is working elsewhere. More positively concerning question 10 all [N=4] respondents identified that their Learning Disability Partnership Board had been involved in the training of health professionals.

In the next section questions 11 through 16, identical questions were posed to those previously reported on, but they were addressed to the social workforce. Once again responses to these questions were variable. Concerning whether training and workforce planning for social care staff for all organisations has been addressed - N=3 responded positively with staff values and LDAF and LDIA being identified in 2 of the 3 responses. No [N=4] responses could identify any outcomes or achievements in relation to Local Learning Disability Partnership Board planning in this area. Concerning involvement of people with learning disabilities in training and workforce matters for social care staff [N=3] responded, responses were variable from being involved in the induction of staff, encouraged to be involved in recruitment, ‘Listen to Us’, through to a non response.

In contrast to the responses for health, question 14 identified that only two [N=2] respondents identified that their Learning Disability Partnership Board had been involved in the training of social care staff. Question 15 sought to identify any remedial action being undertaken by the Learning Disability Partnership Boards in relation to any shortfall in staffing? N=3 respondents identified that they had not and the fourth reported on work undertaken 3 years ago.

Finally in question 17 respondents were asked to identify how well their Learning Disability Partnership Board had addressed workforce and training planning issues since Valuing People (2001) and Valuing People Now (2009). N= 2 thought they had adequately addressed these issues, N=1 thought they had been addressed well, and finally N=1 thought they had not been well addressed. Despite their self reported ‘success’ to this question, and In light of the responses to the preceding 16 questions, it would be difficult to conclude that any of the responding Learning Disability Partnership Boards had adequately addressed these issues.

Finally, because of the very poor response to this questionnaire necessarily there has only been a superficial analysis undertaken, but this low response [31%] is worthy of note, especially as the Partnership Boards have lead responsibility for workforce planning for learning disabilities, and also that a similar postal survey undertaken in the West Midlands SHA produced a similar response (Lancett, 2008\textsuperscript{11}). This it is argued makes it imperative that South Central SHA ensure that they work in partnership with the Learning Disability Partnership Boards to ensure that workforce planning issues are adequately understood, and more robustly planned for future needs and services.

\textsuperscript{11} Lancett, M (2008) Scoping Report on the workforce requirements of NHS providers of Learning Disability services in the West Midlands SHA.
3.5 Summary

Taken collectively these reference groups has identified that there is strong support for learning disability pre-registration nursing education to continue\(^\text{12}\), but it is thought that it clearly needs to be modernised, and highly focussed to be of relevance to the NHS and the wider economy of health and social care provision. In particular specialist learning disability service providers [both statutory and third sector] report that they still require a qualified, regulated health care workforce, and learning disability nurses [could] meet this. These same providers are currently planning new services in the South Central locality and their workforce requirements are based on an assumption that learning disability nurses will continue to be provided though the commissioning of pre-registration learning disability education. Reference groups have indicated that to ensure that learning disability nursing is seen as a viable and rewarding career option that it needs to be widely promoted with local FE college providers - this is also [incidentally] a source of recruits for other fields of nursing. Further, in respect of the wider learning disability workforce this consultation has found variable support in the reference groups, although on balance this has been positive, for a ‘health’ focussed foundation degree geared toward a Band 4 support worker to become an Associate Practitioner [this should be relevant to all professional groups and health and social care specialities] in learning disability, and this sh/would be open to the private and independent sector, and be of relevance to the health and social care work force for the future. Despite their ‘lead’ role in workforce planning the postal survey used in this report has found that Learning Disability Partnership Boards have not undertaken any systematic and or detailed attention to the workforce for the future. It has been found that within some HEIs there are small numbers of academic staff [some as low as 1], and students [some as low as 7], and this arguably exposes South Central SHA along with a range of service providers to considerable risk concerning the continuing educational provision for this element of its future workforce. This is because such low numbers expose this field of nursing practice to, potentially, being perceived as unviable by the HE sector. Perhaps, for this reason there has been strong support for the development of a Regional Academy in Learning Disability by nearly all of the reference groups. In the final section it will be proposed that such an academy should be located within one education provider, and ‘protected’ by articles of governance; thus providing a critical mass of expertise and resource that would occupy a ‘safer base’ within the education sector than it currently does. The work of such an academy must also address the lamentable lack of specialist post qualifying educational provision and this also warrants specialist educational commissioning attention, and this is particularly relevant to the recent criticisms made of the specialist LD NHS workforce; particularly nursing. Also found from this consultation is that there is no formal model to ensure capacity in leadership and research for the future specialist learning disability workforce in health; this should be another central feature of such an academy. The issue of an absence of post qualifying education is raised as a criticism of South Central SHA, more likely it can be accounted for by the scale and cumulative effect of changes in the last eight years to education, workforce, professional regulation and health and social care policy; all of which have affected people with learning disabilities and the services and personnel that support

\(^{12}\) This has been voiced by people with learning disabilities, managers of services [private and statutory], commissioners of services and a range of practitioners.
them; including the wider NHS workforce. Also, there is evidence that other SHAs are also challenged in this respect, therefore it is worth noting that at least four other SHAs are engaged in similar work, and that this perhaps indicates that this is a national issue, rather than an artifact of regional education commissioning and workforce planning. The collective concerns held by this range of people undertaking similar projects at other SHAs led to a recent national learning disability nursing workforce event at the DOH chaired by the Director of Nursing for Mental Health and Learning Disability.

To conclude, the reference groups that has included parents and carers, people with learning disabilities, managers and commissioners of services, students from HE and FE, clinicians and academic staff point to some common concerns that need to be addressed urgently and these include:

- the current model of education commissioning for pre-registration learning disability nursing is not sustainable [further evidence of this will offered in the next section of this report],
- that the complete absence of any specialist learning disability post qualifying education must be addressed,
- that learning disability as a career option in the NHS must be promoted by South Central SHA, not just for nursing but also the wider range of professional disciplines,
- that a ‘learning resource’ be developed immediately for the wider NHS workforce, but specifically for all ‘front line’ NHS staff to better understand the needs of people with learning disabilities and their families and carers,
- that a regional academy in learning disability be established to provide training, education, research, consultancy and leadership particularly for the specialist NHS learning disability workforce,
- that a programme of preparation be developed for an Associate Practitioner in learning disability and finally that,
- South Central SHA should provide ‘high visibility’ clinical leadership for specialist NHS Learning Disability NHS staff who are experiencing unprecedented changes to their roles and contexts of service delivery.

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13 North West SHA is undertaking a mapping exercise of services in learning disability led by Lee Gorman, South Central SHA, West Midlands SHA is undertaking a scoping exercise of NHS services and reviewing workforce and education commissioning lead by Marie Lovett, East Midlands SHA is undertaking a workforce review project led by Nancy Cooke and Yorkshire and Sue Beacock at the Humber and Yorkshire SHA are undertaking a joint mental health and learning disability project to investigate issues related to the workforce.

14 The VPP lead at South Central SHA provided a keynote introduction at a learning disability workforce event hosted at the DOH in August 2009.
In this section data are used to explore, in particular, whether current learning disability nursing education commissions are adequate to meet the needs of the workforce for the future. Also wider workforce issues in specialist learning disability services are outlined. This section presents detailed data that outlines commissions, starters, attrition and exits from the current learning disability pre-registration learning disability nursing courses, along with the student profile for South Central SHA. Finally, this section considers the potential medium and long term risks that South Central SHA, along with providers of services for people with learning disabilities may face, if strategic issues are not addressed.

4.1 Training

South Central SHA through NESC currently commission pre-registration learning disability nursing through five HEI providers. The commissioned, starters, attrition and exits to the learning disability nursing field across South Central for the last three years are outlined in table 4.1 below.

<table>
<thead>
<tr>
<th>University</th>
<th>Cohort</th>
<th>Commissions</th>
<th>Starters</th>
<th>On-Programme</th>
<th>Attrition (%)</th>
<th>Exits (%)</th>
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<td>Oxford Brookes University</td>
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<td>18</td>
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<td>14</td>
<td>11</td>
<td>21.43</td>
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<td>8</td>
<td>11.11</td>
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<tr>
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<td>11</td>
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</table>

Table 4.1 Current and recent past commissions and starters to the Learning Disability Nursing Branch programmes

These commissions are said to be discussed and agreed with both specialist services in South Central SHA, and the Higher Education providers identified above. Although some members of the relevant reference groups, particularly the private sector, in this project reported that they were not involved in any consultation concerning the commissioning process.

These data clearly illuminate a problem in recruiting to these programmes; with some HEIs missing commissions by up to 50%\(^\text{15}\), and this is compounded by an additional loss of ~ 25%\(^\text{16}\) through attrition. It is suggested that the scale of difference between

\(^{15}\) In the case of the University of Bedfordshire for 2007 and 2008 commissions were missed by 75%.

\(^{16}\) This is an overall attrition percentage for ‘in training’ and ‘completers’.
commissions and exits will not be sufficient to meet predicted need in the medium to long term, and this is likely to have a significant impact on the existing specialist NHS learning disability workforce. This potentially leaves South Central SHA and a range of providers exposed to a high level of risk due to a shortfall in this element of the specialist learning disability workforce.

Additionally looking at this from a fiscal perspective the national benchmark price for nursing students is set at ~£7,000, therefore in any one year the potential number of pre-registration learning disability students would equate to ~£1.2 million being allocated to learning disability pre-registration nursing education. Taking into account non commissions and attrition there could be ~half a million pounds loss of potential investment monies to the educational development of the specialist NHS learning disability workforce. Given the challenges currently facing NHS specialist learning disability services that have already been outlined in section 2.4 this is regrettable, and should be urgently addressed through investment in a range of educational initiatives such as post qualifying education, as well as other sections of the specialist NHS learning disability workforce. For example the development of an Associate Practitioner advocated by many in the reference groups. The next section moves onto to consider demographic detail of the current pre-registration learning disability student profile of South Central SHA.

4.2 The current student profile

The student profile is one that is predominantly female (81%), compared with males (19%), where ethnicity of cohort seemingly reflects the ethnicity profile of the local populations, access qualifications show few students enter through National Vocational Qualifications, Open University and Access Courses (9.8%) compared with over (50%) accessing the courses with degrees, 'A' levels and GCSEs and generally speaking a 'more mature' population of students with (62%) being over the age of 21.

<table>
<thead>
<tr>
<th>University</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Age</th>
<th>Qualifications</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Under 21</td>
<td>Over 21</td>
</tr>
<tr>
<td>Northampton</td>
<td>2</td>
<td>3</td>
<td>22</td>
<td>29</td>
</tr>
<tr>
<td>Oxford Brookes</td>
<td>2</td>
<td>3</td>
<td>21</td>
<td>29</td>
</tr>
<tr>
<td>Bedfordshire</td>
<td>1</td>
<td>1</td>
<td>15</td>
<td>24</td>
</tr>
<tr>
<td>Thames Valley</td>
<td>1</td>
<td>1</td>
<td>15</td>
<td>24</td>
</tr>
<tr>
<td>Southampton</td>
<td>1</td>
<td>1</td>
<td>15</td>
<td>24</td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
<td>6</td>
<td>50</td>
<td>73</td>
</tr>
</tbody>
</table>

Figure 4.2 Pre-registration learning disability nursing student profile for SCSHA

These data suggest a subtle difference to nationally available data for all nursing admission statistics for 2007. For example data of those applicants from 2007 show that 10% were male, whereas for South Central SHA it is nearly 20% and concerning age nationally 60% were under 21 and 40% were over 21; the converse is the case for South Central SHA. In the case of ethnicity this can be seen to be broadly similar, (see figure 4.3), to that of other fields of pre-registration nursing. These data must be treated with some caution because the numbers are so small that it would be difficult to use them with any confidence to generalise. Notwithstanding this it perhaps provides some indication as to the ‘kinds’ of people to target as potential recruits to the field of learning disability nursing.
4.3 Employment

From national data from 1995 to 2008 it can be seen that there has been a 56% fall in the numbers of learning disability nurses employed by the NHS, from 12,504 to 7,197 (see figure 4.4). What is not known is what has happened to these nurses. For example what is the scale of movement of these learning disability nurses to the wider health and social care economy, which now support people with learning disabilities in the private and independent sector? How many of these nurses retired? Did these nurses move to other fields of nursing practice? What is known is that for South Central SHA, as a workforce, the numbers of learning disability nurses employed in the NHS has seen little overall movement for the years 2006-2007 and 2007-2008 (see appendix 8.9). Although recent campus closures and transfers are likely to see these numbers reduce. In figure 4.4 comparative data is provided for psychiatry, learning disability nursing, community services and education along with head counts and participation rates. These data show that the learning disability workforce has comparable participation rates (FTE/Headcount) to Education staff or Psychiatry, and a considerably higher rate than Community Services. However unlike the other groups that are being used for comparison purposes, problematic for learning disability is that headcount, full time equivalents and subsequently participation rates have all declined. This could impact on a range of services in the future, because the specialist workforce over recent years has contracted as a result of changes to service delivery and service models. This has until now been seen as

![Ethnicity of Accepted Applications](image)
a necessary refocus of the workforce, but this must now be re-evaluated within the context of challenges to the wider NHS workforce and 'new types of demands' that will be placed on 'new types of specialist learning disability services'.

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Psychiatry Headcount</td>
<td>36,493</td>
<td>36,627</td>
<td>36,109</td>
<td>36,141</td>
<td>36,999</td>
<td>39,529</td>
<td>41,539</td>
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<td>44,726</td>
<td>47,294</td>
<td>48,503</td>
<td>46,478</td>
<td>46,469</td>
<td>40,112</td>
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<td>Psychiatry FTE</td>
<td>34,860</td>
<td>35,444</td>
<td>35,296</td>
<td>34,827</td>
<td>34,974</td>
<td>35,924</td>
<td>38,797</td>
<td>38,176</td>
<td>39,362</td>
<td>41,520</td>
<td>42,787</td>
<td>46,710</td>
<td>46,626</td>
<td>43,295</td>
</tr>
<tr>
<td>Participation Rate (FTE/HC)</td>
<td>90.9%</td>
<td>91.3%</td>
<td>90.3%</td>
<td>90.6%</td>
<td>89.7%</td>
<td>90.6%</td>
<td>86.0%</td>
<td>89.5%</td>
<td>86.5%</td>
<td>87.8%</td>
<td>87.6%</td>
<td>88.1%</td>
<td>87.8%</td>
<td>88.2%</td>
</tr>
<tr>
<td>Learning disabilities Headcount</td>
<td>12,504</td>
<td>12,105</td>
<td>11,111</td>
<td>10,736</td>
<td>9,923</td>
<td>9,497</td>
<td>9,776</td>
<td>9,550</td>
<td>8,950</td>
<td>8,650</td>
<td>8,623</td>
<td>7,583</td>
<td>7,618</td>
<td>7,197</td>
</tr>
<tr>
<td>Learning disabilities FTE</td>
<td>11,310</td>
<td>10,714</td>
<td>9,883</td>
<td>9,329</td>
<td>8,775</td>
<td>8,398</td>
<td>8,440</td>
<td>8,323</td>
<td>7,804</td>
<td>7,526</td>
<td>7,367</td>
<td>6,767</td>
<td>6,593</td>
<td>6,232</td>
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<tr>
<td>Participation Rate (FTE/HC)</td>
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<td>88.9%</td>
<td>86.9%</td>
<td>88.4%</td>
<td>86.3%</td>
<td>87.2%</td>
<td>87.4%</td>
<td>86.9%</td>
<td>83.5%</td>
<td>82.4%</td>
<td>86.9%</td>
<td>89.2%</td>
<td>86.5%</td>
<td>86.9%</td>
</tr>
<tr>
<td>Community services Headcount</td>
<td>43,013</td>
<td>44,914</td>
<td>45,888</td>
<td>47,651</td>
<td>48,972</td>
<td>50,491</td>
<td>52,401</td>
<td>53,814</td>
<td>57,586</td>
<td>61,259</td>
<td>63,257</td>
<td>62,343</td>
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<td>Community services FTE</td>
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<td>36,058</td>
<td>36,671</td>
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<td>39,302</td>
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<td>46,911</td>
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<td>47,448</td>
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<td>Participation Rate (FTE/HC)</td>
<td>76.8%</td>
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<td>75.0%</td>
<td>74.8%</td>
<td>73.9%</td>
<td>73.5%</td>
<td>72.9%</td>
<td>73.0%</td>
<td>72.7%</td>
<td>73.1%</td>
<td>74.2%</td>
<td>75.9%</td>
<td>76.5%</td>
<td>77.3%</td>
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<tr>
<td>Education staff Headcount</td>
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<td>806</td>
<td>665</td>
<td>665</td>
<td>666</td>
<td>756</td>
<td>903</td>
<td>965</td>
<td>1,147</td>
<td>1,545</td>
<td>1,335</td>
<td>1,285</td>
<td>1,180</td>
<td>1,424</td>
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<tr>
<td>Education staff FTE</td>
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<td>733</td>
<td>562</td>
<td>568</td>
<td>562</td>
<td>652</td>
<td>760</td>
<td>819</td>
<td>965</td>
<td>1,140</td>
<td>1,115</td>
<td>1,078</td>
<td>1,004</td>
<td>1,148</td>
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<tr>
<td>Participation Rate (FTE/HC)</td>
<td>92.7%</td>
<td>90.9%</td>
<td>87.5%</td>
<td>85.4%</td>
<td>85.4%</td>
<td>87.3%</td>
<td>84.2%</td>
<td>83.1%</td>
<td>84.4%</td>
<td>84.7%</td>
<td>83.6%</td>
<td>83.9%</td>
<td>85.1%</td>
<td>80.6%</td>
</tr>
</tbody>
</table>

Source #1: 1995 - 2005 Data : Tables 3a/3b
NHS Hospital and Community Health Services, Non-Medical staff in England: 1995-2005
Published by the Information Centre

Source #2: 2006 - 2008 Data Table 3
Non Medical Census Detailed Results 1998 - 2008
Published by the Information Centre

Figure 4.4 Comparative table of psychiatry, learning disability nursing, community services and education head counts with participation rates.

In addition whereas the numbers of learning disability nurses employed in the NHS has shown a trajectory that is reducing on a year on year basis, and workforce modelling has shown that for South Central SHA replacement levels are being maintained in NHS employer organisations. This must now be set in another context of known changes and that is response to the prevalence rates of learning disabilities, changes to complexity of need, new demands placed on the NHS [for example, The Bradley Report, 2009], and the unknown ‘draw’ on NHS expertise from a growing third sector of providers of services. These data provides a necessary level of detail to now consider pre-registration learning disability students moving into this field of practice.

Historically in South Central SHA there is limited data available for first post destination statistics quite simply because they were not routinely collected. And of first post destination data that does exist, this was recorded for nursing as a whole, rather than the data been broken down into fields of practice.
Notwithstanding this there is some more recent data for the 2005 cohorts across South Central SHA in the new Integrated Student Information System [ISIS] that has been made available by the Senior Information Analyst for NESC. These data present an alarming picture - with commissions for South Central standing at N=81, and of this N=61 (75%) started, N=38 (62%) completed, and 27 (43%) obtained employment and 11 (18%) were recorded as other. With the age and gender profile of these cohorts taken into account this output may be further compromised and diminished by higher than expected levels of part time working. Also the figures given here are for starters, if qualifiers and employed are compared against commissions the scale of loss is even more alarming, that is only 47% of the numbers commissioned for learning disability qualified, and only 33% of those commissioned were employed.

The next section broadens beyond nursing to consider data and implications for the wider specialist learning disability NHS workforce.

### 4.4 The current specialist learning disability NHS workforce

Within South Central SHA this project has identified a specialist learning disability NHS workforce ~ 2,500 (see figure 4.6), and this includes the following identified by occupational codes; assistant practitioners, multi therapies, instructor/teacher, occupational therapist, helper, assistant, occupational therapy, manager, physiotherapy, therapists, physiotherapy, manager clinical psychology, consultant therapists, clinical psychology, assistant practitioner, clinical psychology, clerical, administration, nursing medical and dental.

Problematic throughout this project has been that the estimation of this specialist learning disability workforce ultimately has to be based upon Electronic Staff Registers [ESR] data, and this project has routinely identified omissions and incorrect coding. For example on one occasion a phone check to verify the number of learning disability nurses [a validity and reliability check on data] in one service resulted in a recorded 1.6 wte being ‘upgraded’ as 8.6 wte - analysis of workforce data can only be meaningful if staff are correctly coded, otherwise this data becomes an artefact of the process rather than a meaningful measurement.

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17 These figures have been verified with HEIs during September 2009. ‘Other’ refers to unemployed, seeking continuing education or not known.
Notwithstanding a range of quasi validity checks have been attempted during the latter part of 2009 with the project lead for the VPP verifying with senior NHS managers centrally available data to their known workforce through their HR departments, and it is therefore cautiously believed that the current identified specialist workforce outlined in this report broadly represents a reliable and valid account of the workforce as of May 2009.

It should be remembered from section 2.3 that the Valuing People Team at the DOH has recently commented that;

‘in many parts of the country people with learning disabilities and family carers say that access to specialist NHS staff such as speech and language therapists, occupational therapists, clinical psychologists is very limited this should be investigated and the necessary measures taken to ensure this is addressed. The population of people with learning disabilities will increase over the next 20 years and this needs to be factored into all planning arrangements.’

Whereas this project has attempted to address issues overall to the NHS specialist learning disability workforce any shortfall, in the future, would be difficult to ascertain for any other discipline other than nursing. This is because preparation for other disciplines is through generic preparation, and therefore more detailed and further workforce analysis would be needed. However, what is known from the reference groups is that the third sector is increasingly employing a wide range of professionally qualified staff from the NHS, and this does and will in the future include; consultant psychiatrists and psychologists, speech and language therapists and occupational therapists. The significance of the impact of the growing third sector on the NHS workforce is not as yet very well understood.

It is perhaps worth noting that the largest component of the specialist NHS workforce is located at band three, and that the largest component of this banding are ‘nursing’ posts. This means that a significant component of the ‘specialist’ workforce [60%] comprises unqualified personnel, usually working under the supervision of qualified nurses. In order to transform services and to achieve a high quality workforce it is likely that this group of staff will need significant investments in their education and training in the future (Skills Academy for Health, 2009).
Figure 4.6 All NHS specialist learning disability staff by ‘Banding’ located in the South Central SHA area.

Also to be noted is the relative scarcity of band four posts, and equally those at band 7 and above. In order for there to be a perceived career pathway in learning disabilities it is suggested that urgent attention is paid not only to the development of Associate Practitioner posts as advocated by some of the reference groups, but also...
attention be paid to increasing the number of more senior posts in specialist learning
disability services and more generally across the NHS. This is not only to augment
career opportunities for specialist LD NHS staff, but also to provide a greater
resource for the development of leadership roles in the wider NHS but particularly
learning disability services; the subject of much criticism from recent reports outlined
in section 2.4

Special reference to nursing

More recently this field of nursing has developed a range of specialist roles in order
to support people with learning disabilities and their complex needs across a range of
services including health and social care, as well as third sector organisations. It is
often claimed that the majority of learning disability nurses now work in non-NHS
settings, although this cannot be substantiated from routinely collected work force
data.

Of the qualified learning disability workforce numerically learning disability nurses are
the single largest professional group, and collectively they are estimated to comprise
25,00018 registrants; some 3.8% of the total nursing workforce. And in addition as
identified earlier national data shows a fall in the numbers of learning disability
nurses employed by the NHS from 12,504 to 7,197 (see figure 4.6). But as
identified earlier it remains a point of contention as to how this reduction of learning
disability nurses might be accounted for. For example, what is the scale of
movement of these nurses to the wider health and social care economy, which now
support people with learning disabilities in the private and independent sector
through TUPE and or other means, is not known, nor is the number of these nurses
who may have retired? The issue of retirement is worthy of further consideration
especially as some NHS LD specialist staff will be able to retire at the age of 55
under their maintained Mental Health Office Status.

It is widely known that there is a general concern over the numbers of all nurses
likely to retire in the next few years, with NMC data showing that one third of
registrants are over the age of 50 (Snow, 2009). And this is a potential issue in
learning disability services and might well be amplified, particularly as a result of
early retirement through Mental Health Officer [MHO] status and this may impact on
the numbers of learning disability nurses for the future. Anecdotally it has been
reported that there are a large number of learning disability nurses that could access
early retirement through their MHO status. Of the ~ 600 learning disability nurses
employed in South Central SHA 9 (see appendix 8.14) it has been calculated that ~
201 [33%] might be eligible for retirement in the next five years. However, these
figures are equivocal for example, Ridgeway NHS Trust has calculated that N=17
[44%] of the total number of nurses in its ‘specialist’ health services are at medium to
high risk of retiring in the next five years; but they offer a caveat to this scenario.
That is they are able to ‘draw’ on learning disability nurses from another directorate
that gives them access to a total establishment of N=143 learning disability nurses,
this clearly changes the extent of their risk from 44% to 12% of their qualified nursing
work force retiring in the next five years. However, this issue is analysed it is

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18 This figure must be treated as problematic as the number of registrants does not equate with the numbers of
nurses working in their field of practice, and that this figure refers to the UK, whereas most other workforce data
in this report presents data from England.
undeniable that a significant proportion of the qualified workforce will retire in the next five years, and the numbers retiring cannot realistically be said to match the numbers of pre-registration learning disability nursing students currently qualifying.

In summary MHO status along with a decline in the numbers of pre-registration learning disability nurses being commissioned and seen in context of the number of starters and qualifiers should be seen as problematic for the medium term. Simply, the dwindling number of learning disability nurses, caused by a combination of factors described above, will not be sufficient to meet the growing needs of some people with learning disabilities who will need specialist support by the NHS. And this does not factor in any other additional requirement for training and support that will be needed for the wider NHS as more people with learning disabilities will require an equitable service that is able to make reasonable adjustments to support their needs. Nor does it factor in the ‘draw’ that will increasingly be made from the third sector.

4.5 Challenges for the wider NHS workforce

Quite apart from issues concerning the commissioning of a specialist workforce there is now widespread acknowledgement that the needs of this user group are both poorly understood, and often not met by practitioners working in mainstream services; such as the Primary Care and Acute Sector (The Michael Report 2008, 21). Whereas contract specifications and curricula for undergraduate nursing and midwifery programmes currently aim to provide insights into the needs of individuals from vulnerable groups, this will in the future need to be enhanced to specified competencies in supporting people with learning disabilities (The Michael Report, 2008 - Recommendation 1). Whereas this project has been instrumental in accelerating some aspects of recommendation 1 of the Michael Report [see section2.5] in ensuring that this issue forms an integral part of contract monitoring there is the wider issue of those programmes at post graduate level and that part of the NHS workforce that lies outside of professionally driven educational preparation. For example it should be remembered that the self advocates in one of the reference groups for this project talked of the need for all people to understand their needs and this includes for example receptionists, porters and domestic staff. As to the scale of the wider NHS workforce this presents a real challenge as to how this enormous workforce is modernised in its thinking, and the kinds of responses it makes to people with learning disabilities. The scale of this challenge should not be underestimated nor should the risk that the NHS leaves itself open to if it does not seriously address this issue. That is why in the previous section it was recommended that a ‘learning resource’ be developed immediately for the wider NHS workforce, but specifically for all ‘front line’ NHS staff to better understand the needs of people with learning disabilities and their families and carers.

There is also perhaps one further challenge for the wider NHS and that is to see the field of learning disability nursing practice as a legitimate part of the mainstream workforce - practitioners who could be employed in all acute and primary mainstream services to provide ‘hands on’ support, as well as advice to mainstream healthcare workers, and this seems to be advocated from many quarters (Edwards, 2008); this is an issue that the ‘Good Practice in Learning Disability Nursing’ Project (DOH, 2007) has collected evidence on. Such a development would be in addition to
‘Liaison Nurse’ roles that are also being developed in a number of progressive services and projects (See for example Hunt, 2008).

4.7 Summary

In summary, challenges to recruitment to commissions, attrition, viability of learning disability programmes within HE, the very specialist nature of learning disability itself, the creation of a critical mass of both students and academic staff, along with potential workforce issues would all seem to suggest that the current model of education commissioning being pursued for pre-registration learning disability nursing commissioning needs to be remodelled to respond to the challenging agenda that lays ahead for both the health and social care workforce in learning disabilities, as well as the wider NHS workforce.

Concerning workforce data, this has been extensively interrogated by a specialist convened group that included workforce representation from South Central SHA, and the view of this group is that South Central SHA will need to continue to commission at least to the current numbers [circa 60] each year in existing and future contracts. However, it is recommended this requires further and ongoing work, and consideration, not least because it is likely that commissions have been reduced as a consequence of difficulties of HEIs to attract students to these programmes, rather than necessarily being based upon workforce requirements. Also there has been a national failure to acknowledge learning disability services as a complex landscape of health and social care providers, creating an equally complex network of multiple employers making traditional models of workforce planning redundant. For example, data suggests that nursing students exiting these programmes are able to access a range of health and social care providers for employment; rather than a traditional career pathway in the NHS. The project lead has consistently informed the VPT national workforce lead that current policy is failing to adequately articulate the contribution of the specialist learning disability NHS workforce. This has for example, contributed to an apparent and continuing uncertainty over the future of learning disability nursing. This is not helped by national contradictions, for example learning disability nursing is one of the only professional groups to be specifically identified as providing exemplary services, in the recently published Valuing People Now (DOH, 2009). Yet the same document provides no strategic steer regarding the current specialist learning disability health care workforce. Also presented in this section has been some very limited data from the Local Learning Disability Partnership Boards who have strategic responsibility for the development of the workforce in learning disabilities. These data suggests that South Central SHA will need to work closely with these Boards at an operational and strategic level to assist them planning a learning disability workforce for the future. Failure to do this will leave South Central SHA and a range of learning disability providers exposed to high levels of risk with respect to a competent workforce to meet the particularly complex needs of children and young people and adults with profound learning disabilities, those

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19 Data suggests, although this is not irrevocable, that we may be facing a significant loss of staff in the next five years as a result of Mental Health Officer Status.

20 This point has been made at a meeting of the national learning disability workforce of the Valuing People Support Team in March 2009 where it was agreed that this would be raised with the DOH.
with a range of challenging behaviours [including some people with learning disabilities with; mental health problems, Autistic Spectrum Disorder, forensic backgrounds and or who have offended], specialist community learning disability nurses, and learning disability nurses able to support people with learning disabilities as well as the wider NHS workforce in secondary healthcare such as in acute general hospitals, mental health services as well as primary care. The final section of this report that follows will outline new roles in learning disability for the future, propose new educational commissioning practices, a new model for the delivery of learning disability education by the development of a regional academy, identify the need to modernise learning disability nursing and learning disability services and conclude by making a number of recommendations for consideration by South Central SHA.
In this final section it will be argued that both existing and new roles will be needed in the specialist learning disability NHS workforce to take forward the challenging agenda for people with learning disabilities envisaged in Valuing People (2001) and Valuing People Now (2009). Of the existing workforce learning disability nursing in particular needs to be modernised, and refocused, and be of relevance to people with learning disabilities their families and carers, and also the emergent services that are slowly developing to meet their needs. Secondly, this section will rehearse the need to move to a new model for education commissioning for learning disability. It will propose the development of a ‘Regional Academy’ in learning disability, arguing that such a facility would offer opportunity not only for modernising learning disability nursing, but also to act as a resource for the region. A resource with research and consultancy capacity, able to offer leadership and development to learning disability services, as well as the wider health and social care sectors, and that this will necessarily involve partnership working with key stakeholders. This section will also briefly outline the need for a new Associate Practitioner role in learning disabilities; a practitioner educationally prepared and with ‘hands on preparation’ to traverse the gaps between health and social care services, and able to support qualified and registered practitioners from either health or social care. Finally, a series of far reaching recommendations are made that will align the preparation of the existing and future specialist learning disability workforce, and the wider NHS workforce, to better meet the needs of people with learning disabilities and the services offered them. This will require strong clinical leadership from South Central SHA around recruitment, career advice for existing learning disability staff within the NHS and those wishing to join, monitoring the education and training and outcomes in improvement of services of NHS staff in respect of; learning disability awareness, communicating with people with learning disabilities, Human Rights, Disability Discrimination, Capacity to Consent, as well as best interest decision making and making reasonable adjustments.

5.1 New roles and new challenges for the 21st Century

All education programmes designed to prepare the current and future specialist learning disability NHS workforce to support people with learning disabilities must be locate human rights and disability legislation at the very heart of professional preparation. But in addition to the specialist workforce one of the largest challenges facing the NHS is the alignment of an enlightened value base toward people with learning disabilities amongst the wider NHS workforce; the scale of this endeavour is considerable and should not be underestimated. To address this will require further thought by the Health Authority and possibly central guidance from the DOH as well as resource to make this a reality. Notwithstanding this South Central SHA this project, on the basis of findings from people with learning disabilities and their families, should commission a ‘learning resource’ immediately for the wider NHS workforce that should be designed primarily for all ‘front line’ NHS staff in order that they better understand the needs of people with learning disabilities. Additionally both the future specialist and mainstream NHS workforce must learn to practice in non discriminatory and non oppressive ways to. This will require students of health
Learning disability nurses, who currently work in a wide range of organizational settings that includes the NHS, local authorities and the third sector, will face new challenges to their future roles (Alaszewski et al., 2001). These challenges need to be met by an underpinning of valued based services and this will need to be supported by a values based post qualifying framework of education, and the latter needs to be urgently addressed by South Central SHA. It is clear that recent changes to the configuration of services are beginning to dictate a range of new roles that are being embraced by some learning disability nurses, for example supporting secondary healthcare in acute hospitals, mental health services as well as primary care. The latter has been demonstrated to be helpful for example in introducing metrics to improve local service delivery (Giraud-Saunders, A et al., 2003). In the future learning disability nurses will increasingly be found working in CAMHS teams and supporting people with learning disabilities in behavioural distress, or children and young people or adults with profound learning disabilities and complex needs. They will work as custody nurse practitioners, and forensic specialists. More commonly community learning disability nurses now and increasingly in the future will develop new and specialist areas of practice such as sexual health, epilepsy, challenging behaviour or early onset dementia and end of life care as well as maintaining a generic background to their practice.

In England the ‘Good practice in Learning Disability Nursing’ (DOH, 2007) publication has asserted that the majority of learning disability nurses now employed by the NHS can be described as working in one of three practice areas:

- ‘health facilitation - supporting mainstream access’
- ‘inpatient services - for example, assessment and treatment and secure services’;
- ‘specialist roles - in community teams’.

Other, broader developments in health care roles, such as the modern matron, public health roles, and nurse prescribing openings have provided new opportunities in learning disability services. Also to be found are learning disability nurse consultants who are able to offer valuable clinical, supervisory expertise along with regional and national professional leadership. The range of other specialist NHS learning disability professionals are also focussing their roles on providing specialist support to people with learning disabilities and their families as well as offering advice, training and support to a range of service providers in better meeting the needs of people with learning disabilities. All specialist professions in learning disabilities now typically work in inter-professional teams and both for and across a variety of agencies and to augment this there is need to increase the portfolio of post qualifying interdisciplinary specialist learning disability education.

One particular new role that has been advocated by the reference groups is that of an Associate Practitioner and this is separately outlined in section 5.4.
5.2 A new model for education commissioning

Data gathered during this project has demonstrated that the current commissioning model being pursued for the education of pre-registration learning disability nursing could potentially leave South Central SHA, along with a range of other providers of specialist services exposed to a high level of risk. Simply, services over a period of time will be faced with a dwindling specialist workforce, and that current commissions, or more accurately current ‘exits’, along with those choosing to work in the NHS will not be sufficient to replace those leaving, and services will be left unable to respond to the challenging agenda that lies ahead. Arguably South Central NHS could continue to commission the relatively small number of pre-registration students across the region as it currently does from the existing HEIs [currently 5]. However, as reported in this project it has been found that there is variable difficulty in recruiting to these programme/s, and this is matched by an equally variable, but nonetheless, similarly high level of attrition. It has also been found that within some HEIs there are small numbers of academic staff [some as low as 1], and students [some as low as 7]. This is why this report questions whether such a commissioning arrangement is sustainable in the medium to long term; and any decision reached needs to be understood within a context. A context where specialist learning disability service providers, both statutory and third sector, state that they will still require a qualified and regulated health care workforce. Again, this considered alongside workforce data in the previous section points to South Central SHA and the local health and social care economy being exposed to considerable risk concerning the continuing educational provision for this element of its future workforce, because such low numbers expose this field of practice, potentially, to being perceived as unviable by the HE sector.

It is for these reasons that a new and different way of commissioning learning disability education is advocated. A model that has the potential to draw together a larger body of students and staff to create the critical mass that was talked of by the HEI reference group. A model of education that seeks to break away from traditional forms of professional preparation, instead adopting a preparation based on blended learning and supported by ‘open learning’. This model would need to be flexible enough to prepare practitioners who able to respond to the significant challenges that lay ahead for both the health and social care workforce in learning disabilities. The educational model would need to be values based, strongly located within human rights and disability legislation, and accommodate students from a mixed age and ethnic back ground to obtain all of their practice experience locally, and this would be supported by theoretical preparation prepared and delivered by a central education provider. It would be most likely that such provision would be supported by annual residential course/s at the host education institution and that such events would include concentrated study, and the delivery of master classes by leading clinicians and experts from the field of learning disability.

5.3 A regional academy for learning disability - A Centre of Regional excellence

Throughout this project there has been wide spread support for the development of some form of regional resource for learning disability. And it is for this reason that
this report advocates and recommends that the current commissioning arrangements for pre-registration learning disability education cease. Instead it is proposed that commissioning is based on the development of a South Central SHA resource of excellence for all pre and post registration specialist health learning disability education. Such a resource should be based on a commercial model of education delivery, with research and consultancy capacity, and should be based ‘after’ an ‘HIEC or academic health science partnership’ model between key stakeholders. In proposing such a radical shift in education commissioning it is appropriate to consider the risks associated with such a proposal. Possibly the greatest of these risks is that the future configuration of learning disability services are remains uncertain, and that the establishment of such a resource arguably may not address issues of recruitment and attrition in learning disability pre-registration nursing, or improve other more general workforce issues in learning disability and the wider NHS workforce. Also, as some colleagues from HEIs have pointed there are potential problems with practice placement procurement, and a danger of learning disabilities being further marginalised within HEIs. However, on balance the Steering Group for this project believes that the benefits of such a proposal far outweighs the risks, and further that the Steering Group firmly believe that such a proposal responds proactively to the challenges of recruitment, attrition, viability, and the very specialist nature of learning disability, by the creation of a critical mass of both students and academic staff, to address current and potential workforce issues.

Therefore this report proposes the development of a *Regional Academy in Learning Disability* that should be located within one education institution, but ‘protected’ by articles of governance. Such a resource would provide a critical mass of contemporary and reenergised expertise and resource that would occupy a ‘safer base’ within the education sector than it does at present. The work of such an academy would need to urgently address the lamentable lack of any specialist post qualifying - educational provision being commissioned, as well as developing capacity in leadership and research for the future specialist learning disability workforce in health. In addition such an academy should act as a point of intelligence for South Central SHA in relation to learning disabilities and be able to respond to a research agenda linking with cogent areas of expertise for example, public health.

### 5.4 Modernising learning disability nurse education

It has been shown, and for learning disability nursing in particular, that the learning disability specialist NHS workforce has to be seen as relevant to the needs of people with learning disabilities, their carers and the services that they are located within. This makes it imperative that a human rights approach to all education is needed to underpin future practice that will better prepare practitioners to meet the needs of people with learning disabilities. For learning disability nursing this must be clinically relevant to the NHS, and they must be able to skilfully traverse the ‘gaps’ between different care agencies, and be able to support and offer leadership to a range of supporters and carers. Evidently there is need to align the ongoing modernisation of services with modernising elements of preparing and sustaining the learning disability workforce, and throughout this report it has been argued that this also applies to the wider NHS workforce (Barr and Gates, 2008). The Nursing and
Midwifery Council is currently undertaking a significant review of pre-registration nurse education. This review is seeking to identify both generic and field specific competencies. The VPP has been extensively involved in the development of these competencies, and its involvement is ensuring that both the field and generic competencies all recognise the unique health profile of people with learning disabilities, and that all nurses are able to better respond to their needs, and this is particularly so for the filed of learning disability nursing. In order for such developments to succeed learning disability nursing will need to be promoted and supported South Central SHA. This will mean that South Central SHA should accept a clinical leadership role in this respect and develop a recruitment strategy to significantly increase the number of entrants to pre-registration learning disability nursing, and that this strategy should be aligned to the modernising nursing careers work currently being undertaken at the DOH. Also needed is a specific ‘career advice’ facility for existing learning disability staff, particularly learning disability nursing because of their specialist preparation, within the NHS as well as those wishing to join, and or move into other sectors?

5.5 A need for a new practitioner

This report has been informed by a large number of reference groups that have often advocated the need for the development of a new practitioner role in learning disabilities-one that is not so ‘nurse centric’ [as one reference group member described it]. The type of role that has been advocated is widely described in health care as an Associate Practitioner. It is proposed that there is a need for such a practitioner in learning disability services; a practitioner with specialist educational preparation, and with ‘hands on preparation’, who is able to traverse the gaps between health and social care services, and able to support qualified and registered practitioners from both health and social care.

Such a practitioner could also offer some supervisory capacity for other support staff, and under direction from qualified practitioners undertake delegated duties. It should be noted that SfC are leading on the development of a new NVQ qualification framework in learning disabilities, however employers uptake of these awards might be seen as problematic. It should be remembered that the Learning Disability Award Framework [LDAF], and more lately the Learning Disability Induction Award [LDIA] have not been widely undertaken care staff within learning disability services. It should also be remembered that Skills for health is currently scoping a career path in learning disability and developmental and that work is also being undertaken by the DOH ‘careers is learning disability nursing’. Therefore any further development in this area must be cognisant of these initiatives, and ensure that any work undertaken at South Central SHA is complementary to, and not in competition with, these developments.
Figure 5.1 An associate learning disability practitioner

It is proposed that such a practitioner is prepared for their role through some form of Foundation Degree specifically developed for learning disabilities. Such practitioners would be prepared to work within the NHS at band 4 or level 4 within LAs. Such an award would serve as an entry requirement to pursue a professional qualification should an individual choose to. The composition of the programme of study they pursue would be dictated by the needs of people with learning disabilities they will be supporting, the ‘type’ of service they were located in, as well as the registered health or social care professional they were working under the supervision of. Such a practitioner could also support and oversee the work of Personal Assistants, and also offer ‘hands on’ support to a range of other health and social care assistants. All Associate Practitioners would pursue core modules, and these most likely would comprise; communication, person centred approaches to care and support, legislation [human rights and disability], and empowerment modules. These would supplemented by specific modules that would relate to the role that they were expected to undertake in their place of work for example; an Associate Practitioner to nursing in a forensic setting, or a respite setting for children or adults with profound learning disabilities and complex needs would all undertake work based, and need and role specific modules. Alternatively, such a practitioner could be an Associate Practitioner to a Social Worker and provide assistance to people with housing, and or benefits problems and once gain they would undertake work based, and need and role specific modules [see figure 5.1]. It should be clear that the combination of ‘specific’ in addition to ‘core’ modules could provide and inexhaustible combination of possibilities, each specifically tailored to meet both the needs of people with learning
disabilities and their families, the career needs of individual practitioners, and also the needs of a range of service providing agencies.

5.6 Summary

This project set out to respond to concerns regarding the education commissioning of pre-registration learning disability nursing, and concerns for the specialist NHS learning disability health workforce more generally. This was undertaken in response to the scale and cumulative effect of changes to education, workforce, professional regulation as well as central health and social care policy all of which have affected people with learning disabilities along with the services and personnel that support them. This strategic review was undertaken to;

- map the range and extent of services and service providers across South Central SHA,
- establish an evidence base that will support a strategic approach to future educational commissioning in learning disability,
- establish how learning disability staff are deployed [with the possibility of the development of a new learning disability practitioner for health and social care],
- articulate a flexible learning and development framework that supports the career framework for staff who work with individuals with learning disabilities,
- develop an educational model that will ensure that all education programmes commissioned by SCSHA will have incorporated key competencies related to caring for individuals with learning disabilities,
- develop a communication strategy to inform services and practitioners of ongoing work and outcomes.

Each of the above tasks has been achieved. The first task thought be a relatively straight forward exercise using a range of sources such as the National Minimum Data Set (Skills for Care [SfC]), or Commissioners of services lists of providers, or the newly constructed Care Quality Commission [CQC] data base, but it has been found that often these data bases are often incomplete and, or, conflate learning disabilities with a range of other services making it difficult to extrapolate specific learning disabilities services and service users, and the skills of the workforce in supporting the wide range of needs of people with learning disabilities. Notwithstanding this a comprehensive overview of learning disability services is provided at appendix 8.14.

With respect to establishing an evidence base for future commissioning of pre-registration learning disability nursing the project reports on variable problems with recruitment to commissions, and high attrition rates from these programmes of study. Also found was that within some HEIs there are small numbers of academic staff, and this it has been argued exposes South Central SHA, along with a range of other health and social care service providers, to considerable risk concerning the continuing educational provision for this element of its future workforce. The report has studied how learning staff are deployed, and it has been found through engagement with key stakeholders that specialist learning disability service providers report that they still require and wish to employ a qualified and regulated health care
workforce, and learning disability nurses as well as other specialist learning disability meet this requirement. In respect of a flexible learning and development framework that supports the career framework for staff who work with individuals with learning disabilities the project has found support for a ‘health’ foundation degree geared toward a Band 4/Level 4 worker to become an Associate Practitioner. Additionally the project has found strong support for the development of a Regional Academy in Learning Disability. Also found from this consultation is that there is no formal model to ensure capacity in leadership and research for the future specialist learning disability workforce in health; this has been argued should be another central feature of such an academy. Workforce data interrogated suggests that South Central SHA need to continue to commission at least to the current numbers in existing contracts. It has been demonstrated that the VPP has influenced the contract monitoring of all education programmes commissioned by South Central SHA to ensure that they will have incorporated key competencies in caring for individuals with learning disabilities, and that they and their families or carers will be involved in the training of health care professionals, and this influence has also extended to the NMCs review of pre-registration nurse education. A communication strategy has ensured that the project has been promoted at numerous, workshops and conferences locally, regionally and nationally. Finally, it has been found that people with learning disabilities along with parents and carers still report many misgivings about the services they receive from the wider NHS. Based on the findings of this project the Steering Group is pleased to make a number of recommendations to South Central SHA that are listed in section 6 of this report.
6 RECOMMENDATIONS

South Centrals SHA Board is asked to receive, consider and approve the following recommendations. South Central SHA should;

- develop a recruitment strategy to significantly increase the number of entrants to pre-registration learning disability nursing, and that this strategy be aligned to the modernising nursing careers work currently being undertaken at the DOH,
- provide a specific career advice facility for existing learning disability staff within the NHS and those wishing to join, and or move into other sectors,
- provide ‘high visibility’ clinical leadership for specialist NHS Learning Disability NHS staff who are experiencing unprecedented changes to their roles and contexts of service delivery,
- commission a ‘learning resource’ immediately for the wider NHS workforce but specifically for all ‘front line’ NHS staff to better understand the needs of people with learning disabilities.
- monitor the education, training and outcomes in improved services of NHS staff in respect of; learning disability awareness, communicating with people with learning disabilities, Human Rights, Disability Discrimination, Capacity to Consent, as well as best interest decision making and making reasonable adjustments, using the expertise of people with learning disabilities and or their families as well as specialist learning disability NHS staff.
- inform the existing HEIs currently holding pre-registration learning disability nursing commissions within their contracts of its intention not to renew the existing contractual arrangements,
- develop a specification for a competitive tendering process for a new ‘model of learning disability education commissioning’, based on the development of a South Central SHA resource of excellence21 for all pre and post registration specialist health learning disability education. Such a resource will be based on a commercial model of education delivery, with research and consultancy capacity and will be based on an academic partnership model between key stakeholders.
- ensure that educational commissioning decisions for pre-registration learning disability nursing in the future are better informed by contemporary key stakeholders, and that in the short term the numbers commissioned annually should be maintained at a ‘steady state’ and should not fall below ~ 60 students.
- require the ‘Valued People Projects’ brief, remit and plan be revisited and strengthened for a ‘next stage’ project proposal and that this should be submitted alongside the final report to the South Central SHA Board by the end of 2009, for new work streams to commence from January 2010.

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21 A working title might be the South Central Academy in Learning Disability. [SCALD]
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APPENDICES
8.1 Timetable of the VPP 65
8.2 Developed website of the VPP 66
8.3 Easier to read version of the VPP 67
8.4 Trigger Questions used for the reference groups 77
8.5 Semi-structured interview format. 80
8.6 Terms of reference for the Steering Group 83
8.7 Consent form to obtain ‘informed consent’ developed for the VPP 85
8.8 Possible eligibility estimate for early retirement under MHO status based on earliest employment date 87
8.9 LD Nurse Movement 2006 - 2007 and 2007 - 2008 93
8.10 Questionnaire sent to the Local Partnership Boards 88
8.11 Membership of the Steering Group 89
8.12 Membership of the Reference Groups 94
8.13 ESR Data Warehouse NHS Dashboard staff in post report for learning disability nursing for South Central SHA based on full time equivalents and headcount as at last day of November 2008 97
8.14 Service providers and service provision by Shires 98
### Appendix 8.1  Timetable of the VPP.

<table>
<thead>
<tr>
<th>Phase 1</th>
<th>1 - 8 Months</th>
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<tbody>
<tr>
<td></td>
<td>Appoint Project Leader April 2008</td>
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<td></td>
<td>Develop detailed project plan July 2008</td>
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<td></td>
<td>Establish Steering Group August 2008</td>
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<td></td>
<td>Analysis of available literature and policy documentation May 2008 to December 2008</td>
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<tr>
<td></td>
<td>Develop Reference Groups September 2008</td>
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<td></td>
<td>Instigate communication strategy October 2009 to May 2010</td>
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<td></td>
<td>Hold first steering group meeting October 2008</td>
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<td></td>
<td>Report on first phase of project to steering group December 2008</td>
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<tr>
<th>Phase 2</th>
<th>9 -19 Months</th>
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<tr>
<td></td>
<td>Undertake consultative body of work to include development, piloting, field work January 2009 to July 2009 to include;</td>
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<tr>
<td></td>
<td>1. Develop interview schedules and conduct semi structured interviews for commissioners and managers</td>
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<td></td>
<td>2. Develop trigger questions and conduct focus groups for people with learning disabilities, family carers and practitioners, HE representatives</td>
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<td></td>
<td>3. Develop and distribute postal questionnaire for Local Partnership Boards</td>
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<td></td>
<td>4. Continue to refine and update analysis of available literature and policy documentation</td>
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<td></td>
<td>Analysis of phase 2 data August 2009 to October 2009 leading to the outcome for 1 - 4 of phase 2 of an interim report with draft recommendations</td>
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<td>Interim report on second phase of project to steering group November 2009</td>
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<tr>
<th>Phase 3</th>
<th>15 – 24 Months</th>
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<tr>
<td></td>
<td>Write report December 2009 to March 2010</td>
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<td></td>
<td>Identify necessary education strategy to meet organisation and workforce needs December 2009</td>
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<tr>
<td></td>
<td>Commission education and training programmes across NHS South Central</td>
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<td></td>
<td>Disseminate key messages December 2009 to May 2010</td>
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<tr>
<td></td>
<td>Evaluation and review January to May 2010</td>
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Appendix 8.2 Developed website of the VPP.

There is urgent need to undertake a strategic review of the educational commissioning process and attend to workforce planning issues in learning disabilities in SCSSHA. This is because of the scale and cumulative effect of changes to education, workforce, professional regulation and central health and social care policy that have affected people with learning disabilities and the services and personnel that support them. This strategic review will:

- map the range and extent of services and service providers across SCSSHA
- establish an evidence base that will support a strategic approach to future educational commissioning in learning disability
- establish how learning disability staff are deployed (with the possibility of the development of a new learning disability practitioner for health and social care)
- articulate a flexible learning and development framework that supports the career framework for staff who work with individuals with learning disabilities
- develop an educational model that will ensure that all education programmes commissioned by SCSSHA will have incorporated key competencies related to care for individuals with learning disabilities
- develop a communication strategy to inform services and practitioners of ongoing work and outcomes.

The project will adopt a structured multi-method approach to systematically generate robust evidence using a number of data sources. These will include, postal questionnaire survey, semi-structured interview, focus groups and analysis of relevant literature and policy documentation. The project will be led by an expert strategic steering group and will also be informed by reference groups, comprising people with learning disabilities, parents and family carers, commissioners of services and education, service managers from health and social care as well as third sector, learning disability practitioners, and academic staff from Higher Education Institutions ensuring that there is the widest possible consultation with key stakeholders (NHS Workforce Review Team 2007).

For further information on this project please click here.
The Valued People Project

Appendix 8.3  Easier to read version of the VPP.
Who are we?

South Central Strategic Health Authority (SCSHA) covers:
• Berkshire
• Buckinghamshire
• Oxfordshire
• Hampshire
• Isle of Wight.

We look after health care services for people who live here. These services are given by:
• a learning disability NHS Trust;
• Mental Health Trusts; and
• other social care providers [someone giving a service].

There are special [only for people with learning disabilities] services for people with learning disabilities who have:
• behaviour problems;
• mental health needs;
• Autistic disorders [mental disabilities which make it hard to make sense of the world. They also make it hard to understand other people];
• lots of needs such as help with feeding, dressing, and going to the toilet;
• have broken the law and need help.
What is this project about?

We want to see what needs doing to help people with learning disabilities. To make sure we have the right staff and the right services.

Things have changed a lot in the last 10 years.

So we want to see if training needs to change.

People with learning disabilities are no longer living in big care homes. They have more choice. They can:
- stay in their own homes;
- share houses with other people; or
- get help to live somewhere else.

Because of changes in healthcare:
- children with learning disabilities are living longer; and
- there are more older people with learning disabilities needing help.

This means more staff are needed to support them.
There are more special services. Some staff have special training and some do not.

The project aims to:
- look at what services you can get and who gives them in the SCSHA area;
- look at how we plan for the future;
- check that people have the skills needed;
- know what learning disability staff do –
  - are they working in the right places?
  - do we need new sorts of people to support you (someone who is not a social worker or nurse, but who is trained to do the work);
- help staff to get training so they can get the best out of themselves;
- make sure college courses include learning disability skills; and
- make sure we have a way to let people know what we are doing.
What needs to be looked at

We need to look at the training staff can get. We want to have staff skilled in learning disability services.

We need to check that people with learning disabilities are treated fairly. We know that some people have been treated badly. We want to stop this.

We will look at what is happening now. Things like:

- changing needs of people with learning disabilities and their families;
- splitting up of services;
- less chances for staff to get on in their job;
- more demand for special health care;
• people with learning disabilities wanting to get other health services;
• less people wanting to become learning disability nurses;
• people not finishing their learning disability nursing courses;
• changes to rules for skilled staff; and
• mixing of health and social care.

We need to make sure we do what the law says. There are rules that tell us what to do.
Staff and education issues

Most staff working with people with learning disabilities have not taken tests or exams to help them do this work.

A lot of the staff who have been trained are learning disability nurses. There are lots of them in the country. They do a range of special jobs that support people with learning disabilities. Many of these nurses do not work for the NHS.

We do not know if learning disability education for nurses is good enough. We need to find out if we need a new learning disability practitioner. Their job would be to help health and social care staff meet the needs of people with learning disabilities.

Staff skilled in learning disability are being asked to support NHS services to help them make sure their services meet the needs of people with learning disabilities.
Laws and rules issues

There are laws and rules that we must obey. These affect all health and social care services. The main ones are:

- The Human Rights Act 1998
- The Disability Discrimination Act 2005
- Valuing People (DOH, 2001)
- Valuing People Now (DOH, 2009).

We need to make sure any plans include these rules and laws.

These rules and laws make it important for us to check what we do. To see that we have the right staff and services for people with learning disabilities.
Who is helping

Bob Gates is in charge of this project. He will be helped by a **steering group** [a group of people who are experts]. They will be helped by:

- groups made up from people with learning disabilities [their families and carers],
- people in charge of services,
- people in charge of education,
- service managers from health and social care,
- learning disability experts, and
- teaching staff from colleges.
Want to know more?

If you would like more details about the project or would like to help - please contact:

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Appendix 8.4 Example of trigger questions used for the reference groups

The Valued People

Project

Strategic review of educational commissioning and workforce planning in learning disabilities - HEIs Reference Group -

17 April, 24 April and the 8 May, 10.00 - 12.00 mid-day.
There is urgent need to undertake a strategic review of the educational commissioning process and attend to workforce planning issues in learning disabilities in SCSHA. This is because of the scale and cumulative effect of changes to education, workforce, professional regulation and central health and social care policy that has affected people with learning disabilities and the services and personnel that support them. This strategic review will:

- map the range and extent of services and service providers across SCSHA,
- establish an evidence base that will support a strategic approach to future educational commissioning in learning disability,
- establish how learning disability staff are deployed [with the possibility of the development of a new learning disability practitioner for health and social care],
- articulate a flexible learning and development framework that supports the career framework for staff who work with individuals with learning disabilities,
- develop an educational model that will ensure that all education programmes commissioned by SCSHA will have incorporated key competencies related to caring for individuals with learning disabilities,
- develop a communication strategy to inform services and practitioners of ongoing work and outcomes.

The project will adopt a structured multi-method approach to systematically generate robust evidence using a number of data sources. These will include: postal questionnaire survey, semi-structured interviews, focus groups and analysis of relevant literature and policy documentation. The project will be overseen by an expert strategic steering group and will also be informed by reference groups, comprising people with learning disabilities, parents and family carers, commissioners of services and education, service managers from health and social care as well as third sector, learning disability practitioners, and academic staff from Higher Education Institutions ensuring that there is the widest possible consultation with key stakeholders (NHS Workforce Review Team 2007).

**Possible Agenda**

Introductions
Background to the project
One or all of the meetings?
General discussion
Possible trigger questions/ areas of exploration

- What specialist learning disability lecturing staff does your HEI employ?
- What is the age profile of your LD lecturing staff; for example in the next five years how many will retire – will/are these being replaced?
- Do you have a problem with recruitment and retention of LD students?
- What problem/s do you/your students typically encounter?
- Do you think we will need a specialist learning disability workforce for the future and if so what profession/s should/will they be?
- Where will this workforce be based?
- Is there a career in learning disability-particularly in health and more particularly in nursing?
- Currently SC is commissioning circa 60 pre registration LD nursing students with five HE providers should this continue?
- Currently a number of institutions deliver ‘joint’ training programmes is this something that should continue?
- What is the nature of your relationship with your local providers of LD services who are they – what is the nature of your relationship with them?
- Do you have sufficient infra-structure, expertise and resource in LD to deliver an undergraduate programme of study?
- Is there a need for a new type of worker in the health/social care sector for LD?
- What effects will the personalisation agenda have on the LD Workforce?

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http://www.learningdisabilities.scnetworks.nhs.uk/data.asp?DataID=114
Appendix 8.5 Semi-structured interview format.

The Valued People

Project

Strategic review of educational commissioning and workforce planning in learning disabilities – Commissioners Semi Structured Interview –

23 June 11.30 - 12.30 pm.
There is urgent need to undertake a strategic review of the educational commissioning process and attend to workforce planning issues in learning disabilities in SCSHA. This is because of the scale and cumulative effect of changes to education, workforce, professional regulation and central health and social care policy that has affected people with learning disabilities and the services and personnel that support them. This strategic review will:

- map the range and extent of services and service providers across SCSHA,
- establish an evidence base that will support a strategic approach to future educational commissioning in learning disability,
- establish how learning disability staff are deployed [with the possibility of the development of a new learning disability practitioner for health and social care],
- articulate a flexible learning and development framework that supports the career framework for staff who work with individuals with learning disabilities,
- develop an educational model that will ensure that all education programmes commissioned by SCSHA will have incorporated key competencies related to caring for individuals with learning disabilities,
- develop a communication strategy to inform services and practitioners of ongoing work and outcomes.

The project will adopt a structured multi-method approach to systematically generate robust evidence using a number of data sources. These will include; postal questionnaire survey, semi-structured interviews, focus groups and analysis of relevant literature and policy documentation. The project will be overseen by an expert strategic steering group and will also be informed by reference groups, comprising people with learning disabilities, parents and family carers, commissioners of services and education, service managers from health and social care as well as third sector, learning disability practitioners, and academic staff from Higher Education Institutions ensuring that there is the widest possible consultation with key stakeholders (NHS Workforce Review Team 2007).
Possible questions/ areas of exploration.

What, if any, specialist learning disability staff do organisations/services that you commission employ?

Do you think we will need a specialist learning disability workforce for the future and if so what profession/s should they be?

Where is or should this workforce be based?

Is there a career in learning disability?

Currently we are commissioning about 60 pre registration Learning Disability nursing students with five HE providers should this continue?

What, if any, is the nature of your relationship with your local HE/FE provider?

Is there a need for a new type of worker in the health/social care sector?

What effects will the personalisation agenda have on the Learning Disability Workforce?

Bob Gates
Project Leader Learning Disabilities Workforce Development
NHS South Central
Rivergate House
Newbury Business Park
London Road

NEWBURY
Berkshire
RG14 2PZ

Land Line  01635 275676
Mobile        07825 448310

Bob.Gates@SouthCentral.nhs.uk
http://www.learningdisabilities.scnetworks.nhs.uk/data.asp?DataID=114
Appendix 8.6 Terms of Reference

South Central Strategic Health Authority

‘The Valued People Project’ Terms of Reference.

Background

The ‘Valued People Project’ has been established to undertake a strategic review of the educational commissioning process and attend to workforce planning issues in learning disabilities in SCSHA. This is because of the scale and cumulative effect of changes to education, workforce, professional regulation and central health and social care policy that has affected people with learning disabilities and the services and personnel that support them. This strategic review aims to;

- map the range and extent of services and service providers across SCSHA,
- establish an evidence base that will support a strategic approach to future educational commissioning in learning disability,
- establish how learning disability staff are deployed [with the possibility of the development of a new learning disability practitioner for health and social care],
- articulate a flexible learning and development framework that supports the career framework for staff who work with individuals with learning disabilities,
- develop an educational model that will ensure that all education programmes commissioned by SCSHA will have incorporated key competencies related to caring for individuals with learning disabilities,
- develop a communication strategy to inform services and practitioners of ongoing work and outcomes.

The project will adopt a structured multi-method approach to systematically generate robust evidence using a number of data sources. These will include; postal questionnaire survey, semi-structured interviews, focus groups and analysis of relevant literature and policy documentation. The project will be over seen by an expert strategic steering group and will also be informed by reference groups, comprising people with learning disabilities, parents and family carers, commissioners of services and education, service managers from health and social care as well as third sector, learning disability practitioners, and academic staff from Higher Education Institutions, ensuring that there is the widest possible consultation with key stakeholders.

Terms of Reference

- To act as the strategic steering group for the ‘Valued People Project’ ensuring that the project lead discharges their responsibility for developing a report that

22 To be identified as the VPP from herein.
provides a consensus as to future education commissioning for the learning disability work force.

- To ensure that the project considers all matters related to workforce and education commissioning issues in learning disabilities, and that it reflects service requirements, as well expectations held by people with learning disabilities and their families.

- To facilitate cross-agency and wide geographical work, where relevant to education commissioning and work force issues, by promoting the work and any outcomes of the project.

- To ensure that representatives from all key stakeholders are engaged with the project and to advise the project lead of any need to co-opt new members and, or, the necessity for further consultative exercises.

- To provide a focus for discussion and debate for developing an appropriate education model to ensure that all education programmes commissioned by the HA will have incorporated key competencies related to caring for individuals with learning disabilities.

- To oversee the work of the project lead, without involving performance management, and to provide advice and strategic direction where this is thought necessary.

- To formally agree a work programme [known as the project proposal] and to ensure that there is necessary resource available to the project lead.

- To formally approve intermittent and ongoing developmental recommendations from the project leader.

- To endorse and formally approve the final report and recommendations of the VPP to the Health Authorities Board.

**Role Profile for Members**

1. To ensure effective and comprehensive coverage of the aims of the project.

2. To **Quality Assure** the ongoing work of the project in relation to:
   - Tabled reports and documents related to the project
   - The development of web pages to promote the project
   - The development of easy to read documents
   - Formal approval of the final report and recommendations of the project prior to submission to the Board of the Health Authority.

3. To **provide professional, expert and management advice** to the project lead.

4. To **act as a representative andpromoter** of the project where ever this is feasible to ensure the successful achievement of the projects work, and eventual recommendations to Board of the Health Authority.

5. To **contribute** to high level strategic debate concerning the future education commissioning of education for the learning disability work force.

6. To **receive** and formally approve bi-monthly reports from the Project Leader.

7. To **recommend** and **support** the project leader identify other relevant work streams and, or, funding opportunities such as the European Social Fund.
Appendix 8.7 Consent form

The Valued People

Project

THE VALUED PEOPLE PROJECT

CONSENT FORM

NAME:

I agree to take part in the Valued People Project.

I understand that anything I say may be recorded or written down.

I understand that anything I say will not be told to anyone else with my name attached to it.
If I decide that I do not want to continue being part of the project, I can stop at any time.

This form has been explained to me by Bob and Steve.

SIGNED
DATE
## Appendix 8.8 Possible eligibility estimate for early retirement under MHO status based on earliest employment date

### LD Nursing

#### Full time Equivalents

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**Grand Total**

| | 411.5 | 75.7 | 49.7 | 35.0 | 20.4 | 12.9 | 5.0 | 610.2 |

Possible eligibility estimate based on earliest employment date in ESR (NHS or Current org) on/or before 6-Mar-1995. Actual MHO status is not present in the Data Warehouse, although it may be recorded in ESR.

As such this represents a worst case scenario.

#### South Central Staff in Post
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Appendix 8.10 Questionnaire format sent to the Local Partnership Boards

Southampton City NHS
Primary Care Trust

NHS Southampton
Headquarters
Oakley Road
Southampton
SO16 4GX

Tel: 023 8029 6904
Fax: 023 8029 6960
www.southamptonhealth.nhs.uk

Dear

The 'Valued People Project' has been established to undertake a strategic review of the educational commissioning process and attend to workforce planning issues in learning disabilities in the South Central Strategic Health Authority (SCSHA).

Learning disabilities partnership boards are one of the many areas included in this project due to Valuing People and Valuing People Now identifying a role for partnership boards in workforce planning. The involvement of partnership boards will be via postal questionnaires. The questionnaire has been designed for the local partnership board chair / valuing people implementation lead to complete, it has not been designed in an accessible service user format.

I am writing to request for you to complete the enclosed questionnaire. I estimate that the questionnaire will take up to fifteen minutes to complete. Please could you return it in the provided envelope.

Please do not hesitate to contact me if you wish to discuss this further, my e-mail address is vicky.thew@scpct.nhs.uk.

Yours sincerely

Vicky Thew

Clinical governance lead for learning disabilities
General Workforce Questions:

1. Has the Learning Disabilities Partnership Board developed a workforce and training plan?
   Yes ☐ if yes please can you enclose a copy with the questionnaire
   No ☐ please go to question 3

2. Who was the workforce and training plan developed with?

3. Since Valuing People 2001 and Valuing People Now 2009 have been published, how many times each year has 'Workforce Planning' been an agenda item at the Partnership Board?
   a. 2001-2002...................... times
   b. 2002-2003...................... times
   c. 2003-2004...................... times
   d. 2004-2005...................... times
   e. 2005-2006...................... times
   f. 2006-2007...................... times
   g. 2007-2008...................... times
   h. 2008-2009...................... times
   i. 2009-Current.................... times

4. Since Valuing People 2001 and Valuing People Now 2009 have been published, how many times each year has 'Training Planning' been an agenda item at the Partnership Board?
   a. 2001-2002...................... times
   b. 2002-2003...................... times
   c. 2003-2004...................... times
   d. 2004-2005...................... times
   e. 2005-2006...................... times
   f. 2006-2007...................... times
   g. 2007-2008...................... times
   h. 2008-2009...................... times
   i. 2009-Current.................... times

5. How strongly do you agree that workforce and training planning is a priority for the partnership board?

Strongly..................Fairly strongly...............Not Very.............Not at All
6. Do you have a lead for the planning of workforce and training & if so what is the lead’s background i.e. profession/experience and qualifications?


Health Workforce Questions-

7. Has training and workforce planning for health professionals (in all organisations in the field of Learning Disabilities including the independent sector) been addressed by the Learning Disabilities Partnership Board?

   Yes  □ if yes please state how this has been addressed
   No   □ if no please go to question 8


8. Can outcomes/achievements be demonstrated that are directly related to the actions of the Learning Disability Partnership Boards planning as you have described in your answer to question 7?

   Yes  □ if yes please state outcomes/achievements
   No   □


9. How have or how will service users be involved in the health professionals training and workforce matters?

   a. Please detail

   b. If your answer indicated that you have not and do not intend to involve service users in training please indicate why this is
10. Has the Learning Disabilities Partnership Board been involved in the training of health professionals (either directly or indirectly e.g. by funding others to provide training)?
   Yes ☐ if yes please detail
   No ☐

11. Social Workforce Questions:
   Has training and workforce planning for social care staff (in all organisations across the field of Learning Disabilities) been addressed by the Learning Disabilities Partnership Board?
   Yes ☐ if yes please state how this has been addressed
   No ☐ if no please go to question 13

12. Can outcomes/achievements be demonstrated that are directly related to the actions of the Learning Disability Partnership Boards planning as you have described in your answer to question 11?
   Yes ☐ if yes please state outcomes/achievements
   No ☐

13. How have / how will service users be involved in the social care staff training and workforce matters?
   c. Please detail
      ...........................................................................................................................................
      ...........................................................................................................................................
      ...........................................................................................................................................

14. Has the Learning Disabilities Partnership Board been involved in the training of social care staff (either directly or indirectly e.g. by funding others to provide training)?
15. Has planning been undertaken by the Learning Disabilities Partnership Board to address workforce in dealing with any shortfall in staffing?

Yes ☐ if yes please detail
No ☐

16. Can outcomes/achievements be demonstrated that are directly related to the actions of the Learning Disability Partnership Boards planning as you have described in your answer to question 15?

Yes ☐ if yes please state outcomes/achievements
No ☐

17. How well would you state that workforce and training planning have been addressed by the Learning Disabilities Partnership Board since Valuing People (2001) and Valuing People Now (2009) objectives identified the areas for the Learning Disabilities Partnership Board to address? (Choose one)

a. Very well addressed ☐
b. Well Addressed ☐
c. Adequately addressed ☐
d. Not very well addressed ☐
e. Not addressed at all ☐

Thank you for taking the time to complete this questionnaire.
## Appendix 8.11 Membership of the Steering Group for the Valued People Project.

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<thead>
<tr>
<th>Organisation</th>
<th>Name</th>
<th>Title</th>
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<tbody>
<tr>
<td>South Central SHA</td>
<td>Katherine Fenton</td>
<td>Director of Clinical Standards</td>
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<tr>
<td>South Central SHA</td>
<td>Ruth Monger</td>
<td>Head of Workforce Strategy</td>
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<td>South Central SHA</td>
<td>Duncan Goodes</td>
<td>Head of Programme Consultancies</td>
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<tr>
<td>NHS Education South Central</td>
<td>Lesley Sheldon</td>
<td>Head of Education Commissioning</td>
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<td>Mark Statham</td>
<td>Education Commissioning Manager</td>
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<td>Fleur Kitsell</td>
<td>Head of Innovation, Development and Wider Workforce</td>
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<td>South Central SHA</td>
<td>Julie Kerry</td>
<td>Lead Manager Learning Disability, Mental Health and Substance Misuse</td>
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<tr>
<td>Ridgeway Partnership NHS Trust</td>
<td>John Turnbull</td>
<td>Director of Nursing</td>
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<tr>
<td>Berkshire Health NHS Foundation Trust</td>
<td>Julie Bennetts</td>
<td>Assistant Director of Workforce Development &amp; Human Resources</td>
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<tr>
<td>Hampshire Partnership NHS Trust</td>
<td>Nicola Clark</td>
<td>Associate Director of Nursing, Consultant Nurse Learning Disability</td>
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<td>Choice Services Ltd.</td>
<td>Paul Gold</td>
<td>Chief Executive</td>
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<tr>
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<td>Karen George</td>
<td>Head of Commissioning for Adults</td>
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<td>John Dunning</td>
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<td>Vicky Thew</td>
<td>Clinical Governance lead for people with a learning disability</td>
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<td>Julia Bateman</td>
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<td>Skills for Care</td>
<td>Jim Thomas</td>
<td>Programme Head, Lead for Learning Disability</td>
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<td>Skills for Health</td>
<td>Chris Wintle</td>
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<td>NESC</td>
<td>Bob Gates</td>
<td>VPP Lead</td>
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<td>Valuing People Support Team (CSIP)</td>
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<td>Cheryl Priestly</td>
<td>Co-Chair Milton Keynes Local Partnership Board</td>
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<td>Carer Representative</td>
<td>Mike Rowlands</td>
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<td>West Midlands Workforce Deanery</td>
<td>Marie Lancett</td>
<td>External Advisor</td>
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Appendix 8.12 Membership of the Reference Groups.

The Self Advocates

Dr Steve McNally, Oxford Brookes University, and the Ridgeway Partnership NHS Trust. Cheryl Priestly, Co-Chair Milton Keynes Local Partnership Board Tracey Tear, Co-Chair Milton Keynes Local Partnership Board, David Bundy, It’s my life, Newbury, Paul Murphy, It’s my life, Newbury, David Putt, Be Heard, Bracknell, Barbara Draper, Be Heard, Bracknell, Louisa Jones, Be Heard, Bracknell, Kate Green, It’s my life, Newbury, Zoë Krawczyk, United Voices, Slough, Leanne Redshaw, United Voices, Slough, Michelle Powell, United Voices, Slough, Keith Young, Be Heard, Bracknell, Karen Beresford, Milton Keynes, Sue May, Webcas, Maggie Allison, It’s my life, Newbury, Sophie Alexander, Be Heard, Bracknell, Colin Parker, It’s my life, Newbury, Rachael Wild, Newbury, Phil Smith, Isle of Wight, Simon Rashley, Isle of Wight, Anthony Beaumont, Isle of Wight, Bob Gates, Project Lead, NESC.

The Parents and Family Carers.

Mike Rowlands, Milton Keynes, Mr Bogoni, Isle of Wight, Mrs Bogoni, Isle of Wight, Mr Kirby, Isle of Wight, Mrs Packman, Isle of Wight, Mrs Amanda Barford, Bracknell, Mrs Vanessa Escott, Bracknell, Mrs Di Browden, Bracknell, Bob Gates, Project Lead, NESC, Mrs Sally Tannock, LD Action Group Meeting, Basingstoke, Mrs Mo Rowe, LD Action Group Meeting, Basingstoke, Mrs Catrina Knapp, LD Action Group Meeting, Basingstoke, Mrs Fran Lloyd, LD Action Group Meeting, Basingstoke, Mrs Penny Kirkwood, LD Action Group Meeting, Basingstoke, Mr Russell Burton, LD Action Group Meeting, Basingstoke, Mrs Lynda Boobyer, LD Action Group Meeting, Basingstoke.

Managers of services

Sheila Thorn, Disability Service Manager - Basingstoke, Anne Axford - Associate Director (Learning and Development), Portsmouth City Teaching Primary Care Trust, Suzette Jones, Hospital Director, Warby Hospital, Hampshire, Fairhome Care Group, Eileen Tollafied Davis, Berkshire Health Care NHS Foundation Trust, Bob Marks, Clinical Service Leader, Arthur Webster Clinic, Isle of Wight, Lilly Renouf, Team Leader, Meadow Brook Day Centre, Isle of Wight, John Clewley, Proprietor, Isle of Wight, Bob Gates, Project Lead, NESC.

The Practitioners

Graham Duff, Community Team Manager, Adult Social Care, Buckinghamshire County Council., Dave Ferguson, Consultant Nurse (Mental Health in Learning Disability) and Academic Practitioner, Christina Sosseh, Research and Development Nurse, Community Team for Adults with a Learning Disability, Joyce Odozi, Community Learning Disability Nurse, Newbury CTPLD, Mary Codling, Michelle Keenan, Northampton University Learning Disability Nursing Student, Brian Murtagh, Senior Community Nurse, St James’ Hospital, Portsmouth, Dr Rajnish Attavar, Consultant Psychiatrist in Learning Disabilities, Buckinghamshire, Dr Richard, Consultant Clinical Psychologist for Adults with Learning Disabilities and the Isle of Wight Community Learning Disability Team, and the East Berkshire Learning Disability Nurses Forum, Bob Gates, Project Lead, NESC.
HE Academic Staff.

Kay Mafuba, Senior Lecturer, Thames Valley University, Peter Zaagamen, Senior Lecturer, Oxford Brookes University, Professor Michael Preston - Shoot, Dean, Bedfordshire University, Lynne Topham, Senior Lecturer, The University of Northampton, Delia Pogson, Senior Lecturer, Southampton University, Kevin Humphries, Senior Lecturer, Southampton University, Anne Hedges, Field of Practice Lead in Learning Disabilities, Bedfordshire University, John Ross, Senior Lecturer and Common Foundation Programme Lead, Bedfordshire University, Barbara Burton, Head of School, Community Studies, Bedfordshire University, Bob Gates, Project Lead, NESC.

Commissioners of Services.

John Dunning, Joint Commissioning Officer, Hampshire County Council Children’s Services, and Hampshire PCT, Karen George, Head of Commissioning - Adult Services, Learning Disabilities, Hampshire PCT, Maria Hayward, Lead for learning disability workforce development for Adult Services, Hampshire County Council, Alison Barton Smith, Mental Health and Learning Disability Commissioning Manager, Isle of Wight, Bob Gates Project Lead, NESC.

Students from Higher Education and Further Education.

Brian Pratt, Jeanette Masterman, Bebe Cadman, Amy Wiles, Katie Wall, Karen Mehers, Melanie Townsend, Laura Horder, Cathy Doidge - Southampton University, and 25 BTEC National Diploma in Health and Social Care students from Newbury College of Further Education Years 1 and 2 along with their course tutor.

23 Although nominated as Bedford’s representative Professor Michael Preston Shoot was unable to attend any of the reference group meeting dates therefore an alternative date was made for colleagues from Bedfordshire University to meet with the project lead at a later point in the project in Aylesbury.
### Appendix 8 13 ESR Data Warehouse NHS Dashboard staff in post report for learning disability nursing for South Central SHA based on full time equivalents and headcount as at last day of November 2008.

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**Note:** The tables include details on the number of buildings, physical geography, bed capacity, client number, type of client, and number of employees. The information is organized by organization name, status, facility type, number of buildings, physical geography, bed capacity, client number, type of client, and number of employees.
<table>
<thead>
<tr>
<th>Name of Organisation</th>
<th>Status</th>
<th>Facility</th>
<th>Number of Buildings</th>
<th>Physical Geography</th>
<th>Bed Capacity</th>
<th>Client Number</th>
<th>Type of Client</th>
<th>Number of Employees</th>
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<td>NHS</td>
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<td>Newport</td>
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<td>Relate</td>
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<td>Residential</td>
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<td>unkown</td>
<td>LD, Dementia &amp; Old age</td>
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<td>Number of Buildings</td>
<td>Physical Geography</td>
<td>Bed Capacity (No. of homes)</td>
<td>Client Number</td>
<td>Type of Client</td>
<td>Number of Employees</td>
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