

University of
Hertfordshire



Learning Disability Nursing: Task and finish Group:
Report for the Professional and Advisory Board for
Nursing and Midwifery - Department of Health, England.

Bob Gates - Academic and Professional Lead for Learning
Disability, University of Hertfordshire, and Visiting Professor of
Learning Disabilities, University of West London

In collaboration with Clinicians, Higher Education Institutions,
Managers and leading organisations from the field of learning
disability in England and the UK

July 2011



Summary

This brief report presents expert opinion on key issues, and potential solutions concerning the diminishing numbers of learning disability nurses in England. It highlights the difficulties in reliably identifying the national supply and demand for learning disability nurses, and consequently the number of student places being commissioned. It also reports on the number and geographical spread of education and training courses, and key issues associated with clinical placements and presents as problematic the non - strategic way in which this specialist part of the National Health Service workforce is being commissioned, planned and managed. It discusses the plurality of service models and providers in which learning disability nurses now practise arguing that workforce, education, career and leadership issues need to be urgently addressed to ensure that efficient use is made of their knowledge and skills, and that without this it is difficult to see how a compromised workforce can be avoided (Gates, 2011).

It is known that people with learning disabilities carry a disproportionate health burden when compared with the general population (Emerson, 2011). Whereas people with learning disabilities have largely moved away from long term residential care provided by the National Health Service, some still require specialist support from a specialist National Health Service provision, as well as a specialist National Health Service learning disability workforce. And **all** people with learning disabilities will, regardless of these specialist services and staff, need to access the wider National Health Service, and when they do so they are entitled to receive care and support from a workforce that will treat them as equal citizens. There is a known and acknowledged inequity of experiences of people with learning disabilities of mainstream health services, and this is not acceptable (Disability Rights Commission, 2006; Mencap, 2007; Michael Report, 2008; Parliamentary and Health Ombudsmen, 2009). Given this it is difficult to comprehend why the National Health Service is not making the best possible use of its specialist learning disability workforce to assist in addressing this.

The task and finish group conclude that learning disability nursing has moved from a narrowly defined role, within long term care, to a much broader role within the National Health Service and beyond. It is a health profession supported and endorsed by many as unique in its breadth of employment base, located as it is among the various sectors. Learning disability nursing roles span community support specialists, liaison roles between services and agencies, and roles in secure or forensic health settings, and these roles offer support across the age continuum (Manthorpe, 2004). We believe that a unique interplay between four major factors; Higher Education issues, workforce issues, along with poor data and 'intelligence' issues, and field of practice issues collectively threaten and compromise this specialist workforce in the short to medium term (see figure 1). The task and finish group make a number of recommendations to the Professional Advisory Board for Nursing and Midwifery, England that are grounded in expert analysis and interpretation of numerous data sources that has included; Department of Health, England, the Nursing and Midwifery Council for nurses and Midwives UK, Centre of Workforce Intelligence, Strategic Health Authorities, and the Council of Deans, UK.

Learning Disability Nursing Task and Finish Group for the Professional Advisory Board for Nursing and Midwifery - Department of Health, England

1.0 Introduction

In November 2010 the Academic and Professional Lead for Learning Disabilities at the University of Hertfordshire was asked to chair a task and finish group for the Professional Advisory Board for Nursing and Midwifery at the Department of Health for England to explore key issues in learning disability nursing. This included¹;

- Identifying key issues and potential solutions concerning the diminishing numbers of learning disability nurses (see sections 4, 8 and 9),
- Identifying the national supply and demand for learning disability nurses, including the number of student places commissioned the number and geographical spread of education and training courses and the key issues associated with clinical placements (see sections 4 and 5),
- Identifying the typical service models in which learning disability nurses practise to ensure efficient use is made of their knowledge and skills (see section 6),
- Providing a written report with recommendations to the Professional Advisory Board for them to consider and use to inform PAB responses and future actions (see sections 8 and 9).

Subsequently a group of leading senior managers, clinicians, educationalists and other specialists from the field of learning disabilities have been brought together to provide expert opinion on learning disability nursing to inform this final report to the Professional Advisory Board. The report is contextualised within a range of sources of data. For example we have sought data from the Department of Health for England, The Centre for Workforce Intelligence, The Royal College of Nursing, Higher Education Institutions, Strategic Health Authorities, The nursing and Midwifery Council and the Council of Deans, the third sector and where appropriate the group has sought endorsements from appropriate validating bodies. The findings of this group are discussed in some detail in this report leading to a number of conclusions and recommendations which are offered to the Professional Advisory Board for Nursing and Midwifery for their consideration.

The group was asked to²:

- *'Identify a minimum data set including the numbers of qualified learning disability nurses, learning disability student nurse commissions, uptake and attrition rates, Strategic Health Authority workforce plans involving learning disability nurses [see pages 8-19 and appendices 1, 2 and 3],*

¹ The responses to these key issues are to be found in the sections identified in this report.

² The responses to the group's tasks are to be found in the pages/appendices identified in this report.

- *Assess data that the relevant bodies, including: Higher Educational Institutions, social services, criminal justice system and the independent sector will provide to the Professional Advisory Board [see pages 10-12],*
- *Formulate and recommend future learning disability models of service delivery and the provision of education and training that reflects these changes [see pages 12-13],*
- *Suggest approaches for the inclusion of the independent sector in workforce planning and the commissioning of learning disability student places [see pages 9-10, 18-19],*
- *Recommend models of education and training provision in learning disability nursing so that the delivery of care is not compromised by insufficient numbers in particular areas [see pages 18-19],*
- *Assess the need for a marketing and recruitment campaign that will clearly illustrate the vision, roles and career pathways of learning disability nurses [see pages 13-15, 18-19],*
- *Deliver an interim report to the Professional Advisory Board on the progress of the task and finish group [please refer to previously submitted material],*
- *Present to the Professional Advisory Board, a final report with recommendations and 'next steps' set against the specifications in the Terms of Reference' [see pages 18-19].*

In keeping with what we have been asked to do we have used these tasks to help us structure our report. Firstly, we provide a context to learning disability in England that is followed by relevant data about people with learning disabilities, and detailed data of the numbers of learning disability nurses, and of these those that work in the National Health Service. Next we present our understanding of learning disability nurses who work in the third sector and the criminal justice system. Following this we detail the numbers of learning disability nursing students, and highlight issues around commissions, attrition, placements, and student numbers. Next we explore what learning disability nurses do, and the models of care and support they are located in. This is followed by an exploration of some of the wider issues for learning disability nursing including discussion on recruitment, marketing and career issues, before finally sharing endorsements and the conclusions and recommendations we have reached and would like to make to the Professional Advisory Board.

2.0 Context

It seems difficult to conceptualise that less than 20 years ago large numbers of people with learning disabilities were being cared for by learning disability nurses within National Health Service hospitals. There has been a revolution in the ways in which people with learning disabilities are both cared for and supported, and this necessarily has led to nothing short of a revolution to the practise of learning disability nursing. In particular, in England, since the publication of '*Valuing People*' (Department of Health, 2001) we have witnessed a sustained move away from National Health Service dominated residential service provision, and this range of services has all but been replaced with a complex range of service providers, and new types of service provision. Whereas we have seen the final closure of the last long-stay learning disability hospital in England, some National Health Service residential care provision, known as 'residential campuses', has remained (Mair, 2009). Now residential services more typically comprise care homes, independent

living, supported living, as well as people with intellectual disabilities living in their own homes and family homes. Also there is now a contemporary focus on employment and a modernisation of day service configurations, and all of these developments exist alongside the development of personalised services and personal health budgets. Nonetheless 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 and continuing health needs or social care needs. This complex landscape of service arrangements typically involves a range of agencies that includes; the statutory sectors [National Health Service and Local Authorities], the private and independent sector along with the voluntary sectors - the latter of which also includes the provision of intentional communities. The workforce needed to support people with learning disabilities in their preferred life styles has changed considerably, and now involves immediate families and networks of support offered by friends, and a social and health care workforce; the latter of which comprises a range of professional disciplines. The largest specialist discipline is learning disability nursing, and it is this group of professionals that this report considers.

3. 0 People with learning disabilities

There is something in the order of 1, 198,000 people in England who have a learning disability (about 2% of the population). This figure comprises 900, 000 adults - and of this ~177, 000 are known users of services - most of these will have severe or profound learning disabilities. Also there is something in the order of 298, 000 children with learning disabilities in England (Emerson *etal*, 2010). Only 20% of adults with learning disabilities are known to learning disability services, and it is known that the prevalence and complexity of need of this group of people is growing at both ends of the age continuum, and this is particularly so in the case of children with profound and multiple disabilities who are now surviving into adulthood and a rapidly growing population of older people with learning disabilities (Improving Health and Lives - Emerson and Hatton, 2008).

People with learning disabilities are 58 times more likely to die before the age of 50 than the general population; some of these deaths are avoidable (Michael, 2008). Up to one third of people with learning disabilities have associated complex health care needs for example;

- Epilepsy is 20 times greater than that of the general population and a major cause of premature death (Improving Health and Lives - Glover and Ayub, 2010),
- Up to one third will have an associated physical disability - commonly Cerebral Palsy - with attendant health challenges that include; postural distortion, hip dislocation, secondary respiratory infections; dysphagia, gastro-oesophageal reflux, constipation and incontinence,
- Mental ill health is six times more common in children with learning disabilities than other children, and co-morbid conditions such as Autistic Spectrum Conditions and Attention Deficit Hyperactivity Disorder are more common,

- Foetal Alcohol Spectrum Disorder is becoming a major cause of non-genetic learning disabilities, and will present major challenges for the future in disability, forensic and criminal justice services (British Medical Association, 2007),
- Most recently evidence on mortality, general health status, cancer, coronary heart disease, respiratory disease, mental health and challenging behaviour, dementia, epilepsy, sensory impairments, physical impairments, oral health, dysphagia, diabetes, gastro-oesophageal reflux disease, constipation, osteoporosis, endocrine disorders, injuries, accidents and falls have all been subject to scrutiny (Emerson and Baines, 2011),
- A recent report has found choking and epilepsy as being among the most common and preventable causes of deaths of people with learning disabilities. Other issues also found commonly included people with Down's syndrome with thyroid and heart problems. Inhalation problems leading to secondary respiratory chest infections are another major cause of premature death (Improving Health and Lives - Glover and Ayub, 2010),
- There are also a growing number of young people dependent upon medical technology (Kirk, 2008).

Today most people with learning disabilities, especially children, live with their own families and may not need any professional support. However at times throughout their lives they may need intermittent support from Community Learning Disability Teams, and especially input from community learning disability nurses. Models of service delivery for those individuals with complex and continuing health care needs are changing, and are shifting to more personalised services that will require access to an appropriately trained and skilled workforce (Mansell, 2010).

Evidently we are located in the final stages of a paradigm shift of service ideologies away from a National Health Service dominated provision of long term residential services for people with learning disabilities, to a complex landscape of service provision (Malin and Race 2010). Not surprisingly this has raised issues about whether we need a specialist National Health Service workforce in learning disabilities to support the 'health care' needs of people with learning disabilities.

This issue has been accentuated by the now almost complete closure of National Health Service campuses (Department of Health, 2008). This has resulted in many people with learning disabilities now being supported by social care staff; although it is not known whether they will adequately understand the disproportionate health burden that some people with learning disabilities endure (we believe that emerging data from the confidential enquiry being conducted by the Norah Fry Research Centre will support this assertion).

Nonetheless the workforce in social care now has potential access to a Level 2 and 3 Diploma in Health and Social Care, that has replaced both the Learning Disability Qualification [and prior to that the Learning Disability Award Framework] and the NVQ in Health and Social Care. These staff can pursue an '*Adults with Learning Disabilities*' pathway through the Diploma, together with the Level 2 and 3 certificates in supporting people with learning disabilities.

Notwithstanding this welcome development **some** people with learning disabilities will continue to need lifelong support by specialist National Health Services, and a specialist National Health Service learning disability workforce. And **all** people with

learning disabilities will, regardless of these specialist services, continue to need to access to the wider National Health Service, and when they do so they are entitled to receive care and support from a workforce that will treat them as equal citizens. There is a known and widely acknowledged inequity of experience of people with learning disabilities in mainstream health services, and that this is not acceptable (Disability Rights Commission, 2006, Mencap, 2007, Michael Report 2008, Parliamentary and Health Ombudsmen, 2009 (once again emerging data from the confidential enquiry being conducted by the Norah Fry Research Centre will continue to support this - especially concerning issues of the Mental Capacity Act).

4.0 Numbers of Learning Disability Nurses and Learning Disability Nurses in the National Health Service

Of the qualified learning disability workforce numerically learning disability nurses are the single largest professional group, and collectively they are estimated to comprise ~19,000³ registrants in England [see table 3].

The number of new annual registrants over the last 10 years in the field of learning disability is slowly reducing and for this period the arithmetic Mean is calculated as (\bar{x} 538), Median (M 498) and Range 205 (Excluding 2011) [see table 4].

It is known that the numbers of **learning disability nurses employed in the NHS** has continued to fall year on year from 12, 504 in 1995 to 6, 600 in 2009 [something in the order of a reduction of 53%] or ~1,000 a year, with a reducing participation rate that has fallen by 3.9%, and a growing vacancy factor from 2008 [1.3%], 2009 [1.7%] and 2010 [2.0%] (National Health Service, 2010).

It remains a point of contention as to how this reduction of learning disability nurses might be accounted for. For example, the scale of movement of these nurses to the wider health and social care economy, which now supports 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, or who may be working in other areas such as mental health, or end of life care.

The issue of retirement is worthy of further consideration especially as some National Health Service Learning Disability specialist staff will be able to retire at the age of 55 under their maintained Mental Health Office Status. Anecdotally, as well as data informed (Gates, 2009⁴), it has been reported that there are large numbers of learning disability nurses that could access early retirement through this status, and this finding is supported by the Centre for Workforce Intelligence;

*'Specific modelling on the retirement age of learning disability services **has not been carried out by Centre for Workforce Intelligence e.g. the difference of a 65years, 60 years or 55 years retirement age has on supply. Centre for Workforce Intelligence readily acknowledges the potential impact of mental health officer status affecting the numbers of people retiring, more significantly in the short term and also in the future.***

³ 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.

⁴ In South Central SHA it has been calculated that of ~ 600 qualified learning disability nurses ~ 201 [33%] might be eligible for retirement in the next five years.

It is very likely that this makes this figure of those whom will reach retirement age larger, as the threshold for retirement is lowered to 55 years from typical values for male and female and staff; however, Centre for Workforce Intelligence has no evidence beyond anecdotal suggestions and awareness' (Centre for Workforce Intelligence, 2011).

Finally, we suspect that the financial climate may well be fast tracking the early retirement of many experienced learning disability nurses, some of whom have been working at Primary Care Trust and Strategic Health Authority level.

4.1 Learning Disability Nurses in the third Sector

Little if anything is known about the numbers of **learning disability nurses employed in the third sector**, and obtaining workforce data is problematic. Through Ann Norman from the Royal College of Nursing we have used as a proxy measure Royal College of Nursing data held on members who are learning disability nurses, and who are known to be working in the private sector. These data suggest that there are at least 2, 500 known learning disability nurses in England who work in the private and independent sector - this has to be understood as a conservative estimate as to this workforce as it is most unlikely that all the nurses in this sector will hold membership with the College. But of this workforce we know little if anything for example; the age profile, gender mix, qualifications other than initial registration, the nature and scope of their practice, and obtaining any specific data on learning disability nursing from this workforce from current sources of data sets is almost impossible.

Nonetheless the group has also attempted to understand this sectors perception and reliance on learning disability nursing as part of the workforce and their future service models. Time and resource dictated that we were only able to undertake some limited interviews with two major providers in this sector. Professor John Turnbull from the Ridgeway Partnership Trust, and Bob Gates from the University of Hertfordshire posed questions to two separate third sector organisations concerning their thoughts on learning disability nursing, whether it's valued, what they see as the future for this part of their workforce. In general terms it was clear that **learning disability nursing was still highly valued**. In one of the organisations it was identified that in addition to working in learning disability services, learning disability nurses are also recruited to work in mental health units because of their person centred approach to care and also to enable them to acquire essential skills and knowledge around mental health. This organisation also pointed out that the skills of the learning disability nurse were transferable to their Adult Behavioural Intervention services. For this reason, the informants in this organisation felt that the current structure of education is 'about right' because it gives the nurse a broad base from which to work. However, the downside of this was that both organisations felt a newly qualified learning disability nurse required a significant investment in terms of time to give them the skills to practice safely in many of the specialist secure settings. Both organisations supported the continuation of learning disability nurse training, and were both **alarmed by equal measure at any threats to its future**. However, for one organisation further discussion revealed that this organisation is planning on the assumption that learning disability nurse numbers will drop significantly with graduate status. They also expressed disappointment that

traditional careers were being eroded within their own organisation, and that the most senior practising nursing 'clinician' in the future may be a band 6 (equivalent) staff nurse or nurse specialist. They reported that they are already employing qualified learning disability nurses in managerial roles that oversee two ward areas. At the same time one organisation was looking to invest in assistant practitioner roles, and stated that they wished to seek an educational model that could offer them maximum flexibility to work across several different services user groups in their organisation. This organisation also acknowledged the possibility that this could be a good source of recruitment for nurse education in the future.

These two organisations reported different views on the level of engagement with workforce planning and education commissioning processes. Both reported having contacts and peripheral involvement in education commissioning - one reported this to be informal and ad hoc, and the other found it difficult to articulate how they were involved in either apart from contact with this member of the task and finish group. Both reported that they were much more used to dealing directly with providers of education for example, the Higher Education Institutions and one reported the role of the Strategic Health Authorities '*as a bit of a side show*'; notwithstanding this they appeared happy to fit in with current arrangements. One believed that the new White Paper on education offered them opportunities to become more engaged with the process of education planning and commissioning, and at least put them on an equal footing with other providers. Of particular importance was **neither organisation was put off by the idea of being levied to fund nurse education**; both saw nursing as a contributor to their future commercial success. The general consensus was that other independent sector providers would also agree to this preferring to be where the '*action is*' rather than being outside. One organisation already provides a considerable amount of placements, and part of their vision is to be a 'teaching' organisation, the other is developing along similar lines. In the case of one of these organisations the interviewer was informed that they are one of four independent providers that, in combination with the other three, provide half the learning disability in-patient beds in England. Therefore, they believed that they could exert a great deal of positive influence in the education market place. In one organisation the new concept of **skills networks** which is suggested in the new White Paper as the vehicle for bringing together providers in health and social care, General Practitioners and user groups to develop plans for commissioning education was discussed. This is of particular relevance as it has been articulated in work undertaken in the Yorkshire and Humber area, and elsewhere, that makes a clear link between education commissioning and the future needs of the independent sector;

'within current education commissioning there is lack of a structured means for taking account of the workforce planning impact both within this sector [the third sector] and how this might relate to the wider health communities' (Beacock, 2010).

4.2 Learning Disability Nurses in the criminal justice system

Once again when we examined the contribution of learning disability nursing to the **criminal justice system** little if anything seemed to be known at a 'formal' level as to the numbers of learning disability nurses employed, and or what they did, and who employed them. Through Janet Cobb, member of the task and finish group, we

accessed the UK forensic and learning disability network - we believe these data suggest that there is at the very least, but we suspect significantly more, 300 learning disability nurses in England who work in a variety of roles in the criminal justice system for example; Community NHS Community Trusts, Prisons, Youth Offending Institutions, Youth Offending Teams, Child and Adolescent Mental Health Services, Low, Medium and High secure units [including special hospitals], probation service and assistant police liaison officer. Once again extreme caution has to be exercised in seeing this number as anything other than as a conservative estimate of this workforce - some areas of the country have offered anecdotal evidence of growth in this area and this is especially relevant in the light of the Bradley Report (Department of Health, 2009). Interestingly, perhaps worryingly, we now have evidence of learning disability nurses moving to Australia and New Zealand after being '*head hunted*' specifically for their skills in relation to forensic work - organisations are actively using United Kingdom networks to recruit, and adverts appear on a weekly basis in both nursing and more general learning disability nursing journals.

5.0 Numbers of Learning Disability Nursing Students and their preparation

In January this year Jackie Kelly at the University of Hertfordshire on behalf of the task and finish group requested from the **Council of Deans**, the completion of an on-line survey with respect to a range of learning disability student nurse data. The Council of Deans agreed to collate and anonymise these data for release to the Professional Advisory Board. It should be noted that Higher Education Institutions were given the opportunity to opt out of this exercise should they choose to do so. They were asked to supply data on commissions for learning disability for 2010/11, places so far taken up, and levels of attrition and marketing strategies. [N=24] institutions chose to respond to this survey. N=2 have been excluded from any analysis as they were not from England; responses to this on-line survey are to be found in Appendix 7. We have found that as with other supposedly 'same data' sets that we have looked at - these were different yet again. For example, for 2010/11 commissions - Higher Education Institutions claim these to be 484 [see appendix 7]; the Strategic Health Authorities claim them to be 558 [see appendix 6] and for the same period the Department of Health claim them to be 778 [see appendix 5]. Although commissions seemingly are ~700 per annum it should be noted that only 4/500 students are registering with the Nursing and Midwifery Council each year. There are two plausible explanations for this - a failure to register at the end of the programme or the more likely - attrition.

Concerning levels of attrition - Council of Deans give a range from 2.63% to 39% [although it is clear from some responses that these related to one year of a three year programme]. Data supplied from the Department of Health show attrition for 2005/6 at Degree 19% and Diploma 27%, 2006/7 Degree 17% and Diploma 32% and 2007/8 Degree 10% and Diploma 34% [see appendix 5]. Council of Deans report that in all but three Higher Education Institutions places for 2010/11 were taken up with 2 reporting over recruitment. With respect to marketing a range of responses were given that included local advertising, use of Google, networks with local agencies, radio adverts, and liaison with feeder colleges, open days, posters, mail shots and hosting learning disability conferences.

Sue Beacock from the University of Hull on behalf of the task and finish group undertook to write to all **Strategic Health Authorities to establish a data set** on; workforce plans and commissions for 2009/2010 along with actual recruitment for this period, a statement of education commissioning intentions for 2011, the number of Higher Education Institutions offering this field of nurse education in England, attrition and comparison of this attrition to overall attrition and finally any issues that the SHAs wished to bring to the attention of the Professional Advisory Board. After analysis of these data returned we have found it almost impossible to delineate anything **specifically about workforce plans for any of the Strategic Health Authorities specifically concerning learning disability nursing**. Additionally these data believe us to conclude that for 2009/2010 all but one Strategic Health Authority failed to see their commissions for learning disability materialise into recruited students; with 'actual numbers recruited' being between 9% and 50% under commissions. Concerning commissioning intentions for 2011/12 these indicate that 2 are increasing commissions, 7 are reducing commissions [1 by 52%] and 2 are maintaining a steady state. We believe extreme caution should be exercised in the importance attributed to the measure of 'intention' as clearly 'actual numbers recruited' seldom if ever materialise. Concerning attrition these data suggest that for the learning disability field this varied from 8% - 38% [with the average seemingly resting at ~23%] - in general terms this did not compare favourably with overall attrition that was in the range of 9% to 24% [with the average seemingly resting at ~15%]. We believe according to these data that there will be from 2013 only ~19 Higher Education Institutions offering pre-registration professional preparation for the learning disability field of practice, appendix 8 presents an overall geographical summary of educational provision.

We have found placements to be a real issue and cause of concern both for education providers, clinicians and managers of services alike, and we have found considerable variation in opinion and discussion concerning the quality of the placement experiences. In a previous piece of work undertaken these were felt to be of variable quality and relevance [especially in social care] - but overall 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'* (Gates, 2009). An area causing significant challenges is with Community Teams for Learning Disabilities when they are located within Adult Care Services in Local Authorities, this makes decision making pathways complicated, where professional responsibility to accept students on placement seemingly conflicts with line management responsibility to ensure capacity - often responsibilities and priorities become blurred. There appears to be anecdotal evidence that some HEI's continue to use learning disability placements to achieve the requirements of the EC standards for adult nurses. However, we do not view this as problematic as there is a considerable degree of flexibility for achievement of the EC standards in the new NMC competencies.

There is a consensual view that Higher Education providers are being imaginative in securing placements for their students and with a greater emphasis being placed upon the 'learning experience' and it would appear that the *'Hub and Spoke'* model widely adopted is beginning to address some of the concerns that have been voiced. One 'learning experience' that is thought should be addressed by Higher Education

providers is that of obtaining experience of working with children with learning disabilities - it is imperative that the future learning disability nurse obtains such experience and is competent in meeting the needs of people with learning disabilities across the age continuum, and this should be addressed as a matter of priority.

We have also detected concerns over risks associated with the move to an all graduate curricula. Whereas widening participation strategies are increasingly being discussed, the field of learning disability nursing in particular has a history of recruitment challenges, and there exists strong evidence that demonstrates that numbers of places commissioned are routinely not matched against the actual uptake, it is likely that this needs to be monitored and understood at a national level in order to assess any impact on the future workforce.

Finally two points worthy of further consideration; a point made by a number of Higher Education Institutions is the real need to be incentivised into providing this specialist field as part of their pre-qualifying portfolio of educational provision. We have heard from more than one quarter that the existing contracts are often very small making them extremely vulnerable to the internal politics of these institutions as a subsequence of the high cost in maintaining them compared with the income stream realised from the national bench mark price. The second point concerns the ongoing and future potential loss of academic and research capacity amongst the Higher Education sector for this field of nursing through the ongoing loss of lecturing staff with an appropriate learning disability nursing background. We believe that the data that we have studied leads us to conclude that there is overwhelming and compelling evidence to fundamentally change the education commissioning model for this specialist field of nursing at both pre and post qualifying level and move to a regional commissioning model, and that the delivery of education for this field of practice is provided through a limited number of regional academic centres. One strategic Health Authority has already chosen this path, and another strongly endorses this approach (Blythin, 2011).

6 What learning disability nurses do and models of care and support

Much has been said concerning the '*supply side*' of learning disability nursing this section focuses on current and emerging models of care and support, as well as what learning disability nurses do. Learning disability nurses currently work in a wide range of organizational settings that includes the National Health Service, Local authorities and the third sector, and it is clear that they are continuing to face challenges and organic developments to their future roles (Alaszewski et al, 2001). Learning disability nurses remain the only professional group specifically prepared at pre-qualifying level to work as learning disability specialists; this makes them unique. Learning disability nursing has moved from a narrowly defined role, within long term care, to a broader role within the NHS and beyond. It is a health profession supported and endorsed by many⁵ as unique in its breath of employment base, located as it is among the various sectors. Learning disability nursing roles span from community support specialist roles to liaison roles between services and agencies, through to those working in secure or forensic health settings, and these roles offer support across the age continuum (Manthorpe, 2004).

⁵ See section 7 of this report.

More recently this field of nursing has developed a range of specialist roles in order to support people with learning disabilities who have complex needs across a range of services including health and social care, as well as third sector organisations. It is clear that the evolving landscape of services and the personalisation agenda are beginning to inform the development of a new a range of new roles that are being embraced by some learning disability nurses, for example supporting secondary healthcare in acute hospitals, and mental health services as well as in primary care. The latter has been demonstrated to be helpful in introducing metrics to improve local service delivery (Giraud-Saunders *et al*, 2003). They also have an increasingly important role in helping to keep people safe, assist with decisions concerning capacity to consent and best interests, making reasonable adjustments and advising and assisting with making health care both accessible and understandable.

In the future learning disability nurses will increasingly be found working in services that support the social inclusion and personalisation agenda so for example in, Child and Adolescent Mental Health Service teams, supporting people with learning disabilities in behavioural distress, or children and young people or adults with profound learning disabilities and complex needs including individuals dependent on medical technology and this is known to be a growing population which includes children with congenital disorders, premature babies and children involved in trauma resulting in acquired brain injury, most typically road traffic accidents. The current green paper recently published concerning special educational needs makes much of joint working between health, education and social care and it is thought that learning disability nurses are likely to be at the forefront of making this happen (DFE, 2011). They will also work with individuals who currently fail to meet fair access criteria in areas such as custody nurse practitioners, and forensic specialists.

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, early onset dementia, and end of life care as well as retaining and maintaining a generic background to their practice.

In England the 'Good practice in Learning Disability Nursing' (Department of Health, 2007) publication has asserted that the majority of learning disability nurses now employed by the National Health Service can be described as working in one of three practice areas;

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

Although it must be remembered that these practice areas relate just to the National Health Service, it is just as likely in other sectors to find learning disability nurses supporting the wider health and social care economies in diverse roles such as; day services, consultancy work, therapists, workers supporting personal health budgets, and in Local Authorities.

6.1 Wider issues for learning disability nursing

It is known and acknowledged that there is inequity in the experiences of people with learning disabilities compared with others who use mainstream health services, and that this is not acceptable (Disability Rights Commission, 2006; Mencap, 2007; Michael Report, 2008; Parliamentary and Health Ombudsmen, 2009). Given this it is difficult to comprehend why the National Health Service is not making more use of the learning disability nurses in the wider National Health Service workforce. Notwithstanding this there is a very real need to align the ongoing modernisation of services and inclusion with modernising elements of preparing and sustaining the learning disability nursing workforce and this also applies to the wider National Health Service workforce (Barr and Gates, 2008).

Other, broader developments in health care roles, such as the modern matron, public health roles, and nurse prescribing openings have all provided new opportunities in learning disability services. Also to be found are learning disabilities nurse consultants, although **worryingly their numbers appear to be falling**, and we would dispute the numbers identified by the Department of Health as being in post [see appendix 2], we suspect that there are far less nurse consultants than identified. The Department of Health data shows the number to be 41 learning disability nurse consultants in England - we believe the correct figure to be ~31 as of July 2010. These posts offer invaluable clinical and supervisory expertise along with regional and national professional leadership - an already compromised learning disability nursing workforce at senior level has led to a lack of leadership, and this needs to be addressed urgently (Northway *et al*, 2006). Most recently the Royal College of Nursing for the UK has published an important position statement for learning disability nursing (Royal College of Nursing, 2011) that offers a much needed steer for the future of this field of nursing particularly adds to their contribution to the health and well being of people with learning disabilities, and simultaneously provides a clear focus for learning disability nursing. Also the Nursing and Midwifery Council has recently undertaken a significant review of pre-registration nurse education. This review has identified both generic and field specific competencies. This review has ensured that both the field and generic competencies all recognise the unique health profile of people with learning disabilities; in order that all nurses are able to better respond to the needs of people with learning disabilities.

It is not sufficient to merely decide that there is a continuing need for the learning disability field of nursing. In the spirit of equity these nurses, as do others, need a clear career structure, and it is also clear that they need a specific 'career advice' facility given the complexity of their 'field' of practice. They also need to be able to aspire to senior positions, and such senior clinical positions are notable by their absence; for example apart from posts in two specialist learning disability National Health Service Trusts, the most senior positions that these nurses can aspire to is to be a consultant nurse, and it has been shown that their number are dwindling; these nurses and the people they serve deserve better. To punctuate this point there is no learning disability nurse at the Department of Health in England, and no learning disability nurse at the Royal College of Nursing for the United Kingdom⁶, and it is

⁶ The Task and Finish group acknowledge the significant contributions made by the current national leads at the DH and the RCN for learning disability nursing in England but would point out that neither incumbent is a learning disability nurse.

only recently that it has been announced that there is to be a senior learning disability nurse appointed to the Nursing and Midwifery Council for the United Kingdom. In order for learning disability nursing to develop and thrive it needs to be promoted and supported by the Departments of Health, The Royal College of Nursing for the United Kingdom, and the Nursing and Midwifery Council for the United Kingdom. Whereas it is clear that we need to increase the number of entrants to pre-registration learning disability nursing that alone will not be sufficient to address the many challenges outlined in this report. It is attention to the totality of this field of nursing and the likely nursing careers for the future that deserves wider attention.

It would be impossible for the Task and Finish Group to complete this report without making comment on the BBC Panorama investigation into the abuse that was inflicted upon residents of the privately run **Winterbourne View Hospital** for People with Learning Disabilities (BBC, 2011). The Task and Finish Group believe that what was seen on Panorama was both shocking and inexcusable; in fact these were criminal acts. We believe that this documentary underlines the importance of understanding the context in which some nurses work within the third sector. A context often characterised by qualified nurses working in very isolated settings, with little peer support, little or no clinical supervision (Sines and McNally, 2007), and little or no access to continuing professional development, or a clear career structure to motivate this workforce (Gates, 2009). In such settings nurses may often be found overseeing large numbers of unqualified support workers with little or no formal training. The growth in third sector provision has occurred as a result of previous adverse reports on standards of care for people with learning disabilities. For example, 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 **significant** 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 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). However, the current policy of closing NHS campuses and moving people to the third sector has not of itself resolved issues identified in previous investigations into specialist learning disability provision (Mansell, Ritchie and Dyer, 2010). And it should be noted that all investigations and research continues to articulate a need to modernise the educational preparation, and ongoing educational development and support of those providing specialist support for people with learning disabilities. Just as the policy of closing NHS campuses and moving people with learning disabilities to the third sector has not resolved these issues, equally simply denigrating service design, and the staff working in such settings or those commissioning services will also not of itself resolve such outrages. Surely part of any solution must lie in maintaining a highly qualified, sensitive and caring workforce that is able to practise to a nationally prescribed set of competences, and who will be held accountable for their practice through a professional code of conduct, and who can be struck off from a centrally held register [designed to protect the public] if their practice is deemed unacceptable, and the task and finish group believe that nursing - specifically learning disability nursing - is well placed to do this with the caveat that the recommendations in this report are urgently addressed.

To conclude a decline over a number of years in the numbers of pre-registration learning disability nurses being commissioned, contextualised within the number of starters and qualifiers, along with the impact of an ageing workforce, and an annual reduction of ~1000 learning disability nurses employed by the National Health Service year on year, and finally evidence that the number of annual new registrants to this field over the last 10 years is slowly reducing [representing less than ~50% of the nationally claimed commissions each year for England [see appendices 5 and 6] are all cause for concern. This when understood collectively should be seen as problematic for the short to medium term. Simply, the dwindling number of learning disability nurses, caused by a combination of the factors described above, will not be sufficient to meet the growing needs of some people with learning disabilities who will continue to need specialist support by the National Health Service, and a specialist nursing workforce. It should be noted that this does not factor in any other additional and growing requirement from this specialist nursing workforce to train and support the workforce in the wider National Health Service as more people with learning disabilities demand an equitable service that is able to make reasonable adjustments to support their needs and finally, neither does it factor the *'draw'* on this specialist workforce that is increasingly being made from the third sector. This Task and Finish group were asked, amongst other things, to *'Recommend models of education and training provision in learning disability nursing so that the delivery of care is not compromised by insufficient numbers in particular area.'* We believe that the sum total of this evidence supports our analysis and conclusion that there is a need to re-consider education commissioning for learning disability nursing. The group favours the notion of a regional approach⁷ to this issue. This would create a model where commissioning across a region can take account of the whole sector

⁷ The concept of 'regional approach' refers to the newly announced clustering of existing SHA's.

needs and ensure that there is an adequate supply of learning disability nurses into the future, and this has led us to make the recommendation in section 9 (9.1).

Finally, learning disability nursing must be modernised, all educational programmes designed to prepare current and future learning disability nurses must be located within a clear framework of human rights and disability legislation, and these must be at the very heart of professional preparation and practice.

7.0 Endorsements

Earlier in this report it was asserted that learning disability nursing had moved from a narrowly defined role, within long term care, to a much broader role within the National Health Service and beyond. We believe it to be a health profession supported and endorsed as unique in its breadth of employment base, located as it is among the various sectors. On behalf of the group Jim Blair from St George's Hospital - London has sought and been offered a number of endorsements from eminent leaders from the Houses of Lords and Westminster, Mencap, the Royal College of Nursing, The Foundation for People with Learning Disabilities, The Nursing and Midwifery Council, and the Care Quality Commission.

'Healthcare is a crucial area where people with a learning disability still often get a raw deal. Despite good intentions, professionals sometimes fail to truly adjust their services, particularly at moments of crisis, making judgements that influence the care given and as a result, health outcomes continue to be worse.'

'In Mencap we have always been impressed with the contribution that specialist Learning Disability liaison nurses can make to ensuring patients with a learning disability receive the best the NHS has to offer. I have heard stories how the intervention of a skilled practitioner, able to not only understand learning disability but also to support the person to advocate for themselves (and their family) has made key differences - in many cases, saving lives.'

'The impact of Learning Disability Nurses cannot be underestimated and I hope the findings of the report are taken on board. The health (and even lives) of many people with a learning disability rely on this work being mainstreamed across the NHS and not just reliant on talented and dedicated individuals.'

Mark Goldring - Chief Executive Officer of Mencap

'As Royal College of Nursing Chief Executive and General Secretary, I am delighted to see this very important work has been undertaken as a priority. The RCN places great value on learning disability nurses and the very skilled work that they do. Many of our learning disability nursing members tell us of the considerable challenges that they are faced with in pursuit of the best possible care for people with learning disabilities. It is evident that learning disability nurses are demonstrating a great deal of innovation in their practice, which is so important and so worthy of celebration.'

Dr Peter Carter - Chief Executive and General Secretary of The Royal College of Nursing, UK.

'The Foundation for People with Learning Disabilities believes strongly that specialist learning disability nurses have a vital continuing role in securing improved health for the UK population of people with learning disabilities. This embraces in particular four kinds of work:

- helping people with learning disabilities (with their families and supporters) to understand what they can do to promote and protect their own health*
- training and supporting mainstream health services and social care services to provide better care and support to people with learning disabilities*
- contributing to service design for individuals, or leading this for people with more complex health needs*
- direct health interventions with the growing population of people with more complex health needs'.*

Dr Alison Giraud - Saunders - Foundation for people with Learning Disabilities

'People with learning disabilities are more vulnerable, have more complex health needs and have more frequent contact with healthcare professionals than people in the general population. The combination of high student attrition rates and a decline in the numbers of pre-registration learning disability nurses being commissioned form a perfect storm which could lead to a future workforce insufficient to meet the needs of people with learning disabilities. The NMC therefore welcome this report which brings to light the importance of training a future workforce to meet the needs of people with learning disabilities.

In 2010 the NMC set new standards for pre-registration nursing education programmes with learning disabilities nursing as one of the four core fields of practice. Our quality assurance process for new pre-registration programmes is explicit in insisting field specific learning opportunities start from day one. Programmes must demonstrate that sufficient resources are in place to support practice as well as academic learning and also that progression assessments are set throughout the course to ensure students are fit to practise at the point of qualification. Under the new curricula the specific requirements of learning disabilities must be recognised.

It is a priority for the NMC to support the development of learning disabilities nurses and we are appointing a nursing advisor with specific expertise in the field to focus on this priority group of nurses'.

Professor Dickon Weir - Hughes - Chief Executive Officer and Registrar of the Nursing and Midwifery Council for the UK

'CQC supports the findings of this review. Our Essential Standards of Quality and Safety expect that providers have sufficient numbers of staff with the right competencies and skills and experience to meet the needs of people who use services. We recognise that specialist learning disability nursing has an important role to play in ensuring that the sometimes complex needs of people with learning disabilities are recognised and met in both specialist and non- specialist settings'.

Dame Jo Williams - Chair of the Care Quality Commission

'I am delighted to be able to endorse this informative and important report on learning disability nursing.

It is imperative that people with a learning disability receive the highest quality healthcare because of the increased complexity of their needs. Learning disability nurses are an invaluable resource when it comes to ensuring that these needs are met, so the diminishing numbers of these highly skilled staff highlighted in this report makes for worrying reading.

The 'Learning Disability Nursing' report offers astute observations and solutions to the challenges that may face learning disability nurses in the future. I hope that the views it offers will be given the consideration they deserve so that learning disability nurses can continue to carry out their roles at a high standard'.

Rt. Hon. Tom Clarke MP – Chair of the all party learning disability group

'This is a very important publication about the essential work carried out by these specialist nurses.

Mencap's Death by indifference report highlighted the tragic consequences that can result from a breakdown in the quality of care received by people with a learning disability. Too often this is as a consequence of a lack of knowledge about the needs of patients with a learning disability.

It is vital that learning disability nurses are recognised as being a valuable resource, to ensure that people receive the highest quality of healthcare'.

The Lord Rix Kt CBE DL – President of Mencap

8.0 Conclusions

The task and finish group has concluded that;

- 8.1 following triangulation and analysis of data from the Nursing and Midwifery Council UK, the Royal College of Nursing UK, Strategic Health Authorities, England, the Council of Deans UK, the Centre for Workforce Intelligence and the Department of Health England, concerning qualified learning disability nurses, and learning disability nursing student numbers that the **veracity of this collective data has to be treated with extreme caution** (See pages 9 - 14).
- 8.2 that **learning disability nurses' are increasingly being sought to work in child and adolescent mental health teams, acute hospitals** as acute liaison nurses, in the **Criminal Justice System** in a variety of roles and in the **third sector**, and **some are being 'head hunted'** for their specific skills primarily in Australia and New Zealand to work in forensic services as well as in the remaining **specialist National Health Learning Disability services - and this includes Community Learning Disability Teams** (See pages 14 - 18)

- 8.3 there is irrefutable evidence of a reduction in the numbers of learning disability nurses being employed by the National Health Service, it is **not reliably known** how many of these nurses have moved into the third sector, or have been TUPEd into the wider health and social care economies or have retired, and we believe current restructuring of local authority and National Health Services is ‘fast tracking’ **early retirement of learning disability nurses**, especially those who have worked at senior level and with significant experience (See page 9 - 12).
- 8.4. the future learning disability nursing workforce is likely to be compromised by, in addition to 8.1, 8.2 and 8.3, **insufficient commissioning, failure to recruit to commissions and high attrition** and equally we believe that there is real evidence of specialist learning disability nursing Continuing Professional Development being under commissioned if at all.

9.0 Recommendations

Drawing on our analysis of professional interpretation of the evidence available the Learning Disabilities Task and Finish Group would **recommend to the Professional Advisory Board for Nursing and Midwifery for England** that;

- 9.1 **education commissioning for this specialist field of nursing at both pre and post qualifying level moves to a regional commissioning model, and that the delivery of education for this field of practice is provided through a limited number of regional academic centres** informed by all key stakeholders on an ongoing basis - adopting a ‘hub and spoke’ model as envisaged by the Department of Health (Department of Health, 2010) and **monitored by a national group** (See page 17).
- 9.2 an **effective national recruitment campaign is considered** to ‘boost’ levels of recruitment, and thus avert compromise to this specialist nursing workforce in the short to medium term. This should be undertaken simultaneously within a detailed review and articulation of a clear career structure for this ‘field’ of practice. Whereas it is clear that we need to significantly increase the number of entrants to pre-registration learning disability nursing that alone will not be sufficient to address the many challenges outlined in this report. It is attention to the totality of this field of nursing, and the likely nursing careers for the future that deserves wider attention (See pages 12 - 14).
- 9.3 due regard and further work be considered that draws on evidence from the Improving Health and Lives - Learning Disabilities Public Health Observatory, and the confidential enquiry currently being undertaken by the Norah Fry Centre for Research into premature deaths to **inform and direct nursing interventions to improve the health and well being of people with learning disabilities** (See pages 6 - 8).
- 9.4 further work (research) be considered to **identify the specialist learning disability nursing contribution to a reduction in preventable deaths -**

(National Health Service Outcomes Framework, 2011/12; Improving Health and Lives - Glover and Ayub, 2010) (See pages 6 - 8).

- 9.4 further work be considered [this could build on the excellent work that the Royal College of Nursing has embarked on] to **identify and articulate new and emerging areas of practice for learning disability nursing that contribute to the health and well being of this group of people** and this be formally transmitted to the Director for mental health and learning disabilities at the Department of Health on an ongoing basis to inform 9.2 (See pages 14 - 15, 15 - 16).
- 9.5 it should consider recommending the **articulation and promotion of nursing roles within 'mainstream' services that might benefit from learning disability nurse appointments** to bring about greater skill mix to National Health Services, and that might simultaneously assist the inclusion and experience of people with learning disabilities in those services, current examples include; Child and Adolescent Mental Health Services, children with life limiting conditions and liaison nurses (See pages 14 - 15, 18 - 20).
- 9.6 it consider the urgent need for **engagement with the third sector to better understand future workforce requirements**. This is especially relevant within the context of current education commissioning, failure to recruit to commissions, attrition and retirement threats' - all potentially leading to a compromised workforce. The new Education White Paper (Department of Health, 2010) articulates a mechanism for engaging with the independent sector. It is recommended that this should be embarked upon at the earliest possible opportunity, and bring together regional networks to be overseen nationally to ensure that **compromise of this workforce is avoided such as that recently witnessed at Winterbourne View Hospital** (See pages 9 - 10, 15 - 18).
- 9.7 the Royal College of Nursing with the four Departments of Health nursing leads take opportunity to **re-establish the unique contribution of learning disability nursing from a United Kingdom perspective** to promote the health and well being of people with learning disabilities, and acknowledge that this contribution can be made by these nurses in a wide variety of health and social care settings (See page 16).
- 9.8 it is recognised there is a need to influence the **establishment, by the National Institute of Clinical Excellence, of evidence based guidelines for future commissioning in learning disability, and in particular the type of workforce needed to support some individuals with learning disabilities - particularly those with profound learning disabilities and complex needs** (See page 6 - 8).

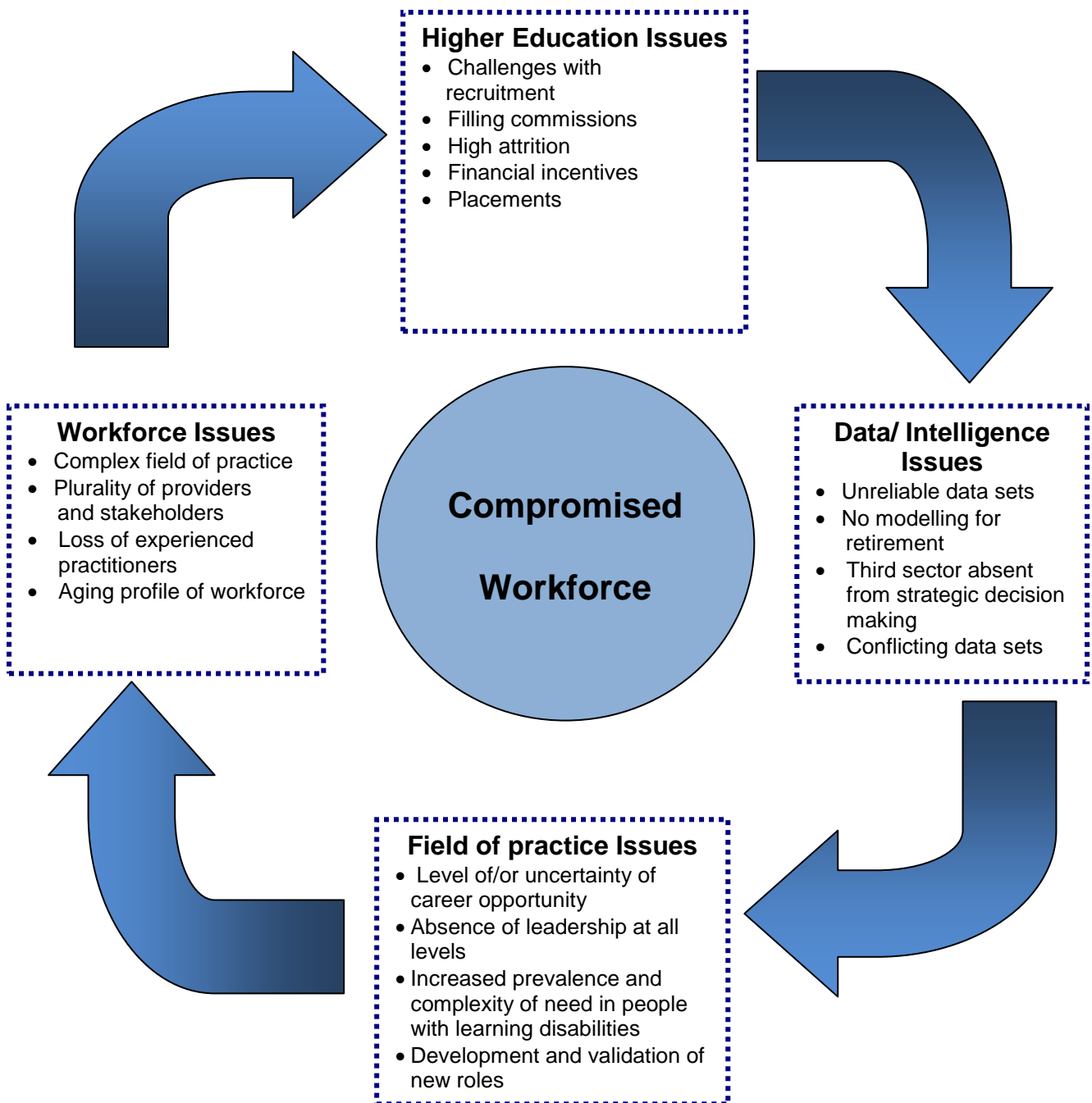


Figure 1 Four major factors compromising the future contribution of learning disability nursing to the health and well being of people with learning disabilities.

Membership of the Group

Sue Beacock, Senior Lecturer in Learning Disability Nursing, University of Hull.

Jim Blair, Consultant Nurse Learning Disabilities, St. George's Healthcare NHS Trust, Senior Lecturer Learning Disabilities, Kingston University/St. George's, University of London.

Paula Braynion, Director of Operations and Nursing, Calderstones Partnership NHS Foundation Trust.

Janet Cobb, Associate Consultant, The Foundation for People with Learning Disabilities.

David Ferguson, Consultant (Nurse and Academic) Practitioner, Hampshire Partnership NHS Foundation Trust and University of Southampton

Professor Bob Gates, Academic and Professional Lead for Learning Disability, School of Nursing Midwifery and Social Work, Faculty of Health, University of Hertfordshire (Chair).

Dr Bob Hallawell, Academic Lead Learning Disabilities, School of Nursing, Midwifery and Physiotherapy, University of Nottingham.

Professor Duncan Mitchell, Manchester Metropolitan University, Senior Research Advisor - Manchester Learning Disability Partnership.

Jackie Kelly, Head of School of nursing, midwifery and social work, Faculty of Health, University of Hertfordshire.

Gwen Moulster, Consultant Nurse, Haringey, London.

Annie Norman, Professional Advisor for Learning Disabilities, The Royal College of Nursing.

Alison Pointu, Director of Nursing and Quality, Barnet PCT.

Dr Ben Thomas, Professional Adviser for Mental Health and Learning Disability Nursing Professional Leadership Team Department of Health

Professor John Turnbull, Director of Nursing and Quality, The Ridgeway Partnership NHS Trust.

Jacky Vincent, Lead Nurse Learning Disability and Forensic Services Hertfordshire Partnership NHS Foundation Trust.

The group would like to thank the help supplied by the Calderstones Partnership NHS Trust for additional commentary and input to this report. Also in particular the contribution of Ian Hall, Head of Learning and Development, Calderstones Partnership NHS Trust and Daniel Marsden, Practice Development Nurse, East Kent Hospitals University NHS Foundation Trust.

References

Alaszewski, A Gates, B Ayer, S Manthorpe, G and Motherby, E (2001) *Education for diversity and change: Final report of the ENB-funded project on educational preparation for learning disability nursing*. Schools of Community and Health Studies and Nursing. The University of Hull.

Barr, O Gates, B (2008) Education for the Future: The Changing Face of Education for Staff. *Tizard Learning Disability Review*. 13. (1). 18-27.

BBC (2011) *Undercover Care: The abuse Exposed*. London. BBC.

Beacock, S (2010) *Report of the Workforce Development Project - Independent sector impacts - evidence and issues*. Hull. NHS Yorkshire and the Humber on behalf of the Directors of Mental health and learning disability services.

Blytin, P (2011) *Interim Report to the Learning Disability Nursing Task and Finish Group for the Nursing and Midwifery Advisory Board*. NHS West Midlands. [Personal Communication to Gates, B February 2011].

British Medical Association (2007) *Foetal alcohol spectrum disorders*. London. BMA.

Centre for Workforce Intelligence (2011) *Workforce Summary - Learning Disabilities Nursing - Winter 2010*. Centre for Workforce Intelligence. London. [Personal Communication to Gates, B January 2011].

Disability Rights Commission (2006) *Equal Treatment: Closing the Gap*. London. Disability Rights Commission.

Department for Education (2011) *Support and aspiration: A new approach to special educational needs and disability A consultation Presented to Parliament by the Secretary of State for Education by Command of Her Majesty*. Cm 8027. London. HMSO.

Department of Health (2001) *Valuing People: a New Strategy for Learning Disability for the 21st Century. Towards Person Centred Approaches: Planning with People*. London. SO.

Department of Health (2009) *Valuing People: Now*. London: Department of Health.

Department of Health (2009) *The Bradley Report: Lord Bradley's Review of People with Mental Health Problems or Learning Disabilities in the Criminal Justice System*. The Stationary Office. London.

Department of Health (2010) *Liberating the NHS: Developing the Healthcare Workforce*. London. HMSO.

Disability Rights Commission (2006) *Equal Treatment: Closing the Gap*. London. Disability Rights Commission.

Emerson, E and Hatton, C (2008) *People with learning disabilities in England*. CeDR Research Report. 2008 1.

Emerson, E Hatton, C Roberson, J Roberts, H Baines, S and Glover, G (2010) *People with learning disabilities in England 2010. Improving Health and Lives*. University of Lancaster. Learning Disabilities Public Health Observatory.

Emerson, E and Baines, S (2011) Health inequalities and people with learning disabilities in the UK. *Tizard Review*. 16 (1). 42-48.

Emerson, E and Hatton, C (2008) *People with learning disabilities in England*. CeDR Research Report. 2008 1.

Gates, B (2009) *The Valued People Project: Report of a strategic review of educational commissioning and workforce planning in learning disabilities*. South Central Strategic Health Authority. Newbury, Berkshire.

Gates, B (2010) When a workforce strategy won't work: Critique on current policy direction in England, UK. *Journal of Intellectual Disabilities*. 14. (4). 251 - 258.

Gates, B (2011) The Valued People Project: user views of learning disability nursing. *British Journal of Nursing*. 19(22) 1396 - 1403

Giraud-Saunders, A Gregory, M Poxton, R Smith, C Towell, D (2003) Valuing Health for all: PCTs and the health of people with learning disabilities. *Journal of Integrated Care*. 11(3). 26-33.

Glover, G and Ayub, M (2010) *How people with learning disabilities die*. IHaL. University of Lancaster. Learning Disabilities Public Health Observatory.

Health Care Commission for Healthcare Audit and Inspection (2006) *Joint Investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*. London. Health Care Commission for Healthcare Audit and Inspection and the Commission for Social Care Inspection.

Health Care Commission for Healthcare Audit and Inspection (2007a) *A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England*. London. Health Care Commission for Healthcare Audit and Inspection.

Health Care Commission for Healthcare Audit and Inspection (2007b) *Investigation into services for people with learning disabilities provided by Sutton and Merton Primary Care Trust*. London. Health Care Commission for Healthcare Audit and Inspection.

House of Lords House of Commons Joint Committee on Human Rights (2008) *A Life Like Any Other? Human Rights of Adults with Learning Disabilities*. London: The Stationery Office Limited.

Kirk, S (2008) *Young People's Experiences of Living with Medical Technology*. Manchester. University of Manchester.

Mair, R (2009) Trying to get it right with campus closure. *Learning Disability Today*. August/September. 9 (6). 10 – 11.

- Malin, N and Race, DG (2010) The impact of social policy on changes in professional practice within learning disability services: different standards for children and adults? A two-part examination: Part 1. The policy foundations: from welfare markets to valuing people, personalization and Baby P. *Journal of Intellectual Disabilities*. 14. (4). 315-328.
- Mansell, J (2010) *Raising our sights: services for adults with profound intellectual and multiple disabilities*. University of Kent. The Tizard Centre.
- Mansell, J Ritchie, F and Dyer, R (2010) Health service units for people with intellectual disabilities and challenging behaviour or mental health problems. *Tizard Learning Disability Review*. 15. (4). 45 – 50.
- Manthorpe, J Alaszewski, A Motherby, E Gates, B Ayer, S (2004) Learning Disability nursing: a multi - method study of education and practice. *Learning in Health and Social Care*. 3. (2). 92-101.
- Mencap (2007) *Death by Indifference: Following up the Treat me right! Report*. London. Mencap.
- Michael Report (2008) *Healthcare for All: Report of the independent inquiry into access to healthcare for people with learning disabilities*. London. HMSO.
- National Health Service (2010) *NHS Vacancies Survey England*. National Health Service. The Health and Social Care Centre. London
- Northway, R Hutchinson, C and Kingdon, A (2006) *Shaping the Future: A Vision for Learning Disability Nursing*. UK. UK Learning Disability Consultant Nurse Network.
- Parliamentary and Health Ombudsmen (2009) *Six Lives: The provision of public services to people with learning disabilities*. The Stationary Office. London.
- Royal College of Nursing (2011) *Learning from the past-setting out the future: Developing learning disability nursing in the United Kingdom*. London. RCN.
- Sines, D and McNally, S (2007) An investigation into the perceptions of clinical supervision experienced by learning disability nurses. *Journal of Intellectual Disabilities*. 11. (4). 307 - 328.

Appendices

Appendix 1

	Community learning Disabilities (FTE)	Other learning Disabilities (FTE)	Community learning Disabilities (headcount)	Other learning Disabilities (headcount)
All qualified nursing, midwifery & health visiting staff	2,734	3,085	2,908	3,217
Nurse consultant	25	14	27	14
Modern matron	24	59	25	61
Community matron	-	-	-	-
Manager	132	172	138	177
Registered nurse - Children	-	-	-	-
Registered midwife	-	-	-	-
Health visitor	-	-	-	-
District nurse	-	-	-	-
School nurse	-	-	-	-
Other 1st level ¹	2,504	2,749	2,663	2,866
Other 2nd level ¹	49	91	55	99

Table 1 Data from the CfWI Source: NHS Information Centre Census 2009, as at September 2009

Appendix 2

England as at September 2009														headcount
	England	North East	North West	Yorkshire and the Humber	East Midlands	West Midlands	East of England	London	South East Coast	South Central	South West	Special health authorities and others		
All qualified nursing, midwifery & health visiting staff	395,229	23,153	59,779	39,728	30,970	41,642	36,965	67,914	27,493	25,956	39,491	2,138		
Community Learning Disabilities	3,126	290	421	377	252	538	433	247	174	156	238			
Nurse Consultant	27	5	11	1	-	1	2	5	-	2	-			
Modern Matron	25	4	1	2	1	7	5	3	1	-	1			
Manager	138	14	29	14	5	14	16	7	13	15	11			
Other 1st level	2,880	258	379	350	246	514	405	214	152	137	225			
Other 2nd level	56	9	1	10	-	2	5	18	8	2	1			
Other Learning Disabilities	3,498	508	453	378	413	504	376	161	272	248	185			
Nurse Consultant	14	1	-	2	2	4	-	4	1	-	-			
Modern Matron	61	9	14	8	3	8	4	2	4	5	4			
Manager	178	25	20	34	29	8	6	10	11	22	13			
Other 1st level	3,146	466	418	325	362	476	361	118	235	217	168			
Other 2nd level	99	7	1	9	17	8	5	27	21	4	-			
Source: The NHS Information Centre for health and social care 2009 Non-Medical Workforce Census © 2010 The NHS Information Centre. All rights reserved.														
England as at September 2009														full time equivalent
	England	North East	North West	Yorkshire and the Humber	East Midlands	West Midlands	East of England	London	South East Coast	South Central	South West	Special health authorities and others		
All qualified nursing, midwifery & health visiting staff	322,425	19,826	50,219	33,437	25,097	34,251	28,884	55,675	21,650	21,025	30,703	1,657		
Community Learning Disabilities	2,734	258	392	330	214	457	381	209	152	137	204			
Nurse Consultant	25	4	10	1	-	1	2	5	-	2	-			
Modern Matron	24	4	1	2	1	6	5	3	1	-	1			
Manager	132	14	29	13	5	14	14	7	13	14	11			
Other 1st level	2,504	228	352	305	208	434	355	178	131	120	191			
Other 2nd level	49	8	1	9	-	2	4	17	6	2	1			
Other Learning Disabilities	3,085	478	415	335	365	428	279	151	255	221	159			
Nurse Consultant	14	1	-	2	2	4	-	4	1	-	-			
Modern Matron	59	9	14	7	3	8	4	2	4	5	4			
Manager	172	24	19	33	28	8	6	10	10	20	13			
Other 1st level	2,749	438	381	284	316	401	265	112	220	191	142			
Other 2nd level	91	6	1	9	16	7	4	24	20	4	-			
Source: The NHS Information Centre for health and social care 2009 Non-Medical Workforce Census © 2010 The NHS Information Centre. All rights reserved.														

Table 2 Data from the DH, Service Priorities
Workforce Capacity September 2009

Appendix 3

England as at 30 Sept each year

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Net Change 1995 - 2008		
Psychiatry Headcount	38,490	38,827	39,109	38,141	38,999	39,529	41,539	42,654	44,726	47,390	48,553	48,478	48,499	49,113	Psychiatry Headcount	+10,623	+27.6%
Psychiatry FTE	34,980	35,444	35,296	34,627	34,974	35,804	36,973	38,176	39,383	41,585	42,529	42,716	42,602	43,299	Psychiatry FTE	+8,319	+23.8%
Participation Rate (FTE:HC)	90.9%	91.3%	90.3%	90.8%	89.7%	90.6%	89.0%	89.5%	88.0%	87.8%	87.6%	88.1%	87.8%	88.2%	Participation Rate (FTE:HC)		-2.7%
Learning disabilities Headcount	12,504	12,105	11,111	10,736	9,923	9,497	9,776	9,550	8,950	8,656	8,824	7,583	7,618	7,197	Learning disabilities Headcount	-5,307	-42.4%
Learning disabilities FTE	11,310	10,714	9,883	9,329	8,775	8,398	8,440	8,323	7,824	7,526	7,367	6,767	6,593	6,232	Learning disabilities FTE	-5,078	-44.9%
Participation Rate (FTE:HC)	90.5%	88.5%	88.9%	86.9%	88.4%	88.4%	86.3%	87.2%	87.4%	86.9%	83.5%	89.2%	86.5%	86.6%	Participation Rate (FTE:HC)		-3.9%
Community services Headcount	43,013	44,914	45,898	47,601	48,972	50,481	52,401	53,814	57,588	61,559	63,257	62,343	61,997	64,387	Community services Headcount	+21,374	+49.7%
Community services FTE	33,040	34,399	34,422	35,299	36,058	36,871	38,221	39,302	41,850	44,989	46,917	47,338	47,448	49,746	Community services FTE	+16,706	+50.6%
Participation Rate (FTE:HC)	76.8%	76.6%	75.0%	74.2%	73.6%	73.0%	72.9%	73.0%	72.7%	73.1%	74.2%	75.9%	76.5%	77.3%	Participation Rate (FTE:HC)		0.4%
Education staff Headcount	1,883	806	665	665	658	758	903	985	1,147	1,346	1,336	1,285	1,180	1,424	Education staff Headcount	-459	-24.4%
Education staff FTE	1,746	733	582	568	562	662	760	819	968	1,140	1,119	1,079	1,004	1,147	Education staff FTE	-599	-34.3%
Participation Rate (FTE:HC)	92.7%	90.9%	87.5%	85.4%	85.4%	87.3%	84.2%	83.1%	84.4%	84.7%	83.8%	83.9%	85.1%	80.6%	Participation Rate (FTE:HC)		-12.2%

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 (Link)
 Published by the Information Centre

Table 3 Data from the Department of Health, showing an annual year on year reduction in learning disability nursing numbers

Appendix 4

		2010	2009	2008	2007	2006	2005	2004	2003	2002	2001
RN5	England	9057	9497	10168	10764	11113	11690	12146	12537	12841	12155
	N Ireland	417	434	461	484	502	518	527	537	537	501
	Scotland	1415	1465	1564	1659	1732	1736	1796	1875	1899	1817
	Wales	530	554	589	623	652	650	671	710	686	650
	Total	11419	11950	12782	13530	13999	14594	15140	15659	15963	15123
RN6	England	2860	3014	3277	3517	3695	3913	4112	4277	4434	4309
	N Ireland	5	6	7	8	8	11	12	12	13	9
	Scotland	25	28	29	32	35	31	28	31	32	32
	Wales	199	209	218	236	251	252	267	281	285	286
	Total	3089	3257	3531	3793	3989	4207	4419	4601	4764	4636
RNLD	England	6653	6485	6225	5867	5447	5082	4690	4180	3602	2870
	N Ireland	305	287	277	266	264	241	221	222	208	172
	Scotland	554	556	549	538	507	458	436	425	385	328
	Wales	337	309	300	290	268	242	208	190	155	122
	Total	7849	7637	7351	6961	6486	6023	5555	5017	4350	3492
SPCLD	England	355	352	344	344	320	301	277	248	211	178
	N Ireland	18	15	12	10	8	7	3			
	Scotland	40	38	39	37	34	29	24	22	15	11
	Wales	37	36	39	39	35	31	24	17	15	14
	Total	450	441	434	430	397	368	328	287	241	203
SPLD	England	49	47	47	42	39	27	18	12	10	2
	N Ireland	6	3	3	2						
	Total	55	50	50	44	39	27	18	12	10	2

Table 4 Numbers of RN5, RN6, RNLD, SPCLD, SPLD who have held effective registration over the last 10 years obtained from the Nursing and Midwifery Council.

		2011	2010	2009	2008	2007	2006	2005	2004	2003	2002	2001
RN5	England					2	3	14	14	17	26	46
	N Ireland						1	1	4	2	2	1
	Scotland											3
	Wales						2	3	4	2	4	6
RNLD	England	5	416	535	577	534	545	533	621	557	587	482
	N Ireland		21	16	19	13	18	24		18	33	30
	Scotland		22	36	29	52	33	45	32	53	47	56
	Wales		29	21	31	24	18	26	23	29	32	25
SPCLD	England		5	7	9	27	30	27	31	31	31	57
	N Ireland		5	6	2	3		4	5			
	Scotland		3	2	1	3	4	4	3	7	4	4
	Wales					3	6	8	6	2	5	8
SPLD	England		3	1	5	4	8	14	9	4	9	1
	N Ireland				1	4						

Table 5 Number of students who completed training [registered] in these parts over the last 10 years obtained from the Nursing and Midwifery Council

Appendix 5

Figure 1 Learning Disability Nursing Commissions 2007-08 to 2010-11

		Q30	Q31	Q32	Q33	Q34	Q35	Q36	Q37	Q38	Q39	ENGLAND TOTAL
		NHS NORTH EAST	NHS NORTH WEST	NHS YORKSHIRE & THE HUMBER	NHS EAST MIDLANDS	NHS WEST MIDLANDS	NHS EAST OF ENGLAND	NHS LONDON	NHS SOUTH EAST COAST	NHS SOUTH CENTRAL	NHS SOUTH WEST	
2010-11 Planned Commissions	Degree	28	72	72	13	0	21	30	0	21	14	271
	Diploma	57	48	96	53	111	35	37	18	24	27	506
	Total	85	120	168	66	111	56	67	18	45	41	777
2009-10 Actual Commissions	Degree	29	49	27	10	5	42	25	0	42	14	243
	Diploma	62	64	102	56	106	38	42	15	0	27	512
	Total	91	113	129	66	111	80	67	15	42	41	755
2008-09 Actual Commissions	Degree	31	18	25	5	0	45	25	0	8	9	166
	Diploma	61	76	61	47	68	49	37	9	26	29	463
	Total	92	94	86	52	68	94	62	9	34	38	629
2007-08 Actual Commissions	Degree	22	16	24	3	3	15	22	0	9	9	123
	Diploma	55	40	64	56	115	60	35	10	33	26	494
	Total	77	56	88	59	118	75	57	10	42	35	617

2010-11 Learning Disability Nursing Student Population

		Q30	Q31	Q32	Q33	Q34	Q35	Q36	Q37	Q38	Q39	ENGLAND TOTAL
		NHS NORTH EAST	NHS NORTH WEST	NHS YORKSHIRE & THE HUMBER	NHS EAST MIDLANDS	NHS WEST MIDLANDS	NHS EAST OF ENGLAND	NHS LONDON	NHS SOUTH EAST COAST	NHS SOUTH CENTRAL	NHS SOUTH WEST	
2010-11 Student Population	Degree	43	132	74	7	4	76	82	2	19	38	478
	Diploma	155	139	204	123	216	102	95	25	201	67	1,328
	Total	198	271	278	130	221	178	177	27	220	106	1,806

Learning Disability Attrition Data

COURSES STARTED IN		National % Attrition
2005/06	Degree	18.89
	Diploma	26.70
2006/07	Degree	16.06
	Diploma	32.00
2007/08	Degree	10.11
	Diploma	34.13

Table 6 Actual/planned commissions/student population/ and attrition data obtained from the Department of Health

Appendix 6

Recruitment 2009/2010	Intentions for 2011/2012	AEI's where LD nursing is commissioned	Attrition	Comparison of attrition to overall attrition
93	81	Northumbria 30 Teesside 51	25%	17.50%
122	120	Chester 28 Edge Hill 28 Cumbria 35 Salford 29	18.50%	24.90%
111	78	Sheffield Hallam 27 Huddersfield 28 Hull 14 York 22 Leeds 38*	19%	16.50%
55	55	Northampton 18 De Montfort 10 Nottingham 27	7.55%	ad 10.9%; ch 8.26%; mh 10.12%
46	45	Southampton 12 Oxford Brookes 16 TVU 14 Northampton 6 Bedfordshire 0 Hertfordshire 45-from Sept 2011	17.79%	9%
65	67	TVU 20 Greenwich 5 Herts 5 LSBU 25 Joint programme SW Kingston 12 Anglia Ruskin 7 - no more from 2011	10%	17%
37	35	West of England 35	38%- 2009 Plymouth Bournemouth/ Plymouth 16%	14%
9	16	Greenwich 13 Kingston 9	1 from 7 left 0 left of the 3 in Surrey	12.40%
78	40	Anglia Ruskin 35 no more from 2011 Hertfordshire 20 (2011) (35 previously) East Anglia 20 (2011) (10 previously)	10.30%	5.20%
97	85	Birmingham City 35 Coventry 13 Keele 14 Wolverhampton 23	38%	24%
		Commission intention =558 as above		

Table 7 Strategic Health Authorities Returned Data

Appendix 7

Results of LD Nursing Survey				
Name of Institution	LD commissions for 2010/11	Places taken up	Level of attrition	Marketing strategies
University A		0	N/A	I believe that our Branch transfers have been due to all students undertaking a year 1 learning disability placement, in good, well supported placement areas
University B		11	9	2.63%
University B		25	23	varies as such low numbers create quite high percentages in any one year 10-40%
University C		20	22	23%
University D		13	13	28.57
University E		12	10	16.7% attrition rate for course 2009/10 NHS london report figures
University F		25	24	
University G		28	28	Commissions tend to remain stable, with some students leaving the branch, but others transferring in. 9%
University H		20	12	minimal - very few leave, 10% across the 3 cohorts
University I		30	30	8%
University J		25	26	
University K		70	10 and we have candidates to interview until July 2011	3%
University L		37	37	Adv Dip/ Dip HE March 07 16% BSc (Hons) Sept 07 17% Adv Dip/ Dip HE Sept 07 0%
University M		14	5 places offered to date, still interviewing, candidates have not yet gone Conditional Firm on UCAS.	21% for Diploma 21% for Degree
University N		30	29	0710 - 31% 0809 - 39% 0909 - 3% 1009 - 0%
University O		26	26	0%
University P		25	25	20%
University Q		10	10	0
University R		25	25	c10%
University S	We have been decommissioned from Sept 2011; we took an intake in of 15 in Sept 2010	All of them (NAI was 16 and we filled those places)	Average is about 20% as per other branches	Joint award with social work.
University T	we used to deliver community learning disability nursing, but the local providers did not release staff to attend this full time and part time provision. We therefore withdrew it from our portfolio.	N/A	N/A	
University U		38	38	
University V (Non-England)	We do not provide pre reg nursing. Only post reg SPQ programs provided and the numbers alter each year, but downward for hte past two years and no SPQ courses in learning disability have run.			Previous DHSSPS sponsored recruitment campaign for Mental health and learning disability was successful in increasing number of applications and success recruits
University W (Non-England)		30	30	5%

Table 8 Council of Deans Returned Data

Appendix 8



Figure 2 Topography of English Higher Education Institutions providing Learning Disability Nurse Education⁸.

⁸ Those Institutions * will only be running these courses until 2013