Shaping the Future:

A Vision for Learning Disability Nursing

UK Learning Disability Consultant Nurse Network
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Shaping the Future: A Vision for Learning Disability Nursing

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**Forward**

Developing the vision for nurses specialising in addressing the health inequalities experienced by people with learning disabilities is timely and welcome as the evidence base clearly demonstrates people with learning disabilities experience significant health needs that frequently go unmet.

This has a significant impact on their quality of life and it is therefore essential for nurses to clearly identify the range of contributions that they can make in addressing those needs.

The Royal College of Nursing Learning Disability Forum is committed to working with people with learning disabilities and their carers to promote health improvement and wider social inclusion. The forum recognises that the vision set out in this report will be invaluable for all people and services involved in the provision of health and social care for people with learning disabilities.

*Michelle Persaud*  
*Chair of Learning Disability Forum, Royal College of Nursing*

The national network of learning disability nurses is delighted to support the publication of the vision for learning disability nurses. All nurses wherever they practice have an important role in meeting the health needs of people with learning disabilities. Learning disability nurses have a vital contribution in working in partnership with people with learning disabilities, healthcare and social care services and the independent sector. By promoting and enabling effective networking and collaborative approaches to care, there is the opportunity for learning disability nurses to help address the health needs of people with learning disabilities across the United Kingdom.

*Caron Thomas*  
*Chair, National Network for Learning Disability Nurses*
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**Introduction**

This document has been produced as the result of collaboration between members of the UK Learning Disability Consultant Nurse Network and others who are involved in meeting the needs of people with learning disabilities.

The first section of the document describes a vision for the future of learning disability nursing and the purpose of the document. Section two considers the context from an historical and contemporary perspective, reflecting on the developments in learning disability nursing practice and evidence of health needs. Section three describes the building blocks for achieving this vision in key areas in which we believe all learning disability nurses have a role to play; **practice, education, leadership** and **research**. Sections four and five describe areas for action and provide recommendations for how these actions can be implemented.

Whilst this document is not intended to provide a definitive reference regarding the needs of people with learning disabilities, or the roles of learning disability nurses, a great deal of information was generated in the course of it’s production. Additional information that will be useful to learning disability nurses and others is included at the back of the document in the form of appendices.

Coming together as a UK wide network to write this document has placed the extraordinarily diverse roles that learning disability nurses undertake into sharp focus and resulted in some very informative and lively discussions. As a group of Consultant Nurses we all have a ‘practice’ component to our roles; lessons learnt from people with learning disabilities, and their families and carers, through our collective direct contact with them has been a major influence in shaping our vision and the contents of this document.

People with learning disabilities themselves do not constitute an homogenous group, and the social and cultural backdrop against which people live and work differs greatly across the UK. We have attempted to reflect this in our vision by focusing on broad principles for developments in health services for people with learning disabilities, and the contribution that nurses must make to these in order to ensure that they are equitable, of a high standard, and able to meet the needs of all people with learning disabilities.

We hope you will find this document informative and thought provoking. We have learned a great deal from each other and from all those who have been involved in producing it.
1. Vision & Purpose

The United Kingdom Learning Disability Consultant Nurse Network believes that in order for the learning disability nursing profession to progress into the 21st century, “with a renewed sense of purpose, devoid of confusion and ambiguity associated with the legacies of the past”, (Jukes and Bollard 2003) it needs a shared vision to promote, articulate, and drive the distinct identity and unique expertise of the learning disability nurse.

The aim of this document is to set out the direction of travel for learning disability nurses and provide a resource to help nurses to understand and articulate their contribution to the health needs of people with learning disabilities (see Appendix a for definitions). In setting out our vision, we recognised that some learning disability nurses across the UK have been at the forefront of practice and service development. However we also recognise that there are nurses who need clarity of purpose to enable them to develop.

Our vision is that:

**Learning disability nurses will lead the way in achieving positive health outcomes for people with learning disabilities. They will use an inclusive and collaborative approach to address barriers to social inclusion and will function as integral members of the wider family of nursing, developing and using their specialist knowledge and skills to improve the health and well being of children, adults and older people with learning disabilities across all settings.**

Learning disability nurses will realise this vision through the effective use of **SPECIALIST NURSING PRACTICE, RESEARCH, EDUCATION and LEADERSHIP**.

This document is aimed primarily at learning disability nurses registered with the Nursing and Midwifery Council (NMC) and those who are training to be learning disability nurses. Its content will also be useful to others who have professional contact with learning disability nurses for example other nurses, service commissioners, local authority services and independent (third) sector providers.

Over the last 30 years the settings in which learning disability nurses practice and the nature of their role, has both developed and expanded (Northway, 2004). Nonetheless no profession can rest on its laurels particularly in the context of rapidly changing and developing services. **This document therefore aims to empower learning disability nurses to:**

- Recognise and articulate their value and impact within a holistic approach to healthcare.
Develop their practice within the context of developing services in their country in the UK.

Reaffirm the place of learning disability nursing within the family of nursing and achieve equal value with other members of the nursing profession.

2. Context

When a professional group sets out a vision for its future development there is a danger that it could be interpreted simply as a means of preserving and promoting its own role. It is thus important to understand that the starting points for this document were:

- The recognition that learning disability services have undergone tremendous changes in the past three decades;
- That despite these changes people with learning disabilities continue to be marginalized, segregated and excluded;
- That there is growing evidence of a very high incidence of unmet physical and mental health needs, including behavioural difficulties, in the population of people with learning disabilities;
- That there is clear evidence that the health needs of many people with learning disabilities are complex, multiple and difficult to understand;
- That this has a negative impact upon many people’s quality of life;
- Our belief that the learning disability nursing profession makes a significant contribution to meeting the health needs of people with learning disabilities;
- That learning disability nurses need to keep step with modernisation and reform in the NHS;
- Recognition that the quality of the relationships nurses have with patients and their families helps sustain confidence in the NHS (DoH 1999).

2.1 Historical perspectives

In setting out a vision for the future we believe it is essential to recall and reflect on the legacies of the past. Many people with learning disabilities have always lived in community settings either with families, independently, or within Social Services’ hostel accommodation (Mental Health Foundation, 2001, Mencap, 1998). Between 1946, when the National Health Service was introduced, and 1971 when the Government (DHSS 1971) announced the need for closure of the long stay institutions, learning disability nurses worked exclusively in large ‘mental handicap’ hospitals. Historically these hospitals provided both community and home to many people with learning disabilities and the roles of nurses were very broad involving the delivery of all aspects of care and support. The day-to-day care that would now be recognised as specialist health provision has therefore traditionally been delivered within long stay institutions and been limited to those residing within them (Phillips et al, 2004).

The community is now fully recognised as the rightful place for people with learning disabilities (DH, 2001; Jones, 1999). This shift has resulted in the closure of most long stay hospitals with many learning disability nurses transferring their caring role from hospital to community settings. It has increasingly been recognised that some people have needs that cannot be met by their direct support staff or carers alone. This
recognition has been associated with the development of dedicated specialist health services in the community. In most areas these services have taken the form of teams of health professionals whose primary focus is on providing specialist health interventions to people with learning disabilities. Whilst the constitution of teams varies greatly from area to area most teams include a significant number of learning disability nurses.

The closure of long stay institutions has also seen the development of alternative specialist in-patient services in the NHS and by independent (third) sector providers. In the main these ‘hospital’ services no longer provide homes for life but have evolved, or been newly established, to provide dedicated in-patient services where people receive specialist health interventions and treatment. Much of the direct care, and a significant proportion of the interventions in these services are provided by learning disability nurses.

2.2 Philosophical Perspectives
A social care model of service provision, in keeping with changing philosophies of care, now predominates in most service settings. In some instances this has been associated with a neglect of health needs in the mistaken belief that a focus on such needs constitutes a drift back towards the medical model. There is also some confusion regarding the difference between a social model of service provision and the social model of disability. The former relates primarily to who provides the support that people with learning disabilities receive. The latter refers to a view of disability which argues that people with impairments are disabled by a range of physical, social, economic, psychological and attitudinal barriers that prevent or limit their full participation in society (Prime Ministers Strategy Unit, 2005). Ill health and behavioural challenges can and do limit participation in society. The primary focus of nursing interventions within the social model of disability is therefore upon reducing or eliminating barriers to good health and thereby increasing social inclusion.

It could be argued that the emphasis given to social models of service provision has resulted in some learning disability nurses having lost, or no longer seeing themselves as members of the wider “family of nursing”. We believe that the proactive involvement of all learning disability nurses in wider nursing developments will bring benefits for people with learning disabilities, their families and carers, and there is much that nurses from other branches of the profession can learn from their learning disability nursing colleagues.

2.3 Policy Context
Devolution of governmental responsibility for health and social care means that England, Scotland, Wales and Northern Ireland have each developed their own policies in relation to the provision of services for people with learning disabilities. Learning disability nursing also needs to be considered within the context of wider developments in nursing and
each country has developed its own policies in relation to nursing and, in some instances, specifically in relation to learning disability nursing (see Appendix b).

Since the closure of all but a few of the long-stay hospitals discreet nursing roles have emerged in both community settings and within mainstream and specialist hospital settings. Current policy calls for actions to ensure that people with learning disabilities are able to access mainstream healthcare provision equipped to meet their needs. Policies across all UK countries recognise that this cannot be achieved without active intervention and support from specialist learning disability health services that are not available from wider ‘mainstream’ health service provision.

Learning disability nurses play a crucial role by providing health assessment, treatment, intervention, education and support for people with learning disabilities, their carers, generic health services and others. This partnership approach between primary care, child health, mental health, acute care, other agencies and dedicated learning disability health services is essential.

2.4 The changing role of the learning disability nurse

Learning disability nurses have responded positively to radical changes in the way services are provided. They have adapted their practice in the face of close scrutiny and have largely moved away from working in closed institutional settings to community based practice in partnership with others.

Changes in the way services are provided have raised questions as to the appropriate role of specialist health services for people with learning disabilities. As a result there is sometimes a feeling amongst the learning disability nursing profession that their knowledge and skills are not fully valued, and that the contribution that they make to meeting the health needs of their client group is not fully recognised, understood, or utilised. Attention has revolved primarily around two questions:

- Whether the support needs of people with learning disabilities are primarily social or health in nature? and;
- Whether nursing support should be of a specialist or generic nature?

Responses to these questions have included a nursing curriculum based upon a social care model (ENB and WNB 1985) and the validation of joint training programmes in the 1980’s producing practitioners qualified as both learning disability nurses and social workers (Brown, 1994). The need for a completely new form of practitioner has also been considered, but rejected.

Cullen (1991) explored options for the role of the learning disability nurse within the context of changing responsibilities arising from new arrangements for community care. The preferred option was for the
health promotion role of the learning disability nurse to be advanced. It was argued that all people with learning disabilities had both health and social care needs although the level and complexity of these needs would vary from person to person. Cullen recognised that nurses could therefore work to address health needs across the range of settings in which people with learning disabilities live and work.

Kay et al (1995) confirmed the Government’s commitment to learning disability nursing. “Continuing the Commitment” sought to clarify and articulate the specific contribution of the learning disability nurse to the support and care of people with learning disabilities. Subsequent policy across the UK has re-affirmed this commitment and identifies the roles that specialist learning disability nurses will play in the delivery of both mainstream and specialist health services to people with learning disabilities.

2.5 Evidence of health needs
Evidence suggests that the number of people with learning disabilities will increase by about 1% over the next 15 years (DH, 2001). Greater numbers of people with learning disabilities are now surviving into adulthood and living longer into old age with many presenting with complex and multiple health needs (DH 2001). A study by the Disability Rights Commission due for completion in summer 2006 will no doubt contribute further to the evidence base regarding health needs. These factors have obvious implications for all services including those provided by learning disability nurses.

There is clear evidence that many physical health needs are more common and are present in greater number in people with learning disabilities (Howells 1986, Wilson and Haire 1990, van Schrojenstein Lantman-de Valk et al 1997). Evidence also points to a differing pattern of health needs and cause of death of this group (Cooper et al 2004), (see Appendix c). As a result people with learning disabilities, despite living longer than has previously been the case, can still expect to have a significantly shorter life expectancy (Hollins et al 1998, Patja 2000) and are much more likely than others in the population to die before the age of 50. Many people experience multiple health needs and life expectancy is shortest amongst people who have the most support needs (McGuigan et al 1995).

In addition to physical health needs people with learning disabilities are at greater risk of developing some psychological disorders, more likely to experience mental health problems, are frequently excluded from services as the result of challenging behaviour and often encounter insurmountable barriers regarding access to mainstream services.

Assessing both the physical and mental health needs of people with learning disabilities can be complex and as a result many health needs go unrecognised and untreated. This can have grave consequences for
some and will have a significant negative impact on the quality of life of the person with a learning disability, their family and carers.

As members of society people with learning disabilities have the right to be valued and supported as equal citizens. This includes the right to receive equitable health care. People with learning disabilities require access to all areas of the health service (DH 2001, Scottish Executive 2002b).

**Section 2 Summary**

- Learning disability nurses must remain true to their philosophical roots and use and create opportunities to challenge marginalisation, stigmatisation, segregation, exclusion and inequalities.

- The health agenda for people with learning disabilities is focused in two broad areas; promoting and maintaining good health and the delivery of specialist health and behavioural interventions. As a profession learning disability nurses must not invest a disproportionate amount of effort in one area at the expense of the other and must ensure that they are able to fulfil key roles in both these areas.

- Learning disability nurses have demonstrated that they are adaptable and flexible in the face of rapid change and close scrutiny. They must continue to adapt, working across service, agency and organisational boundaries to respond effectively to the wide variety of health needs experienced by people with learning disabilities. This group are at particularly high risk of exclusion from mainstream health services and nurses must take on a lead role to ensure that these barriers to healthcare are overcome.

- Learning disability nurses must develop the knowledge and skills to work with those with the most complex needs to ensure that people are able to remain in their own homes and communities.

- The range and complexity of health care needs of people with learning disabilities cannot be met by generic health care services alone. In order to meet the health needs of people with learning disability learning disability nurses must take on a lead role to achieve a partnership approach between dedicated learning disability health services and primary care, child health, mental health, acute care, other learning disability providers, people with learning disabilities and their families and carers.

- Learning disability nurses must ensure that they are fully aware of the developing evidence base regarding the health needs of, and disparities experienced by, people with learning disabilities. They must utilise this evidence to challenge inequalities and inequities in health and challenge the barriers to good health.

**3. Achieving the Vision**

To realise the vision in this document it is essential to consider the contribution nurses make in the areas of specialist nursing practice, research, education and leadership. It is also necessary to identify how learning disability nurses can make a contribution not only at the level of the individual client but also at a group and population level. This section will consider each of these components individually; in practice they should be seen as interlinking and interdependent (Figure 1).
3.1 Nursing Practice

Nursing practice should be seen as a combination of the attitudes, beliefs, experiences, knowledge and skills of the nurse and the way these interact to influence their work, both as an individual and with others, to meet the needs of people with learning disability.

Cullen (1991) commented that no profession could lay claim to a skill that could not be performed by someone else. Against a backdrop of modernisation across the health service role boundaries are diminishing and flexibility increasing. It would therefore be difficult to argue that learning disability nurses fulfil a unique role in terms of the tasks they undertake.

Learning disability nurses are however unique in being the only professional group who are trained exclusively to work with people with learning disabilities. It can be argued that what differentiates learning disability nurses from other health professionals is the breadth, depth and combination of skills and knowledge that are acquired through the process of becoming a registered nurse in learning disability. The ability of the learning disability nurse to make a unique contribution is further enhanced by the opportunities that exist, and that can be created, as the result of working as a health professional, and the frequency and level of contact that most nurses have with people with learning disabilities their families and carers.

Some nurses have gone on to gain more in-depth knowledge, experience and skills to develop one or more areas of their practice further, or to focus on work with a group of people who share a specific characteristic or diagnosis. The areas where learning disability nurses have deepened their knowledge and expertise include profound and multiple disabilities,
challenging behaviour and forensic needs, autistic spectrum disorders, mental health, epilepsy and dysphagia.

Specialist learning disability nursing services must remain flexible and adaptable. As dedicated health professionals nurses should be skilled at what they do and have first hand experience of working directly with people with learning disabilities with the most complex needs.

Good practice is that which combines a values led, person centred approach with the best available evidence when making clinical decisions in healthcare practice (Hincliff et al, 2003). Therefore learning disability nurses need skills in accessing, appraising and utilising evidence in order to plan, develop and deliver interventions designed to promote health gain and strong person centred values upon which to base their practice. Nurses should increasingly be able to demonstrate expertise, and be able to generate and draw upon an evidence base for their practice. These principles apply regardless of setting and whether the nurses’ practice is focussed primarily on facilitating access to mainstream health and other services, supporting people with complex care needs, working with people to help them with their behaviour or (as will be the case for most nurses working in dedicated learning disability services) involves a combination of all these roles and others.

Core themes can be considered to run through all learning disability nursing practice. The degree to which each individual nurse’s role is focussed on a particular core theme, or themes, will differ from post to post.

3.1.1 Learning Disabilities
First and foremost all learning disability nurses are specialists in the area of learning disability itself. Learning disability nurses can demonstrate an extensive knowledge of learning disability that enables them to carry out a range of functions and, when recognised, this is valued by other health professionals, service users and families.

Learning disability nurses play a key role in translating theoretical knowledge of learning disability into day-to-day practice and supporting others to understand the relationship between the needs people have and their level of cognitive and social functioning. Learning disability nurses are able to pair this knowledge with frequent contact with service users, their families and other carers and are therefore in a good position to ensure that issues which specifically arise as a result of learning disabilities are recognised and addressed.

3.1.2 Consent and Best Interests
Obtaining consent to treatment must be seen as a core theme in the work of learning disability nurses. Consent has several important functions. It affirms and safeguards the autonomy of the person, it fosters respect for the person and informed participation enhances the
quality of the healthcare experience (McParland et al 2000). Consent is essential in modern health care and is required within law for each of the four UK countries.

The practice of obtaining consent from people with learning disabilities can be difficult and may involve a series of complex decisions. It is often necessary to make a determination about the capacity of the person to give valid consent and, where it is decided that they lack capacity, the need arises to make decisions in a person’s best interests. Whilst historically it has been the evidence of psychiatrists and psychologists that has been relied upon, learning disability nurses are increasingly taking on an active role in the assessment of capacity and consent.

As the only professional group trained specifically within the field of learning disability, nurses are able to bring a broad understanding of the impact of cognitive impairment on the decision-making capabilities of the people they support. This information is important in making a determination of capacity to consent. Perhaps more importantly, interventions, education and support provided by learning disability nurses can enable some people with learning disabilities to retain and understand information therefore helping them to move from a position of being considered to lack capacity, to being informed sufficiently to make a choice and give valid consent.

3.1.3 Anti-discriminatory Practice
There is no doubt that people with learning disabilities are subject to discrimination on all levels. Mitchell (2000) argues that against a backdrop of discrimination and stigmatisation of people with learning disabilities learning disability nurses have been devalued by colleagues from other branches of nursing. Mitchell states that "the manner in which a person is devalued will affect the way that person behaves". It is therefore particularly important that learning disability nurses develop a sophisticated understanding of the nature of stigmatisation and discrimination. It is essential that learning disability nurses assume equal status with colleagues from other branches of nursing in order to challenge the discrimination experienced by many, if not most, people with learning disabilities.

It is crucial that nurses make effective use of the social and political aspects of their work and take advantage of all the opportunities available in their day to day practice to challenge discrimination and oppression in all its forms.

3.1.4 Behavioural Practice
The term challenging behaviour is a socially constructed umbrella concept embracing many meanings and a wide range and variety of interpretations (Slevin 1995). Studies suggest that 12 – 17% of people who are defined as having a learning disability will display ‘challenging behaviour’ (Emerson et al 1998, Kiernan & Alborz 1996, Emerson et al
making it a relatively common problem that can result in considerable practical difficulties and have adverse effects on health, quality of life and opportunities.

The way society responds to challenging behaviour in people with learning disabilities depends on a broad range of interrelated factors including the circumstances in which the behaviour occurs, the impact of the behaviour, the cognitive and social abilities of the person concerned and external cultural and societal factors. Challenging behaviour and offending behaviour are differentiated in the main by the level of understanding of the person with a learning disability and the societal response to the behaviour in question.

Understanding the causes of challenging behaviour in people with learning disabilities is extremely complex and developing positive behavioural supports has become a key focus of the work of many learning disability nurses.

The need to develop capacity across the wider health services is an important issue for the NHS. Learning disability nurses have a crucial role to play in building this capacity. However, this aim will not be achieved if specialist learning disability nurses neglect the key role that they must play in providing services that respond effectively to needs not otherwise provided for in the wider NHS. Learning disability nurses must continue to ensure that they have skills to work directly with people who develop behavioural challenges and offending behaviour and the credibility to work directly with the person and their carers, other professionals and partner agencies.

3.1.5 Access to Health Care

Regardless of other needs all people with learning disabilities need to access and utilise mainstream health services at some stage in their lives. Therefore the roles of all learning disability nurses may include working directly with people to enable this access and indirect work to influence the ability of mainstream health services to respond effectively to the physical and mental needs of people with learning disabilities. The differing levels of intervention relating to health need can be considered as being for everyday health needs, extra health needs due to the existence of learning disability, and complex health needs (see Appendix d).

3.1.6 Public Health

The purpose of public health is to improve all aspects of the health and well-being of the whole population. Public health policy has been developed separately for each of the countries within the UK (see Appendix b).

Achieving public health is everyone’s business and all healthcare professionals should maximise opportunities available within the scope of
their role to make a contribution. Public health is achieved through public health practice which:

- Takes a population perspective;
- Mobilises the organised efforts of society and acts as an advocate for the public’s health;
- Enables people and communities to increase control over their own health and well-being;
- Acts on the social, economic, environmental and biological determinants of health and well-being;
- Protects from, and minimises the impact of, health risks to the population; and
- Ensures that preventative, treatment and care services are of a high quality, based on evidence, and are of best value. (adapted from Skills for Health, 2004)

The evidence of health need among people with learning disability highlights a clear remit for learning disability nurses to address the wider public health needs of people with learning disabilities. People with learning disabilities need to be included in all the health improvement initiatives aimed at the whole population to ensure they have equity of access to national screening programmes, health education, and health promotion activities. In addition to this, many will require specific, targeted programmes, aimed at their differing health needs (NHS Health Scotland 2004, DH 2001).

An aspect of public health practice is the understanding of the needs of specific groups within the population in comparison to those of the remainder of the population. This process is known as Health Equity Audit. The evidence base for health need in Appendix c provides a population perspective, however, at a local level there is a need to undertake audits. Learning disability nurses, together with other health professionals in specialist learning disability services, have a key role to play in working with colleagues in public health to initiate and complete local audits and ensure that results inform the development of services.

3.2 Education
In order to fulfil the diverse range of roles required and respond to future developments in healthcare provision, learning disability nurses need to be prepared by innovative and forward thinking curricula. Both the content of educational programmes and the means by which they are delivered need to be flexible and adaptable to ensure they keep pace with change.

If the vision set out in this document is to be realised then it follows that learning disability nurses need to be able to address, at a range of levels, the factors which influence the physical and mental health needs of people with learning disability, and be able to use the best available evidence when doing so.

The changing nature of service provision and the rapidly expanding nature of knowledge means that a culture of life long learning must continue to be nurtured. The educational process must provide a vehicle
for the development of knowledge paired with real world opportunities to put this theoretical knowledge into practice. Pre-registration learning must enable students to develop skills to work in direct roles with people with learning disabilities who have the most complex needs and to work collaboratively with colleagues, both within and outside the health service, to respond more effectively to these needs. Life long learning should enhance and develop knowledge and skills further but should not loose sight of the core and unique components of the nurses’ role.

The NHS Knowledge and Skills Framework (DH 2003a) is concerned with the NHS investing in the ongoing development of all it’s staff. Each post outline developed will need to indicate the required post registration requirements for life-long learning.

In addition to uni-professional education there is much to be gained from engaging in shared and joint learning with other disciplines and agencies. Educational opportunities need to be delivered at certificate, diploma, bachelors, masters and doctoral levels in a manner which is sufficiently flexible to enable service users and carers to be involved in the educational process, meet the changing needs of people with learning disability and services, and in a manner that enables learning disability nurses to remain in practice.

3.2.1 Learning disability nurses as educators
All learning disability nurses play a role in the education of people with learning disabilities, their carers and families and other colleagues within services, this aspect is integral to learning disability nursing practice. Formal education of others is for some a small part of the role, where others specialise in education. The crucial skill is to maintain a focus on the role (as in the specialist nursing practice section) whilst integrating research and leadership into the education experience offered.

3.3 Leadership
"The only way we can predict the future is by gaining the positions of power and influence to shape things to come” (Faugier 2004). If learning disability nurses are to lead and shape their own destiny they must embrace the opportunities that have become available through NHS reform by taking on lead roles at all levels. This may present a challenge to nurses who have traditionally been dependant on both hierarchical structures of management and on senior staff (often from other disciplines) for direction.

The educational preparation and ongoing practice of learning disability nurses places them in a unique position. As registered nurses they are accountable for their own practice which must be based on contemporary and valid evidence, governed by the code and standards of the nursing profession (NMC 2004). With this profile learning disability nurses are well placed to take on leading roles.
However, leadership is not about being an expert in a specific area of clinical practice, or having lots of academic or professional qualifications. Whilst it is absolutely essential that nurse leaders are good at their jobs, these achievements alone do not equip people to lead others. Good leaders are those who possess and develop a range of personal qualities that enable them to influence and inspire others. Leaders are passionate, committed, and liberating. They demonstrate recognisable characteristics such as the ability to mobilise or influence the actions of others. They are empowering and demand high standards of themselves and others.

The NHS Leadership Qualities Framework (DH 2003b) provides a detailed description of the range of personal, cognitive and social qualities which contribute to good leadership. This framework can be used by individuals, teams and across services as the basis for development of leadership skills at all levels of practice. These are arranged in three clusters as follows:

- **Personal Qualities** - self-belief, self awareness, self management, drive for improvement and personal integrity.
- **Setting Direction** - Broad scanning, intellectual flexibility, seizing the future, political astuteness and drive for results.
- **Delivering the Service** - Leading change through people, holding to account, empowering others, effective and strategic influencing and collaborative working.

Poor clinical leadership leads to poor standards of care (DH 1999). Learning disability nurses must continue to develop a broad spectrum of competencies to fulfil increasingly independent and autonomous nursing roles and develop their own leadership qualities to enable them to take up leadership roles.

The recognition of potential leaders in the field of learning disability nursing will allow for them to be nurtured with positive opportunities created for their growth and development. Sustainability and success planning are integral to ensuring consistent, high quality care and support for people with learning disabilities, their families and carers where learning disability nurses "gain the positions of power and influence to shape things to come” (Faugier 2004).

### 3.4 Research

Excellence in health care is dependent on research and development (RCN 2004). Yet generally nurses are failing to maximise the opportunities for the nursing contribution within research and development (DH 2000).

Parahoo et al (2000) suggest that learning disability nurses are less likely to report using research to inform their practice than nurses from other branches. Possible reasons for this are suggested as organisational constraints as well as the likelihood that proportionally less research is
Conducted in learning disability nursing when compared to other specialisms. Nonetheless learning disability nurses need to see research and development as crucial to their practice (NMC, 2004), supporting clinical competence and credibility, informing care delivery, and developing the evidence base for nursing and learning disabilities.

To achieve this learning disability nurses need to:

- Access and use evidence in practice;
- Contribute to the development and expansion of the knowledge base from which nurses draw;
- Extend capability and research awareness through its identification as a core competence at all levels;
- Enhance capacity through developing this as a key role with dedicated time identified in practice; and
- Utilise ‘inclusive research’ methods (Walmsley, 2001).

The challenge for learning disability nurses is to understand research as a way to answer day-to-day clinical questions either through networking, accessing evidence, or conducting research. These activities should not be seen as the domain of the few but as one part of each nurse’s broader role. Most nurses will never be employed solely as a researcher or academic and we cannot rely solely on the ability of those who are in those positions to construct the evidence base for clinical practice. Brimblecombe (2004) noted that whilst prioritising the time for research and development activities can be difficult it creates the opportunity to develop skills that contribute to the challenge of new and established practice.

Research and development standards in learning disability nursing should be parallel to those in other health professional groups (RCN 2004). This requires an infrastructure with commitment from individual learning disability nurses, service managers, commissioners and education providers. Research and development should be a core competency from novice to advanced learning disability nurse practitioner.

### 3.4.1 Service User Involvement

How people with learning disabilities can be involved in research and how research is disseminated and accessed by people with learning disabilities is a matter for any learning disability nurse researcher.

‘Inclusive research’ has been developed as a term (Walmsley, 2001) which describes the variety of levels and roles of involvement which people with learning disabilities have from taking part in other people’s research through to owning or controlling the research project. There is still a long way to go before ‘inclusive’ research principles are more widely practiced (Walmsley, 2004), however learning disability nurses need to facilitate the development of ‘inclusive research’ methods in practice.
Section 3 Summary

- Learning disability nurses are unique in being the only professional group who are trained exclusively to work with people with learning disabilities. They must retain this characteristic and continue to work directly with people with learning disabilities.

- The fundamental differentiating factor that informs learning disability nursing practice lies less in what they do and more in how and why.

- Many learning disability nurses have developed additional expertise in the area of behavioural work. Working with people to resolve behavioural difficulties enables them to cope better with both health and social problems and is still a core role for all learning disability nurses.

- Learning disability nurses at all levels must take advantage of, and create opportunities to engage with colleagues within public health, primary care, mental health and other health services to learn more about the specific health needs of people with learning disabilities and respond more effectively and equitably to these needs.

- Learning disability nurses must be able to draw on an evidence base for their practice. They must be skilled in appraising the existing evidence and should increasingly be involved in generating new evidence to inform practice.

- Learning disability nurses must be aware of national policy initiatives and the direction for mainstream health services for responding to and improving public health.

- Good quality education is integral to the role of the nurse and required to ensure that learning disability nurses are fit for purpose in each of the four areas of specialist nursing practice, education, research and leadership. Pre registration and post registration provision needs be flexible in responding to the changing healthcare agenda and the developments in the learning disability nursing role.

- Good leadership is central to the transformation and modernisation of healthcare delivery. Learning disability nurses must make use of their unique position to take on lead roles to influence the development and delivery of mainstream and specialist healthcare services for people with learning disabilities.

- Learning disability nurses at all levels must develop leadership qualities and skills to achieve equal status with other nurses and healthcare professionals, challenge discrimination and reduce inequalities for people with learning disabilities.

- Both the use of research evidence and the undertaking of research studies need to be prioritised within the work of learning disability nurses to ensure a solid evidence base for practice with the inclusion of people with learning disability and their carers as equal members of the research team.

4. Action
The vision in this document cannot be realised without action. This section will explore some of the mechanisms that can be developed and used by learning disability nurses to bring about change.

4.1 Change management
Changes in services for people with learning disabilities have created both challenges and opportunities. Some learning disability nurses have
experienced isolation whilst others have benefited from greater autonomy and an opportunity to practice in a flexible and creative way. As change within all public sector services continues there is a need for learning disability nursing to develop further. Learning disability nurses should be leading this change and not simply responding to a direction of travel laid down by others.

To be effective as change agents, learning disability nurses need to be politically aware; to exercise influence; be adept at networking and think and act strategically. Appendix e provides further information regarding these 4 key areas for effective change management.

**4.2 Influencing policy**

Historically there has been a perception that nursing has had little in the way of influence upon health policy development (Antrobus and Kitson, 1999). However nurses increasingly want and need to become involved in this process (Aroskar et al, 2004). There is recognition that the impact of health policy on nursing can be immense and nurses are becoming increasingly active in bringing their influence to bear on this process.

As core members of the nursing profession, learning disability nurses can and should influence and contribute to the policy process at the formulation, implementation and evaluation stages (International Council of Nurses, 2001; Lee et al, 2002; Scottish Executive, 2002b). Providing a learning disability nursing response (both individually and collectively) to Government consultations is one way in which nurses at all levels can be involved in the reform of policy and process of policy development.

To ensure credibility within the policy environment, learning disability nurses need to publish and disseminate papers detailing good and effective practice to a wider audience. Channelling this work through larger organisations that share similar agendas, is one way nurses can progress their issues (International Council of Nurses, 2001).

Policy makers are one of the major stakeholders in the policy environment. Learning disability nurses must aim to be part of, and influence, this group and provide evidence of the contribution they make in relation to helping to meet the explicit aims of the government of the day. Nurses need to take advantage of fora, organisations and other arenas such as the Royal College of Nursing, the Scottish Parliamentary Forum and National Networks to gain access to policy makers in order to articulate the needs of people with learning disability and the scope of the nursing contribution to improving care.

**4.3 Workforce issues**

In order to ensure that the needs of people with learning disabilities are met by healthcare services and to enable learning disability nurses to develop new roles, commissioners and providers of services need to address a number of workforce issues.
There needs to be an appropriate number of learning disability nurses with the right competencies, right experiences, right skills and right attitudes in the right locations to deliver high quality care. However, the total number of learning disability nurses is not in itself a guide to quality and efficiency. With around 50% of learning disability nurses working outside the NHS, much will depend on the way such nurses are educated, utilised, supported and developed as a skilled resource.

Quality services require effective use of the nursing workforce and, in many circumstances, the pursuit of quality will continue to break down professional barriers and bring further changes and extension to what have been seen as traditional learning disability nursing roles. Whilst the role of learning disability nurses has evolved, and continues to change, there is no evidence to suggest that such posts are not required or that people with learning disabilities, their families and carers no longer need or want the services that learning disability nurses provide.

Workforce planners should take account of the vision outlined in this document when identifying local nursing requirements. Sufficient training places should continue to be commissioned. There are issues with the recruitment of sufficient students to the learning disability nursing branch. There is a danger that there will be insufficient learning disability nurses to enable specialist health services to develop further. Attention needs to be given to student nurse recruitment and retention issues and clear career pathways need to be developed to support this process. Learning disability nurses currently in practice should raise awareness of the role and its value as a career choice and take advantage of opportunities in their own roles to encourage recruitment.

4.4 Career pathways
Learning disability nurses fill a diversity of roles and play a central part in service provision for people with learning disability across a wide range of settings. To fulfil this role they need to retain and develop skills that can respond to current and future challenges within a framework that recognises and rewards the acquisition of skills and the acceptance of responsibility. Flexible career pathways should enhance recruitment and retention and enable learning disability nurses to move between employment in the NHS and other organisations.

Not all learning disability nurses will choose the same career path. Some may remain in a focussed role; some may opt to work in a range of posts that enhance a particular area of their practice and competence, while others may choose to extend their level of responsibility and authority. All roles will, however, encompass some components of practice, leadership, research and education.

In modifying the nursing career model put forward by DH (1999), Appendix f provides detail for how careers in learning disability nursing
can develop by illustrating four different levels. The focus is upon those progressing through a career primarily within clinical practice, where overlaps exist between the levels. The table in Appendix f details the practice, leadership, educational and research components of such roles along with the levels of authority and responsibility and the qualifications required.

Not all learning disability nurses will be working in roles that include the title of nurse (although they may have been appointed due to their nursing qualification, skills and or knowledge). Appendix f uses various levels of worker to encompass a range of job titles currently used across the field.

Nurses working in academic and research roles should be able to draw comparisons to the career framework available to them.

5. Recommendations

The summaries at the end of sections two and three provide guidance to assist and support learning disability nurses to articulate their contribution to the health needs of people with learning disabilities with a renewed sense of purpose and confidence. In addition to the direction provided in the summaries actions involving both nurses and other key players are required at individual, organisational and strategic levels to ensure that the vision set out in this document is taken forward:

Individual Level

- Learning disability nurses and the learning disability nursing profession should be proactive in realising this vision.
- Learning disability nurses should recognise the value of their own roles and take on lead roles in delivering and influencing the development of mainstream and specialist healthcare services for people with learning disabilities.
- Learning disability nurses should actively engage in networks and forums.
- More research needs to be undertaken by learning disability nurses and concerning learning disability nursing. In particular research should focus on the effectiveness of learning disability nursing in addressing the health and behavioural needs of people with learning disabilities Research should be accompanied by increased dissemination, including publication, and increased utilisation of research and evidence in practice.
- Learning disability nurses should be more active in local, regional, national and UK wide policy development (for example in responding to consultation documents, initiating policy development, working with people with learning disabilities to shape responses).

Organisational Level

- Nurse education providers and service providers should take action to ensure that learning disability nursing students have experience and opportunities for the development of skills in a range of settings to prepare them to work confidently...
and competently with people with learning disabilities who have the most complex needs.

- Dedicated learning disability services should invest in and actively promote the development of nursing leaders to raise the profile of the needs of people with learning disabilities and enable learning disability services to work equitably with our partners and challenge discrimination, stigmatisation and marginalisation in all its forms.

**Strategic Level**

- Each country of the United Kingdom should develop a specific strategy for learning disability nursing and the implementation of such strategies should be monitored and evaluated.

- Work should be undertaken to map the career pathways of learning disability nurses. This should include an assessment of the current situation and follow the development of new roles over the coming years.

- Each country in the UK should work towards the development of a nationally agreed curriculum for learning disability nurse training. This curriculum must enable nurses to develop the knowledge, skills and attitudes needed to work competently and confidently with all people with learning disabilities, their families and carers, and partners across mainstream and specialist health services and in other agencies.

- Standards for research and development in learning disability nursing should be developed and disseminated.

- User involvement in learning disability nurse education, practice development and research should be both promoted more widely and monitored.

- Urgent action should be taken to develop and operationalise national and local strategies to ensure that the workforce mix required in the future is developed and available when needed. Workforce issues should be carefully examined and analysed with a particular emphasis on the identification of future workforce requirements including skill mix.

- Further work should be undertaken to build upon this document, with education, research, practice, leadership, service development and workforce issues being considered in more depth.

**6. Conclusion**

This document has sought to set out both a vision for the future of learning disability nursing and the means by which this vision can be realised.

As the result of philosophical change, shifts in societal attitudes to disability, changes in government policy and development of legislation people with learning disabilities should increasingly be included within their local communities and able to access and benefit from mainstream services. The challenge facing services dedicated to the needs of people with learning disabilities will be to ensure that all people with learning disabilities are able to benefit from these opportunities regardless of the
nature or complexity of their needs. Special attention must be paid to those with the greatest needs.

As the largest single professional group who are unique in being trained to work exclusively with people with learning disabilities, learning disability nurses must ensure that they are ready and able to lead the way in rising to this challenge. Learning disability nurses must ‘shape the future’ to improve the health and well-being of all people with learning disabilities and address the barriers to good health and social inclusion.
7. References


Department of Health Social Services and Public Safety (2002) Investing for Health Belfast: DHSSPS

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National Assembly for Wales (2002b) *Inclusion, Partnership and Innovation*, (Learning Disability Nursing Strategy), Cardiff: National Assembly for Wales


Royal College of Nursing (RCN) (2004). *Promoting Excellence In Care Through Research And Development; An RCN Position Statement*. London RCN


Scottish Executive (2001a) *Nursing For Health: A Review Of The Contribution Of Nurses, Midwives And Health Visitors To Improving The Public's Health In Scotland.* Edinburgh: The Stationary Office


Appendix a

**Terms & Definitions**

It is important to recognise that all definitions have their limitations and it is certainly very difficult to find a single ‘definitive’ statement that clearly articulates issues as wide as nursing and health and that can be applied across all contexts and circumstances. The definitions included here are in general use and intended only to provide a starting point. Readers are urged to consider other definitions that may be in use in their own areas and use those that work best in the context of their own services, situations and practice.

**Learning Disability**

Learning disability has been labelled and defined in many different ways including diagnostic, legal and service eligibility definitions. Whilst learning disability is in itself a social construct, the common attributes across all definitions are that Learning Disability includes:

- Significant impairments in intelligence (relating to ability to understand new or complex information, to learn new skills);
- Significant impairments in social functioning (relating to ability to cope independently); and
- Present before adulthood, with a lasting effect on development.

**Nursing**

The Royal College of Nursing (2003) define nursing as:

"The use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health, to cope with health problems and to achieve the best possible quality of life whatever their disease or disability, until death”.

The role of the learning disability nurse has become increasingly diverse with nurses now working in a variety of settings, with a range of client groups, and across the lifespan. For example some nurses work in community teams, others in residential settings. Some work with clients whose behaviour challenges services, others with those with complex physical and/or mental health needs. Some specialise in working with children whilst others are developing roles supporting older people.

**Health**

The World Health Organisation’s (1948) definition of health has been widely criticised for being unrealistic and too idealistic since few people would really feel themselves to be in a state of ‘complete’ well being (Ewles and Simnett 2003).
Dubos (1979) provides a more specific definition arguing that health and disease ‘cannot be defined merely in terms of anatomical, physiological, or mental attributes’ suggesting instead that:

“health relates to the ability of individuals to function in a way which is acceptable both to them and the groups to which they belong.”

Health promotion encompasses emotional and physical health as well as a concern for addressing the determinants of health, including behaviour and psychological well-being. This means that all learning disability nurses, regardless of the setting in which they work, have a health promotion element within their role. For example a learning disability nurse working in a forensic setting may strive to promote better mental health and work with their clients to address their offending behaviour; a nurse working with clients with mental health problems may find that some have physical health problems which also require support; whilst others working with clients with multiple health needs will spend a considerable amount of their time seeking to achieve the best possible physical health for their clients.
<table>
<thead>
<tr>
<th>Country</th>
<th>Nursing Policy</th>
<th>Learning Disability Policy</th>
<th>Learning Disability Nursing Policy</th>
<th>Public Health Policy</th>
</tr>
</thead>
</table>
## Appendix c

### Summary of the Health Needs of People with Learning Disabilities

<table>
<thead>
<tr>
<th>Physical Health Conditions, Illness and Disease</th>
<th>Reference(s)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cancer</strong></td>
<td>Cooke 1997, Hasle et al. 2000, Patja et al. 2001</td>
<td>Cancer pattern experienced, with gastric, oesophageal and gall bladder being highest. Higher levels of leukaemia in people with Down’s Syndrome.</td>
</tr>
<tr>
<td><strong>Cardiovascular</strong></td>
<td>Hollins et al. 1998</td>
<td>2nd highest cause of death. Cardiac abnormalities common in specific syndromes such as Down’s syndrome. Investigation, treatment and monitoring required.</td>
</tr>
<tr>
<td><strong>Dental Health</strong></td>
<td>Cumella et al. 2000, DH 2001</td>
<td>Higher rates than in the general population of both acute and chronic dental problems. Higher rates of tooth and gum disease, with lack of awareness by individual or carer.</td>
</tr>
<tr>
<td><strong>Orthopaedic &amp; Accidents</strong></td>
<td>Center et al. 1998</td>
<td>Higher rates of osteoporosis and fractures experienced with lower bone density when compared to the general population.</td>
</tr>
<tr>
<td><strong>Respiratory</strong></td>
<td>Hollins et al. 1998</td>
<td>Higher death rates associated with pneumonia, secondary to swallowing problems (dysphagia), and asthma and at an earlier age. Highest cause of death for people with learning disabilities.</td>
</tr>
<tr>
<td><strong>Sexual Health</strong></td>
<td>Hollins and Perez 2000, Brown et al. 1995</td>
<td>Limited focus on the sexual health needs of people with learning disabilities who can be victims of sexual abuse with associated sexual healthcare needs. Women with learning disabilities have a low uptake of national screening programmes.</td>
</tr>
</tbody>
</table>

### Sensory

<table>
<thead>
<tr>
<th>Sensory</th>
<th>Reference(s)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hearing</strong></td>
<td>Evanhuis et al. 2001</td>
<td>Hearing impairment of 21% prevalence experienced by those with a mild learning disability under 50 years old compared to 0.2-1.9% in general the population. Higher prevalence within people with profound and multiple impairment.</td>
</tr>
<tr>
<td><strong>Vision</strong></td>
<td>Evanhuis et al. 2001</td>
<td>4% prevalence with mild learning disability under 50 years old compared to 2-7% in general population. Higher prevalence with lower IQ.</td>
</tr>
</tbody>
</table>
### Mental Health Conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Authors</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>Patel et al 1993, Moss et al 2000</td>
<td>Common mental illness in people with learning disabilities at all ages, though often unrecognised. Can present with challenging or disturbed behaviour, making diagnosis problematic.</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>Lund 1985, Doody et al 1998</td>
<td>Higher prevalence rate at 3% compared to 1% in general adult population, associated with more negative symptoms, memory problems, epilepsy and greater support needs.</td>
</tr>
<tr>
<td>Depression</td>
<td>Richards et al 2001</td>
<td>Found to be 22% in people with learning disabilities compared to 5.5% by age 36 in general adult population, excluding social class and physical illness.</td>
</tr>
</tbody>
</table>

### Long Term Conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Authors</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autistic Spectrum Disorder</td>
<td>Public Health Institute of Scotland 2002, Medical Research Council 2001</td>
<td>Estimated to be 60 per 10,000 for children. No data available for prevalence within the adult population. Many have additional health needs – mental health, communication, epilepsy and behaviour problems.</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>Sillanpaa et al 1999</td>
<td>Increased prevalence ranging from 10 - 20% in people with a mild learning disability up to 50% in those with profound learning disabilities. This is compared to 1% in the general population. Epilepsy is of a more complex nature with higher levels of poly pharmacy, complex seizure types and sudden unexplained death as a result of seizures.</td>
</tr>
<tr>
<td>Endocrine</td>
<td>Ali et al 2002</td>
<td>Thyroid dysfunction of 55% found in a group of people with Down’s syndrome, mostly previously unknown or due to a sub clinical hypothyroidism.</td>
</tr>
<tr>
<td>Syndromes</td>
<td>Gilbert 1996</td>
<td>In 1996 just over 2000 syndromes had been described. Of 90 described in detail, 36 have association with an increased incidence of learning disability. Many syndromes are also linked to characteristic behavioural phenotypes.</td>
</tr>
<tr>
<td>Behaviour</td>
<td>Reference</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------</td>
<td>------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Communication</td>
<td>NHS Health Scotland 2004</td>
<td>High prevalence of problems with comprehension, expression and pragmatic communication in social settings. Overestimation of communication abilities by carers</td>
</tr>
<tr>
<td>Challenging Behaviour</td>
<td>Emerson et al. 1998 Keirnan &amp; Alborz. 1996 Emerson et al. 1997</td>
<td>Between 12 – 17% of people defined as having an learning disability will display challenging behaviour. Physical aggression, self injury and destructiveness towards the environment tend to be the most commonly reported forms of challenging behaviour.</td>
</tr>
<tr>
<td>Offending Behaviour</td>
<td>Gudjohnsson et al 1993 Lyall et al. 1995 Murphy &amp; Mason 1999</td>
<td>People with learning disabilities are present in offender populations - various rates reported. 8.6% of suspects interviewed in 2 police stations. 2 – 5% of people within developmental disability services have had contact with the police as suspects. Of 70 people on probation orders 6% have learning disabilities of suspects interviewed in 2 police stations</td>
</tr>
</tbody>
</table>
Appendix d

Levels of Health Need
A range of reliable research findings are now available and enable identification of trends relating to prevalence of health needs. It is important to recognise that people with learning disabilities are individuals and will have differing levels of health need. This has implications for the nature of support that people may require from learning disability nurses. It is useful to consider a way of categorising these differing levels of health need to indicate the nature and extent of learning disability nursing involvement. The table below considers health needs on three levels which may provide a useful framework:

<table>
<thead>
<tr>
<th>Levels of Health Need</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Everyday health needs</strong></td>
<td>For example, everybody needs to be registered with a GP and dentist and to be able to access national screening programmes, chronic disease management programmes and other health promotion programmes which are offered to the population as a whole.</td>
</tr>
<tr>
<td><strong>Extra needs because of learning disabilities</strong></td>
<td>Many people with learning disabilities may require additional support to access health care. For example they may require information to be presented in accessible formats and additional support to prepare for health intervention. In addition some may additional health needs which are associated with their learning disability. For example adults with Down Syndrome require their thyroid function to be regularly monitored and are at increased risk of dementia.</td>
</tr>
<tr>
<td><strong>Complex health needs</strong></td>
<td>Some people with learning disabilities will have complex health needs whereby a number of health conditions can co-exist. These can include (for example) poorly controlled epilepsy, sensory impairments, physical impairments, difficulties with eating, mental health problems, complex behavioural needs and mental health problems.</td>
</tr>
</tbody>
</table>

*Levels of Health Need (adapted from Scottish Executive 2002b)*
Appendix e

Change Management

To be effective as change agents, learning disability nurses need to be:

- **Politically aware** – Learning disability nurses should be aware that they practice in a political climate incorporating national, organisational and local agendas. As such they need to be aware of policy development and their contribution to wider issues such as public health.

- **Exercising influence** – Just being political is insufficient and is rendered useless if the learning disability nurse does not have the skills and knowledge to engage in, and influence the debate. In order to be influential the learning disability nurse must know who and what they need to influence, how they can achieve this, and target issues and individuals selectively.

- **Adept at networking** – A strength of learning disability nursing lies in its ability to work in partnership with others and the value of networks and networking at a variety of levels cannot be underestimated. Key networks such as the National Network for Learning Disability Nursing provide fora for exchange of views and developments as well as identifying possibilities for joint working.

- **Thinking and acting strategically** – Learning disability nurses need to ensure that key issues are addressed at the strategic level. This requires possession of the skills, credibility and confidence to influence policy development, as well as the ability to ‘horizon scan’ in order to ensure that the key issues are both identified and addressed. It is important that strategic thinking is translated into day to day practice by all nurses.
### Career Framework Grid

<table>
<thead>
<tr>
<th>1&lt;sup&gt;st&lt;/sup&gt; level worker (e.g. support worker; HCA; project worker)</th>
<th>2&lt;sup&gt;nd&lt;/sup&gt; level worker (e.g. staff nurse; home leader; senior project worker)</th>
<th>3&lt;sup&gt;rd&lt;/sup&gt; level worker (e.g. charge nurse; team leader; specialist nurse; service manager)</th>
<th>4&lt;sup&gt;th&lt;/sup&gt; level worker (e.g. consultant nurse; assistant director; Head of service)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Performance</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice</td>
<td>Almost all time spent in provision of direct support or intervention.</td>
<td>Post registration practice. Exercises clinical judgement in assessing, planning, delivering and evaluating care.</td>
<td>Some time in provision of direct support or intervention. Undertakes responsibilities that support service delivery. Undertakes service or policy development as directed. Interpretation and evaluation of information from diverse sources to enable informed judgement to set standards</td>
</tr>
<tr>
<td>Leadership</td>
<td>Of peers and of people with learning disability</td>
<td>Of peers, of 1&lt;sup&gt;st&lt;/sup&gt; level workers and of people with learning disability</td>
<td>Of peers, 1&lt;sup&gt;st&lt;/sup&gt; + 2&lt;sup&gt;nd&lt;/sup&gt; level workers and people with learning disability</td>
</tr>
<tr>
<td>Education</td>
<td>Carries out education for peers and people with learning disability</td>
<td>Plans and carries out education for peers, 1&lt;sup&gt;st&lt;/sup&gt; level workers, students on professional courses, and people with learning disability</td>
<td>Informs educational developments Plans and carries out education for peers, 1&lt;sup&gt;st&lt;/sup&gt; + 2&lt;sup&gt;nd&lt;/sup&gt; level workers, people with learning disability and students on professional courses</td>
</tr>
<tr>
<td>Research</td>
<td>Participates in research May undertake simple research studies as part of academic development Appraises and uses in practice</td>
<td>Participates in research May undertake research studies as part of academic development Appraises and uses in practice</td>
<td>Participates in and undertakes research studies to inform service / policy development as directed Appraises and uses in practice</td>
</tr>
<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; level worker</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; level worker</td>
<td>3&lt;sup&gt;rd&lt;/sup&gt; level worker</td>
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</tr>
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</tr>
<tr>
<td><strong>Authority</strong></td>
<td><strong>Authority</strong></td>
<td><strong>Authority</strong></td>
<td><strong>Authority</strong></td>
</tr>
<tr>
<td>Focused on specific client/work context</td>
<td>Acts within specified policies, procedures, guidelines.</td>
<td>Acts under direction. Supports and advises 1&lt;sup&gt;st&lt;/sup&gt; level workers. Reports to 3&lt;sup&gt;rd&lt;/sup&gt; level or above.</td>
<td>Interprets and develops (as directed) policy, procedure or guidance. Receives and acts on reports from 1&lt;sup&gt;st&lt;/sup&gt; + 2&lt;sup&gt;nd&lt;/sup&gt; level workers. Reports to 4&lt;sup&gt;th&lt;/sup&gt; level</td>
</tr>
<tr>
<td>Acts under direction</td>
<td>Acts under direction</td>
<td>Acts under direction</td>
<td>Receives and acts on reports. Reports to positions senior to them (e.g. boards / committees)</td>
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<tr>
<td><strong>Responsibility</strong></td>
<td><strong>Responsibility</strong></td>
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</tr>
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</tr>
<tr>
<td>For own actions</td>
<td>For statutory duties to report (e.g. H+S; abuse, crime). For reporting to 3&lt;sup&gt;rd&lt;/sup&gt; level worker or above. To undertake duties as delegated and guide / advise 1&lt;sup&gt;st&lt;/sup&gt; level workers.</td>
<td>For statutory duties to report (e.g. H+S; abuse, crime). For reporting to 3&lt;sup&gt;rd&lt;/sup&gt; level worker or above. To undertake duties as delegated and guide / advise 1&lt;sup&gt;st&lt;/sup&gt; level workers.</td>
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</tr>
<tr>
<td>For statutory duties to report (e.g. H+S; abuse, crime). For reporting to 2&lt;sup&gt;nd&lt;/sup&gt; level worker or above. To undertake duties as directed.</td>
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<tr>
<td><strong>Qualifications</strong></td>
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<td><strong>Qualifications</strong></td>
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<tr>
<td>Would be expected to work towards NVQ 2/3 in care or related subject and LDAF 2/3. Registered Nurse. Would be expected to continue to develop as guided by the policy for the context of the post.</td>
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