

Good practice in learning disability nursing

Good practice in learning disability nursing

READER INFORMATION BOX

Policy	
HR/Workforce Management Planning Clinical	Estates Commissioning IM & T Finance Social care/partnership working
Document purpose	Best practice guidance
ROCR ref:	Gateway ref: 8748
Title	Good practice in learning disability nursing
Author	DH
Publication date	5 December 2007
Target audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Directors of Nursing, Directors of Adult SSs, Directors of HR
Circulation list	Voluntary organisations/NDPBs, professional organisations
Description	This document provides good practice guidance to support learning disability nursing to make a major contribution to the health and well-being of people with a learning disability in the future
Cross ref	N/A
Superseded docs	N/A
Action required	N/A
Timing	N/A
Contact details	Dr Neil Brimblecombe Professional Leadership Team 133–155 Waterloo Road London SE1 8UG 020 7972 4327
For recipient's use	

Contents

	Forewords	4
	Comments on the guidance	5
	Executive summary	7
1	Good practice guidance	10
	1.1 Aim of this guidance	10
	1.2 Who is the guidance for?	10
	1.3 What is learning disability nursing?	10
	1.4 What do learning disability nurses do?	10
	1.5 Why do learning disability nurses work in this way?	10
	1.6 Developments in nursing as a whole	11
	1.7 Previous guidance for learning disability nursing	11
	1.8 Developing the guidance	11
2	Needs of people with learning disabilities today	12
	2.1 Level of need	12
	2.2 People with learning disabilities and specialist services	12
	2.3 Health inequalities and people with learning disabilities	12
	2.4 Risk of abuse	13
	2.5 Health and social care policy	13

3	Learning disability nursing	15
	3.1 Learning disability nursing today	15
	3.2 Education	15
	3.3 Numbers	16
	3.4 Areas of employment	16
	3.5 Focus of learning disability nursing	17
	3.6 Conclusions	17
4	Recommendations	18
	4.1 Nature of recommendations	18
	4.2 Good practice examples	18
	4.3 Learning disability nursing as a values-based profession	18
	4.4 What every learning disability nurse can do	20
	4.5 What can learning disability nurses do to help you?	21
	4.6 Tackling inequality	23
	4.6.1 Responding to diversity	23
	4.6.2 Supporting physical well-being	25
	4.6.3 Supporting mental well-being	27
	4.6.4 Safeguarding vulnerable people	28
	4.6.5 Influencing commissioning to improve services	30
	4.7 Working in different settings and different ways	33
	4.7.1 Strengthening care in inpatient settings	34
	4.7.2 Making a difference in social care settings	36
	4.7.3 Effectiveness in care management roles	38

4.8	Supporting excellence in practice	38
4.8.1	Developing evidence based practice	38
4.8.2	Developing education to support excellence	40
4.8.3	Ensuring that learning disability nurses have access to support and advice	41
4.8.4	Developing new ways of working to improve services	42
4.8.5	Making use of new skills	43
	References	44
Appendix 1	Numbers of learning disability nurses	46
Appendix 2	Literature review summary	47
Appendix 3	Equality and good practice in learning disability nursing	48
Appendix 4	Summary of good practice benchmarks and recommendations	52

Forewords

Foreword by Christine Beasley, Chief Nursing Officer

Learning disability nurses provide a vital contribution to the well-being of people with learning disabilities. They work through providing direct care and support to those with complex needs and their family carers, and also through helping other health and social care workers respond appropriately. It is important that we consider how the valuable resource of learning disability nursing is best applied to have the greatest impact in contributing to well-being in the future. This good practice guidance provides a valuable set of benchmarks for nurses, service providers, educators and commissioners to consider.

Foreword by Rob Greig, Co-National Director, Learning Disabilities

Learning disability nurses are an essential part of making the *Valuing People* vision happen. They have two particularly important contributions to make. Firstly, the *Valuing People* vision of social inclusion requires people to be supported to be as healthy as possible. Learning disability nurses have both a direct role in supporting that, and an indirect role through their support to and relationships with the mainstream of the NHS. Secondly, on the occasions when people need short-term, specialist help, it is essential that such support and interventions are provided in ways that are evidence based, in line with best practice and in the least restrictive way possible. At their best, learning disability nurses have led the way since the publication of *Valuing People's* in 2001, with innovative work that places people with learning disabilities at the centre of decision making about their health and their lives. However, a great deal is still to be done if practice across all of England is to reflect the best. This document is an important contribution to that process of change.

Comments on the guidance

Learning Disability Task Force

'The NHS needs to improve its services to people with learning disabilities. This guidance is useful because it shares good practice and shows how learning disability nurses can help.'

Nicola Smith, Chair

Mencap

'Learning disability nurses have the knowledge and skills to make a real difference to the ways people with a learning disability are treated in the NHS. Mencap's *Death by indifference* report highlighted the ignorance and indifference that is too often faced by people with a learning disability in the health service. We welcome the good practice of learning disability nurses as they challenge these experiences and make the health service a better place for people with a learning disability.'

Dame Jo Williams DBE, Chief Executive

Royal College of Nursing

'The Royal College of Nursing (RCN) is delighted to have been able to participate in the development of this guide and from which many of our members have been able to offer valuable examples of good practice. It serves as an important reminder that, at a time when there has been much media attention on poor practices, there is a great deal of excellent work being done. The RCN feels strongly that the value and contribution of learning disability nurses cannot and should not be underestimated in delivering quality nursing care to people with learning disabilities.'

Anne Norman, Nurse Adviser

UNISON

'Learning disability nurses make a vital contribution to enabling individuals to have quality of life and maintain as much independence as can be achieved. They work in partnership with other members of interprofessional teams and advocates of service users. This guide acts as a tool to promote their work. However, their numbers are currently decreasing and work is needed, through workforce planning, to ensure that we are able to achieve a successful balance of care, which meets the unique needs of the individual.'

Gail Adams, Head of Nursing

Executive summary

1. Learning disability nursing is a person-centred profession with the primary aim of supporting the well-being and social inclusion of people with a learning disability through improving or maintaining physical and mental health.
2. This good practice guidance makes recommendations as to how their contribution can be made even more effective in the future. Action is needed by health and social care providers, educators, commissioners and learning disability nurses themselves. The recommendations made are not exhaustive and local need will determine the development of these and other actions.
3. People with learning disabilities have an increased incidence of a wide range of physical and mental health conditions, and there has been a steady increase in the number of people with complex needs and those whose health needs are dependent on medical technology.
4. Learning disability nurses utilise a range of skills to provide specialist healthcare to people with complex needs, working in partnership with them and with family carers. Learning disability nurses are employed in a wide range of organisations, in both community and inpatient settings, and typically in multiprofessional teams and in multi-agency settings.
5. Recent reports by the Disability Rights Commission and Mencap have re-emphasised the need to tackle health inequalities for people with learning disabilities. By promoting access to mainstream health services and providing direct specialist support as required, learning disability nurses can work to reduce barriers and support the person to pursue a fulfilling life.
6. The relatively limited number of learning disability nurses currently available requires that the best possible use be made of this precious resource, that roles are carefully targeted to health-related activities as a first priority, and that attention is paid to the need to plan for the workforce of the future.

A values-based profession

7. Learning disability nursing is a profession whose practices and education must be based on clear values, such as that the person with a learning disability must be at the centre of their care and be fully involved in all aspects of planning, care and treatment. Recognising the contribution of family carers and providing support to them in their role is also critical.

What every learning disability nurse can do

8. All learning disability nurses should have the range of essential, core competencies that ensure they can respond to the needs of people with learning disabilities, their families and supporters. Both service providers and educators have a role to play in ensuring that these are in place.

Tackling inequality

9. To help respond appropriately to the physical health needs of people with learning disabilities, service providers and commissioners of primary, secondary and prison physical healthcare should assess how the education and advice needs of staff are currently met and where their services require input from learning disability nurses.

Working in different settings and different ways

Person-centred inpatient care

10. To ensure that learning disability nurses working in inpatient care services provide excellent person-centred care, service providers should assess staff development, training and support needs by measuring against competencies to be developed by Skills for Health and other stakeholders. To attract and develop a skilled nursing workforce requires the development of career structures encouraging specialisation in this area of practice.

Nurses working in social care settings

11. Social care providers that employ registered nurses in non-nursing roles should consider the need to support continued health-focused professional development through individual appraisal processes, in order to help nurses maintain the ability to support physical well-being in these settings.

Nurses working in case management roles

12. Local partnerships should ensure that they are satisfied that the limited resource of learning disability nursing staff is being effectively invested in addressing the mainstream health agenda and not being unduly compromised by learning disability nurses working in case management roles.

Supporting excellence in practice

Education

13. To respond to current challenges, education commissioners should review their current arrangements for commissioning pre-registration education, to identify ways of developing greater expertise in the commissioning and provision of pre-registration education and to ensure geographical equitability of access to training.

Professional support

14. Some learning disability nurses currently feel isolated and lacking professional leadership. All should have access to a named, experienced learning disability nurse who is available to provide advice on professional issues and support them to be effective, assertive and values-based practitioners in a multidisciplinary and multi-agency environment.

New ways of working

15. To ensure that newly learned skills can be successfully applied in practice, needs assessment of people receiving services should inform the pursuing of advanced skills training, and personal implementation plans for nurses should be agreed with managers prior to starting such training.

1 Good practice guidance

1.1 Aim of this guidance

Learning disability nurses (LDNs) currently play a vital role in helping to respond to the healthcare and other needs of people with learning disabilities. This guidance aims to highlight how their contribution can be made even more effective in the future.

1.2 Who is the guidance for?

This guidance is primarily directed at LDNs, their current and potential employers, education providers and commissioners of specialist and non-specialist health and social care services.

1.3 What is learning disability nursing?

Learning disability nursing is a person-centred profession with the primary aim of supporting the well-being and social inclusion of people with learning disabilities through improving or maintaining physical and mental health.

1.4 What do learning disability nurses do?

LDNs act as champions for people with learning disabilities and their families. They undertake a range of activities to promote better health for people with learning disabilities. They do this by advising, teaching and supporting people with learning disabilities, their families and other professionals to enable people to live full and rewarding lives within their communities. They specifically provide nursing input and direct support to people with complex needs related to their learning disability. They work in a wide range of settings. To be effective, all LDNs have to work in real partnership with people with learning disabilities and their families, as well as with other professionals, organisations and the wider community.

1.5 Why do learning disability nurses work in this way?

People with learning disabilities have a right to full citizenship, but mental and physical ill health may present barriers to inclusion and the achievement of the things that are important to them and their families, such as employment. By promoting access to mainstream health services and providing direct specialist support as required, LDNs work to reduce barriers and support the person to pursue a fulfilling life.

1.6 Developments in nursing as a whole

This guidance has been developed in the context of *Modernising Nursing Careers* (Department of Health (DH) 2006), a UK-wide strategy for the future of all of nursing. *Modernising Nursing Careers* identifies future challenges and the key developments that need to take place to ensure that nursing is able to successfully respond to changing healthcare needs.

1.7 Previous guidance for learning disability nursing

The most recent Department of Health guidance for learning disability nursing, *Continuing the Commitment*, was published in 1995 (Kay, Rose and Turnbull 1995). Although some of the important challenges that existed then also exist today, a number of significant developments have taken place in the last few years in terms of policy and service provision. This requires a new look at how the learning disability nursing profession should respond to the needs and aspirations of people with learning disabilities in the future.

1.8 Developing the guidance

A reference group was established to advise on the development of this guidance. There were representatives of people with learning disabilities, family carers, nurses, commissioners, other professions, providers of health and social care, and other key organisations. Further views were gathered around the country through workshops. These were run in collaboration with a range of different organisations, including local NHS trusts, family carers, nursing networks and independent sector providers. A key aspect of this work has been the identification of the best of current practice, of which nearly 300 examples were received.

2 Needs of people with learning disabilities today

2.1 Level of need

There are about 210,000 people with severe learning disabilities in England and about 1.2 million people with mild to moderate learning disabilities (DH 2001a). Learning disabled people have higher rates of a number of physical and mental health conditions and lower levels of provision of healthcare. In the last few years, there has been a steady increase in the number of people with complex needs and those whose health needs are dependent on 'medical technology'.

2.2 People with learning disabilities and specialist services

Due to these changes, there is an increasing need for specialist learning disability services, including LDNs. These services provide support to enable everyone to be included in their community, particularly those with complex and continuing health needs. There is a demand from people with learning disabilities and their families to be supported in their everyday surroundings or as close to home as possible. It is also important that specialist expertise is available to support mainstream provision not just in health services, but also in other places where people with learning disabilities may be vulnerable, such as prisons.

2.3 Health inequalities and people with learning disabilities

People with learning disabilities often do not seek out healthcare. When they do so, there is clear evidence that they frequently face difficulties. Research evidence suggests that the prevalence of learning disability may be markedly higher in some South Asian groups than the rest of the population (DH 2001b). Yet, there may be particular difficulties in accessing appropriate services for some people from black and minority ethnic groups (2001b).

People with learning disabilities are less likely to receive regular health checks and access to routine screening, such as cervical screening and mammography (DH 2001, National Patient Safety Agency 2004, Mencap 2004, Disability Rights Commission (DRC) 2006). They are 58 times more likely to die before the age of 50 and 4 times more likely to die from a preventable cause of death than the rest of the population (Hollins et al 1998). The DRC's formal investigation (DRC 2006)

into the health inequalities facing people with learning disabilities in primary care identified how the mainstream NHS is not meeting the general health needs of people with learning disabilities. An independent inquiry has been established by the Secretary of State for Health to identify the action needed to ensure that people with learning disabilities receive appropriate general healthcare and treatment in England, and to learn lessons from the Mencap report *Death by Indifference* (Mencap 2007).

2.4 Risk of abuse

People with learning disabilities are also at higher risk than most others of suffering abuse. This can happen in any setting. The Healthcare Commission's reports into abuse in NHS learning disability services in Cornwall and Merton and Sutton (Healthcare Commission 2007a, 2007b) have highlighted this.

2.5 Health and social care policy

Historically, many people with learning disabilities were segregated from society and placed in large long-stay hospitals that isolated them from their communities. In the 1960s, there were 65,000 people in such places; however, since the 1970s there has been a government policy of de-institutionalisation. This has resulted in dramatic changes in the lifestyle, experiences, expectations and aspirations of people with learning disabilities, their families and wider society. LDNs have changed their focus of practice and places of work to respond to and support these developments.

The national policy for people with learning disabilities is set down in the Government's White Paper – *Valuing People* (DH 2001). This is a cross-government policy about learning disabled people as citizens, which is underpinned by four basic tenets:

- rights;
- independence;
- choice; and
- inclusion.

The main objective for health is to enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a high standard, and with additional support where necessary.

The White Paper, *Our Health, Our Care, Our Say* (DH 2006), made commitments to introduce comprehensive health checks for people with learning disabilities, to introduce individual budgets, and close and replace the remaining NHS campuses by 2010. There are currently up to 3,000 NHS campus beds, which should be closed and replaced with ordinary housing and support, run and managed outside the NHS.

3 Learning disability nursing

3.1 Learning disability nursing today

LDNs currently work in a wide range of organisations: NHS, local authority and private, statutory and third sector. They typically work in multiprofessional teams and in multi-agency settings. Recent changes in policy are reflected in the range of roles undertaken by learning disability nurses, for example by the increase in numbers working within mainstream healthcare teams such as in acute hospitals, mental health services and primary care.

The majority of LDNs still employed by the NHS can be described as working in one of three practice areas:

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

As with other branches of nursing, in the last few years there has been the development of modern matron and nurse prescriber roles in learning disability services. LDN consultant roles have also been established in some areas and provide valuable expertise and professional leadership (see, for example, Northway et al 2006).

3.2 Education

Learning disability nursing is one of four branches of nursing with pre-registration training courses typically being carried out over three years and leading to either a degree or diploma. Some universities currently provide joint qualifications in both nursing and social work, although there are currently few posts that specifically require both qualifications simultaneously. The future arrangements for nurse education are currently under review by the Nursing and Midwifery Council (NMC).

Many LDNs have developed additional skills through a range of advanced post-registration training courses. Skills-based courses include those relating to 'challenging behaviour', epilepsy management and nurse prescribing.

3.3 Numbers

Despite changes of policy regarding the care of people with learning disabilities across the UK, to date, figures show only a slight decline in the overall number of nurses with a learning disability qualification (see Appendix 2).

However, the number of newly qualifying LDNs registering as nurses has been variable over the last few years in England (Appendix 2) and, worryingly, there has been a general trend towards fewer commissioned student LDN places.

3.4 Areas of employment

Overall, there has been a marked reduction in the number of LDNs employed within the NHS itself, with a drop of nearly 37% between 1996 (12,105) and 2006 (7,583) (The Information Centre 2007). This reflects the need to move from long-term care in the NHS, to enable people to be supported to live in their own homes as part of communities. This process is continuing with the planned closure of all remaining campuses by 2010. Some of those LDNs remaining employed by the NHS are seconded to work as part of jointly managed community learning disability teams.

While most LDNs are now employed in community settings, significant numbers do still work providing inpatient care, for example in assessment and treatment services, forensic services and working in mental health services where there are people with learning disabilities and mental health needs.

3.5 Focus of learning disability nursing

This guidance endorses the expectations in *Valuing People* (DH 2001) that specialist healthcare staff, such as LDNs, will engage in a range of activities additional to a direct clinical/therapeutic role. The proportion of time spent on each additional activity will vary depending on the exact job of the nurse. For example, a registered nurse working in an assessment and treatment unit will mostly provide direct care (although including assessment, teaching and health promotion), while a nurse working as a healthcare facilitator will be using their skills to impart knowledge, influence and train mainstream health staff. The range of activities include:

- health promotion – working closely with the local health promotion team;
- health facilitation – working with primary care teams, community health professionals and staff involved in delivering secondary healthcare;
- teaching – to enable a wide range of staff, including those who work in social services and the independent sector, to become more familiar with how to support people with learning disabilities to have their health needs met;
- service development – contributing their knowledge of health issues to planning processes.

3.6 Conclusions

The last few years have seen a slow reduction in overall numbers of LDNs, this trend is worrying given the changes in demography and the increasing number of people with complex health needs. Ensuring that the health needs of people with learning disabilities are met in the future presents a challenge for commissioners of education and of services. Appropriate local assessments and planning for future workforce needs is required, including for LDN numbers and skills. It is also vital that the best use possible is made of the current resource of LDNs, and that their roles are carefully targeted to health-related activities as a first priority.

4 Recommendations

4.1 Nature of recommendations

The recommendations included here constitute good practice guidance. They aim to support nurses to achieve the benchmarks of good practice included in the text below. Individual organisations will make decisions about implementation based on assessment of local need. The recommendations are not exhaustive and local need will determine the development of other actions. Benchmarks and recommendations are summarised in Appendix 4.

Where recommendations are taken forward, it is rarely likely to be in the power of one individual or, indeed, profession to make that change. Collaboration, consultation, and multidisciplinary and multi-agency planning are likely to be required in most instances. The involvement of people with learning disabilities and family carers in developing new initiatives will be essential.

4.2 Good practice examples

Examples are provided in order to:

- illustrate how recommendations might be translated into practice; or
- demonstrate the possible range of positive practice that LDNs can be involved with, subject to local need.

4.3 Learning disability nursing as a values-based profession

Learning disability nursing is a profession whose practices must be based on clear person-centred values. Specifically, these values should be that:

- the person with a learning disability must be at the centre of their care and be fully involved in all aspects of planning, care and treatment;
- choice and self-determination must be supported by offering timely and appropriate information;
- recognising the contribution of family carers and providing support to them in their role is critical;

- working with those who provide paid support directly is key to ensuring that the health needs of people with learning disabilities are understood and healthy lifestyles are promoted;
- people with learning disabilities have interrelated social, psychological, physical and spiritual needs;
- inequality in all aspects of the life of people with learning disabilities must be actively challenged;
- care must be provided in a way that is based on the best evidence available;
- health interventions should be provided in the person's everyday environment in the first instance and, where this is not possible, then within the least restrictive setting and as close to home as possible.

Benchmark 1: All learning disability nursing practice is values based	
Recommendations	Key contributors
1.1 All clinical policies and education provision for LDNs to be developed through active and direct involvement from people with learning disabilities and family carers.	Service providers, people with learning disabilities and family carers, higher education institutions and training departments.
1.2. All services and individual practitioners to review their current role and policies to ensure that they reflect the stated values of the profession.	Service providers, individual LDNs.
1.3. All education providers to review the content of courses for LDNs to ensure that they reflect the stated values of the profession and changes in policy and service delivery.	Higher education institutions.

Good practice example: User involvement in recruiting nurses

In Hertfordshire Partnership NHS Foundation Trust, people with learning disabilities and family carers are actively engaged in interviewing staff through participation in main panels, service user panels and groups devising questions for interviews. Training is provided in advance and a resource pack has been developed to support involvement. Support is provided before, during and after such participation. Nurses and others, such as consultant psychiatrists, have been interviewed using this approach and it has actively influenced decisions about appointments made.

Contact: jaya.hopkins@hpt.nhs.uk

Good practice example: Improving practice by simulation

Involving people with learning disabilities as simulated patients started at Kingston University and St George's, University of London in 2004. It is coordinated by LDN lecturers in partnership with people with learning disabilities and the Baked Bean Theatre Company. The focus is on helping pre-qualifying nurses across the four branches and social care professional students learn about working with people with learning disabilities.

Contact: Jblair@hscs.sgul.ac.uk



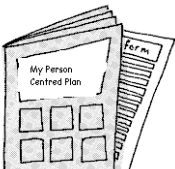



4.4 What every learning disability nurse can do






All LDNs must have the range of competencies which ensures that they can respond to the needs of people with learning disabilities, their families and supporters. The essential competencies that all must have are listed below in broad terms. Skills for Health, in conjunction with the Royal College of Nursing (RCN) and other interested stakeholders, will be identifying the more detailed competences for learning disability nursing, which will be informed by this list. The list reflects only the essential broad competencies that all LDNs working in all settings should have, but there will be many other skills and specialist knowledge needed depending on the exact nature and requirements of each nursing role.

This list will be a useful potential source of information for people with learning disabilities and their carers, other professionals and service commissioners about the contribution that individual nurses may make.

4.5 What can learning disability nurses do to help you?

All LDNs will be able to do the following:

	<p>Use things they know about health and disabilities to help you stay healthy in the future.</p>
	<p>Try to find ways to understand you and what you want.</p>
	<p>Support you to do the things that are important to you.</p>
	<p>Help explain why and how you might be treated for any health problems.</p>
	<p>Try and find ways to help you that are already proven to work.</p>
	<p>Help you to think about ways to keep well and safe.</p>

	<p>Help you to understand why you do something if it is very troubling to you or other people, and help you to do things differently and to cope with any worries or fears you have.</p>
	<p>Make sure that you and your supporter(s) know about other people who can help you, especially people who work in the NHS (health service).</p>
	<p>Work with people who provide care for you to help them to support you in the best way possible.</p>
	<p>Know about important new ideas and information that may help you.</p>
	<p>Help stop people with a learning disability getting unfair treatment.</p>

Benchmark 2: All LDNs have essential competencies for practice	
Recommendations	Key contributors
2.1 All service providers and LDNs to assess whether all LDNs have the essential competencies for practice and for development plans to be put in place as required for individuals or teams.	Service providers, training departments, individual LDNs, sector skills councils.
2.2 Service providers to make easy read information available regarding the essential competencies to share with people with learning disabilities and others.	Service providers, people with learning disabilities, family carers.
See also: Benchmark 12	

4.6 Tackling inequality

Many people with learning disabilities still experience a range of inequalities. In particular, they may be more likely than others to suffer abuse or receive inadequate physical or mental healthcare. Some inequalities may be more likely to arise for people with a learning disability from ethnic minorities or for those in specific age groups, particularly at times when transition between services is required. LDNs potentially play an important part in helping to tackle inequalities, both through direct action and through influencing others' views and actions.

4.6.1 Responding to diversity

There is evidence that people from black and minority ethnic groups may have increased difficulty in accessing appropriate services (DH 2001b). LDNs and other specialist workers have an important role in linking with local communities and ensuring that services can adapt to their needs. Relationships with local minority communities are likely to be facilitated if the learning disability nursing workforce reflects the diversity of local populations. Although precise figures are not available, the consensus is that the current learning disability nursing workforce often does not reflect the ethnic diversity of local populations served.

Benchmark 3: Learning disability nursing is able to respond to the diverse needs of local communities	
Recommendation	Key contributors
3.1 Service providers, in cooperation with higher education institutions, to evaluate how well the learning disability nursing workforce reflects diversity in the local populations served and develop processes to better reflect that diversity in the future, where required.	Higher education institutions, service providers, workforce planners.

Good practice example: Nurse led ethnicity project

In South West Yorkshire Mental Health NHS Trust, an LDN has led a multi-agency/carer ethnicity group to improve services for service users and family carers from black and minority ethnic communities. Outcomes have included the development of:

- a 'talking together' group for service users/carers of South Asian origin and staff;
- workshops with imams and significant others leading to the development of a local South asian community group with the aim of making the community more inclusive for people with learning disabilities;
- accessible leaflets for the South Asian community;
- a post for a black and minority ethnic development worker.

Contact: Janice.muhanha@swyt.nhs.uk

4.6.2 Supporting physical well-being

People with learning disabilities are more prone to a range of physical problems than others. However, general healthcare services do not always have the knowledge, understanding or experience to adjust the manner in which they provide care in a way that responds to individual needs. Equalities legislation, particularly the Disabilities Discrimination Act 1995 and Mental Capacity Act 2005, not only places a requirement on healthcare providers to not discriminate against people with a disability, but also to be proactive and take steps to ensure that people with learning disabilities are involved and can access treatment and care. LDNs are an important potential resource in educating, advising and consulting with other health workers, as well as supporting people with learning disabilities in accessing healthcare. They may do so by being employed directly in these services or by providing such input from external roles.

Benchmark 4: LDNs support the provision of excellent physical healthcare to people with learning disabilities in all settings	
Recommendation	Key contributors
4.1 Service providers and commissioners of general healthcare in primary, general, acute and prison settings, assess how the education and advice needs of staff are currently met and where their services require input from LDNs, in order to ensure that services are responsive and comply with disability equality requirements.	Service providers and commissioners, LDNs, people with learning disabilities, family carers.

Good practice example: Networking to support practice

The Access to Acute (A2A) Network was established in 1998. The Network shares good practice on how the additional difficulties often experienced by people with learning disabilities when entering general hospitals might be overcome. LDNs have found this a valuable source of support and a way of gaining new ideas and skills. This has resulted in work being shared and adopted to suit local needs, with acknowledgement being given as to the origins of the work. Further information is available at www.nnldn.org/a2a.

Contact: Rick.robson@shropshirepct.nhs.uk

Good practice example: Liaison nurse with general hospitals

Frank Garvey works as strategic liaison nurse linking with four general hospitals. The post has led to a number of developments to improve the experience of care and outcomes for people with learning disabilities in Hertfordshire. These include:

- improving signs in hospitals, informed by local people with learning disabilities;
- developing policies to support care in outpatient and accident and emergency departments;
- developing a day's training programme to raise awareness and understanding of clinicians about the needs of people with learning disabilities when receiving general hospital care.

Contact: frank.garvey@hpt.nhs.uk

Good practice example: Supporting essential physical investigations

Amanda Wilson, a learning disability health facilitation nurse, works for Central Lancashire Primary Care Trust. In order to help support a woman with Down's syndrome and severe needle phobia to have blood taken for a thyroid function test, she had to work with a number of other professionals and agencies. After unsuccessful attempts at desensitisation, information was sought from consultant biochemists and via electronic networks about an alternative approach using blood spot testing, and this information was then shared with the GP. After further negotiating with the phlebotomy department and primary care staff, the blood sample was successfully collected in a less anxiety-provoking setting – a day centre.

Contact: amanda.wilson@centrallancashire.nhs.uk

4.6.3 Supporting mental well-being

People with learning disabilities are more likely than others to suffer mental ill health. Treatment may be received through primary care, specialist learning disability services or mental health services. Mental health services are not always adequately prepared to respond to such needs. LDNs can play an important contributing role in the identification, assessment and treatment of mental health problems in a wide range of settings.

Benchmark 5: LDNs support the provision of excellent mental health care for people with learning disabilities	
Recommendation	Key contributors
5.1 Needs assessments to be carried out regarding current staffing arrangements in inpatient and community mental health teams as to whether they adequately meet the needs of people with learning disabilities who also have a mental health need and to assess the specific need to employ LDNs as part of the skills mix.	Mental health service providers and commissioners, LDNs.

Good practice example: Consultant nurse – mental health in learning disability

Dave Ferguson works as a Consultant Nurse in Hampshire Partnership NHS Trust to support the development of systems of care for people with learning disabilities who have mental health problems. He works in collaboration with colleagues from health and social services, as well as with other significant organisations, service users, carers and advocates. He supports and enables the development of skills, for example through training programmes. This helps to reduce risk, improve communication and improve the assessment of mental health needs leading to early intervention and evidence-based treatment plans. Positive outcomes have included the development of a clinical interface protocol between services, development of Wellness Recovery Action Planning training and link nurse developments between services.

Contact: david.ferguson@hantspt-sw.nhs.uk

4.6.4 Safeguarding vulnerable people

People with learning disabilities are at greater risk of abuse than many others, whether living in their own home or in other settings. LDNs can play an important role in helping to protect vulnerable people. This can be with people with learning disabilities who they directly work with and by helping others recognise, prevent or respond to possible abuse, including people with learning disabilities themselves.

Benchmark 6: All LDNs practice actively helps to safeguard vulnerable people	
Recommendations	Key contributors
6.1 All LDNs to attend vulnerable people training at least every two years and on induction into a new employer.	Service providers, individual LDNs.
6.2 All pre-registration nursing courses to include in-depth teaching in the risks, prevention, detection and response to abuse.	Higher education institutions, people with learning disabilities.
6.3 Providers of specialist learning disability services to consider the need to establish specialist posts or roles that can work with health and social care staff, people with learning disabilities and others on the risks, prevention, detection and response to abuse.	Service providers, commissioners, people with learning disabilities

Good practice example: Working with young offenders

A specialist LDN post has been set up by the Kirklees Youth Justice Service to support the youth justice service and ensure that vulnerable young people with learning disabilities are identified and receive an appropriate service. The nurse provides specialist training to the service, the police and magistrates, and facilitates young people with learning disabilities into offender programmes.

Contact: karina.hepworth@kirkless.gov.uk

Good practice example: Adult Learning Disability Abuse Team (ALDAT)

An LDN leads the multiprofessional ALDAT for the Devon Health and Social Care Learning Disability Partnership. The team provides therapeutic support to survivors of abuse, raises awareness and works towards prevention through developing policies, training and providing advice. The team works closely with the Safeguarding Adults Team, the Creative Therapy Team, the Additional Support Team and other key stakeholders.

Contact: cate.dandridge@devonptnrs.nhs.uk.

Good practice example: Safeguarding children and vulnerable adults e-programme

South Essex Partnership Foundation Trust has developed a variety of training methods to help learning disability nursing staff access training in safeguarding children and vulnerable adults in a way that suits their requirements and work patterns. The trust has introduced two unique e-learning programmes. They contain hyperlinks to video clips, trust policies, government documents, research papers and local authority websites which offer additional information on services for clients. Nursing staff have fed back that this has been an invaluable resource, as they can complete parts of their professional development and access all information and services available on safeguarding matters 24 hours a day without needing to leave the workplace. Additionally, a nurse consultant for safeguarding children and adults works within the trust offering leadership to nurses and ensuring that they are able to offer expert advice and support to clients.

Contact: Elaine.Taylor@southessex-trust.nhs.uk

4.6.5 Influencing commissioning to improve services

Having strong and well-informed commissioning is central to tackling the inequalities experienced by many people with learning disabilities. Commissioning is significant in relation to education, specialist and general healthcare services. LDNs have knowledge of the health needs of people with learning disabilities, which is a potentially valuable resource in informing commissioning so that is responsive to those needs.

Good practice example: Learning disability nurses and commissioning

In Leicester City, the primary care trust employs two LDNs in the Commissioning Team. They work across the health community and with the local authority in developing and implementing the local joint strategic and commissioning plan. Their knowledge and skills are used to create a service specification, model of care and outcome measures to meet the health and social care needs of this user group and to ensure quality and value for money. This has resulted in the creation of: supported living options for 35 people being discharged from the closure of a local learning disability NHS hospital, five supported living units to prevent or allow the return to their local community of 12 out-of-area and/or secure hospital patients; and an enhanced community team to meet the need to support people as they move from hospital and out-of-area provision.

Contact: marcus.callaghan@leicester.gov.uk

Good practice example: Influencing commissioning to improve equity of access

Following evidence from two local pilot studies into health checks, the Clinical Lead Nurse, Johanna Lee, developed a framework for the local enhanced service for people with learning disabilities. Funding was sought from the primary care trust board for a complementary funding stream for people with learning disabilities in primary care. This was supported by practice-based commissioning groups and has led to a structured and coordinated standard approach between 35 GP practices. Patients are identified through practice registers and a screening template is utilised that identifies health needs that are more common in people with learning disabilities. Audits are planned to assess impact on health outcomes.

Contact: Johanna.lee@knowsley.nhs.uk

Good practice example: Tackling inequality through a managed clinical network

A managed clinical network was established by LDNs working in Cheshire and Wirral NHS Partnership Foundation Trust in 2006, in order to address health inequalities experienced by people with learning disabilities in the area. The core group of the network meets every six weeks and includes the consultant nurse, health facilitators, champions from areas such as child and adolescent mental health and others. The network has successfully supported a number of innovations, for example established LDNs on key strategic groups within public health departments and on a regional dental access working party, worked with agencies to introduce an ‘anticipatory care calendar’ (a tool that helps meet unmet health needs) and has made presentations to a range of primary care trust boards, GP forums and public health department meetings on health inequalities for people with learning disabilities.

Contact: michele.bering@cwpsnt.nhs.uk

**Benchmark 7:
Learning disability nursing helps to ensure that commissioning of services responds to the needs of people with learning disabilities**

Recommendations	Key contributors
7.1 LDNs, in discussion with their employers, to identify how they can link and engage with commissioners, including practice-based and education commissioners, to ensure that the health needs of people with learning disabilities are highlighted and responded to.	Individual LDNs, service providers, commissioners.
2. Commissioners consider the potential contribution of LDNs to the skills mix required in commissioning teams to make them informed and effective.	Commissioners.

4.7 Working in different settings and different ways

LDNs work in a wide range of settings, in both health and social care. In order to provide the most effective service, the limited resource of learning disability nursing needs to be focused in places where it can make most difference, including:

- strengthening care in inpatient settings;
- making a difference in social care settings;
- effectiveness in care management roles; and
- developing new ways of working to improve services.

Good practice example: Developing a psychotherapy and counselling service

In East Lancashire, a clinical nurse specialist post has been developed in response to the potential vulnerability of people with learning disabilities to mental health problems and a lack of availability of psychological therapies, particularly in relation to trauma, bereavement and loss. The case for the development of the post was made through the gathering of evidence of need, and the role itself required the development of specific skills. The service has been evaluated highly by service users and has won a Nursing Standard award for learning disability nursing and a local Championing Diversity award.

Contact: Isabel.robinson@eastlancspct.nhs.uk

Good practice example: Helping families and 'challenging behaviour'

As part of a joint initiative between Ridgeway Partnership and Barnardo's, a community LDN is involved with running a series of training events for parents and siblings of children with learning disabilities and with challenging behaviour. The three-week course includes information on why challenging behaviour occurs and helps parents to formulate an approach to respond to it. Over 100 parents have been trained so far, and have evaluated the course very positively, particularly mentioning the positive feeling of being in a group and relief that they were not the only one experiencing such difficulties.

Contact: Emma.stafford@ridgeway.nhs.uk

4.7.1 Strengthening care in inpatient settings

LDNs provide the majority of direct care in specialist learning disability inpatient settings, for example assessment and treatment and secure wards. The skills required in such settings are currently not well defined and, as a result, specific and targeted staff development is sometimes lacking. Working in such settings requires great skill and sensitivity, especially in balancing the needs for safety and freedom and in dealing therapeutically with difficult and sometimes dangerous behaviour.

Skills for Health is to work with the RCN and other stakeholders to develop clearly defined competencies for nurses working with people with learning disabilities, including those working in inpatient settings. This will provide a framework for future individual and team self-assessment and for education and training.

Good practice example: Developing a journey map

An Assessment and Treatment Unit for adults with learning disabilities and associated healthcare needs in Lincolnshire Partnership Trust is currently taking part in the Practice Development Unit accreditation scheme. As part of this, staff have developed a journey map to explain to service users their journey through the unit in pictorial form. All service users choose their transport mode and design their vehicle; staff paint the road and buildings and have used various methods to depict how someone can go through the unit in different ways, for example tractors might depict slower progress than sports cars, or a lay-by can depict taking a career break for staff. This initiative has enabled staff to talk to service users in an understandable way, and show how everyone can progress through the journey and what lies beyond.

Contact: Audrey.Whelan@LPT.nhs.uk

Benchmark 8: LDNs working in inpatient care services provide excellent person-centred care, with the aim of successfully supporting people to return to live within their community	
Recommendations	Key contributors
8.1 Service providers to assess staff development/training/support needs by measuring against the defined Skills for Health competencies when complete.	Service providers, individual LDNs.
8.2 Education commissioners and providers to work with service providers in developing training to develop/strengthen competencies.	Education commissioners and providers, service providers, people with learning disabilities, family carers.
8.3 Service providers to review the career structures in inpatient settings to ensure that they offer opportunities for career development and encourage staff to specialise in this area of care and develop high-level skills/expertise.	Service providers, individual LDNs.

4.7.2 Making a difference in social care settings

Many registered nurses work in social care settings, for example as home managers. However, they are not typically employed in specifically nursing roles. Potentially, a nurse can provide added value in such a role, with an ability to recognise and respond to health needs and to liaise with healthcare services as required. However, to provide this role it is important that the nurse remains up to date and continues to maintain non-invasive healthcare skills.

Good practice example: Applying learning disability nursing skills in social care settings

Lisa Gregg-Herrett works as a Quality and Service Development Manager for Choice Support, an independent sector organisation. This role provides the opportunity to use her learning disability nursing skills supporting people with extremely complex needs to move from long-stay hospitals, assessment and treatment units and family homes to new homes of their own. A learning disability nursing background provides the foundation for a holistic approach to establishing complex care and support packages and in areas such as assessment of need and service design and planning. Lisa’s employer has provided extensive training in new areas that complement and build upon existing learning disability nursing skills, for instance in service brokerage and self-directed support.

Contact: lisa.gregg-herrett@choicesupport.org.uk

**Benchmark 9:
LDNs who are employed in social care settings are able to contribute to responding to health needs**

Recommendation	Key contributors
9.1 Social care providers who employ nurses in non-nursing roles to consider the need to support continued health-focused professional development through individual appraisal processes.	Social care providers, nurses working in social care.

See also: Benchmark 2

4.7.3 Effectiveness in care management roles

Significant numbers of LDNs work in integrated community learning disability teams led by local authorities. In some cases, LDNs provide a care management role, where they coordinate care and manage care budgets for individual service users. While they may bring valuable expertise to this role, it is important that this does not detract from their ability to focus on meeting the health needs of people with learning disabilities. Local partnerships should ensure that they are satisfied that the limited resource of learning disability nursing staff is being effectively invested in addressing the mainstream health agenda and not being unduly compromised by LDNs working in care management roles.

Benchmark 10: LDNs carry out formal care management roles only where this is required to meet needs that are predominantly health related	
Recommendation	Key contributors
10.1 Local authorities to establish processes where formal care management roles are only taken on by nurses when: <ul style="list-style-type: none"> • the majority of care required is healthcare; and • there is added benefit to an individual service user by a nurse taking on this role. 	Service providers and commissioners.

4.8 Supporting excellence in practice

In order to make the most difference possible to the well-being of people with learning disabilities, LDNs need to base their practice on the best available evidence. They also require good education and professional support, and should be able to respond to need by developing new roles and skills.

4.8.1 Developing evidence-based practice

It is essential that LDNs utilise the best evidence available to inform their practice. However, to date there is relatively little research evidence directly regarding LDNs' practice (see Appendix 3). Few learning disability nursing departments in universities have a significant role in research and many nurses complete small-scale research projects without publishing their results.

Benchmark 11: LDNs are able to base their practice on sound evidence and contribute to the development of the local and national evidence base regarding the health needs of people with learning disabilities	
Recommendations	Key contributors
11.1 All LDNs carrying out postgraduate courses including a research component to commit to publishing their findings with support from their employer.	Individual LDNs, service providers, research leads, higher education institutions.
11.2 All service providers to consider whether their future research strategies should incorporate opportunity to develop research that will inform future learning disability nursing practice and encourage small-scale projects to link in a coherent, thematic manner.	Service providers, research leads and higher education institutions, individual LDNs.
11.3 Service providers and higher education institutions to assess the need to develop specific means of supporting research awareness and activity, for example journal clubs, research seminars.	Service providers, research leads and higher education institutions, individual LDNs.

Good practice example: Developing evidence-based practice

In Northamptonshire Healthcare NHS Trust, a nurse-led innovation has been the establishment of a multidisciplinary journal club which provides a forum to appraise research. This innovation has helped staff develop confidence and skills in critically appraising research and relating it to practice. The knowledge gained has supported new service developments, such as use of abdominal massage for constipation, use of midazolam as a rescue medication for status epilepticus, and progressive relaxation therapy to help service users with anger management. The development of the journal club has been written up and published in a peer reviewed journal.

Contact: Catherine.hunt@northants.nhs.uk

4.8.2 Developing education to support excellence

The future of pre-registration nurse education is currently under review by the NMC. There are currently a number of challenges for LDN pre-registration education, with geographical variation affecting the availability of courses, compounded by a lack of clear evidence as to whether courses typically equip new registrants with the essential skills required to practise, especially in inpatient care settings. Commissioning varies across the country in terms of its ability to appropriately identify future workforce needs, including the non-NHS workforce, such as nurses employed in independent and third sector organisations.

Benchmark 12: Newly qualified LDNs have the essential skills to practise effectively	
Recommendations	Key contributors
<p>12.1 Education commissioners to review their current arrangements for commissioning pre-registration education to identify ways of:</p> <ul style="list-style-type: none"> • developing informed expertise in commissioning of learning disability nursing education; • ensuring geographical equitability of access to training; and • developing expertise in the provision of learning disability nursing training, for example identifying a limited number of centres of excellence which demonstrate the capacity and capability to overcome geographical challenges and to provide excellence in developmental learning and education for the whole learning disability workforce. 	<p>Individual LDNs, service providers, education commissioners, workforce planners, higher education institutions.</p>

<p>12.2 Education commissioners, with others, to review the ability of local learning disability nursing courses to provide:</p> <ul style="list-style-type: none"> • essential competencies for practice (see section 4.4 above); and • the range of health skills required based on local needs and national policy, taking into account the range of roles and settings that LDNs need to be able to work in effectively, including inpatient care settings. 	<p>Education commissioners, service providers, people with learning disabilities, family carers, higher education institutions.</p>
<p>See also: Benchmarks 1 and 2</p>	

4.8.3 Ensuring that learning disability nurses have access to support and advice

With the number of LDNs working in the NHS declining and greater plurality in types of employment, some LDNs feel isolated and lacking professional leadership. This potentially undermines their ability to be effective, assertive and values-based practitioners in a multidisciplinary and multi-agency environment.

<p>Benchmark 13: All LDNs have access to advice on professional issues</p>	
<p>Recommendations</p>	<p>Key contributors</p>
<p>13.1 Every LDN to have access to a named, experienced LDN who is available to provide advice on professional issues.</p>	<p>Individual LDNs, service providers, commissioners.</p>
<p>13.2 Every LDN to actively seek professional advice and support as required regarding issues that they consider to be challenging or ethically unclear.</p>	<p>Individual LDNs.</p>

4.8.4 Developing new ways of working to improve services

LDNs can potentially make services for people with learning disabilities more responsive and person centred, and make better use of their skills and knowledge through taking on new roles. In particular, recent legal changes have allowed LDNs to take on new roles such as nurse prescribers and as responsible clinicians (the person with overall responsibility for the care of a detained patient) under the Mental Health Act 2007. These developments have the potential to improve care for some people with learning disabilities when based on identified local need and carried out through engagement with key stakeholders.

Benchmark 14: LDNs adopt new ways of working to improve care provided based on local need	
Recommendations	Key contributors
14.1 All service providers to assess how the development of nurse prescribing roles for LDNs may improve the responsiveness of services to make better use of nurses' knowledge and skills, increase efficiency, support the development of new roles/services and increase choice for people with learning disabilities.	Individual LDNs, service providers, commissioners, people with learning disabilities, other healthcare professionals
14.2 All providers of specialist inpatient services to carry out a needs assessment of detained patients to identify particular skills and attributes that should be held by responsible clinicians and whether LDNs or other professionals should be developed to take on such roles in the future.	Service providers, people with learning disabilities, commissioners, individual LDNs and other healthcare professionals.
See also: Benchmark 1	

Good practice example: Improving treatment through nurse prescribing

In South Staffordshire and Shropshire Healthcare NHS Foundation Trust, several LDN prescribers are now practising. In the area, many people with learning disabilities had been receiving long-term anti-psychotic medication from their time living in institutions. A key aspect of the nurse prescriber's role has been to review this while using supplementary prescribing in collaboration with consultant psychiatrists. In many cases, they have been able to titrate, monitor and eventually stop the use of such drugs where there was no evidence of specific need. The nurses have, at the same time, been able to help develop alternative methods of managing certain symptoms or behaviour.

Contact: Ruth.kirkman@ssh-tr.nhs.uk

4.8.5 Making use of new skills

LDNs may currently undertake a range of post-registration training that equips them with valuable skills, such as those in psychological therapies, epilepsy management and working with 'challenging behaviour'. For these skills to be utilised effectively they need to be planned for use as an integral part of service provision, and ongoing supervision and continuing professional development should be provided.

**Benchmark 15:
LDNs utilise specialist skills as required by local planning and strategic needs assessments**

Recommendation	Key contributors
15.1 Where LDNs train in specialist skills, this is to be informed by a needs assessment of people receiving services and for planned action to be agreed prior to training with their manager regarding implementation and ongoing supervision/support for practice to ensure that the skills can be applied post training.	Individual LDNs, service providers, commissioners, people with learning disabilities, family carers.

References

Department of Health (2001a) *Valuing People. A new strategy for learning disability for the 21st century*. London, The Stationery Office.

Department of Health (2001b) *Learning disability and ethnicity report to the Department of Health*. London, DH.

Department of Health (2006) *Our Health, Our Care, Our Say: a new direction for community services*. London, DH.

Disability Rights Commission (2006) *Report of the DRC Formal Inquiry Panel to the DRC's Formal Investigation into the inequalities in physical health experienced by people with mental health problems and people with learning disabilities*. London, DRC.

Healthcare Commission (2007a) *Investigation into services for people with learning disabilities at Cornwall Partnership NHS Trust*. London, Healthcare Commission. www.healthcarecommission.org.uk

Healthcare Commission (2007b) *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*. London, Healthcare Commission. www.healthcarecommission.org.uk

Hollins S, Attard MT, von Fraunhofer N and Sedgwick O (1998) Mortality in people with learning disabilities: risks, causes and death certification findings in London. *Developmental Medicine and Child Neurology* 40: 50–6.

Information Centre (2007) *NHS Hospital and Community Health Services. Non-Medical staff. England 1996–2006*. London, Information Centre. www.ic.nhs.uk/statistics-and-data-collections/workforce/nhs-staff-numbers/nhs-hospital-and-community-staff-hchs-2006

Kay B, Rose S and Turnbull J (1995) *Continuing the Commitment: The Report of the Learning Disability Nursing Project*. London, DH.

Mencap (2004) *Treat me right! Better health care for people with a learning disability*. London, Mencap.

Mencap (2007) *Death by Indifference. Following up the Treat me right! report*. London, Mencap.

National Patient Safety Agency (2004) *Understanding the patient safety issues for people with learning disabilities*. London, NPSA.

Northway R, Hutchinson C and Kingdon A (eds) (2006) *Shaping the future: A vision for Learning Disability Nursing*. London, UK Learning Disability Consultant Nurse Network.

Appendix 1 Numbers of learning disability nurses

Table 1: Total number of nurses registered to practise in learning disability in the UK

Year	2001/02	2002/03	2003/04	2004/05
Number	25,574	25,006	24,864	24,604

Source: Nursing and Midwifery Council, Statistical analyses of the register

Table 2: Initial registrations to practise in learning disability nursing

Year	2001/02	2002/03	2003/04	2004/05
Number	416	*	562	526

*Figure not reported.

Source: Nursing and Midwifery Council, Statistical analyses of the register

Table 3: Commissioned student places 2002–07

	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08*
Degree	112	96	145	108	130	143
Diploma	720	769	699	640	593	642
Total	832	865	844	748	723	785

* Planned numbers only.

Source: Department of Health

Appendix 2 Literature review summary

Aim

A literature review was carried out by the National Nursing Research Unit at King's College London in order to evaluate the nature and scope of research available to specifically inform the practice of LDNs. Learning disability nursing research was defined as any form of systematic enquiry that concerned the work of people employed in a nursing role (whether specialist trained or not), as it impacted on or was experienced by people with learning disabilities, their carers, family members or nurses themselves.

Findings

The review found fewer than 200 studies. The majority of the research came from the UK. Much research is descriptive and only a minority of studies evaluate direct intervention or delivery of care by LDNs. Few studies examine nurse interventions for common problems such as behavioural difficulties. There is little strong evidence about effectiveness. There is a relatively strong theme in addressing physical and mental health care in terms of service development, assessment or client experience although the number of studies in this area is still small in absolute terms.

Conclusions

The extent of learning disability nursing research is currently limited in quantity and its ability to provide reliable, generalisable or verifiable insights. It is acknowledged that research on the activities of other disciplines may also provide useful evidence for nursing practice.

The full report *The research base for learning disability nursing* can be obtained from the National Nursing Research Unit (email nru@kcl.ac.uk)

Appendix 3 Equality and good practice in learning disability nursing

The role of LDNs in helping to respond to the inequalities experienced by people with learning disabilities is central to this good practice guidance. This appendix describes the results of an Initial Equalities Impact Assessment that subsequently influenced the development of the guidance and summarises the sections in this guidance that specifically relate to inequalities.

Initial Equalities Impact Assessment

An Initial Equalities Impact Assessment was carried out to inform the development of this good practice guidance. Following the Department of Health's process for identifying potential areas of significant inequality that might be relevant to nursing practice, information was sought from statistical information, existing research and the views of experts in the field of learning disability practice. This included a reference group of stakeholders (including people with learning disabilities), which was established to advise on the development of good practice guidance.

The issues below were identified as those with potentially significant implications for learning disability nursing practice. These issues were subsequently raised at a series of workshops carried out around the country to inform the development of this guidance, in order to gather any further information and to consider how best the guidance could respond to identified inequalities. People with learning disabilities and family carers attended some of these events.

A) Race

Use of inpatient services – the recent survey of inpatient bed usage by the Mental Health Act Commission (MHAC 2007) showed a higher than average level of black African and Caribbean men as voluntary inpatients (but not detained patients).

Differential morbidity – research evidence suggests that prevalence of learning disability may be markedly higher in some South Asian groups than the rest of the population (DH 2001b).

Access to services – research evidence (DH 2001b) suggests that there may be particular difficulties in accessing appropriate services for some people from black and minority ethnic groups.

B) Disability

Appropriate physical healthcare and health promotion – recent reports from the Disability Rights Commission (2006) and Mencap (2007) indicate marked inequity in access to and the quality of physical healthcare for people with learning disabilities.

C) Age

Transition between children's and adult services – evidence demonstrates problems in ensuring appropriate transfer for people with learning disabilities as they reach the age where they are due to be transferred to adult services (DH 2001). These difficulties can be related to differential availability of services and poor communication and handover.

Services for people with early dementia – people with learning disabilities may be more likely than others to develop dementia at a relatively young age. There is evidence of some difficulty in accessing appropriate mental health services for those with this condition (Holland 2000).

Learning disability nursing and inequalities

While learning disability nursing will not be able to address directly all the inequalities currently existing in the health and social care system for people with learning disabilities, this good practice guidance seeks to ensure that its recommendations:

- do not inadvertently add to inequalities in services; and
- actively identify those areas where changes and developments in nursing practice might make a significant contribution towards tackling inequality.

The summary below highlights the sections of this guidance that most directly relate to issues of inequality and were informed by the Initial Equalities Impact Assessment.

Section 2.3 describes the range of health inequalities that may be experienced by people with learning disabilities.

Section 4.3 emphasises that learning disability nursing must be a values-based profession and these values must include: 'Inequality in all aspects of the life of people with learning disabilities must be actively challenged.' A recommendation is made that all services and individual practitioners review their current role and policies to ensure that they reflect the stated values of the profession and that education providers review the content of courses to ensure that they reflect the same.

Section 4.3 also broadly describes the competencies that all LDNs must have, and these include the ability to help stop people with learning disabilities getting unfair treatment and to make sure that people with learning disabilities and their supporters know about other people who can help, especially people who work in the NHS. A recommendation is made that all service providers and LDNs assess whether all nurses have the essential competencies for practice and for development plans to be put in place as required for individuals or teams.

Section 6.4 reiterates that many people with learning disabilities still experience a range of inequalities.

Section 4.6.1 highlights evidence that people from black and minority ethnic groups may have increased difficulty in accessing appropriate services and that LDNs and other specialist workers have an important role in linking with local communities and ensuring that services can adapt to their needs. Relationships with local minority communities are likely to be facilitated if the learning disability nursing workforce reflects the diversity of local populations. A recommendation is made that service providers, in cooperation with higher education institutions, evaluate how well the learning disability workforce reflects diversity in the local populations served and develop processes to better reflect that diversity in the future, where required.

Section 4.6.2 states that people with learning disabilities are often more prone to a range of physical problems than others, yet general healthcare services do not always have the knowledge, understanding or experience to adjust the manner in which they provide care in a way that responds to individual needs. A recommendation is made that service providers and commissioners of general healthcare assess how education and advice needs for staff are met currently and where their services require input from LDNs in primary, acute, general and prison healthcare settings, in order to ensure that services are responsive and comply with disability equality requirements.

Section 4.6.3 states that people with learning disabilities are more likely than others to suffer mental ill health, but that mental health services are not always adequately prepared to respond to such needs. LDNs can play an important contributing role to the identification, assessment and treatment of mental health problems in a wide range of settings. A recommendation is made that needs assessments be carried out regarding current staffing arrangements in inpatient and community mental health teams as to whether they adequately meet the needs of people with learning disabilities who also have a mental health need and to assess the specific need to employ LDNs as part of the skills mix.

Appendix 4 Summary of good practice benchmarks and recommendations

No.	Good practice benchmark	No.	Recommendations	Key contributors
1	All learning disability nurse practice is values based	1.1	All clinical policies and education provision for LDNs to be developed through active and direct involvement from people with learning disabilities and family carers.	Service providers, people with learning disabilities and family carers, higher education institutions and training departments.
		1.2	All services and individual practitioners to review their current role and policies to ensure that they reflect the stated values of the profession.	Service providers, individual LDNs.
		1.3	All education providers to review the content of courses for LDNs to ensure that they reflect the stated values of the profession and account for changes in policy and service delivery.	Higher education institutions.
2	All LDNs have essential competencies for practice	2.1	All service providers and LDNs to assess whether all LDNs have the essential competencies for practice and for development plans to be put in place as required for individuals or teams.	Service providers, training departments, individual LDNs, sector skills, councils for practice.
		2.2	Service providers to make easy read information available regarding the essential competencies to share with people with learning disabilities and others.	Service providers, people with learning disabilities, family carers.

No.	Good practice benchmark	No.	Recommendations	Key contributors
3	Learning disability nursing is able to respond to the diverse needs of local communities	3.1	Service providers, in cooperation with higher education institutions, to evaluate how well the learning disability nursing workforce reflects diversity in the local populations served and develop processes to better reflect that diversity in the future, where required.	Higher education institutions, service providers, workforce planners.
4	LDNs support the provision of excellent physical healthcare to people with learning disabilities in all settings	4.1	Service providers and commissioners of general healthcare in primary, general, acute and prison settings, assess how the education and advice needs of staff are currently met and where their services require input from LDNs, in order to ensure that services are responsive and comply with disability equality requirements.	Service providers and commissioners, LDNs, people with a learning disability, family carers.
5	LDNs support the provision of excellent mental health care for people with learning disabilities.	5.1	Needs assessments to be carried out regarding current staffing arrangements in inpatient and community mental health teams as to whether they adequately meet the needs of people with learning disabilities who also have a mental health need and to assess the specific need to employ LDNs as part of the skills mix.	Mental health service providers and commissioners, LDNs.

No.	Good practice benchmark	No.	Recommendations	Key contributors
6	All LDNs' practice actively helps to safeguard vulnerable people	6.1	All LDNs to attend vulnerable people training at least every two years and on induction into a new employer.	Service providers, individual LDNs.
		6.2	All pre-registration nursing courses to include in-depth teaching in the risks, prevention, detection and response to abuse.	Higher education institutions, people with learning disabilities.
		6.3	Providers of specialist learning disability services to consider the need to establish specialist posts or roles that can work with health and social care staff, people with learning disabilities and others on the risks, prevention, detection and response to abuse.	Service providers, commissioners, people with learning disabilities.
7	Learning disability nursing helps to ensure that commissioning of services responds to the needs of people with learning disabilities	7.1	LDNs, in discussion with their employers, to identify how they can link and engage with commissioners, including practice-based and education commissioners, to ensure that the health needs of people with learning disabilities are highlighted and responded to.	Individual LDNs, service providers, commissioners.
		7.2	Commissioners consider the potential contribution of LDNs to the skills mix required in commissioning teams to make them informed and effective.	Commissioners.

No.	Good practice benchmark	No.	Recommendations	Key contributors
8	LDNs working in inpatient care services provide excellent person-centred care, with the aim of successfully supporting people to return to live within their community	8.1	Service providers to assess staff development/training/support needs by measuring against the defined Skills for Health competencies when complete.	Service providers, individual LDNs.
		8.2	Education commissioners and providers to work with service providers in developing training to develop/strengthen competencies.	Education commissioners and providers, service providers, people with learning disabilities, family carers.
		8.3	Service providers to review the career structures in inpatient settings to ensure that they offer opportunities for career development and encourage staff to specialise in this area of care and develop high-level skills/expertise.	Service providers, individual LDNs.
		8.4	Service providers to consider the need to adopt benchmarks on best practice concerning physical intervention and restrictive practices.	Service providers, individual LDNs, users of inpatient services, family carers.
9	LDNs who are employed in social care settings are able to contribute to responding to health needs	9.1	Social care providers who employ nurses in non-nursing roles to consider the need to support continued health-focused professional development through individual appraisal processes.	Social care providers, nurses working in social care.

No.	Good practice benchmark	No.	Recommendations	Key contributors
10	LDNs carry out formal care management roles only where this is required to meet needs that are predominantly health related	10.1	Local authorities to establish processes where formal care management roles are only taken on by nurses when: <ul style="list-style-type: none"> • the majority of care required is healthcare; and • there is added benefit to an individual service user by a nurse taking on this role. 	Service providers and commissioners.
11	LDNs are able to base their practice on sound evidence and contribute to the development of the local and national evidence base regarding the health needs of people with learning disabilities	11.1	All LDNs carrying out postgraduate courses including a research component to commit to publishing their findings with support from their employer.	Individual LDNs, service providers, research leads, higher education institutions.
		11.2	All service providers to consider whether their future research strategies should incorporate opportunity to develop research that will inform future learning disability nursing practice and encourage small-scale projects to link in a coherent thematic manner.	Service providers, research leads and higher education institutions, individual LDNs.
		11.3	Service providers and higher education institutions to assess the need to develop specific means of supporting research awareness and activity, for example journal clubs, research seminars.	Service providers, research leads and higher education institutions, individual LDNs.

No.	Good practice benchmark	No.	Recommendations	Key contributors
12	Newly qualified LDNs have the essential skills to practise effectively	12.1	<p>Education commissioners to review their current arrangements for commissioning pre-registration education to identify ways of:</p> <ul style="list-style-type: none"> • developing informed expertise in commissioning of learning disability nursing education; • ensuring geographical equitability of access to training; and • developing expertise in the provision of learning disability nursing training, for example identifying a limited number of centres of excellence which demonstrate the capacity and capability to overcome geographical challenges and to provide excellence in developmental learning and education for the whole learning disability workforce. 	Individual LDNs, service providers, education commissioners, workforce planners, higher education institutions.

No.	Good practice benchmark	No.	Recommendations	Key contributors
12 <i>cont.</i>	Newly qualified LDNs have the essential skills to practise effectively <i>(continued)</i>	12.2	Education commissioners, with others, to review the ability of local learning disability nursing courses to provide: <ul style="list-style-type: none"> • essential competencies for practice (see section 4.4 above); and • the range of health skills required based on local needs and national policy, taking into account the range of roles and settings that LDNs need to be able to work in effectively, including inpatient care settings. 	Education commissioners, service providers, people with learning disabilities, family carers, higher education institutions.
13	All LDNs have access to advice on professional issues	13.1	Every LDN to have access to a named, experienced LDN who is available to provide advice on professional issues.	Individual LDNs, service providers, commissioners.
		13.2	Every LDN to actively seek professional advice and support as required regarding issues that they consider to be challenging or ethically unclear.	Individual LDNs.

No.	Good practice benchmark	No.	Recommendations	Key contributors
14	LDNs adopt new ways of working to improve care provided based on local need	14.1	All service providers to assess how the development of nurse prescribing roles for LDNs may improve the responsiveness of services to make better use of nurses' knowledge and skills increase efficiency, support the development of new roles/ services and increase choice for people with learning disabilities.	Individual LDNs, service providers, commissioners, people with learning disabilities, other healthcare professionals.
		14.2	All providers of specialist inpatient services to carry out a needs assessment of detained patients to identify particular skills and attributes that should be held by responsible clinicians and whether LDNs or other professionals should be developed to take on such roles in the future.	Service providers, people with learning disabilities, commissioners, individual LDNs and other healthcare professionals.

No.	Good practice benchmark	No.	Recommendations	Key contributors
15	LDNs utilise specialist skills as required by local planning and strategic needs assessments	15.1	Where LDNs train in specialist skills, this is to be informed by a needs assessment of people receiving services and for planned action to be agreed prior to training with their manager regarding implementation and ongoing supervision/support for practice to ensure that the skills can be applied post training	Individual LDNs, service providers, commissioners, people with learning disabilities, family carers.

Notes

Notes



© Crown copyright 2007
284940 1p 0.5k Dec 07 (CWP)
Produced by COI for the Department of Health

If you require further copies of this title quote
284940/Good practice in learning disability nursing
and contact:

DH Publications Orderline
PO Box 777 London SE1 6XH
E-mail: dh@prolog.uk.com
Tel: 08701 555 455
Fax: 01623 724 524
Textphone: 08700 102 870 (8am to 6pm, Monday to Friday)

www.dh.gov.uk/publications