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Foreword

My professional commitment to learning disabilities nursing is long standing. It emerged from a personal insight early in my career into the vital role that learning disabilities nurses play in the lives of people with learning disabilities, their families and carers, the very complex and high-level competences they possess, and the advocacy, passion and dedication they show. I am therefore proud, and delighted, to be introducing this report of the UK Modernising Learning Disabilities Nursing Review on behalf of my fellow government chief nursing officers.

The role and profile of learning disabilities nursing has changed significantly over the last three decades. The wholesale shift from institutionalised care to a social model of provision based on independence, inclusion and empowerment has improved significantly the lives of people with learning disabilities, but has served to reduce demand for learning disabilities nursing as a specialism. As a result, the learning disabilities nursing workforce today is smaller and more widely distributed across the health and social care sector than ever before; and while some occupy specialist learning disabilities nursing roles, many others have more generic care or managerial roles.

This has resulted in a lack of focus and direction for learning disabilities nursing, fragmentation of the learning disabilities nursing community and, potentially, a loss of core nursing and specialist learning disabilities nursing skills to the system at a time when demand (which is already growing) is likely to increase. More and more children born with learning disabilities are now surviving into adolescence, adulthood and into older age, with the complex range of medical and health problems that brings: they require specialist learning disabilities nursing support across the lifespan.

In initiating the review, the UK chief nursing officers sought to bring this issue to the forefront for people with learning disabilities, their families and carers, policy-makers, commissioners, services, professional leaders and the learning disabilities workforce so that together we can prepare for the challenges and opportunities ahead. At the same time, we wanted to remind everyone of the very proud tradition that underpins learning disabilities nursing and of the importance of their contribution and commitment in a changing world.

The four countries are now invited to consider the report's recommendations and progress then as appropriate within their own contexts.



Ros Moore

Chief Nursing Officer, Scottish Government

Foreword by the Modernising Learning Disabilities Nursing Review Co-production Steering Group

We are the Co-production Steering Group for the UK Modernising Learning Disabilities Nursing Review and we are people with learning disabilities, people with autism and family carers. We all have experience of learning disabilities nursing and want to see it improve and develop. This should be consistent across the UK.

It has been enjoyable working on this and putting forward our ideas. We can see our ideas in the report but this is only the first step. The implementation stage will be even more important as this will lead to the goal of good outcomes for people. We want to see people with learning disabilities, people with autism and family carers meaningfully involved throughout all this work.

Our hopes are that the recommendations will develop a better future of nursing care for people with learning disabilities throughout their lifespan. People are complex and learning disabilities nurses need to find accessible ways to share information and work with people with learning disabilities to ensure good quality holistic health care. People are the experts on their life, health and care.

We want to see decision-makers buying into these recommendations and committing to budgeting to take them forward. As a group, we value the report and feel that it is important that the recommendations are carried out.

Executive summary

The issue

There are approximately 1.5 million people in Britain living with learning disabilities.^A That number is likely to grow by 14 per cent between 2001 and 2021^B as advances in science and care mean many more children with learning disabilities live longer, more fulfilled lives than has ever been the case before and the increasing adult population of people with learning disabilities grows into older age. While this is very welcome, the governments of the four countries of the UK must be sure their health and social care systems are ready for the changing health needs of people with learning disabilities.

Learning disabilities nursing has always had a major input into the health of people with learning disabilities, their families and carers, and demand is likely to grow. However, as a result of changes in societal attitudes to people with learning disabilities and to their care, learning disabilities nurses have become geographically dispersed within a range of public and independent sector providers and are employed in a variety of roles. The overall number of learning disabilities nurses has consequently decreased over time, with many now nearing retirement.

What we want to achieve

The UK Modernising Learning Disabilities Nursing Review wants to ensure that people with learning disabilities of all ages, today and tomorrow, will have access to the expert learning disabilities nursing they need, want and deserve. That requires a renewed focus on learning disabilities nursing and may require service and strategic investment in building and developing the workforce. The review aims to set the direction of travel for learning disabilities nursing to ensure we can meet current and future demand and that the workforce is ready and able to maximise its role throughout the entire health and social care system. We also want to ensure the best staff experiences and career opportunities for learning disabilities nurses and, most importantly, the best experience of support and care for people with learning disabilities, their families and carers.

The review makes a number of detailed recommendations (seen throughout this report and summarised in Table 2) that are about “strengthening the commitment” to learning disabilities nursing across the public sector. Underlying them are four clear organising principles for supporting reform.

Strengthening capacity

Accurate information on where learning disabilities nurses are working both within and outside the NHS is important for workforce planning and to ensure education programmes remain relevant. Further work is required across the four countries to scope the workforce, including those working in the independent/voluntary sector and in social care, so that strategic workforce development plans are developed and enacted. There should be a clear statement about what we want from learning disabilities nurses going forward and

^A Source: Mencap (www.mencap.org.uk/all-about-learning-disability/information-professionals/more-about-learning-disability).

^B Emerson E, Hatton C (2008) *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England*. Centre for Disability Research: Lancaster.

they should be enabled to plan their career development to meet the needs of people with learning disabilities now and in the future.

Strengthening capability

The values base for learning disabilities nursing remains strong and we should ensure that systems retain and reinforce attitudes and abilities to deliver person-centred and strengths-based approaches. At the same time, skills, knowledge and competencies are changing and must be extended to reflect the changing needs of people with learning disabilities.

Evidence clearly shows that people with learning disabilities have poorer health than the general population. In addition, many have difficulties accessing and using general health services. Learning disabilities nurses have an important role to play in supporting timely access to services, as well as contributing to preventative and anticipatory care.

Strengthening quality

All four countries are currently engaged in significant programmes of system transformation, efficiency and quality improvement. Learning disabilities nurses must embrace that movement and consider how they can demonstrate impact through measurable outcomes and evidence-based interventions that improve safety, productivity and effectiveness alongside traditional person-centred approaches.

A well-prepared, developed and supported workforce at all levels (including nonregistered staff) is essential to the delivery of quality health care for people with learning disabilities and education and training throughout the career pathway is key to achieving this.

Strengthening the profession

Strong leadership will be crucial to ensuring the recommendations from this report are taken forward and that existing networks for learning disabilities nurses across the UK continue to provide a powerful platform from which to celebrate, promote and develop their unique contribution. These have tended to be developed mainly for NHS staff, so a key step is for the learning disabilities nursing profession to embrace members from all sectors to create a critical mass of leaders working together to effect change and advocate for the profession and those they serve.

The way forward

We do not underestimate the challenge this will present. All this will take place in a time of recession, uncertainty and increasing diversity across the four UK health care systems. However, the demographic factors set out above cannot be ignored, and that's why high levels of commitment and engagement from key players are needed. UK government health departments, employers, educators, people with learning disabilities, their families and carers, learning disabilities nurses and wider health and social care staff are all crucial to its success.

Introduction

Health and social care systems across the UK continue to face significant strategic, structural and economic change, with an increased focus on localism and integration, changes in commissioning structures and a strong emphasis on outcomes and transparency. Learning disabilities nursing must adapt to meet the demands of this change.

The UK Modernising Learning Disabilities Nursing Review aims to ensure the best possible services are provided to people with learning disabilities, their families and carers now and in the future and that we have a valued and thriving learning disabilities nursing profession.

Health and social care challenges

Population

The population of people with learning disabilities is increasing across the UK and internationally. Demographic projections suggest that the numbers of people with learning disabilities will increase by 14% between 2001 and 2021 (1), with rises at both ends of the age spectrum linked to better survival rates in premature babies and improvements in health care and general standards of living (2,3).

Health inequalities

The number of individuals with complex needs, including co-morbid health problems and behaviours perceived as challenging, is increasing across the UK (4). A third of people with severe and profound learning disabilities also have an associated autism spectrum disorder (5). People with learning disabilities often experience health and social problems associated with ageing earlier than the general population and there is a higher than average incidence of dementia within some groups (6).

There is evidence showing that many physical, sensory and mental health needs of people with learning disabilities go unrecognised and unmet by services, with consequent negative impacts on their quality of life, life chances, life expectancy and experience of services.

Evidence also demonstrates the increased susceptibility of people with learning disabilities to discrimination and to potential violation of human rights within care settings (7,8).

These compounding issues can lead to people with learning disabilities being at higher risk of poor physical and mental health and to early mortality. If these issues aren't addressed, all services, be they specialist or general, can expect to experience greater demands from people with learning disabilities, their families and carers in the future (9).

Policy shift

Service modernisation initiatives across the four countries are similar in direction of travel, although they may differ in detail. They all aim to:

- promote independence, social inclusion and citizenship;
- develop a service ideology influenced by the social model of disability and values-based, rights-based, person-centred approaches;
- progress the integrated services agenda;
- promote community-based services; and
- ensure equitable access to health care for people with learning disabilities, their families and carers.

Examples of specific policies across the four countries are cited in Appendix 1.

Current position

Learning disabilities nurses remain important in the eyes of stakeholders

In the past, there was some debate about the relevance of learning disabilities nursing in the context of the shift to a social model of provision. Other countries have moved to a workforce with generically prepared registered nurses, or to training more closely aligned to social work or social education. The UK, however, has retained specific preparation towards registration as a Registered Nurse Learning Disabilities for over a century. Some countries are now reconsidering the benefits of having specifically prepared nurses for people with learning disabilities. More recently, there has been recognition that learning disabilities nursing continues to play a crucial role in moving the care of people with learning disabilities from an institutional setting to communities, in championing health improvement and working to tackle the health inequalities experienced by those they work for.

Learning disabilities nursing has a strong values base

Learning disabilities nurses respond to individuals with learning disabilities, their families and carers in a creative, flexible and effective manner, ensuring that interventions are informed by the most recent evidence- and values-based practice. They have a commitment to lifelong learning and promote the empowerment of people with learning disabilities, their families and carers in all aspects of care.

The values base for learning disabilities nursing (see Box 1) is strong and remains the key element underpinning practice. We have built on this base to develop a modernised vision of learning disabilities nursing across the four countries of the UK.

^C "Carer" refers to: "... someone who looks after a partner, husband or wife, son or daughter, relative or friend with a disability or illness. Many carers live with the person they care for, but many look after someone who lives independently, in supported accommodation, in hospital, or in a care home ... Carers are family members or friends who look after someone without pay or financial reward. They are sometimes known as 'informal' carers or more frequently as unpaid carers." Source: Scottish Government (2011) The Future of Unpaid Care in Scotland: headline report and recommendations [online]. Available at: www.scotland.gov.uk/Publications/2006/02/28094157/0

Box 1

The values base for learning disabilities nursing

Learning disabilities nursing is based on clear values that include placing individuals at the centre of care and ensuring they are fully involved in all aspects of planning and intervention. It also acknowledges the critical contribution of family and informal carers.^c Central to this are the following underpinning principles that guide learning disabilities nursing practice.

Human rights

Placing the individual at the centre, valuing choice, inclusion, citizenship and social justice. Incorporates equality, individuality, person-centred and strength-based approaches, empowerment, self-determination, dignity and anti-oppression.

Personalisation

Supporting the individual's control and choice over their own life and services through empowering people with learning disabilities, their families and carers and relinquishing "control".

Equality and inclusion

Recognising diversity and challenging inequality and inequity by supporting people with learning disabilities to use the same services and have the same opportunities and entitlements as anyone else.

Person-centred

Meaningful engagement with people to identify goals significant to the person.

Strengths-based

Focusing on existing strengths, skills, talents and resources and increasing personal competence.

Respect

Valuing the whole person and the diversity of people who support and sustain him or her. Appreciating the contribution of families and carers and, where possible, enhancing the contribution of others.

Partnerships

Recognising that health and social outcomes are interdependent.

Health-focused

Focusing on the individual's health and well-being to enable inclusive lifestyles.

Current role of learning disabilities nurses

Learning disabilities nurses work with people, families and carers with a wide range of abilities and needs and within a diverse range of settings, providing both generalist and specialist nursing care. Consequently, they require a wide range of skills (including "traditional" skills such as care planning and "non-traditional" skills such as accessible communication^d) alongside specific clinical, behavioural and psychological interventions.

^c "Carer" refers to: "... someone who looks after a partner, husband or wife, son or daughter, relative or friend with a disability or illness. Many carers live with the person they care for, but many look after someone who lives independently, in supported accommodation, in hospital, or in a care home ... Carers are family members or friends who look after someone without pay or financial reward. They are sometimes known as 'informal' carers or more frequently as unpaid carers." Source: Scottish Government (2011) The Future of Unpaid Care in Scotland: headline report and recommendations [online]. Available at: www.scotland.gov.uk/Publications/2006/02/28094157/0

^d Accessible communication means designing information that is easier for everyone to use. This may mean producing material in a specific format such as large print, audio or Easy read. (Source: www.romathomas.co.uk/articles/index.php/accessible-communications)

Central roles of learning disabilities nurses can be summarised as:

- effectively identifying and meeting health needs;
- reducing health inequalities through the promotion and implementation of reasonable adjustments; and
- promoting improved health outcomes and increasing access to (and understanding of) general health services, consequently enabling social inclusion.

They also have an increasingly important role in helping to keep people safe and in supporting decision-making around capacity to consent and best interests.

These strengths provide a solid foundation for the development of learning disabilities nursing within the current demographic and policy context.

The UK Modernising Learning Disabilities Nursing Review

Learning disabilities nurses have been at the forefront in introducing and leading new ways of working to support reform, service modernisation and redesign initiatives, but an accountable and forward-thinking profession must future-proof itself.

The UK Modernising Learning Disabilities Nursing Review was commissioned and led by the Chief Nursing Officer for Scotland on behalf of the chief nursing officers across the UK. It reflects a four-country commitment to gathering and considering evidence on the current and future contribution of learning disabilities nursing. At the heart of the review is the commitment to supporting people with learning disabilities, their families and carers to achieve and maintain good health.^E

The review does not stand alone: it is part of an ongoing consultative programme of work (see Box 2).

Box 2

Ongoing consultative programme of work

The programme aims to:

- set out the value that learning disabilities nurses bring;
- identify and share good practice in learning disabilities nursing;
- assess regional recruitment and retention issues;
- prioritise areas for development that reflect future models of care and population trends within specialist and generic services;
- consider what improvements can be made in areas such as education, careers, leadership, research, outcome indicators, public health and workforce; and
- identify the organisational, education and development strategies that will support and enable the learning disabilities nursing profession to realise its full potential.

^E Within this report, “health” is viewed as encompassing physical, social and psychological conditions that enable individuals to achieve their potential (10). Recognising that each person’s potential will differ, the role of learning disabilities nurses is in advising against, preventing and/or removing obstacles that limit the extent to which people with learning disabilities are able to achieve their individual potential.

Each country has involved people with learning disabilities, families and carers in a range of ways, either as members of steering groups or through focus groups and meetings with local organisations. In addition to hosting the UK Co-production Steering Group for people with learning disabilities, their families and carers, the Scottish Consortium for Learning Disability held focus groups for children and young people and people receiving support from forensic services.

The review was supported by a national programme manager reporting to the UK Programme Board, with four country-specific steering groups (Appendix 2).

Review processes included literature reviews, the collection of positive practice examples and visits to practice and education settings. Nurses were involved through workshops, conferences and information in the professional press, and focus groups were held for student nurses. In addition, a consultation was carried out with learning disabilities nursing students across the UK via two facilitated sessions using Facebook webchat, and two UK-wide events were held (one for learning disabilities nursing educationalists and one for professionals working in the independent/voluntary sector).

The review also worked closely with the Royal College of Nursing (RCN) to explore student aspirations and careers and to take forward work on image and recruitment.

Overview of the report

This report is relevant to all who design, develop, commission or deliver services for people with learning disabilities, their families and carers. This includes those working in the non-statutory sector, acknowledging their important role in improving outcomes and experiences.^F

We recognise that people with learning disabilities, their families and carers already benefit from a raft of socially progressive legislation and policy throughout the UK, targeting their needs in areas such as health, social care, transport, housing and benefits. The recommendations consequently build on and support these national and local initiatives.

A fully accessible version of this report is being prepared for people with learning disabilities, their families and carers.

The report is structured around four chapters based on the four key themes set out in the executive summary with sections linking directly to the headings from *Modernising Nursing Careers* (11). Each chapter offers a brief narrative setting out key issues and recommendations for action. Positive practice examples collected through the review processes feature throughout, and the report ends with a conclusion and next steps.

The report's recommendations are also set out in Table 2, where the role of key players is proposed.

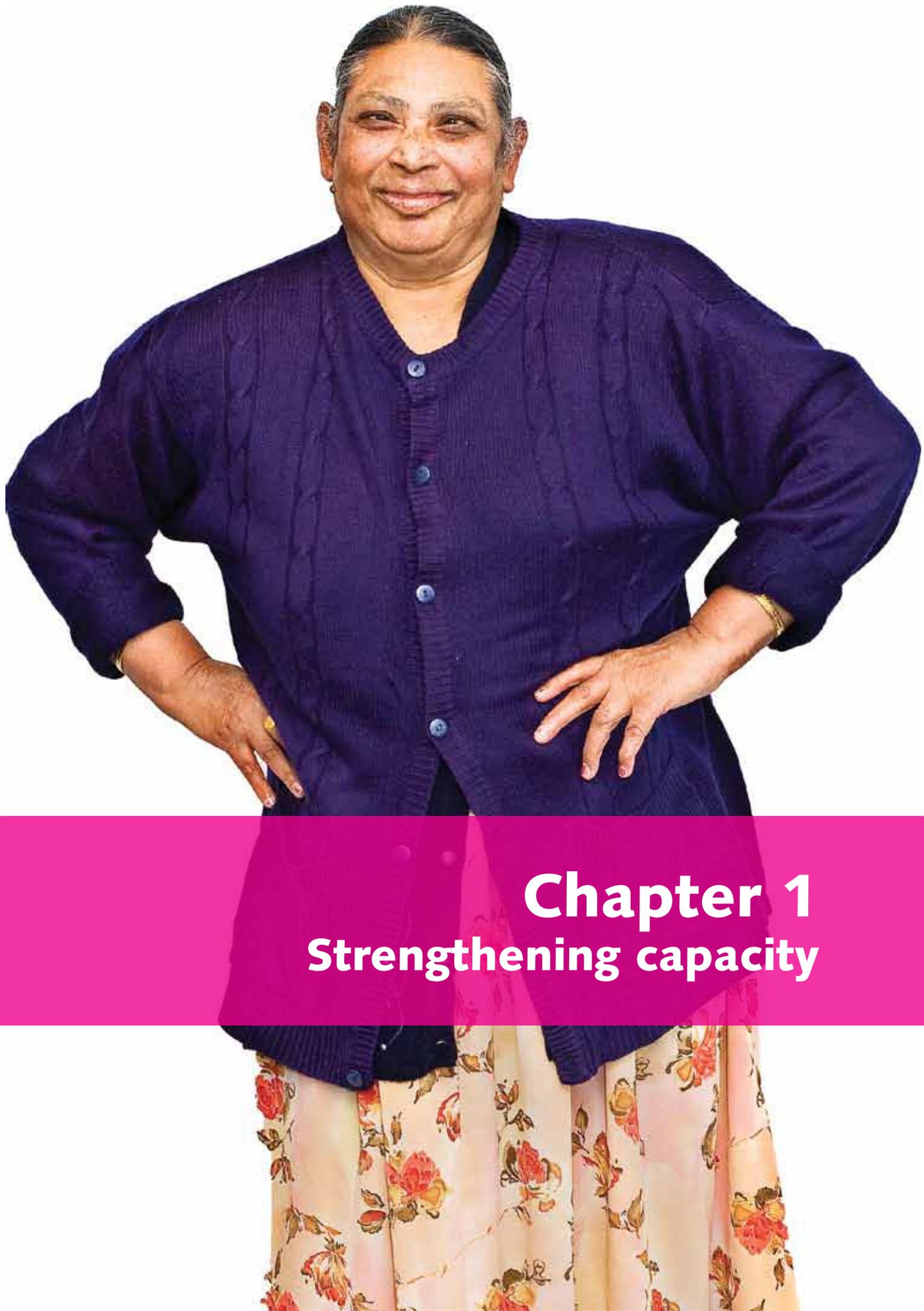
^F NHS provision may include partly or fully integrated health and social care structures/services.

“I’m going into hospital soon and I’m not frightened anymore because [learning disabilities liaison nurse based in the hospital] will be there to make sure I’m all right.”

Person with learning disabilities

“I believe learning disabilities nurses have helped support and move supporting people with profound and multiple learning disabilities onto people’s agenda.”

Senior community resource worker



Chapter 1

Strengthening capacity

Chapter 1. Strengthening capacity

This chapter addresses some of the key considerations underpinning efforts to strengthen capacity through developing the learning disabilities nursing workforce in relation to:

- location and employment
 - strategic workforce planning and development
 - new ways of working and new roles
 - career choices.
-

1.1 Location and employment

Where we are now

Learning disabilities nurses work in a diverse range of settings, including assessment and treatment services, community teams, the independent/voluntary sector, the criminal justice system and the education sector, providing generalist and specialist nursing care.

Changing patterns of service provision mean that most nurses now do not work in institutions. Instead, they work within geographically dispersed, interdisciplinary and interagency community-based models. Some have strong links to, or are even located within, primary, secondary, mental health or acute services, though this is not common.

The independent/voluntary sector has increased its contribution to service delivery, becoming major employers of learning disabilities nurses in the process, although the precise extent of independent/voluntary sector involvement varies among the countries of the UK.

In some cases, learning disabilities nurses are employed in generic caring or managerial roles. This can lead to the loss of their specialist nursing skills to the service and disadvantage those nurses wishing to progress within appropriate career frameworks.

Where we want to be

Given the demographic and policy challenges highlighted in the introduction, there is a compelling case to assess the learning disabilities nursing workforce required to meet needs within general health services. This may include nurses working in health facilitator roles, in mental health or prison health services or in providing specialist input on a consultancy basis. Learning disabilities nursing skills and knowledge should also be valued in independent/voluntary settings.

In circumstances where nurses are employed in generic caring roles, consideration should be given to how the individual's range of nursing skills and expertise can be utilised to best effect to ensure good health outcomes for people with learning disabilities, their families and carers. In addition, nurses working outside the NHS and their employers should give serious consideration to the benefits of maintaining their professional registration.

Positive practice example

Positive behaviour support in community settings

The Richmond Fellowship Scotland is a social care provider supporting people throughout Scotland with a range of needs, including learning disabilities, autism, forensic needs and mental health difficulties.

The positive behaviour support team was set up in recognition of the fact that many individuals displayed behaviours perceived as challenging and that the organisation needed expertise and skills to support individuals effectively and train staff appropriately. The team comprises a manager and six behaviour support advisors from a range of backgrounds and includes staff with a learning disabilities nursing background. The team carries out functional assessments and, following this, behaviour support plans are developed for the local staff team to implement with support. This direct work with staff and people with learning disabilities is a key factor in successful implementation of the approach.

The model includes proactive and reactive strategies such as teaching new skills, developing communication, using reinforcement strategies and making adjustments to the environment as necessary. A periodic service review is implemented as an ongoing quality assurance tool; outcomes from this are graphed and fed back to staff teams to promote their commitment and involvement. Outcomes for people with learning disabilities are demonstrated by improvements in quality of life and reductions in behaviours perceived as challenging. Changes to staff attitudes and approaches are also evaluated.

For further information, contact Anne MacDonald at amacdonald@trfs.org.uk

Recommendation 1

The four UK health departments and the independent/voluntary sector should establish a national collaborative to enable better understanding of, and planning for, a high-quality and sustainable registered learning disabilities nursing workforce across all sectors.

1.2 Strategic workforce planning and development

Where we are now

There are over 21 000 learning disabilities nursing registrants in the UK (see Table 1). Not all of these will be in current employment.

Table 1

Learning disabilities nurses on the NMC register, 2011		
Country	Total number of registered nurses	Number of registered learning disabilities nurses
England	533 205	17 458
Scotland	66 750	1913
Wales	33 416	1030
Northern Ireland	22 564	722
Totals	655 935	21 123

Source: Nursing and Midwifery Council

New registrant numbers have slowly reduced over the last 10 years, and the numbers employed by the NHS have also fallen. Questions on the viability of some pre-registration education programmes across the UK have arisen as a consequence.

We have tried to establish where these registrants are working as part of the review, but this has proved difficult, even within NHS settings. A number of factors could account for this, including learning disabilities nurses moving to employment in the wider health and social care sectors. As a result, we are unable to effectively plan for the future.

It is also worth noting that the current learning disabilities nursing workforce is ageing, with the potential for a significant gap in the workforce as experienced nurses retire or leave the profession.

Where we want to be

Further work is required to collect accurate data in relation to the size, location and setting of the current workforce to effectively plan for the future and to monitor progress with the modernisation of learning disabilities nursing. Systems are needed within each country to enable robust and sophisticated assessments of workforce requirements and enable appropriate responses, such as appropriate levels of education provision with comparisons across the UK. This must be taken forward in a partnership involving the statutory and independent/voluntary sectors to ensure a clearer understanding of future workforce requirements across all sectors and promote collaboration and integration.

Effective planning and the development of flexible working patterns will help to ensure valuable experience is maintained within the workforce.

Recommendation 2

Systems to collect workforce data are required in each country, with links across the UK, for workforce planning for future provision of learning disabilities nursing. These should be able to capture information on service provision, educational and research requirements and should cover the independent/voluntary sector.

1.3 New ways of working and new roles

Where we are now

Learning disabilities nurses are highly valued by people with learning disabilities, their families and carers. Compassion, respect and human-rights based values and attitudes are the core skills people with learning disabilities, their families and carers look for in learning disabilities nurses and in all health professionals. They have told us throughout the review that we are doing well in the following areas:

- encouraging empowerment and participation;
- promoting communication skills, including accessible communication;
- carrying out health checks, supporting access to hospital or primary care, helping with behaviour and teaching people about health;
- helping people to keep healthy and live in the community;
- supporting access to general health care (liaison roles are highly valued); and
- raising awareness around learning disabilities through education and training for all health professionals.

However, they also told us that we need to do better in a number of areas. These are reflected in our recommendations and include the following.

- Some people with learning disabilities do not have good experiences in specialist assessment and treatment services. Learning disabilities nurses need to involve people more in their assessment and treatment in these settings and avoid restrictive practices (linked to Recommendation 8).
- Children with very complex needs who are being excluded from education – learning disabilities nurses could support services to manage this better (linked to Recommendation 6).
- Consistency is important: where possible, people prefer to have the same nurse/named nurse (linked to Recommendation 5).
- Nonregistered workers should have a more robust training in learning disabilities (linked to Recommendation 13).

Where we want to be

Going forward, people with learning disabilities, their families and carers have told us that we should keep on doing the things we do now, but reduce the variability they experience and start to extend the role in the following areas.

- Supporting transition from children's to adult services continues to be problematic and carers would value more involvement from learning disabilities nurses (linked to Recommendation 6).
- Learning disabilities nurses could develop their role around discharge planning (linked to Recommendation 7).
- Learning disabilities nurses need to take time to get to know people, build trust and recognise that the person is the expert (linked to Recommendation 5).
- People with learning disabilities, their families and carers would like to be more involved in the selection of learning disabilities nurses, including students and the nonregistered workforce (linked to recommendations 5 and 11).
- People with learning disabilities, their families and carers could be more involved in nurse education for all fields of nursing. Other nurses still need more knowledge and skills in working with people with learning disabilities (linked to Recommendation 11).
- Nurses could expand their role into other areas, such as mental health and prisons (linked to Recommendation 4).

The potential for learning disabilities nurses to undertake new, advanced and extended roles should be developed in line with advances in other fields of nursing. Evidence collected throughout the review would support particular attention being paid to the development of competence around non-medical prescribing, psychological therapies, telehealth, and new roles supporting children and families (see Chapter 2) and people with learning disabilities within the criminal justice system. Some of these are considered in more detail below.

Criminal justice system

A high proportion of people with learning disabilities (7%, compared to 2.5% in the mainstream population (12)) travel through the criminal justice system as victims or perpetrators of crime, in police custody or within courts and prisons. It is essential to ensure that sufficient numbers of learning disabilities nurses work in these services, utilising their specialist skills in assessment, planning, diversion (where appropriate) and liaising with different agencies within custodial settings and after release.

Non-medical prescribing

Non-medical prescribing offers opportunities to improve access to medicines and reduce waiting times and is positively viewed by people who have experienced it as part of their care (13). The potential for extending roles through non-medical prescribing for learning disabilities nurses should be explored, particularly in relation to epilepsy and mental health care.

Positive practice example

Non-medical prescribing

An epilepsy nurse specialist in Northern Ireland is demonstrating the benefits to people with learning disabilities of undertaking a non-medical prescribing course.

The epilepsy specialist nurse role is varied in that it involves clinical management, education and training, and practice development. The post-holder recognised opportunities to provide advice to people with learning disabilities, their families and carers on medication changes rather than them having to wait for the medical clinician, enabling a timely, effective treatment regime to be initiated and reducing risks by preventing seizures and/or adverse effects.

As a result, the nurse sought to further her knowledge and skills to support competency in prescribing and titrating antiepileptic drugs and her understanding of pharmacokinetic properties and interactions. She successfully completed the non-medical prescribing course and an epilepsy nurse prescribing pathway was agreed within service.

She is now in a position to advise people with learning disabilities, their families and carers on medication changes promptly, based on assessed need. As is the case with the medical consultant who reviews the client's epilepsy at outpatient clinics, she will recommend medication changes to the client's GP, enabling the person's electronic record to be updated and the necessary medication to be provided for the long term. She also provides expert knowledge around epilepsy in people with learning disabilities to support GPs.

For more information, contact Edna O'Neill at edna.o'neill@setrust.hscni.net

Psychological therapies

A growing evidence base around psychological therapies and their benefits for people with learning disabilities supports the development of relevant skills by learning disabilities nurses (14,15). Nurses are encouraged to maintain and practice psychological interventions, supported by effective supervision. The ethos behind this process is to enable nurses to deliver approaches in line with a stepped-care framework, ensuring assessment and treatment delivery at the earliest opportunity and linking with other parts of the care system to reduce hospital admissions.

Telehealth

The increasing use of telehealth and telemonitoring across the UK has the potential to advance the personalisation, strengths-based and assets-focused agenda for people with learning disabilities, their families and carers. Learning disabilities nurses need to explore this potential within the systems in which they work.

Recommendation 3

The development of new, specialist and advanced role opportunities should be considered in light of workforce planning, service development and education provision. In particular, this should focus on the roles of non-medical prescribing, psychological therapies and telehealth and in specific settings such as the criminal justice system, mental health services (particularly dementia) and autism services.

1.4 Career choices

Where we are now

The range of statutory and non-statutory employment opportunities, alongside the integration of health and social care services, means that career choices are not always clear and career options can be limited by a lack of transferability between sectors and employers.

Where we want to be

Career pathways and progression should be clear across all services and settings to allow learning disabilities nurses to plan their career development. *Modernising Nursing Careers* (11) introduced the notion of structured career planning for nurses to enable them to develop knowledge and skills within existing roles that would also allow progression to more senior roles. Many initiatives relating to different levels of the NHS career framework have subsequently been advanced throughout the UK.

Education and training elements at all levels of the NHS career framework should be further developed to outline the knowledge, skills, attitudes and values required by the learning disabilities nursing workforce, including those in specialist practice and consultant nurse roles. This would enable the planning of education to meet workforce development needs, better meet the needs of people with learning disabilities, their families and carers, and act as the foundation for informing future developments in post-registration learning disabilities nursing education, research and scholarly activity. These developments could be utilised across sectors (with appropriate adaptation) to give a coherent career framework.

Positive practice example

Supporting reasonable adjustments

Working as a consultant nurse and senior lecturer, Jim Blair has a remit to lead the delivery and development of clinically effective, safe, lawful and appropriate practice within acute services for people with learning disabilities. The following examples show how the consultant nurse has been able to drive reasonable adjustments in hospitals to enhance the care and treatment experienced by people with learning disabilities.

Katherine has severe learning disabilities and her passport* says she is allergic to eggs. After reading this, the ward sister telephoned Katherine's home to clarify whether she experienced anaphylactic reactions or a rash. This was a precautionary measure, rather than a response to anything that had happened.

Vivek's passport stated that he "bubbles up liquids and regurgitates food". A doctor noted this and knew that this could indicate dysphagia, which can result in a person choking. Dysphagia is more common in people with learning disabilities, so it is vital to look for indications, as there were in Vivek's case, and quickly identify how to ensure optimum nutrition.

Without hospital passports, serious issues may be missed or left unaddressed. Clinicians at St George's Hospital in London were able to act on the information in the passports and to alert colleagues about the issues, resulting in effective care and treatment for both individuals.

Core reasonable adjustments at St George's

The following are standard for people with learning disabilities, their families and carers in St George's Hospital to help reduce anxiety, permit experts (such as family) to provide emotional and advocacy support, and to enable professionals to treat people in an efficient and timely way.

- No fixed visiting times for family, carers and friends of people with learning disabilities is general policy, so they can be with them for as long as they want.
- Food and drink is offered to family and carers to ensure they can be with the person they support at any time.
- The first or last appointment of the day should always be offered, so people who find it traumatic to wait do not have to do so.
- Double appointments are helpful because they permit a fuller assessment of people's needs, which is likely to result in more effective treatment and outcomes.
- A bed and/or chair are provided for a family member or carer.

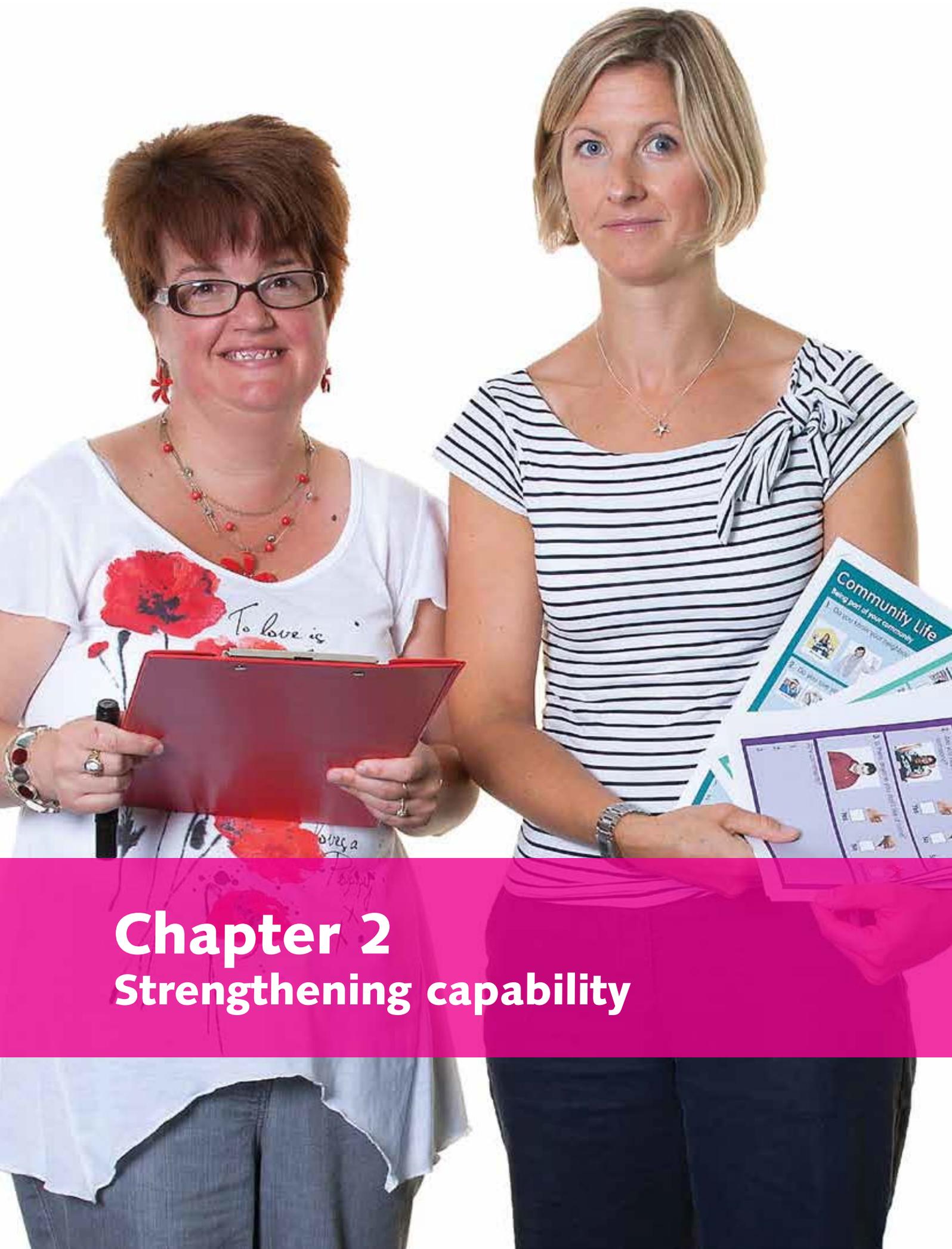
For care and treatment to be equitable, adjustments need to be made so that the health care experiences and outcomes of people with learning disabilities in hospital are improved. An example of reasonable adjustments at St George's involved Trevor, a man who had capacity to consent to have dialysis but who pulled out the tubes after 30 minutes because he was unable to judge how long the procedure had taken and wanted to leave. The reasonable adjustment in his case was to provide a health care assistant to be with him throughout the four-hour treatment to talk with him and encourage him to complete dialysis. Over time, he stopped needing to have someone with him and now has dialysis by himself.

For further information, contact Jim Blair at jim.blair@stgeorges.nhs.uk

*A hospital passport is a guide to the individual's health and well-being that is completed in advance of the hospital visit so that hospital staff have an accurate record of key information relating to their health and medical history (source: www.sabp.nhs.uk/services/ld).

Recommendation 4

Each of the four countries should consider aligning their existing post-registration career frameworks for learning disabilities nursing to clearly articulate the knowledge and skills required by learning disabilities nurses at all levels and across all settings. These developments could be utilised across sectors (with appropriate adaptation) to give a coherent career framework.



Chapter 2

Strengthening capability

“Learning disabilities nursing is vital for ensuring people with learning disabilities and their carers get access to general health care in the same way as you or I do. They help people navigate the NHS system to ensure people with learning disabilities, their families and carers get the best health outcomes and support possible. They also support other health professionals to modify their delivery care models to best suit the client’s circumstances and enable the delivery of true person-centred care.”

Deputy director of nursing, general hospital



Chapter 2. Strengthening capability

This chapter outlines key considerations underpinning efforts to ensure a competent and flexible learning disabilities nursing workforce for the future by:

- maximising the contribution of learning disabilities nursing
 - working with people of all ages
 - addressing health needs
 - providing specialist services.
-

2.1 Maximising the contribution of learning disabilities nursing

Where we are now

The Royal College of Nursing (16) defines 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.”

Learning disabilities nurses are the only professional group specifically prepared to work with people with learning disabilities. This level of preparation, currently provided at degree level, alongside the breadth of biopsychosocial skills, competence and knowledge they develop, makes them a unique and critical component of the delivery of comprehensive services.

Too often in this review examples were cited of how learning disabilities nursing is being under-utilised. Considering the small pool of registered learning disabilities nurses available across the UK and the workforce challenges ahead, it is essential that their expertise is used to best effect for the populations they serve.

Where we want to be

A central requirement for the transformation agenda across the four countries and across all organisations is the need to target the skills, knowledge and competencies of learning disabilities nurses to the right people, in the right places and at the right times.

Positive practice example

Prescriber nurse-led clinics – a community model for people with learning disabilities and epilepsy

A community learning disabilities nurse in Gloucestershire has developed a nurse-led service to enhance epilepsy care for people with learning disabilities, reducing the risk of sudden unexpected death in epilepsy (SUDEP).

Regular appointments, partnership working and training have led to improved recording and medication concordance. This has enabled effective evidence-based nurse prescribing to rationalise people's medication. Reasonable adjustments have also been made by strengthening links and providing relevant data to support access to generic services.

Health outcomes have included:

- 75% seizure reduction;
- 33 people on the epilepsy care pathway with history and medication timeline;
- 9 people accessed a bone density scan, with 7 bone disorders identified (2 results pending);
- 5 women on long-term valproate medication accessed ultrasound scans, with 4 ovarian conditions identified (1 outcome awaited); and
- 544 hours of epilepsy training delivered to carers, empowering people to manage their condition.

The following have been implemented to reduce the risk of SUDEP:

- 17 epilepsy night bed monitors
- risk management plans
- protocols for all people prescribed rescue medication.

Quality, innovation, productivity and prevention savings have also been realised, including:

- reduced unscheduled hospitalisation and emergency calls through improved seizure control, risk management plans and prevention of fractures;
- reduced fuel and travel costs to complement the organisation's Green policy;
- improvements in training, appointment attendance, monitoring and medication concordance, with rationalisation of therapy;
- auditable outcomes using the National Institute for Health and Clinical Excellence's (NICE's) epilepsy-adapted learning disability tool;
- reduction in "did not attend" (13 of 412 consultations); and
- the nurse achieving up to 83 quality monthly contacts (working 22.5 hours/week).

For further information, contact Penny Shewell at penny.shewell@glos.nhs.uk

Recommendation 5

Commissioners and service planners should have a clear vision for how they ensure the knowledge and skills of learning disabilities nurses are provided to the right people, in the right places, and at the right time in a way that reflects the values- and rights-based focus of learning disabilities nurses' work.

2.2 Working with people of all ages

Where we are now

Learning disabilities nurses already make a key contribution to quality nursing service delivery across the lifespan. This includes contact and interventions with babies and children, during school years, at transition to and throughout adulthood and, increasingly, in the later years to end of life. The skills and competencies of learning disabilities nurses must be available at these key life stages.

Where we want to be

Early years

Learning disability nurses should give specific and conscious attention to ensuring the health needs of children and young people with learning disabilities are appropriately prioritised and addressed. Their skills, knowledge and expertise must be maximised to ensure high-quality services and interventions for children with learning disabilities and their families (17).

Not all children with learning disabilities will require support from learning disabilities nurses, and it is essential that the shift towards improving access to general health services for children continues. Learning disabilities nurses nevertheless possess specific knowledge and competencies that can bring added value, particularly to those with the most complex needs, and they must be a central component of services that deliver care to this population in areas such as skills development, mental health and emotional well-being, behavioural management, complex physical health needs and family-focused intervention and support.

Positive practice example

Supporting parents with learning disabilities – new ways of working

The special parenting service in Cornwall provides assessment of parenting skills for people with learning disabilities who are expecting a baby. Areas where support or teaching is required are identified following assessment of knowledge on all aspects of parenting. The service also provides support, advice and consultation to statutory agencies, midwives and health visitors.

Following birth, the nurses work with all agencies involved to ensure that parents can provide “good enough” parenting, ensure that safeguarding issues do not arise and provide follow-up support to parents at identified key developmental stages. The *Parent Assessment Manual* is used as an initial assessment tool: this is designed to assess parenting ability for those with mild learning disabilities. Following assessment, interventions can include solution-focused therapy, video interaction guidance therapy, family therapy and skills teaching. Outcomes include:

- enabling clients to gain the knowledge and skills required for successful parenting
- raising confidence and self-esteem levels
- ensuring good attachment
- reducing family members’ concerns about the parents’ ability to succeed
- empowering the parents to feel confident to access universal services
- reducing the number of referrals to children’s social care over safeguarding issues.

Next steps for the service are to:

- work in collaboration with universal services, midwives and health visitors to promote early referral to special parenting;
- collate evidence from the early intervention project to identify the effectiveness of current interventions; and
- be aware of current evidence-based practice and best-practice guidance to ensure that standards are maintained at the highest level.

For further information, contact Jan Line at jan.line@cft.cornwall.nhs.uk and Paul Thomas at paul.thomas@cft.cornwall.nhs.uk

Older age

Learning disabilities nurses must be prepared for the continuing rise in the number of older people with learning disabilities. These individuals are at risk of a range of physical and mental health conditions and may be frequent users of health and care services and other related agencies. In addition, some people with learning disabilities may be at risk from conditions that are similar to those experienced by older people (such as dementia), but may be too young to access generic older people’s care services.

Recommendation 6

Commissioners and providers of health and social care should ensure the skills, knowledge and expertise of learning disabilities nurses are available across the lifespan. This should be enabled through effective collaborative working across health and social care structures.

2.3 Addressing health needs

Where we are now

There is strong evidence that people with learning disabilities have poorer physical and mental health and greater health needs (including needs related to behavioural difficulties) than the general population. In addition, many have difficulties accessing and using general health services. Learning disabilities nurses have expertise in facilitating and supporting access to general health care services.

The Nursing and Midwifery Council (NMC) standards for pre-registration nursing education (18) reflect the health role and function of learning disabilities nurses, stating:

“Learning disabilities nurses must have an enhanced knowledge of the health and developmental needs of all people with learning disabilities, and the factors that might influence them. They must aim to improve and maintain their health and independence through skilled direct and indirect nursing care. They must also be able to provide direct care to meet the essential and complex physical and mental health needs of people with learning disabilities.”

The contribution of learning disabilities nursing in addressing health needs within the social model of disability has been the source of some confusion. It is important that learning disabilities nurses and services recognise that poor health (in its widest context) limits participation in society.

Where we want to be

As the Learning Disability Consultant Nurse Network (19) states:

“The primary focus of learning disabilities nursing interventions within the social model of disability is upon reducing or eliminating barriers to good health and thereby increasing social inclusion.”

Learning disabilities nurses and their employers should recognise their crucial responsibility in improving health and well-being and reducing inequalities and should engage actively in commissioning, designing, monitoring and delivering services to ensure their accessibility.

A partnership approach across the lifespan involving primary care, child health, mental health, secondary care and specialist learning disabilities health services is essential.

Learning disabilities nurses are ideally placed to contribute to the preventative, early-intervention, strengths-based and public health approaches that are increasingly being applied to the general population to address health needs. While health promotion activity has been at the forefront of learning disabilities nurses' practice for many years, other more proactive preventative and public health approaches to addressing health needs have been less visible in their day-to-day work.

This broader holistic approach to addressing health needs will:

- ensure preventative action and early intervention is a core component of assessment and care planning;
- encourage people with learning disabilities, their families and carers to take a more active role in controlling their own health; and
- support strengths- or assets-based approaches to care and interventions.

There is a clear need for public health interventions to meet the needs of people with learning disabilities, their families and carers and for learning disabilities nurses to engage with colleagues within public health, primary care and other relevant health and cross-sectoral agencies, such as criminal justice and homelessness services.

A proposed model for addressing health needs in the context of learning disabilities nursing is set out in Fig. 1.

Fig. 1

Proposed model for addressing health needs in the context of learning disabilities nursing		
Context	Nursing roles/interventions	Outcomes
Working with children	→ Family support. Early intervention. Skills teaching.	→ Maximised potential of the child. Improved interagency working. Reduced incidence of long-term health issues.
Inequalities in health	→ Health screening/facilitation. Health action planning/interventions. Improving access. Education of others. Policy-influencing. Advocacy.	→ Healthier lifestyles. Reduced morbidity and mortality. Reduced risk for patients in generic services. Social inclusion.
Working with parents and families	→ Supporting parents and siblings of people with learning disabilities. Supporting parents with learning disability. Family therapy. Education/awareness.	→ Family-orientated service delivery. Reduced safeguarding issues. Improved family health and lifestyle.
People facing additional risks	→ Targeting relevant public health needs (e.g. mental health, drugs/alcohol and sexuality). Group interventions. Strengths-based approaches.	→ Enhanced self-care, peer support and independence. Reduced risk and safeguarding issues. Reduced self-harm and distress.
Commissioning	→ Caseload/population needs assessment.	→ Improved and informed commissioning of services.

Positive practice example

Health facilitation

The health facilitator role focuses on ensuring people with learning disabilities live healthier lives and enjoy better health. A significant number of adults with learning disabilities are not receiving a service from community learning disabilities teams but are known to GP practice staff.

A database is presently being constructed in the Southern Trust region of Northern Ireland to provide accurate figures. All practices have been visited by the health care facilitator who will:

- meet with the practice manager to cross-reference names of adults with learning disabilities with practice population lists;
- deliver an education session to GPs, practice nurses and reception staff on health needs and barriers to meeting need;
- encourage practice staff to establish clinics and complete a thorough health check on each individual;
- explain the requirements of the direct enhanced services (DES); and
- agree dates for clinics with GPs and advise on how to ensure good uptake of appointments.

Figures from primary care show that 932 health assessments were carried out in 2009 and 904 in 2010. GPs and practice nursing staff appreciate clinical input and support to develop understanding about people with learning disabilities, especially around behaviour management, communication difficulties, consent issues and health needs. Analysis to date suggests that practices with the health facilitator on site are more likely to meet the requirements of the DES.

A large number of health issues have been identified, including obesity, diabetes, hypertension, lack of medication review and lack of electrocardiograms for people on anti-psychotic medication. Many of these health issues have previously been undetected and unaddressed. GPs and practice staff have developed a rapport with people with learning disabilities, their families and carers, and practice staff have a better understanding of their health issues.

For further information, contact Brea Crothers at brea.crothers@southerntrust.hscni.net or Marie Loughran at marie.loughran@southerntrust.hscni.net

Recommendation 7

Commissioners and providers of health and social care should ensure that learning disabilities nurses are able to collaborate effectively with general health services, including mental health services, to address the barriers that exist for people with learning disabilities to improving their health. This should include proactive health improvement, prevention, whole-family and public health approaches.

2.4 Providing specialist services

Where we are now

Existing specialist services, when appropriately deployed, provide early intervention, crisis resolution and outreach that can reduce unnecessary admissions to hospital through expert assessment, care planning, interventions and evaluations for individuals and their families.

The need for specialist nursing skills in these areas is already significant and is likely to grow in the future. Learning disabilities nurses working within specialist services should possess, or be working towards developing, the appropriate specialist skills and should be able to demonstrate higher levels of judgement, discretion and decision-making in clinical care (20) relevant to their role.

Where we want to be

Evidence collected by the review suggests that assessment and treatment services could further develop and use a range of therapeutic interventions that have positive outcomes for people with learning disabilities. This would require further support and investment in education and development. The specialist role of learning disabilities nursing within assessment and treatment services must therefore be supported through the development of appropriate models of care and provision of relevant education support.

Health care providers and commissioners should review the needs of their populations and make provision to ensure delivery of specialist learning disabilities nursing skills where needed. This may involve reviewing their current workforce configuration and increasing collaboration with education providers.

To ensure that people with learning disabilities and their families receive the best holistic care, skills traditionally associated with acute and community nursing will need to become a core part of learning disabilities nurses' "toolkit".

Positive practice example

Specialist services

A low-secure unit that provides assessment and treatment for men with learning disabilities and forensic issues in Northern Ireland has developed group work and 1:1 therapeutic work for individuals who exhibit behaviours (or who are at risk of committing behaviours) that are sexually harmful to others.

The assessment and treatment programme initially implemented for this group was the Home Office accredited "Adapted Sex Offender Treatment Programme". Prior to implementation, two nursing staff were required to undertake intensive accredited training in advanced group work delivery and complete a period of secondment with probation services, delivering programmes and compiling risk assessments and management plans for offenders. Further training was then completed to deliver treatment specifically to those with learning disabilities.

The programme was based on the cognitive behavioural therapy model, giving individuals the opportunity to take responsibility for their offending behaviour and work towards skills development that would help them identify their specific areas of dynamic risk and formulate relapse-prevention strategies to lower their risk of reoffending.

The work was acknowledged in 2008 when two nurses from the hospital were granted the RCN Nurse of the Year for Northern Ireland award in recognition of setting up and facilitating a programme of treatment that at the time was unparalleled in Northern Ireland.

Nursing staff are providing consultancy on facilitation techniques, programme content and delivery. It is envisaged that nurses who are already qualified to deliver advanced group work will also become involved in training other staff to deliver the new programme. This will lead to a core group of nurses within the hospital who are able to work as therapists, delivering treatment within group work and 1:1 settings and compiling risk assessments and management plans in partnership with people with learning disabilities to facilitate return to community living in the most appropriate and safest way.

For further information, contact Rhonda Scott at rhonda.scott@belfasttrust.hscni.net

Recommendation 8

Commissioners and service providers should ensure that specialist learning disabilities services for complex and intensive needs (including assessment and treatment services across all sectors) employ sufficient numbers of appropriately prepared and supported registered learning disabilities nurses. This highlights the need to support and develop the availability of specialist and advanced clinical skills and knowledge of learning disabilities nurses in all settings.

“I had concerns about the [learning disabilities nurse] student being there... they were completely dispelled... His understanding and natural affinity for dealing with difficult situations mean if he is an example of the future we have no issues.”

Family carer

Chapter 3

Strengthening quality

“Learning disabilities nurses listen to you and make sure I have a say about what happens to me.”

Person with learning disabilities



Chapter 3. Strengthening quality

This chapter addresses some of the key considerations underpinning quality. Clearly, the appropriate preparation and development of learning disabilities nursing will contribute to all chapters of this report, but in this case has been linked to quality in relation to the following issues:

- demonstrating quality outcomes
- quality improvement
- preparing and developing learning disabilities nurses
- maximising recruitment and retention
- developing workforce knowledge and skills for the future
- accessing supervision.

3.1 Demonstrating quality outcomes

Where we are now

Demonstrating the quality, effectiveness and impact of learning disabilities nursing through outcome measurement presents a range of challenges, not least of which is the fact that learning disabilities nurses' work is often placed within a wider interdisciplinary and interagency team context that makes it difficult to identify their particular contribution to achieving outcomes.

Where we want to be

Positive health outcomes not only improve people's health status and quality of life, but also contribute to the achievement of organisational and policy drivers such as person-centredness, safety, effectiveness and efficiency through improving access to general health services, preventing admissions to hospital and securing early discharge.

A measurement framework of outcomes and outcome indicators would allow learning disabilities nurses to demonstrate their effectiveness in assessments, care planning and nursing interventions at individual and service levels within a multidisciplinary context. The potential for such measurement frameworks to be adapted and used across sectors to support health and social care integration should be explored.

A measurement framework should focus on effective assessment, care planning, intervention and evaluation. All interventions by nurses, individually or as part of a wider team, should be based on a competent and structured nursing assessment of the abilities and needs of the person with learning disabilities. Person-centred objectives for nursing interventions with identified timescales for evaluation should then be clearly written within nursing care plans.

An agreed set of indicators developed in collaboration with nurses and people with learning disabilities, their families and carers would allow the contribution of learning disabilities nurses to be evidenced and measured. This is particularly important given the current emphasis on efficiency, effectiveness and added value.

A range of outcomes and outcome indicators can identify effective and high-quality nursing care related to specific roles and practice settings. Examples may include:

- improvements in health status
- increasing access to general health services
- promoting independence and social functioning
- improving nutrition
- enhancing psychological and emotional well-being
- reducing seizures.

A more targeted and specific approach to outcome measurement dependent on role, function and setting may also be necessary. Role-specific indicators (for learning disabilities nurses employed, for example, as health facilitators or those working in acute liaison roles or within forensic services), condition-specific indicators (such as for epilepsy nurses), patient experience and quality-of-life outcome measures (via service user questionnaires and surveys, complaints and compliments, for example) and inclusion of learning disabilities in measurement of generic key performance indicators at service or policy level or via established rating scales (such as the Health of the Nation Outcome Scales for People with Learning Disabilities (HONOS-LD) (21)) will be required.

It is important that people with learning disabilities, their families and carers are involved in determining the outcomes.

Positive practice example

Developing behavioural family therapy

A specialist learning disabilities nurse in Lothian has worked with other clinicians in adapting and delivering behavioural family therapy (BFT) for people with learning disabilities and has trained 18 nurses to use the approach. The service now has three BFT trainers who specialise in learning disabilities and has developed close links with general mental health clinicians and trainers.

The approach is being implemented within several community learning disabilities teams. Clinicians now routinely use a series of outcome measures to monitor its effectiveness, with the client completing the Clinical Outcomes in Routine Evaluation – Learning Disability (CORE-LD) assessment and family members completing the Caregiver Strain Questionnaire (CGSQ) and the Family Functioning Questionnaire (FFQ). Care agency staff also complete an adjusted FFQ.

A successful case study demonstrating a reduction in carer stress for a family member and an increase in functioning for support staff and the family member was presented at the British Association of Behavioural and Cognitive Psychotherapy conference in 2011. A case series of five families was presented at the Seattle Club conference on research in intellectual and developmental disabilities in 2011. The results demonstrated a decrease in family stress on the CGSQ over the five cases, with family functioning improving in all members. There was a decrease in levels of distress in three of the four people with learning disabilities who completed the CORE-LD. It is noteworthy that services had been involved over a prolonged period of time for all five cases, suggesting that their problems were longstanding and that other treatment approaches had not been effective.

Learning disabilities nurses have increased knowledge and confidence following BFT training. The training has also given clinicians a clear structure to deliver the approach. Regular supervision has helped to maintain delivery while maintaining clinician confidence. Plans to further develop this work include:

- continuing to develop the evidence base evaluating the efficacy of the approach;
- expanding the BFT training to all community learning disabilities teams in NHS Lothian and continuing to expand the supervision network;
- developing better pathways for referrals and level of intensity of BFT based on the complexity of mental health issues;
- extending the BFT training to social work, allowing better joint working between health and social care; and
- establishing links with NHS Education for Scotland with a view to developing the approach for nurses on a wider scale.

For further information, contact Keith Marshall at keith.marshall2@nhs.net

Recommendation 9

Learning disabilities nurses, their managers and leaders should develop and apply outcomes-focused measurement frameworks to evidence their contribution to improving person-centred health outcomes and demonstrating value for money. This may require a specific piece of work to scope current frameworks.

3.2 Quality improvement

Where we are now

Learning disabilities nurses embrace the wider drive for evidence-based practice and improvement, but their contribution could be enhanced. Transformational work is currently being undertaken across the UK under patient safety programmes and work to drive quality, innovation, productivity and prevention. Elements of learning disabilities nursing practice may benefit from the systematic application of productivity tools like the Productive Series/Releasing Time to Care and robust improvement science.

Where we want to be

Learning disabilities nurses should increase their involvement in the range of transformational work, productivity, improvement and practice development.

Recommendation 10

Learning disabilities nurses should strengthen their involvement and links to transformational work, productivity improvement and practice development.

3.3 Preparing and developing learning disabilities nurses

Where we are now

A well-prepared, developed and supported workforce at all levels is essential to the delivery of quality health care for people with learning disabilities, and education and training throughout the career pathway is key to achieving this.

People with learning disabilities, their families and carers should be involved in all aspects of curriculum design, development and delivery.

Person-centred care (22) should be the foundation of learning disabilities nurse education. It has been defined as:

"... the delivery of a healthcare experience that recognises and responds flexibly to each person as a unique individual, builds trust and empathy, and engages them in decisions that affect their healthcare and wellbeing. Person-centred care is an approach which recognises that the quality of communication and human engagement with the person receiving healthcare will underpin the effectiveness of the clinical encounter, and therefore impact on the person's healthcare experience and outcomes."

This means working alongside people to identify meaningful goals that fit with their aspirations and the outcomes they want to achieve, rather than focusing on what health and social services think people need.

Where we want to be

Pre- and post-registration education programmes should be designed to reflect issues such as person-centred care and the personalisation agenda and the more complex care needs that are now presenting within the population.

This review focuses on learning disabilities nurses, but the importance of all nursing students at undergraduate level developing core knowledge and skills to work with people with learning disabilities, their families and carers cannot be ignored. This has been emphasised with the NMC standards for pre-registration nursing education (20) and the Michael Report into access to health care for people with learning disabilities (23).

Positive practice example

Supporting the development of skills and knowledge in other fields of nursing (percutaneous endoscopic gastrostomy (PEG))

People who are reliant on their nutrition, hydration and medication being administered via PEG can experience difficulties when their devices block or are removed. This can result in attendance at accident and emergency departments. Community learning disabilities nurses in Swansea work in collaboration with the accident and emergency liaison nurse, specialist nutrition nurse and hospital nurse practitioners to develop individual pathways for direct access to intervention. The outcomes of this work include:

- clear and safe pathways to access secondary care
- reduced risk of invasive interventions such as surgery or endoscopic procedures.

The nurses also identified that people with learning disabilities who had enteral feeding needs were sometimes having to access nursing home facilities for respite care, were relying on registered nurse home visits for domiciliary care, and were unable to access day services unless registered nurses were available. The community learning disabilities nurses worked in partnership with a wide range of organisations to develop a programme of training for independent sector care providers and social services to enable individualised person-centred care plans to be devised, meaning people no longer have to access nursing environments for respite and day services or be reliant on district or continuing care nursing services to deliver support. This process entailed seamless joint working and planning to minimise the identified risks to individuals and those involved in their care, while promoting person-centred services.

For further information, contact Helen Lewis at helen.lewis@swansea.gov.uk or Paula Phillips at paula.phillips@swansea.gov.uk

Recommendation 11

Those who commission, develop or deliver education should ensure that all learning disabilities nursing education programmes reflect the key values, content and approaches recommended in this report. They should also ensure that nurses in other fields of practice develop the core knowledge and skills necessary to work safely and appropriately with people with learning disabilities who are using general health services.

3.4 Maximising recruitment and retention

Where we are now

As we noted previously, the number of providers of pre-registration learning disabilities nursing education has reduced over the years. This will need to be addressed to reflect population and workforce planning needs.

Access to learning disabilities nurse preparation can be problematic for students in some parts of the UK, including remote and rural areas where no learning disabilities nursing education programmes are available locally. High attrition rates are a problem on some pre-registration programmes and the changing face of service provision for people with learning disabilities requires higher education institutions to develop a range of options for clinical placements that support the attainment of competences required by the NMC.

Throughout the review, students said that they feel more valued and better supported where there is strong mentorship in practice placements and close collaboration between practice and education settings. There are opportunities for learning disabilities nursing to trailblaze new models of delivery in education programmes that strengthen work-based support for students and enhance partnership working between education and practice settings.

Where we want to be

New approaches to identify and engage with potential recruitment pools, particularly existing nonregistered staff and students undertaking higher national certificate (HNC) programmes in further education colleges, are required. These opportunities are currently underexploited. The use of IT and social media may offer a route to accessing these groups.

The development of a wider range of accelerated routes and award models could further maximise potential to recruit from existing groups, including nurses on other parts of the register and people wishing to change their careers.

The wide range of educational technology now available provides more flexible options in relation to delivery of education programmes. Flexible and sustainable models of pre-registration curriculum development offer the most positive options for future progression in learning disabilities nursing, and the NMC standards promote these kinds of approaches. Models that support flexibility and sustainability, such as hub and spoke, blended learning approaches and disseminated models, should be considered to support effective delivery of pre-registration education across the UK. Innovative approaches to programme design and delivery that involve people with learning disabilities and families, promote rights-based and person-centred approaches and review options in interprofessional education must be more widely explored.

Recommendation 12

Updated strategic plans for pre- and post-registration learning disabilities nursing programmes are necessary for each country of the UK to support flexibility and ensure an efficient and sustainable model of delivery for the long term. This highlights the need for appropriate numbers of places on pre-registration learning disabilities nursing programmes to meet future workforce requirements.

3.5 Developing workforce knowledge and skills for the future

Where we are now

Post-registration education and continuing professional development (CPD) options are restricted by the relatively small learning disabilities nursing workforce. In addition, data on education needs and development opportunities, including those at post-registration level, are not easily available.

The skills profile of learning disabilities nursing is changing, with greater emphasis being placed on meeting complex health needs and employing specific interventions such as psychological therapies; some learning disabilities nurses are also assuming prescribing responsibilities. There are opportunities for higher education institutions and CPD providers to respond to these changes in the development and delivery of their programmes.

Nonregistered staff already play a vital role, which will change as the role of registered nurses develops. It is important that service providers build an educational infrastructure that meets the needs of this group.

Where we want to be

Creative opportunities for the development of education programmes include blended learning approaches, collaborative working across education providers and across sectors and further development of interprofessional education opportunities.

Positive practice example

Collaborative curriculum design and delivery

The learning disabilities team at Edinburgh Napier University has worked with people with learning disabilities, their families and carers, mentors and other stakeholders for a number of years to influence, design and deliver pre-registration nurse education for learning disabilities. People with learning disabilities, their families and carers and learning disabilities nurses are involved in the selection and interview of students and in developing learning materials, delivering sessions in the classroom, online and in the clinical skills labs, and assessing students in practice.

This partnership approach is central to education provision. In addition to a wide group of people who work as associate lecturers, a learning disabilities nursing development group and stakeholder group meet regularly to review and develop joint initiatives such as creating new modules, expanding the use of educational technology, supporting practice learning environments and promoting practice-based projects. The content of the learning materials has application to practice and the involvement of experts in delivery ensures students experience a strong focus on person-centred, family-centred health care that is relevant to practice.

With the move to increasing use of online technologies, a strategy is being developed to support people with learning disabilities, their families and carers and mentors to develop skills and competence in using technologies such as Elluminate Live and online discussion forums. This work has been commended by NHS Education for Scotland and the agency undertaking revalidation work for the NMC.

For further information, contact Janet Smith at ja.smith@napier.ac.uk

Recommendation 13

Education providers and services must work in partnership to ensure that educational and developmental opportunities for nonregistered staff are developed and strengthened and their benefits are evidenced through appraisal systems, and that educational and development opportunities are available for registered learning disabilities nurses to support their ongoing development, reflecting the needs of people with learning disabilities.

3.6 Accessing supervision

Where we are now

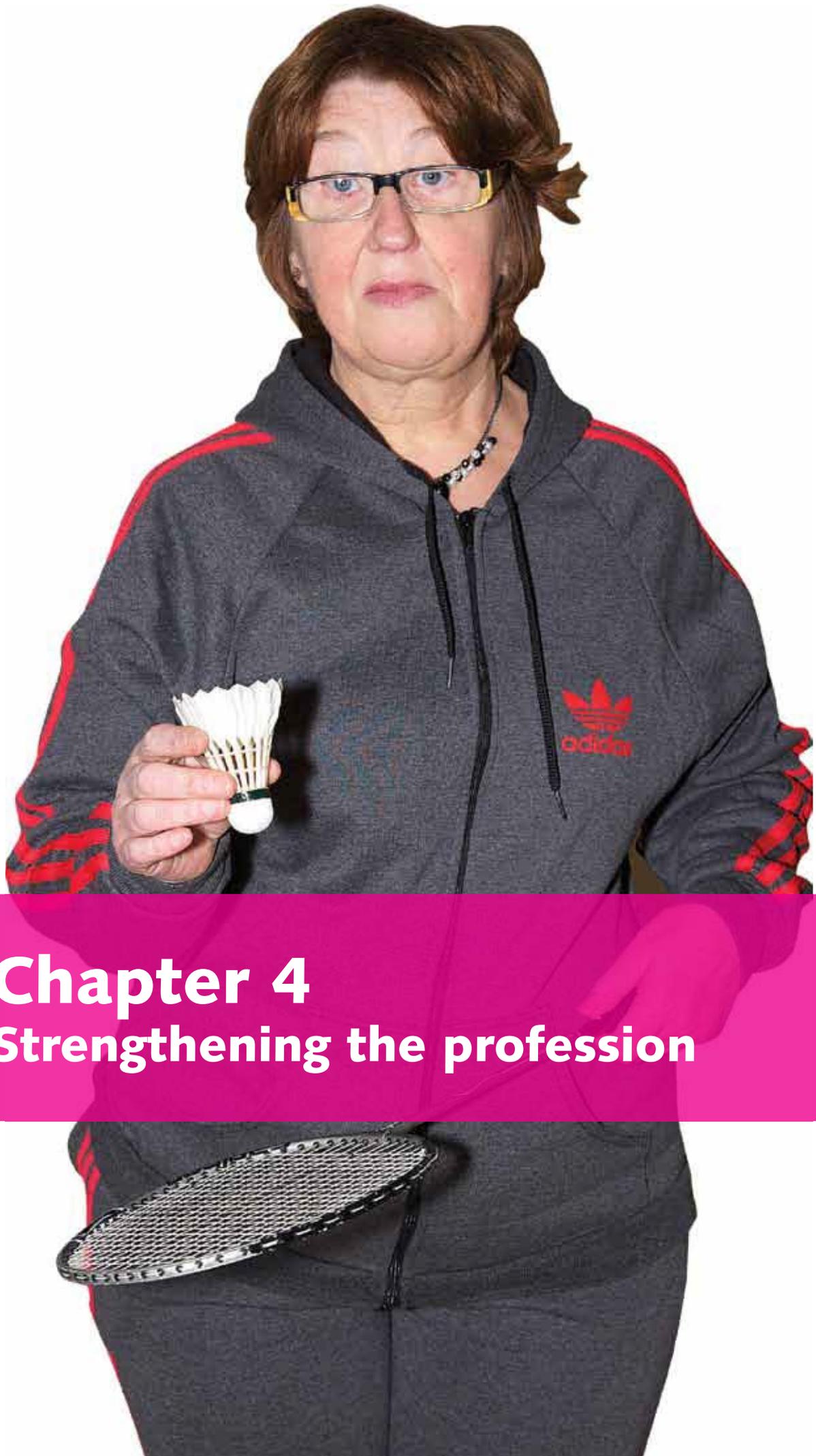
Clinical supervision is recognised as a supportive way to enable learning from experience with the aim of developing knowledge and improving care (24). It was evident through the review processes that learning disabilities nurses engage in supervision at a number of levels and with a variety of professionals during their careers. Engagement with clinical supervision nevertheless varies throughout the UK and possibly between sectors.

Where we want to be

Given the link between effective supervision, reflective learning and safe person-centred practice, supervision should be viewed as essential to contemporary learning disabilities nursing practice and must be supported by employers and nurses. They can demonstrate its value by creating and maintaining protected time and support for clinical supervision and by seeking to illustrate the outcomes of supervision in a way that demonstrates improvements in care.

Recommendation 14

Services should provide systems to ensure that learning disabilities nurses have access to regular and effective clinical supervision and that its impact is monitored and evaluated on a regular basis.



Chapter 4

Strengthening the profession

“Learning disabilities nurses listen to us and respect us as adults.”

Person with learning disabilities

“My eyes have been opened to the world of adults with learning disabilities by the learning disabilities nurse. Delivering teaching sessions about young people and transition together has been an invaluable learning experience for us both.”

Consultant paediatrician

Chapter 4. Strengthening the profession

This chapter addresses some of the key considerations underpinning modernising the learning disabilities nursing workforce in relation to:

- leadership and management
 - promoting the profession
 - research and evidence.
-

4.1 Leadership and management

Where we are now

Health and social care structures often bring together learning disabilities, mental health and/or community services, which means there may not be a senior learning disabilities nurse in a leadership role to ensure that learning disabilities nursing issues are identified and addressed. This local situation is reflected at national level: devolution in the UK has led to differences in policy and service provision across the four countries, which impacts on how leadership is defined nationally. There may not always be clear opportunities for learning disabilities nurses to demonstrate political leadership at this level.

There has been a lack of investment in some areas in leadership roles at senior level, including consultant nurse and advanced nurse practitioner roles, despite changing patterns of need giving rise to a requirement for strong leadership to drive the development of appropriate service provision.

Changing patterns of service provision and organisational structures have had an impact on the scope of management roles, affecting managerial responsibilities, accountability lines and supervision and appraisal mechanisms. Learning disabilities nurses working in multidisciplinary teams often manage, and/or are managed by, other professions.

The demographic profile of the profession indicates that many managers will be retiring from services over the next decade, resulting in a need for sophisticated workforce and succession planning.

Where we want to be

Strong leadership in learning disabilities nursing is essential, given the challenges set out in earlier chapters. Leadership is also important to drive forward the profession and to ensure a modernised workforce is in place to meet current and future needs. Learning disabilities nurses need to continue to acknowledge and develop their clinical leadership responsibilities and demonstrate and develop strong professionalism.

The leadership role should be supported through the development of clear career pathways, succession planning and leadership “champions” in all areas and through the creation of consultant nurse posts in key areas where there currently are none.

The need for a dynamic career and development framework to support learning disabilities nurses to become the leaders and managers of the future has been covered in Recommendation 4.

Positive practice example

Leading and influencing services (palliative care)

Community learning disabilities nurses in Bridgend, Wales demonstrated leadership in service development through making links with local palliative care services to increase their knowledge base and to “map out” services. Working collaboratively with these services, it became evident that individuals with learning disabilities within the locality rarely accessed palliative care services, which reflects the wider picture nationally.

The learning disabilities nurses identified resources to support people with learning disabilities, their families and carers and took measures to raise awareness of their needs for palliative and end-of-life care through an initiative called “Living Well, Dying Well.” This and other measures were presented at a national palliative care conference in 2011.

The awareness-raising has led to requests to provide advice and support, creating opportunities to forge closer links with other services to meet the needs of people with learning disabilities, their families and carers. This work is continuing, with learning disabilities nurses:

- investigating systems to identify individuals with learning disabilities who have a life-limiting condition (this database will enable health professionals to strategically plan person-centred care for their future palliative and end-of-life care needs);
- continuing to work collaboratively with palliative care services to improve experiences of life and death; and
- continuing to contribute to the evaluation of the palliative care and end-of-life pathway with the aim of improving its efficiency.

For further information, contact Sharon Dixon at sharon.dixon@wales.nhs.uk or Claire Jenkins at claire.jenkins4@wales.nhs.uk

Recommendation 15

Leadership in learning disabilities nursing needs to be strengthened in practice, education and research settings with robust, visible leadership at all levels, including strategic and national levels. Services must ensure all learning disabilities nurses in clinical practice have access to a dedicated professional lead for learning disabilities nursing. In addition to existing leadership and development programmes, a UK-wide cross-sector project to nurture and develop aspiring leaders in learning disabilities nursing will be led by the four UK health departments.

4.2 Promoting the profession

Where we are now

Learning disabilities nursing has traditionally had a low profile among the general population and has received less focus than other nursing fields in policy over recent years. The demographic and policy challenges described throughout this report nevertheless mean that raising the profile of learning disabilities nursing is now more important than ever.

Learning disabilities nurses have historically embraced networking, and the strong existing networks for learning disabilities nurses across the UK provide a powerful platform from which to celebrate and promote their unique contribution.

Where we want to be

It is important that the profession is promoted to ensure all sectors are aware of the unique contribution and added value that learning disabilities nurses offer and that learning disabilities nursing is presented as a positive and rewarding career choice.

Promoting the image of the learning disabilities nursing profession therefore has an important part to play in encouraging recruitment, but it goes further than that. It is also about demonstrating to people with learning disabilities, their families and carers, the wider public, fellow professionals and policy-makers the advantages that learning disabilities nurses bring and developing their understanding of what they can deliver.

As part of that endeavour, partnership working with the RCN focusing on how the profession can be promoted to wider professional and lay audiences is being progressed, with a promotional resource under development. This work is expected to be completed in 2012.

The health and social care agenda provides further opportunities for developing networks that could strengthen partnership working across the profession in all sectors. Investment in forward-thinking, high-quality networks could support many of the initiatives outlined in this report.

Positive practice example

Managed Knowledge Network Learning Disability Portal, NHS Education for Scotland (NES)

The Managed Knowledge Network (MKN) Learning Disability Portal, supported by NES Knowledge Services, supports the health and social care workforce working with people with learning disabilities.

The MKN portal provides a sustainable, flexible and responsive means of ensuring that contemporary information on health needs and learning disabilities is available to the workforce quickly and efficiently, providing a platform for sharing best practice, promoting educational opportunities and hosting resources. The link to the Knowledge Network allows access to online journals and 500 bibliographic databases.

The portal also serves to bring together organisations and people with a common interest in finding, sharing and using knowledge to support people with learning disabilities. It includes online opportunities for accessing and sharing knowledge alongside support for development of skills and behaviours in finding and sharing knowledge effectively.

The development of the portal provides a unique opportunity for learning disabilities nursing to engage across all areas of practice and specialties and interface with other professional groups. The rapidly changing health and social care environment requires the learning disabilities nursing workforce to be responsive to change in practice, service alignment and integration.

The portal is designed for workforce use, but it also allows people with learning disabilities, their families and carers to access information and contribute to debates, helping to build confidence and influence in developing practice. The interactive model requires and encourages learning disabilities nurses to take ownership, engage and develop new initiatives and discussions, creating communities of practice.

This developing portal has the ability to network and engage across the UK, consequently linking national initiatives and helping translate them into local practice. The portal can respond, grow and adapt to changing technology, practice and policy.

For further information, contact Tommy Stevenson at tommy.stevenson@nes.scot.nhs.uk. The portal can be accessed at www.knowledge.scot.nhs.uk/learningdisabilities

Recommendation 16

Learning disabilities nurses need mechanisms to share best practice and develop the evidence base to continue to advance as a profession. Services must support learning disabilities nurses to participate in appropriate networks. A UK academic network for learning disabilities nursing will be created to support this drive.

4.3 Research and evidence

Where we are now

While the amount of research concerning learning disabilities nursing is increasing (25), there is still scope to further develop robust evidence. Learning disabilities nursing therefore requires support for:

- research activity
- research training
- implementation of research findings in practice.

Clinical–academic research careers have been promoted as one approach to developing partnerships between education and practice. A greater orientation towards evidence-based and evidence-informed practice can be achieved where educationalists have a clinical commitment within their portfolios and clinicians retain a strong education and research focus in their practice. Clinical–academic posts can promote greater integration between practice, education and research by supporting the enhancement of the evidence and education focus of practice and promoting a strong practice orientation in education and research. Currently, however, there are inconsistencies in the development and appointment of learning disabilities clinical–academic posts across the UK.

Where we want to be

Exciting opportunities nevertheless exist within the NHS and independent/voluntary sector to develop a broader range of clinical–academic roles that would strengthen and sustain practice, education and research provision. These roles should include researchers and educationalists maintaining links with clinical practice through clinical work, supervision of practitioners and joint working on particular practice development projects, and practitioners linking into education and research through teaching, research and initiatives that support education in practice. Clear organisational commitment is required to create models to develop sustainable roles such as these.

Research activity should be directly related to informing the practice of learning disabilities nursing and should focus on areas that add value and provide clear benefits to people with learning disabilities, their families and carers. Collaborative research studies involving higher education institutions that cover a range of geographic areas are required to facilitate larger-scale and comparative studies that can highlight differences and similarities in terms of need and developments. Existing links within the learning disabilities research community in the UK and internationally should facilitate this.

Most important, collaborative working with people with learning disabilities is essential to ensure that research is relevant to their needs and experiences. Learning disabilities nursing already has some good examples in this area and could lead on engaging, enabling and facilitating people with learning disabilities, their families and carers to participate in research.

Positive practice example

Learning disabilities nurses' involvement in research

The Confidential Inquiry into Deaths in People with Learning Disabilities is a three-year research study funded by the Department of Health and the Learning Disability Public Health Observatory in England. It is led by the Norah Fry Research Centre at the University of Bristol and is being carried out across Avon and Gloucestershire. The Inquiry is investigating all deaths among people with learning disabilities over the age of four years with the aim of adding to the current limited body of evidence, detecting any potentially avoidable and modifiable features involved in deaths and learning from positive practice.

The Mencap report *Death by Indifference* (7) highlighted the importance of involving families when evaluating care. In designing the Inquiry, the research team wanted to enable carers to be included and acknowledged that appropriately skilled staff were required to ensure that their views on the deceased were sought, understood and appropriately recorded. At the same time, it was important that their needs, as grieving carers, were also sensitively met.

As person-centred practitioners skilled in communicating with families and possessing sound understanding of the systems of care and complex health problems experienced by people with learning disabilities, a team of 11 learning disabilities nurses, supported by a lead nurse, were recruited to work part time as members of the Inquiry team. The nurses are seconded from their substantive posts to work with families of people who have died, conducting interviews, supporting them and signposting them to bereavement support agencies, if required. In addition, they advocate for the families at multi-agency local review panels held to discuss all death investigations.

For further information, contact Lesley Russ at lesley.russ@bristol.ac.uk

Recommendation 17

Learning disabilities nursing research should be extended to ensure practice now and in the future is evidence based and the impact of interventions can be demonstrated. Services and education providers must ensure that all existing and future schemes for clinical–academic careers have appropriate representation of learning disabilities nursing.

“The learning disabilities nurse has always been aware of the needs of the whole family and the fact that it continued from childhood into adulthood is very reassuring.”

Family carer

Conclusion and next steps



Conclusion and next steps

The UK Modernising Learning Disabilities Nursing Review involved wide engagement with key stakeholders. It heard the hopes, aspirations and concerns of practitioners, managers, educators and researchers and, most importantly, it heard what qualities people with learning disabilities, their families and carers value most in nurses.

While this report could never capture all the learning that emerged from the engagement process, it has attempted to focus on actions that will have the greatest positive impact for people with learning disabilities, their families and carers, the nurses who care for them and the services who support them.

The foundation for these actions and the developments they represent is the underpinning principles and values base of learning disabilities nursing. It is these principles that have served learning disabilities nursing well and which are cherished by people with learning disabilities, their families and carers.

Learning disabilities nurses now have an opportunity to take their services forward to a new level.

This report has set out recommendations across a wide range of areas that reflect the complexity and the importance of modern learning disabilities nursing. The four countries are now invited to consider these recommendations and progress them as appropriate within their own contexts. Some of the recommendations will benefit from implementation at UK level, and a UK Implementation Group is being set up to support the groups that will be established at country level to oversee the development of action plans and onward progression.

The recommendations are set out in Table 2, which shows which agencies/individuals need to take account of, and respond to, each recommendation.

It is important to stress that while the recommendations are central to the modernisation of learning disabilities nursing in the UK and consequently may receive heightened attention, readers should engage fully with the whole report – there are many key messages that should be considered in addition to the recommendations.

Table 2

Recommendation summary						
Recommendation	Action at UK level	Action at country level	Action at service level	Action at education level	Action at commissioning level	Action at individual practitioner level
1. The four UK health departments and the independent/voluntary sector should establish a national collaborative to enable better understanding of, and planning for, a high-quality and sustainable registered learning disabilities nursing workforce across all sectors.	√		√		√	
2. Systems to collect workforce data are required in each country, with links across the UK, for workforce planning for future provision of learning disabilities nursing. These should be able to capture information on service provision, educational and research requirements and should cover the independent/voluntary sector.		√	√	√	√	
3. The development of new, specialist and advanced role opportunities should be considered in light of workforce planning, service development and education provision. In particular, this should focus on the roles of non-medical prescribing, psychological therapies and telehealth and in specific settings such as the criminal justice system, mental health services (particularly dementia) and autism services.		√	√	√	√	
4. Each of the four countries should consider aligning their existing post-registration career frameworks for learning disabilities nursing to clearly articulate the knowledge and skills required by learning disabilities nurses at all levels and across all settings. These developments could be utilised across sectors (with appropriate adaptation) to give a coherent career framework.		√	√			
5. Commissioners and service planners should have a clear vision for how they ensure the knowledge and skills of learning disabilities nurses are provided to the right people, in the right places, and at the right time in a way that reflects the values- and rights-based focus of learning disabilities nurses' work.			√		√	√
6. Commissioners and providers of health and social care should ensure the skills, knowledge and expertise of learning disabilities nurses are available across the lifespan. This should be enabled through effective collaborative working across health and social care structures.		√	√		√	
7. Commissioners and providers of health and social care should ensure that learning disabilities nurses are able to collaborate effectively with general health services, including mental health services, to address the barriers that exist for people with learning disabilities to improving their health. This should include proactive health improvement, prevention, whole-family and public health approaches.			√		√	√

Recommendation summary

Recommendation	Action at UK level	Action at country level	Action at service level	Action at education level	Action at commissioning level	Action at individual practitioner level
8. Commissioners and service providers should ensure that specialist learning disabilities services for complex and intensive needs (including assessment and treatment services across all sectors) employ sufficient numbers of appropriately prepared and supported registered learning disabilities nurses. This highlights the need to support and develop the availability of specialist and advanced clinical skills and knowledge of learning disabilities nurses in all settings.			√		√	√
9. Learning disabilities nurses, their managers and leaders should develop and apply outcomes-focused measurement frameworks to evidence their contribution to improving person-centred health outcomes and demonstrating value for money. This may require a specific piece of work to scope current frameworks.			√			√
10. Learning disabilities nurses should strengthen their involvement and links to transformational work, productivity improvement and practice development.			√			√
11. Those who commission, develop or deliver education should ensure that all learning disabilities nursing education programmes reflect the key values, content and approaches recommended in this report. They should also ensure that nurses in other fields of practice develop the core knowledge and skills necessary to work safely and appropriately with people with learning disabilities who are using general health services.			√	√	√	
12. Updated, strategic plans for pre- and post-registration learning disabilities nursing programmes are necessary for each country of the UK to support flexibility and ensure an efficient and sustainable model of delivery for the long term. This highlights the need for appropriate numbers of places on pre-registration learning disabilities nursing programmes to meet future workforce requirements.		√	√	√		
13. Education providers and services must work in partnership to ensure that educational and developmental opportunities for nonregistered staff are developed and strengthened and their benefits are evidenced through appraisal systems, and that educational and development opportunities are available for registered learning disabilities nurses to support their ongoing development, reflecting the needs of people with learning disabilities.			√	√		
14. Services should provide systems to ensure that learning disabilities nurses have access to regular and effective clinical supervision and that this its impact is monitored and evaluated on a regular basis.			√			√

Recommendation summary

Recommendation	Action at UK level	Action at country level	Action at service level	Action at education level	Action at commissioning level	Action at individual practitioner level
<p>15. Leadership in learning disabilities nursing needs to be strengthened in practice, education and research settings with robust, visible leadership at all levels, including strategic and national levels. Services must ensure all learning disabilities nurses in clinical practice have access to a dedicated professional lead for learning disabilities nursing. In addition to existing leadership and development programmes, a UK-wide cross-sector project to nurture and develop aspiring leaders in learning disabilities nursing will be led by the four UK health departments.</p>	√		√	√		√
<p>16. Learning disabilities nurses need mechanisms to share best practice and develop the evidence base to continue to advance as a profession. Services must support learning disabilities nurses to participate in appropriate networks. A UK academic network for learning disabilities nursing will be created to support this drive.</p>			√	√		√
<p>17. Learning disabilities nursing research should be extended to ensure practice now and in the future is evidence based and the impact of interventions can be demonstrated. Services and education providers must ensure that all existing and future schemes for clinical–academic careers have appropriate representation of learning disabilities nursing.</p>			√	√		

Appendix 1. Key policy and professional drivers within the four countries

England

Department of Health (2001)

Valuing People: a new strategy for learning disability for the 21st century - a White Paper.
London: Department of Health.

Department of Health (2002)

Action for Health, Health Action Plans and Health Facilitation: detailed good practice guidance on implementation for learning disability partnership boards.
London: Department of Health.

Department of Health/Department for Children, Schools and Families (2003)

Together from the Start: practical guidance for professionals working with disabled children (birth to third birthday) and their families.
London: Department of Health.

Department of Health (2007)

Good Practice in Learning Disability Nursing.
London: Department of Health.

Department of Health (2008)

Healthcare for All: report of the independent inquiry into access to healthcare for people with learning disabilities.
London: Department of Health.

Department of Health (2009)

Valuing People Now: a new three-year strategy for people with learning disabilities.
London: Department of Health.

Department of Health (2009)

World Class Commissioning for the Health and Wellbeing of People with Learning Disabilities.
London: Department of Health.

Department of Health (2009)

The Bradley Report: Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system.
London: Department of Health.

Department of Health/Department for Children, Schools and Families (2009)

Healthy Lives, Brighter Futures. The strategy for children and young people's health.
London: Department of Health.

Department of Health (2010)

Raising Our Sights: services for adults with profound intellectual and multiple disabilities. A report by Professor Jim Mansell.
London: Department of Health.

Gates B (2011)

Learning Disability Nursing: task and finish group: report for the Professional and Advisory Board for Nursing and Midwifery.
London: Department of Health.

Emerson E, Baines S, Allerton L, Welch V (2011)

Health Inequalities & People with Learning Disabilities in the UK: 2011.
Improving Health and Lives: Learning Disabilities Observatory.

Northern Ireland

Department of Health, Social Services and Public Safety (2005)

Equal Lives: review of policy and services for people with a learning disability in Northern Ireland: the N. I. Bamford Review.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2005)

A Healthier Future: a twenty year vision for health and well being in Northern Ireland 2005–2025.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2006)

The Bamford Review of Mental Health and Learning Disability (NI): forensic services.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2007)

Complex Needs – the nursing response to children & young people with complex physical healthcare needs.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2009)

Delivering the Bamford Vision. The response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability action plan (2009–2011).
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2009)

Integrated Care Pathway for Children & Young People with Complex Physical Healthcare Needs.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2009)

Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09–2010/11.
Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2010)

Living Matters, Dying Matters – a strategy for palliative and end of life care for adults in Northern Ireland.

Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2011)

Improving Dementia Services in Northern Ireland: a regional strategy.

Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2010)

A Partnership for Care: Northern Ireland strategy for nursing and midwifery 2010–2015.

Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2011)

Learning Disability Service Framework. Consultation document.

Belfast: DHSSPS.

Guidelines and Audit Implementation Network (2010)

Guidelines: caring for people with a learning disability in general hospital settings.

Belfast: DHSSPS.

Scotland

NHS Health Scotland (2004)

Health Needs Assessment Report: people with learning disabilities in Scotland.

Edinburgh: NHS Health Scotland.

NHS Quality Improvement Scotland (2006)

Best Practice Statement: promoting access to healthcare for people with learning disabilities.

Edinburgh: NHS Quality Improvement Scotland.

NHS Quality Improvement Scotland (2009)

Tackling Indifference: healthcare services for people with learning disabilities national overview.

Edinburgh: NHS Quality Improvement Scotland.

Scottish Executive (2000)

The Same as You? A review of services for people with learning disabilities.

Edinburgh: Scottish Executive.

Scottish Executive (2002)

Promoting Health, Supporting Inclusion: the national review of the contribution of nurses and midwives to the care and support of people with learning disabilities.

Edinburgh: Scottish Executive.

Scottish Government (2007)

Equally Well. The report of the Ministerial Task Force on Health Inequalities.

Edinburgh: Scottish Government.

Scottish Government (2008)

Better Health, Better Care: action plan. What it means for you.

Edinburgh: Scottish Government.

Scottish Government (2008)

Achieving our Potential: a framework to tackle poverty and income inequality in Scotland.

Edinburgh: Scottish Government.

Scottish Government (2010)

Getting it Right for Every Child.

Edinburgh: Scottish Government.

Scottish Government (2010)

The Healthcare Quality Strategy for NHSScotland.

Edinburgh: Scottish Government.

Scottish Government (2010)

Towards an Autism Strategy for Scotland.

Edinburgh: Scottish Government.

Wales

Learning Disability Implementation Advisory Group and Welsh Assembly Government (2011)

Practice Guidance on Developing a Commissioning Strategy for People with Learning Disabilities.

Cardiff: Welsh Assembly Government.

National Assembly for Wales (2002)

Inclusion, Partnership and Innovation.

Cardiff: National Assembly for Wales.

Public Health Wales and Welsh Government (2011)

Good Practice Framework for People with Learning Disabilities Requiring Planned Secondary Care.

Cardiff: Public Health Wales and Welsh Government.

Welsh Assembly Government (2004)

Learning Disability Strategy. Section 7: guidance on service principles and service responses.

Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2007)

Statement on Policy and Practice for Adults with Learning Disabilities.

Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2009)

A Community Nursing Strategy for Wales.

Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2009)

Post Registration Career Framework for Nurses in Wales.

Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2009)

We Are on the Way. A policy agenda to transform the lives of disabled children and young people.

Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2010)

Setting the Direction. Primary and community services strategic delivery programme.

Cardiff: Welsh Assembly Government.

Welsh Government (2011)

Together for Health. A five year vision for the NHS in Wales.

Cardiff: Welsh Government.

Appendix 2. Steering group memberships

Co-production Steering Group (supported by Scottish Consortium for Learning Disability)

Ann Burke, Bainsford

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Angela Halpin, West Dunbartonshire

Lorraine MacKenzie, West Dunbartonshire

Rona Membury, Highland

Ian Stones, Aberdeen

Alexander Thomson, Fraserburgh

England

Allyson Kent, Deputy Head of Nursing, Humber Mental Health Teaching NHS Trust

Alison Giraud Saunders, Independent Consultant, Policy into Practice

Alison Armstrong, Director of London Wide Programmes (Mental Health, Prison Health and Substance Misuse)

Amanda Platts, Self Advocate

Geoff Hodgson (supporting Amanda Platts), Supporter Centre Events

Ann Norman, Professional Nurse Adviser: Learning Disabilities/Prison Nursing, Royal College of Nursing

Professor Ben Thomas, Professional Advisor, Department of Health

Daniel Marsden, Practice Development Nurse for Patients with Learning Disabilities, East Kent Hospitals University NHS Foundation Trust

Deborah Hussey, Lincolnshire Partnership NHS Foundation Trust
Team Leader, Learning Disability Services

Felicity Howdle, Information Analyst, Centre for Workforce Intelligence (CfWI)

Gweneth Moulster, Nurse Consultant, Haringey Learning Disability Partnership

Helen Laverty, Lecturer, Nottingham University

Helen Mycock (representing Mencap until January 2012)

Jacky Vincent, Lead Nurse, Learning Disability & Forensic Services, Hertfordshire

Janet Cobb (Chair), Independent Consultant, Jan-Net Ltd

Jean Willson OBE, family carer

Joanna Goddard, Specialist Midwife for Safeguarding Children and Vulnerable Women

Susan Bernhauser, Dean of the School of Human and Health Sciences, University of Huddersfield

Lisa Gregg Herrett, Assistant Director Quality and Staff Development, Choice Support

Marc Pratt, Intensive Health Outreach Team, NHS Gloucestershire

Matthew Hoghton, Champion in Learning Disabilities, Royal College of General Practitioners Clinical Innovation and Research Centre

Paula Brayinon, Director of Operations and Nursing, Calderstones

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Stephan Bruschi, Health Access Manager and Head of Learning Disability Development Team, NHS London

Steven Hardy, Training and Consultancy Manager, Estia Centre

Steven Rose, Chief Executive, Choice Support

Sue Hudson, Practice Development Lead, Suffolk Mental Health Partnership

Sue Turner, Improving Health and Lives Project Lead, National Development Team for Inclusion

Sue Beacock, Associate Dean Learning and Teaching, Hull University

Terri Dorman, Practice Development Nurse, Bedfordshire & Luton Partnership NHS Trust

Tricia Handley, Nursing Manager Adult Social Care, Camden

Vicky Stobbart, Service Manager - Learning Disability, Southwark

Northern Ireland

Anne Campbell, Operations Manager, Belfast Health & Social Care Trust

Barry Mills, Clinical & Therapeutic Service Manager, Belfast Health & Social Care Trust

Claire Knox, carer

Damian McAleer, Nurse Education Consultant, Beeches Management Centre

Donna Morgan, Locality Manager & Lead Nurse, Northern Health & Social Care Trust

Fiona Rowan, carer

Francis Rice (Chair), Director of Nursing, Southern Health & Social Care Trust

Garvin McKnight, Staff Nurse, Muckamore Abbey Hospital, Belfast Health & Social Care Trust

Gillian McMullen, Project Manager Bamford Monitoring Group, Patient Client Council (PCC)

Glynis Henry, Chief Executive, Northern Ireland Practice & Education Council (NIPEC)

John Mc Eleney, Assistant Director, Praxis Care NI

Maurice Devine, Nursing Officer (Mental Health, Learning Disability and Older People), Department of Health, Social Services and Public Safety

Maureen Piggot, Director, Mencap Northern Ireland

Molly Kane, Regional Nurse Consultant Mental Health & Learning Disability, Public Health Agency

Neil Kelly, Operations Manager, Belfast Health & Social Care Trust

Professor Owen Barr, Head of School of Nursing, University of Ulster

Paula McLorinan, Consultant Child & Adolescent & Learning Disability Psychiatrist, Belfast Health & Social Care Trust

Peter Griffen, Discipline Lead, Learning Disability Nursing, Queen's University Belfast

Rosaleen Harkin, Assistant Director of Adult Services, Western Health & Social Care Trust

Thomasina Duff, Staff Nurse, Belfast Health & Social Care Trust

Scotland

Andy Graham, Chair of the Scottish Community Learning Disability Nurses Network

Billy Pate, Scottish Community Learning Disability Nurses Network

Carol Dobson, Chief Nursing Officer, Mental Welfare Commission for Scotland

David Currie, Development Manager, Castlebeck Group Ltd

Elaine Kwiatek, Project Manager, Learning Disabilities Managed Care Network

Gillian Henderson, Mental Health and Suicide Risk Management Advisor, Scottish Prison Services

Hazel Powell, Programme Manager, NHS Lothian

Hugh Masters, Nursing Officer (Mental Health and Learning Disabilities), Scottish Government

Jonathan Gray, Nurse Consultant Learning Disabilities, NHS Highland

June Brown, Nurse Consultant Learning Disabilities/Clinical Lead for Learning Disability Services, NHS Grampian

Linda Allan, Nurse Consultant Learning Disabilities, NHS Greater Glasgow and Clyde

Margaret Serrels, Clinical Services Development Manager, NHS Lanarkshire

Mark Gillespie, Nurse Consultant Forensic Mental Health and Learning Disabilities, NHS Greater Glasgow and Clyde

Melanie Hornett (Chair), Nurse Director, NHS Lothian

Michael Brown, Nurse Consultant and Reader in Health and Social Care, NHS Lothian/Edinburgh Napier University

Rosemary Duffy, Scottish Prison Services

Selina Clinch, Programme Manager, Healthcare Improvement Scotland

Susanne Forrest, Programme Director, NHS Education for Scotland

Tommy Stevenson, Educational Project Manager, NHS Education for Scotland

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Christopher Griffiths, Consultant Nurse/Lecturer, Abertawe Bro Morgannwg University Health Board

Dave Hawkins, Lead Nurse Learning Disabilities, Hywel Dda Health Board

Hayley Tarrant, Head of Learning Disability Services, Powys Teaching Health Board

Jenifer Clarke, Nursing Officer/Public Health and Health Professions Department, Welsh Government

Julie Kendall (Chair), Lead Nurse for Learning Disability Services, Aneurin Bevan Health Board

Ian Mansell, Senior Lecturer, University of Glamorgan

Pete Jones, Clinical Governance Co-ordinator, Betsi Cadwaladr University Health Board

Dr Robert Jenkins, Divisional Head of Learning Disability, University of Glamorgan

Ruth Northway, Professor of Learning Disabilities, University of Glamorgan

Ruth Wyn Williams, Lecturer in Learning Disability Nursing/Lecturer (Welsh medium) in Nursing, Bangor University

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