

Strengthening the Commitment:

Living the commitment

UK Strengthening the Commitment Steering Group



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**UK Strengthening
the Commitment
Steering Group**

June 2015



Foreword

Strengthening the Commitment set out our vision of how learning disability nurses could expand their role to ensure that people with learning disabilities are treated with dignity and respect and receive the care and support they need. In the changing world of health and social care services the role of learning disability nurses is pivotal to achieving this vision. In the past three years a tremendous amount has been achieved in all four countries as learning disability nurses have expanded their skills, knowledge and competencies, developed measurable outcomes and evidence-based interventions, have significantly strengthened their research skills, and are creating a critical mass of leaders to effect further change.

These achievements have only been possible because of the clear commitment to implementation of the recommendations in *Strengthening the Commitment* across all four countries and the leadership shown within each country. We are proud of the great strides that have been made to improve the lives of people with learning disabilities and to ensure that their needs are kept firmly on the health and social care agenda. This report identifies these achievements and celebrates the innovative and successful work that is going on across the United Kingdom led by learning disability nurses working across a range of settings. Our congratulations and thanks to each and every professional who has made such a significant contribution to this work.

The population of people with learning disabilities continues to increase as children born with a learning disability live longer, more fulfilled lives and adults grow into older age. As a consequence, the support of learning disability nurses is even more vital across the age range and in all settings. Learning disability nurses play a vital role in reducing the health inequalities that have all too often been experienced by people with learning disabilities.

'Health services need to understand that people with profound and complex learning disabilities often have multiple health needs so won't fit into generic health structures where one need is addressed at a time, issues need to be tackled collectively. Looking holistically is a key skill of a learning disability nurse.'

Carer, mother of adults with learning disabilities

Despite the great achievements made in the past three years, there remains much to be done. We are busy identifying the next steps in our journey and will be true to our commitment to improve the lives of people with learning disabilities through strengthening the role of the key professionals who work with them to make sure they have better lives.



Jane Cummings
Chief Nursing Officer
England



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Contents

Foreword	5
Contents	7
Executive summary	8
1 Our vision	10
2 How we have approached the challenges	13
Unity and collaboration	13
A commitment to implementation	13
High level leadership	13
Nurturing future leaders	14
Engagement with frontline practitioners and networking	14
Academic networking and the evidence base for learning disability nursing	15
UK Learning Disability Consultant Nurse Network	18
Independent and voluntary sectors	18
Promoting learning disability competence in other fields of nursing	19
3 What have we achieved?	21
Focus on capacity	21
Focus on capability	27
Focus on quality	35
Focus on strengthening the profession	39
4 Our commitment to the future agenda: living the commitment	45
Fact File	48
References	53
Appendix 1	54

Executive summary

This report celebrates the achievements of learning disability nurses across the United Kingdom and the difference they have made, and continue to make, to the lives and health outcomes of people with learning disabilities.

Three years ago, *Strengthening the Commitment* set out a range of challenges based on principles and values that are important to people with learning disabilities, their families and carers. UK government health departments, employers, educators, people with learning disabilities, their families and carers, learning disability nurses, students and wider health and social care staff have all risen to these challenges and are now delivering a significantly improved, person-centred, and imaginative service for people with learning disabilities.

The four countries have worked together to address the challenges and through visible, high profile leadership have developed opportunities to create a learning disabilities service fit for the 21st century. Four broad challenges were identified to support the development of learning disability nursing: strengthening capacity, strengthening capability, strengthening quality, and strengthening the profession. These have been addressed by a strategy of work driven forward nationally and locally and with regular reporting processes that have ensured all countries have kept the challenges firmly in view.

A number of major UK-wide initiatives have supported the vision of learning disabilities services to meet the needs of all those with learning disabilities.

Nurturing future leaders

Leaders are being identified at all levels and supported by innovative programmes to develop personal leadership abilities. For example, a two-day workshop was held for 42 people from across the UK who benefited from the opportunity to explore the development of practice, research, writing for publication and working with leading coaches.

Engagement with frontline practitioners and networking

The success of the implementation strategy has depended on active engagement with frontline practitioners to engage them with the aspirations and practical planning of the initiative. Networking has flourished, stimulated particularly by an explosion in the use of social media. The innovative case studies throughout this report demonstrate the range of work being carried out at grass roots level across the UK.

Developing the evidence base

The academic underpinning, research and the evidence base for learning disability nursing is being strengthened by the work of the UK Learning and Intellectual Disabilities Nursing Academic Network (LIDNAN). A model for collaborative working has been established which future work will ensure a robust academic and research base for the future.

UK Learning Disability Consultant Nurse Network

The UK Learning Disability Consultant Nurse Network have been instrumental in sharing ideas and have developed the Health Equalities Framework which provides an evidence based outcomes framework to reduce the impact of service users' exposure to determinants of health inequalities. It is being adapted for children and young people with learning disabilities.

Independent and voluntary sectors

Many learning disability nurses are employed in the independent and voluntary sector and the Independent Sector Collaborative has been established to ensure a high quality and sustainable workforce across all sectors.

Learning disability competence in other fields of nursing

Staff working in general health and social care settings are seeking to expand their knowledge and ability to communicate with people with learning disabilities. Initiatives across the UK are developing these skills so that people with learning disabilities receive the appropriate care.

We recognise that the job is not yet done and this report also sets out our commitment to the future agenda. A framework of priority actions and associated milestones will be developed and we will ensure that the involvement of people with learning disabilities continues to be central to our framework for delivery.

As new staffing models develop the role of the learning disability nurse will be vital to ensure safe, compassionate and competent care in whatever setting. Every learning disability nurse plays a key role in continuing to meet the needs of people with learning disabilities, their family and carers and continuing to develop learning disability nursing as a strong and vibrant profession.

1 Our vision

When *Strengthening the Commitment* was published in 2012 it set out a clear agenda to meet the challenge of making sure that people with learning disabilities across the United Kingdom had the high quality support from learning disability nurses that they deserved, needed and were entitled to in modern, 21st century health and social care services. Learning disability nurses had the opportunity to implement this agenda and to take their services forward to a new level: in the past three years they have seized that opportunity with both hands.

The population of people with learning disabilities is increasing across the UK. There are approximately 1.5 million people in Britain living with learning disabilities (Learningdisabilities.org.uk). Demographic projections suggest that the numbers of people with learning disabilities will increase by 14% by 2021 as many more children born with a learning disability live longer, more fulfilled lives into adulthood, and the increasing adult population of people with learning disabilities grows into older age. Yet we continue to have evidence that people with learning disabilities experience significant health inequalities and are dying at a younger age than people without learning disabilities.

People with learning disabilities

- **Have poorer health than the general population**
- **Are more likely to need hospital services compared to the general population [26% compared to 14%] (Beacock et al., 2015)**
- **97% of people with a learning disability who die had one or more long-term or treatable health condition (Heslop et al., 2013)**
- **Have difficulty accessing and using general health services**
- **Are 58 times more likely to die aged under 50 than other people**
- **Men with learning disabilities die, on average, 13 years sooner than men in the general population (Heslop et al., 2013)**
- **Women with learning disabilities die, on average, 20 years sooner than women in the general population (Heslop et al., 2013)**
- **43% of deaths of people with learning disabilities were unexpected with repeated problems of delayed diagnosis, poor identification of needs and inappropriate care (Heslop et al., 2013)**

Strengthening the Commitment recognised that the role and profile of learning disability nursing had changed significantly over the previous three decades and that the workforce had become widely distributed across the health and social care sector.

The values and principles that are important to people with learning disabilities, their families and carers and which were spelt out in *Strengthening the Commitment* continue to underpin learning disability nursing. The challenges set out remain as true today as three years ago and there are now new and emerging challenges that need a renewed, fresh focus to make sure we are responsive to the needs of people with a learning disability, and their families and carers while continuing to strengthen the learning disability profession.

Four clear challenges were identified to support the development of learning disability nursing:

- Strengthening capacity
- Strengthening capability
- Strengthening quality
- Strengthening the profession.

We knew that the actions required of the profession were considerable, that they would be taking place in a time of recession, uncertainty and increasing diversity across the four UK healthcare systems. As this report will demonstrate, UK government health departments, employers, educators, people with learning disabilities, their families and carers, learning disability nurses, students and wider health and social care staff have all risen to the challenges and are now delivering a significantly improved, person-centred and imaginative service for people with learning disabilities.

For example, the health and social care organisations in England are delivering a major programme to transform the care of people with learning disabilities. This includes a commitment to redesign care models and services which reduce the need for patient beds and support people in a place they call home. As part of this work new staffing models will be developed and the role of the registered learning disability nurse will be vital to ensure safe, compassionate and competent care in whatever setting.

This report celebrates the achievements made in the past three years and the positive impact that learning disability nurses have on health outcomes. The examples of positive practice in this report have been chosen to be representative of the wide range of innovative work that is taking place in all four countries. There are numerous examples of innovations and developments across the whole UK and the Fact File provides brief information of many of these. We hope that you will find these examples inspiring and useful as you work to improve learning disability services for some of the most vulnerable people in our society.



Unity and collaboration

A key feature of the implementation of the *Strengthening the Commitment* initiative has been the way the four countries have worked together to address the challenges and opportunities to create a modern learning disability nursing service fit for the 21st century. Partnership working across all four countries has been central to our work and every country has contributed to a shared understanding of the agenda and of how to approach it.

Inevitably each of the countries has worked at a different pace as each approached the challenges from a different starting point. The Chief Nursing Officers of each country have been actively and visibly committed to strengthening the role of learning disability nurses and recognise the benefits of having specifically prepared nurses to support people with learning disabilities. All recognise the crucial role that learning disability nurses play in the care of people with learning disabilities whether in specialist hospital services or within community services, in championing health improvement and working to tackle the health inequalities experienced by people with learning disabilities.

A commitment to implementation

Across all four countries there has been a commitment to implementing the recommendations in *Strengthening the Commitment* and to set up systems to monitor progress. A clear programme of work has meant that the strategy has been driven forward nationally and locally and regular reporting processes have ensured all countries kept the strategy firmly in view. There has been progress on all seventeen recommendations and regular reviews of action plans to strengthen services for people with learning disabilities.

High level leadership

A UK-wide Strengthening the Commitment Steering Group has provided strategic leadership and a clear work plan with deliverables. The Steering Group has coordinated activities and initiatives across the four countries and has been the focus for great achievement and celebration. Membership of the Steering Group, see Appendix 1, has included the leads from each of the four countries, student representatives, academics, the independent and voluntary sectors, the Royal College of Nursing, and practising learning disability nurses.

Visible, high profile leadership within and across all four countries has been a key factor in ensuring that the challenges set out by *Strengthening the Commitment* have been kept clearly in view. Members of the Steering Group have acted as role models and a focus for the aspirations of many learning disability nurses by being visible, approachable and actively expanding the horizons of learning disability nursing.

Recently, the UK Strengthening the Commitment Steering Group has been joined by the Deputy Chief Nurse, representing the Chief Nurse, from the Republic of Ireland seeking support and partnership working to modernise learning disability nursing provision in her own country.

The UK Strengthening the Commitment Steering Group has established positive working relationships with key national organisations such as the Royal College of Nursing, MENCAP, the Royal Society of Medicine, the Council of Deans of Health and many others. Such partnerships have ensured that learning disability nursing is regularly considered and reviewed by key stakeholders.

Throughout all four countries there have been examples of initiatives being spearheaded by senior leaders to demonstrate the importance placed on developments such as the Health Equalities Framework (HEF).

Nurturing future leaders

Leaders at all levels of the profession must be supported. A UK-wide initiative by the UK Strengthening the Commitment Steering Group focused on nurturing future leaders within the profession. A leadership programme for 3rd year students attended by 42 people from across the UK included a two-day leadership workshop which explored the development of practice, research and writing for publication with the opportunity to discuss issues in small groups with leadership coaches. The evaluation of the workshop highlighted the value participants found in developing their personal leadership abilities and their confidence to use these abilities to bring about change in practice.

'It's made me brave ... I can go into situations and ask questions.'

Amy Hodkin,
student

Engagement with frontline practitioners and networking

Implementing the strategy has been grounded in working with frontline practitioners to engage them with the aspirations and practical planning resulting from the initiative. There has been bottom-up engagement with action plans throughout the NHS, the independent and voluntary sectors. Clinicians at all points of their careers have engaged with the process and networking has flourished.

There has been an explosion in the use of social media and communities of practice have developed as a result with practitioners sharing good practice and experiences across the UK. Previously learning disability nurses and students tended to be fragmented and could feel isolated but use of Facebook and Twitter alongside numerous more conventional meetings and events, has enabled practitioners to become connected with *Strengthening the Commitment* as an anchor for the development of new ideas. As practitioners move out of their more traditional roles, it is the more important that they are able to stay connected with their colleagues and to exchange ideas and practice and to drive the profession forward.

#ldnursechat

A voluntary, social media based discussion and networking forum set up by learning disability nurses which has developed an international following. #ldnursechat is in talks with universities to promote the profession and to share networking skills.

@WeLDnurses

Connects learning disability nurses, talking and sharing with everyone with a passion for learning disability care. Has 3,982 followers (at June 2015).

<https://twitter.com/WeLDnurses>



Academic networking and the evidence base for learning disability nursing

It was clear that the academic underpinning, research and the evidence base for learning disability nursing needed to be strengthened. The UK Learning and Intellectual Disabilities Nursing Academic Network (LIDNAN) was created to tackle this challenge and has proved highly successful. The aims of LIDNAN are to:

- Represent and promote learning disability nursing education, research and practice development
- Influence and respond to UK learning disability nursing agenda through well-informed debate, discussion and dissemination of material
- Act as a source of consultation and advice to learning disability nurses and others on learning disability nursing education and research
- Share good practice and innovations in the development and conduct of learning disability nursing education and research.

The network has achieved a great deal in the past three years and has established a model for collaborative working which strengthens the profession and ensures a robust academic and research base for the future. Its work plan consists of nine areas of activity including post-registration development. In Scotland the *Career and Development Framework for Learning Disability Nursing in Scotland* (NES, 2013) outlines the developmental needs of the registered nursing disability workforce, reflecting the key priorities for workforce development in *Strengthening the Commitment*.

Positive practice (UK wide)

Developing research capacity and capability in learning disability nursing

The following case study illustrates the work that UK LIDNAN has achieved to develop research capacity and capability among learning disability nurses.

The challenge

Two reviews of learning disability nursing research (Northway et al, 2006; Griffiths et al, 2007) highlighted key limitations of learning disability nursing research relating to both quality and quantity. *Strengthening the Commitment* included two recommendations (16 and 17) relating to the need for practice to be evidence-based and calling for an extension of learning disability nursing research. To progress work in these areas a work stream concerning research was established under the auspices of the Learning and Intellectual Disabilities Nursing Academic Network (LIDNAN).

The aim was to increase research capacity and capability within learning disability nursing to promote better quality of service provision and enhance development of the profession thus linking to all of the key principles of *Strengthening the Commitment*.

The journey

Initial activities focused on developing wide engagement with research by raising awareness and stimulating discussion and interest. A research session was included in the leadership workshop held in July 2013 for 3rd year student nurses. A Facebook group, twitter feed and blog were established in March 2014 and by May 2015 the Facebook group had grown to 1,254 members.

At the Positive Choices conference in 2014 a survey was undertaken of delegates (310 responses) to determine factors affecting the use of research in practice, sources of information used and priorities for future learning disability nursing research. The findings of this survey suggest that whilst practitioners use a variety of sources to access evidence there are barriers to using such evidence to develop practice.

Key priorities for future research were identified as being access to healthcare and health promotion, service user perspectives, and the outcomes of nursing interventions.

A paper detailing findings from this study relating to the teaching of research has been published (Northway et al, 2015). In December 2014 the University of South Wales hosted a research event attended by over 50 delegates from many parts of the UK including students, clinically based staff and academics. All delegates engaged in undertaking a strengths, weaknesses, opportunities, threats (SWOT) analysis that has been used to inform development of a position paper regarding learning disability nursing research.

The results

This work stream is still in its relatively early stages. Nonetheless there has been a great deal of activity and many more learning disability nurses are now engaged in discussions regarding research. This engagement has been at all levels of the profession including students, clinicians and academics and from across the UK.

It has been encouraging that many nurses want to be actively involved in research – the challenge now is to develop frameworks that enable this to happen. The position paper has been presented to the UK Strengthening the Commitment Steering Group and to the Academic Network: discussions are currently taking place as to how its recommendations will be taken forward.

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UK Learning Disability Consultant Nurse Network

The UK Learning Disability Consultant Nurse Network (UK LDCNN) has provided a vital focus for innovation and development across all four countries. The open sharing of ideas and initiatives has meant that ideas have spread quickly and readily. A major piece of work undertaken by members of the UK LDCNN was to develop an outcome measure for learning disability nursing practice: the Health Equalities Framework (HEF). The HEF provides a clear example of nurse leaders stepping up to meet the challenges to the profession laid out in *Strengthening the Commitment*. Its UK wide dissemination demonstrates the value of a collaborative four-country approach and the UK Strengthening the Commitment Steering Group was an invaluable reference group at all stages of its development.

Strengthening the Commitment (recommendation 9) called on nurse leaders to develop outcomes focused frameworks to evidence the value of the learning disability nursing contribution.

The Health Equalities Framework

The Health Equalities Framework (HEF) is a systematically developed, evidence based outcomes framework which was developed by four members of the UK LDCNN (Dave Atkinson, Phil Boulter, Crispin Hebron and Gwen Moulster). It measures the extent to which services are delivered to reduce the impact of service users' exposure to determinants of health inequalities. Exposure to these determinants is known to be associated with premature, avoidable deaths and grossly impoverished quality of life.

All four countries are supporting its rollout and pilot work is ongoing in Northern Ireland and Scotland and has recently been concluded in Wales. In England, where the framework was initially developed, increasing numbers of services are making routine use of the HEF as key outcome measure. Subjective feedback from practitioners suggests the HEF guides nursing practice, validates nurses' decision making and informs caseload management.

The HEF not only measures the difference that services make to individual service users but also allows comparison of differing models of service delivery and informs commissioning decisions by aggregating anonymised data. Outcomes data is set against the context of profiles of population needs so that regional differences can be recognised and explored. The tool can therefore also inform public health strategy for people with learning disabilities.

The HEF, along with supporting materials, have been made freely available to services, practitioners and families alike. It is increasingly being recognised as having value across multidisciplinary teams and has been presented, and well received, internationally. A number of further HEF related initiatives are ongoing including: development of a free HEF app, development of a new HEF for children and young people with learning disabilities and a project which links the HEF to best practice care pathways.

Independent and voluntary sectors

The independent and voluntary sectors have a critical role to play in providing a range of services for people with learning disabilities. Many learning disability nurses are employed in the independent and voluntary sectors. However, the actual numbers of those employed are not known as employment figures for the independent and voluntary sectors are not collected nationally. The four UK health departments together with key partners and representatives from

the independent and voluntary sectors have formed an Independent Sector Collaborative and have held three engagement conferences. The aim has been to establish better understanding of, and planning for, a high quality and sustainable registered learning disability workforce across all sectors. As major employers, it has been important to ensure that the independent and voluntary sector providers are engaged in workforce planning with student nurse education commissioners.

Commissioning arrangements vary across the four countries. The independent and voluntary sectors also offer a varied range of clinical placements and experience for student nurses. Exposure to the independent and voluntary sectors at an early stage in nurses' careers increases understanding and improves flexibility and transferability between sectors and employers. It also increases career options, for example, there has been an increase in the number of learning disabilities nurse consultants employed in the independent sector.

Promoting learning disability competence in other fields of nursing

There are concerns about the numbers of learning disability nurses as demand for learning disability nursing is likely to grow. There are also concerns that many staff working in general health and social care settings are seeking to expand their knowledge of how to improve how they communicate with and respond to the needs of people with learning disabilities and have little access to training. *Strengthening the Commitment* called for those who develop or deliver education to 'ensure that nurses in other fields of practice develop the core knowledge and skills necessary to work ... with people with learning disabilities who are using general health services'.

LIDNAN together with the UK Council of Deans of Health (CoDH) published a report (Beacock et al., 2014) that addressed the question of how to best promote learning disability competence in other fields of pre-registration nursing education. The report's recommendations highlight a number of areas in which higher education provision and the framework that govern it could be developed. The recommendations include:

- a standard competency framework should be developed to support consistent delivery of learning disability competence, based on the priority areas identified in the literature
- people with learning disabilities, their families and carers should be involved in all aspects of curriculum design and delivery
- the role of learning disability nurses and how they support people across a range of settings should feature as part of education delivery
- that HEIs consider a range of activities and models as a means of delivering learning disability education.

In Scotland a series of 'Thinking Space' events facilitated by NHS Education for Scotland brought key stakeholders together to develop plans to ensure student nurses in other fields of practice are prepared to support people with learning disabilities. A number of recommendations were made including:

- supporting students to evidence achievement of Nursing and Midwifery Council (NMC) outcomes through an e-portfolio and placements with people with learning disabilities
- clarifying the roles and responsibilities of the learning disability lead (LDL), recommending an LDL for each institution offering nursing programmes and measuring their impact
- networking among the universities currently offering learning disabilities courses and those who do not.



Focus on capacity

Accurate information about where learning disability nurses work is important for workforce planning. The challenge set by *Strengthening the Commitment* was to scope the learning disability workforce, including those working in the independent and voluntary sector and in social care so that strategic workforce development plans could be developed.

Learning disability nurses have a history of working in a wide variety of settings in health and social care. Consequently it can be challenging to obtain accurate figures of where and how many learning disability nurses are working and in what roles. This is particularly so across the independent sector where there are many individual employers and no centrally collected data for numbers employed. Where we have available data we will continue to monitor trends in workforce numbers and settings. It is clear that there continues to be a need to strengthen the numbers of learning disability nurses, particularly as the numbers of people with learning disabilities increases.

The holistic, person-centred skills of learning disability nurses are valued in the prison service, secure services, forensic services, children's services, general practice, social care (where they may not be employed as registered nurses), the police, voluntary sector, the community, and with families, as well as in the acute sector, accident and emergency and neurosciences. Without good information about the location and activities of learning disability nurses it is difficult to move forward.

The four UK health departments, together with key partners, have held three engagement conferences with the independent and voluntary sector. The aim was to establish better understanding of, and planning for, a high quality and sustainable registered learning disability nursing workforce across all sectors. An Independent Sector Collaborative is taking this work forward.

'The issue is not the lack of services but rather the lack of specialist professionals and expertise working within primary and secondary healthcare.'

Carer, mother of adults with learning disabilities

A core skill of learning disability nurses is to work with people who have complex needs and who may present with challenging behaviour. When a breakdown happens for such clients, skilled learning disability nurses can work as part of a crisis outreach team to stabilise the client's care and condition so that the individual does not have to be admitted to an acute hospital setting. The following case study illustrates how this vital service has been developed in Northern Ireland.

The challenge

Clients with complex learning disability needs who present with mental ill health or behaviour that challenges need specialist care. The challenge was to provide effective support for individuals to enable them to stay in their own homes and avoid unnecessary admission to hospital where possible.

The journey

The Southern Health and Social Care Trust (SHSCT) developed a Learning Disability Crisis Response Service to effectively support clients with complex learning disability needs to remain in the community. The purpose of the service is to provide short-term assessment, support and treatment for adults with a learning disability and their carers in an effort to effectively support clients to remain in their own home and avoid unnecessary admission to hospital where possible.

The crisis response service was developed by two learning disabilities nurses to provide expert assessment, treatment, care planning and evaluation for adults with a learning disability who present with mental ill health or behaviour that is perceived as challenging. This is a tertiary service, delivered by a small team of professional staff as a part of community based specialist services for adult learning disability.

The service is delivered in the 'home' environment as a viable alternative to hospital admission. The direct intervention in the home allows the adult with a learning disability to use the support of family and social networks during times of distress to aid the process of recovery. It also allows for the identification of precipitating environmental factors that may lead to an episode of mental ill health or behaviours that are perceived as challenging in the environment where they occur. This provides the opportunity for nursing staff to work collaboratively to deliver an intervention aimed at ameliorating or minimising these factors.

Acute inpatient services for adults with a learning disability now consist of one ward of 10 beds for short-term assessment and treatment, located alongside acute mental health beds on the Bluestone site at Craigavon Area Hospital.

The development of this team demonstrates the commitment of SHSCT to the implementation of regional policy recommendations as set out in *Transforming your Care* (2011) and *The Bamford Action Plan* (2012-2015). It also effectively demonstrates how the SHSCT has strengthened the capacity of the learning disabilities nurses to meet the needs of clients whilst delivering on the recommendations within *Strengthening the Commitment*.

Strengthening capacity is evidenced in the following ways.

- This team delivers a specialist service to adults with a learning disability outside of traditional roles and places of work.
- Organisational and decision-making skills of team members are harnessed to deliver interventions that encourage empowerment, participation, shared decision-making and minimise risk.
- Team members have acquired greater skills and knowledge particularly in liaising with other health professionals and stakeholders.
- Enhanced ability of team members to engage in high levels of autonomous decision making, discretion and clinical with support available if required from consultant psychiatrist on-call.
- The team act in an advisory role to adults with learning disability and their families/carers and a diverse range of health professionals and stakeholders during periods of periods of mental ill health or behaviours that challenge.
- Training carers/independent healthcare providers to build capacity in managing emergency or crisis situations.

The results

Outcomes for service users

Outcomes for people with learning disabilities are evidenced through the reduction in the number of admission to acute learning disability hospital beds in the host trust. There has been a 60% reduction in the number of admission in the 21 months since the team was formed.

Innovation/continued professional development

As part of this team's development there will be ongoing review of skills requirements and associated competencies. As the service grows and develops it is anticipated that further continuing professional development opportunities will be identified including those at a postgraduate level to enhance the existing skill set of the team in providing holistic care to meet the bio-psycho-social needs of clients.

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The aim of acute liaison nurses is to improve standards in hospitals and to ensure that reasonable adjustments are made for people with learning disabilities so that they are able to access health services. Learning disability nurses in the role of acute liaison nurses work with general nurses to give them the confidence to work with people with learning disabilities. The following case study presents the views of an acute liaison nurse and the mother of two men both of whom have learning disabilities and highlights the vital role played by the acute liaison nurse.

The challenge

This case involved a mother and her two sons both of whom have profound learning disabilities and complex care needs. Learning disability nursing input had been stopped because the community learning disability nursing team resource was redirected, leaving the mother struggling day to day and with an unclear direction for service implementation. The family's GP had over 1,000 patients and did not have the expertise to support the family.

The mother's view

'The challenge primarily was transition to adult services for my younger son. I had already been through the transition process for my older son, 11 years before. My honest feeling was that if he had an acute admission to an adult ward he would die.'

'Both sons had lots of services involved however these were disjointed and we still relied heavily on outreach and short breaks from the children's hospice. We are thankful this had been continued until my son was 21. This time was challenging because of the lack of services for people who can meet the needs of people with profound learning disabilities in healthcare services. The issue is not the lack of services but rather the lack of specialist professionals and expertise working within primary and secondary healthcare. For example there are no specialist acute consultants which is what is provided in paediatric services.'

The practitioner's view

'The mother had to fill in the gaps left by services including invasive treatment that she was told could not be provided in the community. The learning disability nurse (LDN) identified the need for assistance to support the family and ensured their individual needs were met. The lack of engaged service provision was impacting on both sons' health and wellbeing.'

The journey

The practitioner's view

'The mother has provided exceptional care to her sons, the family's resilience has enabled them to meet the challenges thrown at them. The primary liaison LDN identified the sons' health needs through their annual health checks and followed up on identified health needs from their health action plans, as well as implementing identified reasonable adjustments at their GP practice.'

'Both sons had hospital admissions during the past year. This time was stressful, but was eased by the assistance of the acute learning disability liaison nurse who ensured the hospital acute staff were meeting the needs of both sons by implementing reasonable adjustments and arranging for their mother to stay at the hospital.'

'The LDN also helped the mother in a care coordinator role. Service provision in the community for her sons had been problematic due to the complexity of their needs and the LDN's role was to ensure the sons' health needs were being met in a person-centred way, to advocate for the family, and work strategically to ensure the community services were competent and meeting their needs.'

The mother's view

'This journey has not been easy, especially due to the unpredictability of my sons' health. It means there have been emergency situations that have meant advocating for both my son's more regularly than any parent should have to. I have found services create barriers, which has meant I have had to fill the void.'

'I have had vast experience of adult services

for people with learning disabilities and often been told I am unlucky due to my older son being ahead of the increasing population of people coming through transition with profound and complex disabilities. However he has been in adult services for more than 10 years and I have not seen the amount of improvement I would have hoped for.'

The results

The mother's view

'This isn't a situation that can be resolved over night, however the involvement of LDNs across the health services has definitely improved access and treatment for my sons. Having a named person to offer support and bridge the gap between services cannot be undervalued. The answer would be more resources but I am aware this is cannot always be relied upon, but it is often professionals skills which are lacking, this could be resolved by standardised training.'

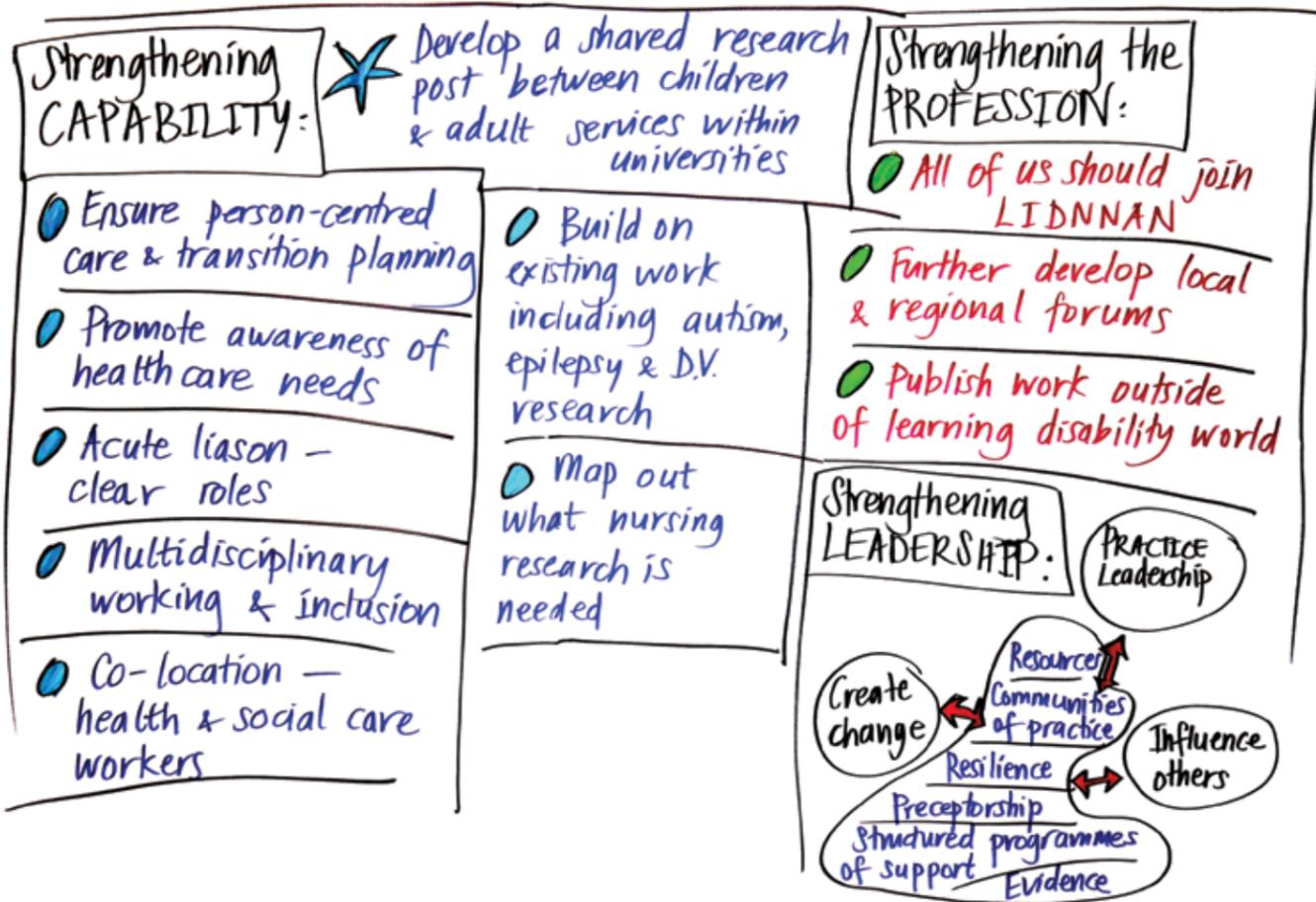
'Health services need to understand that people with profound and complex learning disabilities often have multiple health needs so won't fit into generic health structures where one need is addressed at a time, issues need to be tackled collectively. Looking holistically is a key skill of a LDN.'

The practitioner's view

'The LDN's impact across the health services has ensured steps towards a seamless transition across primary and secondary care as outlined in Valuing People (2001). Being proactive in primary healthcare is looking to reduce premature death among people with learning disabilities whilst the role of acute liaison nurses is to meet deficits in service delivery in secondary care. LDNs have a duty to advocate for improvement to health service delivery to ensure the needs of individuals are being met independently.'

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Focus on capability

The challenge set by *Strengthening the Commitment* was that the skills, knowledge and competencies of learning disability nurses needed to change and extend to reflect the changing needs of people with learning disabilities. Learning disability nurses have an important role to play in supporting timely access to services as well as contributing to preventative and anticipatory care. The following case study relates to strengthening both capacity and capability. It focuses on developing leadership and also enabling experienced learning disability nurses to facilitate learning in practice.

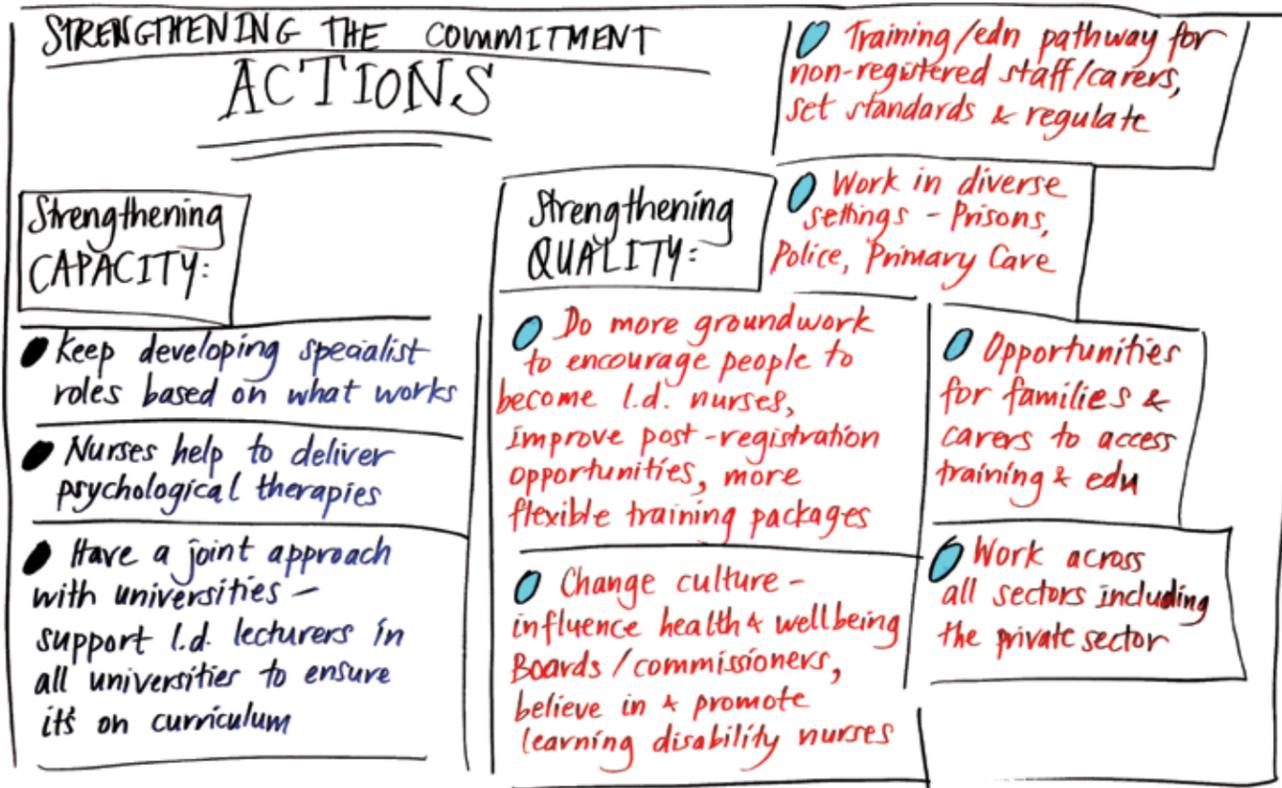


Positive choices: Together we are better

Positive Choices is the only national conference designed to give student nurses the freedom to celebrate the contribution they make to the lives of people with a learning disability. Established before the publication of *Strengthening the Commitment*, the core *Positive Choices* team have worked closely with the UK *Strengthening the Commitment* Steering Group to support implementation and to facilitate the leadership event for 3rd year students. It relies on the goodwill of five universities, speakers who give their time and talents freely, and organisations including the Department of Health, learningdisabilitynursing.com, RCN Learning Disability Practice, who sponsor the event each year.

'Invigorating'

'Supports and inspires'



The challenge

The right support is key to enabling people to live meaningful and fulfilled lives. The skills, attitudes, knowledge and confidence in supporting people are central to getting the support right. Service commissioners and providers face a major issue in providing effective, efficient and equitable services for people with a learning disability who present with challenging behaviours. There may be serious consequences for people with a learning disability and behaviours perceived as challenging, including risk of placement breakdown, neglect, abuse and social deprivation, and staff play an invaluable role in supporting them.

The journey

NHS Education for Scotland recognised the role of support workers in supporting people with learning disabilities and wanted to roll out their educational resource: *Improving Practice: Supporting people with learning disabilities whose behaviour is perceived as challenging. An educational resource for support workers.*

The leadership role of learning disability nurses was recognised and NES recruited experienced learning disabilities nurses from all over Scotland to act as trainers. Trainers attended a series of five workshops to work through a trainer's toolkit that accompanied the resource. Each of the workshops concentrated on a unit from *Improving Practice*:

- Day 1 Value based care and getting orientated
- Day 2 Positive behavioural support and communication
- Day 3 Active support plans and skills development
- Day 4 Reactive and restrictive practice
- Day 5 Future facilitation and evaluation

These workshop enabled trainers to become familiar with the resource, *Improving Practice*, and explore how to make best use of the trainer's toolkit. Trainers then worked through the units with their support workers. The fifth workshop concentrated on future facilitation and evaluation.

The results

Trainers gained tremendously from the group work and the networking. One trainer observed the impact that the *Improving Practice* resource had for the support workers that she facilitated.

'Whilst working through Improving Practice with my two support workers I became aware of a change in their values, their motivation and their interactions with the tenants they were working with. They learnt the skills necessary for planning person-centred care and gained the confidence to implement it, sometimes without the support of the entire staff team. The tenants are being enabled to participate in more active lives and, for one of them, a simple thing like a cup of coffee and a chat with staff before bed has become an integral part of ending the day in a positive way.'

Yvonne Maclean,
community learning disability nurse

Support workers also identified the major changes to their attitudes and practice as a result of participating in the programme.

'Doing this course has opened my eyes to how much the individual was capable of doing for himself. Skills have been lost over time as staff were doing for him and not with him. The activity plan now in place enhances his life and builds on his skills. He is a much happier person.'

Marie White, support worker

'From the start of the course my values have changed and the way I work has changed. I look at the individual now, putting them at the centre of everything that I do and try to encourage them to take part in their own lives more.'

Lesley Robinson, support worker

Improving Practice: Supporting people with learning disabilities whose behaviour is perceived as challenging. An educational resource for support workers. Published by NHS Education for Scotland in 2004. This resource is freely available to staff throughout Scotland.

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The health and social care organisations in England are delivering a major programme to transform the care of people with learning disabilities. This includes a commitment to redesign care models and services which reduce the need for in-patient beds and support people in a place they call home. As part of this work, new staffing models will be developed and the role of the registered learning disability nurse will be vital to ensure safe, compassionate and competent care in whatever setting.

People with learning disabilities suffer a higher incidence of ill health than the general population. In the following case study a team approach succeeded in reducing the numbers of individuals reaching crisis point.

The challenge

There is a higher prevalence of ill health among people with learning disabilities partly because people with learning disabilities and their carers often do not recognise a deterioration in health until the situation has become serious. The intensive health outreach team in Cheltenham recognised that referrals often reached crisis level because of unmet basic health needs such as malnutrition and dehydration. The team also recognised that practitioners needed to have appropriate resource readily to hand in an accessible form to respond to referrals.

The journey

The team identified the need to link care planning with care pathways incorporating the Health Equalities Framework together with the resources related to the determinants of health inequality. Following a series of workshops, nutrition and hydration were identified as factors in the majority of the referrals. The team also recognised that information was not always stored in an organised way to enable practitioners to access it quickly and effectively.

Claire James, administration manager, created a flow chart for nurses and health care assistants which linked resources for care staff and service users. As the flow chart developed, additional resources were created for use by practitioners.

For example, carers often did not understand how to judge the amount of fluids an individual was having during the day. The team created a fluid chart in the form of an image of a jug which carers could mark to show daily intake as the jug 'filled up'. In addition a nutritionist worked with the team to identify foods that were nutritious and hydrating.

The flow charts, linked to the electronic pathway, enabled practitioners to locate relevant resources in a timely way when called out to referrals in residential settings, supported living environments and even over the weekend.

The outcomes

- Electronic care pathways support timely access to services i.e. right person, right place, right time as well as contributing to preventative and anticipated care.
- The care pathways improve safety and increase the productivity of the learning disability nurse through preparation and the ability to access the resources needed for reasonable adjustments and partnership care planning in a timely and responsive manner.
- They enable non-registered nurses to have access to reliable, evidence-based resources in the absence of senior staff thus enabling registered nurses to use their skills to the utmost while spreading their knowledge to all sectors.
- The resource includes easy-read and health information to aid proactive and preventative literature that increases health literacy and prevents unnecessary admissions and improves safety for service users and allows the nurses to respond in a timely fashion so aiding the productivity of the team as a whole.
- The journey to implement solutions has helped staff look at the relationship between health inequalities and the care provided and to recognise that basic healthcare and preventing ill health needed to be embedded in the social care environment before a crisis occurs.
- Staff are more productive in relation to releasing time to care, the independent care providers receive valuable resources to increase health literacy and are better able to offer preventative solutions themselves.
- Service users experience greater consistency of care and advice from learning disabilities and care providers. Students are able to follow the pathways which reinforced their knowledge of using validated procedures, and enable them to provide guidance in a structured systematic approach.
- Health literacy among people with learning disabilities and their carers improved alongside their ability to recognise a deterioration in health before a crisis occurs.
- The approach offers staff clarity and validity and allows them to work to minimise health inequality by using their unique skills while also transferring skills and information to other care sectors.
- The culture has moved from reactive and crisis-led to a more preventative strategy that is also responsive and measurable.
- The resources linked to the electronic pathway provide easy-read and template care plans and visual aids that can be saved and personalised for the individual. These bespoke examples of care planning empower the individual and carers thereby assisting and promoting a move from a culture of exclusion to one of inclusion.

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Many learning disability nurses work in the independent sector. This case study is an example of partnership working between statutory services and an independent sector provider (Public Health Wales, 2013) who up until that time had had no previous experience of working with high-risk offenders. It demonstrates the added value brought to the service by a learning disability nurse.

The challenge

A small independent provider specialising in supporting individuals with learning disabilities and serious challenging behavior, including high risk offenders, values the skills of learning disability nurses in working with these individuals to deliver evidence based treatment programmes.

The journey

A detailed risk assessment using a forensic Structured Assessment of Violence Risk in Youth (SAVRY) risk assessment (Webster, Douglas et al, 1997) enables the multidisciplinary team to work with individuals with high risk behavior including sexual offences to reduce the possibility of a recurrence (Lindsay et al, 2004). A review of the relevant literature (Lindsay and Taylor, 2005) demonstrates the potential benefits of this approach for individuals and the protection of public safety.

The learning disability nurse, who is also the forensic lead, leads and develops the organisation to become knowledgeable and skilled in working with this cohort of complex individuals. Interventions involve a treatment-based approach using adapted material from validated and recognised pathways (Craig et al, 2010) and which may include weekly sessions at the person's place of residence in conjunction with the clinical psychologist from the local learning disability team. The Good Lives Model (Ward, 2011) is promoted to ensure a rich, fulfilling and meaningful lifestyle.

The results

Individuals have a safe therapeutic space for their treatment and are able to discuss their thoughts and beliefs and how they are affected by them. They are then able to understand how thoughts can become actions and actions are offences which have consequences. They also learn coping strategies and gain in confidence.

The benefits for staff are also considerable. The forensic lead ensures staff have clinical supervision and attitudes, confidence and competence have improved as staff now understand the context of how the offence cycles for these individuals have developed over time and how their learning disability impacts on the choices they have made. They now have a healthier, positive relationship with high risk individuals which has helped in the growth of self-esteem.

The organisation recognises the added value that having someone with a learning disability nursing background can bring to a service. They understand that working with people with complex presentations is more than just challenging behaviour and that people are people first and the behaviours they exhibit are in a context which needs to be understood.

Through demonstration, direct work and clinical supervision the organisation has been strengthened in its ability to work with offenders with a learning disability. The added value that having a person employed with a learning disability nursing background has helped to strengthen the service capacity issue and has increased the local options available to commissioners through evidence-based practice, in partnership with statutory services and the independent sector.

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Focus on quality

Strengthening the Commitment highlighted that learning disability nurses need to embrace the movement towards quality improvement and demonstrate impact through measurable outcomes and evidence based interventions that improve safety, productivity and effectiveness alongside traditional person-centred approaches. The following case study demonstrates how learning disability nurses were empowered to modernise their practice and to improve the health experience of people with learning disabilities.

'Learning disability nurses help someone to have the best life they could have.'

Annie Norman,
RCN

The challenge

Strengthening the Commitment set out a number of challenges for learning disability services in Scotland. The learning disabilities nursing team in NHS Lanarkshire has played an active part in taking forward the modernisation agenda set out in the report. The majority of the team are involved in one or more sub-group of the Local Implementation Group.

The journey

One working group carried out a scoping exercise to collect base-line information about the role of the learning disability nurse from people with learning disabilities, their carers, learning disability nurses, other healthcare professionals and other agencies. This information was the driver for the project 'Strengthening our Practice'. The overall aim of the project was to empower the learning disability nurses to modernise their practice and improve the healthcare experience of people with learning disabilities. The project supported the implementation of the Moulster and Griffiths learning disability nursing framework into practice.

The project links to three of the principles of *Strengthening the Commitment*.

- **Capability** will be strengthened by maximising the skills, knowledge and competencies of learning disability nurses within a range of settings, including community, in-patients and the independent sector. The framework highlights the values and rights based aspect of learning disability nursing.
- **Quality** is being addressed through the use of the Moulster and Griffiths model which includes an outcomes focused measurement framework to allow nurses to demonstrate the effectiveness of their nursing process. The project addressed future quality issues by involving student nurses and university lecturers.
- The **learning disability nursing profession** will be strengthened with a focus on incorporating research, reflection and evidence base into everyday practice.

The main challenge for this project was the struggle experienced by learning disability nurses with their desire to improve and modernise their practice while experiencing the pressures of increasing clinical

demands. The joint support of senior nurses and managers was pivotal in addressing the challenges. It was important that the nurses understood and appreciated some of the gaps in their practice and were made aware of the policies and guidance that supported the proposed change.

Funding was sourced from NHS Education for Scotland (NES) to provide a development day for the learning disability nurses in NHS Lanarkshire and the independent sector. There was also representation from student nurses, higher education institutions and a user/carer group.

The day was facilitated by Gwen Moulster who provided an overview of the theory behind the Moulster and Griffiths model and provided practical exercises to complement the implementation. The development day was evaluated extremely positively and was the main driver behind the nurses' motivation to use the model.

The framework is being implemented using the small test of change model: Plan, Do, Study, Act (PDSA). A practice development nurse and two community senior charge nurses have formed an implementation support team. They have re-designed the framework paperwork to meet the requirements of NHS Lanarkshire, set up drop-in support sessions for learning disability nurses involved in the project, and arranged one to one visits to their bases for additional support.

The project is due for completion in May 2015, but initial results are very positive. The project is addressing *Strengthening the Commitment* priorities for the future by raising the profile of learning disability nurses within NHS Lanarkshire and other agencies and is also helping to build relationships with the independent sector through collaboration.

The results

Initial feedback from the learning disability nurses involved in the project is positive. There is already evidence of a culture change as the nurses are aiming to be more outcome focused in their approach and are more aware of the need to seek out the evidence behind their interventions. They feel more confident in having a unified approach across the service, however it will take some time for them to get used to what they perceive as an increase in paperwork. Improved electronic systems may help to address this in the future. The benefits of documenting reflection on a case-by-case basis was initially viewed with doubt, however nurses have been able to see the positive impact, both on care planning and also as a basis for clinical supervision. It can also be used as a means to evidence, revalidation requirements set out by the Nursing and Midwifery Council.

Feedback from carer groups has been positive and the project has been taken to service user groups for consultation. A collective advocacy group has agreed to offer ongoing support to the project.

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Fiona Gibney, Senior charge nurse



Focus on strengthening the profession

Effective, strong leadership was highlighted by *Strengthening the Commitment* as being essential to ensuring that networks for learning disability nurses across the UK provide a powerful platform from which to celebrate, promote and develop their unique contribution. The following case study highlights the leadership programme developed for learning disability nurses in Northern Ireland.

*'My client trusts and relies on me ...
I'll do my best for him.'*

Amy Hodkin,
student

The challenge

Increasing demand for learning disability services, complexity of need and the recommendations of various regulatory and inquiry reports pointed to the need to build the relevant set of leadership and practice development knowledge and skills within the learning disability nursing workforce in Northern Ireland. This challenge was set within the context of *Strengthening the Commitment*. A bespoke regional leadership programme has been developed to equip the profession to meet these demands and to identify and support a cohort of confident, competent leaders to support the learning disability nursing profession, now and into the future. The need for this programme has been recognised and endorsed at ministerial and Chief Nursing Officer level.

The programme has been developed and delivered by the Royal College of Nursing (Northern Ireland).

The journey

The programme focuses on strengthening the profession and aims to help participants develop their leadership knowledge and skills necessary to ensure the delivery of safe and effective care in all learning disability settings. The content has been designed to deliver the learning outcomes concerned with the responsibilities of being a senior nurse working within learning disability services, with a particular focus on effective leadership behaviours, understanding whole systems working, managing the health versus social care conflict, positive performance management culture and the principles of working in and leading effective teams.

At its heart the programme seeks to build leadership capacity and capability to ensure visible leadership for the profession within Northern Ireland now and into the future.

In the context of *Strengthening the Commitment* this leadership programme has focused on helping participants develop competencies and skills in a number of key areas, including:

- leading for change
- practice development methodology
- problem based learning
- root cause analysis.

At a fundamental level the leadership programme will be an important mechanism to support succession planning and raise the profile of learning disability nurses and nursing in Northern Ireland.

In nurturing and developing new and aspiring leaders who are equipped (individually and collectively), Northern Ireland is aiming to transform the culture of service provision for individuals with a learning disability, to raise and improve nursing standards, to develop and role model strong clinical leadership and professionalism within the profession and ultimately to develop and ensure a better future of high quality nursing care for people with learning disabilities throughout their lifespan.

The results

The first cohort of learning disability nurses completed the programme in March 2015 and there will be follow up evaluation to establish the impact on practice and the development of leadership skills and behaviours. However, it is also the intention and responsibility of the Northern Ireland Regional Collaborative for the Northern Ireland Action Plan to ensure that we support and assist in the development of these individuals in a leadership context.

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One of the challenges facing learning disability nursing is the perception of the profession among other nurses, the public and prospective students. Too often we hear reports that learning disability nursing is viewed negatively or that parents of newly diagnosed babies or children with a learning disability do not realise that learning disability nurses are there to support them. The following case study illustrates an approach to introducing young people to learning disability nursing.

The challenge

Merthyr Tydfil is an area in South Wales where people with learning disabilities are mainly cared for by their own families in the family home. One of the day opportunities provided locally is in the college. The Independent Living Skills (ILS) department provides educational opportunities to a client group who have additional health needs alongside their learning disability, therefore recognising that health and social outcomes are interdependent. The lead nurse based in the local health team for adults with learning disabilities recognised that a working partnership was needed between the college and the health team.

The college also provides education to young adults who are embarking on their career paths; some are working towards qualifications to enter nursing. This was felt to be a good opportunity to raise the profile of learning disability nursing and a proposal was offered to the college to deliver a half-day session to a group of students studying on the health and social care module.

One of the challenges was to create a session that would be meaningful, memorable and delivered in a manner to create engagement. The other was to gain positive feedback from all students. While it was not expected that all students would leave the session wanting to become a learning disability nurse, the aim was to raise the profile of the profession and to enlighten potential student nurses.

The journey

The nurses led a session with a group of college students on International Disability Day, promoted by the United Nations. The aims of the session were to promote an understanding of disability issues and mobilise support for the dignity, rights and wellbeing of people with disabilities whilst celebrating the provision of Merthyr College.

The session was made up of:

- a presentation on disability awareness focusing on disability issues and attitudes
- a treasure hunt game to reinforce disability issues and celebrate the college provision. Students were invited to explore the college and locate particular reasonable adjustments that the college provides
- college students from the ILS department being invited to talk about their college course and their experiences in the college. The aim was to bring together the two departments as nursing students may be on a work placement in the ILS department and this would help build bridges
- a presentation on the role of the learning disability nurse describing examples of work, places to work and demonstrating that learning disability nursing is a promising career
- a question and answer session led by learning disability student nurses about their own experiences in university and what the course had to offer. A video created by the university has also been added to the presentation.

The results

Feedback has been positive and appears to have stimulated an interest among students for learning disability nursing and a greater understanding of the role played by learning disability nurses.

'I found this morning very interesting and the opportunity of this session has made my career path clearer. Thanks'

'I found the morning really interesting, it also made me think of different jobs I would possibly like to do.'

'Today's talk was very interesting and helpful, I would like to be a learning disability nurse, thank you very much.'

The session has been repeated to another group of students this year, and it is planned to continue to deliver the session on an annual basis. The aim is to continue raising the profile of learning disability and assist in strengthening the capacity of learning disability nurses.

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Elizabeth Fair – Lead nurse (project leader)
Rhiannon Smith – Community nurse
Rebecca Thomas – 3rd year student
Jessica Bamwell – 2nd year student



In the three years since the publication of *Strengthening the Commitment*, the UK has lived through a period of prolonged austerity; seen ever-increasing public expectations and the rise of social media that moves information at the blink of an eye. The NHS continues to be in the throes of public reform which will see health services delivered within integrated health and social partnerships and in some parts of the UK an increasing mix of statutory and private provision.

The UK-wide Steering Group is committed to continuing its work to ensure that learning disability nurses build on *Strengthening the Commitment* while responding to the challenges of the new health and social care context. We need to meet the needs of people with learning disabilities, their families and carers in 5, 10, 15 years from now. We need to find creative ways for learning disability nurses to collaborate with other professionals and agencies in integrated settings whilst at the same time retaining all that is unique and special about what they offer. We need to make sure that learning disability nurses continue to add value and have impact and that their individual contribution remains valued within a multiprofessional and multi-agency context.

The spirit and thrust of *Strengthening the Commitment* remains as relevant today as three years ago. New and emerging challenges require a renewed, refreshed, refocusing of *Strengthening the Commitment* to make sure that we are responsive to the needs of people with learning disabilities and continue to strengthen the learning disability nursing profession. We have identified four key action areas for cohesive and collaborative action across all four countries. From these the UK Steering Group will set out a framework of priority actions and associated milestones for 2015-2018.

1 Strengthening the unique role and contribution of learning disability nurses

- Learning disability nurses add value to people's lives and we will celebrate and vocalise the contribution they make so it is evident to health and social care professionals, commissioners of services and to the public.
- Learning disability nurses play a key role in identifying children with learning disabilities as early as possible and then in supporting them and building resilience among children and young people with learning disabilities. In 2012 the IHAL estimated that there were 236,000 children in England with severe, profound and multiple, moderate learning disabilities or autistic spectrum disorder. This indicates the scale of the challenge to local authorities in providing adequate services for these children. The highly successful Health Equalities Framework is to be adapted and will be rolled out in line with individual country's implementation plans for children and young people's services, so that the health outcomes of learning disability nurses' contributions can be measured.
- Programmes to transform care and services for people with learning disabilities together with new staffing models will reduce the need for in-patient beds and enable learning disability nurses to deliver safe, compassionate and competent care across all settings.
- People with learning disabilities experience unacceptable health inequalities that put them at risk of disease and premature death. Many of the determinants of poor health can be mitigated by appropriate preventative measures such as better screening, targeted

information, advice and support and reasonable adjustments to ensure people get good quality healthcare. Learning disabilities nurses play a major part in reducing inequalities and their role in public health will be expanded and strengthened to ensure they make their vital contribution to reducing health inequalities among people with learning disabilities.

2 Strengthening leadership among learning disability nurses

- Learning disability nurses are in leadership positions throughout government departments, higher education institutes, the criminal justice system, the independent and voluntary sector, and within health and social services. Their influence is evident in decision and policy making across the four countries in leading change and innovation, and demonstrating the care and treatment that people with learning disabilities should receive. Strong leadership at all levels including clinical leadership is critical to making things happen and we will continue to develop leaders to be highly visible and involved in current economic, political and social issues.
- Learning disability nurses will continue to increase awareness amongst commissioners and non-nursing managers of the benefits of learning disability nursing in terms of delivering measurable outcomes. Leaders in learning disability nursing will demonstrate their impact on improving health outcomes for people with learning disabilities.
- Work will continue to ensure learning disability nurses fulfil a key leadership role and bridge the gap between primary and secondary health services for people with learning disabilities. They ensure that reasonable adjustments are made and support healthcare staff as they work with people with learning disabilities.

3 Regulation, revalidation, workforce and the professional development of learning disability nurses

- Learning disability nurses will be supported to respond to the opportunities and challenges of revalidation, including continuing the development of models of support for learning disability nurses working in all settings and in isolated roles. The potential of reflective practice and clinical supervision to be embedded in day-to-day practice will be explored as a key element of revalidation.
- The standards embedded in the pre-registration learning disabilities nursing curriculum equip nurses with the confidence, attitudes, awareness and leadership capabilities to enter practice with a group of individuals who often have complex care needs. We will continue to deliver and develop the curriculum to make sure that students have a wide experience of learning disabilities and have the necessary skills to contribute to the care of people with learning disabilities.
- Nurses emerging from programmes from all fields of nursing should have a sound insight into how to care for people with learning disabilities who will engage with health services across their life span and across all their healthcare needs. The work started in the four countries to integrate learning disabilities within all nursing programmes in higher education institutions (HEIs) will be driven forward and strengthened.

- Education provision should be developed with co-production at its heart where people with learning disabilities, families and carers contribute fully to the development, delivery and evaluation of nursing programme curricula.
- Resources should be targeted so they have the greatest impact and projects that are innovative and which progress the educational agenda will be supported. Flexible delivery options and support within HEIs will be developed.
- Recruitment to learning disability nursing needs to continue to be strengthened and encouraged. To respond to this, learning disability nurse leaders and practitioners will continue to demonstrate their role in improving people's lives, the variety of settings in which they work and their contribution to reducing health inequalities.

4 Quality improvement, impact and assurance

- New models of care have been developed and will continue to be implemented across all four countries. These models aim to improve the support for and care of people with learning disabilities so they can live with the respect and dignity of any other human being.
- The use of the Health Equalities Framework is already being considered by the four countries and in some instances being rolled out at local level. This will enable the outcomes of learning disability nurses' contribution to be measured and their added value demonstrated.
- Research and investigation into learning disability nursing, and by learning disability nurses, will continue to expand so that a robust evidence base can be further developed. This will contribute to innovative ways of demonstrating the positive impact that learning disability nurses have on healthcare outcomes.
- The strong foundations laid by the Learning and Intellectual Disabilities Nursing Academic Network (LIDNAN) will be reinforced, work streams reviewed, and networks and communication enhanced across all learning and intellectual disabilities nurses working in higher education.
- Learning disability nurses will work with people with learning disabilities, carers, employers and commissioners to ensure that regulation is robust and meets the needs of people with learning disabilities.

Learning disability nurses welcomed and embraced *Strengthening the Commitment* and the range of innovative developments that have been taken forward has been impressive. This report celebrates these achievements whilst recognising that there are many other examples across the UK of learning disability nurses doing exemplary work to ensure people with learning disabilities are treated with compassion, dignity and respect and have the right care, at the right time in the right place.

We also recognise that the job is not yet done and this report also sets out our commitment to the future agenda. Every learning disability nurse plays a vital role in continuing to do the best we can to meet the needs of people with learning disabilities, their family and carers and continuing to develop learning disability nursing as a strong and vibrant profession.

Fact file

These examples of innovative practice have been submitted to the UK Strengthening the Commitment Steering Group. The listing provides a brief description of the work together with email contacts to enable readers to follow up examples of particular interest.

England

Name/contact details	Case study title
Yvonne Courtney and Lynne Westwood Yvonne.Courtney@sssft.nhs.uk L.R.Westwood@wlv.ac.uk	Rollout of Strengthening the Commitment to stakeholders To plan and host a conference involving service users, their carers and supporters, pre-registration learning disability student nurses from two universities (Keele and Wolverhampton) qualified and unqualified nursing staff from SSSFT and neighbouring Trusts. This involved approximately 150 delegates. To work collaboratively with key stakeholders who don't normally work together.
Sally Powell Sally.Powell@glos.nhs.uk	Developing a mainstream parenting course for parents of children with LD Adapting a parenting course based on Webster Stratton and running it. Results showed that parents felt more confident in managing their child's behavior and the child's behavior had improved as have communication skills between parent and child. Involves learning disability nurses, CAMHS services.
Elaine Thomas ElaineM.thomas@sssft.nhs.uk	Implementing the Moulster Griffiths Nursing Model Implementing a new model of nursing care using high quality documentation to support high quality care delivery. The model enabled a means of measuring the success of care delivered through the health equality framework.
Karen Breese and Yvonne Courtney Karen.Breese@sssft.nhs.uk Gwen.Moulster@sssft.nhs.uk	Impact of nursing leadership in enabling effective collaborative working Shows effective leadership from two nurses who lead the Clinical Effectiveness Group. The group has developed an overarching physical health care pathway, revised the epilepsy pathway, held education forums, and increased confidence in service user involvement among other things.
Jim Blair Jim.Blair@gosh.nhs.uk	Better care – healthier lives Eight key principles form the foundation of the work at Great Ormond Street Hospital for people with learning disabilities. Among other initiatives, a protocol has been developed for the preparation and recovery for people with learning disabilities and the hospital passport records the individual patient's likes and dislikes.
Glenn Batey and Declan Munnally Glenn.batey@nhs.net	Internet Risk Awareness Group for people with learning disabilities The aim of the Internet Risk Awareness Group (i-RAG) is to support people with learning disabilities to use the internet in a safe and inclusive manner. i-RAG is the first specific psychoeducational intervention for people with learning disabilities to raise awareness of the risks of using the internet.

Northern Ireland

Name/contact details	Case study title
Gordon Moore gordonw.moore@setrust.hscni.net	Implementation of GAIN Guidelines The GAIN guidelines identify 12 specific areas as the most pressing areas of need for people with a learning disability who use general hospital settings.
Molly Kane Molly.kane@hscni.net	Health facilitation for people with learning disability in Northern Ireland The development of health facilitation as a commissioned and accepted model of improving the health of people with a learning disability in Northern Ireland has relevance across the four themes of <i>Strengthening the Commitment</i> .
Sarah Boyd Sboyd30@qub.ac.uk	Learning disabilities pre-registration programme Student perspective on how the programme strengthens the quality of individual practice and raises the profile of the learning disability profession.
Lisa Hanna-Trainor lm.hanna-trainor@ulster.ac.uk	Looking at retirement options for adults with intellectual disabilities A focus on the service user supports that need to be in place to ensure an effective transition from adult services to those geared to meet the needs and preferences of older people with learning disabilities.
Maria Truesdale mn.truesdale@ulster.ac.uk	Adults with learning disabilities and diabetes Developing a structured diabetes education programme for people with learning disabilities and their carers and assessing potential gains from such a programme.
Edna O'Neill edna.oneill@setrust.hscni.net	A joint epilepsy clinic The clinic enables individuals to receive specialist care locally, in a person centred way with additional time for each clinic appointment. The epilepsy nurse can follow people up in the community in partnership with the learning disability psychiatrist and GP.

Scotland

Name/contact details	Case study title
Gary Docherty gary.docherty@danshell.co.uk	The Danshell Skype family contact project Provides a tangible communication link between service users with learning disabilities and their family/carer. The use of technology (Skype) to enable this process of interactions, ensuring we continue to support families to keep in touch with their relative and opportunities to participate in meetings such as CPA and to contribute to assessment and care planning processes. This project enhances relationships between the company and the families and between the families and the service users.
Jonathan Gray / Allison Ramsay Allison.ramsay@nhs.net	Scottish Senior Learning Disability Nurses Group The SLDSNG has provided consistency and momentum in the implementation of <i>Strengthening the Commitment</i> recommendations across Scotland. The group has focused on improving the profession to ensure that learning disability nurses have the right skills and knowledge to deliver a high standard of care and support to patients and their families.
Heather Duff heather.duff@nhslothian.scot.nhs.uk	Managed Care Network HEF Project The implementation of the HEF across the four health board areas of the Learning Disability Managed Care Network (LDMCN), South East Scotland. The focus initially will be for community learning disability nursing staff and multidisciplinary staff from Borders health and social care. The second phase of the project may include specialist nurses, inpatient service staff and other community learning disability multidisciplinary health and social care staff who work with people who have a learning disability.
June Knight june.knight2@nhs.net	Develop the role of nurse practitioner for people with learning disabilities with a comorbid mental health diagnosis or a suspected underlying mental health condition To provide evidenced based, participative and recovery focused treatment programmes. To include: non-medical prescribing provision. Development and provision of appropriate psychosocial interventions. To support development and implementation of service mental health care pathway. To participate in research and contribute to development of mental health provision for people with a learning disability.

Scotland cont.

Name/contact details	Case study title
Christina Bickers Christina.Bickers@nhslothian.scot.nhs.uk	Programme for support workers supporting people with learning disabilities A training needs analysis was sent out to all healthcare support workers supporting people with NHS Lothian learning disability services. The data informed the type of training to be delivered. This included topics such as communication, higher health needs of people with a learning disability, values/attitudes, etc. The training was delivered over two days and was facilitated by practitioners from across NHS Lothian consisting of AHPs and nursing staff. The training was interactive and support workers were encouraged to participate and share their experiences/knowledge.
Marion Gilchrist, Nicholas Jenkins, Steve Wright, Jan Thomson, and Gareth Davison Marion.gilchrist@aapct.scot.nhs.uk	Getting involved, being involved: shaping a community focused response to Strengthening the Commitment Learning disability nursing leaders within NHS Ayrshire and Arran recognised a need to create opportunities for local communities to become involved in interpreting the vision and recommendations from <i>Strengthening the Commitment</i> , in terms of what was relevant for them. Doing so will help to align the work of the local implementation group with the priorities of those accessing services.

Wales

Name/contact details	Case study title
Victoria Jones Victoria.jones@southwales.ac.uk	Improving quality through collaboration with experts: infiltrating the system! The Teaching and Research Advisory Committee (TRAC) meets monthly at the University of South Wales. Its members are from the third sector across South Wales. It is facilitated by a learning disability nurse lecturer. It is an advisory group to the Research Unit for Development in Intellectual Disabilities (UDID). We aim to advise UDID on all aspects of teaching and research from our perspective as experts by experience.
Elizabeth Prichard Elizabeth.pritchard@wales.nhs.uk	The use of an accessible health goals plan A case study of working with an individual to assess their capacity and understand their needs resulting in a shared plan of support. The learning disability nurse used pictorial support to develop a person centred approach which concentrates on the individual's needs.

Wales cont.

Name/contact details	Case study title
<p>Nichaela Jones and Sue Jones Nichaela.jones@wales.nhs.uk and Susan.jones18@wales.nhs.uk</p>	<p>The development of nurse led clinics for short term interventions on specific healthcare needs The description of the implementation of nurse clinics, led by learning disability nurses focusing on specific issues and problems. The example used to illustrate that service is a sexual health intervention but the clinic deals with a range of issues and provides advice and support on these. These include sleep problems, healthy living, continence and routine health assessments.</p>
<p>Georgina Hobson Georgina.hobson@wales.nhs.uk</p>	<p>Development of dialectical behavioral therapy (DBT) as an approach for people who have emotional regulation difficulties in addition to learning disabilities Nurses are taught to use and apply DBT in group and individual sessions to support people who have additional emotional difficulties.</p>
<p>Tracey Lloyd tracey.lloyd@wales.nhs.uk</p>	<p>Check for change. Development of educational workshops for people with learning disabilities to increase their awareness regarding cancer A Macmillan initiative across Wales encompassing all things related to cancer and learning disabilities. Aims include improving awareness, encouraging screening and early health intervention/diagnosis, supporting all involved, developing existing knowledge.</p>
<p>Rachel Morgan rachel.morgan4@wales.nhs.uk</p>	<p>Implementing reasonable adjustments to enhance care for people with learning disabilities within acute healthcare settings As part of the newly developed hospital liaison role within Aneurin Bevan Health Board work has been undertaken within acute hospital settings to enhance access for people with learning disabilities. This has included implementing reasonable adjustments in relation to timings of procedures, environmental adaptations, staff education and support in relation to capacity and consent.</p>

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Membership of the UK Strengthening the Commitment Steering Group

Name	Representing	Dates
Ros Moore [Chair]	CNOs	September 2012-November 2014
Hugh Masters [Interim Chair, November 2014 – current]	Scottish Government	September 2012-current
Dave Atkinson	Independent Nurse	September 2012-current
Sue Beacock	Learning Disability Nurse Academics Network	September 2013-March 2015
Sue Beacock	Welsh Government	March 2015-current
Phil Boulter	UK Nurse Consultants Network	September 2012-current
June Brown	Scottish Government	December 2012-April 2013
Frances Cannon	NIPEC representing DHSSPS	September 2012-current
Brenda Devine	DHSSNI	September 2012-December 2012
Jenifer French	Welsh Government	September 2012- February 2015
John Goree	Independent Sector	September 2012-March 2015
Bob Hallawell	Learning and Intellectual Disabilities Nursing Academic Network	September 2012- September 2013
Crispin Hebron	UK Nurse Consultants Network	September 2012-current
Amy Hodkin	Student representative	December 2012-current
Susan Kent	Republic of Ireland	December 2014-current
Joshua Kernohan	Student representative	December 2012-current
Elaine Kwiatek	NHS Education for Scotland	May 2014-current
Helen Laverty	Positive Choices	May 2014-current
Jo Lay	Learning and Intellectual Disabilities Nursing Academic Network	December 2014-current
Joanne McDonnell	NHS England	March 2015-current
Debra Moore	Independent Sector	September 2012-current
Gwen Moulster	UK Nurse Consultants Network	September 2012-current
Annie Norman	RCN	September 2012-current
Ruth Northway	Wales National Implementation Group	September 2012-current
Hazel Powell	NHS Education for Scotland	September 2012-current
Margaret Serrels	Scottish Government	September 2013-June 2014
Ben Thomas	Department of Health	September 2012-current
Robert Tunmore	Department of Health	September 2012-April 2013

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■ Julie M Davies, 2nd year student nurse, University of South Wales

■ Hayley Goleniowska, Advocate at Downs Side Up www.downssideup.com

■ Natty Goleniowska

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