

LEARNING DISABILITY NURSING



Capturing the voices of learning disability nurses and people who use services

An independent engagement initiative led by the Foundation of Nursing Studies

Giselle Cope and Dr Theresa Shaw





Celebrate Me: Capturing the voices of learning disability nurses and people who use services

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“Learning disability nurses are highly skilled, highly motivated, cost-effective and highly valued person-centred nurses. Wherever they work they have a proven track record for improving outcomes, reducing the impact of health inequalities and improving people's lives. They have unique, enhanced communication and interpersonal skills, are important educators and can be part of the essential reasonable adjustments needed to reduce morbidity and unnecessary premature deaths of people who have learning disabilities”

Survey participant, 'elevator pitch' to government and policymakers about the importance of learning disability nursing

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When I was a little girl, I grew up in a family that promoted strongly the need to be more rather than have more; I was told the sky was the limit and I could do anything I set my mind to.

It came as a bit of a shock then, when I told school what my career choice would be, to be actively discouraged and told I was 'too clever to blow noses and wipe bottoms!' However, I stuck true to my ambition, supported by my family and became a learning disability nurse (although we weren't called that then!)

Over the past 100 hundred years the history of learning disability nursing has been littered with rumour, myth and prejudice:

- There's no future in it
- You are not real nurses, you don't need to be very clever to do it
- You don't need nurses to care for people with a learning disability
- It only happens behind high walls and closed doors
- It's only about 'warehousing' people
- Anyone can do it

So, what is a learning disability nurse? He or she is an individual with a passion to ensure people with a learning disability get what you and I take for granted – and that's just an equal chance at life! The learning disability nurse is a highly skilled individual who has undertaken a university programme leading to both an academic qualification and professional qualification in nursing the individual who has a learning disability.

This report challenges the myths and misconceptions related to what we do, why we do it and who we are. It reinforces our mantra of 'Together we are better' by writing the narrative from the perspectives of people with a learning disability, families, student nurses and those of us who have been qualified a while. We own our own story and will make it one of equality, respect and future orientation. No longer do we say the sky is the limit, everyone knows there are footprints on the moon. ■

Helen M. Lavery MBE

Welcome to 'Celebrate Me' an initiative commissioned by the then Chief Nurse for NHS England, Professor Jane Cummings and subsequently supported by Health Education England (London Region) to raise the profile of the unique and important contribution that learning disability (LD) nurses make across health and social care.

The review of learning disability nursing undertaken in 2011-12 and subsequent report *Strengthening the Commitment*, has offered recommendations for modernising learning disability nursing roles and practice. In 2015, the UK Strengthening the Commitment Steering Group published its report celebrating the achievements towards realising these recommendations. The group also outlined an ongoing agenda to further strengthen the role of and leadership among learning disability nurses, and to boost regulation and quality.

Alongside all this, the true impact and profile of learning disability nursing appears to be diminishing, despite a growth of new posts in acute care services, and there has been significant reduction in applications to learning disability nursing graduate programmes. Most significantly, in 2017, one university in London was unable to recruit undergraduates for the academic year.

While the outputs shared via the aforementioned *Strengthening the Commitment* report demonstrate progress in terms of the learning disability role and practice, it was clear something new and different was needed. Connecting with the profession at the care interface indicated that the work of learning disability nurses was often invisible and its voice unheard. The Foundation of Nursing Studies (FoNS), drawing on its experiences of undertaking a review of mental health nursing, proposed a 12-month programme of work to enable the voices of learning disability nurses and people with a learning disability to come to the fore and influence the future. Understanding their perspective and experience regarding the work, future preparation and ongoing development of learning disability nurses would add value to existing activity by evidencing the important role learning disability nurses have across health and social care; not just for those people with a learning disability but across the population.

The purpose of this initiative was not to undertake another policy review or programme of research but rather to engage with nurses and people using services to shape a new narrative, from experience, that could help sustain the future of learning disability nursing. The outcomes from our extensive engagement have enabled us to bring to the fore everything that there is to celebrate about learning disability nursing and what needs to be championed for the future, from the voices of learning disability nurses and those of people with a learning disability and their families.

So, unlike many reports you will not find recommendations at the end. What follows first is what we should be celebrating now (the impact of LD nursing) and what we should be championing for the future (to sustain LD nursing). Readers will then be able to go on and read about the engagement activities and more details via words and graphic art, representing what people shared and contributed. ■

CELEBRATE NOW!

THEME 1: LDNs empower the person with a learning disability to have a fulfilling life; they also support the person's family

'Learning disability nurses bring a unique and rare skill set that supports, enables and empowers people with learning disability to have better health.'



a. Person-centredness

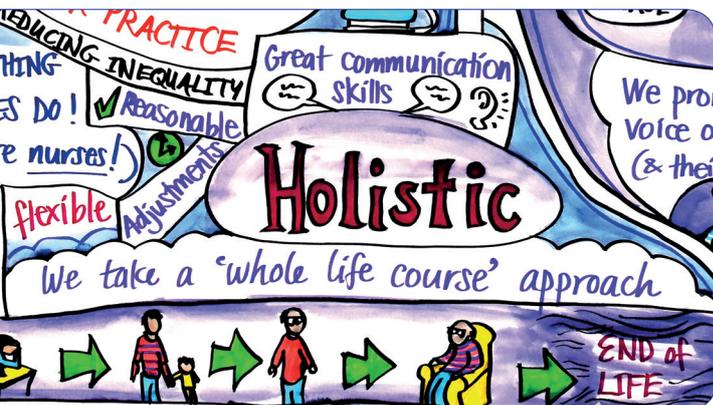
'The range and diversity of our skills, we are also the only truly holistic field of nursing because we work cradle to grave with individuals. Significantly, we focus on enabling and development, not cures.'

'LD nurses are still in my view at the forefront of person-centred care delivery, rather than service-led solutions which too often drive the care.'

b. Values-based practices

'LD nursing is values led in its approach ... LDNs are empathetic, respectful, non-judgmental in their approach and always see the potential in people, and enable people to optimise that potential in order to live fulfilling lives.'

'Building up a rapport with people with learning disabilities and families gaining a trust that cannot be achieved in a 10-minute appointment.'



c. Holistic approaches

'We see the person before the disability.'

'Learning disability nurses are taught through social and holistic theories, focusing on all aspects of a person's life, shaping the care to suit this.'

THEME 2: LDNs promote social inclusion, equity and fairness

'It's about equality and fairness to a particularly disadvantaged group.'

a. Act as advocates

'[We] promote their choices to live their lives as everyone else ... maximise people's potential.'



b. Promote human rights

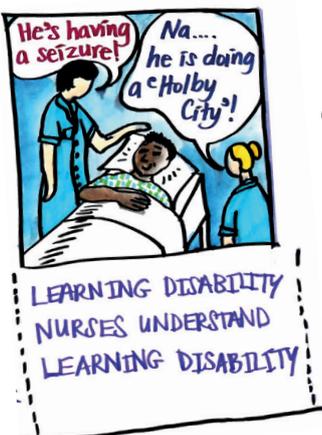
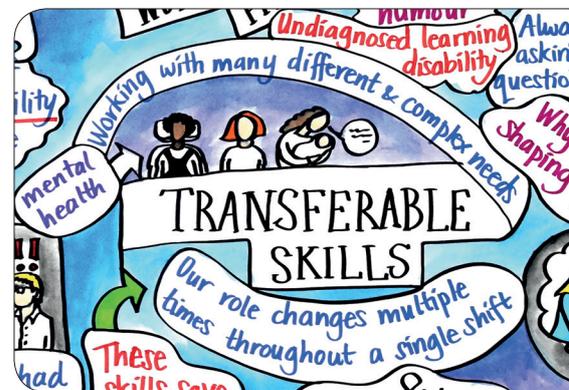
'Learning/intellectual disability nurses exist to support the health of a group of people who face constant health inequality, we do this through direct nursing intervention and by supporting other services to provide that intervention.'

'Everyone in our society is of equal value and has a contribution to make. Learning disability nurses support some of the most vulnerable of those people to live longer, healthier lives and guide and support both them and their families and carers to achieve their potential and make positive contributions.'

THEME 3: LDNs have specialist knowledge and skills

'LD specialist nurses have a multitude of skills in supporting the most vulnerable people in society.'

'LD nurses have three years of specialist training in learning disabilities. They have a holistic approach that considers the whole of the person rather than focusing solely on the physical/ mental health or social needs.'



a. Expertise in learning disabilities (and autism)

'Learning disability nurses are versatile, adaptable and dynamic. They work with children, adults and older people in generic and specialist health and social care, in education and forensic, etc.'

THEME 3: LDNs have specialist knowledge and skills (continued)



b. Communication
'[They] cut through the jargon.'

c. Evidence based
'LD nurses reduce the impact of health inequalities and provide evidence-based care and interventions.'



d. Creative and solution focused
'The unique role uses the knowledge base of the LD nurse to both advocate for and influence the care given to meet each person's individual needs. Having a learning disability is unique to each individual, it's not a 'condition' like heart failure or diabetes which responds and reacts in the same way each time, it's a unique individual who needs help to understand the new health condition they may have and be given information to understand that new condition.'

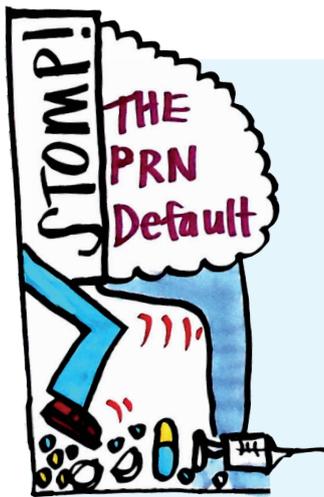


THEME 4: LDNs build capacity for healthy lives

‘Without LDNs the knowledge and understanding of complexity, diagnostic overshadowing and reasonable adjustment diminishes, leading to poorer health outcomes for people and families.’

a. Reduce early and unnecessary mortality

‘Without a professional group with a specific and enhanced knowledge of their needs, the mental and physical health [of people with a learning disability] will worsen and there will be even more deaths of learning disability patients as a result of poor or inappropriate care.’



b. Promote health and wellbeing (physical and mental health)

‘Registered learning disability nurses (RNLDs) are the vital link in delivering specialist healthcare to people with a learning disability and supporting the wider NHS to deliver and develop health services to people with a learning disability.’



CHAMPION FOR THE FUTURE

THEME 1: Strengthening the visibility of LDNs

'It's hard to quantify what we do as it's so varied and difficult to measure. Our role is to be in the background and provide support, reassurance and direction.'



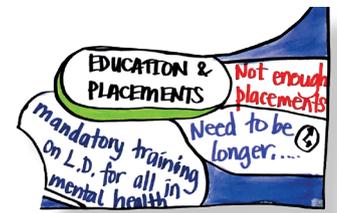
THEME 2: Recognise LD nursing as an equal and valuable branch of nursing

'We are undervalued, unrecognised and a minority in the nursing field.'



THEME 3: Increase the educational provision for LD nursing

'I don't think LD nurse education needs to change ... It is the education of other groups that may need to change.'



'In the future placements will need to be more imaginative to reflect the numerous places where LD nurses end up working.'

THEME 4. Educate all professionals and staff about learning disabilities

'Learning disability awareness training for all staff, not just health professionals working in health and social care, this could include training in basic Makaton.'



THEME 5. Expand economic assessment of LDNs

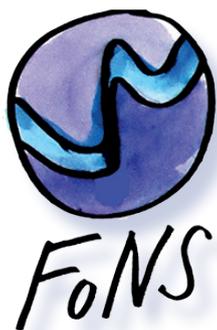
'The work these nurses do saves an enormous amount of money to the taxpayer with all the work they do, reducing the need for other services. Good value for money.'

THEME 6. The role of LDNs as autonomous practitioners

'Perhaps it is the autonomous nature of the role of LDNs that sets them apart from other branches of the profession and makes them ... unique.'

'A seamless professional who utilises preventive skills, intervention skills, signposting, reasonable adjustments – the list is extensive to provide a better outcome for the person with a learning disability.'





WHY FoNS INITIATED THIS WORK

The Foundation of Nursing Studies (FoNS) is a charitable organisation that has developed an excellent reputation at the forefront of nursing. It operates UK wide and across all health and social care settings, and is dedicated to working with nurses and health and social care teams to develop and share innovative ways of improving practice.

It has gained wide credibility nationally and in Europe, working with practitioners and policymakers at all levels and across a range of specialties. The organisation focuses on areas where its expertise can make the most useful contribution to the development of effective, evidence-based practice.

Scoping the initiative

FoNS identified a programme facilitator, Giselle Cope, to lead the work, and a small advisory group of committed and active learning disability nurses from practice, education and research was formed in January 2018 (Appendix 1). The purpose of the group was to refine the scope of the programme and develop an engagement strategy to enable the involvement of those delivering and using learning disability services.

The group undertook a process of identifying 'Claims, concerns and issues (CCIs; Guba and Lincoln, 1989), regarding the value and contribution of the learning disability nurses. Through detailed dialogue, the group was able to identify a number of key questions that Celebrate Me might consider (Appendix 2). Each group member then voted, producing the following top five priority questions:

1. How can we demonstrate the impact of learning disability nurses across sectors?
2. How do we challenge perceptions regarding people with a learning disability and learning disability nursing (promote a more positive image)?
3. How do we make learning disability nursing more attractive?
4. How do we raise the profile of learning disability nursing with employers?
5. How do we influence content, placement and practice exposure within learning disability nurse education?

These questions shaped the view that a key output from Celebrate Me could be the emergence of a new narrative for learning disability nursing.

Our engagement strategy

A guiding principle for this work was the explicit intention to engage learning disability nurses who work at the so-called 'front line' of care delivery – the interface between nurses, people with a learning disability and their families. There was a strong belief that this was the best way to understand the work of learning disability nurses in contemporary practice and the impact they have on the lives of people living with a learning disability. It was therefore important to think about both accessible and creative ways of engaging. To this end, three methods of engagement were identified to gather evidence from experience. These were Twitter tweet chats, an online survey and face-to-face stakeholder events.

Alongside the establishment of this work, a number of other events and initiatives to address issues related to learning disability nursing were emerging. Therefore, the programme facilitator also undertook to attend any relevant events that would create opportunities to profile Celebrate Me, encourage involvement, and to gather views and perspectives.

WHY FONS INITIATED THIS WORK

The number of individual participants/contributors was in excess of 1,000.

Finally, a WordPress site was created in 2018, at LDnurses.wordpress.com, to act as a holding space for the initiative. The site hosts details of activities evidence/outputs and signpost to transcripts and so on. It has provided an open public platform that has enabled the sharing of information in real time to maximise participation.

Working ethically

While this was not a research project, it was important to work transparently and ethically. The tweet chat was, as is usual, conducted in the public domain and as such participants were self-consenting by participation and identifiable by their Twitter handles. For the face-to-face stakeholder events, an information sheet and consent form were created, including the development of an easy-read version. Participants were invited to attend by the host. People with a learning disability who attended were accompanied by a parent or advocate. The hosts and facilitators ensured that all attendees had the appropriate support with reading/understanding the information and consent form. Where needed, additional information was offered. Information collected at the stakeholder events was anonymised. ■

SHARING THE VOICES OF PARTICIPANTS

Tweet chat events and survey

Each tweet chat event was facilitated in collaboration with @WeLDNurses, using the well-respected #WeCommunities social media platform (wecomunities.org).

A brief paper was prepared for each chat and the survey, which included six questions for consideration:

1. Where and how are learning disability nurses having a positive impact on the lives of people with a learning disability and their families within primary, secondary and tertiary care?
2. Why is learning disability nursing an essential role to sustain in primary, secondary and tertiary care above and beyond other people and professionals who deliver services?
3. To what extent is the role of learning disability nursing understood in primary, secondary and tertiary care and how can this be strengthened?
4. What support do learning disability nurses working at the front line of services in primary, secondary and tertiary care need to strengthen their role?
5. Is the current educational provision for learning disability nursing fit for purpose, what needs to change to enhance this and how would you articulate the importance of sustaining programmes to universities, etc?
6. Finally, what would your 'elevator pitch' to government and policymakers be about the importance of learning disability nursing?

The outputs from the tweet chats, including the transcripts and summaries, were shared via the LDnurses.wordpress.com site, which offered an opportunity for further review and critique. It is estimated that more than 150 contributors participated across all three tweet chats.

As part of each chat, @WeLDNurses conducted various Twitter polls to capture who was participating in each chat. This gave some indications as to geographical spread, people's working context and the type of service they work in. During the second and third chats, additional polls were included to capture whether people had participated in previous chats and if they had completed the online survey.

Across all three events, most participants were registered and student LD nurses working predominately within the NHS. There were also participants from education/academic and leadership roles across health and social care, along with a small number of other health professionals. Family/carer involvement was low, although it was extremely encouraging that their views were represented at each of the events. Later in the project we more actively involved people with a learning disability, family members and carers. There was a good geographical spread of contributors within England, with smaller percentages from Scotland and Wales. A small percentage of participants from Northern Ireland contributed in the second tweet chat, which focused on secondary care. The second chat attracted approximately 40% new participants, bringing new perspectives. Participation in the third and final chat was lower and disappointingly there were not as many people working in tertiary care as hoped. Taking this on board, there was a special commitment made to involve nurses working in tertiary care services later in the initiative.

To expand the level of engagement, especially from people not able to or wishing to use social media, an online survey using the same questions as the tweet chats was created. The survey ran for four weeks, from 21 June 2018 to 19 July 2018; 129 completed surveys were returned. Those who completed the survey also worked in a wide variety of roles, across a broad range of sectors, including those who provide direct care and those who have a facilitative role. These included community learning disability nurses, child and adolescent mental health services, acute hospital liaison, roles that support individuals through the criminal justice service, assessment and treatment provision, and more senior leadership and educational positions.

The responses to each question from the three tweet chat transcripts and the online survey were reviewed and collated so that the key messages could be summarised and shared. If you would like to view the transcripts from the tweet chats please visit LDnurses.wordpress.com.

Question 1

Where and how are learning disability nurses having a positive impact on the lives of people with a learning disability and their families within primary, secondary and tertiary care?

There was a strong focus on the holistic and person-centred support given by learning disability nurses – a core element that sets LD nursing apart from the other branches of the profession. Therapeutic skills were also seen as crucial to enabling meaningful relationships for the long term:

‘Building up a rapport with people with learning disability and families, gaining a trust that cannot be achieved in 10-minute appointment.’

This ability genuinely to understand the needs of a person with a learning disability was seen as unique to LD nursing. A focus on the whole person rather than seeing needs in isolation – such as physical, mental health or social needs – was seen as something that was not as present in other branches of nursing. By seeing the person with a learning disability as a person first and foremost, learning disability nurses are able to work with people’s strengths:

‘The range and diversity of our skills, we are also the only truly holistic field of nursing because we work cradle to grave with individuals. Significantly, we focus on enabling and development, not cures.’

Overwhelmingly, LDNs were proud of the impact they have on people with learning disability. They described having a positive impact in a variety of roles across all health and social care sectors, wearing both ‘clinical and social hats’. A key strength was the expansive nature of the role – LDNs describe themselves as versatile, adaptable, dynamic and holistic, across a person’s entire lifespan and supporting people through both health and ill health:

‘LD nurses make a difference through their enhanced communication and interpersonal skills, their ability to educate, influence and negotiate, and a range of transferable and adaptable clinical skills. Nurses reduce the impact of health inequalities and provide evidence-based care and interventions. They work with children and adults and their families, carers and supporters with a range of disabilities and needs.’

‘Learning disability nurses are versatile, adaptable and dynamic. They work with children, adults and older people in generic and specialist health and social care, in education and forensic, etc.’

‘LD nurses bring a unique and rare skill set that supports, enables and empowers people with learning disabilities to have better health.’

The fact that they support and care for some of society’s most vulnerable individuals came across strongly; it was seen as a ‘specialist’ role with specialist knowledge that should be available to everyone who needs this specialist help:

‘In history our society will be judged by how well we care for our most vulnerable citizens.’

‘In a modern civilised society, we need LD nurses to be the reasonable adjustment that mitigates against poor health outcomes and premature deaths.’

The specific role and functions were seen as: acute liaison; health promotion and health facilitation; and promoting positive health outcomes through the implementation of reasonable adjustments. Participants talked about 'saving the lives' of people with a learning disability. Through their knowledge and understanding of complexity and diagnostic overshadowing, they prevent early and unnecessary mortality and enable more positive health outcomes for people.

LD nurses have an impact across a board range of sectors:

'Primary care, secondary care, tertiary care, end-of-life care, prisons, probation, inpatient mental health, community learning disability, social care, assessment and treatment, respite care, child health, schools, CAMHS, older persons, safeguarding, advocacy, clinical leadership and governance, research, higher education. This list is never ending!'

As advocates and educators, they have influence across services and with other professionals, for example:

'It's a specialist role that is able to show other disciplines how to adjust their service in order to give the people [with a learning disability] that they are looking after the care as [they would for] those without a disability and promote person-centred care.'

The role of the LD nurse across services was emphasised through the largest theme that emerged relating to their liaison role in facilitating adjustments for people with a learning disability. The most commonly mentioned role was the acute liaison role:

'Support for acute admissions and outpatients, providing easy read information, complex planning, direct support to the person [with a learning disability], liaising with advice and recommendations to family, carers and hospital staff.'

'[We work] directly and indirectly through supporting/empowering other professionals and support workers in the system to make reasonable adjustments to ensure people with a learning disability have the best possible experience and achieve optimal outcomes.'

The second-most commonly mentioned role was community liaison:

'[Working] in the community, helping with appointments, understanding medication and health needs, visiting and supporting them in hospital.'

It seemed evident that the profile of the liaison role has significantly increased with the publication of reports such as LeDeR and the CIPOLD enquiry (see Further reading, page 50). Additionally, the role has become highly valued by acute service providers.

Interlinked to the liaison role was a theme around enhancing collaborative working. Collaborative working across sectors, for example, between primary care liaison and acute liaison nurses, could enhance effective referrals between the sectors by identifying and clearly articulating any additional needs and reasonable adjustments that a person may require.

However, there was a strong recognition of the disparity of learning disability service provision across the country, and questions were raised about how provision might be standardised.

Advocacy was another aspect of the LD nurse role that came across very strongly, both in relation to navigating healthcare and maintaining quality of life:

'[Learning disability nurses] advocate knowledge in law and entitlement. In healthcare, learning disability nurses are needed to holistically care for people with a learning disability, [who] generally are unable to enter into the symptom description medical model basis of care.'

The role of advocacy was seen as especially important for people who have profound and multiple learning disabilities. This can involve breaking complex information down into appropriate accessible formats and is essential in ensuring equitable access to healthcare, enabling and promoting inclusion and upholding an individual's rights.

In some roles, advocacy involves working with the person with a learning disability outside health or social care settings:

'In my role as a learning disability nurse I work with them [person with a learning disability] alongside social services, health visitors, schools etc to make sure parents have the right support and the right information. We support those with children on a child protection plan ... This includes supporting parents home from the hospital after the birth, when the baby has gone with foster carers, we then increase our support through this difficult time.'

Throughout the data there were many examples from practice demonstrating the impact of the role at the interface of care delivery, for example, the implementation of hospital passports and planning of reasonable adjustments, the use of outcome measures such as the Health Equalities Framework, health screening initiatives that have improved outcomes, psycho education and robust pre-admission to discharge care planning. There was emerging evidence of economic value being demonstrated with reference to the work of the Royal College of Nursing on economic assessment (see Further reading, page 50).

In terms of increasing impact, there was some discussion about the role of 'learning disability' champions as a 'solution' to the lack of learning disability nurses. People who could complement the LD nurse and offer support to others including professionals and those using services and their families (similar to dementia champions). This could also be a way to increase the profile of the profession. While not mentioned directly, it would seem there could be scope for exploring the role of the nursing associate in LD services.

Question 2

Why is learning disability nursing an essential role to sustain in primary, secondary and tertiary care above and beyond other people and professionals who deliver services?

In relation to why the role of the LD nurse must be sustained, the responses were clear: LD nursing saves lives and enables the optimisation of a person's quality of life:

'Without a professional group with a specific and enhanced knowledge of their needs, the mental and physical health [of people with a learning disability] will worsen and there will be even more deaths of learning disability patients as a result of poor or inappropriate care.'

Many participants articulated the LD nurse's unique contribution above and beyond other health and allied health professionals in terms of holistic, person-centred approaches with the knowledge and skills to support

and understand the most complex of individual needs. However, others found this harder. Indeed, as with other branches of the nursing profession, it can be difficult to express this unique contribution and as a result at times participants went down the route of defending the LD nurse role, perhaps in the same way that they defend the people they care for who are also often overlooked by society. This sense of feeling undervalued and defining the role became a common thread throughout all our engagement activities.

In trying to explain their unique contribution they talked about holistic, person-centred care. There was a proposition that they ‘shape’ and ‘reshape’ care to take account of a person's learning disability. They do not fit the person into standardised services but rather they:

‘Fit support to the unique characteristics of an individual.’

‘View people as a number of interconnected areas which may or may not need support and can focus support in the right areas, while not deskilling people in others.’

‘Have a unique role and use their knowledge to both advocate for and influence the care given to meet each person’s individual needs. Having a learning disability is unique to each individual – it’s not a ‘condition’ like heart failure or diabetes which responds and reacts in the same way each time. It’s a unique individual who needs help to understand the new health condition they may have and be given information to understand that new condition.’

Organising, advocating for and enabling reasonable adjustments was seen as a fundamental part of person-centred care. LD nurses are:

‘Often the person-centred reasonable adjustment that enables others to provide effective treatment and interventions.’

They see their role as not just about supporting the person; they also support other professionals:

‘We all work very closely with the people who use our service, which in turn gives us a good insight into the care they require so if they need to go into hospital for example we will help with the care plans including supporting with eating and drinking, mobility, sleeping, how they take medication etc. So even when they use other services, the care received is as much the same as possible and reasonable adjustments can be made available.’

This notion of bespoke person-centred care also promoted discussion and comments in relation to LD nursing being a specialist role:

‘It’s a specialist role that is able to show other disciplines how to adjust their service in order to give the people they are looking after the same care as those without a disability and promote person-centred care’

One participant seemed to sum up the view of many:

‘LD nurses have three years of specialist training in learning disabilities. They have a holistic approach that considers the whole of the person rather than focusing solely on their physical/mental health or social needs.’

Participants question why they are not seen on a par with other fields of nursing and some wondered if their title should incorporate ‘specialist’.

There was a belief that part of the specialist skill set of the learning disability nurse is to bridge the relationship between the person with a learning disability and other healthcare professionals and services:

‘Without LD nurses, the knowledge and understanding of complexity, diagnostic overshadowing and reasonable adjustment diminishes, leading to poorer health outcomes for people and families.’

One important aspect of the LD nurse’s specialist skills was communication. This enables learning disability nurses to interpret diagnoses/procedures and communicate this information to people with learning and communication difficulties, LD nurses are able to:

‘Cut through the jargon.’

And ensure that:

‘Communication is focused on, and information is given to, individuals in a way they understand so where possible people can be empowered to make their own decisions about their healthcare.’

‘Other professionals can acquire these skills but often they do not have the day-to-day experience of being with people with learning disability.’

Their skills go beyond the spoken words, they are able to interpret vocalisations, body language and facial expressions which is essential for people who cannot communicate for themselves.

Legal expertise is also something that sets LD nurses apart from most other healthcare professionals. They are trained to understand the both the Mental Capacity Act and the Equality Act, a skill set that other healthcare professionals generally do not have. When people do not have capacity, LD nurses:

‘Ensure the person’s voice is still heard through best interests.’

‘It is clear from research that many vulnerable adults, who often lack capacity and rely on others to make best interest decisions, are reliant on LD nurses to overcome the hurdles to effective care.’

Sustaining the role of LD nurses within primary, secondary and tertiary care was seen as essential because of the way in which they understand and are able to promote and support the implementation of reasonable adjustments for people with a learning disability and help them make meaningful choices about their care. All this is essential to ensuring individuals have equitable access to healthcare, alleviate the risk of diagnostic overshadowing and over-prescribing of medication, and minimise early and preventable mortality. The ways in which this was achieved often involved creative approaches, with many references to the fact that:

‘[We] have the ability to think outside the box.’

There was a sense that the education and support offered helps the person with a learning disability to feel empowered to seek out their own support in relation to their health and wellbeing. Some other examples from participants add further evidence as to why LD nursing is so important to sustain:

‘People with a learning disability make up 2% of the total population so it is not feasible for all health care professionals to be experts in learning disability.’

‘General trained staff feel they are not “equipped” with the skills and knowledge to support this [the support an individual might need to enable them to attend a routine appointment].’

There were a number of comments reflecting the notion that:

'If we can get it right for people with a learning disability, then we can get it right for everyone.'

Question 3

To what extent is the role of learning disability nursing understood in primary, secondary and tertiary care and how can this be strengthened?

'I'm not sure learning disability nursing is understood or even appreciated.'

The view of many participants was that there was a general lack of understanding and awareness of the LD nurse role across all care sectors, among non-LD nurses and among the public. LD nurses in the tertiary sector in particular felt unappreciated. The lack of appreciation/esteem also extended more generally to the needs of people with a learning disability.

There seemed to be general agreement that there was a need to share positive stories and the experiences of people with a learning disability and their families. These could help create a more positive narrative by celebrating the unique contribution that LD nurses make, day in day out. It was interesting to note that despite the fact that the work of LD nurses has at its foundation a celebration of positive relationships and people with a learning disability, it does not necessarily extend to celebrating itself. This raises a question about the visibility of their role in society: is the profession of LD nursing suffering as the phrase 'disabled by association' suggests?

The idea that LD nurses suffer from discrimination was felt by many. Some participants suggested there remained a prevailing view that LD nursing is not real or proper nursing among the public and among other professionals:

'I'm regularly told I'm not a proper nurse, not a real nurse, not a "nurse nurse" by patients (without a learning disability) and professionals.'

Other explanations included the suggestion that feelings about LD nursing go beyond ignorance. One respondent commented:

'There is still a lot of fear from the general nursing population.'

Another respondent recalled having been told:

'You must be brave – they must be dangerous and unpredictable.'

These and others comments could be seen as evidence that attitudes to learning disability nurses mirror those of society in general towards people with a learning disability.

Exploring the issue of visibility, there was also a view that the nature of the LD nursing role itself could have unintended negative consequences in that, to an extent, it is designed to be invisible:

'It's hard to quantify what we do as it's so varied and difficult to measure. Our role is to be in the background and provide support, reassurance and direction.'

One LD nurse described a situation where she supported a person to get a voluntary job. She had supported the person to fill in the application form, taken the person along for the interview and so on. The LD nurse's role was crucial but the job success belonged to the person with a learning disability; the role of the nurse was almost hidden.

As another participant reflected:

'Learning disability nurses have been too successful in blending into the background.'

This resonates with responses elsewhere:

'Significantly we focus on enabling and development, not "cures".'

There was also the suggestion of mandatory learning disability awareness training for all and the need for better education opportunities about LD nursing within health and social care and across related educational provisions. This could be extended to see learning disability awareness reaching mainstream schools.

The responses included the idea that the profession should promote and raise the profile of what it does through media campaigns, documentaries, TV, film and drama.

There was a strong theme of the vital importance of both national and local leadership in sustaining the LD nursing profession. There was a call for enhanced national recognition of the role through different mediums; one participant drew a parallel to the profile of Admiral Nurses, who are specialist dementia nurses.

Question 4

What support do learning disability nurses working at the frontline of services in primary, secondary and tertiary care need to strengthen their role?

The role of leadership at both a national government level and at a local level to promote and support LD nursing was seen as key. Some participants for example, referred to initiatives supported by the Welsh government and the Chief Nursing Officer for Wales. It was also noted that in terms of recruitment and retention, Wales seemed to be benefiting from having retained the training bursary.

Locally, the role of leadership in understanding and promoting the voice of LD nursing was seen as crucial to influencing commissioners and other professional groups:

'Having support from our leaders inspires people to continue to change and effect change.'

Greater support would allow for 'equality', 'recognition' and 'respect' from other health professionals. This should be nurtured particularly as LD nursing skills are so transferable to many settings and roles.

There was acknowledgement from employers that LD nurses have invaluable transferable skills that enable the nurse to work across a variety of settings. The idea of national benchmarking of the role was proposed as a means of creating more equitable service provision nationally and providing a mechanism to demonstrate the unique contribution of LD nurses.

Support (including funding) for training and education, including CPD, was highlighted as being important in terms of strengthening the LD nurse role. It was noted that the role is constantly evolving, so education opportunities are essential to ensure nurses are equipped for contemporary and future practice.

Finally, there was some debate about whether the title learning disability nurse should be changed to intellectual disability nurse, which is an internationally recognised title and is considered more in keeping with contemporary LD nursing. Would retitling make it easier for nurses to articulate their role and provide better understanding from a public viewpoint? This could be an interesting perspective to explore further.

Question 5

Is the current educational provision for learning disability nursing fit for purpose, what needs to change to enhance this and how would you articulate the importance of sustaining programmes to universities, etc?

There was undoubtedly overwhelming concern about the declining provision of graduate preregistration programmes and a strong message that the closure of programmes needs to cease.

'Education as pre-reg has been diminished, resulting in almost total wipe-out of post-reg education.'

There was a recognition that the removal of the training bursary has had an impact in the recruitment of new LD nursing students in England, especially as it often attracts mature students:

'Not having a bursary severely impacts recruitment to all nursing programmes but particularly learning disability, which tends to attract more mature students.'

'Courses are being closed due to a lack of applicants. While the bursary was in place there were more students coming through and cutting this is leading to recruitment difficulties.'

Another issue discussed was that the lack of varied and good-quality placements means sustaining courses is more difficult:

'It doesn't seem to give a wide enough experience base. However, this is partly due to limited placement opportunity.'

'The scope of practical placements can be limited for some students, which does not give them enough challenge and opportunity to develop.'

'Some placements can be of quite poor quality – no nursing mentor/clinical skills /nursing skills required. Only relevance is working with people with a learning disability. Having a greater look at what placements are being offered, as well as widening placement opportunities (through offering different branch placements).'

'In the future placements will need to be more imaginative to reflect the numerous places where LD nurses end up working.'

There were also some suggestions about widening placement opportunities – for example, extending out into acute settings such as emergency care.

There was concern that the closure of courses would result in a loss of teaching expertise, making it even harder to sustain this branch or field of nursing. There was a sense that political intervention/action was needed to stop universities closing their programmes.

In terms of current educational provision, there was a strong sense that it was fit for purpose:

'I don't think LD nurse education needs to change ... It is the education of other groups that may need to change.'

The view that everyone who works in health and social care should have learning disability education/training was strongly supported, with some again suggesting it should be mandatory. The importance of such training has been reinforced through the findings of the CIPOLD reports and LeDeR review, for example. One participant shared a conversation they had had with a student nurse who noted that in universities where LD nursing programmes were not delivered, there was little understanding of learning disabilities:

'There are 260 nurses qualifying soon who have no education around learning disability in their programme.'

This was significant because of what was described as a fundamental difference between general nurse education and learning disability nurse education. Participants shared:

'In my experience ... general nurses' [education] can be more algorithm and process driven, whereas LD nurses are used to working outside the box to ensure people with learning disability get the bespoke care plans they need.'

'Learning disability nurses are taught through social and holistic theories, focusing on all aspects of a person's life, shaping the care to suit this.'

While examples supporting what the phrase 'thinking outside the box' means were limited, there was a general feeling that the different approach to teaching and learning for LD nurses was what sets them apart from other nurses. In turn, those who have limited understanding of learning disabilities and LD nursing are less able to support a person with a learning disability who requires healthcare services and support:

'LD nurses are still in my view at the forefront of person-centred care delivery, rather than the service-led solutions that too often prevail.'

'LD needs to be in all university courses, especially information regarding autism and sensory needs.'

'We need both specialists and generalists here. The knowledge, skills and confidence to care for the most vulnerable in society needs to be within the skill set of every member of the healthcare team.'

As well as suggesting that all nurses needed greater knowledge of learning disabilities and LD nursing, they also acknowledged that for LD nurses, clinical skills training within LD education could be strengthened:

'We say we are nurses first and foremost but actually without doing extra study in our own time we are not clinically equivalent to our nursing peers upon qualifying.'

'There needs to be more emphasis on clinical skill building and sustaining clinical skills, as it is sometimes felt by learning disability nursing students that they are not regarded as capable clinically in some settings, therefore restricting areas in which learning disability nurses can explore and provide assistance to people with learning disabilities. For example, children's settings will not accept RNLDs as they do not have the required clinical skills.'

'We need to include more general nursing and general health skills in our learning disability training.'

When talking about clinical skills, there was some interesting debate about academic learning and practical experience. Whilst there was no suggestion of LD nursing not being graduate, there was a sense that there needs to be a balance of the need to demonstrate the value of both academic and practice learning:

'Yes, I think [sometimes] it is stressing academic skills too much over clinical knowledge and communication skills.'

'[I'm] concerned good potential candidates are excluded as the profession seeks academic recognition, I would seek clinical input to courses and negotiation between service sector and education to contractually enable the correct numbers of post-grads to roles available.'

'Nursing did need to become more academic but we've moved away from those practical nursing skills, especially in health and behavioural assessments.'

There was also mention that the graduate programmes may discourage some potentially good students, a debate that has continues to prevail across nursing.

Although not raised directly, perhaps the introduction of the nursing associate training may offer opportunity for the future.

Another aspect of course content that could be further improved was around legal knowledge:

'[Our course] does not focus enough on the underpinning evidence and law ... we do not focus enough on the Mental Capacity Act, Mental Health Act or Deprivation of Liberty Safeguards in practical scenarios.'

'Understanding of funds such as Continuing Healthcare Funding and Personal Budgets should be part of curriculum as they are a large part of LD nurses' work.'

Other areas where LD nurse education could be strengthened included increased and sustainable funding for LD education, including post-registration education and continuing professional development. Some also suggested dual training across fields of learning disabilities, mental health, adult and child branches. This was seen as creating a platform for sharing experience and gaining insight into the different fields of nursing. Another idea was greater involvement of those using services in shaping future LD nurse education.

There was further debate about the idea of changing the title of registered learning disability nurse to registered nurse in intellectual disability; perhaps also including autism and other neurological disorders. One participant said:

'It's ridiculous considering intellectual disability is used almost the entire world over we are still talking learning disability.'

Such a change, it was suggested, could help others understand the profession and might enhance credibility, again, raising some discussion about the extent to which LD nursing is valued. Some suggested that LD nurses themselves need to take responsibility for promoting the profession, asking:

'How do we #liveloudly about the positive contribution we make?'

There were ideas regarding how to promote LD nursing as a career – for example, linking with schools, sixth forms, colleges and universities. Investment in marketing campaigns was also suggested to target more mature students. Along with promoting LD nursing, there were some practical suggestions for overcoming course shrinkage, for example:

'Perhaps introduce a hub and spoke model linking centres that don't provide learning disability education to those that do.'

'Look to support mature entrants and perhaps consider a regional rotation programme to sustain a pathway/specialist approach to training.'

Question 6

Finally, what would your 'elevator pitch' to government and policymakers be about the importance of learning disability nursing?

Participants found creating elevator pitches quite difficult, but two in particular stood out strongly:

'Learning disability nurses are highly skilled, highly motivated, cost-effective and highly valued person-centred nurses. Wherever they work they have a proven track record for improving outcomes, reducing the impact of health inequalities and improving people's lives. They have unique, enhanced communication and interpersonal skills, are important educators and can be part of the essential reasonable adjustments needed to reduce morbidity and unnecessary premature deaths of people who have learning disabilities.'

'Our role ensures that people with learning disabilities are recognised and are just as important as anyone else. A learning disability nurse ensures that the individual gets the support required so that they can live their lives to the full and achieve things that they would possibly not have achieved. It is about empowering the person and their family; it is about being an advocate for them so that a difference can be made. I feel that a learning disability nurse is essential to ensuring that a person with learning disabilities is at the heart of all care received, that they have a voice and are fully supported in every aspect of their care.'

The remaining elevator pitches were reviewed and categorised under five themes:

1. Learning disability nurses save lives - it's about fairness and equality for all

'This is a growing population who are living longer and enjoying life, it's so important that access to health does not continue to be the reason this enjoyed life ends at a much earlier rate than the gen pop – learning disability nurses play a role in being this change.'

'Learning/intellectual disability nurses exist to support the health of a group of people who face constant health inequality, we do this through direct nursing intervention and by supporting other services to provide that intervention.'

'Without LD nurses the knowledge and understanding of complexity, diagnostic overshadowing and reasonable adjustment diminishes, leading to poorer health outcomes for people and families.'

'Just look at the LeDeR document – this just screams at the government to make change!! These deaths cannot and shall not go unnoticed! LD nurses use their specialist expertise to prevent these premature and avoidable deaths – it would be a bad idea to not create more!'

'With the continued push for integration for people with a learning disability into society and with the continued health inequalities we have seen and continue to see, the need for RNLDs to be with both health and social care is so important. There are many papers and campaigns showing this.'

'People with a learning disability are part of the electorate too. LD nursing roles are truly holistic, and promoting political engagement among the learning disability population is extremely important. We have the means and abilities to promote and support social inclusion.'

'In history our society will be judged by how well we care for our most vulnerable citizens. In a modern civilized society, we need LD nurses to be the reasonable adjustment that mitigates against poor health outcomes and premature deaths.'

'Identify the significant inequalities that our clients face daily and support us in changing this. Our clients are living longer yet you only have to look at CIPOLD to see how common deaths are. We do an amazing job, imagine how amazing we'd be with your support.'

'Everyone in our society is of equal value and has a contribution to make. Learning disability nurses support some of the most vulnerable of those people to live longer, healthier lives and guide and support both them and their families and carers to achieve their potential and make positive contributions.'

'People with learning disabilities are dying earlier than needed due to health needs not being identified/treated well. The role of a learning disability nurse is to stop this from happening whenever possible to ensure that people with a learning disability are treated with respect and dignity and that care is person-centred and not focused on the fact that someone has a disability.'

'People with a learning disability die too young, often avoidably, and die too often in hospitals and nursing homes where they are poorly supported, miserable and cost a fortune in care. Learning disability nurses are the people who can help change this, we need them!!!'

'It's about equality and fairness to a particularly disadvantaged group.'

'How can it be ethical to avoid meeting the needs of some of the most vulnerable people in society?'

'Saves lives and improves quality of life.'

2. Learning disability nurses are skilled professionals with a broad range of skills, qualities and abilities which ensure better outcomes for people with a learning disability

'RNLDs are the vital link in delivering specialist healthcare to people with a learning disability and supporting the wider NHS to deliver and develop health services to people with a learning disability (and bring so many additional skills and benefits that add value as well).'

'Specialist skill set available for all healthcare settings to tackle a very particular set of healthcare issues. No specialist skills, limited response to tackle the issues.'

'We are the only registered professionals that train for three years in this field. Our skills can be transferred across numerous health and social care settings to improve the care/treatment people receive. People with most complex needs will always require specialist support.'

'LD specialist nurses have a multitude of skills in supporting the most vulnerable people in society.'

'If people with a learning disability are to achieve equitable and best healthcare then nurses who have such vast skills in this field need to be engaged throughout the healthcare journey; we are needed and other services don't have the skill set to do what we do!'

3. Learning disability nurses advocate for people with a learning disability while striving to get their voice heard

'LD nurses are valuable resources that can be used across many areas – most valuable to Individuals with a learning disability and their support networks, to advocate, teach, explain and break down barriers.'

'As a parent of a severely learning disabled adult, joined-up thinking is essential! All available services should be linked, from first contact to discharge. ALWAYS listen to the parent/carer – they know the person inside and out, when we trust it helps on so many levels.'

'Learning disability nurses have a vital role, not only do we support our patients, we also educate people to support people with learning disabilities too! Empowering individuals to advocate for others as well as themselves.'

'People say that learning disability nurses give people a voice – I do not totally agree with that. People with learning disabilities have a voice, it's up to us to help those voices be recognised, understood and, most importantly, listened to.'

'I would say we're similar to a pair of glasses! Glasses help people to see more clearly. LD nurses ensure our patients are heard! We don't speak for them, we speak with them. If we don't then some really important voices get lost.'

'We communicate with those without a voice and care for everyone as an individual while empowering them to speak up.'

'Listen to them, involve them in decision making.'

'People with learning disabilities are people first. We are their voice and we must be heard.'

4. Investing in learning disability nurses will save money in the long run

'Cost-effective person-centred care for some of the most vulnerable.'

'The work these nurses do saves an enormous amount of money to the taxpayer with all the work they do, and reduce the need for other services. Good value for money.'

'Without these nurses there will be a financial impact due to the lack of support for people and families.'

'Ignorance is expensive.'

“ The work these nurses do saves an enormous amount of money to the taxpayer with all the work they do, reducing the need for other services. Good value for money ”

5. Promoting the profession and education

'Needs to be promoted loudly in recruitment campaigns and those such as #NHS70.'

'It is an attractive career, the hard part is getting others to see that.'

'Catch them young. Go to schools.'

'If we didn't have learning disability nurses, who would support people with a learning disability?'

'Do universities have links with schools/sixth forms? Also, great idea: do a #WeLDNs road trip round the UK and showcase who we are and what we do and speak to 18-year-olds making their choice.'

'Also, a drive to encourage more support workers into LD nursing.'

'Help us to improve the care and health of people with a learning disability and their families by supporting the education and employment of more learning disability nurses.'

'Instead of finding a solution, why so quick to cut places or courses? This had been talked about before 2018. Why haven't solutions been put in place previously?'

'Evidence such as the mortality review, recent high-profile deaths and Winterbourne View demonstrates that change is not happening quick enough. RNLDs and disability education need to be embedded within healthcare education to at least attempt to minimise inequalities.'

'Dual training across fields of learning disability, mental health, adult and child. Education needs to involve clinicians at the basic level upwards. It is for the patient's best interests, not who is the best clinician. Universities have great nursing students coming through who are keen to learn and share up-to-date knowledge.'

'Education as pre-reg has been diminished, resulting in almost total wipeout of post-reg. Other nurses would not be happy with this, so we need to demand more – CPD helps to improve on all levels.' ■

STAKEHOLDER EVENTS

Seven regional face-to-face stakeholder events were held during October and November 2018. These events aimed to build on the evidence that emerged from the tweet chats. They were hosted by healthcare organisations in England and one in Northern Ireland to enable further expert review, to scrutinise and add to the developing data/evidence. All participants received an invitation and briefing in advance from FoNS and the host. The events were all co-facilitated by the programme facilitator Giselle Cope, the host and Dr Pen Mendonca, an independent graphic illustrator and artist who captured in real time the emerging themes/key issues at each event. The resulting visual representations of the experiences shared could be viewed by participants at the end of the event to ensure people felt that what they had shared and heard was represented. Additionally, some of the events were recorded and/or notes collated on flipcharts (with permission). All this enable the development of summaries to complement the graphic artwork.

A total of 154 participants attended across all seven events. Participants included practising learning disability nurses, learning disability student nurses, other medical and allied health professional colleagues, educators, researchers, people using services, families/carers and experts by experience. However, because of the profile of participants in the tweet chats a special effort was made to increase the inclusion of nurses working in tertiary care services and people with a learning disability and family members.

Events in which participants were primarily family/carer, self-advocates and experts by experience focused around the following:

- Why is a learning disability nurse is important to you?
- How has or how could a learning disability nurse improve your life?
- Any other support that you would like to have from a learning disability nurse?

Events in which participants were primarily nurses, other professional and students focused on the following:

- Why is a learning disability nurse important?
- What attracted you to learning disability nursing?
- World Café approach to exploring the emerging themes regarding
 - i. learning disability education/courses/placements
 - ii. impact and skills and attributes of a learning disability nurse

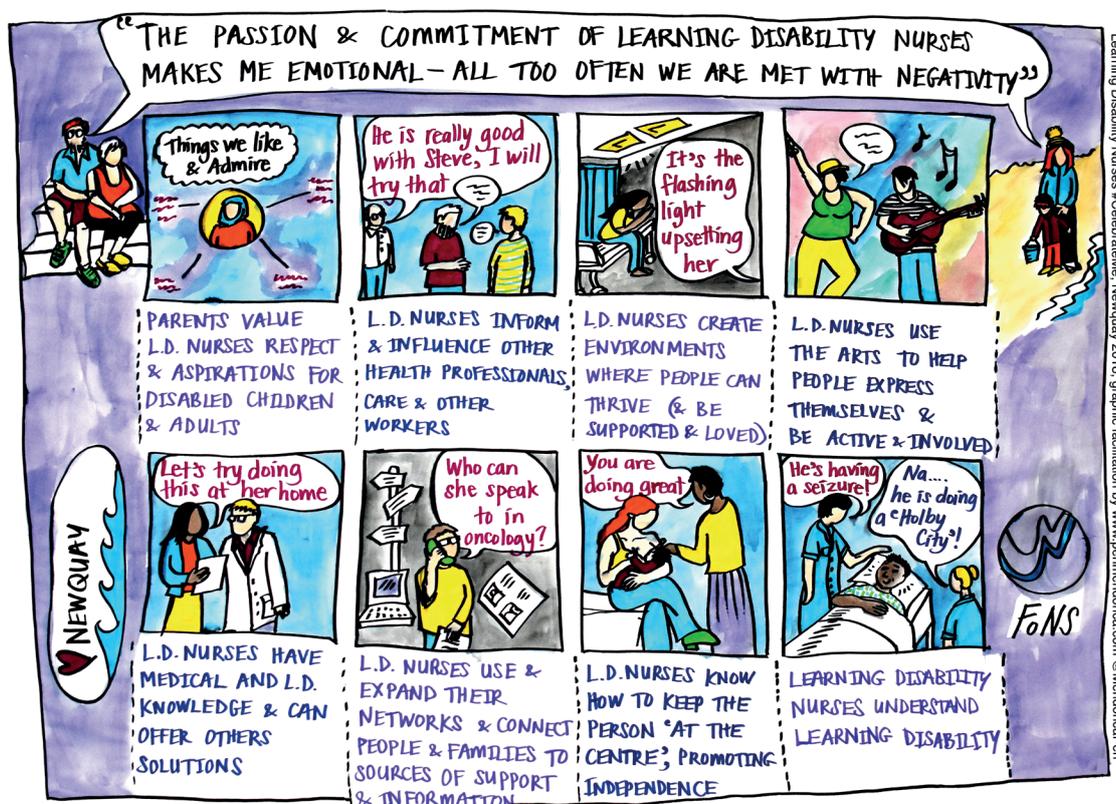
Finally, building on the creation of elevator pitches captured via the tweet chats, the idea of creating an opportunity to communicate directly with the Chief Nursing Officer at NHS England was explored. As a result, a postcard was created addressed to the CNO's office, with the following opening statement provided:

Dear Chief Nurse

A learning disability nurse is important to me because...

Participants at each of the stakeholder events were invited to write a postcard, with a total of 128 volunteering over the seven events.

Stakeholder event 1, 19 October 2018: Families and young people



The Newquay event hosted in partnership with the Cornwall Accessible Activities Programme (CAAP) in Mawgen Porth, Newquay, aimed to capture the experiences and perspectives of family carers and young people in relation to learning disability nursing. Participants included nine family members and three young people. Significantly, most of the families and young people in attendance had had limited or no contact with a learning disability nurse. As a result, the early part of the event focused on their desire to understand and appreciate the remit of an LD nurse, and asked three meaningful questions:

- What do they do?
- How can I find them?
- What can they do for me and my child?

The families felt addressing these core questions should inform the foundations of the provision of learning disability services and strategies within Cornwall.

Some participants had been to the Positive Choices/Commitment conference (Box 1, page 30) hosted by Trinity College Dublin (19-20 April, 2018) and/or previous conferences where they had been exposed to large groups of LD nursing students and registered LD nurses. These participants spoke with emotion about the levels of passion and commitment the students and nurses had for LD nursing. Parents in particular felt the LD nurses and students they met, without exception, greeted their children with respect, showing interest in who their children were, what they did in their lives and what their aspirations were.

Box 1: Positive Choices

Positive Choices is an inspiring and ever-expanding learning disability network that brings together student nurses, academics, other professionals, families and people with a learning disability and/or autism, from all five nations to celebrate all that is learning disability nursing each year at its two-day conferences.

Through connections such as Positive Choices, families could appreciate and understand the value of the LD nursing role across the lifespan of a person with a learning disability.

Through the conversation and discussion, it was notable that the lived experiences of the families had created for them a sense of empowerment. They emphasised that the LD nurses be 'brave' and embrace this; to not be frightened of working

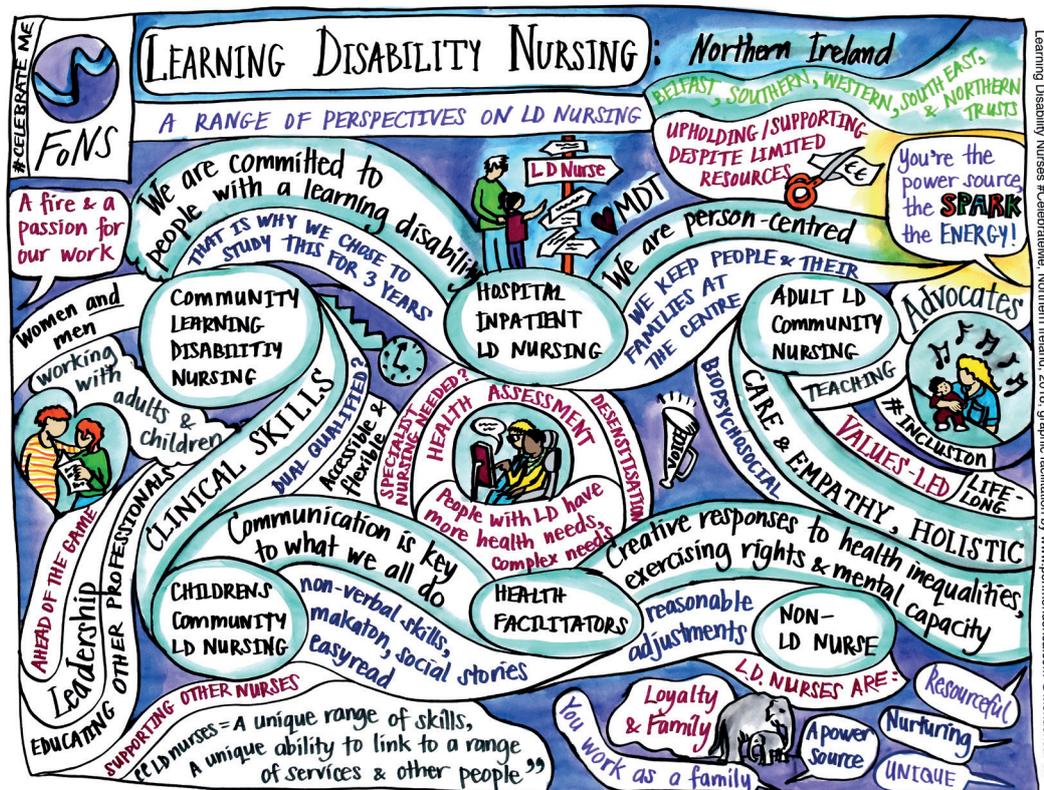
with parents, to see the value of working in partnership. One mother gave a positive example of how a nurse in a hospital listened to her when her son was becoming distressed with pre- and post-operating procedures. The nurse asked 'What can I do to make this better?' Listening to the mother led to an immediate reduction in the child's anxiety levels. This was felt by others as being the skill of using 'creative non-traditional solutions to thinking outside of the box' as the intervention did not follow convention but rather focused on the needs of the boy; in essence, providing person-centred care.

The families generously shared positive and negative experiences, at times emotional and at other times carrying some humour. They also generated lots of practical ideas that might support better access and support to services for families and young people, both more nationally and within their own local community, for example:

- Recognition that a learning disability is a lifelong condition
- Contact with an LD nurse from the birth
- Paediatricians should have enough knowledge to make parents aware of local LD services and support
- Baby packs in every neonatal service for babies with Down's Syndrome
- Clearer criteria for referral and access to LD nurses – make LD nurses more visible
- Information such as posters signposting to relevant LD nursing services in all settings where healthcare is provided
- Learning disability awareness training for *all staff*, not just health professionals working in health and social care – this could include training in basic Makaton

Families also emphasised that it was important that their children with a learning disability and/or autism be seen 'to be a priority and not a problem'. By the end of the event, what transpired was an abundance of positivity and optimism about the role of an LD nurse in improving the life of a person with a learning disability.

Event 2, 5 November 2018: Learning disability nurses



Learning Disability Nurses #CelebrateMe Northern Ireland 2018 graphic facilitation by www.pennindorca.com @MandoraPen

This event was held in Northern Ireland with 31 participants (30 LD nurses and one practice development nurse from across the five health boards in Northern Ireland) who were taking part in the FoNS Creating Caring Cultures programme. The participants individually worked across a wide range of settings, in both inpatients and community services (with people of all ages). As this was a more opportunistic approach, the graphic facilitator was not with the group. Instead, participants were asked in small groups to create their own poster responding to the three stakeholder event questions. These posters were then shared and explained to the whole group; this process was recorded. The posters and the recording were then shared with the graphic facilitator who created a single graphic representing the images and spoken words.

Despite the varied roles and settings there were many cross-cutting perspectives and themes. There was a strong commitment and value placed on working holistically and being person-centred for both the person with a learning disability and their family. There were several references to the notion of ‘being there for’ and ‘holding’ the person. One analogy depicted a person being held by supportive hands with significant people surrounding them. They said of their role:

‘We keep people and their families at the centre.’

In another example, one group talked about navigating pathways and the analogy of seasons of life. The LD nurse is there at every stage, helping the person move through the seasons, their lifespan.

Another group described the support they give to help people ‘live’ as:

‘Bringing all the pieces of the jigsaw puzzle together.’

The participants described the LD nurse as being there, supporting and co-ordinating all aspects of living, including physical and mental health, whereas other health professionals may only focus on their clinical speciality without necessarily considering the wider health and social care determinants that may affect a person's life. This example links with some of the responses that refer to the unique and potentially autonomous role of the LD nurse:

'A seamless professional who utilises preventive skills, intervention skills, signposting, reasonable adjustments – the list is extensive to provide a better outcome for the person with a learning disability.'

The participants emphasised that LD nursing is values led in its approach. For example, LD nurses are empathetic, respectful and non-judgmental in their approach and always see the potential in people and enable them to optimise that potential in order to live fulfilling lives. The personal attributes of an LD nurse include resilience, patience, determination and persistence; this resonates with the values across all the stakeholder events.

In terms of the skills of an LD nurse, many highlighted specialist clinical skills and in particular creative communication skills. This is where they feel they have a significant impact, as they support the person with a learning disability using a range of methods and techniques, from easy read through to pictures and photographs, the use of social stories and Makaton sign language, art and poetry. They also highlighted their role in advocating on behalf of individuals with highly complex needs and in ensuring equality and rights are being upheld, especially for those who cannot verbally communicate. While they recognised that many, if not all, nurses may say they have a unique range of skills, the LD nurse works and links in with other services in supporting individuals, and in doing so is instrumental in a person's care, ensuring a bio-psychosocial approach. They also described their role as health facilitators for the people with learning disabilities and their families.



'We have clinical skills along with behaviour, sensory awareness, social and communication and mental health, which are utilised to assess and plan/implement care to support the person with a learning disability and their family/carers in bio psyche, social/emotional person-centred care.'

Another aspect of the LD nursing role that came across strongly in this group and other stakeholders is the education of other professionals.

Finally, many spoke strongly about their personal commitment to people with a learning disability. They spoke about specifically choosing the branch of LD nursing as a career option:

'We see the person before the disability.'

Event 3, 20 November 2018: Learning disability student nurses



This event was hosted at Wolverhampton University with 43 LD student nurses (years 1-3) from universities in Wolverhampton, Coventry and Keele. We were also fortunate to have three representatives from Dudley's Voices for Choice, a self-advocacy group, who joined and contributed to the event.

The question about why students chose learning disability nursing evoked numerous reasons around three areas:

- Helping people to fulfil all life expectations and stop the stigma attached to learning disabilities
- Wanting to make a difference in light of statistics and evidence relating to premature deaths and mortality rate
- Wanting to uphold people's rights and ensure equitable access to healthcare provision

The students felt inspired by other LD nurses and felt passionately that they could make real differences in all aspects of the life of a person with a learning disability or autism.

Less positively, the participants talked about challenges they experienced as LD nursing students, which they felt mirrored experiences of qualified LD nurses. They were challenged on their reasons for studying LD nursing, for

The participants articulated the notion of working holistically as taking account of a person’s social, psychological, emotional and physical needs. As well as relationships, spirituality and sexual health needs, they described the LD nurse’s ability to ‘look beyond what may initially be obvious’: the ability to ‘peel layers back’ to really appreciate and understand people's experiences. Working in such a way helps to minimise the risk of diagnostic overshadowing and making assumptions about a person's capabilities to consent, and helps them to make choices about their lives.



An example was shared by one LD nurse of a person being automatically assigned ‘a do not resuscitate’ status when requiring a medical intervention because they had a learning disability. The nurse talked about working with a medical professional to help them see why this would not be appropriate. The example resonated with others.

Communication was a vital skill for LD nurses and an area where they had significant impact. Participants shared many examples of what this meant to them. They highlighted the skills needed to support a person with profound and multiple learning disabilities. A high level of expertise is required to support all but especially those with complex needs. The LD nurses are proficient in an array of communication methods, for example Makaton sign language, Picture Exchange Communication

System (PECS), the ability to formulate bespoke, adapted and creative communication care plans, recognising and understanding verbal and non-verbal language, and behaviours indicative of a means of communicating. They also need an understanding of individual cognitive and processing abilities and the ability to break down any barriers that inhibit a person’s communication. There was a high regard for the importance of building therapeutic relationships in being able to support individual needs effectively. An example given of working with a person in long-term care to make a cup of tea safely over a number of weeks illustrated both the skills and tenacity of LD nurses.

In relation to role of the LD nurse, participants described this as involving a higher level of autonomy. As expert practitioners working across a person’s lifespan, their role was seen as highly specialised, supporting ‘the person’, promoting independence, ensuring human rights, advocacy and navigating across healthcare systems and with a range of other professionals to ensure best practice. While in one sense highly specialised, it is perhaps the autonomous nature of the role of LD nurses that sets them apart from other branches of the profession and makes them, as this group described, unique.

Despite the discussion around being specialist and autonomous, participants reiterated what many others said:

‘We are undervalued, unrecognised and a minority in the nursing field.’

As mentioned before, this seemed to mirror how they felt people with a learning disability were viewed. Through discussion, ways of addressing both issues were suggested, including increasing knowledge and awareness of learning disabilities across the profession, mandatory training and a shift in culture. They acknowledged that change was being embraced and noted how far attitudes and services had progressed, observing that 35 years ago, large institutions prevailed and that this change had been driven by LD nurses.

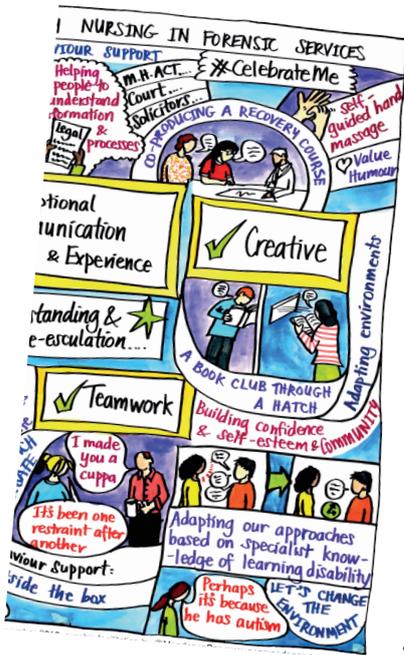


STAKEHOLDER EVENTS



Participants shared how their 'specialist skills' and 'knowledge' of caring for people with a learning disability in a secure environment is critical in maintaining safety but they still retain a recovery and strengths-based approach. They emphasised the importance of their skills and knowledge because they know that if the delivery of care and approaches used are not appropriate, the consequences can be damaging and even catastrophic.

The participants went on to talk about positive risk taking and being creative to build therapeutic relationships.



Participants spoke of the need to have a high level of commitment to work with people who have both a forensic history and learning disability, whose behaviour could be unpredictable and at times violent. Nurses need to have empathy, understanding and acceptance to work therapeutically, rather than adopting a custodial approach.



'It can take a long time to see small steps of progress.'

'We have a lot of dedication towards patients, listening and working with them to give them the best quality of life, skills and safety.'

Teamworking and excellent communication were seen as very important when working in what can be fragile and unpredictable environments. The support of the team is what keeps people going when times are challenging, ensuring incidents are prevented or carefully and effectively de-escalated.





LD nurses strongly associated their role with advocacy and making sure that the person with a learning disability is treated appropriately, and that reasonable adjustments are made, particularly when accessing healthcare. It was alarming to hear of examples where LD nurses had to intervene to question or stop ‘do not resuscitate’ orders that seemed to be based solely on the person’s learning disability.

Despite all this, there was again from this group a feeling that LD nursing is undermined and not seen as real nursing. Many wondered if it was because:

‘People may not know about us; is that why? How is this being reinforced and by whom? Is this why we feel we must keep defending who we are and what we do?’

To counter this they described themselves as resilient and highlighted the positive feedback that they received from the people and families they support, who value their knowledge, skills and commitment.



Event 7, 29th November 2018: Self-advocates, families, experts by experience



Learning Disability Nurses #CelebrateMe, Foundation of Nursing Studies, Manchester People First, November 2018, graphic facilitation by @MendoncaPen www.pennendonca.com

This event was hosted by Manchester People First, a self-advocacy group run by and for adults with a learning disability. The event was co-facilitated with Scott Watkin BEM, senior LD advisor at SeeAbility and also an expert by experience. The event included 22 participants who were a mix of self-advocates from Manchester People First, Future Directions CIC, Brothers of Charity and some family members and carers.

Through the facilitated discussion about the importance of the role, a number of key themes emerged. LD nurses were advocates and enablers; for example, participants talked about their ability to translate and interpret information into easily accessible formats by using simple language or pictorial representation with minimal jargon.

'After my operation I asked the LD nurse to help me get back on my medication. They helped to go through the details of my operation. I did not understand proper. Asked the LD nurse to help to explain in plain English and not jargon.'

Participants highlighted other areas relating to access to health information, understanding their medical history and ensuring people were aware of their legal rights.

Another key theme was improving the lives of people with a learning disability. One participant shared that an LD nurse:

'Got me out of secure services, gave me a good life in the community, gave me choices and listened to me.'



Listening and understanding a person's needs and what matters to them are key attributes, which have a significant impact. Linked to improving lives, participants also spoke about how LD nurses support the health and wellbeing of people with a learning disability through the various health promotion roles and activities they undertake. One participant shared:

'LDNs ... help me with my diabetes and tell me how to stay healthy.'

STAKEHOLDER EVENTS

Other participants shared how LD nurses have supported them in delivering health workshops. People said that LD nurses were crucial in giving support with hospital appointments, putting people at ease and reducing anxieties. Some participants felt LD nurses could support people with a learning disability to access technologies relating to health and wellbeing, with one participant stating 'Google Alexa to remind you to take your medication'.

There was also a key theme that drew attention to the skills of LD nurses in helping individuals with complex needs.

There was agreement that LD nurses 'look at unusual or different behaviour and understand why this is happening and how to cope with it'. This validates the profession's view that LD nurses think 'creatively' and 'outside of the box' as well as nursing in a holistic, person-centred way.



Many participants did highlight the need for more LD nurses. Suggestions included having more within GP surgeries, hospital and community settings. One postcard read:



'My LD community nurse came to my house every morning to help me with my medication. Before that I was in hospital for many months. Learning disability nurses in hospital helped me get out of hospital and get me a community nurse to support me with medication at home. Helped me to get things to help me at home. They are caring and understanding.'

In contrast, there were some participants who were not sure if they had actually met an LD nurse. Some asked 'Well, what do they do?' There were particular questions raised for example, 'Who do LD nurses work for?' and 'How can an LD nurse help me have a better life?' This links back to questions over their identity and uniqueness. An extract from another postcard stated:

'I have never heard about learning disability nurses before so it is important to me to learn about it and what they could do for me in which situations.'

Another participant expressed in a postcard:



'I would like all NHS staff to introduce themselves because I don't know if I have met an LD nurse.'

All this raises questions about the number, visibility and identity of LD nurses – issues that, in part, promoted this initiative.

A final message from one participant related to their own role in training health professionals. They felt it was imperative that people with a learning disability and/or autism be involved in the training of all healthcare professionals, and that this should be co-delivered alongside professionals,

as they are the experts by experience. Some participants had strong views on this, stating:

'We can teach others about learning disabilities: USE US.'

There were some great examples shared, including how they are teaching LD nursing and social work students at local universities. Some gave the example of the SPICE group from Future Directions CIC (futuresdirectionscic.co.uk/spice) who interview, design and carry out assessments/role play/deliver training to student nurses at Salford University. This has been happening for a number of years with very positive feedback from the students and lecturers. ■

Stakeholder postcards to the Chief Nurse (CNO) at NHS England

The opportunity to write postcard to the CNO at NHS England was very well received, with a total of 128 postcards volunteered. The postcards all began with:

Dear Chief Nurse

A learning disability nurse is important to me because...

Participants at each of the stakeholder events were invited to write a postcard. The postcards were reviewed and themed. A total of 22 themes emerged, ranked as follows:

1. Person-centred holistic care (N=32)
2. Range of knowledge and skills (N=31)
3. Ensuring equality of treatment (N=30)
4. Advocate for people with a learning difficulty (N=28)
5. Skilled in communication (N=17)
6. Non-judgmental approach/value all members of society (N=16)
7. Empower and educate people with a learning disability (N=16)
8. Transferable skills (N=13)
9. Provide specialised care (N=13)
10. Profession undervalued (N=12)
11. Personal qualities of learning disability nurses (resilience, patience determination, persistence) (N=11)
12. Can make reasonable adjustments (N=8)
13. Prevent diagnostic overshadowing and understand the causes of behaviour (N=11)
14. Educate others about learning disability, including other professionals (N=7)
15. Ways of working/creativity (N=5)
16. Whole-life care (N=4)
17. Able to help with mental health issues (N=4)
18. Building therapeutic relationships (N=3)
19. Rehabilitation, recovery, quality of life (N=3)
20. Raise awareness of learning disability (N=3)
21. Need to expand the profession and learning disability training (N=3)
22. Long-term care needs in the community (N=2)

Examples of postcards

Dear Chief Nurse

A learning disability nurse is important to me because

Their specialist skills are vital to reducing the stress and improving the experience felt by my son who has severe learning difficulties. They make access to the health service more accessible for people with learning disabilities. There are not enough of them and the service should be expanded.

A PARENT



Chief Nursing Officer

NHS ENGLAND

Dear Chief Nurse

A learning disability nurse is important to me because

I have had experience on the side of a family member who has received care from a learning disability nurse whilst in hospital. When the staff nurse was not listening to the family the learning disability nurse stepped in and ensured my relative's needs were met. As a student nurse, I have seen the importance of a learning disability nurse being an advocate for a vulnerable person in getting the consultant to agree to carry out an operation which he was originally not agreeable to. The operation would not have been queried in a person without learning disabilities. The outcome of the operation is that the vulnerable person now has a good quality of life.

A STUDENT

POSTCARD



FOR ADDRESS ONLY

Chief Nursing Officer

NHS ENGLAND

Dear Chief Nurse

A learning disability nurse is important to me because

My brother, who has Down's Syndrome and autism would not be alive today but for the skills and timely intervention of a learning disability nurse ten years ago. My brother and others like him who have profound social anxieties can withdraw into themselves so much so that they cannot tolerate people touching them or invading their personal space. In this state of mind, it is easy for support staff to ignore them and they become more and more physically and emotionally neglected. When a learning disability nurse was brought into review our complaints she could see immediately, without our having to explain, what was wrong ... because she not only had the training, she also had the empathy that I believe is the reason most learning disability nurses take up the profession. My family and I will be forever grateful to her.

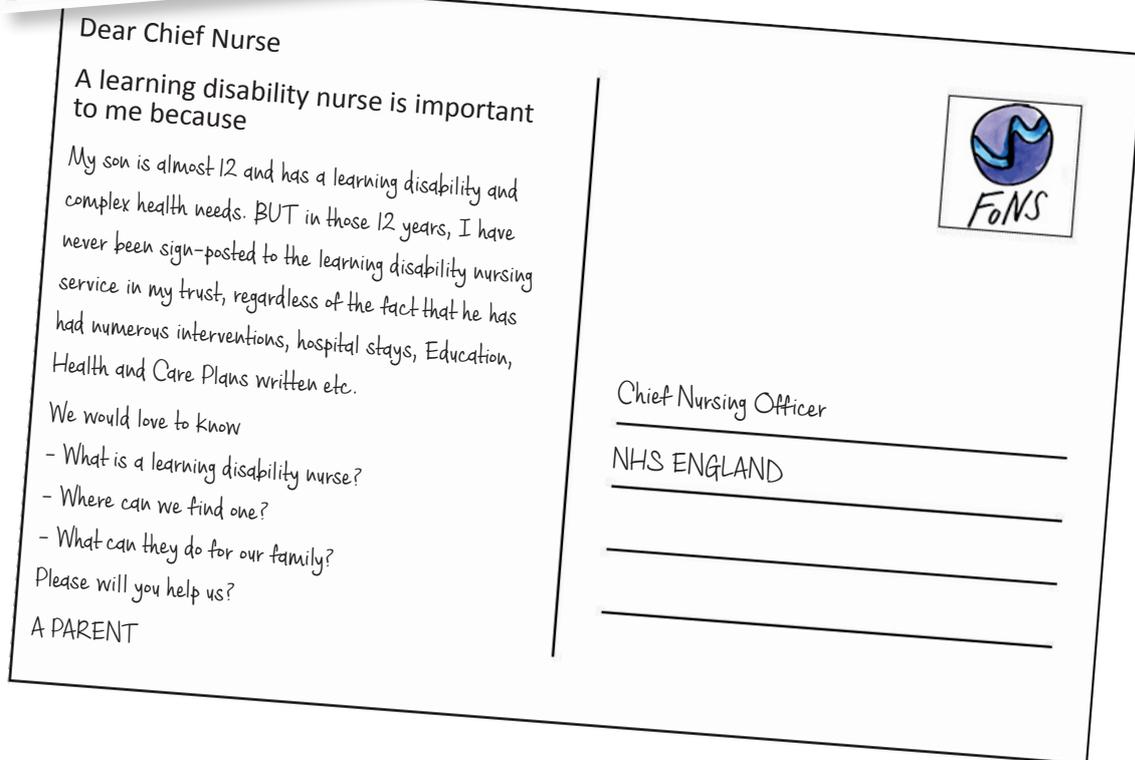
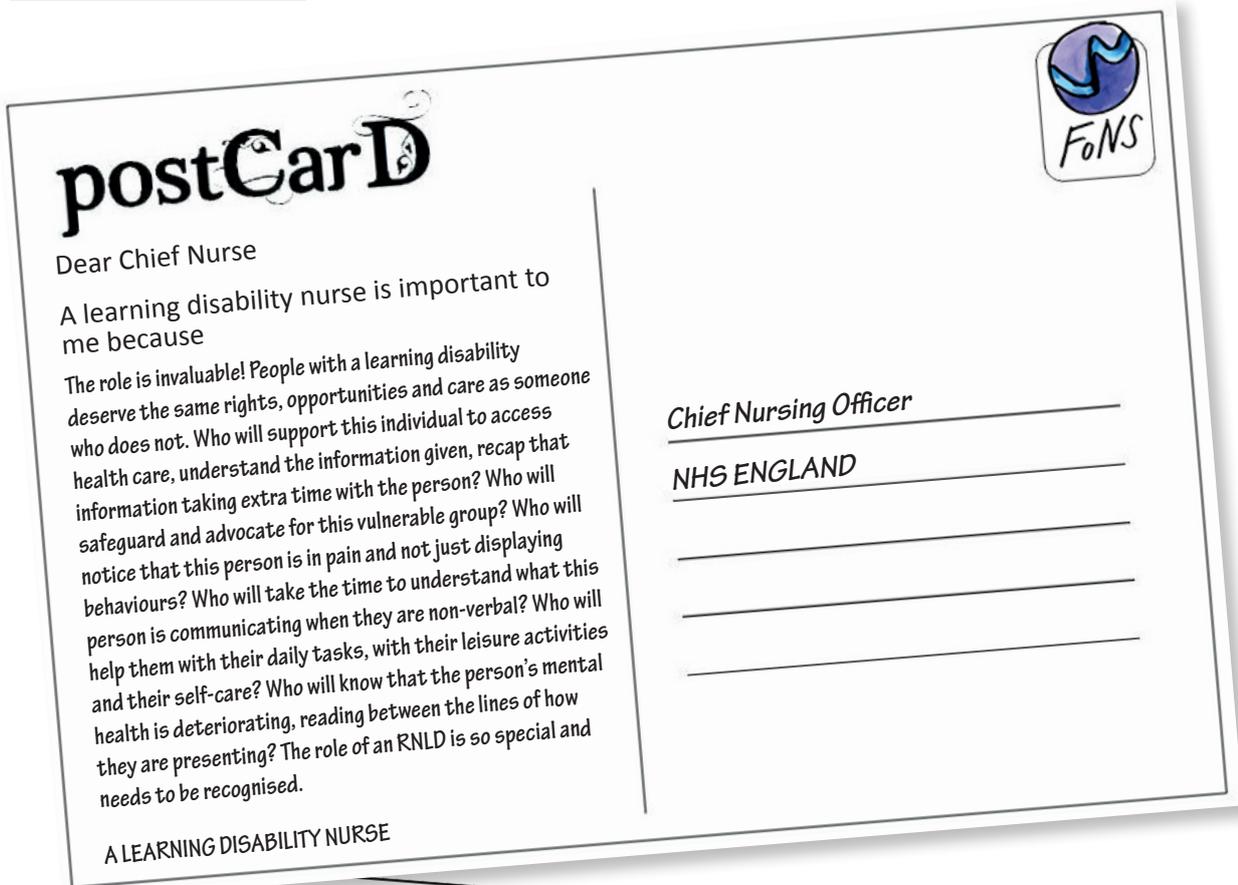
A FAMILY MEMBER



Chief Nursing Officer

NHS ENGLAND

Examples of postcards



OTHER ENGAGEMENT EVENTS

As mentioned earlier, the past year in particular has seen an increase in activity related to learning disability nursing, including initiatives looking at workforce, education and perceptions of the role.

This has resulted in a number of events and meetings that the programme facilitator has been invited to join to share details of Celebrate Me and use as opportunities to gather further evidence related to the programme aims.

Appendix 3 outlines the events attended and the potential reach in terms of participation. ■

My final reflections and thoughts as a registered learning disability nurse and project lead for the Celebrate Me initiative

What has struck me since the start of this work, although not a surprise, has been the sheer passion, drive and resilience of those working within the profession to support the lives of people with a learning disability and their families. It is exhilarating and uplifting and keeps my passion burning!

Through this work, we have brought to the surface the commitment there is within the learning disability community to champion the unique and valued contribution of this branch of nursing at all levels. I genuinely hold onto this each day and smile; I can honestly say I am proud when I say, hello my name is Giselle and I am a registered learning disability nurse.

As we move through this 100th year of learning disability nursing, I am still saddened to hear how some members of the profession are experiencing a stigma for wanting to be and being a learning disability nurse; some express feeling undervalued, overlooked and the 'Cinderella' branch of nursing. People have told us this is sometimes because the role remains 'misunderstood' and often 'hidden'. Is this a reflection of the fact that people who have a learning disability are themselves often undervalued and overlooked? In this momentous year, is it now time to bring to the fore and make visible what we as learning disability nurses do and hold up high our valuable contribution? As many participants in this initiative have said 'Let's start celebrating'. It is time to 'Celebrate Me'.

Within these celebrations it is imperative we give recognition to how people with a learning disability and their families are supported across all health and social care settings. The exuberance in creatively supporting individuals across the lifespan to ensure person-centred care is at the core of service delivery and should not be underestimated. These key messages need to be shared with others across the nursing family and with other health and social care professionals.

At the start of the 'Celebrate Me' initiative, there was a sense that a new narrative for learning disability nursing was needed. What we have uncovered is that the narrative is there, and it is strong. What is now needed is for every member of the profession to be sharing the positive narratives, otherwise we risk perpetuating further negativity within the profession. Each of us should be the catalyst for change and champion what is needed for the future.

What has been so powerful about 'Celebrate Me' is feeding back from the frontline what needs to be celebrated and what we need to champion for the future. To strengthen these messages, we need to ensure the involvement of people with a learning disability and families in shaping future services. People using services have categorically said 'use us', 'we are experts'; they want to support the profession and help people to understand what is like to have a learning disability.

Finally, the profile of learning disability nursing has grown massively. This year alone has seen a surge in initiatives, both national and local, in profiling the profession. So, do we have a future? Well the voices from those who have contributed to 'Celebrate Me' clearly say we do. To ensure that any uncertainty is eradicated, we need to capitalise and build on this momentum as we move through this centenary year of learning disability nursing. We need to build on what there is to celebrate now by taking up and working with the areas to champion for the future. This will ensure the momentum we have now continues beyond this year and way into the future. ■

“ Is it now time to bring to the fore and make visible what we as learning disability nurses do and hold up high our valuable contribution? ”

Giselle Cope, Registered Learning Disability Nurse and co-author of Celebrate Me

My final reflections and thoughts as a registered nurse and co-author of *Celebrate Me*

“ I encourage all learning disability nurses to celebrate from the rooftops about your amazing skills and commitment; let's attack the doubters with positivity rather than defence ”

This initiative grew from a piece of work led by FoNS to review the work of mental health nurses at a time when that profession, like learning disability nurses, wanted a vehicle to help them more clearly articulate their role and contribution, and be acknowledged as central to high-quality and safe experiences for people using care services. We set out with an aim to create a new narrative for learning disability nursing that would offer an evidence base from practice to help sustain the role for the future.

From the outset of our engagement with both the profession and people using services, it became clear that it was not a new narrative that was needed; we needed to make the existing and powerful narrative visible. We needed to bring to the fore both the outstanding skills of learning disability nurses and the essential role they play in supporting the person with a learning disability and their families. This is all highlighted in the list of themes and subthemes that we must ‘celebrate

now’. Alongside this, it also interesting to note the top five themes that emerged from the idea to write postcards to the Chief Nursing Officer (see page 43). I was curious that ensuring reasonable adjustments are made for the person with a learning disability (while often talked about) was lower down the list. One person did talk about learning disability nurses being the ‘reasonable adjustment’ that people need, but for me, the really significant themes to emerge have been those around person-centred ways of working, specialist knowledge and skills, and commitment to advocacy – all of this across the lifespan.

Interlinked with the above is the professional nature of the work of learning disability nurses, which strikes me as much more autonomous than other branches of the profession. Unlike that of adult, child or mental health nurses, it stretches beyond identification of health issues, treatment and potential cure. From listening to people who use services and their families, I began to see the role of the learning disability nurse as so much more. Arguably, as emerged through one of my dialogues, there are parallels that could be drawn between learning disability nurses and midwives, who offer that holistic care and support for the women and baby – being there for the whole experience and having the skills and authority to act within their scope of practice. I wonder if further exploration of the role of the learning disability nurse in terms of autonomous practitioner rather than specialist might strengthen understanding of the ways in which they make a difference and are different to other branches of the profession.

As part of this reflection, I want to say how much I have enjoyed the opportunity to engage with learning disability nurses, people with a learning disability who use services and their families. I have learned a great deal and often felt quite humbled and emotional about some of the stories people have told us. As a society, we still have some way to go in terms of both embracing the rich contribution people with a learning disability offer us and affording them equal opportunity. I have similarly found it difficult to hear learning disability nurses describe ways in which members of the wider nursing profession undermine and undervalue their role – this is unacceptable. For the future, I encourage all learning disability nurses to celebrate from the rooftops about the amazing skills and commitment you have; let's attack the doubters with positivity rather than defence.

So to conclude my reflections and thoughts, I want to draw attention again to all there is to celebrate, and to urge nurses, educators, researcher and policymakers to help take forward what needs to be championed for the future. This report is very different from the norm, particularly policy documents and guidance. It is about people who have told their story and aspirations. Let us all listen and act. ■

Dr Theresa Shaw

How the work of Celebrate Me has enabled the voices of people with disabilities to be heard, and opened up a dialogue on the role of learning disability nurses

When we look back over the past 30 years, it is quite incredible to think about how services to support people who have learning disabilities have changed and evolved. It is not surprising that the role of learning disability nursing has morphed and changed alongside this. This continuous evolution has enabled learning disability nurses to widen their scope of practice and to demonstrate their value and contribution across an array of health and social care services.

One of the challenges of this evolution is how to articulate the role. Learning disability nurses are driven by a strong values base that puts the person at the centre of everything they do. The role is not difficult to define and yet many find it difficult to articulate. Celebrate Me provides insight into how people who have learning disabilities and their families and carers experience learning disability nursing, as well as an understanding of how learning disability nurses and other health and social care practitioners perceive the role.

Celebrate Me, highlights the role of the learning disability nurse in reducing health and social care inequalities, from both a physical and mental health perspective across the age spectrum. It provides multiple examples of the knowledge, skills and experience that learning disability nurses use when working with people who have learning disabilities and the ability to draw on specialist knowledge and expertise to enable them to work with the person, their families and across the health and social care economy; the ultimate goal being to support people to have a good and healthy life.

The work of Celebrate Me has enabled the voice of people who have learning disabilities and families to be heard, with a clear message: to be brave and embrace the opportunities to work together. This message needs to be welcomed with wide open arms. We know that people who have learning disabilities are continuing to die prematurely; we know that people are continuing to be detained in hospital environments when there may be more suitable alternatives. As we move forward, we need to take the passion and desire that learning disability nurses have to improve health outcomes and reduce inequalities and use this to further evolve the role.

Celebrate Me has opened up important conversations with people, their families, learning disability nurses and other health and social care professionals. It has enabled an essential dialogue to start on the role of the learning disability nurse today, but more importantly it helps to shape what the future of learning disability nursing looks like. It identifies that services and organisations alone cannot define the role of the learning disability nurse, but that people who have a learning disability and their families need to be at the heart, and that working with people in collaboration is essential. The success of Celebrate Me is the voice and narrative that it brings from different people's perspectives and it is a launch pad for further discussions on how the role of learning disability nursing evolves for the future. It is an opportunity to come together with people and their families to further shape and evolve the role and promote equality #togetherwearebetter. ■

Rebecca Chester MBE, Chair, United Kingdom Learning Disability Consultant Nurse Network

“ We need to take the passion and desire that learning disability nurses have to improve health outcomes and reduce inequalities and use this to further evolve the role ”

References

The Celebrate Me initiative has provided evidence from experience in sharing the voices of those working at the frontline and people using services through words, narratives and graphic art.

Provided below is a small selection of references in support to the findings from Celebrate Me.

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APPENDIX 1: Advisory group members

Jim Blair, Independent Consultant Learning Disability and Associate Professor Learning Disabilities Kingston and St Georges Universities

Rebecca Chester MBE, Consultant Nurse, Learning Disabilities, Berkshire Healthcare NHS Foundation Trust, and Chair, United Kingdom Learning Disability Consultant Nurse Network

Giselle Cope, Practice Development Facilitator, FoNS (Project Leader)

Kevin Elliott, Clinical Lead, NHS England

David Harling, Head of Learning Disability, NHS England and NHS Improvement

Hilary Gardener, Strategic Liaison Nurse for Adults with Learning Disabilities, Primary Care, Hertfordshire

Louise Jenkins, Strategic Liaison Nurse for Secondary Care and Tertiary Care, Hertfordshire

Helen Lavery MBE, Professional lead for Learning Disability Nursing University of Nottingham and Facilitator of the Positive Choices Network

Kay Mafuba, Professor of Nursing, College of Nursing, Midwifery and Healthcare, University of West London

Ann Norman, Adviser: Criminal Justice/ Learning Disability Nursing Department, RCN

Ruth Northway OBE, Professor of Learning Disability Nursing, University of South Wales

Dr Theresa Shaw, FoNS (Advisory Group Chair)

Jonathan Slater, Nurse Consultant, National Learning Disability Service, Nottinghamshire Healthcare NHS Foundation Trust

Hazel Watson, Director of Nursing, Deputy Chief Nurse, NHS England (South)

Pauline Watts OBE, Former Chief Nurse, Public Health England

APPENDIX 2: Key questions and voting by the advisory group

- How can we demonstrate the impact of learning disability nurses [across sectors]? (7 votes)
- How do we contribute to the development of learning disability nurses?
- How do we influence national policy?
- How do we challenge the perception of people with a learning disability and learning disability nursing? [promote a more positive image] (5 votes)
- How do we influence the content, placement and practice exposure within learning disability education? (2 votes)
- How do we prepare students and the current workforce to work across a wide range of service provision?
- How do we make learning disability nursing more attractive? (5 votes)
- What strategies would support retention and wellbeing?
- How do we raise the profile of learning disability nursing with employers? (2 votes)
- How do we ensure learning disability nurses get the right support?

APPENDIX 3: Other engagement activities and events, April – December 2018

Date and event	Description
<p>April 19-20, 2018 Positive Choices Conference, Dublin Two workshops 60 participants</p>	<p>Two interactive café-style workshops were facilitated. The cafés gave participants an opportunity to explore the value and contribution that learning disability nursing makes and to think about the future of the role. The cafés were facilitated using the ‘six thinking hats’ concepts of Edward de Bono. It was a great forum that allowed participants to be early contributors to the data.</p> <p>At the end of each café, participants shared messages to future prospective student nurses who might be considering learning disability nursing as a career option.</p>
<p>24-25 April, 2018 UKLDCNN (UK Learning Disability Consultant Nurse Network) 20 participants</p>	<p>FoNS presented the Celebrate Me project and created an opportunity to explore with the network the purpose, aim and aspiration for this work.</p>
<p>9, 10, 15, 17 May, 2018 Health Education England Learning disability nursing workforce summits in North Region (67 participants) Midlands and East (49) South Region (76) London and South East (94) Total participants: 286</p>	<p>FoNS presented at all four summits to promote the project. Flyers on how to engage with FoNS were sent out electronically to all attendees. There has been reciprocal sharing of all outputs from each event.</p> <p>All regional workforce summit events had been convened jointly by the National Learning Disability Nursing - Task and Finish Group (Transforming Care Programme) and Health Education England regions.</p> <p>The key purpose of the event was to discuss and agree local and regional priorities and actions, and to contribute to national strategic actions, that will value, sustain and develop learning disability nursing for the future.</p>
<p>4 June, 2018 Learning Disability Professional Senate 28 participants</p>	<p>FoNS presented the project to the Learning Disability Professional Senate, which brings together professional leaders from across the UK to provide a collective voice of specialist health and social care practitioners. The senate provides cross-professional collaboration, strategic advice and innovation to develop both mainstream and specialist services for children and adults with learning disabilities.</p>
<p>6 June, 2018 FoNS celebration event 125 participants</p>	<p>The project was represented as a poster display at the FoNS celebration in 2018. Attendees had an opportunity to contribute their views and experiences via postcard replies.</p>
<p>31 July, 2018 LIDNAN (Learning and Intellectual Disability Nursing Academic Network)/UK Nurse Consultant Network Summit on Learning Disability Nurse Education 91 participants 56 postcards returned</p>	<p>FoNS presented the project and its progress at the summit. During the presentation a space was created for participants to contribute to the data by completing a postcard to FoNS. 56 returns were collated.</p> <p>This summit was called to discuss the crisis in recruitment and commitment to learning disability nurse education in England and to agree appropriate action. Attendance was by network members; people contributing to learning disability nurse education from higher education; NHS England; Public Health England; the Department of Health and Social Care; and other stakeholders.</p>
<p>Exemplar Healthcare Approximately 15 people supporting the project.</p>	<p>FoNS worked in collaboration with Exemplar Healthcare, Pathways care home, which is an eight-bed, nurse-led care home for people with multiple learning disabilities. They created the Celebrate Me canvas artwork in conjunction with staff, service users and family. The artwork represents a collaborative celebration of the service users residing at the home.</p>

ACKNOWLEDGEMENTS AND THANKS

This Initiative could not have been possible without advice and support from so many people.

Health Education England (London) and NHS England for funding support

Professor Jane Cummings, former Chief Nursing Officer for England and former Executive Director at NHS England, who initially commissioned this work

Ruth May, current Chief Nursing Officer for England and an Executive/National Director at NHS England and NHS Improvement

Therese Davis, Regional Chief Nurse LaSE Health Education England (London)

The Celebrate Me Advisory Group

Teresa Chinn, MBE, Registered Nurse and Social Media Specialist

WeLDNurses

Dr Pen Mendonca, Graphic Illustrator and Artist

Angie Emrys-Jones and Sandy Lawrence, Operations Directors CAAP, (Cornwall Accessible Activities Programme)

Northern Ireland's health and social care trusts: Belfast Health and Social Care Trust; Southern Health and Social Care Trust; Western Health and Social Care Trust; South Eastern Health and Social Care Trust; and the Northern Health and Social Care Trust

Sean Ledington, Lecturer, and Lynne Westwood, Senior Lecturer, University of Wolverhampton

Simon Lloyd, Head of Forensic Nursing and Interim Operational Pathway Lead, Low Secure, Midland Partnership NHS Foundation Trust.

Jonathon Slater, Nurse Consultant-National Learning Disability Service, Nottinghamshire Healthcare NHS Foundation Trust

Andrew Needle, Manchester People First

Scott Watkin BEM, Senior Learning Disability Advisor, SeeAbility, and Expert by Experience

Pathways, Exemplar Healthcare

National Learning Disability Nursing, Task and Finish Group co-chaired by NHS England and Health Education England

Positive Choices and Positive Commitment Network

UK Learning Disability Consultant Nurse Network

Health Education England: North Region; Midlands and East; South Region; London and South East Region

The Learning Disability Professional Senate

LIDNAN, (Learning and Intellectual Disability Nursing Academic Network)

Tim Bryson, Bryson Consultancy

A huge thank you to all participants who have given their time to be part of Celebrate Me and have contributed through the tweet chats, online survey, roundtable events, completion of various postcards and through other national engagement events.

Thank you to all those who have contributed.

Why I chose learning disability nursing

It all started with me chatting to a man in a charity shop who has Down's syndrome. He was working there in a voluntary capacity and this elicited feelings in me that, even though I did not know him, I was really pleased for him that he had the opportunity to experience the workplace, help with tasks, as well as to interact with different people.

Our conversation pulled on my heartstrings, although I cannot explain logically why, and acted as a catalyst for me to explore working in the learning disability field further. I felt drawn to consider how I could help those who will be always vulnerable in society, but was also conscious that roles within this sector would involve empowering people and not just 'doing for them'.

Since I've begun to read the academic texts that underpin this specialism of nursing, I realise I made assumptions about this man enjoying his time in the shop and that he had chosen to go there. I now know to always question: 'Is this person centred?'; "Was it a truly person-centred plan that resulted in this placement?' I would need to ask him how much his views had been taken into account and acted upon. This concept is certainly at the heart of what all learning disability nurses do!

The role appears to me to be a perfect combination of psychology-based approaches and creativity, coupled with valuable clinical skills – a combination that could maintain and potentially improve a person's health and wellbeing holistically. The overarching aim of the learning disability nurse is to ensure that people with learning disabilities in their care receive equitable access to healthcare. I cannot think of a greater cause to champion than this. ■

“ I felt drawn to consider how I could help those who will be always vulnerable in society ”

Catherine Gibbons, first-year nursing student, learning disabilities, University of Cumbria



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