

This is Us – This is What We Do.

A report to inform the future of Learning Disability Nursing

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Foreword

As Chief Nursing Officer for England, I know the difference learning disability nurses make to the lives of the people and families they support.

In 2019 as we celebrated 100 years of the learning disability nursing profession it was humbling to hear about the direct impact learning disability nurses

make every day across services in which they work, and impressive to see how the profession has evolved.



This report highlights the ideas and the energy upon which the profession is founded. It captures the true voice of people and families who are supported by learning disability nurses. It also illustrates the uniqueness of this branch of nursing with a very open and honest account of what it is like to be part of the profession; identifying some of the challenges and the opportunities for change.

At a time when our nursing professions face many challenges, it is extremely heartening to see how learning disability nurses are maintaining their resourcefulness and professional resilience. It's also helpful to hear from the profession itself, where we need to strive for different or better, to keep the brilliant people we have, and to attract new people in. Most of all, this report reminds us what a very rewarding, uniquely skilled career this is to be part of.

Ruth May

Chief Nursing Officer for England

I very much welcome the findings in this report as they have personal significance to my experience. My teenage son Oliver had a mild learning disability, autism, cerebral palsy and epilepsy as a result of bacterial meningitis as a baby. I became aware of learning disability nurses in the last year of Oliver's life. The difference the learning disability nurse made to Oliver's experience in hospital was phenomenal.



The learning disability nurse made sure that Oliver's voice was heard. This was something other colleagues struggled to do. They didn't understand the nuances people with a learning disability have, they didn't understand the importance of reasonable adjustments and the positive outcome they can have on the persons health and wellbeing.

At home, Oliver had the support of a community learning disability nurse who quickly built up a good relationship with him, enabling Oliver to develop the skills and confidence to live the life that he wanted to live. Overall, the input of learning disability nurses made Oliver's life more fulfilling.

I am grateful for how honest those contributing to this report have been. As the report highlights, learning disability nurses need to be recognised as equal and valued members in the family of nursing and beyond. The views in this report clearly articulate that we need to raise the profile of learning disability nursing, whilst continuing to share and celebrate in the amazing range of work they deliver.

Paula McGowan

NHSE&I Context

In 2019 learning disability nursing celebrated 100 years of the profession, and in doing so, learning disability nurses from across the United Kingdom came together to mark this important milestone in the history of what remains both a unique, and yet sometimes misunderstood branch of nursing.

For learning disability nurses, the centenary of the profession provided a helpful opportunity to showcase the range of outstanding work they deliver; pioneering person-centred care, protecting people's rights, and always working in partnership with the people and the families they support.

Across the four nations of the United Kingdom the message is clear, there has never been a better time to become a learning disability nurse. There are more entry routes than ever before to become a learning disability nurse, there is dedicated funding to support recruitment, and there are explicit strategies and action plans in place; with each respective nation driving forward a resounding message of the worth and the value of learning disability nursing.

As a career choice, learning disability nursing is extremely rewarding and presents an attractive offer for individuals who may want to diversify in their career. As many examples attest, the range of roles which learning disability nurses fulfil, goes some way to illustrate the adaptability and the transferability of their skills and knowledge.

Yet there are some important myths to dispel. Learning disability nursing is not limited to working solely within specialist services, the true merits of the role are equally suited to working within many mainstream environments; with learning disability nurses driving inclusion and delivering new and innovative ways of working.

Importantly, the basis of this report is founded on the voices of learning disability nurses and those who have experience of them. By gathering a broad range of opinion, the report offers some helpful pointers for discussion, and provides further insight into the how the learning disability nursing profession is perceived, along with suggestions for strengthening the profile.

This report by NDTi, refers to the notion of a '*reset*' for learning disability nursing, by which it is proposed, the profession not only reasserts its unique identity and worth but invites the voices of its critics to understand where it might improve. It is this aptitude for listening and learning, coupled with an outstanding resilience, that will preserve the learning disability nursing profession for another 100 years and beyond.



1. Summary

This report reflects on and celebrates learning disability nursing in England. It discusses how learning disability nurses are educated, what skills they have, how they themselves, and others perceive their role, the challenges the profession faces, and what the future might hold. This discussion is based on data collected from learning disability nurses, health and social care professionals, family carers and other interested parties, via social media platforms (Twitter, Facebook) and online forums² in January 2020.

This report has been written to inform readers of the narratives surrounding learning disability nursing, as told directly by learning disability nurses themselves or by those with experience of the profession. The paper puts forward the proposition for a learning disability nursing reset, meaning; the profession itself should take on, develop and, where necessary, reset some of these narratives in order to respond to the ideas shared, continue promoting and growing the role, and to reaffirm the difference the role makes to people with a learning disability and their families.

² [#HumanToo](#), [PANDDA](#), [Autism Support: Parent & Carer](#), [ADHD friendly family support UK](#), [PBS Network Alliance](#), [Autism Friendly UK](#), [A support group for Parents \(Swindon Autism, ADHD\)](#), [EHCP support group](#), [Neurodiverse UK](#), [Positive Commitment - a partner to Positive Choices](#), [Action 4 SEND](#), [ESUK](#), [Southend SEND Parents \(SSP\)](#), [EHCP Experiences and SEND Support](#), [Positive Behaviour Support Chat](#), [National Network of Learning Disability Nurses](#), [Parents of Autism Girls UK](#), [Educational Equality](#), [Disability World](#), [Australian Network For Positive Behaviour Support](#), [FIGS - Fighting Inequality for Girls on the Spectrum Campaign Group](#), [Group: SEND National Crisis March](#), [Promote Learning Disability Nursing](#), [Learning Disability Nurse.com](#), [Parents HemiChat](#), [AUTISM AND SPECIAL NEEDS ACTION GROUP](#), [Royal College of Nursing Students](#), ['Positive choices' Learning Disability Nurses are fantastic society](#)

KEY MESSAGES IN THIS PAPER

- ❖ One of the resounding messages we heard, is that learning disability nurses are invaluable to people with a learning disability, their families, and health and social care services. They are holistic practitioners who bridge the gap between the medical model of the health service and the social model of people's lives. By working in this way, learning disability nurses often stop what could be a traumatic experience for people and their families by making them feel safe and understood.
- ❖ Learning disability nurses are health educators and they are not afraid to challenge the status quo. This ensures that colleagues across the NHS, and beyond understand the needs of the people with a learning disability and provide care, support and treatment that is personalised to the individual.
- ❖ The work learning disability nurses do has a major economic impact. For example, their presence often lessens pressure on services by addressing people's holistic health and social needs in more personalised ways, facilitating reasonable adjustments, enhancing communications and care coordination. This in turn helps reduce health inequalities, premature deaths and readmissions.

However:

- ❖ Currently there is a national shortage of learning disability nurses and there is a need to better promote the value of this specialist branch of nursing. In some examples, we heard how some health and social care professionals have never met a learning disability nurse. Additionally, we heard from some family carers who told us they had never heard about learning disability nurses and therefore were unsure how to gain access to their input and expertise.
- ❖ In some examples, learning disability nurses themselves highlighted the need to build a stronger reputation and tackle some of the misconceptions about their role. Many learning disability nurses told us their colleagues have frequently referred to them as not being 'proper nurses' and were, at times disrespectful to them. There was a strong plea from learning disability nurses that all health and social care staff should receive learning disability training that highlights the value and the contribution learning disability nurses make across health, social care and beyond.
- ❖ There is an established need to recruit and train more learning disability nurses. This is due in part, to the reduction in the workforce caused by fewer universities offering the course along with the removal of nursing bursaries in recent years. However, with the advent of a new national action plan for learning disability nursing, there are a range of exciting options being developed to encourage people to become a learning disability nurse. This includes initiatives to enhance the reputation of the profession, strengthen career routes into nursing, raise the profile of the amazing work of learning disability nurses; whilst providing several new financial incentives to support students whilst studying.



2. Introduction

Learning disability nurses in England provide specialist health and social care and support to people with a learning disability, their families and supporters. This support can be provided in a variety of settings, including people's homes, schools and colleges, workplaces, hospitals, GP surgeries, mental health services and prisons, to name but a few.

The support learning disability nurses give to people and their families is invaluable to those who receive it. It can help improve and maintain an individual's physical and mental health, break down barriers in services that prevent people living independently and ultimately help them live a fulfilling life.

Yet, despite the value of the work they do, the learning disability nursing profession is facing significant challenges. Recent years have seen a 40% decline in the workforce leading to critical staff shortages and a reduction in the number of people joining the profession.

This is a challenging situation for any profession to face, but for one that is seeing the need for its services increasing, due to the growing population of people with a learning disability, the rising health inequalities they're facing and the high numbers of [premature mortality rates](#), these are particularly challenging times. The wider [NHS Long Term Plan](#) goes some way to addressing these issues, but the basis of this report was to hear from those directly involved with the profession, in order to understand what more can be done.

In January 2020 the leading activist and campaigner [Paula McGowan](#) was commissioned by NHS England and Improvement (NHSE&I) to present her social media (Facebook and Twitter) followers and numerous online forum members with 12 questions about learning disability nursing. The questions were compiled by the national learning disability team in NHSE&I and are taken verbatim from learning disability nurses themselves. This approach was chosen due to the phenomenological nature of data intended to be collected; and to gain firsthand, feedback about the experiences of respondents in relation to the phenomenon of learning disability nursing in England. That is, the aim of this work was to hear from those with direct experience of learning disability nursing, whether as learning disability nurses themselves, allied health and social care professionals, people with a learning disability, family carers or other interested parties, and learn from them what can be done to continue growing the profession and raising the profile of the work they do, including what aspects of the role should be held up as exemplars of its value. Paula McGowan was commissioned to collect this data due to her status as a campaigner for better health care for people with autism and learning disability in England, including the [Oliver McGowan Mandatory Training](#) (OMMT) for all NHS staff, and her large and varied online following.

The questions asked to elicit the data explored in this report were:

- 1.** If I'm an employer and only have a finite pot of money, why should I look to employ a learning disability nurse?
- 2.** What makes learning disability nurses good value for money?
- 3.** Can you give me 5 specialised skills only learning disability nurses possess?
- 4.** Answering only yes or no, do we need to change the name of learning disability nurses?
- 5.** Does current learning disability nursing curriculum and training in universities need to change?
- 6.** What's the best way to encourage and inspire people to train as a learning disability nurse?
- 7.** What's the one thing you would change about learning disability nursing?
- 8.** Does learning disability nursing have a unique selling point and if so, what is it or what should it be?
- 9.** Would it help if learning disability nurses had a specific, nationally agreed competency frameworks for their jobs, and if so, what specific outcomes would you want embedded?
- 10.** Does learning disability nursing need its own charter or accord to help the health and care system better understand what we do?
- 11.** How can the learning disability nursing role become stronger in helping to foster inclusion and challenge discrimination?
- 12.** In 3 words, what does the future look like for learning disability nursing?

The National Development Team for Inclusion (NDTi) were commissioned to analyse the responses received to these questions, to draw out the key themes that are discussed in this report.

A note on data

The focus of this work was upon learning disability nursing in England. Due to data being collected via social media and online forums, responses were received from across the globe. Most of these responses focused on learning disability nursing in England, but where they didn't, they were omitted from the analysis.

In addition, it is important to note that where numerical data is presented and discussed, this is caveated with the understanding that due to responses being collected via social media (Twitter and Facebook) and online forums, the numbers quoted may not be accurate.³

A note on language

The language used throughout this report is shaped by the responses given by those who contributed, this means that some jargon words are used, along with colloquialisms, slang and abbreviations such as 'LD' instead of 'learning disability' and 'pwlds', instead of 'people with a learning disability'. In addition, where appropriate, RNLD (Registered Learning Disability Nurse) is used when talking about learning disability nurses.

Whilst the questions asked in this work did not specify a clinical response, the majority of answers received were clinically focused. As a result, this report leans more towards a health focus, rather than covering the breadth of work learning disability nurses do across health and social care. Where feasible discussion has focused on all aspects of health and social care, but this has not been possible in all sections.

The term learning disability used in this report is used to collectively describe a group of people who might be referred to having a 'learning difficulty' or 'intellectual disability' outside of health and social care settings and elsewhere in the world.

³ The exact number of responses cannot be accurately counted due to the data being collated outside NDTi. Lack of access to raw data and the source being social media means it is not always clear where responses have come from. For example, some responses are spread across multiple entries in the data set due to participants running out of characters on Twitter or responding in conversation to other participants.



3. What is learning disability nursing?



Four of the 12 questions asked focused on understanding what a learning disability nurse is, what they do, what skills they have and what they offer people with a learning disability, their families and the health service. Most of the responses to these questions were from learning disability nurses themselves, along with several allied health and social care professionals and family carers. Below are the 8 key attributes respondents described learning disability nurses having:

Our Specialist Knowledge



Learning disability nurses are nurses first and learning disability specialists second. They have the clinical skills of registered nurses combined with specialist learning disability knowledge. This combination is seen as their **'superpower'** as they have the clinical knowledge to ensure holistic care and treatment is provided within the context of someone with a learning disability's life. Some of the other learning disability nurse's **'superpowers'** include being facilitators, educators, advocates, clinical experts, leaders, and

mediators. These attributes, help prevent issues such as diagnostic overshadowing, health inequalities, premature deaths and inappropriate admissions.

"We're the only LD specialist - how can you offer specialist LD service without LD specialists?"

"...we are specialists, we have a unique knowledge & skillset, & we support a patient group who require that little extra"

"...we have specialist knowledge in many different essential areas that without these skills, adults and children with learning disabilities become far more vulnerable to getting negative outcomes"

Our Person-Centred Approach



A learning disability nurse's approach is **highly person-centred**. They spend time getting to know the person they are working with and their family, understanding their desires, values, their family and friends, their social circumstances and they support people across the lifespan. Working in this way allows learning disability nurses to build trust and therapeutic relationships with people and ensures they get the best outcomes from their engagement with health services

"The subtleties of looking after a person with a learning disability are unique. The knowledge these nurses can bring to an organisation is essential to promote patient centred care to all"

"Learning disability nurses have the person at the centre of all care, they can be there at the beginning, the middle and the end of someone's journey through services. Their knowledge, skill and warmth helps the person navigate through the different services."

We are Holistic Practitioners



Learning disability nurses help support people with a learning disability to receive health and social care support and interventions, that not only meets their physical needs, but also their emotional, social, economic and spiritual needs. Many learning disability nurses feel they are one of the few healthcare professionals who truly **embody the principles of holistic care** in their everyday work.

"Our understanding and skills around people with LD are holistic. We can meet most of a person's needs in relation to their LD as well as their medical needs. This would not be the case if a nurse from another field or allied health professional took the role instead."

"We look after the whole person, physical health, mental health, emotional wellbeing, communication, self-help (enablement), we support to increase self-esteem, access to services, ensure services are treating our patients fairly and equally, or support into work and are truly holistic practitioners!"

We are Skilled Communicators



Learning disability nurses are highly skilled communicators. They are not only **trained in using alternative communication formats** such as Makaton, they are skilled observers with the time to ensure someone's non-verbal communication is 'heard'. These skills allow the voices of people with a learning disability to be heard in the course of their treatment where they might not be otherwise. Learning disability nurses often design and create resources, such as a hospital passports, or unique communication aids to ensure people's voices are heard and to ensure other health and social care professionals understand people's rights and what they might need to meet their often complex needs.

"Our communication skills are far better and adaptable to meet individual needs"

"They will have knowledge and understanding of a range of conditions to help ensure the patients get their needs met and can make reasonable adjustments. They can communicate the patients' needs to other staff to ensure the right care is given"

"I'm an adult RN, we had an AMAZING LD Liaison where I used to work. I could call her any time for advice, and she'd come down to see patients with me and help with communication assist items"

Learning Disability Nurses are Advocates



One of the greatest roles the learning disability nurse plays is that of critical friend and advocate for people with a learning disability and their families. As well as being a critical friend to colleagues in the health and social care system. Given their skills as **expert communicators**, learning disability nurses spend

time getting to know the people with a learning disability they are working with to ensure they understand their needs, wishes and values, before facilitating and providing the independent support they need to have their voices heard and their rights upheld in any health and social care setting. Their role also involves assisting people with a learning disability and their families to access and understand information relevant to their treatment and care so they can make informed decisions and choices

“An LD nurse would be the ‘voice’/advocate for the person with LD’s needs. This is currently down to the parents in a clinical situation, and as such it is not always successful for a number of reasons, most notably because the parents are emotionally involved with the patient, whilst trying to care for them, and also trying to communicate with staff, all at the same time. A LD nurse would have both involvement in the patient’s welfare and a level of professionalism and status which would enable them to support the process of care...”

We are Problem Solvers



Learning disability nurses are **skilled problem solvers** who must regularly think creatively to ensure the best outcomes for the people they are working with, often in the face of adversity, prejudice or discrimination. Their person-centred approach to supporting people and families means they can adapt what they do based on the needs of the individual; one size does not fit all.

“We are flexible, adaptable and have a common-sense approach to all situations. We try to look at the whole person and treat as an individual, not as a condition or a ‘problem’. We love co-production and collaboration. We solve problems and enable people to live to the full.”

“LD nurses are able to adapt to any situation and learn as they go. They are masters at communication and have skills and know how to think outside the box and put in reasonable adjustments when necessary”

We are Teachers



A learning disability nurse teaches their fellow health and social care colleagues about people with a learning disability through their presence in any given environment and the resources they use to support someone through their care, support and treatment. Learning disability nurses also teach people with a learning disability and their families about **how to live happily and healthily** in their homes and local communities. Working in this way also helps prevent health emergencies and crises emerging.

“Having worked as a paediatric nurse in a setting with lots of children/young people with learning disabilities, we were a mix of paedics, adult & LD nurses. It was our LD colleagues who were integral in ensuring we as a team understood atypical behaviours, that our communication skills were optimised & they ensured the children/young people's voices were truly heard, whether or not they could verbalise them independently. My LD nurse colleagues had training & skills in these areas that no other nursing branch had. They could teach/share these skills with the rest of us and, even though the LD nurses remained the experts, I do think we were generally enabled to be a team who really did better understand & advocate for the children/young people. Had we not had LD colleagues on our team (as could actually have happened - there was no legal reason to employ them in this setting) we would have had far fewer skills/understanding to meet the needs of those in our care. Quality of care would have undoubtedly dropped as the rest of us simply didn't have the same training (or life experience back then) that LD nurses had.”

Learning Disability Nurses are Workforce Multipliers



As learning disability nurses are nurses first, **their presence increases the clinical and knowledge capacity** of many care environments. In many instances learning disability nurses are often deployed in challenging situations to support an individual in a range of settings, providing expert advice, or additional cover on top of normal staffing levels. This enhances the awareness of approaches of other professionals and can improve people's experiences of

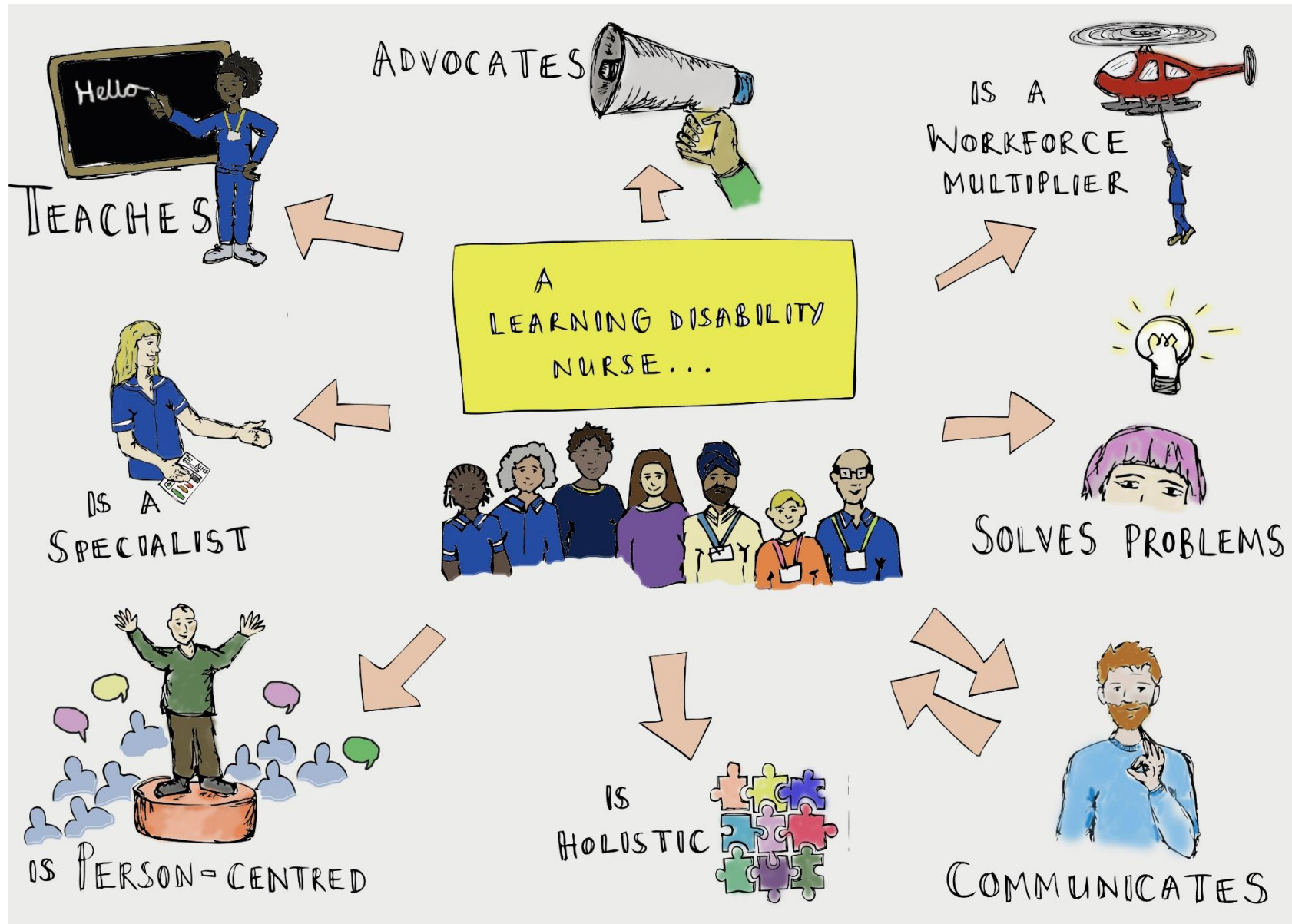
generic services.

By equipping colleagues with a greater knowledge of the needs of people with learning disabilities, this increases the capacity of health professionals to ensure they provide the right care, support and treatment, which in turn, reduces the likelihood of poor outcomes; and if based in the community, they often help prevent unnecessary admission to hospital in the first place.

"We have the same basic skills as General Nurses plus a lot more specialised skills. We help increase the quality of care provided to people who have a Learning Disability when admitted to or attending hospital. As a result, families will enjoy an improved experience, patients will spend less time in hospital and so be at less risk of a hospital acquired infection. We can prevent premature death by ensuring all relevant investigations are carried out and prevent the individual being re-admitted to hospital. We can decrease the workload of acute ward staff and increase their confidence in caring for patients who have a learning disability. Our specialised knowledge and input will reduce DNAs, help make reasonable adjustments for a better environment for patients with LDs, prevent inappropriate admissions and reduce litigation cases due to poor health care and outcomes as staff will understand LD better. We can help save so much money."

As these 8 key attributes illustrate, learning disability nurses are highly skilled and adaptable nurses who ensure people with a learning disability receive equitable health and social care services to people without a learning disability. The work they do bridges the gap between different services, through the delivery of highly personalised support that upholds their rights and respects their values; something that has historically been neglected within healthcare. The work learning disability nurses do ensure the right treatment is given first time and reduces what could be a traumatic experience for people and their families by making them feel safe and understood. Additionally, this brings range of cost savings across the health and social care system.

Figure 1. What is a Learning Disability Nurse?





4. Areas to *reset* in learning disability nursing

Figure 2. What challenges did respondents tell us learning disability nursing faces?



Whilst it is evident that learning disability nurses provide an invaluable service to people with a learning disability and their families, their profession is not without its challenges. Responses to almost all the questions highlighted and discussed these challenges from the viewpoint of those witnessing and experiencing them. These responses have been analysed and grouped into 6 main categories.

The need to strengthen the perception of the profession



The greatest challenge learning disability nurses feel the profession is facing is the perception some health and social care professionals have of their role, skills and abilities. Many respondents shared their experiences of being told they are not 'proper nurses' as they lack the clinical knowledge and skills of their non-learning disability counterparts. They also talked about regularly being disrespected by other professionals in their place of work.

"Our reputation within the nursing field is awful. Quite often we are not considered to be 'proper nurses'"

"There is a complete lack of recognition from other professionals for the work we do and how important it is."

"Others assume that LD nurses aren't proper nurses."

The need to raise the profile



Many learning disability nurses feel their profession does not have the profile it deserves in health and social care, which can result in a lack of clarity about who they are and what they do. More needs to be done to promote the fantastic work learning disability nurses deliver across the United Kingdom.

Several respondents reported that they had not come across a learning disability nurse in their place of work:

"...learning disability nursing has such a low profile that needs raising. We need to shout it from the rooftops! Our profession is 100 years old, yet we go unrecognized. We've always been about person centred care. We do amazing work with amazing people, but too quietly!"

"I'm an RGN, and in 25 years of practice, I still have not encountered an RNLD."

Some family carers also said that whilst they had heard of learning disability nurses, they had seldom come across them in their local hospital or surgery:

"I know they exist, but whenever my son goes into hospital, we don't meet them. They aren't offered to us, so I presume there aren't any?"

Whilst others weren't aware of the profession and didn't know they might be able to request their support in their local health and social care services:

"I've never even heard of a learning disability nurse. What does a learning disability nurse do? Is this at a hospital, a therapy center, or like someone who comes into the home to help to do something like respite care for

The need to increase training



The learning disability nurse workforce in England is not felt to be large enough to meet the current and future needs of people with a learning disability accessing services. Newly qualified nurses are therefore desperately needed to strengthen the workforce and support the ongoing growth of services both now and in the future. Whilst several universities currently offer degrees (both undergraduate and postgraduate routes to become a learning disability nurse) the impact of the loss of the nursing bursary resulted in a decline in applications and insufficient numbers of new nurses are qualifying.

However, with the recent announcement of financial incentives to encourage more applicants into nursing, it is hoped this will result in an increase in the number of people training to become learning disability nurses.

Several learning disability nurses feel that a lack of marketing and promotion of the profession is contributing to this problem and this must change to make sure the profession continues to flourish and make a difference to people's lives.

"... recruitment to the profession is vital and a shortsighted Govt without vision is to blame. They didn't support citizens with a learning disability by withdrawing bursaries. Of course, this was always going to affect LD nurse recruitment and now you can't do the course anywhere. There needs a special, powerful hard hitting Dept of Health drive to recruit LD nurses. That's long overdue."

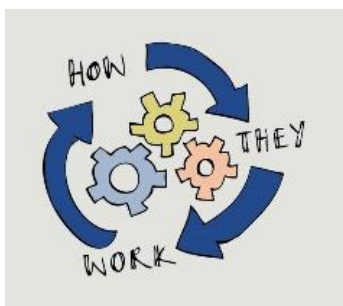
The need for a clearly defined career path



The career progression of a learning disability nurse is not felt to be clear to those who currently work in the field or to many other health and social care professionals. This is a challenge to the profession, as it caused some learning disability nurses to leave their role and pursue alternative occupations which have a more clearly defined career progression, as well as dissuading potential new nurses away from pursuing a career in this profession.

“Most people when entering a profession are ambitious and want to do well. They will want to be able to one day support a family and a home. Nursing has a well-established career path, the grades and pay increase as does responsibility. One can go into leadership, management, research, specialist clinical jobs that attract grades of band 7 and above. However, learning disability nursing has no clear structure towards a career. Really kind, clever, thoughtful skilled practitioners stay within bands 5/6 forever. We are asking people to enter a profession that is unlikely to give them a salary above £32k (or whatever it is) ever. Learning disability nursing is specialist and should be given that status. I’ve known many people who have not done learning disability nursing for this very reason. I don’t mean more pay for nurses, that’s a different issue. I mean a career path, proper structure so that people know it’s there should they want it”

The need to deliver proactive not reactive care and support



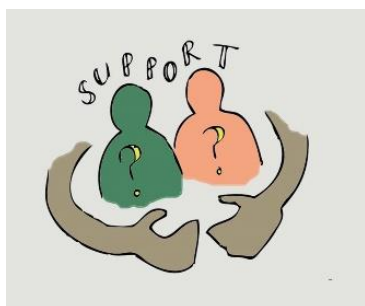
The work of a learning disability nurse can at times, be reactive rather than proactive. This is something many learning disability nurses would like to see change. Whilst reactive work is sometimes necessary and an element of this will always be

needed, many respondents would like more opportunity to focus on the proactive and preventative aspects of their role to help people with a learning disability have the care and support they need in order to prevent hospital admissions and crisis situations occurring.

“...being able to be more proactive and not just troubleshooting. More health promotion, more time with patients and not computers.”

“Because of our low profile, we tend to be called in when people are in crisis which doesn’t allow for consistent, proactive work.”

The need for effective eligibility criteria for services



The eligibility criteria for receiving support from a learning disability nurse can be much more stringent than many working in the profession and family carers would like. It is suggested by respondents that support should be available to anyone with a learning disability who requires it, and not someone with a learning disability who meets a certain set of criteria.

“I’d like to be able to broaden the scope of my work. When you know you could support someone to have a better quality of life, but they don’t “fit the criteria”, that’s devastating and goes against my nursing instincts and training.”

From this discussion it is evident that learning disability nursing in England is facing several challenges, many of which are closely interconnected and cyclical in nature. The reduction in the number of learning disability nurses in England in recent years, has seen a reduction in the workforce. In some examples we heard how health and social care professionals didn’t know about, or have ever worked with, a learning disability nurse and are not familiar with the role or the work they do. As a result, this situation may be influencing the assumptions held by other professionals that learning disability nurses do not figure as prominently as other branches of nursing.

Yet contrary to these assumptions, more learning disability nurses are urgently needed, not only to improve the service available to people with a learning disability, but to raise the profile of the profession within health and social care and beyond. However, due to some of the reputational challenges the profession is facing, the reduced marketing about the profession and the previous lack of financial support to fund their studies, which up until September 2019 saw a decline in applications, almost half the universities who offered a learning disability nursing degree courses ten years ago have stopped doing so.

So how does learning disability nursing respond to this situation? Where learning disability nurses are in post, known about and utilised, the difference they make to people with a learning disability, their families and the wider health and social care sector is invaluable and makes a positive impact in terms of outcomes.

What can be learnt from the respondents in this piece of work about how learning disability nursing in England can reset itself to ensure this scenario is relevant for everyone with a learning disability who needs them? The following sections of this paper explore this issue from the viewpoint of those with lived experience of the profession.

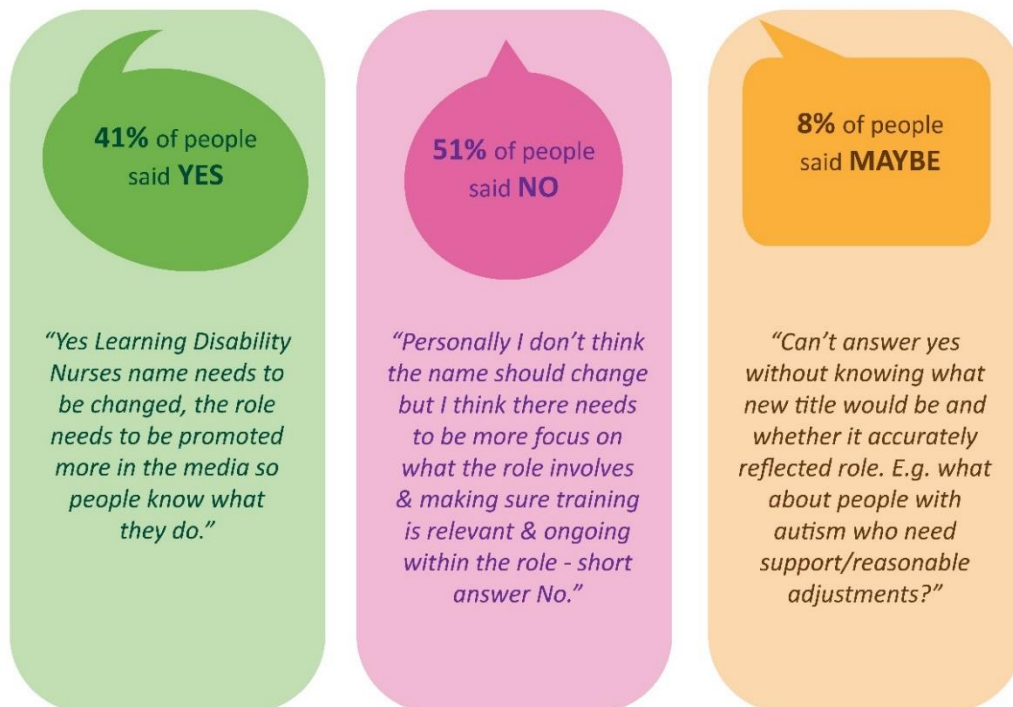


5. How to address the challenges faced by learning disability nursing

As the previous section has highlighted, learning disability nursing is currently facing a number of challenges. Several questions expressed an awareness of these challenges and focused on possible solutions. The responses to each of these questions are summarised below

a) Should the name of learning disability nursing be changed?

Figure 3. Should we change the name of learning disability nursing?



As figure 3 (above) highlights, the majority of people (51%) felt that the learning disability nursing name **should not be changed**. The reasons given for this were varied, but included: previous name changes had been confusing especially for non-learning disability specialists; a change of name to include autism (which is often suggested) could mean that people with a learning disability and no autism would miss out on services and that this change would create a two tier learning disability nursing workforce as there are already qualified nurses who are not autism specialists; the name says what they do so why should it change?

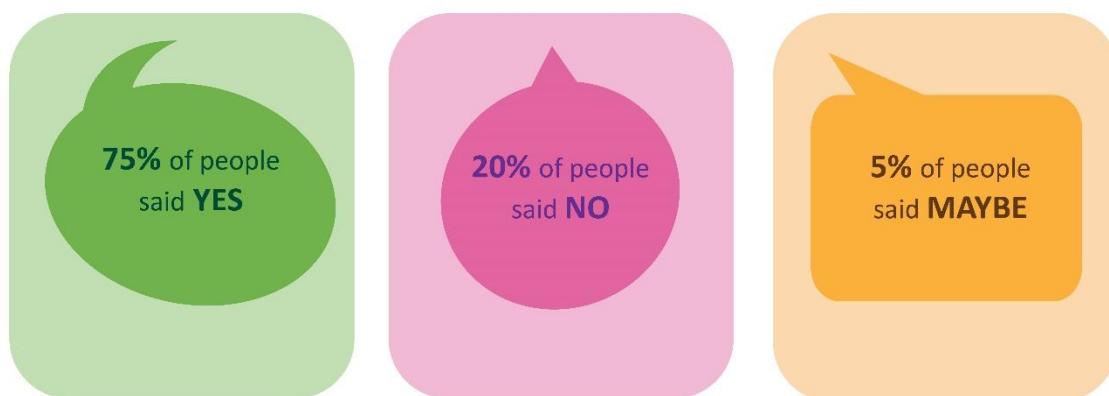
"I don't think it should be changed as Learning Disability Nurses sound like nurses who are really good with people with learning disabilities."

Having said this, 41% felt the name should be changed to ensure it represented who they support and what they do (see quote above).

The remaining responses (8%) suggested that changing the name might be useful, but the reasons for doing so would need to be clear. These individuals were concerned that if the change of name was due to the stigma that surrounds the profession then the time and money to be spent on rebranding the profession could be better spent educating health and social care professionals, as well as the general population, about what they do, how they do it and the assets they bring to services.

b) Does the current learning disability nursing curriculum and training in universities need to change?

Figure 4. Does current learning disability nursing curriculum and training in universities need to change?



The overwhelming majority of responses (75%) felt that the curriculum **does need to change** to ensure that qualifying learning disability nurses can further hone their skills and expertise in order to work across all health and social care disciplines and beyond. As well as ensuring all qualified learning disability nurses receive continuous training in these areas via regular top-up courses.

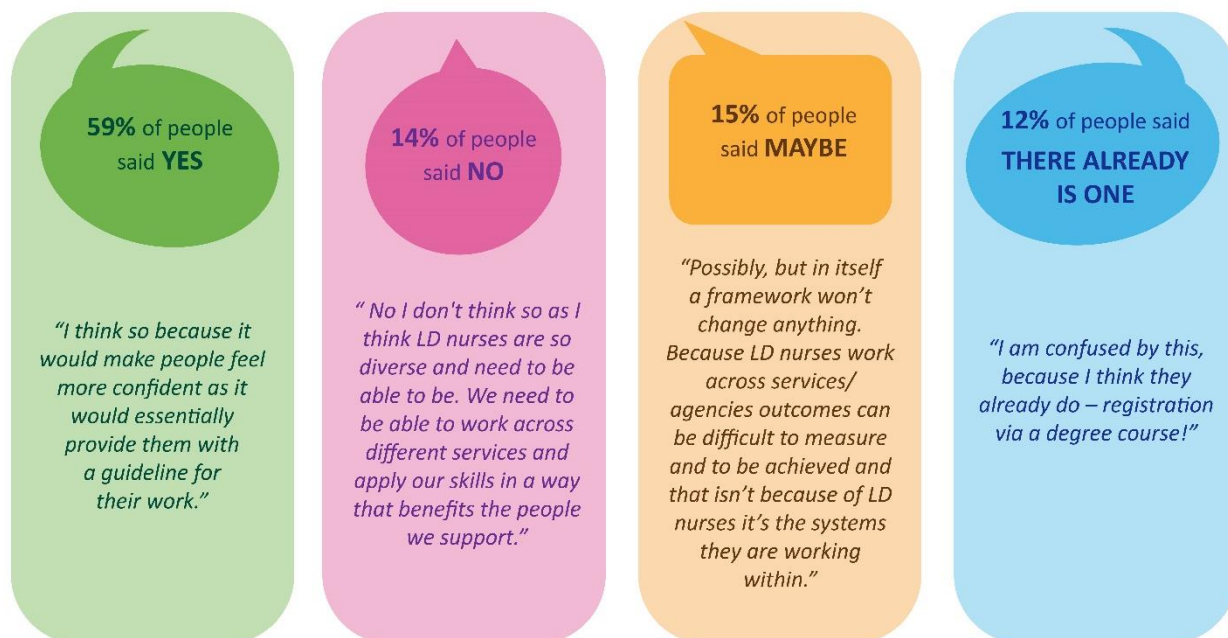
In addition, respondents felt that if the pre-registration learning disability nurse curriculum were to include topics, such as; autism, physical health, challenging behaviour, speech and language, and mental health to name a few, this would go some way to remedying some of the other challenges the profession is facing.

"...it's absolutely essential LD nurses receive regular updated courses to ensure they act in line with the law and regulations."

"Prioritise training support and funding, we are particularly affected by reduced numbers of qualified staff coming through from training, if we can't recruit, we can only fire fight not be proactive."

c) Would it help if learning disability nurses had a specific nationally agreed competency framework for their jobs, with specific outcomes embedded?

Figure 5. Should there be a nationally agreed learning disability competency framework?

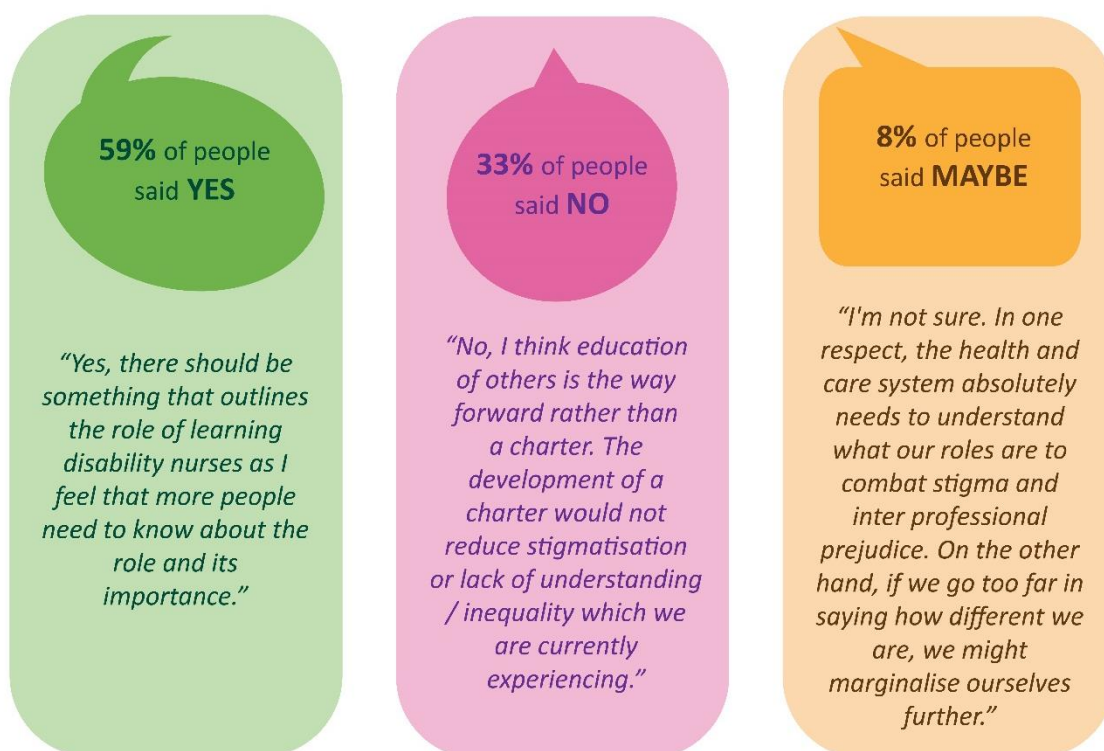


As figure 5 (above) highlights the majority of respondents (59%) felt that having competency framework for learning disability nursing **would help** learning disability nurses feel more confident about what they do and why. Respondents further stressed that having such a framework would ensure learning disability nurses would be better placed to help educate and support their health and social care colleagues about what they do and why; something that might, in time, improve the perception of the profession and encourage more people to train.

Whilst such a framework is seen as something that should happen by the majority of respondents, 12% stated that there already is a nationally agreed competency framework for all nurses and therefore questioned why learning disability nursing should require something different or additional to all other nurses.

d) Does learning disability nursing need its own charter or accord, to help the health and care system better understand what you do?

Figure 6. Does learning disability nursing need its own charter or accord?



As shown in figure 6 (above) 59% of respondents felt that learning disability nursing having its own charter or accord **would be beneficial** to the profession for reasons like that of the competency framework (previous page). One of the greatest challenges facing learning disability nursing today is the perception allied health and social care professionals have of the profession and the impact this has upon people with a learning disability. Having a charter or accord that clarifies what a learning disability nurse is to health and social professionals would support them to be more confident in working with people with a learning disability, and may go some way to breaking down the barriers to ensuring people with a learning disability get the support that others take for granted.

However, it is important to highlight that for those who did not feel that such a charter or accord should be created (33%), or should maybe be created (8%), they stated they don't believe learning disability nursing should have to change in order to meet the needs and expectations of health and social care professionals. Rather, these professionals should be given training to understand learning disability and the role of learning disability nursing within the current health and social care system.



6. What does the future hold for learning disability nursing?

As the discussions throughout this document have highlighted, learning disability nursing is a unique and dynamic profession, but equally faces a range of challenges. However, the future is for the learning disability nursing profession is bright. As evidence attests, where learning disability nurses are employed, known about and utilised by people with a learning disability, their families and other professionals, the work they do is invaluable to all involved.

Learning disability nurses' specialist knowledge, person centered and holistic approach, communication and advocacy skills, and problem solving abilities and transformational leadership means they can ensure people with a learning disability and their families are heard and supported throughout their engagement with health and social care services, often preventing diagnostic overshadowing and readmission to services. This not only ensures people with a learning disability and their families feel safe, heard and understood in settings that can often be scary and traumatizing, it is thought to save health and social care services money. As a result, it is paramount that learning disability nurse training, which is the only dedicated degree level qualification for this area of care, must be preserved.

However, recent years has seen a significant reduction in the number of universities offering learning disability nursing courses, partly caused by the reduction in applications to study, due the removal of the nursing bursary. This situation, along with large numbers of qualified RNLDs leaving the profession, has led to a 40% decline in the RNLD workforce in England, creating critical shortages and a reduction in services in many areas.

Data collected from respondents cited here offers valuable insights into the culture surrounding learning disability nursing that helps us understand why the workforce has reduced so dramatically. Learning Disability nurses themselves are aware of some negative perceptions being applied by others to the role, alongside the need to raise the profile of the profession within the health and social care arenas. Some professionals hold the naïve view that learning disability nurses are not 'proper nurses' despite the fact the curricula and standards to which they are trained is to the same degree level qualification as other areas of nursing, health and social care. Respondents suggested that this can add to a misunderstanding of their role and the work learning disability nurses do.

Whilst the removal of the nursing bursary had a significant impact on the learning disability nursing numbers in England, it is hoped the reintroduction of financial incentives across nurse training; with an enhanced award for those entering learning disability and mental health nursing, should see numbers increase.

In addition to increasing the number of learning disability nurses working in England, respondents feel that a nationally agreed competency framework and charter or accord should be created. They suggest that if learning disability nurses feel they had a formally agreed career framework with some specific job profiles to support this, then it would not only help educate others about the validity of the role, it would help raise the profile of the profession.

A strong theme running through the narratives of this work is the need, not only for learning disability nursing to continue rising to the challenges it faces, but more importantly, for all health and social care professionals to reasonably adjust their practice in order to understand and respect learning disability nurses, the work they do, the impact they have and the unique forms of support they provide to people with a learning disability and their families. The most pronounced of these themes related to training for all staff about learning disabilities and the work of learning disability nurses. It is hoped that training, such as the [Oliver McGowan Mandatory Training in Learning Disability and Autism](#) (that Health Education England and Skills for Care are overseeing the development and evaluation of) will go some way to improving health services available to people with a learning disability and their families more generally.

Reflecting on these points, the majority of respondents believe the future for learning disability nursing is extremely positive. There are a growing number of initiatives to support its growth, there is a new national action plan to attract, retain, develop and celebrate the profession, and if the points raised in this paper are used as a springboard to inform a *reset* of the profession, it is hoped this highly rewarding career, will continue to flourish.

When asked to describe in 3 words to describe the future for learning disability nursing, the following most common words were used; ***Challenging, Exciting, Rewarding and Needed.*** (figure 7 on the following page).

Figure 7. The future of learning disability nursing





7. Recommendations

Based upon the responses received to the questions asked by Paula McGowan via social media (Facebook and Twitter) and online forums in January 2020, and NDTi's analysis and reflections on these, the following recommendations could help reset learning disability nursing and broaden the invaluable service it offers. These actions have been grouped into shorter- and longer-term recommendations.

Short term recommendations

- Both a national competency framework and learning disability nursing charter/accord should be created to promote the skill, competencies, benefits and attributes. This could help ensure other health and social care professionals know what learning disability nurses do, how they work and why, contributing to the wider system change that is needed. However, such a framework and accord, must integrate with the core principles of the training for all allied health and social care professionals (detailed below).
- The career pathway available to learning disability nurses in England must be reviewed to ensure that it is equal to the progression routes of other health and social professionals.
- There needs to be a positive and high-profile marketing campaign to encourage more people to qualify as learning disability nurses. This campaign must highlight the invaluable work learning disability nurses do (discussed in section 3), the funding now available to complete the training and the clear career paths available to new nurses (once the review has been carried out in the point above). The campaign should be targeted to commissioners and providers of services (who recruit nurses) as well as potential new students in schools, colleges and other branches of nursing.
- The pre-registration learning disability nursing curriculum in England (including post-qualifying) should be reviewed to ensure that newly qualifying learning disability nurses are able to work across all health and social care disciplines and have a greater understanding of autism and other areas of expertise. This training should include, but not be limited to, covering proactive system change methods, preventative and health promotion approaches, facilitation and education skills, as well as skills sharing and joint learning with other branches of nursing and health professions.

- All health and social care staff employed in England must receive mandatory learning disability training that not only covers working with people with a learning disability, but also informs participants of the work learning disability nurses do and how they can work with them to support people with a learning disability through their health and social care journeys.
- This training should be viewed as an opportunity for the learning disability nurses profession to engage with other professions, demonstrate their skills, share experiences and initiate change through delivery and profile raising. The training should not be something learning disability nurses view as happening separate to them, but with and alongside them.

Longer term recommendations

- The name 'learning disability nurse' should remain as it is and be celebrated. Broadening the name to include 'autism' would likely cause confusion and potentially create a two-tier learning disability nursing service.
- Once the population of learning disability nurses has increased (as a result of the steps listed in the 'short term' section) the role of learning disability nurses should be actively be promoted to people with a learning disability, their families and supporters.
- There needs to be clarity within the health and social care system on who would benefit from the input of a learning disability nurse.
- Research should be undertaken into the role of learning disability nursing and to explore the value it adds to health and social care services. A specific cost-benefit analysis of their role is highly recommended. Where possible this research should be undertaken in partnership with learning disability nurses themselves.

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