The Role of Learning Disability Nurses in Specialist Learning Disability In-Patient Settings in England.

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October 2023





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A note on language

The language used throughout this report is shaped by the responses given by those who contributed to the research. 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, RNLD is used when talking about Registered Learning Disability Nurses.

Furthermore, 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.



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1. Foreword

We very much welcome the findings of this, the second report in a series about the role of Learning Disability Nurses in England and we would like to thank all everyone who took the time to participate.

This report has a specific focus on the invaluable contribution and role of Learning Disability Nurses in supporting people who use specialist in-patient settings and has gathered information and opinion from a broad range of individuals and professionals, including people with a learning disability, their family members, Allied Health Professionals, Student Nurses as well as Learning Disability Nurses themselves.

Whilst building on the findings of the earlier 2020 report 'This is us- this is what we do' the report seeks to highlight, through the honest accounts of all who participated, the unique work of Learning Disability Nurses who work in specialist in-patient settings, the challenges they face and the difference these Nurses make to the people they support.

It is positive to hear from people with a learning disability and their family members, who outline just how essential the input of Learning Disability Nurses have been to their experiences of care and highlights the distinctive skills and knowledge these Nurses possess.

It is also equally powerful to hear from Learning Disability Nurses who are working or have worked in specialist in-patient settings who describe some of the unique challenges they have faced, especially in terms of a distinct career pathway and some of the observations which the profession is subject to.

At a time when the nursing profession as a whole continues to strive to find new ways to address the challenges it faces, the participants in this report offer their own unique examples to illustrate how their work positively enhances the perception of learning disability nurses working within this specialist area of care.



David Harling National Deputy Director for Learning Disability Nursing National Nursing Directorate of the Chief Nursing Officer for England NHS England



2. Summary

This report is the second in a series about the role of learning disability nurses in England. It builds on the report published in December 2020 'This is Us – This is What We Do', with a focused exploration of the role of learning disability nurses (RNLDs) in specialist in-patient settings in England. It explores what role RNLDs play in the support and treatment of people with a learning disability in specialist in-patient settings; what impact this role has upon the individuals and families they support; how RNLDs themselves view their role within specialist in-patient settings; what challenges the profession faces in this sector; and what the future might hold.

Data to inform this report was gathered in 2021/2 via online surveys and conversations with people with a learning disability, their family members, student learning disability nurses, RNLDs who have worked in specialist in-patient settings in the past and those who currently work there, as well as other members of Multi-Disciplinary Teams.

This work was funded by the learning disability team within the national nursing directorate at NHS England, in a bid to inform a role description for RNLDs in specialist in-patient settings.

Key Messages

- Where RNLDs are in place and known about in specialist inpatient settings, they are invaluable to people with a learning disability, their families, and supporters.
- RNLDs within specialist in-patient settings require many of the same skills as <u>RNLDs</u> <u>more generally</u> with an added focus upon the complex emotional support people require and the transitional nature of the service offered. They provide proactive, reactive and crisis support to individuals who are often acutely unwell and presenting with an array of challenging needs. This holistic support helps individuals and families navigate an often challenging experience to ensure they receive the treatment needed and timely discharge.
- However, the profession in this setting is facing many of <u>the same challenges that</u> <u>learning disability nursing in general faces</u>, which appear to be exacerbated by the seemingly negative perceptions the general public have of specialist in-patient settings and those that work in them.
- Participants suggest improving the perception of specialist in-patient settings, alongside a review of the resources and systems available, to help raise the profile of the role and increase the number of people/pre-registration nursing students choosing Learning Disability Nursing as a career option.



3. Introduction

Learning disability nursing in England celebrated its centenary in 2019, marking 100 years since the first national certificate for what was then known as "mental deficiency nursing" in 1919.

During this 104-year period, the profession has grown into an invaluable role that provides specialist holistic health and social care support to people with a learning disability, their families, and supporters. This support is delivered in a variety of health and care settings, including within specialist learning disability in-patient settings.

Approximately <u>1.3 million people</u> in England have a learning disability, 50% of whom are estimated will require specialist in-patient support during their lifetime for a <u>mental health</u> <u>condition</u> or <u>challenging behaviour concern</u>. The latest data suggests there are currently <u>2,030 individuals with a learning disability and/or autism in specialist in-patient settings in England</u>.

The history of people with a learning disability and autistic people receiving treatment and support within specialist in-patient settings in England, as well as elsewhere, has a long and sometimes controversial history. The breadth and depth of this history and the debates surrounding it reach far beyond the scope of this report, but it is important to explore its most recent history in order to provide an overview of the landscape in which this research has been undertaken.

In 2011, an undercover <u>BBC investigation</u> at Winterbourne View Hospital near Bristol highlighted the devastating impact a predominantly untrained workforce, working under poor clinical management, can have on the treatment provided to individuals within specialist learning disability in-patient settings.

The Department of Health responded to this investigation with the publication of <u>Transforming Care</u> in December 2012. This national response placed the learning from the BBC investigation front and centre by emphasising the need for a well-trained workforce led by good clinical and managerial leadership within all specialist in-patient settings in England. In addition, the publication also set out a number of actions and legal duties relating to how and when all large-scale specialist in-patient hospitals in England should be closed. The focus of these duties was upon local areas improving their provision of housing and support for individuals, with a requirement that any future inpatient setting, be smaller by design, focused on delivering time limited interventions and be based locally so people can stay close to home. Running in parallel, and not unconnected to Transforming Care, a review of learning disability nursing across the UK was undertaken in 2011/2. This led to the publication of <u>Strengthening The Commitment: The Report of the UK Modernising Learning Disabilities</u> <u>Nursing Review.</u> This report set out a vision to strengthen the capacity, capability, quality, leadership, and visibility of learning disability nursing across the four nations. Importantly, Transforming Care asked local areas for a progress report on Strengthening the Commitment. These reports fed into the <u>Strengthening the Commitment: One Year On</u>, which said that the profile of learning disbiality nursing had increased and the role was gaining more recognition, but more work was needed.

Despite this, in 2018 there was a 40% decline in the overall RNLD workforce in England. The reasons for this cannot be attributed to one particular cause, but it has been <u>reported</u> that the removal of bursaries to study the profession (reinstated in September 2020) alongside a reduction in the number of universities offering learning disability nursing programmes, resulted in fewer RNLD's qualifying.

Data for the impact this reduction in the overall RNLD workforce has had on specialist inpatient settings is not available, but it is likely to be significant given the size of the reduction. In fact, the reduction in this setting might be higher than within other settings, due to the effect the negative press specialist in-patient settings have received since 2011. Evidence from the <u>general nursing population</u>, <u>social work</u> and <u>third-sector providers of</u> <u>community services</u>', suggests that those working in these roles experience stigma-byassociation to scandals in specialist in-patient care which negatively affects their professional quality of life and leads to many leaving the setting or their professions completely. It is reasonable to assume that RNLDs in specialist in-patient settings will have had similar experiences, thus causing higher numbers to leave the setting.

This combination of factors, in addition to the <u>widely cited</u> issues of stress and burnout for RNLDs in specialist in-patient settings, poses a range of challenges, from recruitment and retention, to ensuring continued investment in learning disability nursing as a whole.

<u>The NHS Long Term Plan</u> and <u>All-England Plan for Learning Disability Nursing</u> are focused on addressing these challenges, and this research is intended to-garner a greater understanding of the role of RNLDs in specialist in-patient settings from the view point of those employed in the role, AHPs, people with a learning disability and their families/carers. It is hoped that exploring the role in this way will allow for an exploration of the specific challenges RNLDs in this setting face and identify potential solutions for how they can be addressed in the future.



4. Methodology

The aim of this research was to garner a greater understanding of the role RNLDs play within specialist learning disability in-patient settings in England, in a bid to help inform a more detailed role description and to describe some of the core competencies of the role.

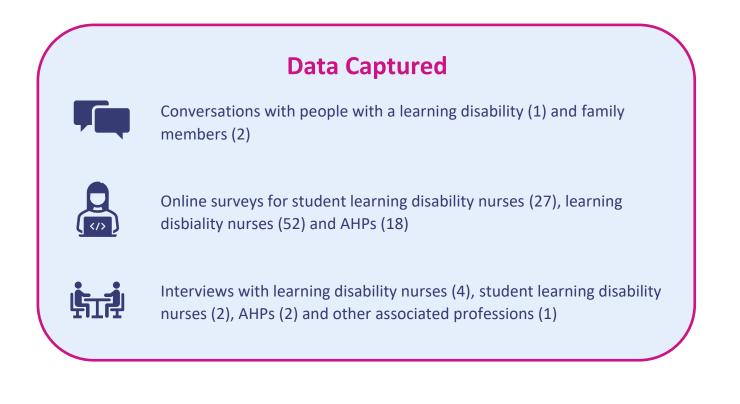
The project began in mid-2021, with the hope of gathering the views and experiences of people with a learning disability who had recently had a learning disability nurse involved in their treatment whilst in a specialist in-patient setting, and those of family/carer's where a learning disability nurse had not been involved in their relative's treatment within a specialist in-patient setting. These individuals were able to share their views and experiences with the project via any method that felt comfortable to them including, but not limited to, written methods (including prose and poetry), visual methods (photos, drawing, painting etc.) audio/media methods (audio recording, short video recording), or via a conversation with the research team (online or on the phone).

Due to only a small number of participants and to ensure the voices of people with a learning disability and their family/carers underpinned the research, the decision was taken in November 2021 to undertake a small number of purposefully selected 1:1 conversations with people with a learning disability and family/carers. These conversations focussed less on individual lived experiences and more upon capturing the questions they felt should be asked of learning disability nursing within the specialist in-patient arena. These individuals were also offered a 1:1 debriefing session with a psychologist.

The questions gathered in these conversations were used to form the basis of an online survey and interview guide to gather data from student learning disability nurses, registered learning disability nurses working in specialist in-patient settings and those who had previously worked in one, as well as Allied Health Professionals (AHPs)

Surveys were hosted online in the Spring 2022 (March/April) with links to participate circulated via the networks previously mentioned. The data captured in the surveys went through an initial stage of analysis to further inform and strengthen the interview guides. Interviews were then undertaken between May and July 2022 with those individuals who had expressed an interest in taking part within the survey they completed (details below).

The data captured via all of these sources (conversations, surveys, and interviews), was thematically analysed and the findings are presented in the following chapters of this report.





5. A role description

In this chapter what people with a learning disability, their family/carers, student learning disability nurses, RNLDs and AHPs told us about the role of learning disability nurses within specialist Learning disability in-patient settings in England is drawn together. The chapter is written in the style of an annotated role description for the position with illustrative direct quotes from participants used where possible.

5.1 About the role

As a key member of the in-patient team, the post holder will play a pivotal role in the care and treatment of individuals with a learning disability in our care. The post holder's work will involve a range of activities including providing day-to-day holistic support, being the main point of contact for family members, and working alongside internal and community-based teams to aid recovery and support discharge.

The people with a learning disability and family/carers we spoke to told us that RNLDs within specialist in-patient settings are the key individual(s) to making an in-patient stay a positive experience. All acknowledged that an in-patient stay can be distressing for everyone involved, but having an RNLD to help navigate the process, communicate with family/relatives, and provide holistic not just clinical support, means the treatment received is co-ordinated, appropriate, and timely, with no one left isolated by the experience.

Family/carers strongly emphasised how important the role of an RNLD in navigating their relatives stay and communicating with them was when their relative was receiving treatment a long way from home, particularly during the COVID-19 pandemic when no visits could be made.

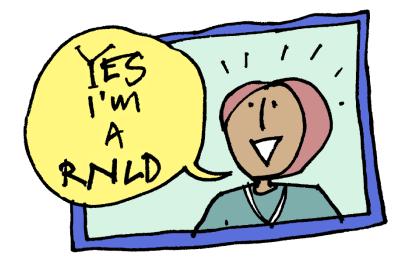
"The difference from when she had one [RNLD] to when she hasn't was huge. The first time we didn't know what was happening, trying to find out was awful you'd ring and if anyone answered they didn't know what was going on, I'm not sure they even knew who she was. The next time was like a different world. [Name of nurse] was brilliant, we knew exactly what was happening. We could ring, nothing was too much trouble. As a mum that made such a difference, I didn't feel isolated, I knew where my daughter was and that she was OK."

5.2 Key activities

*These activities have been taken from the information provided by RNLDs about the work do/have done in specialist in-patient settings and those observed by AHPs

The key activities undertaken in the role are:

- Support and occasionally lead the admittance of individuals for treatment.
- Undertake mental and physical health assessments of individuals at admittance and on a regular and ongoing basis.
- Be the named 'Key Worker' for a number of individuals receiving treatment. This will include being the main point of contact for their family/relatives.
- Be responsible for the writing, reviewing and implementation of Multi-Disciplinary Team care plans and risk assessments for individuals receiving treatment.
- Work holistically and in a person-centred way with all individuals receiving treatment.
- Liaise with and support internal teams to ensure holistic person-centred care is delivered at all times.
- Administer medication as required.
- Lead and co-ordinate shifts as required.
- Oversee and support the discharge of individuals, including liaising with communitybased teams to find appropriate placements and providing transition training to staff at discharge destinations.



5.3 Success in the role

*These attributes are taken from the analysis of the skills RNLDs and AHPs told us RNLDs in specialist in-patient settings need to have. The person appointed to this role will:





be a skilled communicator: Communication is key to this role with the post holder able to use alternative communication formats such as Makaton and be a skilled observer of non-verbal communication. In addition, the post holder will be able to design, and create resources for individual's receiving treatment and colleagues to use during their time with the service and in their onward care.

be person-centred: The post holder will be responsible for ensuring the mental health needs of individuals are supported and treated, whilst also maintaining their wider physical, social, economic, and spiritual needs during treatment.





be organised yet adaptable: This role is based in an often fast paced and dynamic environment. The post holder must be highly organised to ensure the needs of individuals and the wider service are met, whilst being adaptable to the responsive nature of the support individuals often require.

be a creative problem solver: The post holder will need to be a skilled problem solver who is able to think creatively to ensure the best outcomes for individuals are achieved and discharge supported. Their person-centred approach to supporting people means they will be able to adapt what they do based on the needs of the individual.





be calm and compassionate: The post holder will be working with individuals and families/relatives at what can be an emotionally distressing time. They will also be working with individuals whose mental health and the associated complexities will fluctuate throughout their treatment. The post holder will need to be able to react calmly and with compassion to ensure the best outcomes for individuals are achieved and discharge supported.

be able to build relationships: The post holder will be confident and comfortable at building relationships with a variety of individuals quickly and professionally. Relationships will need to be built with the individuals receiving treatment, their family/relatives, AHPs within the service, and health and social care colleagues within community-based teams. These relationships will often need to be formed in difficult circumstances, so the post holder will need to approach each with sensitivity and compassion.



be resilient: The post holder will need to have the capacity to thrive in a demanding environment. The people they will be supporting will be experiencing an emotionally distressing time, which has the potential to impact on the post holder. Their ability to work well in a team will mean they can support themselves and their colleagues.

be a teacher: The post holder will work with both internal and external multidisciplinary teams to ensure the support individuals receive is holistic and person centred. This will often involve providing both formal and informal training to ensure the rights of individuals are upheld, and discharge placements are ready and equipped to meet the often-complex needs of individuals. This may involve pioneering new approaches to ensure their onward care helps and supports them to thrive in the community.





work well in a team: The post holder will need to be able to work well within a multidisciplinary team to facilitate the treatment and support the discharge of individuals. Their communication skills, organised nature, ability to build relationships and person-centred approach will support this.

5.4 Discussion

The role description presented in this chapter brings to fore the attributes, skills, and key activities RNLD's in specialist in-patient settings in England require to support people with a learning disability through their treatment and discharge. It highlights that RNLDs in these settings provide proactive, reactive and crisis support to individuals who are often acutely unwell and presenting with an array of needs that may be described as challenging. The support RNLDs provide is invaluable to both the individuals themselves and their families/relatives at what can be an extremely difficult time. Many of the skills and attributes that they require to do their role well echo those of <u>RNLDs more generally</u> with an added focus upon the complex emotional support people require and the transitional nature of the service offered. Furthermore, the work RNLDs do in this setting ensures family/carers/relatives are not isolated from the treatment their relative receives and are able to navigate the sometimes complex specialist in-patient and onward care system.





6. The challenges

This chapter draws on the learning garnered from the RNLDs and wider Multi-Disciplinary Team members who contributed to this research about the challenges learning disability nurses in specialist in-patient settings in England currently face. These challenges should be viewed as knowledge about the profession, not criticisms, that can be learnt from and utilised to help the profession in the future.

6.1 Perception of the role

The greatest challenge learning disability nurses who work or have worked in specialist in-patient settings faced is the perception of their role. RNLDs shared their experiences of often not feeling listened to or taken seriously by their health and social care colleagues.



"To be taken more seriously! We are not a 'jack of all trades' We should have more of a voice and be listened to. We are paid professionals who know the people we support. We look after their holistic needs and always place the person at the centre of their care."

"We should be valued for our role and respected by other professionals."

In addition, many RNLDs told us that the perception the general public has of their role doesn't reflect the scope and expertise of the profession, which means many of them are reluctant and sometimes afraid to tell people what they do.

"I don't tell people where I work, I say I am a learning disability nurse, but I don't tell them where... I'm afraid of what their response will be...the media have made it worse, what happened [Winterbourne View] was bad and people should know about it, but it's not all like that everywhere...people need that support..."

6.2 Profile of the role

Participants in this research told us that the profile of RNLDs in specialist in-patient settings needs raising in parallel to improving the perceptions of the role.



"Change the narrative around working in in-patient settings. The support we give is invaluable...they're not [in-patient settings] bad places where bad things happen...if that's what people think why they would want the job? We know what we do, we need to tell people about it, LOUDLY. We need to take control of the narrative."

In addition, one of the families we spoke to was not aware that there were RNLDs who worked in specialist in-patient settings despite experiencing numerous admissions.

> "I didn't know there could have been one...there never has been...I am sure it would have made such a difference."

This experience suggests that the profile of RNLDs in specialist in-patient settings needs raising with other health and social care professionals, but with parent/carers/family members and members of the public.

6.3 Career progression

As well as raising the profile and promoting the perception of the role of RNLDs in specialist in-patient settings, the career path of an RNLD in this sector is seen by those who contributed to this research as being a key challenge to the profession.



"There needs to be more opportunities to progress with different specific roles like that on community teams with banding that reflects the work being done." A number of participants reflected that working in a specialist in-patient setting was an expected part of their early career journey that was progressed away from rather than progressed within

"...it's a bit like a rite of passage, something you have to do not somewhere you want to stay. The experience was...its where I cut my teeth, but I left for a promotion and better pay once I had done my time."

In addition, many of the students who contributed to this research told us that they had worked in a specialist in-patient unit as one of their placements. Whilst the majority had enjoyed or were enjoying the experience, only 1 (out of 27) was considering a career in the sector with the majority (20) saying they were 'not sure'. The reasons given for this uncertainty were widely cited to be the lack of certainty about what that career might look like or where it might lead.

6.4 Professional autonomy

One of the greatest challenges RNLDs feel their profession faces within specialist in-patient settings, is the lack of professional autonomy they have, which impacts on their ability to provide holistic treatment that aids recovery and supports discharge.

"The ability to support people to increase in skill and readiness for discharge. Neither the environment nor staffing compliment or support this."



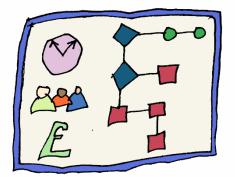
"To be empowered to make decisions regarding the care of their patients".

Some of the RNLDs we spoke to suggested that specialist in-patient settings could shift towards becoming a Nurse led service that meet the needs of patients through holistic Multi-Disciplinary Team working to reduce lengthy stays in hospital.

" The in-patient service should be a nurse-led service. Guided by the principles of nursing care and standards, with a clinical and holistic focus". "All in-patient settings should be run by nurses. A holistic and person focused approach to treatment would reduce time as an in-patient and help people get back home. People shouldn't be in hospital for years, months maybe for some, but never years."

6.5 Resources and systems

As section 6.4 suggests, the experiences of RNLDs in this research suggest that for many, the resources, and systems in place around specialist in-patient settings do not always support the work they do, or their ability to achieve the best outcomes for the individuals they work with. But where those resources and systems *do* support the RNLDs work, people within specialist in-patient settings were felt by participants to have better experiences within the setting.



Participants also told us there were not enough RNLDs to support all the people who need it in specialist in-patient settings, and that those nurses who are in post do not have enough time to complete all the tasks expected/required of them. There was also an over reliance on paperwork in specialist in-patient settings, that the hours worked are long and often antisocial hours, which leads to stress, burnout, and a high turnover of staff especially for RNLDs working alone, and the discharge processes are unrealistic.

> "Pressure in work appears to be building up and having the right amount of staff on shift is a constant battle."

"I do mostly enjoy my job but do find it challenging and stressful at times. Being an LD nurse on your own can at times feel isolating."

"We need protected time in our days in order to ensure the environment and care planning meets the need of the patients LD."

"There needs to be an achievable discharge process that doesn't take months to start." RNLD participants who currently worked in and those who had recently left employment in specialist in-patient settings felt that in many instances individuals with a learning disability and mental health needs would be better served with proactive support in the community rather than reactive support within a specialist in-patient setting. But the lack of investment in community support and too few RNLDs in this sector as well, often means that specialist in-patient settings are all that is available even when it is a social care placement that breaks down not a specific mental health/challenging behaviour concern:

"Working on an Assessment Treatment Unit, the majority of admissions are social care placement breakdowns, not necessarily because of mental/behavioural disorder. When the assessment and treatment phase is complete the individuals become delayed transfer care patients. In our Unit at one stage five out of six patients were delayed discharges, exceeding a 12-month timeframe. There is little community provision with the knowledge and skills and not enough RNLDs."

As this quote suggests, the speed of discharge for individuals is another challenging area for RNLDs and AHPs in specialist in-patient settings. Participants from all professional groups contributing to this research highlighted their concerns with discharge and the need for resources and systems to be adapted.

"Working within in-patients is rewarding on the whole, although frustrating at times in relation to delayed discharges. In-patient units frequently get heavily criticised for patients remaining in so long however they are generally ready for discharge quickly after admission however delays are faced within the community rather than the treatment within in-patients."

6.6 Discussion

From the discussion in this chapter, it is evident that learning disability nursing in specialist in-patient settings in England is facing several challenges, many of which are interconnected and cyclical in nature. Many are also aligned with the challenges the wider RNLD profession faces more generally.



Participants in this research suggest that at present the greatest challenge the profession faces within specialist in-patient settings is the lack of RNLDs working within it. The reason for this cannot be assigned to one particular factor but are suggested to be related to the reputational challenges and low profile the role has in this sector. As well as the limited resources and systems challenges facing wider specialist in-patient service provision in England that lead qualified RNLDs to leave and student RNLDs to feel it is not a viable career option. It is also thought, although not explicitly mentioned by participants, that the wider decline in the RNLD workforce more generally over recent years is likely to have had an impact.

So how does learning disbiality nursing respond to this situation? There is currently work being undertaken to address many of the RNLD workforce issues presented in this chapter, as part of the <u>All England Plan for Learning Disability Nursing</u>. In a bid to help strengthen and develop this work, participants in this research were asked about what they would like to see for the profession within specialist in-patient settings in the future. The following chapter will bring this report to a close with an exploration of what participants believe can be done to address these challenges in the future.



7. A look to the future

This chapter builds on the previous by presenting what people with a learning disability, their family/carers, student learning disability nurses, RNLDs and AHPs think the future of learning disability nursing in specialist in-patient settings in England should look like. It explores directly how they feel the challenges presented in Chapter 6 can be addressed, as well as their thoughts, ideas, and questions for the profession to consider.

7.1 The need for RNLDs in specialist in-patient settings

As has been previously alluded to, the family/carers that contributed to this research believe that learning disability nurses in specialist in-patient settings are pivotal to the provision of holistic treatment and timely discharge for patients. For the families we spoke to who had not had a RNLD overseeing their relatives care, they felt isolated and disconnected from the treatment being delivered.



"It's terrifying. You see your child suffering and you can't help...they are taken away, miles away...the other end of the country and you hear nothing. No one tells you anything. No one answers the phone."

Whilst those families/carers who had had a RNLD involved, felt more positively about their experience.

"Of course, the experience wasn't good, it was an awful time for our family, but having [name of nurse] there to explain things to us and for us to ask for when we rang, made a bad situation more liveable." The people with a learning disability that we spoke to, did in general support the role of learning disability nurses in specialist in-patient settings as they felt they were important to the system as it stands now, but they posed a challenge to the research as to whether we were asking the right question.

"I thought that in-patient settings were supposed to have closed down. Shouldn't that be what you are asking...why are there still ATU's? If they don't exist, then learning disability nurses won't be needed there."

A number of RNLD's felt similarly, stating the role was important in the current system of specialist in-patient provision, but that this provision should cease being provided as was intended within Transforming Care.

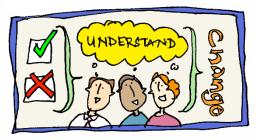
"All in-patient settings should have been but still need to be closed with all resources transferred out to the community as Transforming Care should have done (in my opinion this has not happened as typically the idea is wonderful, but the implementation is appalling). That's where we [RNLDs] should be, in the community."

However, the subject of whether all specialist in-patient settings in England should be closed is a contentious subject and the focus of much debate. These debates were evident in this research, where a number of RNLDs, student learning disability nurses and AHPs felt that for some people with a learning disability period of support in a specialist in-patient setting will be needed throughout their lives and when this is the case an RNLD plays an important role.

> "There are heated debates about in-patient units, usually between people who don't understand what they are like, what they do and who they are for, and lots of discussion about how Transforming Care has 'failed'....The reality is there will always be patients that require in-patient care even if some believe that not to be the case ...in-patient units can and should get better at providing this support and learning disbiality nurses are key to this."

7.2 Change systems and resources.

As the last quote in section 7.1 alludes to and in line with Transforming Care's goals, specialist in-patient settings and RNLDs within them will be needed in the future, but the current provision of these services need to change their systems and resources to ensure the work they do is able to support recovery and appropriate discharges.



Many RNLDs shared how they thoroughly enjoy their job, particularly seeing individuals progress through their recovery and develop new skills and abilities. Yet they shared this with a '*despite everything*' sentiment.

"I love seeing the patient journey and the difference made to people's lives. There is always a challenge, and I enjoy the everyday ones, but at times it can be overwhelming and frustrating especially with the speed of discharge. It is SO slow and you then see people deteriorate."

"The role is rewarding and interesting. Stretched resources, complicated care systems and care providers, weary staff. The ropes between them can be frayed."

As such, both RNLDs and the AHPs in this research suggest that time should be taken to understand the systems and resources challenges affecting specialist in-patient settings in England in greater detail, to ensure changes can be based on a better understanding of the mechanisms currently at play.

> "It is clear that what's happening at the moment isn't working and hasn't been for a long time. It's all very well asking if learning disability nurses are needed, but what we need to understand is why some people with a learning disability have been detained in a hospital for over 10 years!"

In addition to this broader and longer-term exploration for change in the future, some RNLDs suggested that short term action could be taken to increase the number of RNLDs working in specialist in-patient settings. How they suggest doing this is explored in section 7.3

7.3 Improve perceptions and raise the profile.



In Chapter 6 it was clear that the greatest challenges facing RNLDs in specialist in-patient settings are the perception both AHPs, health and social care professionals and the general public have of the role, as well as the low profile it has amongst potential new and student learning disability nurses.

Throughout the research RNLDs, student learning disability nurses and AHPs shared actions that could be taken to improve this situation in the future.

"Offer training to health professionals and rotational opportunities, provide clear career progression and remove tuition fees."

"Promote the breadth of the role, which is often misunderstood."

"Change the narrative around the role. When there is a negative story in the press, we need a learning disability nurse to champion the work we do that is as loud, maybe louder, than the misinformation often reported."

Participants feel that actions such as these, will increase the number of RNLDs wanting and choosing to work in specialist in-patient settings in the future which may begin to mitigate the challenges of too few RNLDs in post, the lack of time available to complete tasks, and the long antisocial hours that can lead to stress and burnout. In addition, an increased awareness of the role of AHPs and other health and social care professionals may go some way to changing the lack of professional autonomy many RNLDs in specialist in-patient settings feel they lack but desire.

7.4 Increase the awareness of learning disability.

Finally, in addition to refining the perceptions of the RNLD role in specialist in-patient settings with AHPs and other health and social care professionals, RNLD participants also suggest that in the future more needs to be done to increase and improve the awareness of the needs of people with a learning disability. Participants shared that, sometimes, they didn't feel heard by colleagues but as one participant explained.



"We are specialists, we have trained for this. LD nursing is the only profession that studies LD specifically. Other professions study in a generic fashion and then branch into LD Health Services. I spend a lot of time correcting misconceptions and teaching, more could be done in training, especially within LD Health Services to improve knowledge."

Work is being done as part of the <u>All-England Plan for Learning Disability Nursing</u> to raise awareness of learning disability, but, as this participant suggests, the impact of this is not yet being felt within settings amongst AHPs. It is hoped that the legal duty placed upon all health and social care providers to provide training for their staff in learning disability and autism under the <u>Health and Social Care Act 2022</u>, will begin to improve the situation highlighted in the above quote in the near future.



8. Discussion and recommendations



8.1 Discussion

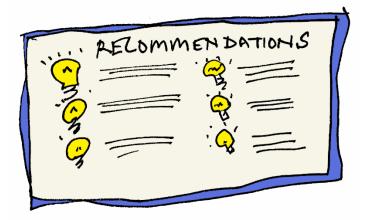
This report has built on NDTi's previous report "<u>This is Us – This is What We Do</u>', with a focused exploration of the role RNLDs in specialist in-patient settings in England. It has explored the role RNLDs play in the support and treatment of people with a learning disability in specialist in-patient settings, what impact this role has upon the individuals and families they support and how RNLDs and AHPs view their role within this setting, through an annotated role description (Chapter 5). The report has also presented the challenges the role/profession currently faces in this arena and explored how these might be addressed and learnt from in the future.

Discussion in this report has highlighted that RNLDs in specialist in-patient settings require many, if not all, of the same attributes as <u>RNLDs more generally</u> with an added focus upon the complex emotional support people require and the transitional nature of the service offered. It highlights that RNLDs in these settings provide proactive, reactive and crisis support to individuals who are often acutely unwell and presenting with an array of challenging needs. The work these nurses do has an invaluable impact on the people with a learning disability they support and their family/carers at what is often a difficult and emotionally distressing time. They provide holistic support to individuals that aids recovery and ensure family/carers are not isolated from the treatment their relative receives. Their work also supports people and their family/carers to navigate the sometimes complex specialist in-patient and onward care system.

Yet despite the positive impact the role has upon the individuals it works with, it suffers from many of the <u>same challenges that learning disability nursing in general faces</u>, which are exacerbated by the seemingly negative perceptions the general public have of specialist inpatient settings and those that work in them.

This is something participants strongly suggest needs to be addressed in the future if the other challenges facing the role are to be overcome. That is, if the perception of the role is altered then it is likely that more people will consider undertaking pre-registration learning disability nursing degrees and choosing specialist in-patient settings as the foundation for their career whilst those who are qualified may not leave the sector. Something which will help ensure that more people with a learning disability and their family/carers can receive the appropriate support and treatment when they need it most. It is hoped that the work being undertaken to address many of the wider RNLD workforce issues and raise the understanding and awareness of learning disability as part of the <u>All-England Plan for</u> <u>Learning Disability Nursing</u>, will go some way to address the perception issues flagged in this report, but a focused approach to the specific challenges relating to specialist in-patient settings will also be beneficial.

There are of course a number of broader challenges that need to be addressed to help the RNLD role in the setting, which participants suggest should be based on a better understanding of how the resources and systems within the provision of specialist in-patient services in England could be better utilised. Furthermore, many participants felt that RNLDs must be integral to and leaders in any system changes.



8.2 Recommendations

Based on the information shared and the discussion in this report, the following recommendations could help the role of RNLDs in specialist in-patient settings in England meet some of the challenges it currently faces and grow in strength and number

There needs to be a positive and high-profile marketing campaign to encourage more student learning disbiality nurses and qualified RNLDs to consider specialist in-patient settings as a potential place of work. This campaign must highlight the invaluable work learning disability nurses do and the funding now available to complete the training. 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 Role Description presented in this report could be the starting point for this campaign.

Recommendations

- There needs to be a focused and sensitively managed approach to improving the perception of specialist in-patient settings for people with a learning disability undertaken more broadly in society.
- The career pathway available to RNLDs in specialist in-patient settings must be reviewed to ensure that it is equal to the progression of RNLDs in other settings.
- There needs to be a focus among all those working in specialist in-patient settings in England, not just within learning disability nursing, on shifting the narrative surrounding RNLDs and the work they do.
- Research needs to be done to explore how specialist in-patient services manage systems and allocate resources to understand how these could potentially be used differently.
- All AHPs should 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 journey.