Changing Our Lives

Opening Doors:

Learning disability nursing in forensic settings

August 2023

Making an ordinary life *possible.*

Changing Our Lives is a rights-based organisation. We work in partnership with disabled people and people with lived experience of mental health difficulties to find solutions to social injustice and health inequalities.

All of our work is rooted in the belief that no one is too disabled and that no one's mental health is too complex to lead an 'ordinary life'.

Our approach rests firmly on the social model of disability. As such, we don't believe people's lives should be limited or defined by labels or diagnoses, and we are committed to reframing how society views mental health and disability.

Our vision is of a society in which disabled people and people with lived experience of mental health difficulties of all ages are afforded universal human rights, resulting in them being in control of their own lives as equal citizens.

Opening Doors, August 2023

Contents

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Introduction and background

In 2020, Changing Our Lives was commissioned by NHS England to identify good practice in learning disability nursing, publishing a series of examples of the work that nurses do and the impact this has on the lives of people with learning disabilities.[1]

This work identified a series of stories and experiences from a range of different service settings, but very few of the examples we were given focused on the work of learning disability nurses in forensic services. As a result, NHS England asked us to undertake an additional piece of work with nurses in forensic services in order to highlight the nature of the work and identify good practice.

The nature of forensic settings

By definition and because of issues of environmental security, the work of learning disability nurses with people in secure settings happens behind closed doors. It is a role that is not always known about or well understood, even by health and social care professionals in other parts of the system. Unfortunately, in recent years, examples of poor practice in these settings have made national headlines. When improving quality of life and health outcomes for people with learning disabilities it is vitally important that poor practice is exposed. However, it is also important that good practice is acknowledged, shared and learnt from.

Learning disability nurses working in forensic settings are part of a multidisciplinary team that has a responsibility to achieve a safe and caring environment for people with learning disabilities who have, in the main, experienced high levels of trauma and unmet need. *Opening Doors* acknowledges that changes need to be made to ensure the NHS achieves the aims of its national plan *Building the Right Support*,[2] and shines a light on the ways in which good practice by learning disability nurses can be part of making this happen.

1 Changing Our Lives (2020), *Best practice and challenges in learning disability nursing* [link] and Changing Our Lives (2020), *Resetting the narrative* [link].
2 NHS (2023), *Homes not hospitals: Building the Right Support update* [link].

Changing Our Lives spent time in four different secure hospitals around the country, meeting primarily with nurses, but also with families and patients. Using the *Learning Disability Improvement Standards for NHS trusts* as a framework,[3] we have captured the stories and reflections of learning disability nurses, which they feel constitute good practice. Many of these examples and experiences are about 'opening doors' for the patients they support, enabling them to achieve positive outcomes and move forwards in their lives.

The four standards concern:

- Respecting and protecting rights (meeting duties under the Equality Act and making sure that reasonable adjustments are made)
- Inclusion and engagement
- Workforce
- Specialist learning disability services

People with learning disabilities in hospital services

In February 2023 there were 2045 people with learning disabilities and autistic people in specialist inpatient settings in England, the majority of whom are in secure hospitals. Of these, 1,145 people (56%) have had a total length of stay of over two years. This includes 350 people who have been in hospital for more than 10 years.[4]

Changing Our Lives believes passionately that no one is too disabled to have an ordinary life. We know that many people with learning disabilities and autistic people in specialist inpatient services would not need to be in hospital if they had appropriate person-centred support and the right level of resources in their own homes.

We are therefore committed to supporting people to leave hospital as quickly as possible with the right support, and we are actively involved in achieving this goal through our advocacy and planning work alongside individuals, as well as undertaking research such as our NIHR study with University of Birmingham, *Why are we stuck in hospital?*.[5] We also work with people who have previously been in hospital to produce *Hospital to Home* books.[6] Showcasing the art of the possible, these stories demonstrate what people's lives are like now, and charts the practical support that helped them to leave hospital or to move to less secure settings.

Changing Our Lives believes that the current system has significant challenges and urgently needs to change. Reducing the numbers of people who are in hospital requires whole system change. We also recognise and have met people who have told us that they need to be in hospital for a period of time. While people are in hospital, they deserve the best care at what is for many an exceptionally low point in their life. Good nursing care in secure settings will therefore contribute greatly to people's experience of hospital, to their ability to leave hospital in a timely fashion and to preventing readmission. Good care benefits everyone.

3 NHS England (2023), *Learning Disability Improvement Standards for NHS trusts* [link].
4 NHS Digital (2023), *Learning Disability Services Monthly Statistics, AT: February 2023* [link].
5 University of Birmingham (2023), *Why are we stuck in hospital?* [link].
6 Changing Our Lives (2024), *Hospital to Home* [link].

Our approach

Changing Our Lives spent time in four secure hospitals, across low, medium and high secure settings. We spoke to learning disability nurses in a wide variety of roles. During these conversations, nurses discussed how they saw their role, highlighted the challenges they face and shared examples of practice that had led to real outcomes for the people they support. Following a conversation with one nurse about an example that had significant impact for the family of one person, we spoke to this family and their story is included.

The examples we have chosen to include here focus on the ways that learning disability nurses in specialist inpatient services make a positive difference to people's lives. Some of the practice we observed wasn't groundbreaking or exceptional. However, against a backdrop of challenges, both in the work needed to reduce the numbers of people in secure settings, and the individual examples of poor practice that have been highlighted in national news, we think it is important to highlight the scope and impact that good quality, consistent learning disability nursing can have.

Nurses and families in this project were starkly honest with us in describing the poor care that people with learning disabilities had experienced in their lives, both in previous specialist inpatient units and in other settings. We are well aware from our own work, and from national work to improve quality that there are still people experiencing this poor care.

Throughout this project, we heard lots of examples of positive practice and frequently asked the question: "*How can we make it like this everywhere?*" We hope that by showing what is possible when good nurses do their job well - using not just the knowledge and skills they have acquired through their training but through their own personal values and attributes - that we can contribute to a national conversation the responsibility we all have to ensure that people with learning disabilities and autistic people live an equal and ordinary life in their own communities.

The nature of the role

In our conversations with nurses, we asked them to describe their role as a learning disability nurse in just one or two words (see Figure 1).

Figure 1: What does it mean to be a learning disability nurse in forensic settings?

Building on these initial insights, subsequent sections of this report highlight the challenges which nurses face when trying to work in these ways, then share a series of stories with positive outcomes. While these illustrate many of the qualities from Figure 1, they also reveal a number of other qualities, attributes and contributions which shine through across multiple stories.

The challenges

The learning disability nurses we met identified a number of factors that make it harder to respect and protect people's rights and to practice in a person centred way. In particular, there were 8 main barriers that cut across a number of different people's experiences.

1. There aren't enough of us!

The challenge that was spoken about most often was that of staffing. Sometimes this was a general issue to do with lack of staff which just made everything more difficult. However, sometimes it was that there were not enough learning disability nurses on learning disability wards, with mental health nurses filling the gaps. This is a national issue with staff shortages across health and social care well documented, and the NHS *All-England Plan for Learning Disability Nurses* aiming to grow and retain the workforce.[7] Beyond these general challenges, however, nurses felt that the reputation of specialist inpatient care and the isolated nature of some hospital settings could be additional barriers, as could the complex and often challenging nature of the work involved.

2. Being based in larger mental health hospitals

The wards we visited were for people with a learning disability but were usually part of a much larger forensic mental health hospital. The *Mental Health Act 1983: Code of Practice* defines blanket restrictions as *"rules or policies that restrict a patient's liberty and other rights, which are routinely applied to all patients, or to classes of patients, or within a service, without individual risk assessments to justify their application."*[8]

Nurses felt that some blanket restrictions or hospital rules did not take into account the differing needs of people with learning disabilities or autistic people as opposed to those on the general mental health wards:

"For learning disability you have to think a bit differently."

"One size fits all doesn't work in learning disability."

This idea is discussed further in the story *Rethinking Blanket Restrictions* (see pp.14-16).

7 NHS Health Education England (2020), *All-England Plan for Learning Disability Nurses 'Resetting the profession'* [link].

8 Department of Health (2015), *Mental Health Act 1983: Code of Practice* [link].

3. Bringing colleagues along to work in the same way as us - reasonable adjustments are not optional

Another common barrier was the need to embed the principles of reasonable adjustments and person-centred approaches with other members of staff in different departments. For example, nurses frequently found themselves having to advocate on behalf of their patients with colleagues from security or infection control departments. However, this process could be lengthy, and inflexible adherence to policy and protocol in a range of different settings and for a range of different reasons, meant that learning disability nurses were sometimes overruled. One nurse spoke about the many months it took to get permission from security for a patient to have a DVD recording of their father's funeral, which they had not been able to attend, to help them with the grieving process and another about the difficulties in organising for one patient (in a single person service) to have guinea pigs in their garden.

4. We're always in the spotlight for the wrong reason

As mentioned earlier, there is considerable scrutiny of specialist inpatient hospital services, both in terms of policy and the media. At the time of one of our visits, there was a news report discussing the negative aspects of secure care, highlighting the distress felt by people and families. During the same news report there was discussion of someone who was living a much more ordinary life, in what appeared to be their own home, showing what was possible. What was omitted from the report was that this person was also living in a secure hospital setting, supported by an excellent team of staff, albeit in a single person service. Thus, hospitals were blamed for *"locking people away"*, but not praised for the work they had done to help someone lead a more ordinary life.

5. We've always done it like that

Some nurses felt that they were still working in a relatively closed culture and that change can be very slow. One nurse spoke about the barriers they faced trying to remove set times for drinks and snacks and replace it with patients being able to make a drink and get a snack whenever they wanted. The change took 12-18 months to bring about with huge opposition from some staff who had concerns about the risks of patients making their own drinks.

6. We don't have the freedom to respond in the moment

Nurses in secure settings operate under a legal framework, that was originally developed to keep patients, staff and members of the public safe. However, due to some of these restrictions and processes within secure settings, it can be very difficult to be spontaneous and react quickly to the needs of a patient. For example, when a patient is detained under the Mental Health Act, their leave from hospital (known as Section 17 leave) is authorised by a responsible clinician, and may come with conditions about how it is taken.[9] If someone suddenly wants to go for a walk it's not that simple. One nurse spoke about an individual who hardly ever wants to go out on Section 17 leave, but that when they do want to go, they need to go straight away. This causes logistical difficulties for staff as there is considerable paperwork attached to someone leaving the ward on leave. They can't take advantage of the good weather or of someone "*having a good day*" in a way that those supporting people in the community can.

7. Compassion fatigue

Some of the patients have come into the forensic inpatient setting via the criminal justice system having committed serious and at times distressing crimes. There is also a real risk of nurses being injured as patients react to the distressing circumstances in which they find themselves. Patients are often experiencing the lowest point in their life and have the label of 'complex' and nurses need to be resilient, empathetic and trauma informed in their approach to avoid compassion fatigue.

8. People shouldn't be here

Nurses were conscious of the fact that some of the people they worked with shouldn't be in hospital, or shouldn't be on a particular ward with a particular level of security. Some managers felt pressured into admitting patients even though they knew the environment was not the right one for them, simply because the alternative, for that person, would be less appropriate. When people were ready for discharge, nurses were keen for them to move on and to be living a different life outside of hospital. They were frustrated by common barriers and delays in the system which meant that people remained in hospital longer than they needed to be.

9 NHS (2022), *Mental Health Act* [link].

Stories of good practice

D and H's story

"It's the first time we have had a good night's sleep… in seven years."

This simple statement says everything about how D and H feel about the support their son, C is receiving at his current hospital and indeed a lot about how his support was in previous secure settings.

Recalling their first visit to C in his new hospital they spoke with wonder about how the room had furniture and pots of tea. *"Here it's like normal."* This was in stark contrast to visits at his previous hospital where he spent three years in locked seclusion. Family 'visits' took place either side of a locked door, with D and H speaking to C through a window. It was unthinkable that he would be allowed anywhere near hot drinks.

"If you treat someone like a proper person, they act like a proper person."

C is a caring and loving person with a real sense of adventure. Before his years in hospital he had wide-ranging interests. D and H spoke about the connection that nursing staff have made with C and the difference this has made to him and his progress. His favourite film is *Robin Hood, Men in Tights*. His named nurse S, went away and watched the film so that she could talk to C about it. A seemingly small gesture, but showed C that she was interested in him and helped to build the strong trusting relationship and relational security that is so important to his recovery. *"She can get him to do anything."*

One of the things that has stood out for D and H is the kindness and enthusiasm that staff show towards C. They described many reasonable adjustments that nursing staff have made to support C. Some of these have been in relation to his access to health care and daily routine - his named nurse spent time talking to the team administering COVID-19 boosters about how best to support C through the process; he goes for a walk around the grounds accompanied only by one female member of staff, against usual hospital policy. Other reasonable adjustments have added a richness to his life - arranging for 32 artificial candles for his birthday celebration; arranging for a camera to be available to take photos during a special celebration in the hospital chapel that could be shared with him and his family.

The thing that has made the biggest difference to D and H and what has finally led to them being able to sleep at night, apart from knowing that C is so much happier, is the relationship they have with nursing staff at the hospital.

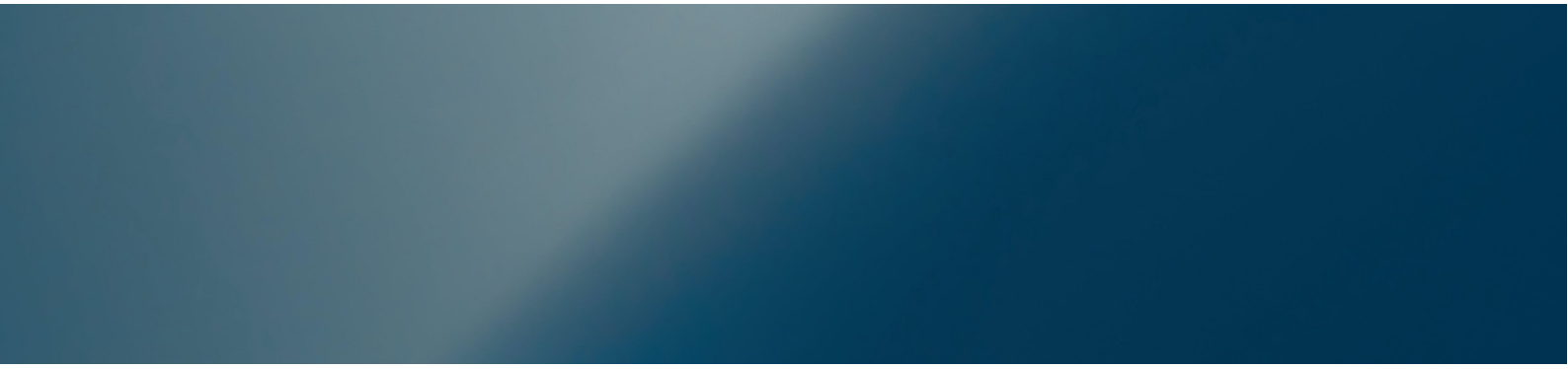
The tone for this was set at admission. C arrived at the hospital at the height of the COVID-19 pandemic and therefore had to isolate for ten days in his room. Staff spoke to D and H every day to let them know how C was doing.

Since then, D and H have continued to have a strong relationship with nursing staff. They spoke about,

"An openness to talk about what happens… A willingness to share… [this] makes so much difference to us."

During one visit, a staff member mentioned a blob tree as a tool they use with patients to help them identify how they are feeling each morning. When it became apparent that D and H were not familiar with the tool the nurse went away and brought back a blob tree to show to them.

D and H feel involved in C's care in a way that has not always been the case in other settings. As an indication of the open and honest relationship between the hospital and the family, and a willingness to listen, the hospital have since invited D and H to give a presentation at a forthcoming conference, an opportunity they are looking forward to, *"it's very therapeutic for us."*



Rethinking blanket restrictions

Clinical Nurse Practitioner, S, takes a creative approach to her role, which consists of a mixture of direct therapeutic work with patients and supporting other staff in their own practice. Some of her ideas are deceptively simple, such as using superhero origin stories to explore the experiences her patients have dealt with in their past, or introducing doorway discos into the hallways of a trauma informed ward, *"If the person next to you is dancing, you feel more relaxed and feel their intention is not to hurt you,"* S explains, describing the dance sessions as an opportunity to foster connection, turn-taking and empathy among the people she works with. People remember and request each other's favourite songs, as well as noticing when someone doesn't like a song and asking for it to be changed.

Despite the rules and restrictions inherent in a forensic nursing setting, S feels that patient engagement is even more crucial here than in the community. She says that forensic services are subject to a range of regulation, legal duties and inspection. Any restriction has to be documented precisely and discussed with patients. Every therapeutic decision S makes has to be rationalised and justified. For S, there are very few simple black and white decisions in forensic nursing, far more common are the grey areas, where an approach has to be rationalised and tailored to the individual.

An exception to these individual decisions are the blanket restrictions that each ward operates under. In the hospital where S works, there are some restrictions in place across the whole hospital, and others which are based on the needs of people in individual wards. S says the term 'blanket restrictions' may sound harsh, but we all live with blanket restrictions of some kind, the example she gives in the community is that of speed limits on the roads.

"We don't have to say we like going at 20mph, but we all understand why reducing our speed is important."

As well as the need for everyone to know and follow these restrictions, it's important that the blanket restrictions aren't just seen as *"the way we've always done things"*, so in the hospital where S works, they are reviewed regularly.

"Sometimes just saying something aloud makes you realise how ridiculous it is. We have a staff office on the ward with big windows. One of the restrictions was 'Do not look through the office window.' Windows are made for looking through!"

This was discussed with patients, and a new rule was agreed that patients can gesture through the window if they need to speak to staff, but that staff can't always come out immediately. In turn, staff were responsible for making sure that confidential information wasn't visible through the window.

For about 18 months, S worked with patients on two wards to review their blanket restrictions and to ensure that patients understood the rationale behind them. Every patient was invited to join discussion sessions, and those who couldn't access a group session were consulted with on a one-to-one basis. It soon became apparent that although staff may have one justification for why a rule was in place, this wasn't always obvious to patients who often had their own understanding of the rules. One was for all patients to sit in the communal area for 20 minutes after medication. While this was a useful precaution for some people, for those whose medication was a moisturising cream the wait felt pointless. Another was that patients could only access hot drinks at set times, despite staff being able to have hot drinks throughout the day. This was seen as needlessly restrictive, without reducing the actual risk of a hot drink being spilled. These rules were both removed.

Rules that worked were kept. Keeping a set time for snacks meant that activities didn't have to be stopped for patients to go into the dining room throughout the day. A restriction on walking around during mealtimes was kept. S was initially surprised that patients felt this rule should be upheld, but patients pointed out that depending on the trauma a person had experienced, they may feel uncomfortable if others were walking around with cutlery, and also that if cutlery went missing, it made it quicker to search the area around the seat with the missing cutlery than for everyone in the dining room to be searched.

"They're actually in those shoes, so they see it from a different perspective."

For S, what was more important than the content of the restrictions was the process of patients working together with staff to understand what works and why. Early discussion sessions started with staff answering questions before patients could. S encouraged them to step back and let patients lead the conversation.

"Too often in hospital the power indifference creates a them and us situation. The most beneficial thing was having this engagement and then following it up with action. People felt listened to."

Staff learned new things about the opinions and personalities of patients who previously had shut off from communication. Carefully curating conversations so that the quieter voices got their chance to be heard led to the team understanding individual trauma that may never have been explored or documented. Conversations about the rules were a vehicle for finding out what makes people anxious and why.

S feels that the power imbalance inherent in a forensic setting has been shifted slightly by these conversations.

"One person was so angry when he first arrived here. He would argue against everything. We've seen such a change in him since he became involved in patient engagement. He told me 'I think about my answers now. Now I'm thinking about other people.'"

As nursing staff, S says that she tries to put herself in someone else's shoes, but it's often much more complex than it seems from the outside. Being able to discuss these restrictions openly enables patients and staff to have more open conversations about other parts of their lives and lived experiences.

Since the discussions, S has created a 7-minute briefing for staff, and patients have created posters for new patients explaining the reasoning behind what a blanket restriction is and why we have them. New patients bring fresh perspectives though, and the restrictions will be reviewed again as things change. This patient engagement has now been applied to other areas and S feels that this is a really powerful tool for patients.

"If they are involved in the decisions we are making, they understand why things are in place, it makes it easier for them to follow the rules and gives them a feeling of responsibility for looking after themselves and others."

Unlocking life for H

S is the Neurodiversity Lead Nurse in a secure hospital, and says that all the people she works with have been through incredibly difficult experiences by the time they arrive.

"Everyone comes in with very low self-esteem. Everyone here has had a traumatic past. There is a lot of work needed to build people up again, but the one thing we have is the luxury of time."

When S first started her role she knew she never wanted to *"contain and control"* but rather wanted to use the power of the nursing role to make a positive change in patients' lives.

"As nurses we're there with the patient 24/7. We wake them up, we assess if they're fit for therapy that day, we administer medication, sort food, monitor their progress."

For her, the learning disability nurse in a forensic setting is a powerful link between patients and other professionals, and a key facilitator of the therapeutic process.

The nature of the hospital where S works means that the team needs to follow national policies and procedures for both healthcare settings and prison settings, and are audited both by HM Prison Service and by the Care Quality Commission. S feels that national policies and procedures are not always built around the needs of people with learning disabilities, let alone autistic people, and that following the rules without considering an individual would often mean that the person gets lost within the paperwork.

A 'rub down search'[10] was an example of a rule that caused extreme distress for one of the patients S worked with. When moving off the ward for any reason, all patients and staff are searched by a member of security staff of the same gender as them on all clothed areas, including their arms, legs and torso to check for contraband items. When COVID-19 restrictions were in place, the rub down search was changed in response to infection control measures. The ward was equipped with a magnetic wand, and patients were instructed through a self-guided search, which involved rolling sleeves up, taking items out of pockets or moving collars.

10 'Rub down search' is the term used in this setting for what is usually called a 'pat down search' in other settings.

H arrived on the ward after the COVID-19 restrictions had eased, when the rub down process was back to being conducted as normal. H has been in care most of his life and has historic trauma. He has very rigid thinking and multiple sensory needs which impact every area of his life. H can't take a shower as it feels like pins and needles on his skin. In hospital he takes a bath. In the meeting room, H can't sit on the chairs as they are too sturdy for him. He always chooses to sit on a bean bag. Over the previous years, H had found himself in more and more secure settings due to repeated breakdowns in communication between himself and staff. As they struggled to understand what his thoughts were, H displayed more and more frustration.

When he first arrived the idea of the rub down search was absolutely intolerable to H. He would threaten to assault staff if they tried to carry out a rub down search, and would end up refusing to leave the ward. He couldn't access the most basic amenities in the hospital, the shop, the library, or activity sessions. Without a rub down search H couldn't see his parents or his solicitor. Staff recognised that this was an urgent issue, as H's life was absolutely on hold. Most importantly, H couldn't access any medical appointments. Some healthcare was able to be done on the ward, but H was in need of an MRI scan, which he would have to leave the ward for.

A series of meetings were held among H's multi-disciplinary team to find a solution. Eventually, a more sensitive version of the magnetic wand was found, and it was agreed that H could do an instruction led search, as others had done during COVID. Initially this was granted as a temporary exception to the security procedure, with some staff expecting H to eventually get used to the searches and be able to tolerate the rub down search. S did a lot of work with the security team to get them to understand the impact of H's sensory needs and that he would likely never be able to tolerate the same rub down search as everyone else. As a compromise, S's team were asked to help desensitise H to the search in any way they could.

Finding a search that H could tolerate opened up a range of opportunities for H. He visited the hospital shop and library, went out on a bike and to music sessions and was able to get the medical attention he required. S escorted H on his first walk after he was able to leave the ward, and was struck by how many questions H had about every step of the process, from which way they were walking next, to which direction the gate would open. S realised that H's anxiety required an overwhelming effort to overcome, just to interact with his surroundings on the simplest level. For H, sometimes the toll of undergoing the search and doing an activity was enough to burn his resources out, after which he would spend several days in his room regrouping.

However, once H saw how the team around him were trying to limit the discomfort he felt and saw the opportunities that the search opened up, he agreed to try to work with staff to move closer towards the standard rub down search. He asked if he could choose staff that he trusted to do part of a search to see if he could tolerate it. The unknown is incredibly difficult for H, so the more he witnessed searches and built a rapport with staff, the more he was able to tolerate until he reached a point where he didn't need the magnetic wand and could tolerate a rub down search. This ability to tolerate the search was greatly impacted by the other pressures and anxieties H was experiencing. When his parents were able to visit him face-to-face for the first time in 3 years, H's anxiety about the rub down search reached such a heightened level that he almost cancelled the visit in order not to have to go through it. A member of H's staff team suggested that he could have the search in his room, and this was just the minor adjustment that made the search possible for H. When he finally saw his parents in person, H's face lit up.

After his success with the rub down search, H wanted to visit the hairdresser at the hospital. Because of his sensitivity to touch, the temperature of the water and even the shower head were changed so they weren't causing H pain. He told staff where to stand in the room so that he didn't feel overwhelmed by their presence, and H was able to achieve his goal of having his hair dyed blue.

For S, H's story is a reminder that policies are only as good as the people they serve. Following the rub down search policy to the letter would have prevented H from having a life. Seeing H's individual needs was what gave him the framework he needed to reach his end goal. S admits that the process wasn't perfect, but that the consistency and openness staff displayed allowed them to build a working relationship with H that allowed them to rethink mistakes and come at them from a different angle. For H, seeing the willingness of staff to cooperate with him gave him the trust and confidence to have honest conversations about his own care, it showed him that his care didn't have to be done to him, but that he was an expert voice among the professionals he was working with.

K's story

K is a young woman. She spent a number of years in hospital. Her family were very involved and were both very supportive and very critical of the hospital team. They questioned decisions that were made around restrictions for K. The family were very well connected and very strong advocates but there was a lack of clarity around roles and sometimes they made decisions that weren't theirs to make.

The family advocacy made the team challenge their own decision making and brought about a real change in culture leading to a considerable reduction in restrictive practice.

K used to engage in risky behaviours which led to her team being very risk averse. Her behaviour closed the door to community leave. If there was a serious incident, the culture on the ward demanded a period of stabilisation on the ward of 3 to 4 days before resuming community leave.

When the team really thought about why this was the case, they realised that K didn't need a period of stabilisation. They moved to a situation where, if there was a serious incident in the morning she would still go out in the afternoon. Her escalation to doing something very risky happened so quickly that the risks were no greater in the afternoon.

The ward organised some circle of support sessions for K with an external facilitator. They realised during these sessions that what her parents wanted for K and what the ward team wanted for K were different but crucially they were both also different to what K wanted for herself. They used the sessions to have open and honest conversations with her family and to clarify everyone's role in K's support. Most importantly they began to really listen to K and focus on her goals.

For example, K was very overweight. They had considered lots of different options to support her with this, including what they saw as more person-centred options like getting her a personal trainer. But when they really listened to K, she didn't want to lose weight as she didn't feel ready yet.

Instead they worked on her goals. She began to go to her local youth zone as she wanted to meet other people her own age. This was a massive shift for the team as it went against hospital policies and procedures. There was a blanket restriction in place that meant patients did not mix with children. When her team thought about it, they decided this was not a risk for K and they advocated hard for this to be allowed. They worked with the social work department, hospital managers and the manager of the youth zone to enable this to happen.

They supported her to set up social media accounts. They had to work with security on this as this is not usual practice in a secure hospital. They also worked with infection control to enable her to have a hamster.

G, the ward manager at the time, was open and honest about the fact that the work with K and her parents brought about a massive shift in culture of the team and really made them question restrictive practices.

This shift in culture and the open and honest relationship with K's family led to a collaborative partnership resulting in K's discharge from hospital.

The legacy of this collaborative work continues. It has led to the nursing team being more open to try new things and to constantly question, *"Why not?"*

G said, *"We don't always agree to everything that is suggested but we spend more time thinking through before making a decision… Even now I still say to myself 'What would Mr and Mrs W say?' when faced with a decision regarding someone's care and support."*

M's story: An example from Rampton Hospital

This is an open and frank account of one individual, referred to here as M, who has been a patient in Rampton Secure Hospital for the last 18 years. M's story was written prior to the *Opening Doors* project and came about through an agreement with Rampton Hospital to highlight an example of an individual being supported to move beyond restrictions. It differs from the previous examples of good practice as the real names of key individuals working with M are included.

The account is based on conversations with staff members and reflects how positive moves were made to change the culture around the individual from one of fear and demonisation to a culture in which the individual's *"violence"* became understood as communication and person centred interventions were put in place in a high secure setting which by its very nature has restrictions which limit individual freedoms.

It is important to acknowledge the complexity of issues and myths that surround Rampton. Patients in Rampton are more often than not stigmatised, subject to prejudice and painted by the media and often the public and professional imagination as violent and beyond rehabilitation. Individuals ready to leave Rampton may be perceived to be too high risk and better left within the confines of a high secure setting. Social care providers may be hesitant to support individuals to move on, seeing the potential risk before the person.

"As a person M's really funny, very friendly and affectionate. M grabbed me the other day and got really close and looked me in the eyes. It was great." - Billy

"M is a really kind person and very loving. He can get unhappy but now he is generally very happy." - Lisa

"M can be really bubbly, funny and cheeky." - Jamie

"You need to know when to back off and give M space just like anyone. You don't push anyone to do anything, so why should we force M to do what he doesn't want to do? In three years I've only seen one incident with M. Shouting is an incident is it? M seems to have a connection with me which is great." - Billy

M was first admitted to residential care aged 16 after a few difficult years in a mainstream school where he experienced severe bullying. Prior to this M had been diagnosed with special educational needs aged 13 and had attended a special school but when the school was closed he was transferred to mainstream provision. By age 22, after a series of criminal incidents, M was admitted to a medium secure unit and a year later transferred to Rampton as the unit was finding it difficult to manage M. M was diagnosed as having a learning disability and schizophrenia but it wasn't until 2018 that he received a diagnosis of autism.

First experiences in Rampton

When M arrived in Rampton he was treated the same as any new admission. Staff attempted to engage with him in the admission process, however, he refused to engage with staff and the admission process was never completed. After the first few months M ended up in seclusion a great deal and as a result he was moved to an individual suite with five staff. After 12 months of significant assaults and injuries a decision was made for staff to wear protective equipment which from M's point of view looked quite intimidating, a face visor, protective vest and limb pads. M was very fit and very flexible and despite staff wearing protective equipment he was still able to inflict significant bodily injury which resulted in further criminal charges.

Over the years M became demonised and staff were fearful of working with him. M ended up in an automated unit, where physical distance from staff ensured less injuries. M lived in this automated unit for 3 years. He moved to his present room in June 2010 which is also automated but within a ward environment rather than an individual suite.

Dismantling a negative culture

Bringing about a shift in culture needs challenging and brave individuals who are passionate and willing to take a lead and set an example to others. M had several key individuals who were part of his life who worked to gradually create a climate where cultural change was possible. These individuals were Sarah Foster, Lead Nurse, Rachael Humpston, Lead Occupational Therapist, Mick Taylor, Staff Nurse and Jonathon Slater, Consultant Nurse.

"It needed someone to take these risks in order to change the culture and Sarah and I both did this." - Jonathan

In summer 2017 Jonathan attended M's Care and Treatment Review. When Jonathan looked at M's care he found that M had a reputation for doing significant harm to people. As staff knew that M was averse to forced medication and treatment, gradually over the years staff had stepped back and as a result there was limited staff interaction. Or else when there was interaction, staff were on full alert.

Jonathan was keen to improve the quality of life for M and change the culture and myths that had developed around him.

"M is a lovely person. He is an absolute gem. You can have such a good time being with him. Some people just saw a monster. I wanted to change this." - Jonathon

So Jonathan took his concerns to the governance group and a quality improvement plan was put in motion for M.

"In all of the work that went on around M, M was missing. No one really knew the real person." - Jonathon

Then in 2018 Sarah Foster became M's named nurse. By this time, M was beginning to come out of the automated unit and staff had begun to make his rooms more personal. Speech and Language Therapy was brought in to work with M and a suite of different communication approaches were used including intensive interaction, a range of visual resources, now and next boards and social stories. A Communication Passport was also developed.

"M is very needs led in his communication with others. He only chooses to interact with others when he wants to. If he doesn't want to speak to the person, he will put his tongue in front of his teeth making it impossible for the individual to understand what they are saying. However if he wants to speak to you, he will be quite easily understood." - Sarah

At the same time, an assistant psychologist explored M's history, reviewing all of his history that had been forgotten.

"This whole process helped staff become more confident and more understanding of M." - Jonathon

The first turning point

Jonathan took this history to the staff team so they could get an appreciation of the context of M's life and some of the underlying reasons for M's violence. This was seen by staff as a significant turning point.

Second turning point

Jonathan started to turn up on the ward and ask staff to unlock M's door but staff were still reluctant as they felt unsafe. However, as the ward now had Sarah on it and some of the younger staff who didn't know much of the previous culture, they were very supportive of M coming out of his room. One day Jonathan, Sarah and Billy went into the ward day room with M and turned the TV on. M kept turning the volume up and he put his hand on Jonathan's shoulder and started to swear loudly. The hand never squeezed his shoulder and Jonathan wasn't afraid but knew that M was trying to tell him something, he just couldn't understand what it was.

After a while M took his hand off Jonathan's shoulder and backed away and Jonathan worked out that all M wanted was to change the channel. After this at least six or seven staff came up to Jonathan and were puzzled at what he was trying to do, thinking he was in danger. They felt M should have been managed differently after this, howeverJonathan, Sarah and Billy knew this was just M trying to communicate what he wanted.

"M's style of communication had become part of the myth that surrounded him, painting him always in a negative light as risky and an individual who posed a threat. He was simply saying that he needed to watch a different channel." - Jonathon

Following this, Sarah and Jonathan got together and started with a fairly basic ABC chart to record behaviours. They found that roughly 95% of his *"aggressive behaviour"* was simply a form of communication. There were some times where there was violence present but these times were minimal. Jonathan and Sarah shared this new approach with staff and gradually the staff learnt when to step back and appreciate that M was merely trying to communicate, resulting in staff becoming less restrictive.

"We knew that if M was agitated, we needed only minimal staff to dampen down the situation. M will often find himself in fight or flight mode and if he chooses to fight, having more staff around means the situation escalates." - Jonathon

It is at this point that a case was made for M to have an individual key worker. The key worker spent time with M between 9.00am and 4.00pm each day and modelled how to work with M for other staff members. The appointment of a key worker happened at a time before the specialist autism service was established, so is considered by staff who know M well as a crucial intervention.

Third turning point

Then Sarah started floating the idea of M's door being unlocked. One day when M was being weighed staff were trying to set the weighing machine up for him but he communicated quite clearly that he was able to set the weighing machine up for himself and weigh himself. After this M went back to his room and closed his door and with encouragement from Jonathan he spun the top lock on the door and after a couple of minutes he was able to close it. As staff saw it, M was gradually showing that he could learn how to lock and unlock his own door and retain this knowledge and skill. So from this point onwards M had more freedom.

Life in 2022

From 2021 after 15 years in segregation, M is no longer segregated. He comes out of his room when he wants, except from 8.15pm until 8.45am when his room is locked like all patients in Rampton. He also joins his peers when he chooses to in the dining room for meals. He accepts his monthly health checks and makes requests for physical health needs to be met.

"M's doors are always open and he is no longer segregated. Recently he came out for his birthday and the other patients sang happy birthday to him." - Lisa

"It's now a world away from where we were with M." - Sarah

"For the first time I sat with M in the dining room and had a coffee with him. I also sat in his room with him with his door open and I ate dinner with cutlery. This would never have been done years ago." - Jonathan

"M will come out of his room for a drink and to get a snack. He might have his drink and snack in the main area but then he will go back to his room. M feels very calm in his own space." - Jamie

"M has done exceptionally well. He is now very confident coming out of his room and sometimes wants to socialise with other people." - Lisa

M now only needs one member of staff with him. M can do his own washing and tidies an area of the garden.

Although the room M is in started off as a segregated space, M describes his room as his 'flat' and staff now see it now as his safe space where he is comfortable. However, that's not to say staff are not encouraging M to have a life beyond Rampton and there are currently plans and discussions in place around this move with commissioners.

M will go for walks around the grounds and chooses which staff he wants to do this with, as he has certain staff he prefers and he associates with going outside.

"The first time he went outside in years he was trying all the doors to explore different parts of the hospital. He was really inquisitive but you would be after being inside for all those years." - Sarah

Relationships

Building trusting relationships is at the heart of the team's approach to working with M. In order for M to trust staff, the team worked to enable M to build his self-esteem by showing him that he was understood, and that they were interested in him.

"Building relationships with M is the most important thing. This makes modelling difficult because although new staff members can learn the ways to communicate and work with M from existing staff members, as relationships are all important what one staff member can do with M, another staff member can't as M will make the choice of how he wants to work with you." - Sarah

"I think it's great that relationships with staff have built up over time and M now has key staff that he really trusts. Years ago M had a reputation for being very violent and we had to wear protective clothing to work with him." - Lisa

"We found a group of staff who will positively risk take and we wrap this group of staff around M. This risk-taking is based on a solid bank of evidence." - Jonathon

How staff see M today

"Staff see M very much as a person now, in the past they just saw the risk." - Sarah

"When I first met him, you couldn't have conversed with him. You couldn't get into his room and you couldn't get him out of his room. Now you can have a conversation with him. He comes out of his room and goes for walks. He has come on leaps and bounds." - Jamie

"We went for a walk on Sunday. He said he didn't want go out because he was scared and he asked if I could hold his hand. When I held his hand he was happy to walk. There is only one other male staff member he's ever let do that." - Jamie

"I've heard some horror stories but I've never felt uncomfortable around M. In the last year there has been nothing but progress. M's social interactions have improved as he now talks to staff. M's room is definitely his safe space and now he comes out five or six times a day." - Billy

"M definitely knows what he wants and he'll tell you what he wants in his own way. It's definitely not advisable to block his path, if he has something to do he goes and does it and then wants to get back to his room." - Billy

Key qualities

Reflecting on the good practice examples given in the previous section, there are a number of qualities and attributes that struck us as being at the heart of work and the roles of learning disability nurses. Nurses who make a difference for their patients are:

Curious

In an environment where it is far easier to say 'no' than 'yes', change was brought about for patients by nurses asking one simple question: *"why?"* In one setting, nurses spoke about this curiosity being prompted by strong family advocacy.

A family member asked the team, *"Why can't they do that?"*

The nurses began to ask the same question. This led to a young woman trying new things and in time to being discharged.

Resilient

During our visits we met some extremely resilient nurse leaders. They gave examples of instilling this same resilience in the teams they led. One nurse leader spoke about the tool they use to detect early signs of stress and burnout. They support ten people in individual packages, each with their own staff team. This can be very intense for team members. Nurses always discuss burnout in supervision. They use the stress and burnout tool when necessary but always if there are a higher number of incidents in an area than usual. Staff are moved from a team if they request it or if early stages of burnout are detected. The nurse leader explained that a quick and honest response to a team member who is struggling means that staff are happy to then rotate back into the team after a period of time working elsewhere.

In one team they were struggling to maintain a stable core team due to the high level of intensity in supporting an individual. The nurse leader recognised that staff sometimes just needed somewhere to go for five minutes to take a breath. They created a small space within the property for staff if they needed a brief pause.

Another nurse spoke about how important everyone in the team's voice is.

"Everyone who works with B, their voices are important."

One nurse team leader spoke about the fact that he does drama with one individual so he has some insights that others don't have. Other members of the same team have different relationships and different connections with the individual, so they too see different sides to the person.

One nurse leader spoke about the regular breakfast meetings they have with teams. They focus on a different individual each time, presenting their formulation and reviewing their PBS (Positive Behaviour Support plan) with the whole team. Meetings are held at this time to capture both day and night staff.

In depth training, focussing on a person's formulation that included the whole team from health care assistants to hospital managers, from local area commissioner to the person's family has meant that everyone involved in the person's care are on the same page and all have the same understanding of the person.

For one individual this has meant that staff expectations are lower. The person does not *"have to"* go out every day or a certain number of times a week. Staff are confident in their abilities and in the decisions they make and the person is much happier.

"They display endless empathy and care. Resilience is high."

In one service there appeared to be a real focus on trauma informed care. All staff complete an annual two day physical intervention training course. The first of the two days is devoted to trauma informed support so staff are consistently reminded of the reasons behind behaviours of concern.

Leaders

One ward manager spoke about how they slowly changed the culture on the ward. He wanted patients to feel listened to and for them to build trust with staff. He acts as a positive role model for other staff by always trying to ensure a positive outcome when patients ask for something: ***"Yes means yes."***

Patients slowly started talking to staff and telling them, however they could, what they needed. This approach also reduced restrictive practice.

One patient regularly destroyed the remote control from the TV and inserted a component into his urethra. Whenever that happened the previous response would be to strip his room of everything. But this didn't help. The ward manager changed the approach. When it next happened, instead of stripping out his room they left everything as it was and gave him another remote. He responded to this much more positively and a conversation began about why he was doing it and what he needed. Now he will hand something over that he could use to self harm if he feels he might use it.

Another patient didn't like to sit with other people at mealtimes. There were often issues where he would throw his meal or other things and be very disruptive. The ward manager changed the approach and now he sits by himself at mealtimes and there are fewer incidents.

This approach builds trust.

Tenacious

One nurse spoke about J. He had a long history of being in and out of seclusion with frequent incidents of attacking staff. J moved from low secure to medium secure and at one point a referral was made for an assessment from high secure services. He found the environment of medium secure very challenging and his clinical team were very concerned about him. He had a change of medication which helped and moved back to low secure, welcomed back by his old team. He is now in transition to move into the community, however he is scared of leaving his team which is impacting on his transition. The transition could have fallen down at any point but two nurses in his team are absolutely determined the transition will work. They have reassured him that he can ring up whenever he wants to. They have fought hard for extra transition money so that the transition can (*rightly*) go at his pace.

"We stuck with him."

Creative

One individual smeared faeces in their room when they were annoyed or distressed about something. Nurses arranged for one of his walls to be painted with blackboard paint and gave him lots of chalk. Now he writes his protests down (with often very *"colourful language"*). This has reduced the episodes of 'dirty protest' and also enabled staff to talk to him about what is annoying or distressing him as they can read what he has written. Typically he will then rub it off.

There is a service reconfiguration at one hospital with a ward closing, meaning there is a concerted push for everyone to be discharged. A number of the women are very anxious about leaving. They have been in hospital (and indeed together as a group) for a long time. The nurse has invited a woman who has been discharged fairly recently and is living in her own home to come back for coffee and to talk to the women about what it is like to live in her own place in the hope this will help to alleviate their anxieties.

Reflective

Although some nurses still felt they were working within relatively closed cultures, others spoke about changes that had come about for patients as a result of openness. This ranged from open, honest conversations within teams, to regular reflective practice sessions led by nurses, to inviting parents to provide training for staff in how best to support their son or daughter.

"There is a culture of openness. Where we have got things wrong you can say, 'it was our fault, we got that wrong.' You can openly say that."

"There is an openness to talk about what happens [and] a willingness to share."

Reflective practice was mentioned by many of the nurses we spoke to. In one hospital a couple of nurses were speaking about a team on another ward that they admired. They spoke about the fact that the team start by asking patients *"What is it that you want?"* They build on what is most important to the patient with a belief that there is *"nothing that can't be achieved."*

This ethos was evidenced on the day of our visit as one patient was going for their first driving lesson.

When we asked these nurses what made the team they admired such a strong team they gave the following responses:

- Good leadership
- Open
- Transparency
- Supervision
- Debriefing
- Reflective Practice

And they, themselves reflected that these factors, many of which overlap, created a culture of trust.

Mediator

Several nurses gave examples of the importance of building good relationships with other professionals. In one instance this was with the case workers from the Ministry of Justice who were instrumental in someone being granted additional leave (a key moment in someone's journey towards discharge). In another instance this was with the acute liaison nurse at the local general hospital where patients were frequently transferred for physical healthcare.

"Collaboration is key."

Person centred

A phrase that is easy to say but perhaps hard to achieve in a secure setting, some of the examples were were given and some of the attitudes we heard expressed illustrated that some nurses were genuinely providing person-centred care within the confines in which they were working. Sometimes this came in the form of a reasonable adjustment (see Figure 2).

One person needed dental treatment and it was required that everyone in the room would need to wear close fitting face masks for infection control. This person has a small team of staff that he feels comfortable with, but all of them had beards. His team shaved their beards off so they could safely support him to access dental treatment.

One person has suffered significant trauma in their past. His behaviour can be difficult to manage especially if they become distressed or have "a meltdown". The nurse acknowledged that whenever an incident occurs, particularly out and about, the person's reputation is damaged. She strongly believed that he should be able to visit his family and go out and about in the community, within the restrictions of leave.

On one occasion, whilst he was out, he spilled a drink. This re-triggered his trauma and he became incredibly distressed. The response team were required to get him back to the hospital safely.

The team reflected on the incident and realised that due to his trauma it was very difficult to predict when something might happen that would cause him to "have a meltdown". They wanted to ensure he could still go out whilst also protecting his reputation from further damage.

Rather than ban all leave (not an uncommon response in similar situations) a member of the nursing team suggested using a vehicle with a toilet and a sink as well as taking a comfort pack that he could use to get clean if anything was spilled. This reasonable adjustment means that he can continue to build up his leave. He now goes out to visit his family every other week and is going to a family wedding soon.

Figure 2: Examples of person centred care.

At other times this was expressed through their attitude when talking about an individual they were supporting.

"The golden thread was stepping into V's world. We have our policies etc., but she's not aware of that."

When talking about someone who was afraid to leave hospital, nurses said they focused on what was the most important thing to her - her relationship with her son. They worked hard to help her develop her relationship and helped her to see that she would see more of her son if she left hospital.

Summary

The learning disability nurses we met through this project had one more quality in common: they were humble. It was in fact quite difficult to get them to talk about things they thought they were doing well, even amongst those in the most senior positions. As a group of nurses they do not shout loudly about what they do. It is not clear why this is the case but looking back at the challenges highlighted earlier in the report could go some way to explaining their reluctance to promote their work.

As the smallest field of nursing practice, learning disability nurses are a scarce commodity. As a result they are sometimes in the shadow of their mental health colleagues whose numbers dominate the hospitals they work in, they are trying to deliver person centred care in a system governed by rules, regulations and the law and the impact of recent exposés into poor standards of care within a number of specialist inpatient services places further scrutiny on their roles.

However, from speaking to learning disability nurses as part of this project it was clear to us that they are a key asset in bringing about change for people with learning disabilities. When done well, learning disability nursing is tenacious, person-centred, rights based, creative and resilient. As part of a wider multi-disciplinary team, learning disability nurses are so often the constant figure in a person's life in an inpatient setting. As one of the nurses we spoke to said, *"We're there 24/7 with the patients."* From waking a person up and supporting with medication and food, to checking whether the person is in a good frame of mind to engage with therapy, from expertly getting to know the sensory world of the person to supporting them through difficult conversations with people in their lives that they are trying to rebuild relationships with, the learning disability nurse is often the member of the team who knows the person and their priorities inside out. This may not always be the image that we conjure up when we hear the words 'learning disability nurse', but for people with learning disabilities and autistic people going through arguably one of the most difficult experiences of their lives, the consistent, practical and patient presence of a learning disability nurse can make all the difference.

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