

Resetting the Narrative: What Learning Disability Nursing Means to Me

Stories from people with a learning disability, autistic people and their family members

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Changing Our Lives



Changing Our Lives is a rights-based organisation that works alongside disabled people and people with lived experience of mental health difficulties, as equal partners to find solutions to social injustice and health inequality.

Even today, people with learning disabilities and autistic people continue to face significant health inequalities in the UK. They are still more likely to receive poor quality health care; are less likely to be able to access mainstream health services; and continue to die younger than the general population. Far too many people are still in inpatient settings because their needs have not been met in their communities.

Changing Our Lives is committed to raising awareness of health inequalities and sharing best practice so that the standard of healthcare can be raised for all people with learning disabilities and autistic people everywhere.

Introduction

Health Education England commissioned Changing Our Lives to compile a range of stories from people with a learning disability, autistic people, and their families, all foregrounding the impact made by learning disability nurses on their lives.

Rita, Marc and Dylan's stories showcase how the learning disability nurse makes healthcare personalised to the individual, ensuring that their specific needs remain at the forefront, through reasonable adjustments and on-going negotiation within the healthcare environment. All three stories demonstrate how these interventions not only result in improved outcomes for the person's physical health but also an improved quality of life overall.

Bethany and Matthew's stories speak of how learning disability nurses play a vital role in the work of Transforming Care, moving people trapped in hospitals into their own homes or surroundings that are facilitating a move to their own home.

Roxy and Joan's stories are an illustration of the important role played by learning disability nurses in championing the mental health needs of people with a learning disability and autistic people. More often than not, mental health is not fully recognised by the wider health and social care environment. When practitioners meet a person with a learning disability or an autistic person, the individual is typically reduced to the label of learning disability or autism, and thus the significance of their mental health, which is a universal aspect across all our lives as human beings, is overshadowed and dismissed.

Mary and Ronnie's stories are a testament to the vital importance of working in co-production with people with a learning disability and autistic people. Whether it be co-design of services, or co-delivering training and evaluation of health provision, people with lived experience need to be seen as equal and essential partners.

These stories were sourced from across England, and capture only a snapshot of people's experiences. We know there are far more examples and far wider themes within learning disability nursing than one book can contain but in compiling these stories we hope to have made a start.

Personalising healthcare and using reasonable adjustments

Marc's story

Marc has been supported for several years by Sarah Pope, an acute liaison nurse. Sarah first met Marc when working for Chase Hospital, which subsequently became part of the Royal Free NHS Foundation Trust. Sarah now works as the Safeguarding Adults Lead Nurse at North Middlesex University Hospital. While working with Marc, Sarah has facilitated a range of reasonable adjustments; liaised with other hospitals; and, as Marc's mom explains, shared her knowledge that meant Marc could have his voice heard. This is Marc's story, as told by his mom.

Marc is 29 years old and lives at home with his family. His keen interest in sports has developed since his young days when I took him to watch gymnastics while I coached. Dates are set in his diary a year in advance to watch his favourite events including gymnastics, synchronised swimming and figure ice skating. Together with his personal assistant (PA) his passion for sport has taken him as far afield as California to watch The Four Continents Ice Skating. Closer to home Marc has visited sporting events all over the country but definitely prefers it when they are far enough away to need a hotel stay.

The Paralympics in 2012 was going to be a busy year for Marc's diary. It also became a year when Marc would begin a very important relationship with Sarah who is an acute liaison nurse working at his local hospital, The Royal Free NHS Foundation Trust.



When an unusual lump was noticed Marc knew, after talking things through with his family, that he needed to go to the GP to have it checked. Marc was not in any discomfort but understood that it still needed to be looked at. The GP examined him and referred him for an urgent ultrasound scan. A couple of days later, as I already knew Sarah, I decided together to go straight to the local hospital to discuss the appointment with her. Sarah told Marc and I where to go for the ultra sound and that she would be there to meet us when we arrived. As promised she was there to greet us and we were called in straight away, as Sarah was able to make sure we didn't have to wait. Later that evening I received a phone call confirming our suspicions that Marc had testicular cancer. I chatted to Marc and we agreed that it needed to get sorted to get "rid of the bad bit".

Sarah was ready with information, visual aids and the right words to talk to Marc about his diagnosis, gradually building up a portfolio of information for him to use. Marc understood that they needed to get rid of the "bad bit", was well informed about who he would meet next and what would happen before every appointment. He chose to be accompanied by me and his PA during these appointments.

At his next appointment Marc's PA was able to administer some of the tests that were needed before his operation could take place and Sarah was able to be in the background making everything seamless and normal, allowing me just to be there to support my son. The portfolio of visual aids, clear communication and preparation that Sarah had put into place with Marc at

the centre meant that he was able to face his challenges in a calm and well informed manner.

On the day of his operation Marc was first on the list and walked down to theatre fully dressed, with me by his side. When he woke he was fully dressed, again with me by his side. This was so important to him and had all been talked through and agreed upon with Sarah, making sure Marc's needs and wishes were acted upon at every stage of his journey. As he opened his eyes I was the first one he saw and I told him,

'It's all gone, the bad bit'

Marc looked at me, closed his eyes and slept peacefully.

In 2013 Marc discovered an unrelated tumour. Sarah was there again to give Marc all the information he needed to understand the procedures that would follow, including a meeting with the person who would be administering the treatment. She took pictures of the procedures and people that would be involved in his care and made sure that he knew who would be next on shift. As he was looked after in the teenage cancer unit at the University College London Hospitals NHS Foundation Trust and his medication was in a backpack the feeling was more like being in a hotel than a hospital, which was particularly suited to Marc. He even felt relaxed enough to take advantage of a photo opportunity with visiting boy band Blue. Sarah's chart enabled Marc to tick off his days of chemotherapy so that he knew exactly what was still ahead of him. He was also able to use a scoring system of 1-5 to indicate where his pain level was in order to receive the right medication and support.



When further treatment was needed and Marc was referred to The Royal Marsden, there was a side annex ready for him and the TV had already been tuned into his favourite YouTube gymnastic channel.

The knowledge that Sarah gave me meant I made sure Marc had his voice heard. It couldn't have gone any better.

This trusting and empathetic relationship was also felt by Marc, as expressed when he sees Sarah as he always goes flying over to her.

Sarah even made sure that the district nurse who visited was male, as Marc preferred.

The teamwork people displayed was what made Marc's experience so good. Marc was at the centre of the team supported by the acute liaison nurse, informed and prepared to make the right decisions and choices to enable the best outcomes.



Sarah Pope reflects on her work with Marc and the role of a learning disability nurse.

The first time I met Marc and Jane was at the Chase Farm Hospital Ultra sound department. We had a number of telephone calls prior to the appointment and I quickly realised how important it was going to be to get things right first time. Having the ability to be able to quickly assess a person's learning disability needs and what reasonable adjustments need to be in place is just one of the many qualities of a learning disability liaison nurse.

In this case I needed to make sure the sonographer was aware of Marc's needs and how they were going to need to communicate with him. It was also important to ensure we had cleared the area to make space for Jane, who needed to be there to provide Marc with constant reassurance and support.

From that first meeting I was then able use the knowledge obtained to prepare the staff in each area and department to successfully support Marc for the further investigations and treatments. We even arranged for Jane to be in the CT Scanning room talking Marc through the whole process from behind the glass screen. On one occasion it was necessary for Jane to be present for the CT scan with Marc as he was very anxious about having the contrast injected into his arm. We planned this session with the radiography team and talked through all of the options and risks. Although Marc was able to understand this was an important procedure to have, as a clinical team, alongside Jane, we all agreed that Marc did not fully understand the complexities of the need for a CT with contrast and therefore we completed a Mental Capacity Act assessment and a best interests decision. As part of this process we explored the plan for Jane to be in the room with Marc, including the risks to Jane. The procedure went ahead with no delays and was successful. Jane was also able to be in the anaesthetic room when Marc was sedated for surgery and there in recovery when he woke up.

Being able to support Marc and Jane so quickly and working with the clinical teams to put the right reasonable adjustments in place reinforced their confidence and trust in me as the learning disability specialist.

This continued after his surgery when care transferred to the University College London Hospitals (UCLH). At that time UCLH did not have a learning disability liaison nurse and I was given permission to continue to support Marc at the Macmillan Teenage Cancer Centre where he had his chemotherapy. The team at UCLH was excellent and really welcomed the support to understand Marc and his learning disability. It made a huge difference to the way in which care was provided. We developed a care plan, with easy read information about each process and procedure, we took photos of all the staff so Marc knew the faces of those who he would be working with every day he was there.

We also developed pain tools and other resources to support the staff to recognise when Marc was feeling unwell or when he was getting upset, angry, wanted to be left alone etc. These were invaluable during his chemotherapy and supported the staff to provide safe consistent care but also allowed Jane to be mom to her son. This was particularly relevant during the chemotherapy when Marc was experiencing horrendous side effects. We had already discussed with Marc what the side effects may be including vomiting, hair falling out etc so when he had them, both he and Jane were not surprised.

We continued this way of working throughout his patient journey for his cancer care including outpatient appointments, PET scans and further investigations.

The relationship I developed with Marc and Jane has continued over the years. Any new health issues Marc has, Jane is on the phone asking my advice and relies on me to help her learn all she can about the condition to ensure staff and those around Marc are able to provide reasonably adjusted support. I have also been able to put her in contact with other acute liaison nurses within other trusts where Marc has had appointments and act as a resource to them and share what works!

It is so important for the acute liaison nurse to not only be there as the expert in learning disabilities, supporting and directing the staff to understand the person's needs and provide reasonably adjusted care, but also to provide support to family members and carers who have often spent their whole lives explaining their cared for person's needs. To have someone on your side who understands the learning disability is priceless.

Rita's story

Rita's story illustrates how the Health Facilitation team from North Staffordshire Combined Healthcare NHS Trust worked with her son to improve the quality of his healthcare. The reasonable adjustments they facilitated ensured that Rita's son, who cannot tolerate physical touch, was able after 6 months of desensitisation to have blood tests.

My son is 38 years old and he lives at home with me. He has a learning disability and is autistic. At the age of 18, he was diagnosed with epilepsy as well. Because of his autism he doesn't like to be touched, I don't know why, he just doesn't. For many years the GP has wanted him to have a blood test to check his health and that his medication is working as it should. People have tried over the years but my son has been too frightened.



The health facilitation nurse came to us after a referral from the consultant psychiatrist. She talked to me about blood test desensitisation and what is involved. The nurse then met with the day centre manager and key worker to involve them in this process. The key worker included 2 sessions every week into my son's timetable and it took over 6 months for him to be ready to try having an actual blood test.

Then the nurse contacted the GP and he provided the blood card, adding in a few extra tests to monitor his general health such as high cholesterol and diabetes. After a visit to the local health centre's blood clinic, we found out that his veins were really hard to find, so the nurse then arranged with the phlebotomy manager at The Royal Stoke Hospital for my son to have his bloods taken there.

The hospital made sure that my son didn't have to wait long and that he could be supported by his key worker and nurse too. Other reasonable adjustments included the collection of capillary blood instead of venous blood and the use of paediatric sized collection bottles. This meant that not as much blood was needed. My son coped so well at the hospital and at no point was any kind of restraint used. If he had become distressed at any time, the team would have just stopped. I don't want my son to be scared of needles like me.

The good news is that all the blood test results came back normal. I'm just so pleased and am thankful of the work the whole team did including the health facilitation nurse, GP, day centre key worker and manager, phlebotomy manager and consultant psychiatrist. It hasn't been easy I know, because he is so frightened, but it's done now.

A few words from Rosanna Zacune

My name is Rosanna Zacune and I am a health facilitation nurse working as part of Community Learning Disability Team based in Stoke on Trent. We are a small team made up of 2 learning disability nurses, an acute liaison nurse and an enablement worker. We have been up and running for 3 years and our aim is to address the health inequalities faced by people with learning disabilities. We firmly believe that every individual needs to be in good health to access everything else that life has to offer. Our daily work is extremely varied and we aim to make sure all the services that care for an individual work well together and communicate with each other.

I first met Rita and her son when the consultant psychiatrist working with them recognised that he needed a blood test and contacted me about this. I linked up with all of the people supporting Rita and her son along the way to make sure that he was comfortable and prepared for his appointments. This included the blood screening service, the day service team, the GP and the psychiatrist. By speaking to the GP I also made sure only one blood test would need to be administered to cover all the health care checks required at the time.

I spoke to everyone along the way to plan carefully and make sure things were done in the best way to support Rita's son including the people who helped him on a daily basis in his home. I talked to everyone involved before appointments, made changes to the way things were done if needed and went along with them to make sure everything went smoothly. Our hope as a team is that this way of working together and making sure health care services meet everyone's needs becomes a normal way of working and eventually we do ourselves out of a job!

Dylan's story

Dylan is a young man who wanted to enter adulthood feeling empowered to make his own choices, without being limited by disability or health conditions. This story, written from his mom's perspective, tells how Dylan and his mom found a care provider who utilises both the skills and experience of learning disability nursing and combines them with a keen interest in utilising new technology to support individuals in their care. This approach ensures that Dylan's health is maintained, leaving him free to live a life of his choosing.

Dylan, my son, is supported by Home From Home Care, in a residential home in Lincolnshire. This is a great location for him to take advantage of walking which he loves. He enjoys his own space, playing all kinds of music from Mozart to Abba, but also chooses to enjoy the company of others living close by, when he's in the mood. Good food also rates highly among his interests. As his life is full, on his weekly Skypes to me I know I better have some interesting news or he sometimes just wanders off to pursue one of his other interests!

Dylan was very happy at school as a young boy and they always supported him really well with his personal, educational and dietary needs. In fact, his love of great food really began at Sheiling School. When Dylan left school this was the beginning of many challenges and confrontations for us. Finding a place where Dylan could begin his young adult life where he would be happy, fulfilled and make his own choices about how he would live was not an easy task.



The challenges....

Many people have diabetes and manage this well whilst carrying on with life's rewards, difficulties and daily expectations. Unfortunately, whilst looking for somewhere Dylan would like to live, his diabetes became the biggest priority to the funding provider. With this in mind, the funder thought that a nursing home with 24 hour nursing care the only safe and sensible place for him to go. Dylan and I absolutely disagreed and so began our fight to find him a place where he could be supported to live his life in the way he chose.

Having a full life...

After having a request for funding turned down by the council for a place in Aberdeen, Dylan's elder brother heard of a place called Home From Home Care and we decided to pay it a visit. It was a beautiful place surrounded by countryside where Dylan could have his own home, including a garden but also linked to a communal lounge where Dylan could socialise with other people who lived there if he chose. I immediately felt that this would be a home where Dylan could begin to enjoy this new chapter of his life and have the support he needed to make his own choices, whilst managing his medical needs.

This home showed me that they would be able to present very carefully recorded data about Dylan to convince the funding authority that they could cater for his medical needs. We are still required to do this every 6 months to prove that Dylan's needs are being met and the detailed statistics Home From Home Care have meant he can stay in his home.

A few words from Hazel Ashmore, who is learning disability nurse trained and is currently the Senior Myicro Clinical Manager at Home From Home Care

Home From Home Care aim to minimise health inequalities, including the failure to recognise that a person is unwell or to make a timely diagnosis as the person themselves may not be able to articulate how they are feeling. We have developed screening tools that use evidenced based practice and guidance to screen for indicators of potential health risks in 10 different areas:

Nutrition & hydration

Mobility & positioning

Skin integrity

Falls

Infection

Mental Health

Oral Health

Ears and hearing

Eyes and vision

Sleep

These ensure that any risks to health are identified so that more in depth risk assessments can be completed to define how risks will be monitored, controlled and managed. We record and manage data in a way which enables us to analyze patterns and trends effectively and in real-time, especially crucial for people who do not use words to communicate.

Support staff record data very simply with a few clicks in a form on a tablet or mobile phone as it is happening. Additional detail is pre-populated in the background which gives the data greater value. This data is also used to identify the story the individual is communicating through their behaviour. Recording simple data from behaviour, they are able to translate what is being communicated by individuals.

**Enabling people to leave hospital
and live in their own homes**

Matthew Dolton's story

This story highlights the importance of the learning disability nurse in a Transforming Care setting. Matthew had been detained in hospital for years when Mary Emma Turner, known in her work as Mem, started to work with him. Mem works in the Community Learning Disability Team with the Isle of Wight NHS Trust.

My name is Matthew and I'm 33. I've spent several years of my life in different types of hospitals. I didn't want to be in hospital and didn't like living there. I come from The Isle of Wight but had to live in hospitals in different places in England. Living in a hospital means you don't have any freedom, but at the same time I think that being in a hospital helped me as well. If I had not been on a section, I would have just walked out.

When Mem, the learning disability nurse, started working with me, she supported me to find a flat where I could live independently. Now I live in my own flat I can make my own decisions and come and go as I like. I told Mem what I wanted and she helped me get it.



Now I have freedom. I really enjoy riding on the buses or the trains. I ride the buses more than trains as I have a bus pass that lets me do this for free. I know all of the bus numbers and routes. Riding on the bus helps me to relax and so I do this most days. I really like it when the bus goes fast and I sit upstairs.

When I was in hospital I liked that Mem came from my area to help me. This was important to me. She gave me a lot of support. I still speak to Mem every week on Teams and on email. Knowing I have this support is important in my life.

I love having my own flat. I chose all of the furniture. During lockdown I have chosen to live back with my family in Portsmouth but look forward to returning to my own home when things change. If I need Mem's support when I do this, I know she is only a call or email away. In many ways I'm like her boss as I know I can ask for her input when I need it for the things that I want help with.

Mem describes her work with Matthew

Matthew struggled to manage his emotions and his actions and reactions for many years and many day to day situations caused him to feel under significant stress. He found himself in different hospital settings including medium secure care and locked and open rehabilitation hospital placements. He became somewhat stuck within the hospital system. He had clearly made requests to return to his home town on the Isle of Wight and this was considered on a regular basis by the legal frameworks around him (Mental Health Review Tribunals, Hospital Manager's Hearings and under the Care Programme Approach).

Working with Matthew provided an opportunity for us all to work within the Transforming Care agenda. We looked at Matthew's situation in a different way to try and fit a community service around him in a bespoke way, rather than him having to fit in with a rigid community service. A number of community placements were explored, although it was difficult to find a suitable one due to the complexities of Mathew's needs. A couple of placements were however found.

I made arrangements for him to view the properties to involve him in the process and enable him to make informed decisions on where he wanted to live. Matthew was consistently saying he wanted to maintain as much of his independence as possible, but have the support 24 hours a day if needed for emotional and practical support.

A placement was found in the location Matthew wanted to live and he was looking forward to his move. However, 4 days prior to the move, we learnt the placement would not be going ahead. As the Community Care Officer I made contact with the inpatient unit and discussed the situation with the psychologist working with Matthew to agree a plan of how to support him with this news and how and who would deliver the news to him. Matthew coped with this news incredibly well and the joint working between the local community and inpatient team meant he was safeguarded with his emotions and supported appropriately.

There had been a time when Matthew would have reacted very differently and this could have resulted in a decline in his mental state and possible prolonged stay in hospital.

Whilst we waited for a suitable placement, Matthew raised how he wished to go and stay with his parents. We worked with him in a person centred way between the community and inpatient team to support him to do this, whilst he still remained a patient at the specialist hospital.

After this, we found a supported living placement located opposite a residential care home, with the same provider. We identified that this could provide the unique support Matthew required as it would allow him to maintain his independence, as well as have the back up of support 24 hours a day from the care home nearby if needed and could be an opportunity for him to access support exactly when he needed it at any time of the day, as well as have some core hours set aside for him, as he wished.

The placement was organised and Matthew continued his progress in the community whilst waiting for it. This was helped by the supportive mechanisms in place under the CPA and Section 117 Aftercare of the Mental Health Act, as well as the hard work Mathew had put in to maintain his mental state.

Matthew continues to be doing well and leads on his care in the community under CPA. The Covid-19 pandemic has caused him some anxiety so he made the decision to stay with his parents throughout lock down. I and the support team continued to support him from a distance. We were led by him with this and built a model of support around him using video call technology throughout the week and via email, as this was a useful mechanism for Matthew to communicate his feelings and any problems he has. There are a number of professionals involved in his care and clear communication between all parties also enabled seamless care that responded to a change in his needs and circumstances and enabled him to be repatriated back to the Isle of Wight.

This has made a world of difference to Matthew. It has enabled him to finally be discharged from hospital to a home of his own and live back in the community in the right setting and with the right level of support. He has been involved in discharge planning from the start of the process and has said he feels safe and happy with the support he has been given to enable this.

This was a goal he had been working towards for many years and something that has enabled him to now be able to function well and succeed with his life in the community. He is now able to implement the coping mechanisms he learnt whilst in hospital and access support whenever he needs it, which so far has worked well to prevent relapse in his mental state. He has found great pleasure in decorating his home the way he wants to and also takes pride in his home, keeping it clean and tidy and even beginning to cook and bake his own food, which he has said he enjoys.

Bethany's story

As her story details, Bethany has been institutionalised for most of her adolescence: moving between hospitals, her mental health progressively declined until eventually she ended up in seclusion and segregation for 3 years. Bethany is still in hospital, however, she is gaining more independence everyday and getting closer to living in her own home in the community.

Hi, my name is Bethany. I'm autistic. I live in a different world to most other people. I like things to go my way and I like to be in control because if they don't I get anxious and very frightened.

I get overwhelmed very easily by things that other people find easy to cope with. I can't concentrate when lots of people are talking. I can't cope with unexpected events and noises. I don't like trying to follow rules that people give me and I struggle with understanding people who speak with accents and give me too much information in one go.

Growing up I couldn't do the things mum, dad, and teachers told me to do because I needed to be in control. My head won't let me do things sometimes – it tells me to run away or it makes me lose control of my emotions. This meant I didn't get to stay at home – I went to schools where I stayed overnight and I only saw mum and dad at the weekends. This made me sadder and I didn't understand why it had to happen.

Staff at school didn't understand me and MY autism – they thought I had the same autism as everyone else's. It doesn't work that way. So I struggled more and more and more until eventually the professionals in my life made me go to a hospital. I thought I wouldn't be there long because hospitals make you better with medicines and operations and things like that.

The hospitals hurt me though. They are bright and it hurt my head and gave me headaches. The noises were non-stop with other children crying and screaming or just laughing and playing music very loud. They didn't ask me what noises I wanted to hear – I would have chosen the sound of the sea or relaxation CDs. I like the sea, I like the cold water and I like the things that live in it like crabs and fish. The noise of slamming doors was constant. Big, heavy doors that banged loudly and the noise of keys being turned. It reminded me all day that I was locked up and I hadn't done anything wrong. The hospital wards made my behaviours worse because I couldn't do what they wanted. The pressure I put on myself to be good was as hard as the rules they said I had to follow. To go home I had to 'be good'. I wanted to go home more than anything in the world but the pressure this put on me was too much to cope with. I couldn't do it.

So they locked me in a room. It didn't have a window I could see out of. I didn't know if it was day or night outside. It had a little window into the corridor and staff sat outside watching me all the time. In the shower. Getting dressed. On the toilet. Both men and women.

When mum and dad visited they couldn't give me the hugs I needed. I could only hold hands through the little hatch in the door. They had to kneel down to talk to me properly.

This treatment made me even worse. I wanted to hurt myself and I put my clothes round my neck. Staff came in and held me down. They hurt me. They took off my clothes and made me wear safe clothes that scratched and itched and made me feel worse because of my sensory needs and I struggled more and more till they gave me injections. I just wanted normal things to comfort me. Things like my pets, my toys, and my iPad so I could watch the videos of Cirque du Soleil that calm me down. I wasn't allowed them.

I thought I would be in hospital forever because nothing changed – even when I went to different hospitals - they still locked me away. They said I was dangerous. I wanted to be safe.

I just needed people who understood how I felt and who knew what I needed.

My dad did loads of campaigning about my care. He went on the news and took part in TV programmes and conferences. After legal action they admitted my care was wrong.

After 3 years of being locked in seclusion and segregation I was finally moved to a place that works for me. Every member of my new care team understands my autism. They know how to reduce my anxiety. They let me do the things that I want to do at the time I want to do them.

Where I live now doesn't have doors that bang shut. It's so peaceful. I can go out when I want to and do the things a 19 year-old wants to do. I've had my hair cut and changed the colour lots of times. I can wear make up and I had my ears pierced. I can phone or Zoom my family whenever I want to. In the summer, I wanted a water fight but staff hadn't got clothes to change into. I was grumpy so I told a member of staff they could borrow some of my clothes...so HE did!!! A man wore my clothes so he could help me. It was the best day of the summer. Lockdown gave everyone the experience of being locked away from the people they love and this helped staff understand my feelings when I was locked away.

Best of all I have my pets! My 2 guinea pigs came to live with me straightaway and I was helped to choose a rabbit who I named Thumper. My dad brings the dogs to see me and we go for long walks together.

I still have times where I get anxious but everyone who works with me helps me. They see it as a part of who I am. They don't blame me and they don't pity me, they simply help me by offering support and understanding and then they find new ways to stop it happening again. They know how to do this because they have had the right training about me. I am so happy!

My dad asked me what has made the biggest difference to me. That's easy.

People stopped trying to make me live in their world.
Instead they all moved into mine.



Jeremy, Beth's Dad's thoughts...

"There would never be a situation around Beth where someone says 'that's not my job!'"

The success for Beth has been about team. A team that works for, to, and around Beth. A team that knows and understands her needs. A team is defined as a group of individuals working together to achieve their goal. Beth's team at Mersey Care NHS Foundation Trust are doing just this and see her as the expert in attaining that goal, asking her for advice and posing her questions like, 'What do we need to do?' and 'What do you see being the solution?'

There is an acknowledgement from Beth that people have certain roles. However, the job titles of these individuals hold no importance to Beth, only that they can offer her the support that she needs, when she needs it. A team that truly offers bespoke, person centred support. A team that models for Beth and each other and by mirroring the same approach appear 'equal' to Beth. This is a critical element of the support that she requires, as working in this way allows Beth the choice and control that has previously been stripped from her.

Mersey Care's approach intentionally avoids any reflection of the hierarchical structure that sits silently behind it. Something that should never touch those in receipt of support. They are a specialist service, involving a wide range of health and social care professionals, including learning disability nurses in the support that they provide. The HOPE(S) model that they work to aims to embed person centred working and this supports Beth with her own personal development, paying particular attention to her avoidance of demands. Their flexible approach uses hobbies that she enjoys, as a vehicle to show Beth how to deal differently with situations. For example, Beth enjoys role play, so through this interest the team can focus scenarios around something that might upset Beth, like an argument or difference in views. This considered and creative approach enables Beth to talk about her anxiety in these situations and label her own mood.

Mersey Care paid for me to stay in a local hotel for three days prior to Beth moving there while I trained the whole team including the responsible clinician, psychologist, nurses and health care assistants. This training incorporated the whole of Beth's life story – who she is, how she had got to where she was and what moving towards an ordinary life might look like for her.

Beth's care needs had previously been described as 'incredibly complex'. It's not, it just needed the right people, with the right skills, in the right place, doing the right thing – with the right support.

The staff at Mersey Care are amazing. Their dedication, their skills and understanding have enabled Beth to develop in ways that I always knew she could achieve, but that had been previously prevented by restrictive inpatient settings.

**Richard Harrop is a learning disability nurse and ward manager at Mersey Care.
Here are his thoughts on working with Bethany:**

Bethany is great to be around and has a remarkable thirst for fun and enjoying life. She's lived through several traumatic years but is now coming out the other side, exploring her identity (experimenting with new haircuts, buying new clothes) as well as learning new things each day. Learning disability nurses play a very important part of Bethany's team who offer holistic support along with a range of other professionals. As a team we are led by Bethany; we step into Bethany's world and learn from her. Why would we take any other approach? It's clearly not worked when people have tried to fit Bethany into a service. Individualised support needs to be wrapped around Bethany. Having the right people at the right time to support Bethany is fundamental to Bethany's happiness.

On a daily basis Bethany is supported to make her own choices. We are aware that too many choices for Bethany may be overwhelming and that too much change can also cause anxiety. However, within that context we give her as much choice as possible. In fact, on a day-to-day basis Bethany has complete control over what activities she does and how she spends her time, for example Bethany recently accessed 'aerial hoop' gymnastics classes in a local town. There are some 'non-negotiables' in place like access to alcohol and there are some restrictions that have been imposed for us all during the pandemic, however generally the nursing team focus on promoting Bethany making her own choices.

We know that ideally Bethany should not be in a hospital, but while she's waiting to be supported in the community in her own home, we will do our best to make sure that her day-to-day life does not resemble living in a hospital. For instance, Bethany has a rabbit, guinea pigs and has just bought some new fish. Bethany has also recently upgraded her iPhone, which along with her iPad has proved essential for maintaining contact with her parents, which has unfortunately been impacted upon by national Covid restrictions. Living in a hospital, while she gets ready to have her own home, should not impede her ability to live a good quality life.

Prioritising mental health

Roxy's story

Roxy's story highlights the importance of learning disability nurses championing the mental health needs of people with learning disabilities. As Roxy says in her story, 'People sometimes think that people with learning disabilities don't have mental health needs. All they see is the learning disability.' Collaborating on the Green Light Toolkit with Sue Bridges, the Consultant Nurse (Learning Disability and Autism) from Norfolk and Suffolk NHS Foundation Trust, not only improves Roxy's mental health and confidence, it also enables Roxy to educate professionals and other people with a learning disability and autistic people.

Hi, my name is Roxy Begum. I am 39 years old. I have a learning disability, physical disabilities and I am also deaf. I have experienced mental health difficulties in my life.

I live in my own bungalow and have carers support me twice a day. I love my home, my independence and freedom. I like dancing, especially Asian dance.

I am a self-advocate and a Green Light Champion for the Norfolk and Suffolk NHS Foundation Trust.

I have known Sue Bridges for about 20 years. Sue is a learning disability nurse who now works in the mental health team. Sue used to support me when she worked in the learning disability team. I am now supported by the mental health team. The Green Light toolkit helps mental health services meet the needs of people with a learning disability or autistic people.



Green Light's impact on me personally

Getting up in the morning and having something important to do helps to improve my mental health. Working as a volunteer has given me confidence and power to speak up about my mental health experiences.

The Green Light toolkit is important to me personally because I need staff to understand my needs and I need extra time to build relationships and trust with staff. It helps me to teach staff about the importance of communication and understanding. I need information in easy read to help me understand. If I went to the hospital, I need to feel safe. I need a quiet room, so I feel relaxed as I am vulnerable. The Green Light toolkit helps me to help mental health staff meet my needs. It has also given me confidence and power to speak up about my mental health experiences.

Developing as a trainer

As a Champion for the Green Light I have developed as a trainer. I have done lots of work with Sue, including:

- I am developing training with Sue so staff are made aware of the needs of people with learning disabilities.

- I am teaching mental health staff about reasonable adjustments.

- I have been filmed telling my story.

- I have taught nursing students at the University of Suffolk.

I have trained staff on the mental health ward where I was a patient. They got some things wrong when I was a patient but now they have had the training and I know they understand my needs better, in case I need to go into hospital again.

I am a member of the Green Light Network. It is great to work with the team and share good practice.

I have worked as a volunteer to make easy read leaflets for the NHS. This is important because I need easy read and I can help the Green Light easy read group to make things more accessible. I know what I need and what might help others.

I have also been on interview panels to employ NHS staff. I know if someone is going to be a good member of staff by the way they interact with me.

Understanding mental health

People don't understand learning disability and mental health. People sometimes think that people with a learning disability don't have mental health needs. All they see is the learning disability. When you talk about mental health, people say it is attention seeking. Sue knows that it is not like that. She helps people to understand what I need.

People need to remember to believe in themselves. At the end of the day mental health can be an illness, like physical health; we can't get rid of it, it is part of us. As much as we don't want it, it's not going away. We have to work together to make things better and fight the stigma.

When I talk about my mental health I say I have an illness; it kills me inside. It makes me feel like I am not coping but I have brilliant support around me. I trust Sue and she helps me 100%, with all sorts of things such as communication. Having someone support me that I trust is very important because I think that if you don't have trust in the person, then it's difficult to have trust in yourself.

Advocating for myself and others

Sue helps me to have a voice and advocate for myself. Since working on Green Light, I am now more confident to speak up for myself. I know that there is help if I need it.

I also like to speak up for others. I like to help others to get a good experience of services! This is important to me. The Green Light work has made a positive difference to my life and improved my mental health. If I can do it, other people can do it.

We are still doing Green Light work during COVID-19 and there needs to be more staff who understand learning disability. Training is important and this is not just about training learning disability nurses but making sure all nurses and other staff, such as staff in mental health services, know about people with a learning disability.

Joan's story

Joan's story is an example of what can be achieved when learning disability nurses work together to coordinate a multi-agency response. Becky, Clair, and Philippa, while each prioritising different aspects of Joan's care, take an integrated approach overall, forming a circle of support around Joan that works symbiotically to maintain Joan's mental and physical health.

My name is Joan and I live with my husband Ray. We met at an adult education class and have been married for 13 years. We live in our own home with support.

Sometimes I get stressed by day to day things, such as managing money, doing things around the house, relationships, and my health. When I get stressed I find it hard to cope. I can get anxious and a little depressed. When I feel like this, I start to think I am not well. When I am not worried about things, I am very independent. When I am feeling ok, if something goes wrong, I can find solutions.

When I am stressed and anxious, the way I cope with it is by calling emergency services. I call lots of times until I am admitted into hospital. Hospital feels like a safe place for me.

Working with Becky, Clair and Philippa, they have helped me to be less anxious and worried about things. They have given me easy read information and told me about my health. Now I know about diabetes, why I need to drink enough water, how to stay healthy, and why smoking is dangerous. I know to buy food that is low in sugar and low in fat because of my diabetes. This is a big change in my life. I am very proud of this.

They have also supported me in hospital appointments. This has made me less anxious. They also make sure I understand what's happening when I am in the appointment. They have supported me with diabetic eye screening and having a flu jab. I have never wanted a flu jab but agreed to have one for the first time this year.

I go out on walks with Clair and Sandy, the dog. This gives me time to think about things and talk about what worries me.

Joan has 3 nurses working as a team alongside her: Becky Hankin, a learning disability nurse from the Community Learning Disability Team in Kent Community Health NHS Foundation Trust; Clair O'Callaghan, a nurse prescriber in training from the Mental Health Learning Disability Team in Kent and Medway NHS and Social Care Partnership Trust; and Philippa Harris, a Learning Disability Liaison Nurse In Maidstone and Tunbridge Wells NHS Trust.

Reflecting on their roles, Becky describes the work they do as a team:

Joan has a mild learning disability. Over the years Joan has had contact with mental health services and in more recent years with learning disability services. Joan has struggled with anxiety and depression throughout her life. Joan can also experience mild physical health symptoms related to her diagnosis of type 2 diabetes, being a heavy smoker, with limited fluid intake and reoccurring sciatica.

Joan's coping strategy has been to call emergency services repeatedly until she is admitted to hospital; at times Joan was attending the emergency department two or three times per week. Joan's perception of hospital is that it is a safe place that enables her to 'reset'. Within the emergency department Joan has previously displayed significant challenging behaviours which put her and others at high risk of harm.

The overall aim of the learning disability nursing interventions were to support Joan to reduce her anxiety, develop appropriate coping strategies, and ultimately to reduce calls and

attendances to the emergency department. To achieve this, an MDT (multi-disciplinary team) approach was vital. The learning disability nurse coordinated this MDT, which involved liaising with Kent Police, Frequent Attender service, Psychiatry, Psychology, Social services, Emergency Department staff, Ambulance staff, and care provider staff.

Part of this liaison work involved training the emergency department and acute trust security staff to put reasonable adjustments in place to maintain Joan's privacy and dignity. A number of other community based interventions were also introduced to help reduce Joan's anxiety, provide health education around her health conditions and show her how to self-manage these anxieties at home.

As a result of these interventions, we have seen over recent months a significant reduction in Joan's admissions to hospital. Hospital admissions that do happen have been more successful; Joan has not presented any risk behaviours; she has engaged in any medical interventions required; and been discharged successfully home without any repeat attendances in a short time frame. This is a really positive outcome for Joan and her husband Ray.

As we are working together as a team of 3, our roles compliment each other.

Clair focuses on Joan's mental health, and, with the aid of her pet therapy dog, Sandy, supports Joan on walks. The aim of this support is to improve Joan's mental wellbeing by encouraging her to talk about anything that is worrying her and to assess if medication is working effectively, while at the same time monitoring to see if there any signs of mental health decline. Throughout lockdown, this input has been effective in reducing Joan's anxiety and hospital admissions. Joan really looks forward to this and has developed a very close bond with Sandy; Joan has learnt how to care for Sandy and this has been a really positive focus for Joan.

I have worked with Joan on health education sessions using easy read information and resources to support her to understand more about her health, on topics such as diabetes, how to lead a healthy lifestyle, the risks of smoking, and the risks of dehydration. This has also enabled the team to come to the conclusion that, when well, Joan does have capacity to make decisions about her health. The result of this input is that Joan now knows what diabetes is and can explain it to others; she has made a lot of changes with her diet; and is now buying low sugar and low fat products – this is a very big achievement for Joan. I also support Joan to attend hospital appointments to help reduce her anxiety, and to ensure that she has understood the information she has seen. I use easy read information to help prepare Joan for any medical interventions, for instance a diabetic eye screening and the flu vaccination (Joan has always refused the flu vac until this year!)

Philippa takes the lead co-ordinating all the meetings with the hospital team. This has enabled us all to agree a very clear hospital admission plan which minimises Joan's anxiety, enables her to engage with any medical intervention, and reduces the risk of repeated admissions. Philippa has also established bespoke staff training to accident and emergency staff and hospital security staff to ensure that anyone supporting Joan in hospital is aware of her needs and the hospital admission plan. In recent admissions this plan is being followed and Joan has much more successful admissions in which she has not presented any behaviours that

challenge, she has accepted medical intervention and been discharged home the same day or next day without any repeat admissions.

Becky and Clair have worked with Joan and Ray to produce a short video in which Joan talks about how the team has worked with her.

It can be accessed via the following link:

https://drive.google.com/file/d/1Gs0YYKgJYBcFWqVpNI5upr_YI-JgHWpa/view



**Coproducing with people
with learning disabilities and
autistic people**

Mary's story

This story is about Mary, an active member of a self-advocacy group. Michael Fullerton, who has a background in learning disability nursing and is now the Clinical Director at Achieve Together, supported Mary and the self-advocacy group to produce easy read booklets. Mary speaks about her work and the difference it has made to her life.

I am 28 years old, and live in my home in South East London, supported by Achieve Together. I am an active member of [Campaign 4 Change](#), a self-advocacy group made up of people with learning disabilities and autistic people.

We have worked on lots of campaigns, providing presentations on a range of subjects over the years since I joined in 2017. We have a #MindYourLanguage campaign to let staff know how we wish to be spoken to and spoken about, a Hate Crime campaign and a Stay Up Late campaign to name a few!



Working as part of Campaign 4 Change, alongside Michael, we produced three easy read booklets on "Transgender", "Accessing Pornography Online" and "Keeping Safe Online".

The first booklet provides people with information to feel more comfortable about themselves and helps other people across the country to know what transgender is. "Accessing Pornography", helps people feel better about their sexuality and informs them how to access pornography safely. "Keeping Safe Online" helps people to access the internet safely. These booklets have presented at different conferences, including the Learning Disability England conference and a Supported Loving network meeting.

The Campaign 4 Change group now includes two people with profound and multiple learning disabilities. Having people with profound and multiple learning disabilities in the group has had a positive impact. They have been brave in representing themselves and therefore others with similar needs. Also, I have not come across another self-advocacy group where this group of people has been included. This has had a positive impact on the whole group and helped all of our understanding of the needs of different people.

I have been involved in many presentations with Michael to different groups across the country concerning all sorts of issues for people, from attitudes to sexuality to putting more hoists in hotels.

I have developed in confidence as a result of this work. This work has also meant that I have become more aware about relationships as I have been introduced to the [Supported Loving Network](#). This has made me more knowledgeable about sex and relationships. I feel confident in talking about it, which I couldn't do before.



Ronnie Treston's story

Ronnie's story illustrates the impact made by a learning disability nurse on the professional development of an individual with a learning disability. Ronnie and Daniel met when Daniel was looking for experts by experience to co-develop and co-lead training. Ronnie is now an artist and freelance teacher. Daniel Marsden is a Senior Lecturer in Learning Disability Nursing at Kingston and St George's Joint Faculty Health, Social Care and Education.

For years now I have been interested in training doctors to make sure they do a better job. This interest first started when I met Daniel Marsden in 2010. We met when he came to the local Learning Disability Partnership Board. He was looking for people with a learning disability to help him train healthcare staff and make healthcare better and my support worker said I should give it a go. Daniel contacted me about a month later and coincidentally, I happened to be in hospital at the time. From that point on we worked together on different pieces of work. All of the work was about improving the health of people with a learning disability and making them more aware of their rights.

In 2007, *Death by Indifference* came out and this really inspired me. This report, written by Mencap, looked at the deaths of 6 people with a learning disability. It showed that people did not need to die, if there was better healthcare.

Over the years, I worked with Daniel training lots of health professionals, making them aware of what it is like to have a learning disability and be in hospital. We held workshops for people with a learning disability and families, making sure they knew what good healthcare looked like. We asked their opinions on what we could do to make healthcare better. Over time I got invites to speak at different universities and even got an invite to go the House of Commons!

Having experts by experience advise health professional is important work. You are not chosen for the qualifications you have. You are chosen because of your life experience. Being an expert by experience means you are looking through the eyes of a person with learning disabilities and this is important.

Working with Daniel gave me real confidence. I had always struggled with reading and writing but then he introduced me to easy read and that made my life a lot easier. In the early days there was not as much easy read information in hospitals and health centres but now I see it everywhere.

Daniel also introduced me to mind mapping. This helped with my presentation skills as I used mind mapping to remind me what I wanted to talk about when I made a presentation.

For several years I worked with the Breast Screening Unit in Canterbury. My role was to label envelopes and send them out. As there was a different name on each form and envelope, this really helped my reading to develop.

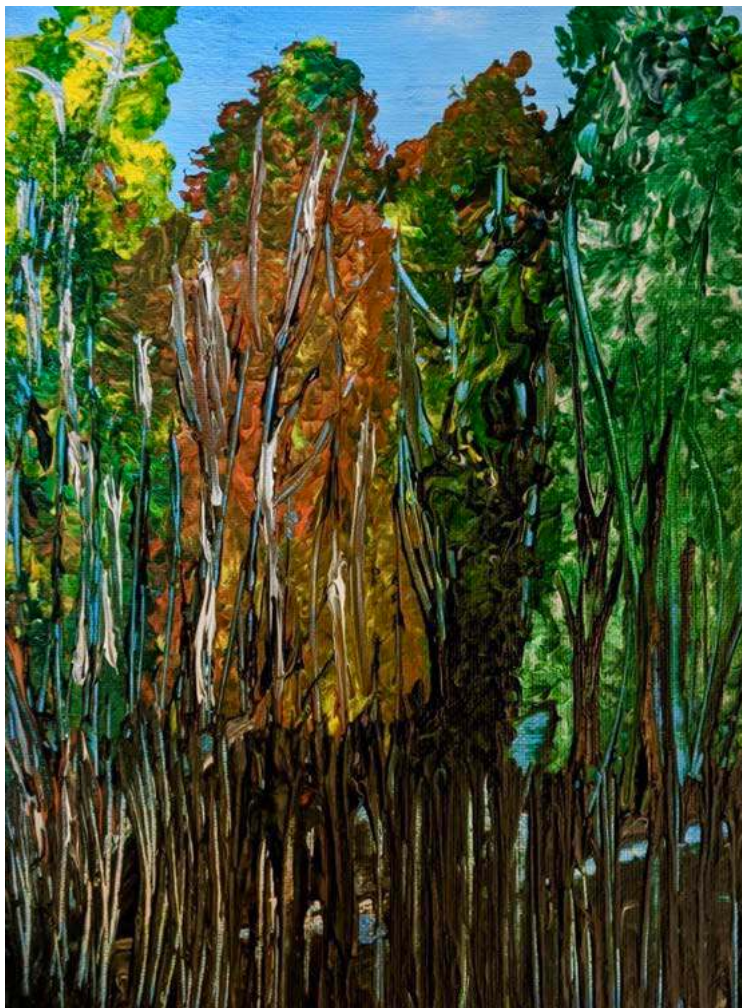
Working in all of these health settings and being recognised as an expert by experience made me more confident. I knew I was doing something really important in my life.

In the last few years, I have taken all of the skills I developed and the experience from working within health settings, and now I work for Home Group Housing Association delivering training up and down the country.

I am also an artist. I enjoy exploring art. When you produce a piece of art you enter a different world. I work on lots of different types of art including drawings and Lego sculptures. A few years ago Home Group Housing Association hired a gallery for me to display my artwork and sell some prints and photographs I had taken. I donated all of the money raised to the housing association's local welfare fund to help other people facing hardship. I've also raised

well over £20,000 pound for various charities over the years. I've spent hours out in the cold in my homemade costumes collection donations, attending carnivals, holding face painting sessions and running stalls.

This piece of art is called The Evaluation. You can find it on the Rightfullives website.



Ronnie and Daniel worked on an evaluation of a 2015 Health Education England commissioned piece of work where 3 experts by experience and 3 learning disability nurses delivered training to 120 mainstream professionals on reasonable adjustments for East Kent Hospitals University NHS Trust.

Whilst working on the evaluation, Ronnie produced this piece of art. Ronnie said:

"The workshops were intended for healthcare professionals to get a view of how we work with people with learning disabilities, so the painting shows a clearer picture in the middle getting brighter as the workshop runs through the day. Also note the move from red to green highlights. This shows poor areas moving into green areas, showing a better understanding of the needs of people with learning disabilities."

Daniel reflects on his work with Ronnie

Ronnie was instrumental in my work. I met him at a Partnership board meeting in 2010, and he approached me about wanting to be involved in teaching hospital staff. Over the subsequent 6 years we worked in partnership at East Kent Hospitals teaching staff and I was always impressed with his abilities not only to engage staff, but also to be confident enough to facilitate their learning. He's definitely the only person I've ever worked with that elicited a round of applause from a group of tired junior doctors on induction in a short session before lunch!

The piece of work that we last worked on was the evaluation for the Reasonable Adjustments workshops funded by Health Education England. We spent some time talking about what he learnt from the process for the evaluation, then he presented me with the painting called *The Evaluation*. Ronnie provided me with a full outline of how the colours relate to RAG rating and the lines link to increased understanding.

The original sits next to my work desk, as both it and he remain a complete inspiration.



[The Evaluation](#) by Ronnie Treston



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