Celebrating 100 years of learning disability nursing #RNLD100
Welcome to this special newsletter to celebrate the 100th anniversary of learning disability nursing.

Learning Disability Week this year is 17-23 June and Friday, 21 June will be the focal point of the centenary celebrations. Learning disability nurses work to provide specialist healthcare and support to service users, parents and carers, to help them live a fulfilling life. They have excellent communication and interpersonal skills as well as patience and resilience.

In this newsletter we celebrate some of the 111 learning disability nurses who undertake a variety of different roles at our Trust. In fact, the majority of them do not work directly with service users who have a learning disability.

However, the skills they have developed are highly transferable which means many of our qualified learning disability nurses are working successfully in various other clinical areas.

We are commissioned to provide learning disability services only in Suffolk and Waveney. In Norfolk, community learning disability services are provided by Norfolk Community Health and Care NHS Trust (NCH&C) and inpatient services by Hertfordshire Partnership University NHS Foundation Trust.

However, across both counties, we have a network of about 200 “Green Light Champions”, who support people with learning disabilities and/or autism who have mental health problems. They undertake this role voluntarily and have carried out some phenomenal work to improve people’s experience of services, working together in a pioneering, innovative way to drive quality improvements. They include staff working in all areas of the Trust, service users and champions in other organisations, such as Suffolk Community Services and NCH&C.

The Green Light Toolkit enables adjustments to be made to ensure these service users receive healthcare in the same way as everyone else.

I hope you enjoy our celebration of the centenary of learning disability nursing!

Sue Bridges
Nurse Consultant (Learning Disabilities / Autism)

Case Study: Stuart Richardson

NSFT Chief Operating Officer Stuart Richardson can still remember being told off by his ward manager for being “too friendly” with the patients shortly after qualifying as a learning disability nurse in 1993.

At the time, he was working in a large institution in Yorkshire, which had once been a workhouse, where patients were not allowed their own belongings, including clothes. Some patients had lived there all their lives.

Stuart, who later gained a degree in learning disability studies while working as an LD nurse in the community, described that early period of his career as a “hard time” and welcomes the progress that has been made since.

“I’m pleased that we’ve moved away from a medical model to one where multidisciplinary teams care for people with a learning disability, and that we’ve advanced from advocacy to self-advocacy where service users and patients have more of a voice,” he said.

“I’m proud that our Trust has successfully implemented the Green Light Toolkit, which many other organisations have struggled with, thanks to colleagues like Sue Bridges and Dawn Collins, Deputy Chief Nurse.”
The charity Mencap estimates that about 40% of adults with a learning disability also have mental health problems, which is more than double the rate in the general population.

That is why Roxy Begum, who is 37, is so well qualified to help train our learning disability and mental health staff, and also mental health nursing students at the University of Suffolk in her home town of Ipswich, roles which she undertakes with huge enthusiasm. As well as having a learning disability and mental health issues, she has physical health problems which means she is a wheelchair user.

“I’m a self-advocate and I like to share my personal experiences of healthcare with NSFT staff and students so they can learn from them”

A Green Light Champion and regular attender of Green Light Network meetings, Roxy has worked for many years with Sue Bridges, Nurse Consultant (Learning Disabilities / Autism).

“For example, I’ve spoken to staff on Poppy Ward at the Woodlands unit about the bad experiences I had there, which were about poor physical access and a complete lack of Easy Read leaflets and booklets. These issues have been addressed so that nobody will have to go through what I experienced.

“There have also been times when staff have only seen my wheelchair or just focused on the fact that I haven’t got any legs.

“It’s important that staff see the person in the wheelchair, speak to you as an individual and do all they can to meet your needs in the most effective way possible.”

Case Study: Roxy Begum

NSFT’s learning disabilities nurse will be at the House of Commons on 21 June to take part in an event to celebrate the centenary of learning disability nursing.

Sue Bridges, Nurse Consultant (Learning Disabilities / Autism), has been invited to take part by David Harling, Head of Learning Disability, NHS England and NHS Improvement.

Last year, she won the Learning Disability Nurse Award category of The National Learning Disabilities and Autism Awards. It will be an opportunity for Sue to meet MPs and Baroness Sheila Hollins, who has long campaigned to improve the care of people with a learning disability. The crossbench life peer is emeritus professor of the psychiatry of learning disability at St George’s, University of London, and has a son, Nigel, who was born with learning difficulties.

Sue is one of the country’s 25 learning disability nurse consultants, some of whom will be joining her at the House of Commons, and a member of the Learning Disability Consultant Nurse Network.

Adult and CAMHS learning disabilities services in Suffolk

NSFT’s learning disability community teams are based in East Suffolk (Ipswich), West Suffolk (Bury St Edmunds) and in Lowestoft (Oulton).

There are adults and LD CAMHS teams in each locality. They support people with a moderate to severe learning disability who have a mental health condition or challenging behaviour.

In Suffolk there is also a learning disability liaison service working closely with colleagues in primary care, offering advice, consultation, training and occasional joint assessments to adults with learning disabilities who have complex needs, ensuring people have annual health checks and access to good physical healthcare.

Walker Close is the inpatient assessment and treatment service based off Foxhall Road, Ipswich, that serves the Suffolk population.

Also based there is an intensive support team, working in the community with service users, parents, carers and social care teams, to prevent admission to hospital.
Historically, people with a learning disability received care within their own homes, in workhouses or asylums. The UK’s first learning disability nurses were registered as “mental deficiency nurses” in 1919.

In that year, the Medico-Psychological Association (MPA), the national body for psychiatrists, awarded the first national certificate for mental deficiency nursing. This was the result of a desire to improve standards but also to exert control over the growing number of institutions spawned by the Mental Deficiency Act of 1913, which recommended segregation and institutionalisation.

The term “mental deficiency nursing” was used until after the Second World War when it was replaced by “mental subnormality nursing” and then renamed “mental handicap nursing” in the 1970s. Learning disability nursing became the accepted term in the 1990s.

Learning disability nursing has come a long way since the 1842 Lunacy Act

We have staff working at our Trust today who qualified as a “Registered Nurse for the Mentally Handicapped” (RNMH), a job title which has been replaced by “Registered Nurse Learning Disability” (RNLD).

The 1972 Briggs report suggested nursing was not the right place for work with the “mentally handicapped”. This led to the Committee of Enquiry into Mental Handicap Nursing and Care and the 1979 “Jay Report”, which recommended LD nursing be replaced by a role based in social care.

NHS-employed community “mental handicap” nurses were gradually introduced from the mid-1970s, forming part community learning disability teams.

Now a Psychological Therapist with Wellbeing Norfolk and Waveney, based in King’s Lynn, she continues to play a role in helping improve care for people with LD by volunteering as a Green Light Champion.

“People with LD don’t have any inhibitions and have a really lovely way of looking at the world.

“They always treat others with respect – to them, it’s not important what colour your hair is or if you have the latest trainers, which I find really refreshing.

“Now that we know so much more about the health inequalities of people with a learning disability, learning disability nurses have never been more needed.

Now I’ve kept my passion for LD going by signing up as a Green Light Champion.

“I want to play a part in further improving the Wellbeing Service for people with LD by making sure they can access the service in the same way as everyone else.

“My experiences as an LD nurse have helped in my current role as I feel I’m able to meet the needs of people from all walks of life and can hopefully help empower them to better mental health. It’s definitely a career path I’d recommend.”

<table>
<thead>
<tr>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1842</strong> Lunacy Act recommends asylums for “pauper” lunatics with no clear distinction between people with mental health problems and learning disabilities</td>
</tr>
<tr>
<td><strong>1919</strong> First certificate in “mental deficiency nursing” awarded by the Medico-Psychological Association</td>
</tr>
<tr>
<td><strong>1948</strong> Institutions and “colonies” for learning disabilities subsumed into the new NHS, becoming “hospitals”</td>
</tr>
<tr>
<td><strong>1972</strong> Briggs report suggests support for people with learning disabilities should be outside nursing profession</td>
</tr>
<tr>
<td><strong>2001</strong> Valuing People white paper emphasises rights of people with learning disabilities to “lead their lives like any others” and highlights key role of nurses in providing support</td>
</tr>
<tr>
<td><strong>2011</strong> Winterbourne View care scandal is exposed by the BBC’s Panorama programme</td>
</tr>
<tr>
<td><strong>2019</strong> 100th anniversary of learning disability nursing</td>
</tr>
</tbody>
</table>
How did Walker Close get its name?

Dr Jane Walker, who died in 1938 at the age of 79, was the 45th woman to be included on the General Medical Register.

She developed an interest in the treatment of tuberculosis (TB). In July 1892, she opened a small sanatorium at a cottage in Downham Market in Norfolk, with six beds, using Walther’s method of fresh air and good nutrition.

In 1901, she opened the East Anglian Sanitorium at Nayland in Suffolk, initially with 30 beds.

All of these ventures accepted only private patients, but the Nayland sanatorium opened a wing for local authority patients in 1904. Later, it became a school.

When Dr Walker died in 1938, the local authority bought the property which was used by the British Legion in 1943 to treat mainly women. Although it joined the NHS in 1948, the Legion continued to run it until the discovery of the antibiotic streptomycin, which finally cured TB, enabling all the sanatoriums in England to close in 1959.

The property then became the Jane Walker Hospital to care for those with mental handicap.

This remained the use of the hospital until 1991 when the residents moved to a new purpose-built, core and cluster residential site.

Named after her, Walker Close housed 36 people in six bungalows in line with community care.

The residents moved out to private and voluntary housing providers in the early 2000s, and Walker Close now accommodates assessment and treatment units for people with a learning disability, Coastal IDT and Child Treatment Centres.

Special event to celebrate learning disability nursing over the last 100 years

Our Trust will take part in a public event being held in The Forum, Norwich, to mark 100 years of learning disability nursing.

“Learning disabilities: a journey of discovery and reflection” is being organised by the UEA’s School of Health Sciences and will take place at the venue on Friday, 21 June and Saturday, 22 June, 10am-4pm. Go along to:

- Learn about learning disabilities and autism
- Find out about local services
- Become a “Treat Me Well” ambassador with Mencap
- Learn more about sign language and forms of communication
- Explore sensory impairment
- Explore the range of professional careers in learning disability support

Part of our Trust’s involvement will be a focus on the work of our Green Light Champions.

Norfolk Community Health and Care NHS Trust will be doing some filming at the event for a recruitment video.

Attendance is free. For more information, email: HSC.LDWeek@uea.ac.uk
It took Andy Madel many years to find his true vocation in life but after 10 years as a learning disability nurse, there is no looking back.

Andy, who will be 50 this summer, is a staff nurse in our adult learning disability assessment and treatment unit in Walker Close, Ipswich, consisting of two wards for adults.

Although he still does pool shifts for the Trust’s adult mental health wards, he sees his future very firmly with our learning disability service.

Andy said: “My first experience of someone with a learning disability was as a teenager playing football in the road with a boy who had Down’s syndrome. I first started to care for people with LD when I was working in the private sector as a community support worker on an independent living project.

“I soon realised that I wanted to join the NHS and successfully applied for a healthcare assistant post at Walker Close in 2003, qualified as a RNLD [Registered Nurse Learning Disability] in 2009 after three years and I’ve been at Walker Close ever since.

“I thoroughly enjoy working with people with learning disabilities and, as with all branches of nursing, I find it very rewarding to help people get through difficult times and contribute to their recovery and often an improvement to their quality of life. There’s an altruistic sense with nursing that you’re doing something worthwhile.”

Looking ahead, Andy is focused on contributing to the ongoing development of the inpatient service at Walker Close and the further integration of Positive Behaviour Support (PBS), where active support of the person combines with an understanding of their behaviour as a form of communication to develop an environment and approach that helps them more effectively.

“People are admitted to the ward because they are unwell, primarily with mental health or behavioural issues, and when they are improving we often help them to learn new skills, enjoy life again and become more independent”

Case Study: Andy Madel

New post to improve LD training

Staff from across Suffolk who work with people with a learning disability will receive consistent training following the introduction of a dedicated new role designed to reduce health inequalities and improve standards of care.

The new Contracts and Service Development Manager post has been jointly funded by Suffolk County Council and NHS West Suffolk and NHS Ipswich and East Suffolk clinical commissioning groups (CCGs). It comes after Sue Bridges, Nurse Consultant (Learning Disabilities / Autism) with our Trust, led a multi-agency project looking at standardising training across more than 200 housing, health and social care organisations who provide care in Suffolk.

Her recommendation was to create a single post to ensure everyone receives consistent training in the 19 learning disability core subjects, which include identifying a learning disability, communication, safeguarding, wellbeing and physical health. The post has now been advertised and the successful applicant will take up the role later in the summer. The success of the initiative will be evaluated after two years.

Sue said: “I am really pleased that we have been able to work in partnership to create this important post. We hope that it will improve health outcomes for people with learning disabilities, who can die up to 27 years sooner than the rest of the population due to the inequalities they currently face.

“Education and training is really important. By improving the knowledge of care staff, we ensure they are able to effectively support people to get the right health checks and access to better care.”

Care providers will be required to complete the training as part of their contract.
Our Primary Learning Disability Nurse Service is responsible for improving care by making sure people who have a learning disability and are aged 14 and above can receive annual health checks. The team also helps GPs to make reasonable adjustments so that it is easier for people with LD to get to appointments.

These can include allowing extra time, making sure signage is clear and easy to understand and providing information in an Easy Read format.

In addition, they work with health, social care, education and other partner organisations to raise awareness of the needs of people with a learning disability, as well as supporting individuals and families to get the right healthcare using reasonable adjustments.

The team is made up of Jerry Newman (inset), who covers the Ipswich area, Steph Chamberlen, who is based in West Suffolk, and Sharon Hobson, who covers the East Suffolk coastal area. Our Trust is currently recruiting to the fourth post covering Stowmarket, which is vacant following the retirement of Tracey Stewart in May.

Jerry, who qualified as a LD nurse in 1990, said: “People with LD face considerable health inequalities. Their health needs are not always easy to identify, which can mean they have a shorter life expectancy and are at higher risk of chronic health conditions, poorer physical and mental health and admissions to acute hospitals.

“That is why annual health checks are so important – they give GPs the chance to check people’s general health and pick up any undiagnosed conditions.

“We’ve received fantastic feedback on the service we provide so far, and are working hard and aiming to hit the national target of ensuring 75% of people on the register receive an annual health check by 2020.

“The job is hugely enjoyable. It’s really rewarding to know that we are making a difference and raising awareness of LD in primary care.”

To refer to the team, email: liaison.nursesLD@nsft.nhs.uk or call 01284 733300.

Better care for people with learning disabilities

People with learning disabilities are now getting more support to look after their physical health, thanks to a team of specialist nurses working in GP practices across Suffolk.

The skills that Rachel Petty-Cook used while working for six years as a learning disability nurse are invaluable in her current role as a PMA (Prevention of Management and Aggression) practitioner.

“I know from my experience as a learning disability nurse that people communicate in multiple ways,” said Rachel, who is based at Hellesdon Hospital and fills one of the Trust’s 13 PMA practitioner posts.

“As well as teaching staff how to manage challenging situations, her role includes supporting clinical teams in West Norfolk and the Suffolk Adult Learning Disability Service in Walker Close, Ipswich.

“I share this knowledge with our staff caring for patients so that they can proactively manage a situation to keep everyone safe”

“People are often surprised that as a PMA practitioner, I question the notion of restraint,” said Rachel. “If you reflect on why someone is behaving aggressively, you can often de-escalate them through understanding the reason for the behaviour.”

Rachel, who is 53, qualified as a learning disability nurse in 1998 at the age of 32 after three years of training at the UEA.

She then spent six years working at Little Plumstead Hospital, near Norwich, and became interested in PMA while attending a PMA course at Hellesdon Hospital and learning of a need for PMA practitioners with a background in learning disability nursing.
Case Study: Sarah Glendinning

A fortnight’s work experience while still at school more than 20 years ago gave Sarah Glendinning a taste for working with people with a learning disability.

Desperate to avoid an office job, she spent time at a day centre for people with cerebral palsy in Ipswich run by Scope, the national disability charity.

Three years later, at the age of 18, she embarked on RNLD nurse training and, after qualifying, spent the first 4½ years of her professional life supporting people with severe and profound learning disabilities in residential care in Haughley and East Bergholt, Suffolk.

She then qualified as an RNMH after an 18-month conversion course and worked as a community mental health nurse, based in Ipswich, before two years ago taking up her post as a Mental Health Link Worker at GP practices in Aldeburgh, Framlingham, Leiston and Saxmundham.

Sarah, aged 37, said: “I enjoyed my work experience all those years ago because I’m interested in the lives of other people, trying to understand them and help them, and there was a focus on social inclusion and activities.

“Although most of my time is now spent in mental health, the skills I developed as a learning disability nurse, particularly around communication, patience and tolerance, make me better at my job.

“I now work with people who have mild to moderate mental health problems but when they also have a learning disability, I make sure that reasonable adjustments are made”

who would benefit more from a longer, face-to-face meeting.”

Sarah takes referrals from GPs and then refers them to the most appropriate organisation, such as Wellbeing Suffolk, secondary mental health care or services provided by the voluntary sector. She is also one of the Trust’s Green Light Champions.

Case Study: James Massey

James Massey is an “expert by experience” who works closely with our Trust to help make improvements for patients with a learning disability.

Having spent 18 of his 38 years in a variety of hospitals, James, who has a diagnosis of learning disability and autism, has a wealth of experience to draw on and share.

Now living in supported accommodation in Lowestoft, he has for the past three years been a member of the Waveney Learning Disability Service Users and Carers Forum, and is its current Deputy Chair.

The Forum is an opportunity for service users to share their experiences, to be involved in the development of services and for healthcare professionals to seek views on topics like being in hospital or particular medications.

James, who cannot read well, is also a member of the Trust’s Easy Read Group. One of the projects he has been involved in is producing an Easy Read reminder card for service users to bring along to consultant appointments.

“Learning disability nurses are important because they believe in you and help you speak up, loud”

Sue Medley, Learning Disabilities Specialist Nurse, said: “When I qualified as a ‘Registered Nurse for the Mentally Handicapped’ in 1991, it was unthinkable that we would work closely with service users.

“However, they have so much to offer and after almost 30 years I still often find they give a perspective I would never have considered. I’ve known James for many years and we have a mutual respect for each other, in exactly the same way that I do for any other colleague.”

Sue added that James’s involvement in the Forum and Easy Read Group has helped to improve his mental health wellbeing.