

Connect for Change:

an update on learning disability services in England

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Foreword from Mencap and the Challenging Behaviour Foundation

Despite all the promises since Winterbourne View there has been a shocking lack of change on the ground for individuals and families, meaning thousands of people with a learning disability are still in inpatient units, often far from home, friends and family, where they are at increased risk of neglect and abuse.

We welcome that NHS England is now driving forward a programme to close inpatient units and ensure that the right support and services are developed for people with a learning disability and behaviour that challenges in their local communities.

It is vital that robust community support and services are developed so that people are properly supported in their local community, otherwise people are at risk of placements breaking down and ending up back in units.

Alongside housing and care providers with the right skills and well-supported and trained support staff, it is crucial that there are professionals in the community, such as nurses, psychiatrists and psychologists, with the right expertise in positive behaviour support to provide support to individuals, families and providers. There also needs to be enough of them so that people do not have to wait a long time for the support they need.

These professionals must be able to support children and adults with a learning disability and behaviour that challenges early on, before behaviour escalates, not just at crisis point.

This report gives an important reality check. Robust community teams with the right expertise, who are able to support people at the right time, in the right place, require investment. Professionals, including learning disability nurses, with the right expertise in the community are a vital part of building the right support to help thousands of people in inpatient units to move back to their local communities and ensure that people get good-quality support early on to reduce the risk of them being sent to units.

Jan Tregelles, Chief Executive, Mencap and Vivien Cooper, Chief Executive, The Challenging Behaviour Foundation.

Executive summary

After the exposure of the abuse at Winterbourne View, people with learning disabilities and their loved ones were promised change. Nearly five years later there has been little improvement to the lives of thousands of individuals who were promised that the care and treatment they receive would change for the better.

Despite numerous investigations and high-profile reports, the pace of progress has been unacceptably slow. Repeatedly, promises and ambitions have not been translated into the action that is needed to transform services. The Coalition Government pledged to move all those wrongly placed in hospital into more appropriate settings in the community by July 2014.

This promise remains unmet.

The number of people in inpatient facilities actually increased over 2015, showing a revolving door of admissions and discharges; a system which is failing thousands of people.

Why is the gap between the ambition and the implementation so great? A key and critical factor is the reduction and devaluing of the learning disability workforce. The disconnect between workforce planning and service design is magnified in this complex health and social care setting. Without a skilled and specialised workforce to treat and care for people there will be no health and social care services.

In the past five years the learning disability nurse workforce in the NHS in England has been cut by a third; over 1,700 learning disability nursing posts have been cut since May 2010. Five hundred and forty of the jobs cut have been those of the most senior and experienced nurses: there has been a reduction of 40% in band 7 and 8 nurses.

Learning disability student nurse training places have also been cut by 30% over the past decade, with numbers remaining consistently low since 2011. In 2016/17 learning disability nursing is the only field of nursing education where, despite a national shortage of nurses, the number of student places fell even lower than last year.

The cuts made to learning disability nurse numbers are the most dramatic reductions observed across all fields of nursing in all NHS settings. If there was ever an intention to phase out this specialised strand of

nursing, cuts to the workforce and the supply line are sure-fire measures to achieve it.

Increasingly, learning disability services and the workforce are being transferred to non-NHS providers. Nurses have told us that in many cases this impacts negatively on their terms and conditions, reporting reductions in pay, annual leave and other benefits when being forced to work outside the NHS.

With fewer newly qualified learning disability nurses coming through than ever before, significant cuts to jobs in the NHS, and large scale re-provision to the independent sector, the RCN remains deeply concerned about the learning disability nursing workforce.

Transforming and delivering high-quality services does not happen as a result of reports and good intentions. Learning disability nurses tell us this approach has failed to deliver change in the past five years. A dedicated workforce, sufficient in numbers, with the right people, with the right breadth of knowledge and skills, is what is needed to truly transform care in this multi-faceted health and social care setting.

Learning disability nurses are highly skilled nurses who care and treat people with complex mental and physical needs. Interventions by specially trained learning disability nurses result in improved patient outcomes and help people to live more independent and fulfilling lives. These skilled nurses are part of the solution to delivering integrated personalised care and can lead the way in providing positive behaviour support to those who need it.

The national initiative *Transforming Care* is finally setting out a clearer pathway to shifting care from hospitals into the community. It is still too early to determine its success. But it is clear that further steps must be taken to ensure that the workforce is in place to support the transformation of the care provided in frontline services.

As NHS England embarks on its course towards growing community services and closing inpatient facilities, it is critical that funding solutions are in place to secure quality services over the long term, regardless of the provider of care. Only with sustained investment in both services and a skilled workforce will people with learning disabilities and their families finally see the change they have been waiting for.

Recommendations

The Royal College of Nursing (RCN) proposes the following recommendations to address the issues highlighted in the report.

Workforce

- A long-term workforce strategy that connects workforce planning to the transformation and delivery of services for children and adults with learning disabilities.
- Every acute hospital should employ at least one Learning Disability Liaison Nurse. By 2020/21 all acute hospitals should have 24-hour Learning Disability Liaison Nurse cover.
- Up-skill all general nursing staff to care for those with learning disabilities and/or autism, or those who display behaviour that challenges.
- An increase in the number of learning disability student nurse training places to grow an appropriately skilled workforce.

Services

- Ensure that quality community services are commissioned to support the appropriate transition of people from inpatient care to living more independently in the community.
- Establish long-term commissioning arrangements of community services to protect children and adults who rely on vital services in the community.
- Newly commissioned services in the community must provide support to children and adults, and those who care for them, to help prevent crises, and not just be available at crisis point.
- Positive behaviour support to be embedded across organisations and training to be provided to those who may be caring for someone who presents behaviour that challenges.

Learning disabilities and nursing in England

The number of people with learning disabilities and/or autism who may also display behaviour that challenges is steadily increasing.¹ More children and young people with learning disabilities are living into adulthood with a range of complex needs, and increasing numbers of adults with learning disabilities and associated health needs are living into older age. The number of people with learning disabilities known to GPs has gone up every year for the last six years.²

It is estimated that in England in 2013 there were 1,068,000 people with learning disabilities, including 224,930 children and 900,900 adults.³

The needs of people with learning disabilities are changing. Some people with a learning disability also have other physical and emotional conditions, meaning that it is common for people to present with multiple and layered physical and health needs. A small number of people with learning disabilities also display challenging behaviour. Sometimes people with learning disabilities have very complex needs that require care and support from a range of professionals across health and social care.

Developments over the past 20 years have meant that the way that we treat and care for people with learning disabilities has fundamentally changed. It is widely agreed that people with learning disabilities should live in the community and be supported to live full and inclusive lives. Part of this support includes access to specialists with the knowledge, skills and experience that cover a range of health needs.

Past investigations and inquiries have highlighted the need for increased education and training of health care practitioners to ensure that the diverse needs of people with learning disabilities are met. Health and social care practitioners must have the knowledge and skills, or the ability to gain access to specialists to provide person-centred care that

is appropriate to the needs of the individual and their family.

Nurses are a fundamental component of these multi-disciplinary teams.

In England learning disability nursing is a distinct strand of nursing with its own educational framework: a specialised area requiring tailored education and training.

In the RCN's position statement on the role of the learning disability nurse we highlight and explain the value of learning disability nursing. The role of the learning disability nurse is central to supporting people, particularly those with complex needs. Part of the role of a learning disability nurse includes:⁴

- undertaking comprehensive assessments of health and social care needs
- developing and implementing care plans
- working collaboratively with health and social care professionals
- providing nursing care and interventions to maintain and improve health and promote wellbeing
- providing advice, education and support to people and their carers throughout their care journey
- enabling equality of access and outcomes within health and social care services
- providing education and support to promote healthy lifestyle and choices
- acting to safeguard and protect the rights of people with learning disabilities when they are vulnerable and in need of additional support.

¹ Throughout the report the term 'people with learning disabilities' will be used as an umbrella term to cover those with learning disabilities, autism and/or challenging behaviour whilst acknowledging there are differences between these complex conditions

² www.improvinghealthandlives.org.uk/publications/1241/People_with_Learning_Disabilities_in_England_2013

³ Identified at School Action Plus or statements in DfE statistics as having either a primary or secondary Special Educational Need associated with learning disabilities

⁴ RCN (2014) *Learning from the past- setting out the future: Developing learning disability nursing in the United Kingdom* www.rcn.org.uk/professional-development/publications/pub-003871

Learning disabilities policy in England

Back in 2011 the BBC's *Panorama* programme exposed the abuse of people with learning disabilities in the private hospital, Winterbourne View. The scandal led to the Coalition Government stating that 'hospitals are not homes' and pledging to move all people with learning disabilities who are inappropriately placed in hospitals, like Winterbourne View, into community care by 1 June 2014. Despite the commitments set out in the Department of Health's national policy response *Transforming Care: A National Response to Winterbourne View Hospital* the pledge was unmet. In fact, in June 2014 there were still more people with learning disabilities being admitted into hospital than there were being discharged.

And now in 2016, the promise to move all those inappropriately placed in hospital still remains unfulfilled.

Due to the slow progress and the failure to meet the pledge, the Chief Executive of NHS England, Simon Stevens, commissioned Sir Stephen Bubb to consider how a new national framework for learning disability services could be implemented. Sir Stephen Bubb's starting point was that in the twenty-first century it is not acceptable for thousands of people to be living in hospital when, with the right support, they could be living in the community. Therefore, one of the primary aims of the proposed framework is to grow the community provision needed to support people inappropriately placed in hospitals to be able to live more independent and fuller lives.

In November 2014, Sir Stephen Bubb published *Winterbourne View – Time For Change* and made recommendations for a national commissioning framework under which local commissioners should secure community-based support for people with learning disabilities.

Then, in early 2015, the Coalition Government set up the Transforming Care for People with Learning Disabilities Programme (*Transforming Care*). The programme, led by NHS England, the Local Government Association, the Association of Directors of Adult Social Services, the Care Quality Commission, Health Education England and the

Department of Health aims to improve the care for people with learning disabilities, in particular by shifting care out of hospitals towards community settings. Transforming care for people with learning disabilities is also a top priority in the NHS England 2015-16 business plan.

In February 2015 The National Audit Office (NAO) published its report *Care Services for People with Learning Disabilities and Challenging Behaviour*. It identified a number of barriers to transforming care services, as well as solutions, including developing pooled budgets and developing specialist skilled community teams.

In the same month at a Public Accounts Committee focusing on the NAO report, Simon Stevens committed to publishing a closure programme in autumn 2015.

In June 2015 he announced 'fast-track' sites that would receive additional support for services for people with learning disabilities. The fast-track sites have now had access to a £10 million transformation fund to support the work.⁵

NHS England also promised 'rapid and sustained action' to tackle the over-prescribing of psychotropic drugs to people with learning disabilities after research from various health bodies showed that rates of prescribing were much higher than with the general population. In the majority of cases these drugs were prescribed with no clear justification and use was prolonged, often without adequate review. They also found there is poor communication with parents and carers, and between different health care providers.

The summer of 2015 also saw the publication of *Transforming Care* Delivery Board's progress report, which set out progress on the introduction of Care and Treatment Reviews (CTRs), the fast-track sites, the completion of the *No Voice Ignored*, *No Right Ignored* public consultation and tests of a new Learning Disability Skills and Competency Framework for the workforce. The report states how the *Next Steps* publication sets out a clear ambition for a radical re-design of services for people with learning disabilities.

⁵Fast-track sites are Greater Manchester and Lancashire; Cumbria and the North East; Arden, Herefordshire and Worcestershire; Nottinghamshire; and Hertfordshire www.kingsfund.org.uk/projects/new-gov/mental-health

Concurrently, Sir Stephen Bubb published his interim report *Winterbourne View – Time Is Running Out*. He highlighted the areas where some progress had been made but also gave a strong warning to Government, commissioners and providers that action needs to be taken urgently to ensure the commitments of *Transforming Care* can be met safely.

His report highlighted his concerns over leadership and the fact that very little had been communicated to key stakeholders on how the transformation will be achieved. He also clearly warned that without ‘gearing up the capacity and response of providers’, clinical decision makers will be powerless to recommend anything other than an inpatient bed if they do not have alternatives.

The risk, he says, is a ‘revolving door’ where people are re-admitted into inpatient facilities because they have been discharged into the community to inappropriate provision. This ‘revolving door’ has serious implications for the health and wellbeing of people and impacts their families.

At the end of the year, NHS England published *Building the Right Support*, the national plan to develop community services and close inpatient facilities. This plan aims to shift money to the community and to reduce the use of inpatient beds

by 35%- 50% over the next three years, including the closure of the last stand-alone learning disability hospital in England. NHS England will also make £30 million of transformation funding available in addition to the £10 million already available for the fast-track sites.

In the wake of all this activity the RCN sought the views of learning disability nurses to better understand the impact policy initiatives have had on the frontline since the exposure of the abuse at Winterbourne View.

The RCN surveyed 1,100 learning disability nurses from across the UK, including 771 nurses in England. The survey included questions on topics such as access to services, improvements, community provision, impact on patients and staffing levels. In addition, we carried out in-depth interviews with nurses whose jobs have been transferred outside the NHS to explore their experiences in more detail.

This RCN research demonstrates just how slow any progress has been since Winterbourne View. The RCN also found that there is a worrying disconnect between services and the workforce; both requiring investment if care is to be truly transformed for people with learning disabilities.

Services

Inpatient services

Following Winterbourne View the Department of Health commissioned the collection of detailed information relating to the prevalence of learning disabilities in England and access to services. The Health and Social Care Information Centre (HSCIC) publishes monthly Assuring Transformation data around indicators such as admissions, discharges/transfers, and length of stay in hospital. Recent data shows that there are still thousands of people with learning disabilities in hospital despite plans to move people out of hospital.

Figures from December 2015 give a snapshot of the issue. At the end of the month there were 2,595 people with learning disabilities in NHS-funded hospital care; however it is likely that the number is greater as 10 Clinical Commissioning Groups failed to provide data. In fact, the recent *Learning Disability Census 2015* estimates there are 3,480 people with a learning disability in inpatient units.⁶

2,515 of the 2,595 patients identified in the Assuring Transformation data had been in hospital since the previous month. There were 105 discharges/transfers from hospital but also 80 admissions.

Table 1 shows that although there has been progress, with the number of discharges increasing, there are fluctuations in the monthly number of people being admitted to NHS-funded inpatient facilities. There is clearly still the demand for treatment and assessment in hospital, largely because the community provision needed to keep people out of hospital is unavailable.

Table 1: Number of people with learning disabilities admitted to and discharged from hospital

	Discharges/transfer	Admissions	CCGs that submitted data
Feb-15	75	30	161
Mar-15	95	50	197
Apr-15	100	75	167
May-15	70	50	159
Jun-15	90	65	171
Jul-15	85	85	186
Aug-15	80	60	169
Sept-15	100	50	184
Oct-15	80	75	189
Nov-15	80	50	185
Dec-15	105	80	204

Source: Information provided from CCGs for Learning Disability Services Monthly Statistics - Commissioner census (Assuring Transformation), Experimental Statistics
www.hscic.gov.uk/catalogue/PUB17190/ldsm-feb-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB17448/ldsm-mar-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB17634/ldsm-apr-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB17738/ldsm-may-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB17860/ldsm-jun-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB18173/ldsm-jul-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB18486/ldsm-aug-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB18793/ldsm-sep-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB19062/ldsm-oct-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB19637/ldsm-nov-15-exec.pdf, www.hscic.gov.uk/catalogue/PUB19833/ldsm-dec-15-exec.pdf

⁶Health and Social Care Information Centre, *Learning Disability Census 2015*
www.hscic.gov.uk/catalogue/PUB19428/ld-census-initial-sep15-rep.pdf (p. 76)

This ‘revolving door’ shows a system that is failing people with learning disabilities.

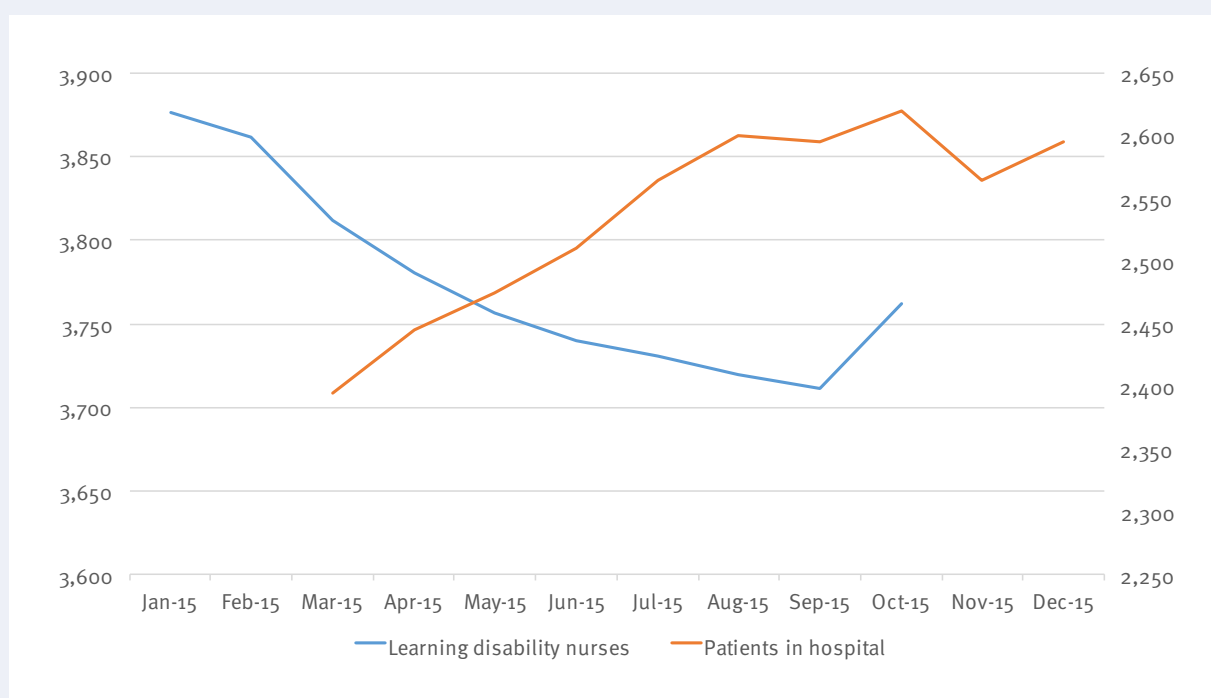
Our survey of learning disability nurses suggests that this is largely because the right services are not in the right places. Seventy-three per cent of nurses said that they have seen cuts to learning disability services in their area in the past year. Over half (52%) disagreed with the statement that people with learning disabilities can access the right care in the right place when they need it.

The inability to access the right care and support to help people live independently can often result in deterioration and the person having to be admitted or readmitted into hospital.

Sixty-three per cent of nurses agreed or strongly agreed that people with learning disabilities are often in hospital for longer than they should be. This view is reinforced by the HSCIC’s 2015 annual *Learning Disabilities Census Report*, which shows that the average length of stay for an inpatient with learning disabilities is 4 years 11 months (1,794 days) and on average a person stays 63.7 kilometres from home.⁷

Figure 1 shows that according to Assuring Transformation data, inpatient numbers did increase over the first half of 2015 with numbers remaining relatively stable since. At the same time there was a significant and worrying reduction in the number of NHS learning disability nurses.

Fig 1: CCG learning disability inpatient numbers and NHS learning disability nurse numbers January-July 2015



Source: www.hscic.gov.uk/catalogue/PUB19670/nhs-work-stat-oct-2015-nur-area-levl.xls and Learning Disability Services Monthly Statistics - England Commissioner Census (Assuring Transformation), Experimental Statistics March – December 2015

⁷ Health and Social Care Information Centre, *Learning Disability Census 2015* (www.hscic.gov.uk/catalogue/PUB19428/ld-census-initial-sep15-ref-tables.xlsx)

Central to delivering *Transforming Care* is discharging people from hospital or transferring them to the most appropriate facility. The first step in achieving this aim is reviewing the care plans of people in hospital settings. As of mid-September 2015 there had been 2,020 CTRs of people in hospital.⁸ Learning from CTRs has helped develop a new approach which helps to prevent unnecessary admissions and identify people who are at risk of admission.⁹ It is important that this learning continues and is shared widely to help tackle the large number of people with a learning disability in hospital.

Following Mencap's report *Death By Indifference* in 2007 and the Health Service Ombudsman's report *Six Lives* in 2009, steps were taken to help improve the care of people with learning disabilities in NHS general acute hospitals. One of the important steps taken was the introduction of Learning Disability Liaison Nurses.

Learning Disability Liaison Nurses help promote access to services by directly supporting people but also by developing hospital and community systems, influencing policy and educating hospital staff. However, freedom of information requests from Mencap in November 2014 showed that 42% of 165 NHS acute trusts did not have a Learning Disability Liaison Nurse. Mencap also found that on average, each trust only had 30 hours of learning disability nursing cover out of 168 hours in the week.¹⁰ The RCN survey supports these findings, with 50% of nurses saying their employer did not have an acute Learning Disability Liaison Nurse.

The RCN calls for every acute hospital to employ at least one Learning Disability Liaison Nurse. By 2020/21 all acute hospitals should have 24-hour Learning Disability Liaison Nurse cover.

Learning Disability Liaison Nurses need to have the appropriate level of seniority so they can bring about real change at the trust to improve the care for all those with learning disabilities who access hospital services. The RCN suggests that a similar role should be rolled out within primary care and community services so that the whole care journey is covered.

Community services

The cornerstone to delivering *Transforming Care* is to have an appropriate range of services for people with learning disabilities in the community. Worryingly, 85% of learning disability nurses say there are not enough of the right services in the community to support and care for people.

Despite the ambitions post-Winterbourne View to improve community services, only 22% of learning disability nurses agreed with the statement that there are now better services in the community than there were three years ago; 47% disagreed or strongly disagreed.

For many people, the right support in the community should prevent the need for inpatient admission. However, there are situations where a person with a learning disability does require a period of inpatient assessment and treatment. It is crucial, however, that they are able to access an early discharge to an appropriate community service with learning disability nursing support as part of the package. The RCN fully supports the commitment to transfer people out of inpatient services, but is alarmed at the strong message from nurses that the appropriate services are not in place in the community to safely support the closure of inpatient services.

The RCN fully supports the ambition to deliver new services in the community, but emphasises these services must be safe and appropriately staffed with a skilled and caring workforce. NHS England should ensure that only high-quality local services with learning disability nursing support are developed.

The plan is to close some hospital facilities over the next three years. The RCN is also concerned that some hospitals and services are already closing before robust provision in the community is available, leaving people without the support and help they need. In some cases commissioning arrangements are changing and independent providers are closing unsustainable services.

The RCN is aware that some independent providers have already had to make strategic business decisions to meet commissioners' requirements and have had to close a number of their hospital services for those with learning disabilities. Closures may happen at short notice with minimal

⁸ *Building the Right Support*

⁹ *Next Steps*

¹⁰ www.mencap.org.uk/news/article/public-loses-faith-nhs-failing-people-learning-disability

time for consultation with clients or staff. It can be difficult for people with learning disabilities to manage this change and it can be very unsettling. Disruption, not properly planned and supported, can have very serious consequences for a person's physical and mental health.

To implement effective services in the community, wider issues must be tackled. It is crucial that the over-prescribing of people with learning disabilities with psychotropic drugs is addressed. Medication should not be prescribed to control behaviour

that could be managed in other ways. Similarly, restrictive practice should always be used as a last resort, in a safe and positive manner.

Positive behavioural support has been shown to provide better outcomes for people.

The RCN calls for positive behaviour support to be embedded across organisations and for training to be provided to those who may be caring for someone who presents behaviour that challenges.

Joe

Our son Joe is 40 years old. He's a boisterous person, with a wicked sense of humour. He loves being out and about, and he has a big family who love him to bits.

Joe has a severe learning disability and behaviour that challenges. He doesn't use many words.

When communicating with Joe, staff need to listen to him and repeat back to him what he has said. They must not try to pass it off with saying: "Ok Joe, yes mate," if they don't understand what he is trying to say, as Joe will become frustrated and upset by this, which will lead to incidents happening.

Joe had been successfully living with a friend in supported living, but he became unsettled when the manager and other familiar members of staff left. Nothing was done by social services to change his support despite his family's requests. After an incident, he was detained under the Mental Health Act and sent to a unit 130 miles away from home.

After 2 years, and battling with the authorities, we managed to get him home.

He is now living in his own place with support. We are so pleased that he is now back living close to us. But we really worry about there being no proper

monitoring of Joe's placement by Continuing Health Care who fund his service and no ongoing involvement from the community team to keep under review how Joe is.

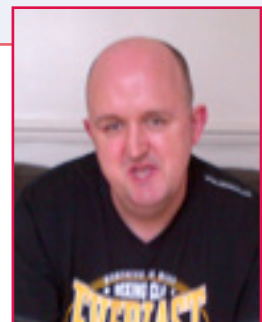
A learning disability nurse did support Joe's transition out of hospital back into the community. But this support was short-term.

I think Joe's package of care in the community is very fragile. If Joe got into crisis again there is no named community LD nurse to support Joe and the provider – someone who knows Joe well and understands his needs. The community team has limited capacity so there is no guarantee he would be able to see someone straight away.

I worry that a crisis situation could easily result in Joe being sectioned again.

I don't want Joe to even get to crisis point. I want professionals in the community to be keeping track of Joe and be there to provide back-up support early on to Joe and his staff team if needed.

Sue, Joe's Mum



The disconnect

The RCN has continually highlighted the disconnect between workforce planning and service delivery. In November 2014 we published *Turning Back the Clock? RCN Report on Mental Health Services in the UK*. The report exposed that despite pledges to improve mental health care and grow community services, the mental health nursing workforce had been significantly cut. This is largely at odds with the commitment to parity of esteem.

The recent NAO report *Managing the Supply of NHS Clinical Staff in England* has also voiced strong concerns about the reliability of local workforce plans and the extent to which they account for changes in how services are delivered. The NAO recommends that all key health policies and guidance explicitly consider the workforce implications.

Building the Right Support needs to go further in considering the workforce and cost implications for delivering the change that is required.

The NAO also demonstrates how the focus on meeting efficiency targets and trying to balance both top-down health policies and bottom-up workforce planning can result in not having the right people with the right skills in the right services. Nowhere can this be seen more than in the care for people with learning disabilities.

In relation to other key national workforce policy proposals, the impact of changes to student nurse funding and the move to student loans is worryingly uncertain. There is a serious risk that future learning disability nurses may be deterred from entering the profession. There is also the risk that removing the central commissioning of training places will impact on nursing supply and that there will be a failure to match national policy priorities or address workforce shortages in specific settings such as learning disabilities.

Workforce

Staffing levels

Staffing levels and overall workforce numbers directly impact on the quality of care delivered to patients. The RCN continues to be concerned about staffing levels across all settings but there has been a marked reduction in staffing levels across learning disability settings in the past year. Nurses reported falls in staffing levels in both the NHS and independent providers. As Table 2 shows, 42% of nurses said that they have seen the staffing levels of registered nurses decrease over the past year. Similarly, nearly a third (29%) of respondents said that the number of health care assistants in the nursing establishment had also fallen.

Table 2: Staffing level changes over the past year

	Registered nurses	Health care assistants
Decreased	42%	29%
Stayed the same	39%	48%
Increased	12%	14%
Not sure/Don't know	8%	9%

Safe staffing levels are critical when caring for people with learning disabilities and those who present challenging behaviour. The right number of nurses is needed to protect both patients and nurses and to ensure that patients are receiving high-quality care and support. The National Institute of Clinical Excellence (NICE) withdrew the work planned to produce a guideline for nurse staffing levels across learning disabilities settings. The work will now be carried out by NHS Improvement and Quality in conjunction with the Chief Nursing Officer. The RCN strongly supports this vital work.

Nurse numbers

Providers need access to a sufficient supply of learning disability nurses to safely staff settings. Table 3 shows that the total number of learning disability nurses in the NHS has fallen by a third since 2010. This reduction of 1,726 registered nurses in learning disability settings is a serious concern.

Part of the reduction can be attributed to some NHS services being re-provided by non-NHS providers, with nurses also being transferred. Unfortunately, at present there is no national data collection across all providers showing how many nurses have been transferred outside the NHS, and how many nursing posts have simply been cut.

However, the decline of learning disability nurses in NHS general acute and community settings impacts on the entire health care workforce. The presence of specialist learning disability nurses can assist in the upskilling of general nursing staff in all areas, as people with learning disabilities often require access to the full range of health services for both mental and physical health needs.

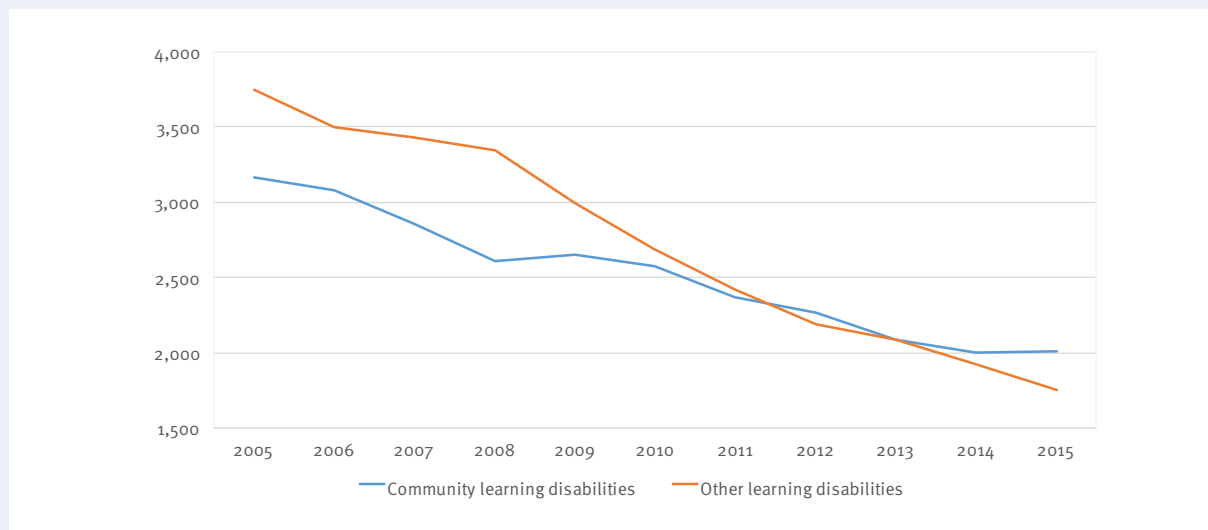
Table 3: Learning disability nurses 2010-2015

	May-10	May-11	May-12	May-13	May-14	May-15	Oct-15	Difference	% change
Community learning disabilities	2,571	2,416	2,316	2,150	2,017	2,003	2,010	-561	-22%
Other learning disabilities	2,916	2,508	2,249	2,156	2,047	1,754	1,752	-1,164	-40%
Total learning disabilities	5,488	4,924	4,566	4,306	4,064	3,757	3,762	-1,726	-31%

www.hscic.gov.uk/catalogue/PUB16933/nhs-staf-2004-2014-non-med-tab.xls
www.hscic.gov.uk/catalogue/PUB19670/nhs-work-stat-oct-2015-nur-area-levl.xls

Data over the past decade presented in Figure 2 shows a dramatic decline in the number of learning disability nurses. This is surprising considering what we know about the population of people with learning disabilities being diagnosed earlier, living longer and having more complex health needs. The decline in nurse numbers over the past 10 years also shows an erosion of the value of the learning disability nurse that seems largely at odds with *Transforming Care*.

Fig 2: Learning disability nurses 2005-2015



Note: 2005-2014 data September each year. 2015 is the latest data available from October 2015 provisional statistics.

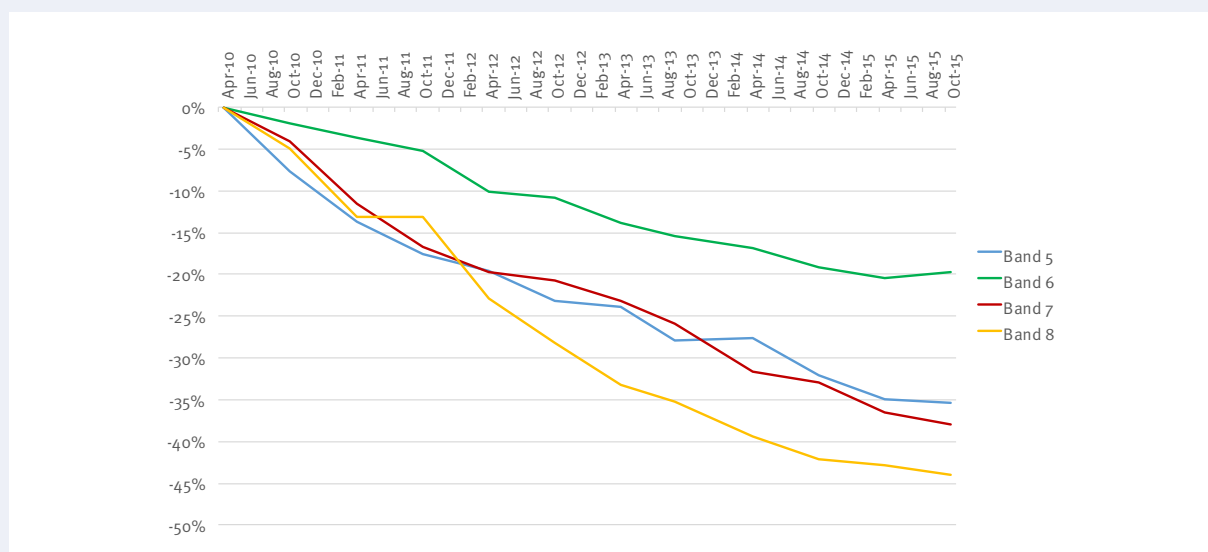
www.hscic.gov.uk/catalogue/PUB16933/nhs-staf-2004-2014-non-med-tab.xls

www.hscic.gov.uk/catalogue/PUB19670/nhs-work-stat-oct-2015-nur-area-levl.xls

Skill mix

Not only has the number of nurses decreased drastically, but HSCIC data shows that proportionately more senior nurses have been lost in the NHS in England than in other Agenda for Change bands. Figure 3 shows the 40% reduction in band 7 and 8 learning disability nurses; that is a loss of 540 senior NHS nursing posts.

Figure 3: Number of nurses in learning disability settings by AFC band 2010-2015



Source: Freedom of information request, HSCIC, 2016

The RCN survey goes further than these headline figures, with 37% of nurses saying that they had seen evidence of down-banding or downgrading at their place of work.

When services are re-provided or re-organised nurses are seeing their jobs downgraded and in the long term their pay reduced when pay protection clauses come to an end. Twenty-eight per cent of respondents had seen their employers cut pay for those caring for people with learning disabilities. It is unacceptable that affordability challenges are resulting in the downgrading of nurses and being substituted with more junior and cheaper care.

Student commissions

As shown in Table 4, the number of student commissions has steadily decreased over the past decade. The planned number of places commissioned dropped by 18% from 2010/11 to 2016/17 and there has been a fall of 30% over the past decade. The Health Education England (HEE) 2015/16 workforce plan shows that providers are predicting a decreased need for learning disability nurses by 2019. HEE explains that this may in part be a result of the planned shift to non-NHS providers. However, the RCN shares HEE's concerns that this is being driven by affordability concerns. The HEE 2016/17 commission announcement has seen student places fall by 26 places and does not appear to be aligned to *Transforming Care*. The RCN calls for an increase in learning disability nurse commissions over the next few years to significantly increase supply.

Table 4: Number of learning disability nurse places commissioned: planned vs actual 2004-2016

	Planned	Actual
2004/5	1,083	844
2005/6	960	706
2006/7	910	723
2007/8	798	617
2008/9	811	629
2009/10	755	723
2010/11	777	642
2011/12	614	574
2012/13	612	618
2013/14	876	603
2014/15	653	-
2015/16	664	-
2016/17	638	-

Source: Dr Dan Poulter MP (www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2015-02-09/223887/) and Health Education England's HEE Commissioning and Investment Plan 2016/17

Future workforce

Learning disability nurses play an integral part in supporting people to live independently and should be trained in providing positive behaviour support. Cuts to nurse numbers, senior posts and student commissions over the past five years highlights how undervalued the learning disability nursing workforce has been despite this being a time of ‘transformation’ for learning disability policy.

In order to truly transform care, health and social care providers delivering these services need to deploy dedicated people, in sufficient numbers and with the right skills and breadth of knowledge to provide whole person-centred care.

As the drive towards moving people out of hospital and embedding new community services continues, it is important that the inpatient learning disability nurse workforce is provided with the support and training to re-skill to work in community-based settings.

Part of HEE’s ongoing work is in developing and testing a new Learning Disability Skills and Competency Framework. This work is expected to be rolled out in early 2016. The RCN welcomes the new framework but would emphasise the particular role that learning disability nurses can play in upskilling all health and social care staff and raising standards when caring for people with challenging behaviour.

The RCN calls for a long-term (five-to-ten-year) nursing workforce strategy that underpins *Transforming Care*.

Strengthening rights

One of the pillars supporting *Transforming Care* is the commitment to help strengthen the rights of people with learning disabilities. There has been some progress in this area and the Department of Health completed the *No Voice Unheard, No Right Ignored* consultation.

In our response, the RCN highlighted that many of the proposals seem to be covered by existing legislation. The RCN agrees that NHS communities should have the same duties as local authorities, to put people's wellbeing at the heart of what they do. This includes making sure that people are helped and supported to stay close to home for their care, support and treatment in the least restrictive setting as a first option wherever possible.¹¹

A central element of the proposals in relation to strengthening rights is the 'right to challenge' any decision to admit or continue to keep a person in inpatient care. When asked, 38% of nurses

agreed that people and their families are currently empowered to challenge any decision to admit them to inpatient services; 24% disagreed and 38% neither agreed/disagreed.

In November 2015 the Government published its response to the *No Voice Ignored, No Right Ignored* public consultation. It set out action over a three-year period. Many organisations were critical, saying it was weak and did not meet the green paper's original vision of empowering individuals and families to challenge inpatient admissions and to have more control over their care and support.

Strengthening the rights of people with learning disabilities must remain on the political agenda, perhaps through amending or enforcing existing legislation. The pace of change cannot be allowed to slow now that the consultation response has been published.

Service improvements

When asked for an overall opinion, only 16% of nurses said they had seen improvements to services in the past three years. Forty per cent said services are about the same but 44% said they had got worse. However, learning disability nurses did identify some specific improvements:

- Some patients had been moved closer to home, and there were more placements in community settings.
- Greater safeguarding measures and nursing input into the process.
- More robust Care Quality Commission inspections and monitoring use of the Mental Health Act.
- A shift towards a more patient-centred approach to deliver better-quality care.
- Shared and more in-depth care planning.
- Better access to primary care services and some closure of inpatient units.
- Greater emphasis on positive behaviour support and increased amounts and quality of training.
- Increased transparency, with service users being more involved in decision making.
- More open approach to raising concerns and whistleblowing with better policies in some areas.

¹¹www.rcn.org.uk/-/media/royal-college-of-nursing/documents/policies-and-briefings/consultation-responses/2015/june/1515.pdf

Commissioning

There is great variation in the experiences of patients, their families and nurses alike. The variation in the quality of services available is unacceptable.

A key factor in improving future services is through the effective commissioning of services. All commissioners should be operating with the shared understanding that hospitals are not homes and that pooling funding across health and social care will help with the provision of integrated services for patients. The RCN supports Sir Stephen Bubb's recommendation that local commissioners should follow a mandatory framework; a step that should help minimise the variation in service provision.

Detailed consideration must also be given to the quality and capacity of existing services. Future specialist services that are commissioned must also have longevity.

Increasingly, the NHS and local authorities are commissioning independent providers to provide learning disability services. Some of these independent providers are leading the way in service design for assisting people with learning disabilities to live as independently as possible.

However, NHS England must have clear oversight of commissioning arrangements and assess whether changes to commissioning may have an adverse impact on patients.

The RCN is concerned that with some providers changing regularly, mergers or the purchasing of smaller enterprises there may be a negative impact both on patients and the workforce.

It is argued that closing inpatient care facilities will free up money that can then be reinvested into community services, following upfront investment. It is critical that the upfront investment is spent effectively to grow community provision across England, not just in the fast-track site areas.

The RCN welcomes the development of the 49 *Transforming Care* partnerships and hopes that these will be key in commissioning the range of community services needed across England, with local people driving local change.

The RCN calls for commissioning and service design to be linked to national and local workforce planning.

Integration

The current approach to the provision of learning disability services is complex. At present, there is differential entitlement to receiving them; free at the point of delivery for health and means-tested for social care. This has created a fragmented system of health and care, often leading to people's fundamental needs not being met, and resources being wasted through unnecessary duplication.

Recently there has been a national shift towards a more integrated approach, joint commissioning, pooled budgets and co-ordinated service, in order to meet increasingly complex health and care needs. This is especially important for people with learning disabilities, who are more likely to need to access a range of different services to meet both their physical and mental health needs. The recent service model for commissioners highlights the need for access to specialist health and social care support in the community via integrated specialist, multi-disciplinary health and social care teams.

The move to integrate learning disability services has been accompanied by an increased emphasis on personalisation and the choice agenda, as well as prevention-based approaches and a more flexible use of funding. There is national recognition that the current configuration of services does not meet the needs of people and their families in a coherent way. Therefore, the new service model for commissioners is underpinned by a strong emphasis on personalised care and support planning, personal budgets and personal health budgets.

Personal budgets, which are intended to deliver tailored, personal care plans to service users, are a core component of delivering integrated care. Some adults with learning disabilities may already have the right to a personal health budget through NHS continuing health care. However, by April 2016, NHS England expects that personal health budgets, or integrated personal budgets across

health and social care, should be an option for all people with learning difficulties, in line with the recommendations set out in Sir Stephen Bubb's review. Where people are unable to manage the budget themselves, it can be done on their behalf via a virtual budget, or they can opt for more traditional commissioned services. However, even with commissioned services it is expected that there will be a high level of "co-production" with the full involvement of the individual, the carer and the family or advocate to design and shape the service.

In a bid to promote responsive care, a selection of health care tasks are now able to be delegated to a patient's personal assistant via the care planning process. However, important questions still remain around the delegation, training and accountability of personal assistants. There needs to be more discussion as to how personal assistants will be supported to take on these responsibilities, trained in the new skills that will be required and assessed to ensure competence. Given that personal assistants can be employed either by the budget holder, or by a third-party organisation, thought also needs to be given to the pay and conditions of the individuals who will fulfil these roles. Additionally, a clear framework is required for the effective delegation of clinical tasks to personal assistants. It is vital that each member of the nursing team is clear about their level of accountability and that personal assistants are not expected to deliver complex care tasks without the appropriate competencies.

One of the key national initiatives supporting these developments is the Integrated Personal Commissioning (IPC) programme. This is a pioneering initiative to blend health and social care funding for some of the people with the highest care needs, allowing them to direct how it is used through personalised care and support planning, and personal budgets. The IPC financial model attempts to shift incentives towards prevention and coordination of care, through the development of an integrated capitated payment approach. This is intended to align financial accountability and outcomes. Nine demonstrator sites have been selected to pilot this approach with a defined patient cohort, and at present, four out of the nine sites plan to include people with learning disabilities at high risk of institutionalisation or placement. This approach has significant potential, but it will need to be monitored closely to determine its viability.

Integration holds significant potential for people with learning disabilities and the RCN welcomes the increased drive towards person-centred and co-ordinated care. National integration programmes such as the Integrated Personal Commissioning programme, alongside locally led partnerships (such as section 75 agreements), provide the opportunity to improve the quality and experience of care for people with learning disabilities.

However, the true benefits cannot be realised whilst such initiatives remain piecemeal. In particular, the rollout of integrated personal budgets must be accompanied by investment in market shaping, and a decrease in block contracts, if individuals are truly to be able to access the services they need. Commissioners will also need to address the current use of NHS resources proactively to free up money for personal health budgets and avoid double funding.

The RCN survey showed that 40% of nurses had seen evidence of integration in their area, with only 25% saying they had not. Thirty-five per cent of respondents said they neither agreed nor disagreed that there was evidence of integration in their area. The integration agenda appears to be slowly filtering through to frontline nurses. However, 28% of nurses said that lack of integration was one of the key barriers to improving care for those with learning disabilities. There is still a worrying level of variation across services in England.

Integration has significant implications for the nursing workforce.

Increasingly specialist roles will need to be part of a multi-agency community team, to deliver services wherever people live, rather than in institutions or building-based services. This will be a major shift for some staff, especially for learning disability nurses affected by the fast-track closures. The delivery of care in the community will require a different culture, new values and attitudes, as well as a much more flexible and person-centred response. In addition to these cultural aspects, a number of key practicalities must be considered. For example, will the move to working across local authority and NHS boundaries affect nurses' terms and conditions? Who is responsible for ensuring that staff working in multi-disciplinary teams have access to the necessary training and development? To ensure a smooth transition to a more integrated system, these questions need to be answered. And soon.

Additionally, community-based behaviour, support and outreach teams will need to be strengthened, with an emphasis on keeping people as independent as possible in the community, and preventing crises which might otherwise lead to

unplanned hospital or institutional care. Learning disability nurses will also have an increasingly key role to play in personalised care and support planning, as well as supporting people with learning disabilities in shared decision making.

Case study: How Salford is making it happen

Supporting people with a learning disability and behaviour that challenges is everyone's job – social care and health professionals, commissioners, providers, housing, and children's services. Salford Council and NHS

"It is not quick work – you need a long-term strategy, but the benefits are clear. The quality of people's lives is improving. Before, when we were sending people out of area, money was just disappearing out of Salford. Now we are spending money investing in local services to ensure that people with a learning disability and behaviour that challenges can have a fulfilling life in Salford."

At Salford they work in partnership and the community team is made up of both health and social care professionals. Salford has a joint service with a pooled budget which means no arguments about continuing healthcare or what contributions health and social care should be making. Salford City Council and NHS Salford run training in managing behaviour that challenges for everyone supporting people with a learning disability – including independent providers, day services staff and respite staff. The training involves families and focuses on positive behaviour support. In Salford, they have one Positive Behaviour Support policy for adults.

The policy covers health, local authority and the third sector. It means that everyone is on the same page and committed to supporting people with behaviour that challenges to live in Salford. As well as making sure adults do not have to go out of area to get their needs met, Salford work with colleagues in children's services to support them to develop the one-policy approach across education, health and the local authority. This will equip children's services with the right skills, so that young people do not have to go to school out of area, however complex their behaviour.

The service employs Learning Disability Nurses in a range of roles including Team Managers, Community Nurses (Co-ordinators), Health Facilitators and Clinical Nurse Specialists, the nurses work as part of the joint service alongside social workers, Psychiatry, Psychology, Physiotherapists, Speech and Language Therapists, Occupational Therapists and Art therapists. Community Nurses also take the lead in adult safeguarding with their patch areas and others take the lead in specific areas e.g. epilepsy. The work of this range of Learning Disability Nurses has been vital to delivering good quality services in Salford for people with learning disabilities.

Re-provision of services

Service re-design and the re-provision of services to non-NHS providers directly affect service users and their families. However, the re-commissioning of services also has a direct impact on employees, including thousands of nurses and health care assistants.

Often when nurses are transferred from the NHS to new employers this is done under TUPE

agreements.¹² TUPE rules apply to protect employees' rights when the organisation or service they work for transfers to a new employer. However, they do not protect skill mix or staff numbers.

The survey and interviews conducted by the RCN revealed that there was a broad range of experiences. The type of experience was often linked to the size of the independent provider and

¹² TUPE refers to the 'Transfer of Undertakings (Protection of Employment) Regulations 2006' amended by the 'Collective Redundancies and Transfer of Undertakings (Protection of Employment) (Amendment) Regulations 2014'.

whether it was a specialist learning disabilities organisation or an organisation providing general care across different specialities.

The RCN survey identified nurses who have had their roles transferred from the NHS in the past three years; 33% found it to be a positive experience, 45% said it was neither positive nor negative and 22% said it was a negative experience. This suggests that a large proportion of nurses did not find the experience negative but as the sample size of 24 was too small to make broad assumptions, the RCN carried out a number of in-depth interviews to further interrogate nurses' experiences of being transferred from the NHS to another provider.

Some nurses said that they had been more able to implement creative ideas and solutions when delivering services. Some nurses said that they had more opportunities to work in business development and management and felt that working in the independent sector would help them progress into management more quickly.

Negative experiences and concerns tended to focus on the direct impact to nurses' employment contracts, including their terms and conditions and benefits and the devaluation of the role.

Nurses were very anxious about changes to their contracts and the terms of their TUPE agreements. Specifically: undergoing a reorganisation and having to reapply for a job at some point in the future; changes to employment policies and practices; having to reapply for their current job again; having further TUPE agreements if their employer is de-commissioned or the company are taken over; or that they will be made redundant.

Terms and conditions are often eroded when a nurse is moved to a non-NHS provider. Nurses reported that there is often:

- an annual leave entitlement decrease
- a change to pay dates
- a significant reduction in pension arrangements
- the loss of bank holiday payments
- a reduction or cancelling of unsocial hours payments
- a reduction in travel expenses
- a reduction or cancelling of transport for work allowance
- issues over lone worker safety.

Importantly, the reduction of the transport for work allowance often impacts upon the service nurses are able to provide to their patients. A vital part of being a learning disability nurse is to support people to live full, independent lives. Nurses reported that the removal of a transport for work allowance often meant that nurses were unable to take patients on visits; sometimes visits that have become an important part of their routine. This can have a significant impact on a person's wellbeing.

Some of the other concerns raised by nurses were:

- the impact that the transfer of services has on patients, especially given the lack of consultation with them and their families
- the lack of induction into the new company or role
- little or no clinical supervision in many independent provider organisations, though this varies depending on the size of the organisation
- having to seek clinical supervision or nursing leadership from outside the organisation
- the impact of being the only registered nurse in the care setting on the revalidation process
- that for-profit organisations take cost-cutting measures to increase profit margins at the expense of patient care
- the impact of cuts to local authority funding
- the need for some commissioners to better understand the services they were commissioning
- the need for some providers to have a better understanding of both the complexity of needs and range of services that are required in the community
- fear of being de-skilled in their new role
- insufficient student placements in non-NHS providers and that they were losing the benefit that student nurses bring to a clinical or care setting
- the lack of opportunity to do additional training.

The RCN continues to be concerned about the erosion of nurses' terms and conditions when services are re-provided to non-NHS providers. As more jobs are cut within the NHS and services are re-provided to non-NHS providers, learning disability nurses will have even fewer opportunities to work within the NHS. The RCN fears that this may make learning disability nursing a less attractive option to prospective nurses.

Conclusion

The ambition to transform the care that people with learning disabilities receive must continue. Despite laudable policy ambitions to transform care following Winterbourne View, thousands of people remain inappropriately placed in hospital because there are not the right services in the community to support them. The pace of change has been far too slow.

Learning disability nurses tell us that there has been little or no improvement in learning disability services for children and adults over the past five years. Forty-four per cent of nurses told us that they have actually got worse.

Separately, the learning disability nurse workforce in the NHS in England has been cut by a third in

the past five years. Over 1,700 learning disability nursing posts have been cut since May 2010. Of these posts, 550 have been those of the most senior and experienced nurses: there has been a 42% reduction in band 7 and 8 nurses. Learning disability student nurse training places have also been cut.

The disconnect between workforce planning and service design is magnified in this complex health and social care setting – these need to connect for change.

Transforming Care is finally setting out a clearer pathway to shifting care from hospitals into the community. Highly skilled learning disability nurses are part of the solution and are key to delivering more integrated and personalised care.

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