

Transforming Care WHERE NEXT?

A Briefing for the All Party Parliamentary Group for Complex Needs and Dual Diagnosis





The most important thing is to carry on living in my house, woodwork, keep doing the charity shop, going to town, keep seeing my family, and the important one I never never want to end up back in where I was before. It makes me so sad and that's why I don't ever want to be back in hospital.





People with a learning disability have a right to live a life based on basic human rights with the same choices and opportunities as their non-disabled peers.



July 2019

ABOUT THE APPG FOR COMPLEX NEEDS

The All-Party Parliamentary Group (APPG) on complex needs and dual diagnosis was established in 2007 in recognition of the fact that people seeking help often have a number of over-lapping needs including problems around access to housing, social care, unemployment services, mental health provision or substance misuse support. In most cases each service is administered by separate service providers. The result is that people with multiple or complex needs fall through the gaps in service provision.

Providers recognise that the best model for helping those individuals with a dual diagnosis or complex needs is through an integrated service that aims to address all of the issues they face.

Secretariat is provided by Turning Point¹, a large social enterprise which specialises in working with people with complex needs. The APPG has a network of nearly 300 members including the voluntary, community and social enterprise organisations, academia, local government,

the NHS, regulatory bodies and individual service users/family members. The work of the APPG is diverse and has covered issues such as mental health and the criminal justice system; looked after children and care leavers; sex workers; legal highs; veterans and joining up policy on multiple needs from the perspective of those on the frontline. The group undertakes inquiries into key topics, gathering written and oral evidence from the network and undertaking surveys of service users and professionals.

Thanks to everyone who has contributed to this report. Particular thanks go to:

Andrew Jacks

After 30 years in various secure hospitals including Rampton and St Andrew's, Andrew moved into his own home last year. Andrew spoke to the APPG about his experiences of living in hospital and the process of making the transition to living independently.

Yvonne Cooper

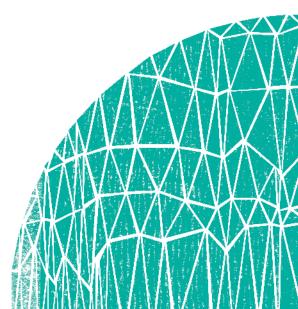
Yvonne is a Supported Living Manager at Turning Point. Yvonne worked closely with Andrew during the course of 2017 to make his transition from hospital into his own home a success. She currently manages a team of 90 support workers who support 20 individuals with learning disabilities to live independently in their own homes across Derby and Chesterfield.

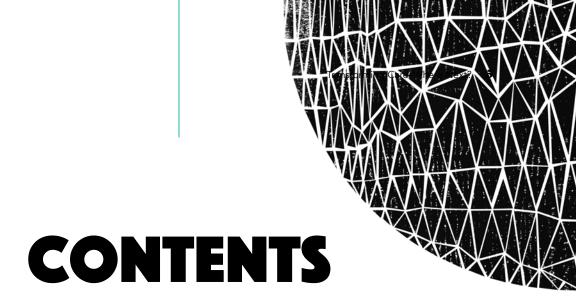
Mark Brown

Mark is a parent and carer, an independent researcher, and activist on learning disabilities and human rights. Has worked in partnership with service providers for over twenty years. He is co-founder of Rightful Lives and developer of the Rightful Lives website - an online exhibition that explores the theme of human rights and people with autism and/or learning disabilities. In February 2019 Mark presented a briefing paper to the APPG for Complex Needs: Transforming Care and Building the Right Support: Where are we now and what next? This paper forms the basis for a large proportion of this report. The full paper is available

Ray James CBE

Ray was the Director of Health, Housing and Adult Social Care at Enfield Council for over a decade and was previously President of the Association of Directors of Adult Social Services (ADASS). He joined NHSE in 2017 as the first National Learning Disability Director, to drive improvement across the country on services for people with learning disabilities.





Foreword | 6

Introduction | 7

Case Study: Andrew's Story | 8

The Implementation of Transforming Care | 10

Process Evaluation | 11

Inpatient numbers | 12

Care and Treatment Reviews (CTRs) and Care Education and Treatment Reviews (CETRs) | 13

Building the Right Support and the NHS Long Term Plan | 13

Making it work | 14

Strategic commitment | 14

Preventing admissions | 14

Partnership | 14

Transparency, data collection and ethics | 14

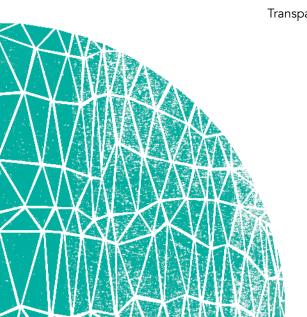
Funding | 15

Families | 15

Workforce | 15

Recommendations | 16

References | 17



FOREWORD



Lord Victor Adebowale CBE Co-chair for the All Party Parliamentary Group for Complex Needs and Dual Diagnosis

Transforming Care is the national policy for moving people with learning disability and autistic people out of long stay secure hospitals when they don't need to be there - i.e. they are able to live in the community with the right support without posing a threat to themselves or others. The government has not delivered change at the pace initially promised and many people remain in secure hospitals when they could be living with much better quality of life, in the community. This is a human rights issue because people with a learning disability and autistic people living in secure hospitals are at risk of being sedated, restrained and isolated from their family and friends. The government's ambition remains and it is one of the key commitments in the NHS Long-Term Plan, published in January 2019.

In February 2019, the APPG for Complex Needs held a meeting to look at Transforming Care and how we can make it work. This report includes some of the evidence shared at the meeting. The discussion reinforced for me the huge importance of a person's relationship with their community and their family in what it means to live a good life. People with learning disability and autistic people who are living in secure hospitals are being denied this right. The health and social care system has a bad habit of letting process getting in the way of intention – we need to go back to the intention - nobody should be in a secure hospital unless they absolutely need to be there and when someone does go into hospital it should be for the shortest time possible and with the highest quality care.

INTRODUCTION

It's thought up to 350,000 people in England have a severe learning disability and that this figure is increasing. A learning disability rarely exists alone, often people have other complex needs, including autism, physical disability, mental health needs, behaviours that can challenge and/or sensory needs. For example, it is estimated that between 25% and 40% of people with learning disabilities also have a mental health need; prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population and behaviours that challenge are shown by 10% -15% of people with learning disabilities.

Many of the people with learning disabilities who continue to live in secure hospitals are far away from their homes and families and many of them have been there for a very long time. This group are at risk of being subject to traumatic and unnecessary restraint, seclusion and over medication. The Winterbourne View scandal in 2011, which resulted in a number of care workers being jailed for violent and degrading abuse of residents with severe learning disabilities, led to a

shift in government policy with a focus on the closure of specialist inpatient hospitals and long-stay institutions.

In 2015 the government launched Building the Right Support, its most recent strategic policy initiative under what had come to be known as the "Transforming Care Agenda". The term Transforming Care was first used in the Department of Health's 2012 report Transforming Care: a national response to Winterbourne View Hospital and since then it has become a shorthand for the work that this and the previous government have done to reduce the number of autistic people and people with learning disabilities in inpatient hospitals.

Despite some progress, the closure of hospital beds has been slow. The original deadline of 2014 to move everyone with a learning disability out of inappropriate hospital settings was missed. Following the publication of the national strategy: Building the Right Support, a 3 year programme began in April 2016 to reduce inpatient capacity by between one third and one half by

April 2019 and build better facilities and support in the community. The Transforming Care programme has resulted in a reduction in the total number of people in inpatient units and the closure of some inpatient beds. Since 2015 around 635 people, who had been in hospital for over five years were supported to move to the community. However, as of July 2018, there were still 2,400 people in inpatient hospitals and data published by NHS England in March 2019 indicates that at least 22603 people are still being detained.

A 10 year plan for the NHS was published in January 2019 which includes a target to reduce inpatient provision by half of 2015 levels by 2024 – essentially reasserting the 2016 objectives but extending the time frame. Clearly we still have a way to go. This paper reports on the discussion at the meeting on the APPG for Complex Needs and Dual Diagnosis which took place in February 2019 focussing on what we have learned from the Transforming Care programme to date; what we know about what works; and what needs to be happen to make Transforming Care work for more people.

8

Case Study: ANDREW'S STORY

After 30 years in various secure hospitals including Rampton and St Andrew's, Andrew moved into his own home last year. Andrew spoke to the APPG for Complex Needs and Dual Diagnosis about his experiences of living in hospital and the process of making the transition to living independently.

Andrew has been supported by Turning Point to live independently in his own bungalow for the past year. Before he moved into his bungalow in 2018 Andrew was in hospital for 30 years –and he was in Rampton for 10 years and for 9 years of this his family weren't allowed to visit him. He left hospital in 2018 following a year of planning and preparation and getting to know Turning Point staff and building up his links in the community.

Today, Andrews enjoys a close relationship with his sister who lives nearby and they go out together a couple of times a week. Andrew loves shopping at charity shops – he enjoys having his own money to spend. Very sadly his mum died shortly before he moved into his house – so she

never saw him out of hospital living in his is own place. Andrew went on holiday recently with his sister and he is very excited about getting a rabbit in the summer.

At the APPG meeting Andrew talked about the way staff treated him in hospital: the strict rules he had to live by in hospital e.g. around what you could and couldn't eat; experiences of violence from staff and other patients and the negative impact this had on his mental health; his positive experiences of starting to go out into the community during the transition, feeling respected and supported by Turning Point support workers, enjoying his independence, hobbies, making friends, his voluntary work and his relationship with his family.

- "At Rampton...one of the staff beat me up and put me in seclusion...I was that bruised... One of the patients battered me, I was bruised and battered 4 times"
- "They said I wasn't reasonable. I was getting stressed and nervous and down."
- "I pushed and pushed and pushed

to get out. Because it was driving me mental. Every ward round meeting I asked 'when can I leave?'"

"The staff at Turning Point did a wonderful job for me... they supported me and looked after me and I was treated with respect."

"I'm a lot happier where I am in my own house. I can go out whenever I like. I have a peaceful life."

"I've got neighbours who talk to me. I go to them or they come to me. I offer them tea or coffee."

"I never never want to end up back in where I was before. It makes me so sad and that's why I don't ever want to be back in hospital."

Yvonne Cooper, Supported Living Manager at Turning Point talked about the transition process. She said that once they had agreed that Andrew was coming out she started going in hospital once a week. She started talking to Andrew. She said that once she had established a relationship, she introduced a small staff team and gradually increased the hours

the team were spending with Andrew, taking him out. The staff were spending time learning about Andrew.

She said they worked with the multi-disciplinary team which included a psychologist, a speech and language therapist and a psychiatrist to understand Andrew's needs and to develop a support plan.

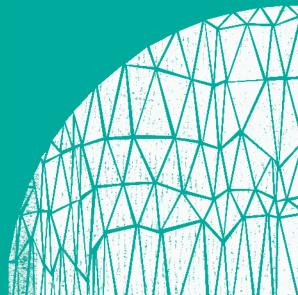
As part of that the journey
Yvonne went on the ward round
once a week. Yvonne said that
if Andrew engaged in behaviour
the hospital didn't like – they
wouldn't let him out. She recalled
an instance during the transition
period when Andrew had gone
out shopping with Turning Point
staff. He brought back sweets
and the hospital staff confiscated
them which angered Andrew.
As a result of his behaviour the
hospital refused to let him go out
the following day.

Yvonne said that in supported living there aren't any rules. There aren't any locked doors, you don't have to have permission to do something. She said it was a brand new commissioning team so there was learning curve for



lots of the professionals involved. She said Andrew was involved in choosing his house. "My house it's a nice house. I've got a TV, ointments, I've got everything. I've got 2 sheds."

Yvonne said that one of the learning points for her about the transition process was the need to sometimes push back on the rules a person has to live by in the hospital. It is important to help people focus on the things that will be different e.g. managing your own finances, working on the skills you'll need around the home and hospital staff need to help facilitate that.



THE **IMPLEMENTATION** OF TRANSFORMING CARE

An independent assessment of the implementation of Transforming Care programme⁴ concludes that Transforming Care Partnerships were underfunded which meant that in many cases they have been unable to implement Building the Right Support. The review questions NHS England's assessment of the impact of the policy to date arguing that the number of people in in-patient hospitals had gone down by 14% rather than the 20% claimed by government. Nevertheless, it is argued that Building the Right Support is good policy, with wide support but that there have been difficulties implementing it. People are particularly supportive of the introduction of Care and Treatment Reviews and Care, **Education and Treatment Reviews** and that the changes that had been made to them in 2017.

Mark Brown's briefing provides an outline of the major elements of Transforming Care - Building the Right Support; identifying

the National Service Model. Care and Treatment Reviews and Transforming Care Partnerships as key.

The National Service Model is based on nine principles, and the idea that these principles should underpin local services for people with learning disabilities and autistic people. So, through the local delivery of the National Service Model people would be entitled to

- 1. a good and meaningful everyday life
- person-centred, planned, proactive and coordinated care
- 3. choice and control
- support from and for their families/carers as well as paid support and care staff
- housing
- mainstream NHS services

- 7. specialist health and social care support in the community
- support to stay out of trouble
- 9. treatment in a hospital setting for no longer than they need

The hope was that with local services based on these principles in place, demand for inpatient hospital provision would go down. In addition to this, a form of individual assessment called a Care and Treatment Review (CTR) would be used to prevent unnecessary admissions, they would also help in preventing long stays in hospital and ultimately work to get people out of inpatient hospital. Later in 2016 Care, Education and Treatment Reviews were introduced for young people in inpatient hospitals.

The Transforming Care Partnerships (TCPs) were set up in early 2016 in order to

implement Building the Right Support and the National Service Model. They were made up of clinical commissioning groups, local authorities and other stakeholders. Once they had been established, each partnership was required to develop a local implementation plan indicating how they would go about delivering Building the Right Support in their area and meet the national objectives that had been set, including the introduction of the National Service Model by March 2019.

The briefing paper also notes that...ultimately the success or failure of Transforming Care/Building the Right Support would be measured by the policy's ability to reduce the number of people detained for assessment

and treatment in inpatient hospitals.

The expectation was that 35-50% of inpatient provision would be closed and that by 2019 inpatient hospital care would only be needed for between 1300-1700 people.

As part of their implementation plans the TCPs also put in requests for the funding that they expected to need and according to the briefing and based on information from a Freedom of Information request, a little over £85 million would be needed by TCPs in order to implement Transforming Care across the country. The gap between the funding that was requested and the funding provided is illustrated in Graph 1, which shows the

funding requested in blue and the funding actually provided in orange.

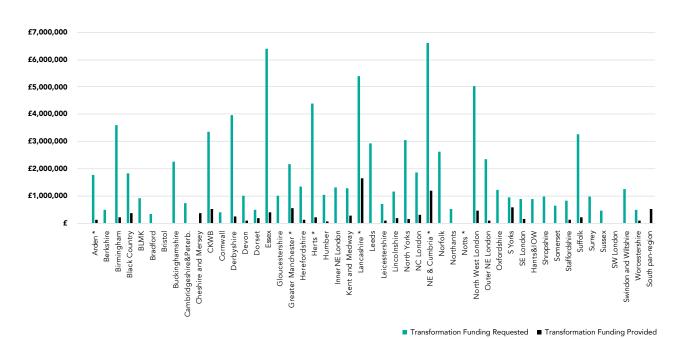
In his briefing Mark Brown argues that the gap between the funds that were bid for, and the funds received will have had a significant effect on their ability to deliver the changes needed. It will also have had a significantly demotivating effect on many of the partnerships that received little or no funding

So, what do we know about how well Transforming Care is doing?

Process evaluation

The progress being made by Building the Right Support is being reviewed in a number of ways. So, for example its

Transformation funding requested and funding allocated in 2016-17



processes are being monitored in an NHS commissioned evaluation that is being carried out by the Strategy Unit and others. This has found that the values and aspirations of Building the Right Support have been well received and helped to bring about improvements in practice and partnership working. It also makes a number of recommendations which have been listed in the briefing:

- 1. Efforts to implement Building the Right Support for all people with a learning disability, autism or both must remain a priority for the NHS and social care
- 2. There is a need to reemphasise the broader aims of Building the Right Support
- 3. There should be an increased commitment to co-producing solutions with individuals and families at local and national level
- 4. Commissioning must be improved
- 5. Commissioner-provider collaboration must be encouraged
- 6. More should be made of information from Care and Treatment Reviews
- 7. There must be better policy alignment
- 8. Support the social care workforce

- The supply of accessible housing must be increased
- 10. The financial model underpinning Building the Right Support needs to be clarified
- 11. More work is needed to pool or align budgets across health and social care
- 12. Communication must improve
- 13. Implementation has centred on performance management and assurance; a more rounded approach is required

Inpatient numbers

The briefing paper goes into the question of inpatient numbers in a lot of detail.

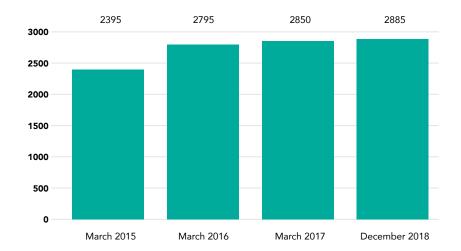
Measuring the progress achieved by Transforming Care/ Building the Right Support in reducing inpatient numbers is surprisingly tricky for a number of methodological reasons. This

is important because without an accurate understanding of the impact the policy has had on inpatient numbers, policymakers cannot make informed decisions about a policy that is integral to the rights of thousands of people and that involves expenditure of hundreds of millions of pounds.

The scale of the problem is illustrated below. The Assuring Transformation figure for the number of people in an inpatient hospital in March 2015 was initially 2,395. By March 2016 the figure for March 2015 had risen to 2,795 and by March 2017 the figure for March 2015 had risen to 2,850. In fact the figure would continue to be adjusted in 2018 and now stands at 2,885 - a 20.46% increase on the original.

It took a very long time to come to a "final" figure. So, when trying to work out how much progress Transforming Care has made which figure should we choose? The first instinct might be to choose the most up to

Variation in Inpatient Numbers for March 2015



date figures for each available month and this appears to have been what NHS England have done when discussing the issue in the NHS Long Term Plan. In which they make the following claim "Since 2015, the number of people in inpatient care has reduced by almost a fifth". It would appear, that they have come to this estimation of Building the Right Support's progress by taking the "final" figure for March 2015 and the current "provisional" figure for December 2018. By doing that, they are able to identify a reduction in the number of inpatients of 560, a reduction of 19.41% - "almost a fifth".

Mark Brown contends that this approach is likely to significantly overestimate the rate of progress that has been achieved because the latest figure is likely to increase over time. He estimates the rate of progress in the reduction of inpatient numbers up to December 2018, to be 14% rather than the 20% claimed by NHS England and that progress made between January and March 2019 appears to have increased that figure to around 16%.

Care and Treatment Reviews (CTRs) and Care Education and Treatment Reviews (CETRs)

An evaluation of the roll out of Care and Treatment Reviews carried out by Pathways Associates indicates that they have had a positive impact. People who have used them have felt that they have made a significant difference to the quality of care and support that is being provided and to the number of people being discharged.

Building the Right Support and the NHS Long Term Plan

Mark Brown's briefing paper finishes by looking at the NHS Long Term Plan and any possible implications this might have for the future of Transforming Care and Building the Right Support.

The NHS Long Term Plan makes autistic people and people with a learning disability a priority for the next ten years. In doing so it sets the following target in relation to people in inpatient hospitals:

"By March 2023/24, inpatient provision will have reduced to less than half of 2015 levels (on a like for like basis and taking into account population growth)"

This is in effect a re-statement of the higher end of the original 2015 target, with an additional proviso relating to population growth. And just to remind ourselves 50% of 2885 is 1443.

An important component in trying to achieve that target will be the use of a 12 point discharge plan and a strengthening of CTRs and CETRs for under 25s. The plan also makes a commitment to increase investment in "intensive, crisis and forensic community support".

In addition to this are commitments to improve the understanding of learning disability and autism across the whole of the NHS, as well as a pledge to expand the STOMP-STAMP initiatives to reduce the reliance on medication.

The NHS Long Term Plan does not mention Transforming Care Partnerships, and nor does it make any reference to the National Service Plan that was a key component and objective of Building the Right Support.

What the plan does incorporate are the newly introduced Learning disability improvement standards for NHS Trusts

- Respecting and Protecting Rights
- 2. Inclusion and Engagement
- 3. Workforce
- **4.** Specialist learning disability services
- A checklist of key steps which need to be taken to move towards discharge



MAKING IT WORK

A number of key themes emerged from the APPG on Complex Needs meeting on Transforming Care in terms of the barriers and enabler for making the policy work.

Strategic commitment

Government is committed to continue working towards the goal of reducing the numbers of people with a learning disability and autistic people living in long stay hospital and this is reflected in the NHS 10 year plan.

"For the first time - the NHS's major strategic plans include explicit reference to people with Learning Disabilities and autistic people. This isn't just about specialist services but also about tackling wider health inequalities." RAY JAMES, NATIONAL DIRECTOR FOR LEARNING DISABILITIES, NHSE

Preventing admissions

More admissions are being prevented however, this isn't the case across the country and more can be done to prevent admissions e.g. through the introduction of dynamic risk registers.

"Every area needs to put a dynamic risk register in place which identifies people with complex needs at risk of admission and identifies how we support these people. "

"4 out of 5 Care and Treatment Reviews (CTRs) and Care **Education and Treatment** Reviews (CETRs) don't result in admission to hospital. Why are they different? They put the person at the centre and bring in independent clinical expertise." RAY JAMES, NATIONAL DIRECTOR FOR LEARNING DISABILITIES, NHSE

Partnership

Strong partnerships between: local government and the NHS, the needs for mature relationships between commissioners and providers and specialist and community teams are key to preventing admissions and readmissions and enabling a smooth transition out of hospital.

"It comes back to good old fashioned working together. Finances shouldn't get in the way of working together. For Turning

Point it is important to keep the ongoing dialogue with health providers that keeps Andrew out of hospital. We need to do more to share good practice." **ELAINE** BARKER, TURNING POINT

"The majority of crisis referrals come from private providers ... there is always pressures to discharge from ATU after 12 weeks and specialist services need to work more closely with providers." JACQUIE SHENTON, NURSE CONSULTANT

Transparency, data collection and ethics

Data quality and availability is a key issue in terms of transparency about the implementation of the Transforming Care policy. Partly this is related to the fact that lots of data is collected by health services and comparatively little collected by the social care system. At the APPG meeting there was some discussion about the pros and cons of collecting more data to highlight variations in practice and outcomes.

"There's been a lot of talk about some areas doing things well and others not. I look for these things. But its very difficult to find out which these areas are. My plea is for the whole debate on Transforming Care to be more transparent" MARK BROWN, RESEARCHER AND PARENT

"My concerns are that while someone is in the health system we get information via the Mental Health dataset but when they move we lose all that data. Adult Social Care data does not tell us who is where and the main reason for them being there. We need to know that someone's care is being organised and how is the care being provided. It has been looked at but it has not happened. We can only get a snap shot rather than longitudinal data. Right now if someone is in a Learning Disability unit I can identify if they go to A&E, if they die, but if they move across to Adult Social Care settings the information flows stop. There is power in data." GIOVANNA MARIA POLATO, CQC

"I completely and utterly support the principle of open data. But I also completely support the UN Convention on the rights of persons with disabilities⁵. Are we in danger of people not having the same rights and options and services? People should be supported have the same rights and choices as their non-disabled peers. There is balance there to be struck. Tracking service use should not promote institutionalised practice and

mitigate people's right to live a life based on basic human rights with the same choices and opportunities as non-disabled peers." **SAMANTHA CLARK**, CHIEF EXECUTIVE, LEARNING DISABILITY ENGLAND

Funding

The issue of funding was raised several times. Transforming Care Partnerships did not receive the funding they felt was needed to implement the policy which may explain why progress has been slower than anticipated. There is pressure on social care budgets. Between 2010-11 and 2016-17 there has been a 3% reduction in spending on social care services and almost two thirds of local authorities are having to draw down on their reserves in order to meet their statutory responsibilities which means there are arguments between health and social care about who picks up the bill. In some cases this goes on and on while people remain in hospital. The expansion of Personal Health Budgets, where funding follows the individual, may provide individuals and families with greater control and help people move out of hospital more easily.

Families

Families often play a key role in an individual's wellbeing and support and advocating for a person's best interests and yet they can often be cut out of discussions between professionals. "Families need to be involved in this discussion. I know families aren't everything but what families bring to this is vital. If you are trying to get someone out of hospital or to prevent them going – they have a vital role to play." MARK BROWN, RESEARCHER AND PARENT

Workforce

A key theme throughout the discussion was workforce: poor pay in social care, skills and training, a lack of highly skilled specialist staff and negative attitudes towards working in the care sector.

"In many areas of the country – the biggest issues isn't money it's a skilled workforce with the right training. We spend too much energy talking about the challenges and not saying what a fantastic and rewarding job it can be. This is the case for frontline care and support workers through to specialist psychiatrists. We need serious thought about how we grow the workforce."

RAY JAMES, NATIONAL DIRECTOR FOR LEARNING DISABILITIES, NHSE

"We need properly trained staff – this is where things are failing. Staff are poorly paid.

Large providers take over smaller providers and dilute the care that is provided. We feel our role is to provide a link between CCGs, adult social care and providers.

We know the money issues are there." JANE REYNOLDS, LEARNING DISABILITY OUTREACH NURSE

RECOMMENDATIONS

Preventing admissions

- 1. There needs to be a robust community infrastructure in place which stops admissions happening in the first place. This should include 24 hour, multi-disciplinary crisis support teams which can support community social care providers and families in people's homes. These teams should be skilled in crisis response and working with behaviours that can challenge in people with learning disabilities and autistic people.
- 2. Crisis support teams should hold a risk register which includes all individuals with a learning disability and autism people at risk of hospital admission.

Transparency and Accountability

3. NHSE needs to be more transparent about progress with implementation of Transforming Care. NHSE should publish a geographic breakdown of: the percentage of people who

have received CETRs and CTRs by area and the results of CETRS and CTRs which shows in each area how many people with a learning disability and autistic people are in hospital who don't need to be there.

Workforce

- Staff supporting people with complex needs moving out of long stay secure hospital environments into the community need to be better paid. This is a demanding job and having a stable staff team massively increases the chances of someone being able to stay out of hospital. Social care providers are only able to pay what they are funded to pay by commissioners. Service delivery contracts need to promote better pay for support workers.
- 5. The workforce needs to have a broader skill set that includes autism and mental health and staff supervision needs to reflect the complexity of the work.

Social Care Green Paper

6. The forthcoming Social Care Green paper should acknowledge the successes and failures of the Transforming Care policy and put in place enablers to allow the policy to be fully implemented. In particular it should include commitments to: improve pay for support workers and improve transparency in the implementation of Transforming Care by requiring additional reporting by NHSE and greater transparency and accountability around progress with implementing Transforming Care.

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