
TIME FOR CHANGE: THE CHALLENGE AHEAD

CONTENTS

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Thanks

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FOREWORD	3
EXECUTIVE SUMMARY	5
The Challenge Ahead	5
Key Recommendations	6
BUILDING THE RIGHT SUPPORT	7
The Closure Programme	7
Beyond Beds	9
'Right Care in the Right Place'	11
The Prevention Revolution	12
A WORKFORCE THAT WORKS	15
Social Care Careers	16
Accreditation of Positive Behavioural Support	17
A HOME, NOT A HOSPITAL	20
Social Property Fund	22
Payments	23
ACCOUNTABILITY: A RED LINE	24
Independent Evaluation	24
Rights	25

May 2016 will mark the 5th anniversary of the Panorama programme which exposed abuse and neglect at Winterbourne View Hospital, a private assessment and treatment unit (ATU) for people with learning disabilities and/or autism. In its aftermath the Government made a promise to move everyone with learning disabilities and/or autism inappropriately housed in a hospital out of those settings. The deadline was June 2014, and it was missed.

As a result I was asked by Simon Stevens to chair a steering group to examine services for people with learning disabilities and/or autism. I published my report, *Winterbourne View: Time for Change* in November 2014. The conclusion of that report was that institutions must close, and rights for people with a learning disability, their families, and carers must be strengthened. These clear recommendations were accepted by NHS England and by the Government.

In the last year real progress has been made; I believe that there has been a step change in approach with the acceptance that institutions must close.

We have a new deadline. By 2019 the Transforming Care programme intends to reduce the number of inpatient beds by up to 50% nationally. Community-based services will be developed to prevent people from being admitted to hospital and to ensure there are meaningful alternatives to hospital-based care across the country.

A year after my first report, and eight months after Simon Stevens' commitment to the Public Accounts Committee to produce a closure programme, I publically welcomed the release of *Building the Right Support*. This is a national programme for the closure of institutions such as Calderstones, and a new *Service Model* which explains the key principles that should underpin all services for people with learning disabilities and/or autism.

I am convinced that NHS England is committed to transforming services for people who have been failed previously by promises to change the system. Regional and local partnerships have been established to produce their own plans for putting the national vision into action – these must be finalised by April 2016.

My message is that failing to deliver this new programme is simply not an option. Another deadline, another target, cannot mean another broken promise. There is a commitment to closures and to developing community care. There is a step change in the attitudes of the national partners responsible for setting the agenda. But delivering such a universal transformation of services will not be delivered easily. Without the power to mandate local organisations, NHS England must incentivise and support a huge and varied set of stakeholders.

Workforce development, housing, investment and the rights of people affected by this programme are all treated in this report. These are the key aspects of delivery; without them, beds can be closed, but there will be nothing suitable put in their place. Success will be recognised *only* when the closure of hospitals is made possible by the development of community-based services, with people who have learning disabilities, their families, and carers at the centre of their design.

The most important part of putting this report together – published a little over a year after my initial paper – is the national consultation I conducted with people affected by the Transforming Care programme. I wanted to know how the programme is advancing, what problems it is trying to solve, and those problems which it is failing to address. The only way to get the truth is to ask those who experience learning disability services every day. I put a call out and received responses from people with learning disabilities and/or autism, self advocates, family members and carers, practitioners, providers large and small, and independent experts. ACEVO also held consultation meetings and I have spoken directly to people whose experience of these services goes back far beyond 2011 and Winterbourne View Hospital.

A clear message from this consultation has been that individuals do welcome what Transforming Care is trying to achieve. But they are cynical as to whether or not they will see organisations working in partnership to design the bespoke support which individuals want, no matter how complex their needs or how many different health, social care, and educational organisations are involved.

So this report expresses the views and experiences of the people most affected by Transforming Care. It focusses on whether or not the programme can actually deliver on what it has promised. It needs to be noted that still, to date, around 3,500 people are in institutional care.

So the task is great, but the programme is deliverable. However we must remember that the number of people with learning disabilities, including children, is much larger than the number of those who are in hospital. Of the estimated 1 million people with learning disabilities in England, around 300,000 are children.

I have made two key recommendations:

1. We need an independent evaluation of this programme. It would be a needless scandal if we came to 2019 only to find one more promise has been broken. We need real-time, independent evaluation commissioned by the Department of Health with the commitment to publish all interim and final evaluation reports. As the recent Mazars report into Southern Health Trust has shown, no national programme for change should be mobilised without assured accountability in place.
2. I am also calling for an office of Learning Disabilities Commissioner to be established. The holder of this office would have a statutory duty to promote and protect the rights of all people with learning disabilities and/or autism in England. The Government's response to the Green Paper *No voice unheard, no right ignored* does not commit to legislative change to enshrine in law rights for people with a learning disability. A Learning Disabilities Commissioner would be responsible for ensuring appropriate rights for people and their families. Nearly five years after the scandal at Winterbourne View Hospital we are still waiting to see any changes – it is time that someone is given the job that needs doing, which is making life better for all children and adults with learning disabilities and ensuring their rights are respected and enhanced, and their views taken seriously.

I am confident that Transforming Care will achieve changes on the ground. But the challenge has been underestimated before. We have failed people with learning disabilities and their families before. We have a chance to put this right. Let's do it.



Stephen Bubb

Sir Stephen Bubb, Chief Executive of ACEVO

THE CHALLENGE AHEAD

In October 2015 the Transforming Care programme published a national plan for services for people with learning disabilities and/or autism – *Building the Right Support*. This review welcomes the plan, and its commitment to reducing the number of inpatient beds by increasing the availability of community-based support. But such a step change will be challenging across the country, and particularly in those regions where reliance on hospital beds is high.

Building the Right Support uses Assuring Transformation data to estimate that there are 2,600 patients currently in hospital-based settings but the number could be as high as 3,480¹. Furthermore, this does not take into account the wider population of children and adults in England who are at risk of admission to a hospital setting.

While it is right that a national plan for closures should be measured by the number of beds that are decommissioned, Transforming Care's remit goes much beyond this. A robust system of measures needs to be established with strategic direction from the national programme to avoid 'institutional' cultures from emerging in the community – we need to know that services are ensuring individuals have a choice over the support they receive, independence, and that it is delivered in a way that puts their interests front and centre.

Prevention has a key role to play here. This is not just about saving money; it is about managing peoples' needs and circumstances in a safe and cost effective manner. This ultimately means the extent of their need reduces and with the right support they are able to become more independent.

Most forms of preventative work require upfront spending which results in longer-term savings, either financial or in reduced reliance on reactive and acute forms of support. This poses one of the major challenges for *Building the Right Support* – the investment needed to ensure service providers can train their workforce effectively, build robust community teams, and develop housing solutions.

Finally, and most importantly, the rights of people with learning disabilities and their families continue to be undermined. Without independent evaluation of the Transforming Care programme we risk being failed again in 2019 – this should be commissioned by the Department of Health as a matter of urgency. A Learning Disabilities Commissioner should also be instated with a statutory duty to protect and enhance the rights of people with learning disabilities.

KEY RECOMMENDATIONS

1. *The Transforming Care programme must ensure all Fast Tracks and Transforming Care Partnerships have made prevention and early intervention an explicit priority in their delivery of the national plan. It is not enough to say they want to reduce reliance on hospital-based settings – they must demonstrate how they are creating a 'prevention revolution' in their region.*
2. *The Transforming Care programme must consider the accreditation of training in Positive Behavioural Support with a view to establishing an appropriate body to manage the design of a PBS Standard and tiered accreditation systems for individuals and organisations delivering and receiving PBS.*
3. *NHS England has indicated that £15 million will be made available to Transforming Care Partnerships for capital projects. This review calls on NHSE and DH to explain publicly how this fund will be administered and, given £15 million is unlikely to be adequate, how it will ensure that sufficient continuing investment is available as the rate of people being discharged increases over the next 3 years.*
4. *A Social Property Fund should be established to facilitate transitions out of inpatient settings and build capacity in community-based services. The Fund, seeded with £10 million from NHS England and/or Government, could leverage some £200 million from other investors to make investment more easily accessible to expand community-based services.*
5. *Government must make an explicit exemption for supported housing from the capping of housing benefit to Local Housing Allowance Rates. Anything short of this will put at risk hundreds of thousands of vulnerable people, including individuals with learning disabilities and/or autism.*
6. *The Department of Health should commission an independent evaluation of the Transforming Care programme. The body commissioned will be mandated to publish all interim and final reports and should be in place no later than August 2016. Interim reports should be published at the end of 2016, 2017, and 2018. Transforming Care partners should act on the findings.*
7. *Government should establish the role of a Learning Disabilities Commissioner with a statutory duty on the post-holder to promote, enhance, and protect the rights of people with learning disabilities and their families in England.*

BUILDING THE RIGHT SUPPORT

It takes a scandal for society to take notice. The exposé of abuse and neglect at Winterbourne View was a case in point – in 2011, the spotlight fell heavily on systemic weaknesses in the way services for people with learning disabilities and/or autism are designed by commissioners, and delivered by providers. The history of learning disability services is chequered. The balance between ensuring acute, specialist services are available in an emergency, and ensuring people are able to live independent and self-determined lives in their chosen communities has proved to be challenging. Despite *Valuing People* being published in 2001 the last long-stay hospital in England only closed in 2009.ⁱⁱ

The abuse at Winterbourne View Hospital not only caused public outcry; it indicated a worrying trend by which 'short-stay' units for assessment and treatment were being seriously misused and individuals were remaining in hospital for over five years. Reasons vary but, typically, discharges become delayed because of a lack of appropriate care outside of hospital and risk-averse cultures which see individuals being kept in hospital settings with little to no ability to challenge such a decision.

The Time for Change review has been active for 18 months. This is short shrift compared to the years that individuals and their families have had to experience the often complex and unwieldy services offered to people with learning disabilities and/or autism. But over the last year we have seen national organisations – NHS England (NHSE), Association of Directors of Adult Social Services (ADASS), Health Education England (HEE), Care Quality Commission (CQC), Local Government Association (LGA), Department of Health (DH) – recognise that there is no quick fix to systemic inadequacy and acknowledge that a radical change is needed to the way services are designed, delivered, monitored, and supported.

THE CLOSURE PROGRAMME

In February 2015 NHSE chief executive Simon Stevens made a commitment to Parliament's Public Accounts Committee to produce a national closure programme by autumn 2015. This programme would be to scale back the number of beds available in hospital settings, which are often inappropriate because people are placed there for too long, are miles away from their home and family, rely too much on reactive strategies and make it too hard for individuals to transition successfully back into their community. The simple truth is that too often, people are admitted to hospitals only because those beds are available where alternatives ways to support them in their community are not.

True to word, NHSE and its Transforming Care partners have produced *Building the Right Support* – a national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism. Its explicit commitment to closures is a step change – where we have seen previously a risk-averse culture back away from alternative and innovative ways of developing services, we are seeing national organisations accept that a catalyst is needed.

There is no silver bullet – this review acknowledges that bed closures alone will achieve nothing and, at worst, have a very negative effect on NHS England and local authorities' ability to deliver services. But it is clear that without a commitment to reduce hospital beds, beds will continue to be filled without due consideration of how people can be supported in their own home and communities.

Building the Right Support is explicit. It sets out clear targets to be reached by March 2019.

Capacity for no more than 10-15 inpatients in CCG-commissioned beds per million of population	Capacity for no more than 20-25 inpatients in NHS England-commissioned beds per million of population
At minimum, 35% to 50% of inpatients beds will close by 2019	

These planning assumptions are ambitious. While their well-intended nature should be welcomed, the scale of the challenge cannot be underestimated.

Building the Right Support uses Assuring Transformation (AT) data to identify 2,600 inpatients in hospital care.ⁱⁱⁱ If Transforming Care meets its target percentage reduction in beds nationally, 1,300 – 1,700 beds will remain which correlates with the 'per million' planning assumptions across CCG and NHSE-commissioned beds.

However, these assumptions do not add up entirely. Assuring Transformation is not the only data set that measures how many people with learning disabilities are in hospital care. The Learning Disability Census (LDC) also provides an overview. Given the two data sets have slightly different methodologies there are discrepancies when compared:

- 2,140 people are common to both collections;
- 855 people who appear in the LDC do not appear in the AT collections;
- 480 people who appear in AT do not appear in the LDC.

The LDC has stated that taking these differences into account, the number of inpatients at the end of 2015 was closer to 3,480.^{iv}

Given the specificity of *Building the Right Support's* planning assumptions, it is important to note that they are based on 2,600 identified inpatients receiving treatment or support in a facility registered with the CQC as a hospital. It may be the case that this estimate of numbers falls short and that reducing the number of beds by 50% would still see over 1,700 beds available.

This does not begin to take into account the wider population of people with learning disabilities and/or autism, including children and young people who do not come directly under the purview of Transforming Care. One study says that of the estimated 1,068,000 people with learning disabilities in England, over 200,000 are children.^v In 2014 it was estimated that well over 300,000 0-18 year olds had learning disabilities in England.^{vi} In 2011, Eric Emerson and Chris Hatton said that the need for social care service for adults with learning disabilities will see a sustained growth until 2030, with an average annual increase of 3.2%.^{vii} This study took into account the numbers of children who would transition at 18. While Transforming Care has a very specific remit, targets will not be met without appreciating the wider population and trends.

As it stands, 'success' relies on the programme having correctly identified all individuals with a learning disability and/or autism currently in NHS or CCG-commissioned hospital facilities. Transforming Care has established Fast Track Sites to catalyse the delivery of this programme locally and, more recently, it has established Transforming Care Partnerships (TCPs). These must ensure there is enough flexibility in their plans to ensure they can develop comprehensive services for present challenges, and in the longer term to ensure they have the capacity to offer a variety of support options to those at risk of future admission, both adults and children.

Targeted Support is a core part of the Nottinghamshire Fast Track strategy, aiming to provide 'whole life' support – 'seamless care and support as children progress into adulthood and into old age.'^{viii} This requires an 'at risk of admission register' to enable both adults and children to receive

preventative support, early intervention being key to helping to reduce the severity and frequency of challenging behaviour. This displays a recognised need to understand the growing population of children with learning disabilities and/or autism – TCPs need to heed such lessons from the experience of the Fast Tracks. Just as accurate data-collection has been a stumbling block for the national programme, local and regional areas will fall at the first hurdle if they are not able to understand the current, future and at-risk populations in their communities.

*“Adults with challenging behaviours don’t just appear from thin air...
We must begin with the children.”*

Consultation Response, 2015

BEYOND BEDS

This takes us beyond the singular metric of bed reduction. Not only does a community placement need to be developed for every bed closed, but the wider state of support services for people with learning disabilities and/or autism needs to be reviewed comprehensively.

Fig. 1: Reduction in bed usage (%) implied by national planning assumptions, by proposed transforming care partnerships^{ix}

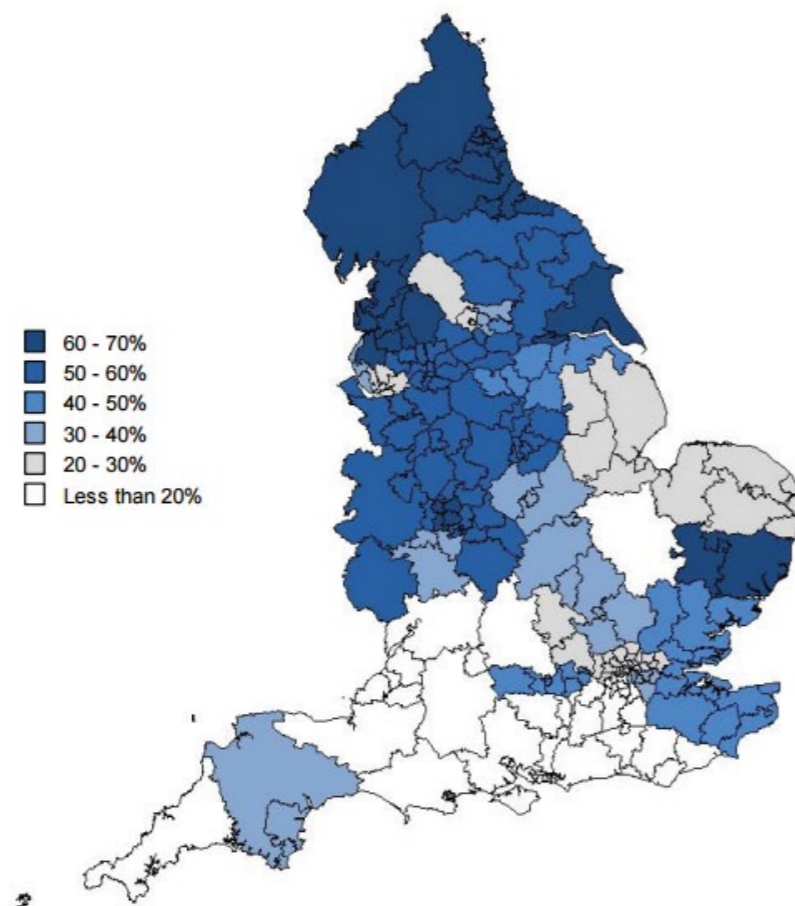


Figure 1 shows national variation in how many beds different regions will have to close to come midway between the 35-50% reduction. It is right that a national plan for closures should be measured by the number of beds that are decommissioned, but Transforming Care’s remit goes much beyond this. It is charged with managing a process by which individuals who have been placed in hospital settings inappropriately, or for far too long, are given the opportunity to move out into a community-based setting that is right for them. Health, social care, and educational sectors will all continue to play a role, but Transforming Care exists within a health and care system that is trying desperately to integrate services, offer bespoke solutions to individuals, and to ensure that people receive person-centred support which puts their interests and aspirations at the heart of service design.

This requires mature, flexible and outcomes-based assessment to measure how successful all of this is for individuals. Have their lives been improved for the better – how is this measured? Distance from loved ones, living as independent a life as possible, receiving the support they need from the people they want, ‘placements,’ and ‘support packages’ sustaining and remaining resilient to changes in people’s lives or circumstances – currently, there is no robust system of outcome measures, no sense of who would conduct such assessment, and no strategic direction from the national programme.

As it stands we risk measuring the success of social care and community-based support simply by the lack of referrals back to the health sector – admission to an ATU. While Transforming Care’s new *Service Model* outlines what ‘good’ looks like, there is no mention of appropriate measures, beyond bed closures, which can enable commissioners, providers, and families to define clear outcomes for the individuals they are supporting, and how these can be measured.

It is vital that all the Fast Tracks and TCPs develop clear evaluation strategies for their overall plans, and that they receive the support necessary from the national system partners to ensure not one region gets left behind.

What are Transforming Care Partnerships?

After the publication of Building the Right Support, the country’s 211 Clinical Commissioning Groups (CCGs) were asked to cluster together into 49 ‘Transforming Care Partnerships’ (TCPs) by 15th December 2015. This number has since reduced to 48 TCPs and includes the 6 Fast Track Sites which have served as pilot sites since summer 2015.

These clusters range from a single CCG, such as Cambridgeshire and Peterborough which has a population of over 900,000, to the London North, Central & East TCP which includes 12 CCGs.

TCPs will vary in terms of the level of partnership the CCGs displayed before they were clustered together for this programme. Therefore central support from the national programme will be provided to help them form plans for delivering the changes that are needed.

This is as near to mandating local bodies that NHSE has been able to get. While asking CCGs to cluster and collaborate with local authorities comes with its challenges, this approach to delivering a national programme will ensure that local needs and local community-based groups are better identified.

'RIGHT CARE IN THE RIGHT PLACE'

This review has been vocal in calling for the closure of 'institutions.' But what is an institution? Large, stripped-back and foreboding buildings, Victorian or neo-Georgian architecture, looming over their surroundings from a distance that represents the isolation of those residing within? Where such architecture remains, we are offered a glimpse into the way this country has treated vulnerable people throughout history – the workhouse, the mental asylum, the long-stay hospital.

What does an institution look like in relation to social care? 'Committing' an individual to an institution connotes their placement into a system that is concerned with more than that person alone, which has rules and organisational mechanisms with which to maintain order – shared wards, locked wards, wards that are secure in order to 'contain' people for one reason or another.

It is critical, however, to understand that 'institutional' does not just mean a building. It is the way in which people interact within those buildings that dictate whether or not those placed in them are exposed to institutionalisation. The culture of institutionalisation that characterised long-stay hospitals included a range of practices and attitudes:

- Strict codes of conduct;
- Hierarchical systems of management;
- Lack of staff training;
- Strict routines which offer no opportunity for choice, such as when to go to bed;
- Over-reliance on reactive strategies, including physical and chemical restraint.^x

Such practices can be found in any organisation providing support to people with learning disabilities and/or autism. Where it is associated with 'institutional' buildings alone, there is the risk of missing its emergence elsewhere.

"A lot of care homes in the community are still run as institutions. An institution can look like one, or it can be how it's run inside. Before, I used to live in another care home, and that had massive electric gates around it. It stuck out like a sore thumb. That is an example of what it would look like from the outside. At the moment, I live in a care home which looks like a normal house. It's not run very well inside...they do your shopping once a week. I don't agree – sometimes you just feel like having something else. It's on a piece of paper behind a cupboard door, and that's a bit institutional."

Consultation Response, 2015

Institutional practices are not synonymous with malicious intent. Organisations rarely go out of their way to create negative environments but a range of factors can cause services to slip. For example, where commissioners drive down prices, it becomes much harder to recruit good staff. Where there are not enough staff to provide a personalised service, institutionalised forms of working are more likely to emerge.^{xi}

This review wants to see the closure of hospital-based settings because it believes that allowing individuals choice, variety and freedom can only be achieved when they are living in the community, near their friends and family.

Transforming Care talks about the 'right care in the right place.' This does not just mean moving

someone from a hospital setting back to their home community – it means giving them a choice over the support they receive, and ensuring that it is delivered in a way that puts their interests at its heart.

Just as ATUs have, in parts, come to resemble long-stay hospitals, this review does not want to see community-based residential or domiciliary services come to resemble ATUs. This is not new. As written in 1996^{xii}:

“ It is recognised, though, that the success of the replacement of institutions and the development of community capacity is still elusive. It is contingent on our ability to recruit and train support staff, to maximise public as well as family and community supports, to ensure adequate advocacy for people with intellectual disabilities in decentralised settings, and to persuade local and national policy makers that any reduction of financial supports is a false economy that may ultimately result in re-institutionalisation and re-segregation. ”

As such, it will not be good enough to move individuals from hospital settings into equally large units, where similar practices could emerge easily. Also, all support services, no matter how small, must demonstrate that their organisational practices do not amount to anything that could be considered institutional. The Care Quality Commission (CQC) has a clear role here – not re-registering ATUs as care homes with nursing, or registering new settings which are large and not community-based is absolutely critical if we are to transform services now and for the future.

The Voluntary Organisations Disability Group has recently published a solution-based paper for overcoming the barriers to good commissioning.^{xiii} Co-production of services with commissioners is crucial, as is the long-term and strategic commissioning that we need to see to stop haphazard procurement of services that do not integrate, or enable providers to develop robust support and services.

The key to avoiding institutional practices is prevention. Preventing individuals' reliance on acute settings, preventing 'bad' practices from emerging, and preventing systems from spending on short term interventions instead of long term solutions all mean slightly different things, but amount to a critical need – investment in preventative support and services.

THE PREVENTION REVOLUTION

Prevention can be interpreted variously in the health and care sector. It is referred to as a cost saving exercise by which authorities can save the money they spend treating people in acute settings by spending what often ends up being much less money on longer term prevention. But cost savings should never be the only aim. Prevention is about managing peoples' needs and

circumstances in a safe and cost effective manner; which ultimately means the extent of their need reduces and they are able to become more independent.

Most forms of preventative work require upfront spending which results in longer-term savings, either financial or in reduced reliance on reactive and acute forms of support. ACEVO has been calling for a 'prevention revolution' in health and care for some time,

“ in which preventative support, advice and treatment is fully integrated into all stages of the care pathway, with the aim of addressing the determinants of ill health, supporting people to manage long-term conditions more effectively, and providing treatment and support in communities, reducing the need for treatment in acute settings. ”^{xiv}

In relation to services for people with learning disabilities and/or autism prevention is often referred to when talking about preventing people from being admitted to hospital. Two issues often get conflated –

1. The cost of hospital-based care, which is an acute setting, is very expensive. Preventing people from being admitted often saves money in the long term;
2. Hospital-based care should never be the preferred option for an individual – a hospital is never a home. The only reason someone gets admitted to such an acute setting is because their needs or behaviour reaches a state that cannot be managed with existing support in the community. As such, preventing people from being admitted to hospital, by providing adequate services in the community, is vital.

There are various angles by which you can arrive at the word 'prevention' but it is clear that when prevention is working, people are being supported appropriately in their communities – the touchpoint of this review.

NHSE have indicated that the average cost of placing someone in a hospital is £175,000 per year.^{xv} This amounts to a cost of around £600 million per year to provide support to over 3,000 people. The most recent data from the Personal Social Services Research Unit (PSSRU) shows that the average annual cost of residential care in the community for adults with autism and complex needs is just under £112,000.^{xvi}

The average reduction in annual costs for an individual's support across the case studies compiled by *Winterbourne View & Social Investment* (a report commissioned by this review) is £134,000. These are big reductions after initial investment has been made in capital projects and centre on the reduction of 'hours' needed as individuals increasingly need less intensive support.

“(On a family member's care in the community) It must be in excess of £250,000, something like £300,000 a year. Certainly not a cost of some of the places in the NHS, but it is not cheap. To work with someone as complex as —, you cannot do this 24 hours a day non-stop. You have to perhaps look at 8 or 10 members of staff point of view - that makes it quite expensive. Things do still go awry. But, it's absolutely stark, very rare now,

a couple of months between, rather than so many a day. I would hope that eventually, we can reduce these costs.”

Consultation Response, 2015

The case is clear, if predominantly anecdotal. The rationale for continuing to make only short-term interventions is entirely lacking. It is not in the best interest of individuals, it is not to save money, it is not to improve any situation at all; it is simply to cope in emergency situations where more meaningful solutions do not exist.

“However, we have significant concerns that the Strategy [Building the Right Support] does not adequately address the specific issues faced by children and young people in health in-patient settings, or have a sufficiently preventative focus to ensure children and young people are supported to develop a place in their community as they move into adulthood.”

Consultation Response, 2015

ACEVO's Five for the Future campaign argues for targeted interventions to increase the amount government spends on preventative services across the board. We have argued that 5% of government spend should be diverted towards preventative services - less than we spend on paying the interest on our national debt. Now that the Care Act has put prevention on a statutory footing there is a real opportunity for Transforming Care to lead the way in innovating preventative services –

This review calls on the Transforming Care programme to ensure all Fast Tracks and Transforming Care Partnerships have made early intervention and prevention an explicit priority in the delivery of their national plan. It is not enough to say they want to reduce reliance on hospital-based settings – they must demonstrate how they will be creating a 'prevention revolution' in their region.

Investing in prevention means many things - workforce development, advocacy, family rights and the housing needs of local areas remain challenges to overcome. Humane public services and Transforming Care depend upon it.

Building the Right Support is a broad roadmap. It serves as a top line articulation of what NHSE wants to see, and a commitment to close beds. The document dictates the minimum number of hospital beds per million population, recognising that as long as beds are available, they will be filled and alternative support not developed.

There is an emphasis on pace in recognition of the failed attempts to deliver on similar roadmaps only a few years ago. The sister document, a new *Service Model*, outlines the key principles that should underpin a variety of services that must be embedded within three years. NHSE have made it clear that TCPs need to work structurally *and* culturally to deliver real change by 2019.

In order to do this, communities need an appropriately trained workforce. The seventh principle of the *Service Model* is 'I can access specialist health and social care support in the community.'^{xvii}

“Everyone should have access to integrated, community-based, specialist multidisciplinary health and social care support for people with a learning disability and/or autism in their community that is readily accessible, when needed”

Commissioners are being asked to secure intensive 24/7 support functions in their communities.

But this workforce does not exist; the requisite number of extra staff will not appear for want alone. *Building the Right Support* does not deliver a roadmap for workforce development and it is treated as 'Annex B' in the *Service Model*. A national vision for recruiting, training, and retaining staff is conspicuous by its absence.

It is right that Fast Tracks and TCPs have the autonomy to identify regional needs, and their own locally-determined roadmap. But devolving such a critical component of their programme without any national standards, support or expectation risks the failure of Transforming Care within the year.

This review is clear that a strategic approach to workforce development is necessary across education, health and social care for adults *and* children. Estimates vary, but at least 10,000 extra members of staff will be needed if the majority of people are to be moved from inpatient settings and supported in community-based services. This includes frontline and managerial staff across the country. Currently, the adult social care workforce supporting people who have a learning disability and/or autism is 121,000.^{xviii} An increase of at least 8% is therefore needed – not insignificant. And this does not take into account continuing and enhanced support for those at risk of admission, or going through transition into adulthood. When we also consider the specialist training required to support people with very complex needs, and the time pressure on developing hundreds of community placements by 2019, it is clear that CCGs, local authorities, and their partners in TCPs need intense support to ensure they are meeting, cumulatively, a huge need.

Without a roadmap, tensions could develop between short and long term priorities. We have seen the Fast Tracks – established in summer 2015- show a point of emphasis on developing crisis and intensive support teams in their communities, the rationale being that such teams stand between an individual and admission to an ATU. Where effective crisis teams can be developed, individuals are less likely to be admitted to an acute setting because they can receive support in their home instead.

In the short term, ensuring such teams are established will immediately provide a community-based and multiagency infrastructure that can prevent admissions. But there is another argument – while developing intensive support teams is critical, it is the development of the right community-based staff working daily with individuals that will reduce dependence on *any* crisis intervention, be it acute or community-based.

Having intensive teams arrive at an individual's house, often with a medical bent, is only the lesser of two evils, the greater being admission to a hospital in the absence of any community support at all. The priority must be the development of a resilient and capable community-based workforce overall. This requires TCPs to see beyond the short term and steward their local markets toward the provision of longstanding and supportive environments, in continuing and meaningful dialogue with people with learning disabilities, their families, and carers.

SOCIAL CARE CAREERS

The urgent need for a resilient workforce goes much beyond the learning disability sector. The ageing population and increasing prevalence of chronic conditions married with huge pressures on local authorities' financial capability and the implications of raising the National Living Wage are universal and immediate challenges to the social care sector: Adult social care faces a £4.3 billion black hole by the end of the decade.^{xix}

It is not in the scope of this report to treat these issues directly but such a difficult context must render Transforming Care taking a strategic approach to workforce development all the more important.

One of the most important elements of the Transforming Care programme is the transition of people from health-based settings to social care settings. While individuals and their families should not feel a structural difference between any forms of support they receive – integrated and person-centred pathways remains a national vision – there is a clear difference between career pathways in health and care pertinent to workforce development. Individuals may work across sectors but a distinction can be made:

HEALTH	SOCIAL CARE
Standardised 'roles' with standardised T&Cs	Roles and services designed around individual case; varying T&Cs
Pre-employment qualifications, training and screening which is not funded by the employer	Training provided and funded by the employer post-employment
Opportunities to 'shadow' and preceptorship	Employees expected to 'hit the ground running;' training and learning is done on the job
Aspirational career pathway with Continuing Professional Development	Linear career pathways; few development options other than changing employer
Services are perennially available for people to use (if someone needs surgery a hospital does not need to recruit a surgeon especially)	Services are bespoke; if the service is not specifically needed then there is not continuing funding for it

Simple distinctions never serve to represent appropriate nuance; proactive social care providers do develop comprehensive and continuing CPD offers and the Chancellor's Spending Review announcement to replace grants for student nurses with loans is one more debating point for an NHS under immense pressures.

But where social care providers work in competition with other providers, health sector colleagues rarely feel this pressure. Given the onus on social care providers to deliver their own training, well-intended providers can be punished when commissioners prefer low-cost contracts over those which incorporate quality training for staff.

This raises two questions – how can Transforming Care ensure that workforce development is a shared priority for providers delivering training, and commissioners who must account for its cost, and can social care learn from its health counterpart with regards to the professionalisation of roles? This is not only to make them attractive to as many people as possible, but to assure service users of the quality and standardisation of training.

At this time, it is typical that front line social care support is delivered by relatively unqualified, low paid workers in settings where staff turnover is high, and any training that is given tends to focus on reactive strategies rather than the proactive development of supportive environments. If one of the most important aspects to Transforming Care is the training and retention of staff to support people with highly complex needs, and prevent that support from breaking down for want of expertise or staff satisfaction, we need to think critically about how organisational cultures can change in the social care sector to secure a workforce that will develop proactively supportive environments for the people they work with.

ACCREDITATION OF POSITIVE BEHAVIOURAL SUPPORT

In July 2015, this review spoke out on the use of physical and mechanical restraint on individuals with learning disabilities and/or autism, and maintains its position on the matter. However, there is a wider comment to be made about the use of reactive strategies which may not include physical restraint but do impact on a person's liberty. These can take place without parallel work to assess why a person's behaviour has become challenging and a framework for working with them to address any issues.

The cohort of people at the heart of the Transforming Care programme are those who have been placed in hospital-based settings such as Calderstones, for whom such placement was never or is no longer appropriate. Calderstones hospital supports people who present with extremes of challenging behaviour and people predominantly get admitted to an ATU when their behaviour is deemed too challenging for them to be supported in their home.

It is absolutely critical that any discussion of this cohort appreciates that challenging behaviour is maintained because of the way that it is responded to, by the behaviour of *others*.^{xx} A core part of any workforce training must be to understand why challenging behaviour occurs and a member of staff's role in that.

"When the term 'challenging behaviour' was introduced, it was intended to emphasise that problems were often caused as much by the way in which a person was supported as by their own characteristics. In the ensuing years, there has been a drift towards using it as a label for people. This is not appropriate and the term is used in this report in the original sense."

Mansell Report, 2007

Positive Behavioural Support (PBS) is the recommended framework for working with people with learning disabilities at risk of behaviour that challenges. Recognition of this continues to gain momentum in England and many organisations, employers and others, offer training packages in PBS.

PBS is a framework for developing an understanding of behaviour that challenges rather than a single therapeutic approach, treatment or philosophy. It is based on an assessment of the broad social, physical and individual context in which the behaviour occurs, and uses this information to develop interventions. The overall goal of PBS is to improve the person's quality of life and of those around them, thus reducing the likelihood of challenging behaviour occurring in the first place.

PBS Academy, 2016

While there is recognition of the value of PBS in the abstract, we are yet to see a PBS 'standard.' Without this – a shared understanding of what constitutes right and effective PBS training – any form of intervention or training can be 'badged' as PBS in order to gain the kudos of association with its principles. For example, training that only focusses on reactive strategies and how to deploy them in the best manner can be called PBS training. But PBS goes much beyond such strategies, however ethically deployed, to focus on creating supportive environments which reduce the likelihood of challenging behaviour. Just as 'challenging behaviour' has become a term used much more widely than initially intended (see above), PBS risks becoming a positive label for something that does not represent the transformation of services.

The nearest we have got to a Standard is the PBS Coalition's Competency Based Framework currently hosted on the PBS Academy's website.^{xxi}

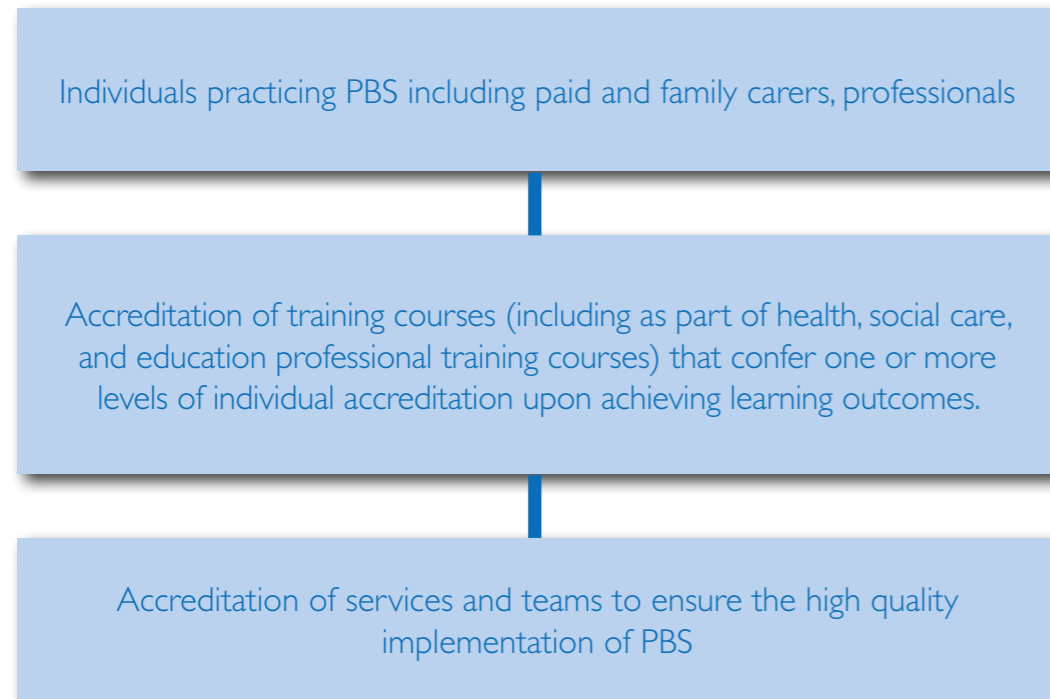
As is the theme of this report, where a national vision has been developed, its delivery still waits to be borne out. NICE guidelines have recommended key PBS-based practices, such as functional assessment, but there is no explicit recommendation of its use.^{xxii} Fast Track sites such as Greater Manchester are clear on their intention to deliver regional PBS hubs and academies.

As the importance of PBS-based practice pervades the sector, it is vital that PBS training is formalised. This means developing accreditation for courses, and regulation of PBS practitioners. Without formal accreditation there is the risk of poor quality practice being delivered; as people with a learning disability, family members and practitioners will not in themselves be PBS experts, they will not be in a position to recognise its poor implementation.

So as demand increases, we need a national system or Standard. Given that it is based on creating a wide framework of support, across all the environments in which a person lives, there is no one organisation currently that can administer an accreditation system across health and

care, education, and in people's homes. A new, independent, organisation is needed to take on a national accreditation role.

Tiers of Accreditation



We must remember that it is the failure to develop good local support and services for people with behaviour that challenges which has led to the increase in acute placements that are expensive and out of area.^{xxiii}

Developing a workforce must include accredited training in PBS-based practices which enable staff to move beyond reactive strategies and create supportive environments.

This review calls on the Transforming Care programme to consider the accreditation of training in Positive Behavioural Support with a view to establishing an appropriate body to manage the design of a PBS Standard and tiered accreditation systems for individuals and organisations delivering and receiving PBS.

This review can not hope to adequately treat an issue as wide-ranging as workforce development. It has simply sought to give an idea of need, and an idea of the sorts of practices that need to be developed formally if the transformation of community-based services is to be achieved. At the heart of this lies the principle that a hospital is never a home.

A HOME, NOT A HOSPITAL

The fifth principle in the new *Service Model* is that:

“People should have a choice about where and with whom they live – with a choice of housing including small-scale supported living, and the offer of settled accommodation. This includes security of tenure.”^{xxiv}

Availability of suitable housing options is at the absolute core of transitioning people from hospital-based support. All indications point to a need for increased housing supply.

Housing options are various. Not everyone leaving an ATU will find themselves living in a flat by themselves and carers. But not everyone will need to move into smaller residential units either. The more options, the more choice for individuals and the more community-based flexibility there can be.

One distinction that is important to make, however, is that that between supported housing and residential care.^{xxv} These both exist in the community but are not interchangeable. Residential care settings see all services, including accommodation and care, provided by the same organisations under the same contracting arrangements. Supported living, on the other hand, sees people with learning disabilities and/or autism owning or renting their home and having choice and control over the support they get, and who they live with (if anyone). An individual can change their care provider without endangering their housing.

“That’s the key, isn’t it? There needs to be different types of housing, and people have a choice.”
Consultation Response, 2015

This review is clear that residential care is not, by default, quasi-institutionalisation. Neither should supported living be, by default, the preferred option. For individuals who have been in large facilities for many years, particularly in shared accommodation, moving to individual supported living may be a leap too far.

“[After 12 years in a hospital] Now, I’m in my own flat, with a charity. I get a lot of support there. I’ve got more independence now. It’s getting used to it. When I first came out I thought it was hard. I didn’t have people telling me what to do, things like that. [Now] I go college. I work with elderly people as well.”
Consultation Response, 2015

One of the major differences between residential care and supported housing, from an organisational perspective, is the way in which they are funded and commissioned. Residential care is a simple ‘product’ for CCGs or local authorities to commission. All aspects of support are provided by a single organisation; it is no more complex than commissioning hospital care.

Supported housing is more difficult - different sorts of purchases being required from different places. Often, housing provision seems to fall outside the purview of the commissioner, which can

often leave care providers having to help individuals find housing themselves.

Another option is shared ownership. This sees people with learning disabilities and/or autism, in partnership with other bodies, purchase a property. This is not widespread, but is interesting. A programme called Home Ownership for People with Long-term Disabilities (HOLD) is one example. It is designed to allow people with a long-term disability to buy a share of a property. As with other options, this will not be appropriate for everyone – individuals may still have to source a mortgage for their part of the property, and complicated legal and extra costs will apply as for all other home-buyers. But its essence provides an important opportunity for people with learning disabilities and/or autism to move beyond the rental market.

“--- has lived in her flat since May of this year [2015] and is very content.”

Consultation Response, 2015

But it remains the case that while the majority of people with a learning disability want to live independently – 7 out of 10 want either to live by themselves or with friends - 60% live with family and friends or in a registered care home (residential setting).^{xxvi}

Personal budgets could provoke a step-change. Once an individual has control over the funding for services, they are able to choose whether to purchase a complete residential care package, or split the various services they need over several different sources. Where commissioners no longer have decision-making power, individuals do not have to experience them simply following the path of least resistance.

“When visiting ---- at Winterbourne View I spent time talking to other patients... I didn't know about the abuse taking place but could clearly see there was a despondent atmosphere of boredom.”

Consultation Responses, 2015

This cannot be the only answer, however. With at least 1,300 people with learning disabilities and/or autism, often with highly complex or challenging needs, expected to be moving out of hospital by 2019, there will be significant demand for new accommodation.^{xxvii} Added to this are those individuals who will not be admitted to ATUs as a result of this transformation – between September 2014 and September 2015 this was 852 individuals according to Assuring Transformation data.^{xxviii} Also, we cannot forget the estimated 41,547 children who have learning disabilities who are likely to show behaviours that challenge.^{xxix}

This requires investment. The overall support for TCPs from Transforming Care is £45 million in addition to existing CCG and LA budgets. £15 million will be made available nationally for capital projects, and £30 million has been made available on a match-funding basis for commissioners to 'double-run' services – so a total transformation fund of £75 million. This is not an insignificant amount but this review does question how, or whether, the Transforming Care programme concluded that this was sufficient. The cost of developing comprehensive housing options across the country is high – given the administrative and strategic support TCPs require, as well as workforce development ambitions, how much direct investment there will be in housing remains to be seen.

individuals is DH's Care and Support Specialised Housing programme. This has provided around £130 million, which has helped build over 3,500 homes.^{xxx} The second phase, announced in February 2015, will provide an additional £120 million, and is expected to provide a similar number of homes.

It would only take half of the homes constructed under Phase 2 to be diverted towards the Transforming Care programme to ensure that all individuals leaving ATUs would have access to housing on discharge. Indeed, the prospectus for phase 2 of the programme specifically welcomes bids for homes designed for people with learning disabilities and/or autism.^{xxxi} Of course, bidding for this funding round closed before *Building the Right Support* was announced – a missed opportunity?

As it stands, there is little indication of how these needs will be met. *Building the Right Support* repeatedly mentions 'innovative housing' options, and there is a direct hint to social investment (a point raised many times by this review) but as with workforce, little strategic direction exists.

“The difference in my son's behaviour is so profound now he has his own space.”

Consultation Response, 2015

SOCIAL PROPERTY FUND

In 2014 the Social Investment Business and Big Society Capital commissioned a report by the social impact investment company Resonance, as part of this review. *Winterbourne View & Social Investment* is an excellent and comprehensive report and should be read by everyone interested in solving the challenges ahead.^{xxxii}

It examines the investment needed to develop those areas highlighted in this report – workforce development, community infrastructures for in-area community teams, and flexible capital for property development.

“Better commissioning alone might in itself reduce net inflows to inpatient facilities but, without this investment impetus, constraints on providers will continue to imply thousands of individuals remaining in this situation for decades to come”

Winterbourne View & Social Investment, 2014

If Transforming Care is successful then the rate at which discharges from hospital occur is set to ramp up significantly. Property provision needs to keep up. Resonance estimated that a property fund of up to £200 million will be needed to provide additional property that can be leased to specialist housing providers. It recommended a specialist Social Property Fund should be established by NHSE and/or DH with £10 million of seed investment. A new Community Interest Company should be set up to channel funds, manage the flow of funds that result from the closure of inpatient units, and deploy them to a variety of capital projects to increase the capacity

of community-based housing options.

NHSE has indicated that £15 million will be made available to Transforming Care Partnerships for capital projects. This review calls on NHSE and DH to explain publically how this fund will be administered and, given £15 million is unlikely to be adequate, how it will ensure that sufficient continuing investment is available as the rate of discharges increasing over the next 3 years.

A Social Property Fund should be established to facilitate transitions out of inpatient settings and build capacity in community-based services. The Fund, seeded with £10 million from NHS England and/or Government, could leverage some £200 million from other investors to make investment more easily accessible to expand community-based services.

PAYMENTS

The supply of housing is one thing, paying for it is another. Here, we see a labyrinthine system in which a range of different options come together, one way or another, to help individuals pay for their housing. This has been made more complex by the Chancellor's announcement during the Spending Review 2015 that housing benefit in the housing association sector will be capped at Local Housing Allowance Rates (LHRs).^{xxxiii} The Treasury's rationale is that Housing Benefit should not subsidise families to live in social houses that many working families cannot afford, and to ensure Housing Benefit costs are better controlled to prevent social landlords from charging inflated rent (Housing Benefit is the predecessor to LHRs).

But as it stands, there is no appropriate exemption for supported housing. This presents a major threat to the financial viability of housing schemes for vulnerable people because the intensive housing management required to support people, such as those with learning disabilities and/or autism, is paid for by charging higher rents. These are then covered by housing benefit for those unable to work.

Suitable alternatives are rarely found in the private rented sector, particularly where significant adaptations have to be made. If supported housing is not made exempt from this policy, housing associations will be rendered incapable of planning with any certainty.

Supported housing has been given a one year exemption from another policy – the annual 1% reduction in social housing rates that housing associations have to make until 2020 – but as it stands, the Transforming Care programme sits in a testing context for supported housing overall.

It is crucial that welfare reforms do not inadvertently make it uneconomic to build or adapt homes for people with learning disabilities and/or autism - a point made in this review's first report.^{xxxiv} As well as preventing future development, this cap will start affecting tenants from April 2016 – less than seven weeks from the publication of this report. The consequence, if not tackled, will be less housing for people moving out of hospital settings.

This review calls on government to make an explicit exemption for supported housing from the capping on housing benefit to Local Housing Rates. Anything short of this will put at risk hundreds of thousands of vulnerable people, including individuals with learning disabilities and/or autism.

ACCOUNTABILITY: A RED LINE

INDEPENDENT EVALUATION

Building the Right Support is ambitious, wide-ranging and calls on CCGs, local authorities, schools, third, public, and private sector providers across the country to cooperate, be proactive and recognise the urgency with which change needs to take place.

Given past failures, and significant amounts of money being spent to support the Transforming Care programme, it is entirely reasonable to call for a funded independent evaluation of its progress. The fact that Transforming Care is made up of disparate programmes is no excuse for not seeking comprehensive evaluation of the programme nationally, and regionally. As explained elsewhere in this report, simply counting bed reductions is not sufficient to confirm the sustainable outcomes that people with learning disabilities need from their services. A range of methods and data sources would be required to adequately survey all the aspects of what will make Transforming Care a successful programme for change.

This would be a major commitment by Government. But given the failed promises of recent and older history, those affected by those failures deserve real time independent assurances that *Building the Right Support* is being delivered to time, and to the ambitions that matter – to use their own words, 'right care, right place.'

The most important part of this evaluation would be a prospective study of the Transforming Care cohort currently in inpatient settings to gather direct data on their lives now and then 12 months later. This would be a direct test of whether the Transforming Care programme is directly making a difference to people with a learning disability. For example, evaluations should track the sorts of settings being registered by CQC and make recommendations accordingly. The evaluation would need to be established by August 2016, at the latest, and should look to include the following:

Interviews with members of the key Transforming Care Working Groups nationally to collect perspectives on the overall effectiveness of the programme's processes and outcomes.

A prospective study of the Transforming Care cohort currently in inpatient settings to gather direct data on their lives now and then 12 months later.

Interviews with members of regional Transforming Care boards and partnerships to collect perspectives on the national and regional effectiveness of the programme's processes and outcomes.

Interviews with family carers and people with learning disabilities in receipt of Care and Treatment Reviews.

Direct and detailed analysis of a sample of Care and Treatment Review reports, tracked over time to assess the process by which CTR-related outcomes are achieved.

When Behaviour Support Plans are developed as a result of Care and Treatment Reviews these would be subject, as a sample, the quality auditing using established BSP quality-rating tools.

Online surveys to capture data from users of the main outputs of the Transforming Care programme, such as the new Service Model. This would include how outputs are informing practice.

This review calls on the Department of Health to commission independent evaluation of the Transforming Care programme. The body commissioned will be mandated to publish all interim and final reports and should be in place no later than August 2016.

There is also a pressing need to ensure that those individuals at the heart of the scandal that catalysed the Transforming Care programme are not forgotten. An independent review of where former Winterbourne View patients are, and the lessons that have been learned during their transition away from the unit would be highly valuable. Too often, reactions to and reviews into cases such as Winterbourne View are not read in concert together; for example Serious Case Reviews should have joined up responses which set more strategic directions for how lessons learnt will be evidenced.

When this does not happen, we continue to see the rights of people with learning disabilities and/or autism, and those of the families, undermined.

RIGHTS

Alongside NHSE's *Building the Right Support*, DH has issued its response to the consultation introduced by Norman Lamb. The consultation sought to explore ways in which people with learning disabilities could be supported to lead more independent lives and have more choice and control over services they receive.

The government's response has been lacklustre. It sets out a three-year 'phased approach' which lacks any sense of urgency and fails to set a strategic direction for how any of the complex issues raised in the consultation will be tackled.

DH has failed to drive the agenda and individuals, their families, and carers will continue to be alienated from decisions made about their support. The response did pick up on this review's demand for a 'Charter of Rights,' but its proposed version is non-mandatory – simply another guidance piece. Proposed amendments to the Mental Health Act to enable people and their families to challenge decisions made to detain them (a part of the right to challenge called for by this review) will be subject to further consultation.

Something profound is needed to ensure the rights of people with learning disabilities and/or autism and their families are being improved at a pace akin to the structural changes to the way services are being commissioned. It cannot be that one Transforming Care partner falls short, undermining the others' efforts.

The Transforming Care programme is a partnership of six national organisations. There are two challenges to this – plenty of organisations are conspicuous by their absence (education perhaps the most notable), and there is no one 'leader' charged with changing services, bringing elements together and spotting where further partners need to be brought in.

Issues that affect people with learning disabilities and/or autism and the services that support them cross over multiple government departments. The gap in overall leadership for services for people with learning disabilities needs addressing.

Just as a Children's Commissioner was called for following the Victoria Climbié Inquiry, in reference to the UN Committee on the Right of the Child, there is a firm argument for establishing an office of Learning Disabilities Commissioner. A position dedicated to promoting and protecting the

rights of all children and adults in England with learning disabilities and/or autism could catalyse the change we need. Its sole ambition would be to make life better for individuals and families, by making sure their rights are respected and enhanced, and their views taken seriously.

This review calls on government to establish the role of a Learning Disabilities Commissioner which puts a statutory duty on the holder to promote, enhance, and protect the rights of people with learning disabilities and their families in England.

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