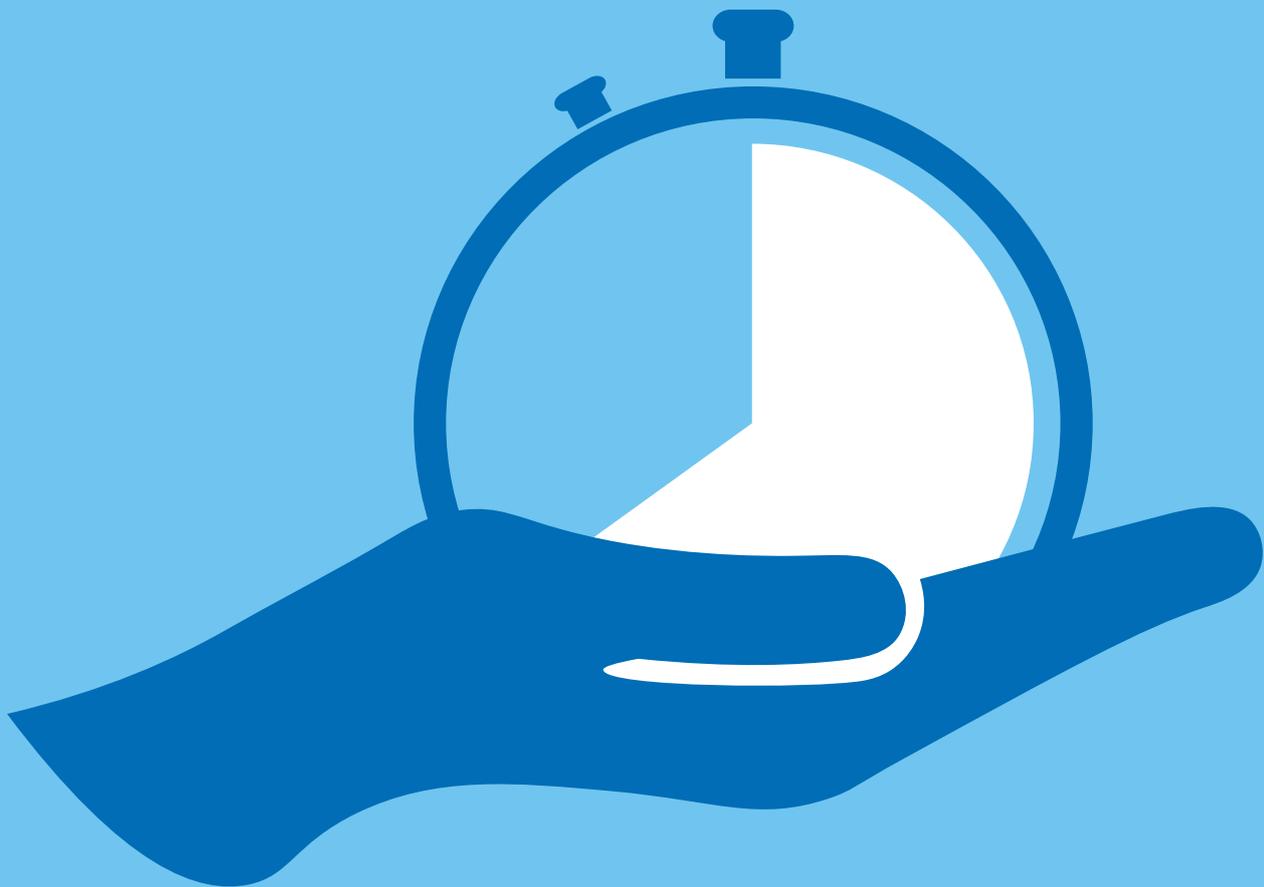


WINTERBOURNE VIEW – TIME IS RUNNING OUT

The 6 month independent review of the Transforming Care and
Commissioning Steering Group, chaired by Sir Stephen Bubb

July 2015



WINTERBOURNE VIEW – TIME IS RUNNING OUT

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Thanks

The authors of this report would like to thank the transforming care and commissioning steering group and all those who contributed to our work and this report. All mistakes contained herein are our own.

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FOREWORD

When *Winterbourne View – Time for Change* was published in November 2014, still more people with learning disabilities and/or autism were being admitted to inpatient facilities than being discharged. This is despite a promise from Government to close institutions such as Winterbourne View. *Time for Change* has been widely supported but I understood the deep scepticism of people with learning disabilities and/or autism and their families that anything would actually change. I am acutely aware that we do not just want more reports.

I believe that things have changed, and that we will see the closure of inappropriate institutions and the scaling up of community provision that has been needed for so long. The leadership being displayed by NHS England's CEO, Simon Stevens, does give me that optimism. The Government endorsed my report and moved forward with a consultation on its recommendations, including the 'right to challenge' for people with learning disabilities and/or autism and their families. That is a step change.

The report laid out a clear roadmap of action – a new national framework in which commissioners choose community-based provision over hospitals. The programme would deliver closures and enable providers to work in partnership to offer new facilities, to ensure community support and independence for people with learning disabilities and/or autism. In particular I argued that people with learning disabilities and/or autism must have a central role in designing the care that will best meet their needs. And they should be able to challenge decisions when it does not.

There has been progress since the publication of my report. We have seen a definite shift in the direction and commitment to change which was not apparent when I started the review. At last we have an acceptance that institutions must close and I congratulate Simon Stevens on making his promise to the Public Accounts Committee that NHS England will produce a closure timetable. We expect this to be published in October.

The last Government were swift to move on the recommendations to strengthen the rights of people with learning disabilities and/or autism and their families. A consultation has been made through the Green Paper *No voice unheard, no right ignored*, which has seen over 400 responses. I look to the new Care Minister, Alistair Burt, to move on introducing legislation that will enshrine peoples' 'right to challenge' in law.

The number of people being discharged from institutions is now greater than those being admitted. At the end of May 2015, over 1,700 Care and Treatment Reviews had been conducted. However it remains abundantly clear that a 'revolving door' of discharges and admissions will continue unless a closure and transition programme is acted on.

NHS England has made it a top strategic objective to improve the health outcomes for people with learning disabilities, by implementing new service models that provide care for people in their communities rather

than in hospital. The Care Act is a landmark piece of legislation, and the Green Paper is progress that should not be underestimated.

But the pace of change remains slow, and this is unacceptable. While a priority for NHS England, the Transforming Care programme has not yet delivered anything tangible in terms of new community facilities or closures. This is worrying; robust community provision does not appear overnight. And yet the closure of institutions can only happen when there are sustainable alternatives built up by commissioners and providers.

In responding to *Time for Change*, the Transforming Care partners committed to a series of actions. I accepted Simon Stevens' proposal that my steering group be reconvened in 6 months to review progress and that a formal stock take of actions be taken in 12 months. So this report is a warning call – my steering group was clear on the changes that need to take place. Where positive step changes have been made, I have recognised the success. Where delivery has been lacking, my appraisal will be severe.

I will be reviewing the adequacy of closure plans when published. The Transforming Care programme recently announced five 'fast-track' sites where services will be shifted away from hospitals. These sites will help shape the service model that is being developed to re-design care across England. A programme of action is clearly starting to take shape. But we must expect a closure programme to cover the country and not just five areas. We know that people with learning disabilities and/or autism are often in hospitals very far from their families – a nation-wide programme is therefore essential.

The scaling up of community provision is a fundamental part of this programme. Yet there has been little to no discussion with providers and stakeholders outside of the Transforming Care partners. Lack of communication from the centre prevents local commissioners and providers from readying themselves for change, or even being aware that they will be expected to respond to a new service model.

That is why I have set up a Provider Delivery Taskforce, alongside the Voluntary Organisations Disability Group and Housing and Support Alliance. This will work with excellent providers of community-based care (using NHS England and LGA's own 'Ensuring Quality Services' guidelines) to make sure they can be responsive and proactive in transitioning people out of institutions. But that is not enough.

Time for Change was clear that building this capacity in the community is an absolute priority. But the two recommendations made to this effect – workforce development, and investment in community-based services – have seen little progress. This is unacceptable and risks undermining the work being done elsewhere to create a new framework of care for people with learning disabilities and/or autism.

So I am now calling on NHS England to establish a **Transition Taskforce** which will be mandated to work with providers, commissioners, people with learning disabilities and/or autism and families to set out the national framework for scaling up community provision. It will plan for 'shovel ready' schemes that can be sustainably established to allow for the closure of institutions and the appropriate transition of individuals into

the community. The Taskforce will examine the financial models that are needed, as well as how to secure a skilled workforce.

This will build on the excellent services that are already provided by charities and social enterprises, many of which pioneer innovative ways to support the wellbeing and independence of people with learning disabilities and/or autism outside of hospital settings. For example, there is wide-ranging good practice for staff training and Positive Behaviour Support. I am clear that restrictive practices, such as the use of mechanical restraint or seclusion have no place in the 21st century of care for people with learning disabilities and/or autism, and this report gives recommendations to that effect. Given that it will take time to effectively transition care from institutions into the community, there must be steps taken now to ensure people are receiving the best support.

Since November, I have visited and spoken to a number of providers, as well as institutions about *Time for Change*. Any closure programme will lead to concern within this sector, especially the workforce, around whether such a shift can and will be managed effectively. Individuals with learning disabilities and/or autism, their families and carers cannot be isolated from the Transforming Care programme; they must be at its core.

I want to thank all of my colleagues on the steering group, and all those I have met or spoken to. In November, I cautioned NHS England and its partners to be realistic about the timeline for success – to not promise another ‘false dawn.’ However the call for urgent action remains and I will be holding Transforming Care to account on its commitment to deliver lasting change.

I will review further progress at the year anniversary of the publication of *Time for Change* – the steering group will be reconvened on 7th December 2015. I expect to see change being delivered on the ground. This is the opportunity for us, as a nation, to provide the care that people with learning disabilities and/or autism deserve and have been denied for so long.



Stephen Bubb

Sir Stephen Bubb

About this report

1. When *Winterbourne View – Time for Change* was published in November 2014, still more people with learning disabilities and/or autism were being admitted to inpatient facilities than being discharged. This is despite a promise from Government to close institutions such as Winterbourne View.
2. The report laid out a clear roadmap of action – a new national framework in which commissioners choose community-based provision over hospitals. The programme would deliver closures and enable providers to work in partnership to offer new facilities, to ensure community support and independence for people with learning disabilities and/or autism. In particular Sir Stephen argued that people with learning disabilities and/or autism must have a central role in designing the care that will best meet their needs. And they should be able to challenge decisions when it does not.
3. A joint response was made by the Transforming Care programme in *Transforming Care for People with Learning Disabilities – Next Steps*. Sir Stephen is now leading an independent review of the work of the Transforming Care partners – Department of Health, NHS England, Health Education England, Care Quality Commission, Association of Directors of Adult Social Services, and Local Government Association – to ensure sufficient action is being taken to improve the way services for people with learning disabilities and/or autism are delivered.
4. This report is Sir Stephen's six month review. The steering group was reconvened on 6th July 2015, and ongoing engagement has been had with those partners that have taken responsibility for acting on recommendations, as outlined in the Transforming Care response. Each stakeholder has submitted an update on their work, for review by Sir Stephen and the group. This report records those responses and offers a reflection on where we are, and where we need to be.

The missing pieces

5. NHS England has made it a top strategic objective to improve the health outcomes for people with learning disabilities, by implementing new service models that provide care for people in their communities rather than in hospital. The Care Act is a landmark piece of legislation, and the Department of Health's Green Paper on the rights of people with learning disabilities and/or autism – *No voice unheard, no right ignored* – is progress that should not be underestimated.
6. But the pace of change remains slow, and this is unacceptable. While a priority for NHS England, the Transforming Care programme has not yet delivered anything tangible in terms of new community facilities or closures. This is worrying; robust community provision does not appear

overnight. And yet the closure of institutions can only happen when there are sustainable alternatives built up by commissioners and providers.

7. There are two areas where it is clear that not enough progress has been made. The first is a question of leadership. In the six months that have passed since *Time for Change*, very little has been communicated to key stakeholders about the particulars of how transformation will be achieved. Communication needs to move beyond the walls of the state - providers, individuals and local stakeholders must be brought in as equal partners as a matter of urgency. Transformation will only be delivered through a robust, transparent process in which stakeholder engagement is taken seriously. High quality independent advocacy is often cited as a powerful tool, and yet there is little evidence of how this will be funded, delivered and made available to all.
8. It is also clear that while we have the promise of a closure programme, little attention has been given to the need for gearing up the capacity and response of providers. It will be impossible to deliver a closure programme without ensuring robust community provision. While Care and Treatment Reviews are being rolled out as a tool for assessing individual circumstances, decision-makers will be powerless to recommend anything other than an inpatient bed if they lack the tools or avenues to do otherwise. This is a simple point, but absolutely critical to squaring the circle of care services.
9. In response ACEVO has teamed up with Voluntary Organisations Disability Group and Housing & Support Alliance to establish a Provider Delivery Taskforce to get on and do what needs to be done to identify good provision, and how to scale it up. Providers will work to the *Ensuring Quality Services* guidance and champion the effective delivery of the services needed to transform care for people with learning disabilities and/or autism.
10. Social investment also has a crucial role to play. *Time for Change* was accompanied by a report – *Winterbourne View and Social Investment* – which laid out potential models for using social investment to drive the transformation programme. But this review has identified a failure to scope social investment fully, the commitment made in the Transforming Care response. This must be seen as a failure on the part of the Transforming Care programme to act on the practical questions of implementation. A closure programme requires the retraining of staff, the development of community-based facilities, a transition programme and alternative investments to underpin change. Moving forward, it is the job of the partners to link up the work streams that have been taken on in response to *Time for Change* and provide a seamless new model of care for people with learning disabilities and/or autism. Failure to give due attention to any of the pieces will have significant consequences elsewhere.

Strengthening rights

11. This report recommends that the new Government introduces new legislation swiftly following the Green Paper consultation that ended in May. The Transforming Care progress report says that it will publish a response to the Green Paper by the autumn, but a ‘right to challenge’ needs to be enshrined in law, so that individuals and their families and/or advocates are truly empowered to question the care they receive.
12. ‘The Bradley Report five years on’ made it clear that there is still progress to be made for people with learning disabilities and/or autism in our courts and prisons. This report reiterates the call for a cross-government response, from the Ministry of Justice to Department of Health. Without this, people with learning disabilities and/or autism will not receive the support they need at all stages of the criminal justice system.

Closures

13. This review expects a closure programme to be published in October 2015. This programme will need to demonstrate strong leadership and set out a clear plan for the whole country. Without this, the Transforming Care programme will not be able to deliver on meaningful and lasting change to the way care and support is designed and delivered for people with learning disabilities and/or autism.

Building capacity in the community

14. This report recommends that NHS England and its partners establish a Transition Taskforce, independently chaired. This would include providers, commissioners, individuals with learning disabilities and/or autism and families to lead on the national framework for scaling up community provision. Unless these key stakeholders can come together to work on a practical scheme for making sure there is sufficient support in place, sustainably funded, then Transforming Care will fail to deliver any meaningful transformation at all.
15. *Time for Change* called on NHS England and the Government to establish a ‘Life in the Community Fund’ to facilitate transitions out of inpatient facilities. This report recommends that the Government move quickly to act on social investment options for building up the community provision, as this a crucial part of moving care out of inpatient facilities.
16. This report recommends that the Care Quality Commission (CQC) should undertake a review of restrictive practices with a view to banning physical restraint methods, such as the emergency response belt.
17. The Government must also review the scope of the CQC to have powers for reviewing the care provided to individuals with learning disabilities when cared for in supported living. It is essential that people with learning disabilities and/or autism are given full protection.

ABOUT THIS REPORT

1. Last year, the Government failed to meet its pledge to support everyone with a learning disability and/or autism inappropriately placed in hospital to move to community-based support no later than 1st June 2014. In response, NHS England developed a programme plan to accelerate change. As part of this Sir Stephen Bubb, chief executive of the charity leaders network ACEVO, was asked to make recommendations for a national commissioning framework under which local commissioners could secure community-based support.
2. Sir Stephen chaired the Transforming Care and Commissioning Steering Group, comprised of representatives from the third sector, NHS and local government. Over the course of its work, the group was supported by a range of stakeholders, from people with learning disabilities and/or autism and their families, to commissioners, third sector organisations who work with and/or represent people with learning disabilities and/or autism, providers and academics. The membership of the steering group can be found in the appendices.
3. The steering group's report – *Winterbourne View – Time for Change* – was published in November 2014. It outlined a roadmap for action –
 - A closure programme for in-patient care institutions;
 - A Charter of Rights for people with learning disabilities and/or autism and their families;
 - A 'right to challenge' for people with learning disabilities and their families, and the right to request a personal budget;
 - A mandatory framework for local decision-makers to follow that sets out who is responsible for which services and how they will be held to account;
 - Improved data collection and publication, including key indicators such as admission rates, length of stay, delayed transfers and the number of beds by commissioning organisations;
 - Improved training and education for NHS, local government and provider staff;
 - A social investment fund to build capacity in community-based services.
4. A joint response was made by the Transforming Care programme in *Transforming Care for People with Learning Disabilities – Next Steps*. Sir Stephen is now leading an independent review of the work of the Transforming Care partners – Department of Health, NHS England, Health Education England, Care Quality Commission, Association of Directors of Adult Social Services, and Local Government Association – to ensure sufficient action is being taken to improve the way services for people with learning disabilities and/or autism are delivered.

5. This report is Sir Stephen's six month review. The steering group was reconvened on 6th July 2015, and ongoing engagement has been had with those partners that have taken responsibility for acting on recommendations, as outlined in the Transforming Care response. Each stakeholder has submitted an update on their work, for review by Sir Stephen and the group. This report records those responses and offers a reflection of where we are, and where we need to be.
6. This will be followed by a formal twelve month review, drawing from engagement with a wide range of stakeholders. This reflects the wide remit of *Time for Change*. While originally asked to make recommendations for a national commissioning framework for NHS England, it remains clear that any such framework must be accompanied by action from others – local government and providers – and by a stronger rights framework for people with learning disabilities and/or autism, and their families and carers.

A CHANGING LANDSCAPE

Where we are now

1. Much has happened since November 2014. The Care Act has come into force, Simon Stevens has promised a closure programme to the Public Accounts Committee, and NHS England has announced a range of new initiatives for forcing the pace of change.
2. It is clear that we are no longer just describing the problem. There has been a step change in the approach of the Transforming Care programme and firm commitments made to accelerate change and deliver a new framework of care for people with learning disabilities and/or autism.
3. The Transforming Care response to *Time for Change* outlines how the programme will look to reduce a reliance on inpatient care nationally.¹ Its commitments include –

TIME FOR CHANGE
RECOMMENDATION

People with learning disabilities and/or autism should be given a 'right to challenge' their admission or continued placement in inpatient care

TRANSFORMING CARE
PROGRAMME COMMITMENT

To roll out Care and Treatment Reviews for people in inpatient settings and at the risk of admission.

The Government and NHS England should force the pace on commissioning by requiring local commissioners to follow a mandatory framework.

To set out a model for health and care services for children and adults with a learning disability and/or autism who have a mental illness or behaviour that challenges, to describe –

- outcomes to be achieved;
- the kind of services that should be place;
- the standards that those services should meet.

A 'Life in the Community' Social Investment Fund should be established to facilitate transitions out of inpatient facilities and build capacity in community-based services.

To build on the Resonance report, by identifying a region, locality or cluster of localities to test the feasibility of different social investment models.

Health Education England, Skills for Care, and Skills for Health should fully scope out the gaps in training and development of staff caring for those with a learning disability and/or autism, and then develop a national academy to expand existing good practice and fill identified gaps.

To carry out scoping work to identify current gaps in the provision of workforce development.

4. On the 3rd July, the Transforming Care partners published a progress report. It reiterates the priority areas that make up the programme of action that it has committed to –
 - Empowering individuals;
 - Getting the right care in the right place;
 - Workforce;
 - Regulation and inspection;
 - Data and information.²
5. This programme of action is underpinned by the NHS England Business Plan 2015 – 16. One of its top priorities for improving health is to transform care for people with learning disabilities by

“improving the health outcomes for people with learning disabilities, by rolling out care and treatments reviews and implementing new services models.”³
6. *Time for Change* recommended that a new commissioning framework should be accompanied by a closure programme of institutional inpatient facilities, to reduce the number of inpatient beds and catalyse the development of community provision. At a Public Accounts Committee evidence session in February 2015, Simon Stevens said that “care will have to be re-provided in a more radical way,” and that this means some facilities will need to close.⁴ He said that details of a closure programme could be expected in around six months.⁵
7. The guiding principle of this recommendation has been “above all, do no harm.”⁶ *Time for Change* was clear that a closure programme must be accompanied by better community-based support and provision that has the capacity to transition people out of institutionalised care. Without an effective transition programme, there can be no firm assurances that people with learning disabilities and/or autism will receive the care that they need and want.
8. NHS England has announced waves of locally targeted pilots to encourage the adoption of good practice and to test innovation. This includes the Integrated Personal Commissioning programme which went live 1st April 2015. It will bring together health and social care budgets at the individual level by supporting NHS bodies, councils and voluntary organisations to partner and submit innovative plans for the transformation of the care of certain services, including those for people with learning disabilities.

2 *Progress Report from the Transforming Care Delivery Board (2015)*

3 NHS England, *Building the NHS of the Five Year Forward View – NHS England Business Plan 2015 – 2016 (2015)*

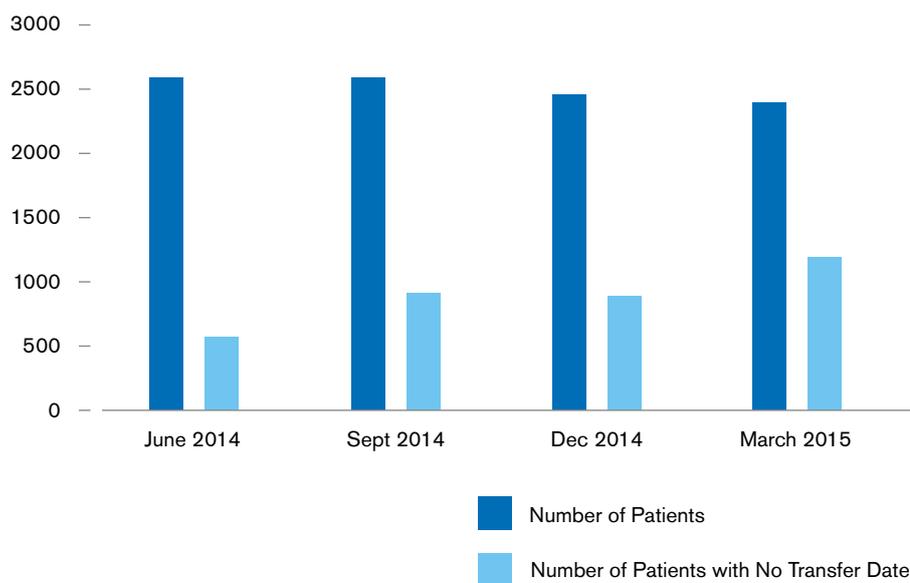
4 <http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/public-accounts-committee/care-for-people-with-learning-disabilities/oral/18031.html>

5 <http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/public-accounts-committee/care-for-people-with-learning-disabilities/oral/18031.html>

6 *Winterbourne View – Time for Change (2014)*

9. The Transforming Care programme has also announced five ‘fast track’ sites that will bring together organisations across health and care to transform care specifically for people with learning disabilities. They will receive additional ‘technical’ support from NHS England and have access to a £10 million ‘transformation fund’ to accelerate change. These are promising overtures. But has it resulted in any change?
10. The Department of Health’s response to the Winterbourne View scandal (the ‘Concordat’) recognised that failings were widespread across the care system. A data collection process – Assuring Transformation – is now being embedded to ensure that public awareness of those commitments made in the Concordat is transparent and robust. Responsibility for collecting this data did sit with NHS England, but has recently passed to the Health and Social Care Information Centre (HSCIC).
11. The data shows a slight decrease in the number of people registered as being in inpatient facilities (see fig. 1).⁷

Figure 1



*March 2015 data collected by HSCIC

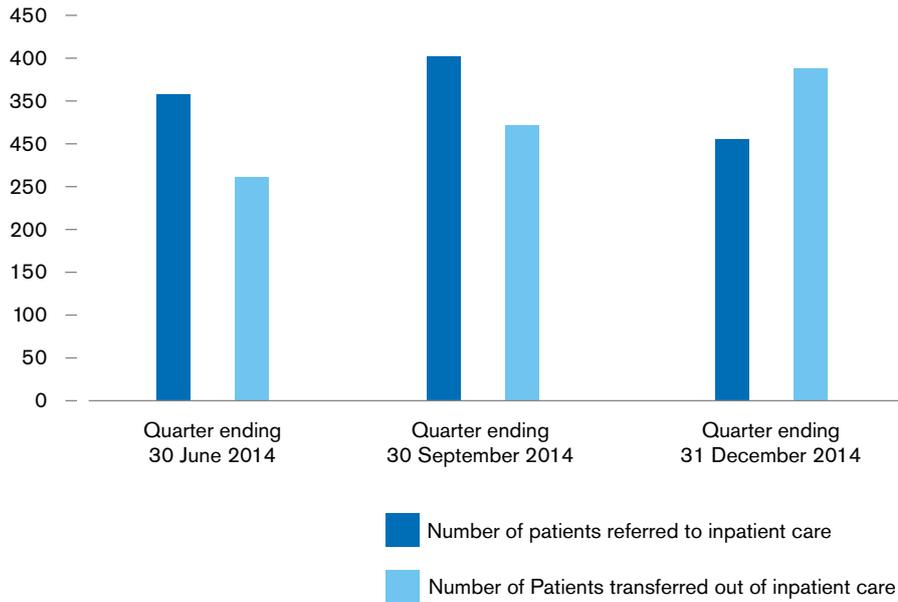
7 NHS England, Quarterly ‘Assuring Transformation’ data, published at <http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/atd/> and HSCIC, Learning Disability Services Quarterly Statistics, published at <http://www.hscic.gov.uk/article/6328/Reports-from-Assuring-Transformation-Collection>

12. However, it is important to note that the HSCIC data does not include responses from 47 CCGs. While a slight momentum has been built over the last six months, the pace needs to improve drastically.
13. The data also tells us that nearly half of inpatients do not have a set date for transfer back to the community. The main reason given for this on an individual basis is that a clinical decision has been made to not pursue a transfer date. It is absolutely essential that such a decision is based on the ability of an individual to live successfully in a community setting, rather than the significant hurdles that still exist in transitioning people into community settings. These include risk aversion among clinicians, financial disincentives to discharge, a lack of independent advocacy as well as the 'catch 22' situation in which an individual's behaviour is negatively affected by being in an inpatient facility.⁸
14. The Transforming Care programme needs to deliver a robust framework for overcoming these systemic barriers. This needs to incentivise decision-makers to focus on discharge planning from the outset and enable providers to plan for the earliest possible, safe discharge from the point of admission.⁹
15. Data collections show the number of people being referred to inpatient facilities compared to that being discharged. Until the end of 2014, NHS England collected quarterly data (see fig. 2).¹⁰

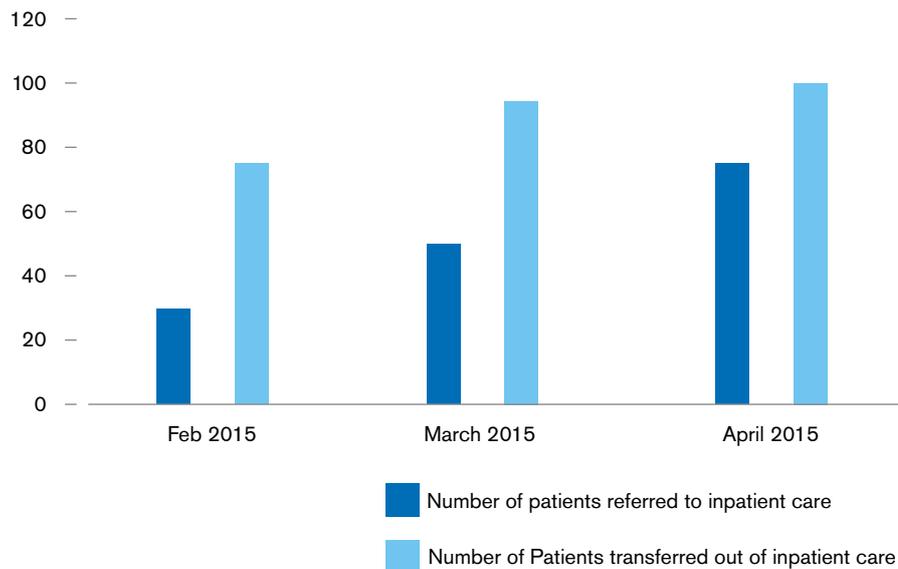
8 Resonance, *Winterbourne View and Social Investment* (2014)

9 *Winterbourne View – Time for Change* (2014)

10 NHS England, Quarterly 'Assuring Transformation' data, published at <http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/atd/>



Data collected by the HSCIC shows progress on a monthly basis in 2015.¹¹



- 16. Since *Time for Change* was published, the trend has been for discharges to outnumber referrals. But this data also shows the number of people being referred to inpatient facilities rising overall. While this may be impacted on by the number of CCGs reporting back, this should not be the picture we are seeing six months on.

11 HSCIC, Learning Disability Services Quarterly Statistics, published at <http://www.hscic.gov.uk/article/6328/Reports-from-Assuring-Transformation-Collection>

The missing pieces

17. There are two areas where it is clear that not enough progress has been made. The first is a question of **leadership**. In the six months that have passed since *Time for Change*, very little has been communicated to key stakeholders about the particulars of how transformation will be achieved.
18. There has been a flurry of public announcements in the lead up to this six month review, such as the five fast tracks sites, but little has been put in place to prepare providers and local stakeholders for what actions and responsibilities they will be taking on. Communication needs to move beyond the walls of the state – providers, individuals and local stakeholders must be brought in as equal partners as a matter of urgency.
19. From this review, it is clear that the Transforming Care programme has moved forward in identifying where the gaps are in current provision, and it has started to outline a new commissioning model to draw up local closure plans. But transformation will only be delivered through a robust, transparent process in which stakeholder engagement is taken seriously.
20. It is also clear that while we have the promise of a closure programme, **little attention has been given to the need for gearing up the capacity and response of providers**. It will be impossible to deliver a closure programme without ensuring robust community provision. While Care and Treatment Reviews are being rolled out as a tool for assessing individual circumstances, decision-makers will be powerless to recommend anything other than an inpatient bed if they lack the tools or avenues to do otherwise. This is a simple point, but absolutely critical to squaring the circle of care services.
21. The risk of a ‘revolving door’ therefore persists. People readmitted to inpatient facilities because they have been discharged to unsustainable or inappropriate alternative provision does nothing to improve standards or drive a truly preventative solution. This is crucial given the projected growth in the number of people with learning disabilities requiring community-based support over the next 10 years, which has been estimated to be between 37,000 and 52,000 by 2030.¹²
22. A practical programme for building up community provision needs to take place in tandem with the closure programme. This does not seem to be happening.
23. In response ACEVO has teamed up with VODG and Housing & Support Alliance to establish a Provider Delivery Taskforce to get on and do what needs to be done to identify good provision, and how to scale it up. Providers will work to the *Ensuring Quality Services* guidance and champion the effective delivery of the services needed to transform care for people with learning disabilities and/or autism.

24. But this also requires a firm response from the Transforming Care programme. This report recommends that NHS England and its partners establish a Transition Taskforce, independently chaired. This would include providers, commissioners, people with learning disabilities and/or autism and families to lead on the national framework for scaling up community provision. Unless these stakeholders can come together to work on a practical scheme for making sure there is sufficient support in place, sustainably funded, then Transforming Care will fail to deliver any meaningful transformation at all.

STRENGTHENING RIGHTS

1. **The Government should draw up a Charter of Rights for people with learning disabilities and/or autism and their families, and it should underpin all commissioning.**
 - 1.1. *Time for Change* was clear that, as a point of principle, the rights of people with learning disabilities and their families must be upheld at all stages of their care. This does not just mean improving the current system; people need to be empowered to help change the system to make sure their rights are fundamental to the decisions made about their care.
 - 1.2. The Care Act has now come into force – this enshrines in law the principle that individual wellbeing be the central concern when designing care and support. It will underpin adult social care commissioning by incorporating the essential elements of social and economic wellbeing and making sure decision-makers consider individuals’ views, wishes and beliefs.
 - 1.3. Time will tell if the Care Act as it is currently drawn will prove clear and persuasive enough to ensure that this principle comes to underpin every individual’s care.
 - 1.4. But the Care Act only applies to decisions made by local authorities. Individuals with complex needs will need support from across health and social care. While much has been said about the importance of joint commissioning between the two, it is equally clear that the principle of wellbeing needs to apply across the board. The Department of Health’s Green Paper – *No voice unheard, no right ignored* – has consulted on this question by asking whether NHS commissioners should share new local authority duties around promoting individual wellbeing.¹³
 - 1.5. While the principle of wellbeing is critical to ensuring that there is a step change in the way services are designed for people with learning disabilities and/or autism, *Time for Change* is clear that more commissioner-led decision-making alone will not effect change. Individuals with learning disabilities and/or autism and their families need to be clear on their rights, at all times, else there will be a barrier to them effectively engaging with their care.

- 1.6. This is why *Time for Change* recommended that a Charter of Rights be specifically drawn up for people with learning disabilities and/or autism. The Care Act enshrines the principle of wellbeing in law, and draws together disparate legislation that came before. But for individuals with learning disabilities and/or autism and their families, it remains one of many laws or policies that must be navigated when assessing and delivering care.
- 1.7. There is yet to be seen a Charter for Rights for people with learning disabilities and/or autism. This would be a clear and universally accessible document that clarifies the rights people already have, and outlines the support they have access to, including independent advocacy, for using them.
- 1.8. Legislation like the Care Act could give this Charter ‘teeth,’ by mandating commissioners to base their plans on the rights and wellbeing of individuals. This would be included in the Charter, but would not in itself provide the package of information that they should be able to access easily. Without this, we will continue to hear from individuals and families that they feel powerless to engage with or challenge decisions.
- 1.9. The steering group recognises that the Department of Health’s Green Paper has consulted on this issue. In fact, it goes beyond *Time for Change* by suggesting that individuals receive a ‘personalised summary of rights that are relevant to their individual circumstances’ as soon as reasonably practical following the start of discussions about a potential admission.¹⁴
- 1.10. We look forward to hearing what responses the consultation has had on this question. While this would be an important part of making sure individuals with learning disabilities and/or autism are informed about specific circumstances as and when they happen, there is still a need to bring together all the rights that exist under the Mental Health Act Code, Care Act *et al* across the fields of health and social care.
- 1.11. This should include a clear statement of rights, such as the right to a personal budget, the right to trained and independent advocates, and the right to support to exercise human rights.
- 1.12. A Charter of Rights is the first recommendation of the *Time for Change* report. Aptly so; a Charter is a simple change, but is absolutely non-negotiable. Only by setting out a Charter of Rights will the Transforming Care partners sufficiently tackle the widespread lack of awareness of the issues faced by people with a learning disability and enable individuals to become ‘agents of change.’¹⁵

14 Department of Health, *No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions* (2015)

15 *Winterbourne View – Time for Change* (2014)

2. The Government should respond to the ‘The Bradley Report five years on’.

- 2.1. *Time for Change* recommended that the Government respond to the recommendations of ‘The Bradley Report five years on,’ to set out how cross-government action will tackle the issues raised.
- 2.2. The Transforming Care programme did not commit to leading on this recommendation but people with learning disabilities and/or autism will continue to receive inappropriate care in the criminal justice system if no action is taken. ‘The Bradley Report five years on’ made it clear that there is still progress to be made. This report reiterates the call for a cross-government response, from the Ministry of Justice to Department of Health. Without this, people with learning disabilities and/or autism will not receive the support they need at all stages of the criminal justice system.

3. People with learning disabilities and/or autism should be given a ‘right to challenge’ their admission or continued placement in inpatient care.

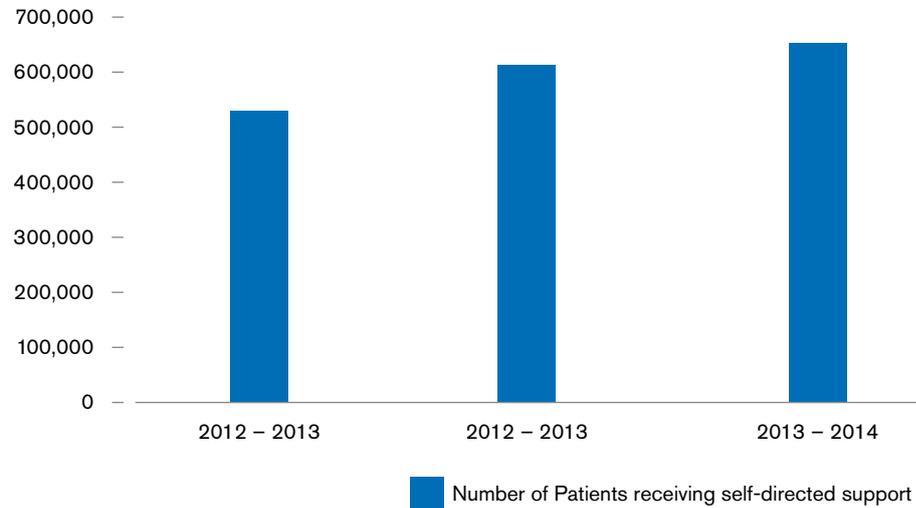
- 3.1. The Care Act recognises that individuals have the expertise of lived experience. They are best-placed to judge their own wellbeing. A Charter of Rights is about enabling them to describe what this looks like for them. *Time for Change’s* second recommendation looks to extending the rights of people with learning disabilities and/or autism and their families – they should have the ‘right to challenge’ any decision to admit an individual to an inpatient facility, or to keep them there.
- 3.2. This needs to apply across a person’s care journey, from the point of admission to any decisions to change or continue a form of care. This right would be accompanied by free support from an independent ‘multi-disciplinary’ team, including ‘experts by experience’ – family carers or people with learning disabilities who have had experience of inpatient services or been at risk of admission themselves.¹⁶
- 3.3. NHS England’s response has mainly been around the rollout of Care and Treatment Reviews. These are part of a strategy to ensure that the individual is central to any decisions made about their care. They bring together the commissioner, an independent clinician, ‘expert by experience,’ and the individual receiving the care. The stated aims of a Care and Treatment Review include ensuring the person is safe, that they are getting good and effective care, exploring whether a plan is in place for their future and assessing whether their care and treatment could be provided in the community.
- 3.4. Individuals who were inpatients on 1st April 2014 who did not have a discharge plan have been receiving Care and Treatment Reviews to review the appropriateness of their care. As at the end of May 2015 over 1,700 Care and Treatment Reviews had been completed.¹⁷

- 3.5. These reviews offer a critical platform on which to assess an individual's care with their interests, and the expertise of independent stakeholders, at the heart of the process. They look set to ensure that proper discussions are had around the options and risks that are relevant to particular individuals at particular times. *Time for Change* recognised that many individuals with learning disabilities and/or autism will not feel able to challenge the decisions taken about their care, particularly if they are in inpatient settings. This means that it is right that there is a responsibility on the part of commissioners to ensure a Review is undertaken, with the patient's permission.
- 3.6. But the 'right to challenge' is not just about mandating the NHS or local authorities to actively question and discuss the options available to an individual. Any mechanism for providing a 'right to challenge' must enable individuals and their families to challenge decisions themselves, and provide them with the support and information to do so.
- 3.7. As the Department of Health's Green Paper indicates, there are many facets to this. Alongside a review to challenge admissions to inpatient settings, individuals may seek transfers or discharges once admitted and look to request discharge planning if it is not already in place on admission.¹⁸
- 3.8. One of the most important counters to re-institutionalisation is to empower people to ask what aspect of their care, if anything, is preventing them from being supported outside of an inpatient facility. Individuals do have the right to request a Review; this would be exactly the sort of information that a Charter of Rights could describe and enable.
- 3.9. This report recommends that the new Government introduces new legislation swiftly following the consultation that ended in May. The Transforming Care progress report says that it will publish a response to the Green Paper in the autumn, but a right to challenge needs to be enshrined in law, so that individuals and their families are truly empowered to question the care they receive.

18 Department of Health, *No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions* (2015)

4. NHS England should extend the right to have a personal budget (or personal health budget) to more people with learning disabilities and/or autism, along with support to manage those budgets.

Figure 3



- 4.1. At the end of March 2014, 62% of all those eligible for community based services were accessing care and support through a personal budget across England (see fig. 3).¹⁹ Use of personal budgets has seen a steady rise year-on-year.
- 4.2. This is set to increase at pace with the Care Act now enshrining the right to have a personal budget in law from April 2015. This represents a cultural change that commissioning services need, towards designing care for one person at a time, based on a whole-life care plan that incorporates the principle of treating individuals as experts in their own needs and interests.
- 4.3. Again, the Care Act only applies to social care in this instance. But it is clear that personalisation is high on NHS England's agenda given the promise to rollout personal *health* budgets beyond Continuing Health Care in the year to come.
- 4.4. But the split between health and social care remains a barrier to meaningful personalisation. *Time for Change* recommended that the extension of this right be linked closely with the Integrated Personal Commissioning (IPC) programme, to support local areas to pool funding across health and social care.²⁰ The only way to drive personalisation is to blend health and social care funding at the level of the individual and allow them to direct how the money is used.

¹⁹ Health and Social Care Information Centre, *Community Care Statistics, Social Services Activity, England – 2013 – 14, Final release* Available at: <http://www.hscic.gov.uk/searchcatalogue?productid=16628&topics=0%2fSocial+care&sort=Relevance&size=10&page=1#top>

²⁰ *Winterbourne View – Time for Change* (2014)

- 4.5. Four out of the nine IPC demonstrator sites will include people with learning disabilities in their plans. This is a crucial opportunity to prove that there has been a step change in delivering individualised care, from describing what it looks like to action. Local areas will need support from the national partners to make sure they are publishing the number of people taking up these budgets and the impact on their lives so that lessons can be learnt and commissioners held to account.

5. The Government should look at ways to protect an individual's home tenancy when they are admitted to hospital.

- 5.1. *Time for Change* included this recommendation to emphasise the wide-ranging consequences for people who are admitted to inpatient settings. While the Transforming Care response has not treated it specifically, it is clear that if the programme of action works effectively, such issues will arise from considering the needs and concerns of individuals with learning disabilities and/or autism.
- 5.2. It can not be the case that people run the risk of having nowhere to live when they are discharged from hospital. Section 47 of the Care Act created a duty for local authorities to work with housing associations to ensure that a person's tenancy remains secure while they are an inpatient.
- 5.3. The Transforming Care partners are starting to articulate a robust programme for care across health and care. It is clear that the rights, values and beliefs of individuals will play a much bigger role in the design of care. But they must be careful to not miss the detail. By not protecting an individual's home tenancy, decision-makers will risk delaying a discharge further down the line because time will have to be given to finding suitable accommodation.
- 5.4. The issue of housing will require greater partnership working, and a model which ensures commissioners and providers can predict future needs, respond to immediate concerns and plan in a timely manner. Services continue to be too reactive, dealing with crises as and when they emerge. This flies in the face of the prevention and personalisation agendas that the Transforming Care partners purport to lean on. Well thought out discharge plans that are in place at the point of admission are therefore crucial.

FORCING THE PACE ON COMMISSIONING

6. The Government and NHS England should force the pace on commissioning by requiring local commissioners to follow a mandatory framework.

- 6.1. When *Time for Change* was published the basic pillars of an effective commissioning framework were recognised – a shared vision, pooled budgets, active engagement and a robust understanding of need.
- 6.2. Visions have come before – Valuing People, Fulfilling Potential. Transforming Care can benefit from these, but must move radically if it is going to deliver the change that is needed. It needs to finish the job.
- 6.3. The key to this will be the model of care it lays out. Personal budgets, the ‘right to challenge,’ and capacity-building in the community will mean little if commissioners do not have the mechanisms to shift services out of inpatient facilities. NHS commissioners and local authorities should not have to take risks, or go against the grain, to provide individuals with care outside of a hospital setting.
- 6.4. *Time for Change* recommended a mandatory framework; a system in which it is impossible for the status quo to remain. Through partnership working the national partners can ensure that a commissioning framework speaks to commissioners across health and care on an equal level.
- 6.5. Progress has been made. The Transforming Care programme recently announced that it would be working in five ‘fast track sites’ to bring together health and care organisations with the technical support they need to change services. It is claimed that these sites will help to shape an approach that can then be delivered across England. It is good to see that Transforming Care is committing proactive support for local commissioners, including a ‘transformation fund’ – this will enable local decision-makers to submit plans that are robust, pro-active and sustainable.
- 6.6. But this approach will fall short without strong leadership and a clear communication of outcomes. Local commissioners need to be engaged in what good looks like, any model will need a whole life-course approach and objectives must be clearly measurable. The programme must not isolate itself within five sites – this would work against the key principle of personalised care and fundamentally fail to promote the collaborative attitudes that are needed to help people back into their communities.

- 6.7. Nearly 60% of people in inpatient facilities are more than 20 km away from their home postcode; 18.2% have been identified as placed over 100km away.²¹ Working in five areas will likely require local commissioners to work further afield to ensure that provision is available where and how individuals need. This applies to the IPC programme as well as the fast track sites – local plans must join up and this requires strong leadership and assurance from the centre.
- 6.8. In their response to *Time for Change*, the Transforming Care partners committed to supporting local areas to adopt good practice at pace.²² This is important – a transition plan for moving people out of inpatient facilities requires great consideration, but ‘complexity’ can only be an excuse for so long.

7. Community-based providers should be given a ‘right to propose alternatives’ to inpatient care.

- 7.1. Enabling providers to take an active role in peoples’ care would be a strong indication of a step change in commissioning culture. But this has not been achieved. There has been no commitment within the Transforming Care programme to allow quality local providers to work with individuals and their families to actively propose potential packages of community-based care.
- 7.2. Transforming Care has committed to testing innovation and ‘getting the basics right.’²³ Ensuring providers are part of the drive to form innovative solutions should be a basic staple of any new model that seeks to incentivise the system away from filling hospital beds. *Time for Change* has called for providers, with the permission of individuals and families, to have a right to put forward potential support options; at the very least providers need to be core partners for transformation.
- 7.3. The fast track sites identified by the Transforming Care programme have committed to co-production of learning, and sharing of expertise. This review will assess closely whether community providers are given the platforms they need to showcase excellent care services, and to work with individuals to develop those services around their needs.

21 Resonance, *Winterbourne View and Social Investment* (2014)

22 *Transforming Care for People with Learning Disabilities – Next Steps* (2015)

23 *Transforming Care for People with Learning Disabilities – Next Steps* (2015)

CLOSURES

- 8. The commissioning framework should be accompanied by a closure programme of inappropriate institutional inpatient facilities, driven by tougher registration requirements, local closure plans, and leadership by NHS England.**
- 8.1. The latest Learning Disabilities Census report showed that patients have an average length of stay of 547 days; in 2013, the average was 542 days.²⁴ This is a damning indication of how little real movement has been achieved over this time. The Concordat was clear that too many people with learning disabilities and/or autism are admitted to inpatient settings when admission could be avoided, too many stay too long, and so too many are in inpatient settings at any one time.²⁵
 - 8.2. That is why there needs to be a closure programme working alongside a new model for commissioning services. Otherwise, a surplus of beds will continue to delay change.
 - 8.3. In February 2015, Simon Stevens announced that a closure programme would be issued by autumn 2015. NHS England is committed to delivering a transition plan for inpatient facilities, drawing on the IPC programme that has been live since April 2015.
 - 8.4. Six months on from *Time for Change*, this review looks forward to the programme from Transforming Care. To be effective it will have to draw together a new commissioning framework with local closure plans that can actively decommission bed surpluses, transfer skilled staff into community services, recruit train and support the workforce in the community and work in close collaboration with people with learning disabilities and/or autism, their families and providers.
 - 8.5. This programme will have to be clear, and demonstrate strong leadership. We already have one failed timetable for transfers; NHS England cannot repeat the mistakes of the Concordat.

BUILDING CAPACITY IN THE COMMUNITY

9. Health Education England (HEE), Skills for Care, Skills for Health and partners should develop as a priority a national workforce ‘Academy’ in this field, building on the work already started by Professors Allen and Hasting and colleagues.

- 9.1. Despite its vision to shift care out of hospitals and have more people supported in their communities, the community workforce has shrunk significantly in the past five years. On top of this, NHS England has lost 1,500 learning disability nurses since 2010.²⁶
- 9.2. Building the skills of the workforce was a major priority for *Time for Change*. There is no dearth of best practice guidance for local commissioners and providers to embed into workforce development, but there needs to be concerted programme of action to support the long-term development of the workforce in services for people with learning disabilities and/or autism.
- 9.3. The Transforming Care response was to commit to a first step in developing a workforce which provides person-centred care support – a scoping exercise to identify current gaps in provision. But there has been little evidence of action.
- 9.4. HEE is a Transforming Care partner. In responding to this review, HEE has reported on its activities over the last six months. The emphasis so far has been to generate an appropriate governance structure for this workstream. This includes a national delivery network with representation from thirteen local education and training boards to support local delivery. It plans to established a Workforce Expert Advisory Group to be chaired by Baroness Sheila Hollins.
- 9.5. The programme of action will include the development of a learning disability skills and competency framework, which will rolled out early next year after piloting. This includes spreading Positive Behaviour Support (PBS) training at scale, as part of the work to reduce restrictive practices.
- 9.6. Given this outline of action, this review will work closely with the partners to ensure that it remains action-focused. If it falls behind, any new service model that is introduced will fall at the first hurdle and prove unable to provide individuals with care in the community.

- 9.7. Excellent community provision needs an excellent workforce which can deliver services and respond to crises. Providers should be able to work with community teams to ensure that when extra support is needed, they are not forced to place individuals in inpatient facilities. Commissioners should be rewarding providers who invest in workforce training, and deliver excellent outcomes.
- 9.8. One of the most shocking aspects of the Panorama programme that exposed Winterbourne View was the evidence of physical abuse and neglect of people with learning disabilities. In the wake of this scandal, the Care Quality Commission (CQC) undertook 150 unannounced inspections of NHS and independent care services. These uncovered wider concerns about standards of care. It is clear that some institutions use physical restraint, including use of the emergency response belt. This report recommends that the CQC should undertake a review of restrictive practices with a view to banning physical restraint methods such as the emergency response belt. This would help drive transformation at the pace we need to ensure the work of HEE and its partners can be embedded within commissioning practices. Just as community provision will not be built up without the scaling back of inpatient facilities, a comprehensive commitment to PBS training and techniques will not be achieved without the scaling back, or banning, of restrictive practices.
- 9.9. The Government must also review the scope of the CQC to have powers for reviewing the care provided to individuals with learning disabilities when care for in supported living. It is essential that people with learning disabilities and/or autism are given full protection.

10. A 'Life in the Community' Social Investment Fund should be established to facilitate transitions out of inpatient facilities and build capacity in community-based services.

- 10.1. *Time for Change* was clear – transformation will only happen if there is investment to help community-based providers expand. The steering group commissioned a report – *Winterbourne View and Social Investment* – from Resonance, a social impact investment company. This laid out inter-linked solutions for the capital needs of providers, centred on a Government-backed vehicle with a social mission to improve outcomes for people with learning disabilities and/or autism.
- 10.2. In the response to *Time for Change*, the Department of Health has taken responsibility for scoping this idea further. However, six months on there has been no evidence of any action to implement such an exercise, or build on the significant body of work that the social investment report provided.
- 10.3. The update that the Department of Health has submitted to this review has emphasised the importance of delivering the transformation programme, particularly in the five fast track sites, which will include identifying further capital funding to support the transition.
- 10.4. It is suggested that the fast track sites will prove fertile ground for exploring how certain funds, such as 'outcomes-based payments' could work 'on the ground.' The reason given is that work needs to be done with local commissioners to enable them to feel confident that this type of financial mechanism can deliver helpful solutions.
- 10.5. This makes sense. But the lack of commitment to scope social investment options fully must be taken as a failure on the part of the Transforming Care programme to act on the practical questions of implementation. A closure programme requires retraining of staff, the development of community-based facilities, transition programme and alternative investments to underpin the change. Moving forward, it is the job of the partners to link up the work streams that have been taken on in response to *Time for Change* and provide a seamless new model of care for people with learning disabilities and/or autism. Failure to give due attention to any of the pieces will have significant consequences elsewhere.

HOLDING PEOPLE TO ACCOUNT

- 11. Action on the recommendations should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level.**
 - 11.1. Data on key indicators (such as admission rates, length of stay, and number of beds), need to be collected and published so that local commissioners and national bodies can be held to account on the implementation of these recommendations.
 - 11.2. As discussed above, responsibility for collecting data around the number of people with learning disabilities in inpatient facilities now rests with HSCIC. This Assuring Transformation data is starting to provide a clear, monthly picture. A responsibility to report on where local areas are in terms of transitioning individuals in the community should be an embedded part of any new commissioning framework that is drawn up.

APPENDIX

MEMBERSHIP OF THE STEERING GROUP

Sir Stephen Bubb (chair)	ACEVO
Jane Cummings	NHS England
Andrea Pope-Smith	ADASS
Andrea Sutcliffe/Alan Rosenbach	CQC
Bob Ricketts	NHS England
Dave Williams	Salford CCG
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Dr Roger Banks	Independent Psychiatrist
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Karen Flood	National Forum of People with Learning Disabilities
Kate Quail	Mencap
Mark Lever/Mark Milton	National Autistic Society
Robert Longley-Cook	HFT
Sharon Allen/Marie Lovell	Skills for Care
Shaun Clee	NHS Confederation/2gether NHS Foundation Trust
Steve James	Avenues Group
Vicki Raphael	National Valuing Families Forum
Vivien Cooper	Challenging Behaviour Foundation

“This is the opportunity for us, as a nation, to provide the care that people with learning disabilities and/or autism deserve and have been denied for so long.”

Sir Stephen Bubb
CEO, ACEVO

ACEVO

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