
WINTERBOURNE VIEW – TIME FOR CHANGE

Transforming the commissioning
of services for people with learning
disabilities and/or autism

A report by the Transforming Care and Commissioning
Steering Group, chaired by Sir Stephen Bubb – 2014

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FOREWORD

The Winterbourne view scandal, exposed by the Panorama programme, shocked the nation. It led to the Government pledge to move all people with learning disabilities and/or autism inappropriately placed in such institutions into community care by June this year. Not only has there been a failure to achieve that movement, there are still more people being admitted to such institutions than are being discharged. This has caused anger and frustration.

In light of the need to achieve progress Simon Stevens, the CEO of NHS England, asked me to consider how we might implement a new national framework, locally delivered, to achieve the growth of community provision needed to move people out of inappropriate institutional care.

Only by a big expansion of such community provision can we achieve a move from institution to community. So we need a mandatory national commissioning framework that delivers that expansion, pooled budgets, and a focus on the individual's needs not the system boundaries. The role of the many voluntary and community organisations that both advocate for and provide services for people with learning disabilities and/or autism is crucial to that aim, as are the individuals themselves, their families, clinicians, managers and professionals across the health service and in local councils, who need to work together to achieve a dramatic turn-around.

In tackling this challenge it became clear to me that we need both a major expansion of community delivery driven by better commissioning but also, crucially, the empowerment of people with learning disabilities and/or autism and their families. That means a clear and robust Charter of Rights and an effective "Right to Challenge", backed by strong advocacy and support, that enables citizens to demand change. We also propose that community based providers have the right to propose alternatives to inpatient care from commissioners. And we support a major expansion of the right to request a personal budget; again we believe this underpins an empowerment of the individual citizen to have care and support appropriate to them.

In other words we need to drive change from the top through better commissioning and from the bottom up through empowering people and families to challenge the system.

Underpinning a shift to community provision and away from inappropriate institutional care are exciting proposals for workforce development and a new social finance fund. In developing community provision we need social finance to support capital development so we propose a "life in the community social investment fund" which will support the provision of working capital, investment in housing and an investment readiness partnership fund. This is a new proposal but we recognised that developing community provision needs the funding that social finance can provide and I urge Government and NHS England to push ahead with funding to make this happen promptly.

The steering group were clear about the crucial importance of workforce and skills development. This must happen alongside developing community facilities. We were particularly impressed with the momentum around the idea of the Academy set out on this Report. We must ensure that momentum for change is built on by all those involved.

And finally, as well as a mandatory national framework for commissioning that is locally delivered we must have active decommissioning of inappropriate institutional care and closures of such institutions. The timetable and process requires further discussion but a twenty-first century approach to the care and support of people with learning disabilities cannot be based on long-term care in an institution.

In putting together this report I want to thank all my colleagues on the steering group, and all those I have met or spoken to, and those who submitted many comments and documents. Even when critical we recognised this came about through the anger of those who have seen a system fail them.

In 1851, the American physician and philanthropist Samuel Gridley Howe wrote about the “evils” of institutional care. He wrote, “all such institutions are unnatural, undesirable and very liable to abuse. We should have as few of them as possible, and those few should be kept as small as possible. The human family is the unit of society.”

That essential truth underpins our proposals for change and we know they have widespread support. We recognised that as a nation when we closed the old mental health asylums and we must recognise it again here.

I have recommended to the chief executive of NHS England that my steering group be brought together again in 6 months to review progress on our recommendations and that we have a formal stock take of actions taken in 12 months’ time. We can act as a driver for change but clearly it is the institutions themselves that must deliver these recommendations. And deliver them they must.

Over the past few years people with learning disabilities and/or autism have heard much talk but seen too little action, and this forms the backdrop to our recommendations and our desire to see urgent action taken now to make a reality of the Winterbourne pledge. They deserve better and this Report provides recommendations on that essential road map for change.



Stephen Bubb

Sir Stephen Bubb

EXECUTIVE SUMMARY

About this report

1. This report is the product of NHS England asking Sir Stephen Bubb, chief executive of charity leaders body ACEVO, to make recommendations for a national commissioning framework under which local commissioners would secure community-based support for people with learning disabilities and/or autism. This came after a pledge made in the wake the Winterbourne View scandal – to enable people with learning disabilities and/or autism inappropriately placed in hospital to move to community-based support by June 2014¹ – was missed.
2. Sir Stephen was supported by a steering group of representatives from the voluntary sector, the NHS and local government, individuals with learning disabilities and/or autism, and family members of people with learning disabilities and/or autism. Over the course of its work, the group engaged with a range of stakeholders (from people with learning disabilities and/or autism and their families to commissioners, providers and academics).
3. Whilst originally tasked with drawing up recommendations for a commissioning framework, it was clear to the steering group that any such framework formulated by NHS England would need to be accompanied by related action from others (including most obviously central and local Government), and our recommendations reflect this. Our starting point is that it is not acceptable in the twenty-first century for thousands of people to be living in hospitals when with the right support they could be living in the community, and that to force change we need both more ‘top-down’ leadership (from NHS England, local government, central government and other Arms-Length Bodies), and from the ‘bottom up’ more empowerment for people with learning disabilities and/or autism and their families. Our recommendations are aimed at both.
4. The failure to meet the Winterbourne View pledge above means there is now a great deal of anger and frustration surrounding this issue. In responding to this report, NHS England and its partners need both to act with urgency, and to be realistic about the timeline for success, so that they do not promise yet another ‘false dawn’.

The problem

5. Some people with learning disabilities and/or autism who present challenging behaviour and/or complex mental health problems may need to be admitted to inpatient settings to be assessed and treated – particularly if they are liable to detention under the Mental Health Act on the recommendation of mental health professionals or a court. But many are admitted when their admission could have been prevented had they

1 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

received better support in the community, and many stay in hospital too long, when with the right support in the community they could be discharged. The result is that for many years too many people with learning disabilities and/or autism have been, and continue to be, in inappropriate inpatient settings – often a very long distance away from family and home.

6. We must see a step change on two fronts: a) putting in place the community-based support to safely discharge people currently in inpatient settings (of whom the latest NHS England data collection showed there were 2,600)², and crucially b) supporting children, young people and adults in the community to prevent admissions in the first place (focusing on a much larger number, most urgently perhaps some 24,000 adults in England who present severe challenging behaviour³).
7. By a very long way, this report is not the first time anyone has considered these issues. Many have done so, over many decades. So why has there not been more progress? Our view is that:
 - It is not that we don't know 'what good looks like'. That has been described many times, from Professor Mansell's⁴ authoritative report in 1993 onwards.
 - Nor is it that we don't know what kind of commissioning we need to secure that good care. The Concordat published after the Winterbourne View scandal set out the necessary key steps very clearly (starting with pooled budgets and joint local commissioning plans), and has been followed by a range of further analysis and guidance.
 - Instead, it is that we make it too hard for stakeholders across the system to make change happen, and too easy to continue with the status quo. And we do not give enough power or support to the people most eager and best placed to make things change – starting with people with learning disabilities and/or autism themselves and their families.
8. Our recommendations therefore aim to make it easier (or mandatory) to do the right thing, harder (or impossible) to do the wrong thing, and to empower and support the agents of change.

Recommendations

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.** The Charter should clarify existing rights, and set out new rights we propose below. The mandatory commissioning framework later in our recommendations should require all commissioners to invest in services that make these rights 'real' and easily used.

2 NHS England, Quarterly 'Assuring Transformation' data, published at www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/

3 K. Lowe et al, Challenging Behaviours: prevalence and topographies. *Journal of Intellectual Disability Research*, 51, 625–636 (2007)

4 J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)

2. **The Government should respond to ‘the Bradley Report Five Years On’,⁵** to ensure that people with learning disabilities and/or autism are better treated by the criminal justice system
3. **People with learning disabilities and/or autism and their families should be given a ‘right to challenge’ decisions to admit or continue keeping them in inpatient care.** They should receive independent expert support to exercise that right, including high-quality independent advocacy.
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,** including all those in inpatient care and appropriate groups living in the community but at risk of being admitted to inpatient care.
5. **The Government should look at ways to protect an individual’s home tenancy when they are admitted to hospital,** so that people do not lose their homes on admission and end up needing to find new suitable accommodation to enable discharge.

Forcing the pace on commissioning

6. **The Government and NHS England should require all local commissioners to follow a mandatory commissioning framework.** The funding and responsibility for commissioning services for this group should be devolved as much as possible from NHS specialised commissioning to Clinical Commissioning Groups. Learning from the strengths (and weaknesses) of the Better Care Fund, a mandatory framework should then require the pooling of health, social care and housing budgets, and mandate NHS and local government commissioners to draw up a long-term plan for spending that funding in a way that builds up community services, makes the Charter of Rights above real, and reduces reliance on inpatient services. NHS England, central Government and local government representatives such as the Local Government Association and Association of Directors of Adult Social Services should support and assure the drawing up of local commissioning plans, and unblock systemic barriers (including Ordinary Residence rules and eligibility for Continuing Health Care). There should be a named lead commissioner in each area, working collaboratively with a provider forum and people with learning disabilities and/or autism and their families.
7. **Community-based providers should be given a ‘right to propose alternatives’ to inpatient care** to individuals, their families, commissioners and responsible clinicians.

Closures of inpatient institutions

8. **The commissioning framework should be accompanied by a closure programme of inappropriate institutional inpatient facilities.** This active decommissioning should be driven by a tougher approach from the Care Quality Commission, local closure plans, and closures led by NHS England where it is the main commissioner. NHS England should come to a considered, realistic view on what is possible – but then it should

5 G. Durcan, A. Saunders, B. Gadsby & A. Hazard, *The Bradley Report five years on: an independent review of progress to date and priorities for further development* (2014)

set out a clear timetable not just for reductions in admissions or inpatient numbers, but for closures of beds and institutions.

Building capacity in the community

9. **Health Education England, Skills for Care, Skills for Health and partners should develop a national workforce ‘Academy’ for this field, building on the work already started by Professors Allen and Hastings and others⁶.** The Academy should bring together existing expertise in a range of organisations to develop the workforce across the system.
10. **A ‘Life in the Community’ Social Investment Fund should be established to facilitate transitions out of inpatient settings and build capacity in community-based services.** The Investment Fund, seeded with £30 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.

Holding people to account

11. **Action on the recommendations above should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level.** Data on key indicators (such as admissions rates, length of stay, delayed transfers, number of beds by commissioning organisation) should be collected and published. Both local commissioners and national bodies (including NHS England, DH, the LGA and others) should be held to account for implementing our recommendations above – local named lead commissioners by local people, NHS England and central Government, and national bodies through existing governance structures (such as the Transforming Care Assurance Board chaired by the Minister for Care and Support).

6 Their proposal is outlined at https://drive.google.com/file/d/0B_At2T3XSWfTd2VOcTRrOURMZW8/edit?pli=1

ABOUT THIS REPORT

1. After the Winterbourne View scandal, the Government and a large number of partners signed a Concordat pledging action on care for people with learning disabilities and/or autism who present behaviour that challenges and/or complex mental health problems. The Concordat promised: “health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than 1 June 2014”. It envisaged a “rapid reduction in hospital placements for this group of people”, and “the closure of large-scale inpatient services”.⁷ But that pledge was missed.
2. Following the failure to meet that pledge, NHS England developed a programme plan and asked Sir Stephen Bubb, chief executive of charity leaders body ACEVO, to make recommendations for a national commissioning framework under which local commissioners would secure community-based support for people with learning disabilities and/or autism.
3. Sir Stephen was supported by a steering group of representatives from the voluntary sector, the NHS and local government, Gavin Harding MBE as co-chair of the Department of Health’s Transforming Care Assurance Board, individuals with learning disabilities and/or autism, and family members of people with learning disabilities and/or autism. Over the course of its work, the group engaged with a range of stakeholders (from people with learning disabilities and/or autism and their families to commissioners, voluntary sector organisations who work with and/or represent people with learning disability or autism and their families, providers and academics). The membership of the steering group is set out in the appendices.
4. When we refer to community based services we mean smaller more personalised services within a community setting where there is good access to local amenities and services. People supported are able to exercise choice and control over where they live, who they live with and who supports them and truly feel that where they live is their home. The label applied to the service – such as supported living or registered care – should in no way impact on the quality or feel of the service provided.
5. The steering group was supported through focus groups with individuals with learning disabilities and/or autism and their family carers, and by an expert reference group on social investment. The latter group was supported by research on the potential role for social investment from Resonance Ltd, which formed the basis for much of our thinking on social investment and which is being published alongside this report.⁸

7 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

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

6. In formulating this report, over several months the steering group met with or heard from a wide range of stakeholders. We held workshops with people with learning disabilities and/or autism, with providers and with commissioners. We looked at the considerable volume of work already undertaken on this issue – the reports by Professor Mansell of 1993 and 2007,⁹ the review by the Department of Health undertaken after the Winterbourne View scandal,¹⁰ the subsequent Concordat signed up to by stakeholders across the system,¹¹ *Ensuring Quality Services* by the LGA/NHS England,¹² and reports and guidance by a very wide range of organisations, including but not limited to the Joint Improvement Partnership hosted at the Local Government Association, Think Local Act Personal, the National Development Team for Inclusion (NDTI), the Royal College of Psychiatrists and the British Psychological Society, the Housing and Support Alliance, Skills for Care, the Challenging Behaviour Foundation, the Challenging Behaviour National Strategy Group and others. A number of organisations spoke to us or submitted evidence directly, including the Ideas Collective, CHANGE, Shared Lives Plus, and Prof. Richard Hastings at the University of Warwick. We have drawn heavily on their ideas and views, and are hugely grateful for their engagement.
7. Whilst we were originally tasked with making recommendations for a national commissioning framework for NHS England, it is clear to us that any such framework formulated by NHS England must be accompanied by related action from others – most obviously, local and central government – and by a stronger rights framework. Our recommendations reflect this.

9 J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)

10 Department of Health, *Transforming Care: a national response to Winterbourne View hospital* (2012)

11 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

12 LGA & NHS England, *Ensuring Quality Services* (2014)

THE PROBLEM WE ARE CONFRONTING

Where we are now

1. The problem we are dealing with is, we believe, well understood. It has been well described a number of times, by people with learning disabilities and/or autism themselves, their families, charities and campaign groups, the Department of Health, professional organisations, the Local Government Association and NHS England. We summarise it here for clarity, rather than as a new addition to the debate.
2. Some people with learning disabilities and/or autism who present challenging behaviour may need to be admitted to inpatient settings to be assessed and treated – particularly if they are liable to detention under the Mental Health Act on the recommendations of mental health professionals or a court. But
 - a) many are admitted when that could have been prevented had they received better support in the community,
 - b) many stay in hospital too long, when with the right support in the community they could be discharged.

The result is that for many years, at any one time far too many people with learning disabilities and/or autism could (and still can) be found in inappropriate inpatient settings.

3. After the Winterbourne View scandal, the Government and a large number of partners signed a Concordat which promised: “health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than 1 June 2014”. It envisaged a “rapid reduction in hospital placements for this group of people”, and “the closure of large-scale inpatient services”.¹³
4. Since then, hundreds have been transferred out of inpatient care – NHS England’s quarterly data collections show that between 30 September 2013 and 30 September 2014, 923 people were transferred out of inpatient care. But crucially, numbers admitted have been consistently higher than numbers transferred out – with 1,306 individuals admitted over the same period.¹⁴
5. Individuals with learning disabilities, their families, commissioners and clinicians, will still say that many of those inpatients could be discharged, or that their admission could have been prevented, if there were better

¹³ Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

¹⁴ NHS England, Quarterly ‘Assuring Transformation’ data, published at www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/

support available in the community. And NHS England's care reviews are still finding significant numbers of people in inpatient settings who could and should be discharged with the right community-based support in place. Too often, people are still placed in inpatient settings a very long distance from family and home.

6. The pledge in the Concordat is still valid. We still need to do better both at
 - a) Putting in place the community-based support to safely **discharge people** currently in inpatient settings (of whom the latest NHS England data collection showed there were 2,600),¹⁵ and
 - b) supporting people in the community to **prevent admissions** in the first place – with that early intervention starting at the earliest possible stage in childhood, but most urgently with better support provided to adults in the community with severe challenging behaviour (of whom there are much larger number, perhaps some 24,000 people in England¹⁶).
7. Stakeholders were clear to us that this latter need to focus on early intervention and prevention cannot be overlooked. The intense focus on the 2,000–3,000 people currently in inpatient settings is welcome, but it must not be at the expense of catering for the larger number at risk of admission. Failure to do better for them will result in failure to reduce inpatient numbers overall.

Where we need to get to

8. Again, there is broad consensus on what the world should look like for people with learning disabilities and/or autism who present behaviour that challenges. It has been described repeatedly by people with learning disabilities and/or autism themselves, their families, Professor Mansell (in 1993 and again in 2007),¹⁷ the Department of Health (in its 'model of care' published after the Winterbourne View scandal),¹⁸ the Winterbourne View Joint Improvement Programme (in *Ensuring Quality Services*),¹⁹ the NDTI (in the DH-funded *Guide for commissioners of services for people with learning disabilities who challenge services*)²⁰ and others. Again, we summarise 'what good looks like' here for clarity rather than with the intention of adding anything new to the debate:
 - The presumption should be that people live in their own homes, not in hospitals. A hospital, whatever the quality of the care it provides, is not a home.
 - The system needs to respect and uphold the rights of people with learning disabilities and/or autism (general human rights and rights

15 NHS England, Quarterly 'Assuring Transformation' data, published at www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/

16 K. Lowe et al, Challenging Behaviours: prevalence and topographies. *Journal of Intellectual Disability Research*, 51, 625–636 (2007)

17 J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)

18 Department of Health, *Transforming Care: a national response to Winterbourne View hospital* (2012)

19 LGA & NHS England, *Ensuring Quality Services* (2014)

20 NDTI, *Guide for commissioners of services for people with learning disabilities who challenge services* (2010)

specific to people with disabilities), ensuring that they are able to exercise choice and control over their lives and that they are treated with dignity and respect.

- Services need to support people as human beings to lead whole lives (rather than simply as ‘patients’ who need to be treated for medical problems)
 - Support needs to be provided over the whole life course, from birth to old age, and we should seek to intervene early to prevent crises rather than simply responding to them.
 - The system needs to combine highly personalised support with reasonable adjustments that ensure access to universal services
 - Services need to incorporate building blocks that we know to be crucial to success, such as: multi-disciplinary community learning disability teams able to provide support with communication, physical and mental health and social needs; care coordinators; support for families to look after family members at home, including short break services; high-quality independent advocacy services; appropriate housing; access to education, work and meaningful activities; extra support in times of crisis; access to Positive Behavioural Support and highly-skilled staff throughout the system (all set out in more detail in the Mansell reports,²¹ the joint report of the Royal College of Psychiatrists, British Psychological Society and the Royal College of Speech and Language Therapists in 2007,²² or the NHS England/LGA guide *Ensuring Quality Services*²³).
 - Where a spell in inpatient settings is truly necessary, it should be as local as possible, and enable speedy resolution to crises in a way that builds resilience for the individual and their family
 - People with learning disabilities gave us a strong message that a good system will be co-designed with, and employ, people with learning disabilities and/or autism and their family members
9. There is also broad agreement about some of the mechanisms required in commissioning practice if we are to have services that meet the above, and these were clearly spelt out in the Transforming Care Concordat that followed the Winterbourne View scandal. They included:
- Pooled budgets and joint commissioning, accompanied by strong local leadership. The Transforming Care Concordat stated: “the strong presumption will be in favour of pooled budget arrangements... CCGs and local authorities will set out a joint strategic plan to commission the range of local health, housing and care support services to meet the needs of people with challenging behaviour in their area.”²⁴

21 J. Mansell, *Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs* (1993), and revised edition (2007)

22 Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, *Challenging Behaviour: a unified approach* (2007)

23 LGA & NHS England, *Ensuring Quality Services* (2014)

24 Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

- Personalisation. The Concordat pointed to the importance of personal care plans for each individual, and pledged that inpatients “should be receiving personalised care and support in community settings”.²⁵ Subsequent work, such as Think Local Act Personal and the NDTI’s 2014 report on personal health budgets for people with learning disabilities,²⁶ has pointed to the potential benefits of personal budgets as a tool for achieving personalised care.
- Contracts that incentivise or require best practice. The Concordat pledged a range of actions to make it easier to: reward best practice through the NHS commissioning for quality and innovation (CQUIN) framework, embed Quality of Health principles in NHS contracts and Quality of Life principles in social care contracts, and hold providers to account.²⁷
- Support for commissioners. There has been widespread recognition that local commissioners do not always have the capacity or capability to lead the kind of service transformation hoped for, and the Concordat led to a range of actions to support commissioners, ranging from practical tools (such as toolkits or service specifications) to guidance (such as that by the Royal College of GPs and Royal College of Psychiatrists²⁸) to workshops as currently being run by the Joint Improvement Programme. People with learning disabilities and/or autism and their families have argued strongly that they and their local groups should be partners in commissioning decisions.
- Provider and workforce development. Again, there has been widespread agreement that for more people with learning disabilities and/or autism who display challenging behaviour to be supported successfully in the community, community-based providers and workforces will need support and development. A large number of pledges in the Concordat focused on workforce development, with actions ranging from guidance for social workers to minimum training standards for healthcare support workers to guidance for commissioners on workforce development.²⁹

Why has there not been more progress?

10. As the above makes clear, this steering group is not the first time anyone has thought about this issue, by a very long way. For decades people have argued for change and described what good care looks like, and how we can commission it. The Winterbourne View scandal made the need for change even clearer, and resulted in a wide range of commitments from Government and others. But the problem remains. Why?

²⁵ Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

²⁶ Think Local Act Personal & the NDTI, *Personal Health Budgets: including people with learning disabilities* (2014)

²⁷ Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

²⁸ Joint Commissioning Panel for Mental Health, *Guidance for commissioners of mental health services for people with learning disabilities* (2013)

²⁹ Department of Health, *Winterbourne View Review: Concordat: a programme of action* (2012)

11. Our view is that progress has been so slow not because we haven't described what good looks like, or how we need to get there, but because it has been too hard to do the right thing and too easy to do wrong thing, and the people most eager to change the system (people with learning disabilities and/or autism and their families, enthusiastic providers, clinicians and commissioners) have had too little power or support to do so.
12. Clinicians are being asked to admit fewer people who present challenging behaviour to inpatient settings, and to discharge others, on the basis that they can be appropriately supported in the community. Many clinicians would like to do just that, and some manage it – but too often they do so in spite of the system, not because of it. They are being asked to keep people in the community or discharge to the community when many will worry that the community-based support on offer is insufficient, or not there at all. They do not want to see individuals unsupported in the community, and many will have seen precisely that happen with subsequent placement breakdown and a need for readmission. They are being asked to take this approach when many work for providers that are not financially incentivised to have a culture and a drive to get people supported in the community, but that instead have an incentive to keep inpatient beds full. And clinicians are being asked to do this when the people who have the expertise to suggest to them realistic community-based alternatives are often unable to, because they lack access to information about the individual's needs.
13. Both health and social care providers are being asked to expand their community-based capacity to support people who present behavioural challenges in order that they are not admitted in the first place, or can be safely discharged from inpatient settings. Many would like to do just that, and some manage – but again, too often despite the system not because of it. Providers are being asked to invest significant sums of money in new staff, training and sometimes new or altered accommodation, months in advance of them taking on new clients and being paid for their care. They may not have the capital to make that upfront investment. Sometimes they are asked to put those services in place at impossibly short notice. And they are asked to make the upfront investment when they are fundamentally not confident that commissioning or clinical behaviour will change, and that there will be predictable revenue streams to pay for their investment.
14. People with learning disabilities and/or autism and their families are being asked to play a central role – speaking up for their rights, acting as partners in designing packages of support, perhaps managing personal budgets, challenging poor practice, being directly involved in the appointment of their care staff. Some do. But too often they experience it as an exhausting battle against the system. Others do not know what their rights are, don't have the support to express or use them. Still others do not know what good community-based potential alternatives could be created for them, and know only the community services that have failed them before.
15. Frontline staff are being asked to behave differently – to think more often of people as people and citizens with rights (not just patients with problems), to engage individuals or their families in care more, to be aspirational about what people can achieve, to make greater use of Positive

Behavioural Support. Many do – but again, less because of the system than in spite of it, because we are asking them to do so without a great deal of support or training, and without incentivising the organisations they work for to make it a priority.

16. And commissioners (CCGs, local councils and NHS specialist commissioners) are being asked to collaborate across organisational boundaries to transform a highly complex system, taking risks in the process. Some have, but again, too often in spite of the system not because of it. Because they are being asked to do all this when many have limited time and capacity to give to the issues, lack expert support, are constrained or slowed down by organisational disputes over who pays for what and whose responsibility an individual should be, and may lack the backing from local leaders that they need to push through change and negotiate compromise between different interests. And they are being asked not to put people in inpatient beds when often those beds have been paid for on a block contract, come at no marginal cost, and feel like the safe option.
17. We need to make it easier (or mandatory) for all these stakeholders to do what we are asking of them. We need to make it harder (or impossible) for them to settle for the status quo that we are agreed must stop. And we need to empower the agents of change – those commissioners, providers, clinicians and above all, people with learning disabilities and/or autism and their families, who are battling for things to be done differently. That is what any new commissioning framework needs to do, and what our recommendations aim to achieve.

RECOMMENDATIONS

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. We have heard, loud and clear, the message from people with learning disabilities and/or autism and their families that the system needs to do a better job of respecting and upholding their rights, and listening to what they have to say. This is about doing what is fundamentally the right thing, respecting people's human rights as a point of principle. But it is also about empowering people who could help change the way the system works for the better, but who too often struggle to make themselves heard. In the context of the problem described in the previous chapter, it is about empowering the agents of change.
 - 1.2. People with learning disabilities and/or autism and their families have an array of rights in law or Government policy – through human rights law, the Equalities Act, the NHS constitution, the Mental Health Act, the Care Act, the Mental Capacity Act, the UN Convention on the Rights of Persons with Disabilities, and so on.
 - 1.3. But in our engagement with stakeholders over the course of our work, we heard that the lived experience of people with learning disabilities and/or autism and their families is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored.
 - 1.4. In some cases, people with learning disabilities and/or autism and their families may not be aware of the rights they already have, or may not have access to the support they need to exercise those rights (such as access at the right time to an advocate or lawyer – for instance, during a crisis, at point of admission, or when in an inpatient setting).
 - 1.5. In other cases, there are doubts over whether the rights of people with learning disability are being respected in practice as originally intended. For instance, as the Government has recognised,³⁰ there have been occasions where the safeguards in the Mental Health Act have not been properly applied, leading to the recent consultation on updating the Mental Health Act Code of Practice.
 - 1.6. There are also serious concerns about the treatment of people with learning disabilities and/or autism by the criminal justice system, and whether their rights are being properly upheld.

In 2009, the ‘Bradley Report’³¹ described a widespread lack of awareness of the issues faced by people with a learning disability and communication difficulties in the criminal justice system. Since then, there has been significant progress, but the ‘Bradley Report Five Years On’,³² published this year, found more needs to be done and made nine recommendations for action. This area was outside our remit to explore in detail, but we recognise how fundamentally important it is. We recommend that the Government respond to the recommendations of the ‘Bradley Report Five Years On’, setting out how cross-government action will tackle the issues raised.

- 1.7. To make the rights that people with learning disabilities and/or autism and their families already have feel real, we recommend that the Government should set out a Charter of Rights for people with learning disabilities and/or autism – and then require commissioners to shape local services around those rights.
- 1.8. Any such charter should build on existing work (such as the ‘We Have the Right’ statement put together by people with learning disabilities with support from CHANGE for the purposes of this report, or the Challenging Behaviour Charter drawn up by the Challenging Behaviour National Strategy Group, both of which can be found in the appendices). The Charter of Rights should clarify the rights people already have, and the support they can access to use them. It should clarify how professionals (commissioners, clinicians and others) should respect those rights – including in respect to upcoming changes to the Mental Health Act Code of Practice.
- 1.9. To give the Charter of Rights ‘teeth’, local commissioners should be required to base their local commissioning plans on it, and to set out how they will make those rights real – for instance, by:
 - ensuring information is accessible and available in a range of formats (including easy read) and adapted for individual needs;
 - commissioning high-quality independent advocacy services for people with learning disabilities (including people with complex needs), brokerage support, and supporting self-advocacy and family advocacy groups. Particularly for individuals who do not have family, or do not have a supportive family, such support is critical;
 - offering personal budgets – and strong support for people with learning disabilities and/or autism and their families to use them;
 - ensuring that at key moments (such as prior to admission) people with learning disabilities and/or autism and their families know their rights, know what support they can access to exercise them, and know how to access that support;

31 Lord Bradley, *The Bradley Report* (2009)

32 G. Durcan, A. Saunders, B. Gadsby & A. Hazard, *The Bradley Report five years on: an independent review of progress to date and priorities for further development* (2014)

- employing and working in genuine partnerships with people with learning disabilities and/or autism and family carers throughout the system – in drawing up commissioning plans, in hiring staff, in ensuring providers meet high quality standards, in scrutinising and holding commissioners to account, sitting on provider boards of director, and so on. Some of this good practice commissioners could require through the contracts they let to providers, and NHS England should show leadership by employing people with learning disabilities and/or autism at a central level to help drive service transformation.

1.10. Action to make this Charter of Rights ‘real’ should be central to the mandatory commissioning framework we set out below.

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

- 2.1. In addition to making existing rights feel more ‘real’, we propose extending the rights of people with learning disabilities and/or autism and their families – starting with a ‘right to challenge’.
- 2.2. A ‘right to challenge’ would allow a person with learning disabilities and/or their family to challenge a decision to admit them to hospital or keep them there, should they so wish. Such a right should 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. Building on the process already developed through NHS England’s existing programme of care and treatment reviews and reviews by NHS England’s Improving Lives Team, together they would ask what assessment, treatment or safeguarding was to be undertaken/was being undertaken in an inpatient setting that could not feasibly be done in the community. The independent support would help individuals and families understand what community-based alternatives might be possible. Based on the presumption set out in the Mandate from the Department of Health to NHS England after the Winterbourne View Scandal (“the presumption should always be... that people remain in their communities”), the review triggered by this right to challenge would only recommend admission/continued placement in hospital if it concluded that the assessment, treatment or safeguarding could only be effectively and safely carried out in an inpatient setting.
- 2.3. We recognise that many individuals with learning disabilities and/or autism will not feel able to challenge the decisions taken regarding their care, particularly if they are in inpatient settings. In such cases, it is essential that the commissioners paying for their care take the responsibility to challenge the appropriateness of their admission or continued placement in inpatient settings. We expect all commissioners to ensure a care and treatment review is undertaken with the permission of the patient or their carer in order to confirm if inpatient treatment is appropriate.

3. 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

- 3.1. The ‘right to challenge’ outlined above should be allied to an extension of rights to have a personal budget (or personal health budget),³³ building on existing rights for those eligible for Continuing Health Care and social care funding. A right to have a personal budget (or personal health budget) should be considered for:
- **People who are inpatients and those at risk of admission:**
If an independent review linked to a ‘right to challenge’ found that an individual could avoid admission or be discharged with the right package of assessment, treatment, support and safeguarding in the community, the individual and their family should have a right (but not an obligation) to a personal budget (or personal health budget) to put that package in place.
 - **People with learning disabilities and mental health needs.**
For instance, people with learning disabilities who are on the Care Programme Approach would be a readily identifiable group who might benefit.
 - **Children and young people with learning disabilities.**
Children and young people who have significant health needs could be offered personal budgets (or personal health budgets) to enable them to remain living in the community and avoid out of area placements.
- 3.2. Personal budgets and personal health budgets encourage a change in thinking. Instead of commissioning services for groups, support is designed for one person at a time, based on a whole-life care plan that focuses on what matters to the person and their family. As now, people should be able to take their budget in a variety of ways – as a direct payment, as a notional budget, or as a budget managed by a third party (known as an individual service fund in social care).
- 3.3. Local areas will need national support to make this extension a reality, and the centre (the Department of Health, NHS England and national partners) will need to invest in that support. This should include:
- Ensuring close links with the Integrated Personal Commissioning programme, to support local areas to pool funding across health and social care.
 - Publishing the number of people taking up personal budgets (or personal health budgets) and the impact on their lives, so local health and social care commissioners understand progress and can be held to account.

³³ The term personal health budget is used where care is funded by the NHS, while personal budget is used in social care.

- Putting in place a national support programme for local commissioners, to enable them to actively promote personal budgets (or personal health budgets) as an option for these groups.
 - Ensuring that the other recommendations of this report are implemented in ways that encourage and promote uptake of personal budgets and personal health budgets.
- 4. The Government should look at ways to protect an individual's home tenancy when they are admitted to hospital, so that people do not lose their homes on admission and end up needing to find new suitable accommodation to enable discharge.**
- 4.1. We heard that on being admitted to hospital, it is common for people with learning disabilities and/or autism to lose their tenancy. Not only can that be distressing for the individual, the need further down the line to find suitable accommodation can cause delays to discharge. It was not in our remit to look into this issue in detail, but we recommend that the Government explore ways to protect the tenancies of people with learning disabilities and/or autism when they are admitted to hospital, so that they can return to the same home on discharge if they wish to.

Forcing the pace on commissioning

- 5. The Government and NHS England should force the pace on commissioning by requiring local commissioners to follow a mandatory framework**
- 5.1. The basic pillars of what is required at a local level from NHS and local authority commissioners has already been described (and committed to by a range of partners) through the Transforming Care Concordat and elsewhere, namely:
- One shared vision, driven forward by active senior leadership, based on the presumption that hospitals are not homes, and that people should be supported to live in the community.
 - One pooled budget, allowing maximum flexibility for commissioners to fund what individuals truly need, and aligning the financial incentives on all commissioners to invest in community-based provision.
 - One robust plan for commissioning on a whole life-course basis, supporting early intervention and support (from early childhood onwards), expanding the provision of community-based support and care, and reducing the number of inpatients and inpatient provision. That plan should be based on a robust understanding of current and future need, a range of existing best practice guidance, and active engagement with people with learning disabilities and/or autism, their families and providers.
- 5.2. Many local commissioners (in local councils and clinical commissioning groups) are enthusiastic about making this shift happen, and there is much good practice to draw on. But a great

many local commissioners do not have the three pillars above in place. The most recently published stocktake by the Winterbourne View Joint Improvement Programme³⁴ found many areas were not pooling budgets, commissioners, providers and families continue to cite disputes over who should fund what as a reason for inappropriate placements, and the growing number of people in inpatient settings suggests that in many areas, what local plans were drawn up did not meet the scale of the challenge. We have heard that common causes include:

- Lack of local leadership, and weak accountability. Where local commissioners have been successful in expanding community-based provision and reducing the need for inpatient beds, active senior leadership backing has often been cited as key to their success. But where that leadership has been lacking, the national organisations do not appear to have been able to hold local commissioners to account, and nor do people with learning disabilities and/or autism or their families.
- Systemic barriers. Local commissioners have pointed to a number of systemic barriers to success, such as inconsistent application of rules around Continuing Health Care (CHC) funding, Ordinary Residence rules, NHS Responsible Commissioner rules and difficulties engaging with specialist, secure (forensic) commissioners.
- Insufficient support, assurance and challenge. Commissioning services for people with such complex needs is a highly-skilled job, but we heard that commissioning capacity has reduced in many areas, and that in some areas that lack of capacity is a significant obstacle to progress. The Concordat has resulted in a wide range of useful support for commissioners, from the Joint Improvement Partnership (JIP) and others. But there needs to be more ‘on-the-job’ support for, and challenge or assurance of, the drawing up of local commissioning plans to ensure that they are sufficiently robust. Critically, there must be a strong role for people with learning disabilities and/or autism and their families in providing that support and challenge.

- 5.3. To overcome these barriers, we believe national organisations such as NHS England, departments across Government, other Arms-Length Bodies and the LGA need to play a more robust leadership role – unblocking barriers and devolving funding, setting out a mandatory framework for local commissioners to follow, and providing more support and assurance to local commissioners as they do so.
- 5.4. NHS England should devolve the budget and responsibility for commissioning services for this group as much as possible from NHS specialised commissioning to Clinical Commissioning Groups (CCGs), so that local commissioners are more clearly incentivised

34 LGA & NHS England, *Winterbourne View Joint Improvement Programme: Stocktake of progress report* (2013)

to ensure there is adequate community-based provision, and admitting an individual to a secure bed is never the ‘easy option’ for local commissioners. NHS England and its partners at a national level should also remove the systemic barriers that make it harder for local commissioners to invest more in community-based provision and to disinvest in inpatient beds, such as the difficulties local commissioners report having as a result of Ordinary Residence rules, Responsible Commissioner rules and eligibility for Continuing Health Care funding.

- 5.5. Through a mandatory framework, NHS England should require local NHS commissioners to pool their spending with commissioners of social care and housing services for adults with learning disabilities who present behaviour that challenges, and mandate them to produce a single, outcomes-focused plan for using that spending, covering a period of a number of years. Clearly, the successful engagement of local government is critical here. Whilst NHS England cannot mandate local authorities to commission in a particular way, it should seek to work with others (the LGA, ADASS, DCLG, DH) to ensure that the commissioning framework is fit for purpose from a local government perspective, and that the local authorities are fully engaged as equal partners in the drawing up of joint local plans. The NHS should also make the pooling of budgets dependent on that engagement.
- 5.6. Local plans should be required to follow a basic mandatory framework, answering questions such as:
- What the **measurable objectives** the plan aims to achieve (e.g. what improvements in health, wellbeing and independence we want to see, what reduction in need for inpatient provision we want to see, or what reduction in use of ‘out-of-area’ inpatient placements, over what timeframe)
 - **How those goals will be achieved** (taking into consideration what we know to be key to success, as set out in existing literature such as the Mansell reports³⁵ and *Ensuring Quality Services*,³⁶ and including how the rights of people with learning disabilities and/or autism and their families will be made real, as above, and how the local workforce will be developed, as below).
 - How the plan ensures local services take a **whole life-course approach**. Appropriate services need to be available for children, young people and adults, with efforts to prevent the need for inpatient services starting in early childhood, and an effective approach in place to managing transition from children’s services or residential education to community-based adult services. We heard throughout our work that more effective support for children and better transition between children’s and adults’ services will be critical earlier intervention in childhood and improving the transitions between will be critical.

- **Who is responsible** for success, including at senior leadership level, and with a single lead commissioner clearly identified
 - What **analysis of current and future need** has been undertaken
 - **How these plans have been co-produced** with people with learning disabilities and/or autism and their families, providers and clinicians. Local providers should be brought together in a forum to collaborate with one another and with commissioners to ensure comprehensive local services are available.
- 5.7. The commissioning framework should also describe the kind of approach to commissioning we need to see. For instance, we believe commissioners need to:
- Take a more proactive, long-term approach – planning what kind of services will need to be in place for people from childhood onwards, rather than reacting to crises as they emerge
 - Take a more collaborative approach to engaging with providers. Commissioners need to stimulate the market, encouraging the entry and development of smaller, more innovative providers. They also need to engage with providers more proactively in planning services for individuals and for the population as a whole, giving providers greater opportunities to put forward alternative options. The commissioning framework should make clear that this is both entirely permissible under procurement law and to be actively encouraged.
 - Take a more outcomes-based approach, so that payment is increasingly linked to outcomes for people, rather than hours of support provided
- 5.8. Alongside the commissioning framework set out above, there needs to be more support and assurance from NHS England, the Department of Health and the LGA, who should build on the work of the Winterbourne View Joint Improvement Partnership and provide more intensive, ‘on-the-job’, action-focused support to local commissioners, helping them to draw up and implement commissioning plans as above, and to extend the uptake of personal budgets. To ensure that local plans are realistic and robust, NHS England and the LGA should also scrutinise and assure them. This process should also involve scrutiny by panels (at local and national level) of people with learning disabilities and/or autism and their families. Local commissioners that submit plans which are insufficiently ambitious or robust should be given extra support to improve them.
- 5.9. In pursuing this agenda, NHS England and its national partners should learn from the strengths and weaknesses of the Better Care Fund,³⁷ which also mandated the pooling of budgets, and

³⁷ The Better Care Fund is a £3.8 billion budget, pooling health and social care funding, to support transformation and integration of health and social care services. More detail can be found at www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/

the drawing up of local joint plans with support and assurance from the centre.

- 5.10. Alongside the model above, the commissioning framework should include measures to facilitate swift, safe discharge from inpatient settings back into the community, such as a standard contract that includes financial incentives for inpatient providers to focus on discharge planning. Currently, the way in which many inpatient providers are contracted gives them no financial incentive to focus on discharge planning from day one (and indeed they may be financially incentivised to keep as many beds full for as long as possible). That should change, so that contracts incentivise the kind of behaviour we want from inpatient providers – including planning for the earliest possible, safe discharge from the point of admission.

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

- 6.1. We heard that a barrier to discharge is often that responsible clinicians in inpatient settings will be concerned that appropriate support is not available in the community, and struggle to see how an appropriate community-based support package (potentially including continued assessment, treatment and safeguarding) could realistically be put into place. That can then lead to decisions that it is too early to discharge, or start planning for discharge. To tackle this, community-based providers considered by local commissioners to be of sufficient quality and reliability, and given permission by individuals or their families, should be given the ability to understand the detailed needs and wishes of people in inpatient settings (through access to information, clinicians or the individual and their family), upon which basis they can put forward a potential package of community-based support for consideration by the individual, their family, the commissioner and the responsible clinician. This should be an opportunity for people who can put together innovative solutions – providers, voluntary organisations, support brokers, advocates – to take the initiative.

Closures

7. The commissioning framework should be accompanied by a by a closure programme of inappropriate institutional inpatient facilities, driven by tougher registration requirements, local closure plans, and leadership by NHS England

- 7.1. We are clear that there must be closures of inpatient institutions:
- The presumption, in the twenty-first century, ought to be that people with learning disabilities and/or autism live in the community, not in hospitals
 - People with learning disabilities and/or autism and their families have been very clear that this is what they want. Some, such as the self-advocacy groups who submitted their views to us via CHANGE, argued that all hospitals for people with learning disabilities and/or autism should be shut. Others believe some

hospitals should remain open, providing a high-quality, locally-integrated service more clearly focused on assessment, treatment and discharge – but they want the number reduced. Some suggested that it is learning disability-specific mental health facilities which should be closed, with universal mental health services making the necessary adjustments to be inclusive of people with learning disabilities alongside others. Whatever the precise way forward, the consensus in favour of significant closures is clear.

- This is also an assumption already signed up to by stakeholders across the system via the Concordat that followed Winterbourne view. The Concordat was clear that currently too many people with learning disabilities and/or autism are admitted to inpatient settings when admission could have been avoided, too many stay too long, and so too many are in inpatient settings at any one time. The corollary is that we have too many inpatient beds, some of which should be closed.

7.2. So we are crystal clear that there must be closures. But we are also clear those closures must be implemented in the right way:

- A guiding principle should be ‘above all, do no harm’ – closures must be accompanied by more and better community-based support in place, and must be driven by what is best for people with learning disabilities and/or autism and that alone.
- We must not close down one set of institutions only for another to appear. People with learning disabilities and/or autism and their families were clear that small residential care homes and group homes can be ‘institutions’ in that they can be places where people don’t choose who to live with or how to spend their time and don’t feel like home. We have also heard fears that some inpatient hospitals could simply ‘rebadge’ as residential care or nursing homes. We need to ensure that the community services we replace hospitals with are genuinely what people with learning disabilities and/or autism want, and the CQC needs to be vigilant against allowing hospitals simply to go on providing the same institutional care under a different label.
- To say we should close inpatient wards is not the same as saying we do not need all the people who work in them, with the expertise that they have. Whilst care in inpatient settings is of variable quality, in places people are providing assessment, treatment and support to the highest standard. Some of that assessment, treatment and support can and should be provided in the community, in people’s own homes. The packages of support people need to live in the community are likely to require input from professionals such as support staff, psychologists, occupational therapists, psychiatrists, nurses, some of whom are likely now to be employed in inpatient providers. The shift in care we are seeking is more likely to require professionals to work in different ways and different settings than to stop being involved altogether. The professionals working in inpatient

settings need to be part of the solution, and part of the remit of the national Academy we propose below must be to help make that happen as part of a managed transition.

- 7.3. Given the consensus that we currently have more inpatient provision than we should need, we propose that the CQC should act as a market entry regulator and work with local commissioners to determine any future registrations of planned local assessment and treatment or inpatient units. It should announce that after a transitional period, it will significantly raise the quality threshold that inpatient settings will need to meet, including measures such as size of institution and average length of stay taken into account in regulatory judgments (recognising that appropriate length of stay will vary according to need). Any inpatient settings that fail to meet the bar should be considered in breach of the relevant fundamental standards. The approach needs to be ambitious, overt and public, such that it sends a clear message to providers about what the future holds.
- 7.4. Earlier in this report we proposed a mandatory commissioning framework for commissioners of health and social care services, with local commissioners required to draw up a plan for reducing reliance on inpatient beds, and that plan then scrutinised and assured by national system leaders with the involvement of people with learning disabilities and/or autism and their families. Part of that planning process should include a forecast for the number of inpatient beds each area believes it should have, based on a population needs assessment. This should be developed in partnership with others people with learning disabilities and/or autism and their families. A plan to actively decommission any beds surplus to that requirement, together with the transfer of skilled staff into community services where appropriate, can then follow. These local closure programmes should be implemented in close collaboration with people with learning disabilities and/or autism, their families and providers.
- 7.5. Finally, NHS England, as a direct commissioner of many inpatient services, should also decommission inpatient services that it currently pays for that are surplus to need. It should seek to start doing this at the earliest opportunity, sending a clear signal to the provider market about the direction of travel.
- 7.6. NHS England should set out a clear timeline for a closure programme of institutions which do not accord with the model of care that the Government committed to following the Winterbourne View scandal³⁸. We have heard differing views on what that timeline should look like. The Housing and Support Allowance suggested to us that the number of people with learning disabilities and/or autism in inpatient settings could be reduced to 1,500 and admissions reduced 75% by 2018. Groups of people with learning disabilities brought together by CHANGE called for an end to admissions

in three years, and all institutions specifically for people with learning disabilities to be closed after that – though some people with learning disabilities also said that they wanted better-quality, smaller and more local inpatient services to remain. Some local areas will be able to achieve change quicker than others. The picture is mixed. NHS England should come to a considered, realistic view on what is possible – but then it should set out a clear timetable not just for reductions in admissions or inpatient numbers (as has been tried unsuccessfully to date), but for closures of institutions.

Building capacity in the community

8. Health Education England, 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 Hastings and colleagues

- 8.1. We will only successfully prevent people with learning disabilities and/or autism and challenging behaviour needing to be admitted to inpatient settings, and discharge those currently in hospitals, if we can achieve a major expansion, and major improvement in quality, of community-based support services (including robust preventative and pro-active care that starts before problems manifest, care coordination and brokerage, advocacy, appropriate housing, care and support, multi-disciplinary community learning disability teams, crisis support and respite services). Without that expansion and improvement in quality, people will continue to have crises and be admitted to inpatient institutions, and many people with learning disabilities and/or autism, their families, clinicians and commissioners, will continue to be nervous about discharge from hospital back into the community.
- 8.2. We heard a consistently strong message that building the skills of the workforce (from care assistants to doctors and nurses to commissioners) should be a major priority here. Critically, this support should be available to family carers too, who should be recognised as fundamental partners in care.
- 8.3. As a result of the programme of work set in train following the Winterbourne View scandal, we now have a significantly enhanced and growing corpus of best practice guidance on working with people who display challenging behaviour (the Concordat has led, for instance, to a wide range of new or updated guidance for commissioners, social workers, clinicians, healthcare support workers, universal services on reasonable adjustments and more). There are also academics, trainers, providers and commissioners across the country with real expertise in supporting people with challenging behaviour in the community. There is a range of guidance on how local commissioners and providers can embed this good practice through workforce development.
- 8.4. What is needed now is a concerted programme of action to spread that expertise and codified good practice across the workforce, significantly expanding on the provision already available.

The proposal put together by Professor Richard Hastings and Professor David Allen for an ‘Academy’ to deliver that³⁹ is persuasive, particularly in its articulation of the need for a programme of action that:

- has two clear goals: firstly, supporting the system transformation that we hope to see in the immediate future in localities across the country as we build capacity in community services and reduce reliance on inpatient provision, and secondly, supporting the continued long-term development of the workforce in services for people with learning disabilities and/or autism who display challenging behaviour.
 - achieves those goals through:
 - a programme of training and development available to stakeholders across the system (local leaders of commissioning agencies and provider organisations, provider staff, clinicians, families and carers, individuals with learning disabilities themselves). This needs to focus both on providers of long-term care and support, but also on the community ‘infrastructure’ that providers, people with learning disabilities and/or autism and their families need to be able to rely on, particularly to manage crises – community learning disability teams, psychologists and psychiatrists able to assess people where they are living and develop appropriate support plans, and so on.
 - quality kite-marking or accreditation (of training providers and of support providers, whose variable quality we heard is a major issue for commissioners and people with learning disabilities and/or autism and their families) and
 - supporting the continued development of a bank of evidence, best practice, minimum standards, toolkits and guidance.
 - brings together and helps coordinate (rather than seeking to replace or replicate) the large number of organisations and individual experts already working to build the skills of the workforce in this area – including many people with learning disabilities and/or autism themselves and their families.
- 8.5. We believe any such programme of action should include a clear role for people with learning disabilities and/or autism and their families, who should be employed to help deliver it.
- 8.6. We are also clear that any programme along these lines needs to be action-focused – at least in the immediate future, as much a national taskforce or action programme as an ‘academy’, closely aligned to the mandatory change programme that we set out above. But whatever the name, we have heard a clear consensus (from people with learning disabilities and/or autism and their families, providers, commissioners, clinicians, academic experts) that there

is a pressing need for urgent and significant investment in workforce development in this field. We therefore recommend that Health Education England, Skills for Care, and Skills for Health build on the momentum generated by Professor Hastings' and Professor Allen's proposal, working with them and stakeholders across the system (including in the self-advocacy movement and the voluntary sector), to fully scope out the gaps in training and development of staff caring for those with a learning disability and/or autism who display challenging behaviour, and then develop a national academy along these lines to expand and develop existing good practice and to fill the identified gaps.

9. 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.

- 9.1. The conundrum we currently face is that people with learning disabilities and/or autism, their families, clinicians and commissioners are nervous of keeping people out of inpatient settings, or discharging them more quickly, in the absence of stronger community-based services. Providers of community-based services, on the other hand, are nervous of investing in expanding their offer in the absence of greater certainty that those services will be called on by commissioners and clinicians.
- 9.2. The risk we are asking providers of community-based services to take here is significant: for any one person with learning disabilities who displays behaviour that challenges, a support provider may need to recruit and train a number of support workers. In some cases, where suitable accommodation might not be available, a housing provider might need to make adaptations to existing stock or even invest in new buildings. The local community learning disability team might need to invest in recruiting and training more staff (nurses, psychologists, psychiatrists, GPs, speech and language therapists, occupational therapists) to provide support as and when it is needed. This recruitment, training and occasionally investment in property would need to happen months in advance of a person moving in or starting to receive the support, and the provider(s) being paid for delivering it.
- 9.3. We can reduce the risk that we are asking providers to take by reforming commissioning and clinical practice, so that providers have greater confidence that if they invest in expanding community services, there will in fact be take-up. Our hope is that our other recommendations will do that. A mandatory framework should shift commissioning practice – particularly by requiring commissioners to engage with providers in drawing up local plans, to pool budgets and thereby make for more flexible revenue streams, and to set clear targets for shifting care out of inpatient settings and into the community. Strengthening the rights of people with learning disabilities and/or autism and their families should make it easier for people who want and can be cared for in the community rather than inpatient settings to avoid admission or speed up discharge.

Our proposed reforms to the commissioning of inpatient settings should do the same. But even with these changes to commissioning practice, we will still be asking providers to take a big risk by investing large sums of money in expanding community provision, without certainty that those services will be called on or adequately commissioned. And we are making this ask of a set of providers, often in the voluntary or public sectors, many of whom do not have significant capital of their own to invest, and who are unable, unused or unwilling to access capital from investors.

- 9.4. We therefore believe there is a strong case for making such investment capital more easily available, so that community-based services can be expanded more quickly.
- 9.5. We recommend that the Government should allocate £30 million from LIBOR fines or other sources to a ‘Life in the Community’ Social Investment Fund – in other words, an investment vehicle with a social mission to improve outcomes for people with learning disabilities and/or autism who display challenging behaviour in the community.
- 9.6. That investment fund should use its capital to leverage that of other investors, so that the pool of capital ultimately available would be multiples of whatever endowment it received from NHS England or the Department of Health. Research commissioned for this steering group and published alongside this report⁴⁰ suggests that public investment of the order of the above could leverage investment from others such that the size of the fund might ultimately reach some £200 million. Over time, funds received from the sale of any public sector inpatient units could also be channelled into this fund. Sitting alongside a mandatory commissioning framework, and a national academy aimed at developing the skills of the workforce across the system, it should catalyse an injection of investment into community-based services during the period of transformation we envisage over the next few years. It should do this by addressing three needs:
 - a) Above all, a need for working capital to enable a range of providers to scale up community-based services in advance of that support being commissioned and made use of – including services that can help make transitions happen, such as independent advocacy and brokerage.
 - b) In some local areas and for some individuals, a need for capital to secure suitable housing – a need which may grow if we are to see the kind of shift from inpatient provision to community-based support that we hope to achieve.
 - c) A need to build up investment-ready partnerships or consortia of local providers, from across the public, private and voluntary sectors. Building successful community services is likely to involve a significant degree of partnership working between a range of individual organisations in one local area, and it is also

likely to require smaller, more innovative providers to be able to engage with commissioners.

- 9.7. To address these two capital needs, the Government-backed fund we are proposing should start by exploring three potential inter-linked solutions, namely:
- a) A ‘payment for outcomes’ fund, whereby investment would be advanced to community-based services upfront, for example to fund working capital to increase staffing teams and also some specialist property adaptations, and the investors would be repaid their investment by commissioners when and only when a reduction in inpatient provision had been safely achieved because more people were being successfully supported in the community. The research commissioned for this report suggests that seed funding of £10 million from NHS England and/or the Government could result in a £30 million payment for outcomes fund.⁴¹ Clearly, any outcomes-based commissioning would need to be carefully designed to avoid perverse incentives, learning from other outcomes-based commissioning models across public services.
 - b) A linked social property fund, whereby a fund would acquire properties and refurbish them if necessary, before leasing those properties to housing providers. The research commissioned to support this report suggests that seed funding of £10 million from NHS England and/or the Government could result in a social property fund of up to £200 million.⁴² For such a fund to work, it will be essential to ensure that any future welfare reforms do not inadvertently make it uneconomic to build or adapt homes for people with learning disabilities and/or autism by capping housing benefit for this group at a level too low to justify investment in their housing. We are also clear that this fund must be to finance the building or acquisition of homes to suit individual needs – not to build homes that risk becoming a new set of smaller institutions. This will be achieved by ensuring that the fund is focused on its social impact mission from the start, as well as being a viable and scalable investment vehicle.
 - c) Additionally, a £10 million ‘market development fund’, building on similar initiatives by the Cabinet Office, which would support the building of local partnerships or consortia and support them to be ‘investment-ready’, as well as supporting smaller, more innovative providers to expand their services.
- 9.8. Excerpts from the Resonance report can be found in the appendices, setting out how the ‘payment for outcomes’ fund and linked social property fund could work in more detail.

⁴¹ Resonance, *Winterbourne View and Social Investment* (2014)

⁴² Resonance, *Winterbourne View and Social Investment* (2014)

Holding people to account

- 10. Action on the recommendations above should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level.** Data on key indicators (such as admissions rates, length of stay, delayed transfers, number of beds by commissioning authority) should be collected and published. Both local commissioners and all relevant national bodies should be held to account for implementing our recommendations above.
- 10.1. Local commissioners should be held to account by local people, including those with learning disabilities and/or autism and their families (for instance through learning disability partnership boards or similar). They should also be held to account by NHS England.
 - 10.2. National bodies should be held to account through existing governance structures that include people with learning disabilities and/or autism (such as the Transforming Care Assurance Board co-chaired by the Minister for Care and Support and Gavin Harding MBE).

APPENDIX 1

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
Dominic Slowie	NHS England
Dr Roger Banks	Independent Psychiatrist
Gavin Harding	Co-Chair, Department of Health Transforming Care Assurance Group
Hazel Watson	NHS England
Jan Tregelles	Mencap
Juliet Beal	NHS England
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	Inclusion East
Vivien Cooper	Challenging Behaviour Foundation

APPENDIX 2

‘WE HAVE THE RIGHT’ STATEMENT

In June 2014, CHANGE and Lumos organised an event to discuss closing institutions for people with learning disabilities. 100 people with learning disabilities attended, from 35 self-advocacy groups. CHANGE then consulted with this group in drawing up a document – ‘We Have the Right’ – submitted to the steering group responsible for this report. The text of the document is below, and available at www.changepeople.org/blog-and-news/we-have-the-right-have-your-say-on-institutions-now/

“People with learning disabilities have the same rights as everyone else. No one should be made to live where they don’t want to live, just because they need support.

Yet tens of thousands of people with learning disabilities in Britain do not have this right and they should.

Institutions should be closed and replaced with ways of supporting people with learning disabilities which allow us to live in ordinary homes, in our community, with the people we choose.

Institutions aren’t just big buildings. Some small buildings like residential care homes and group homes are really institutions, because they are places where people don’t get to choose who to live with and how to spend their time and they don’t feel like home. No kind of institution should be seen as acceptable.

Before someone moves into an institution, they and their independent advocates should have the right to challenge that decision and to keep on challenging it.

To challenge decisions, people with learning disabilities need to have more power. We could have more power if we are able to:

- Have high quality easy read information that is quality checked by employed people with learning disabilities
- Have Access to a personal budget (such as a Direct Payment) or a Personal Health Budget
- Have trained and properly independent advocates to support us to make decisions and a person who looks after our personal budget money (broker) to support us to spend our money differently
- Be employed and work in support of other people with learning disabilities as advocates, peer supporters, service planners commissioners and inspectors.

- Support self advocacy organisations to become sustainable, find ways to employ people with learning disabilities and develop peer-to-peer working.
- Have powerful representation from employed people with learning disabilities at every point where decisions are made about us.
- Make the people who have made decisions about us explain why they have made that decision at regular meetings which commissioners and directors have to attend.
- We want to be involved in the development of a clear transition plan supporting people with learning disabilities to move from institutions into community based living.
- That every Joint Strategic Needs Assessment and Local Health and Wellbeing strategy is made to show clearly how it considers the needs of people with learning disabilities, and steps they are taking to ensure people with learning disabilities have greater power.
- Councils and the NHS must be made to stop admitting anyone else with learning disabilities into residential care and nursing homes within the next 3 years.
- Councils and the NHS must be told that all residential care homes and nursing homes must close within 10 years, and people with learning disabilities supported to move into their own home, living with only the people they choose to live with.
- CHANGE and the self-advocacy groups want to come up with a definition of institution.”

APPENDIX 3

CHALLENGING BEHAVIOUR

NATIONAL STRATEGY

GROUP CHARTER

Members of the Challenging Behaviour National Strategy Group⁴³ believe that better support and services could be provided for children and adults who are perceived as challenging, and have developed a charter which sets out the rights of these individuals and the action that needs to be taken. The text of the Charter is reproduced below and is also available at www.challengingbehaviour.org.uk/strategy-group/charter.html

Rights and values

1. People will be supported to exercise their human rights (which are the same as everyone else's) to be healthy, full and valued members of their community with respect for their culture, ethnic origin, religion, age, gender, sexuality and disability.
2. All children who are at risk of presenting behavioural challenges have the right to have their needs identified at an early stage, leading to co-ordinated early intervention and support.
3. All families have the right to be supported to maintain the physical and emotional wellbeing of the family unit.
4. All individuals have the right to receive person centred support and services that are developed on the basis of a detailed understanding of their support needs including their communication needs. This will be individually-tailored, flexible, responsive to changes in individual circumstances and delivered in the most appropriate local situation.
5. People have the right to a healthy life, and be given the appropriate support to achieve this.
6. People have the same rights as everyone else to a family and social life, relationships, housing, education, employment and leisure.
7. People have the right to supports and services that create capable environments. These should be developed on the principles of positive behavioural support and other evidence based approaches. They should also draw from additional specialist input as needed and respond to all the needs of the individual.

8. People have the right not to be hurt or damaged or humiliated in any way by interventions. Support and services must strive to achieve this.
9. People have the right to receive support and care based on good and up to date evidence.

Action to be taken

1. Children's and adults' services will construct long term collaborative plans across education, social and health services and jointly develop and commission support and services to meet the needs of children and adults with learning disabilities, their families and carers.
2. Local Authorities and the NHS will develop and co-ordinate plans to:
 - Reduce the exposure of young children with learning disabilities to environmental conditions that may lead to behavioural challenges.
 - Promote the resilience of young children with learning disabilities who face such environmental conditions.
 - Provide early intervention, support and services that will meet the individual needs (including communication needs) of young children who are showing early signs of developing behavioural challenges.
3. Active listening to the needs of the family will lead to the provision of appropriate and timely support, information and training.
4. People will be supported to have a good quality of life by individuals with the right values, attitudes, training and experience.
5. The NHS and services will proactively plan to ensure that people receive the same range, quality and standard of healthcare as everyone else, making reasonable adjustments when required. People will have an individualised health action plan and be supported to have access to annual health checks to ensure all health needs are met.
6. People and their family carers will receive support and services that are timely, safe, of good quality, co-ordinated and seamless. They will be proactively involved in the planning, commissioning and monitoring of support and services including both specialist and general services.
7. A person-centred approach that enables and manages the taking of risk will be used to ensure that people have access to family and social life, relationships, housing, education, employment and leisure.
8. Local authorities and the NHS will know how many children and adults live in their area and how many they have placed out of area. On the basis of information from person-centred plans all agencies will plan and deliver local support and services.
9. Services will seek to reduce the use of physical intervention, seclusion, mechanical restraint and the inappropriate or harmful use of medication with the clear aim of eliminating them for each individual.
10. All services and agencies will strive to improve continually, using up to date evidence to provide the best support, care and treatment to deliver positive outcomes for individuals.

APPENDIX 4

SUMMARY OF

RECOMMENDED SOCIAL

INVESTMENT STRUCTURES

FROM *WINTERBOURNE*

VIEW AND SOCIAL

INVESTMENT (2014)

To provide input to the steering group chaired by Sir Stephen Bubb, Resonance were commissioned by Big Society Capital and the Social Investment Business to produce a report on the potential role for social investment in transforming care for people with learning disabilities and/or autism. Their report, *Winterbourne View and Social Investment*, is available at www.resonance.ltd.uk.

Winterbourne View and Social Investment recommends a hybrid approach which uses two linked investment structures in a complementary way:

- 1) A 'Payment for Outcomes' Fund to provide working capital funding to providers in order to scale up projects and staffing teams as well as specialist property adaptations, ultimately funded by longer term savings to health budgets, and financed by social investment.
- 2) A linked Social Property Fund to help providers respond to increased property needs if provision was significantly scaled, providing a more standardized leased housing option across the sector, promoting plurality of providers and localised housing/support choices for individuals, and acting as a focus and catalyst for action.

Winterbourne View and Social Investment argues that whilst the two structures could, in principle, be developed independently, and one could exist without the other, in practice there are strong reasons to develop the two in a coordinated and complementary way. The report argues that Government seed investment/support is needed to kick-start this, providing leadership, confidence to investors and sector stakeholders and an acceleration of timelines. The report further argues that whilst better commissioning alone might in itself reduce net inflows to in-patient facilities, without this investment impetus, constraints on providers will continue to imply thousands of individuals remaining in this situation for decades to come, and the likelihood of future "Winterbourne View" scenarios recurring.

'Payment for Outcomes' Fund

The purpose of this element of the structure would be to help providers to fund the transitional costs of supporting a resident into their new home (advocacy/brokerage and staff mobilisation) and any required adaptations

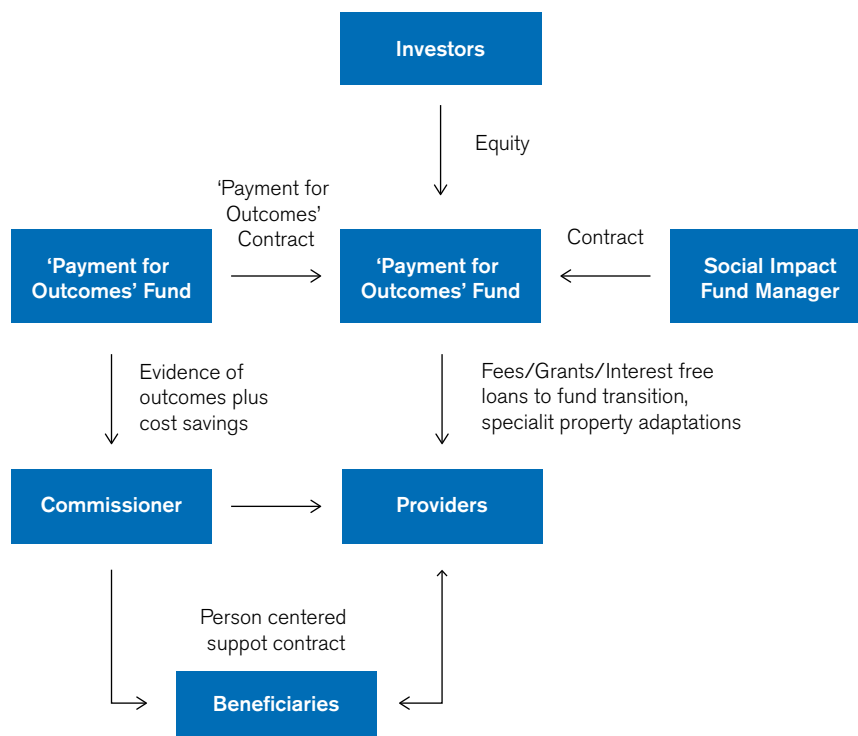
that are above and beyond a standard specification which can be economically provided by a housing provider (including a Social Property Fund) which may be necessary for some tenants but not others. Examples of this could be the conversion of a bedroom to a wetroom, all room air conditioning, or significant strengthening to the fabric of a building.

This funding vehicle (which could take on a number of different legal forms, but is referred to simply below as the Special Purpose Vehicle or “SPV”) would have a payment-for-outcomes contract with the NHS England (and other commissioners as they are willing) where payments would be triggered by clear delivery of sustained support and specific positive outcomes for individuals, which would be expected to be at a meaningfully reduced cost in the longer term compared with the inpatient facility.

For example, if the expectation was that, in time, a resident could be supported at a cost of £1500pw in the community, compared with £2500pw in the inpatient facility, then a one-off payment of, say, 50% of this expected saving would be paid to the SPV in the event of the provider achieving the positive ‘outcome’ for the resident of successfully making this move. In this scenario, assuming a sharing of 50% of the expected saving over a 12 month period, a payment of £26,000 would be paid – an amount which could cover the specialist property adaptations, transitional cost of the provider and a financial return to investors in the ‘Payment for Outcomes’ Fund. The report notes that at this stage all figures around expected savings are indicative and for illustration purposes only, but the authors point to anecdotal evidence of annual expected savings per individual of anywhere between £50–125k.

The generic structure of a ‘Payment for Outcomes’ Fund is set out below:

Figure 1: ‘Payment for Outcomes’ Fund



Winterbourne View and Social Investment argues that this structure:

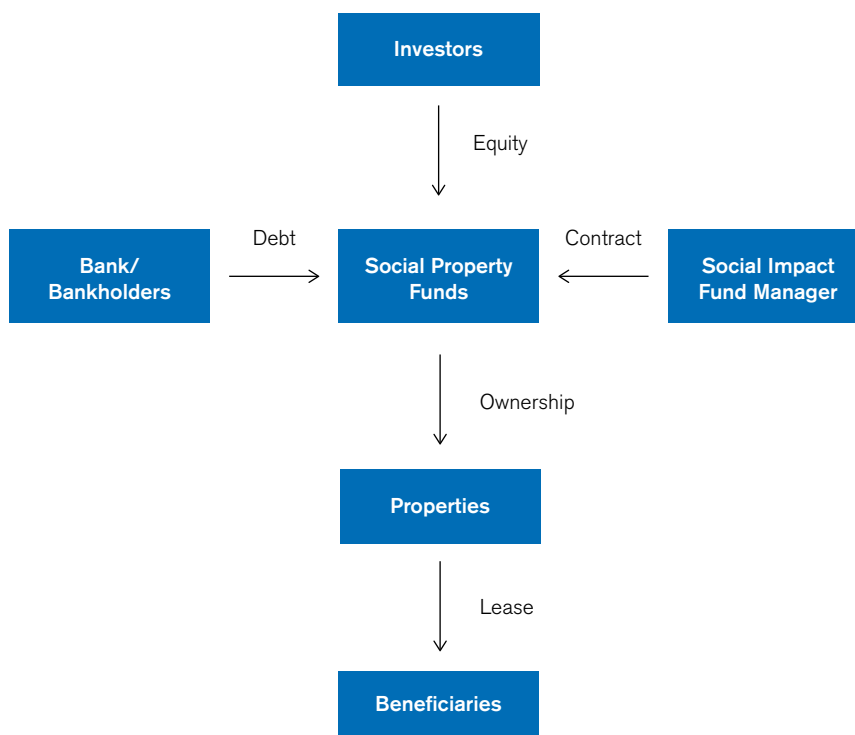
- Meets the needs of the sector to help individuals – based on their research, the authors believe that the immediate need is for providers to have the working capital and commissioning clarity to scale up provision from the relatively small numbers who are currently being transferred out of inpatient facilities. A ‘Payment for Outcomes’ Fund focuses on these two issues directly. It gives providers the data and contracting certainty to plan for scaling up activity, and the capital to do it, rather than simply attempting to respond to shorter term, ad hoc commissioner requests.
- Makes best use of Government support – the main intervention from Government would be to ensure that an attractive ‘Payment for Outcomes’ contract could be offered. This might involve in the short term some payments which were overlapping (eg if block contracts for inpatient beds could not be immediately unwound) but would ultimately be driving towards savings for Government in this area.
- Fits with reasonable investor requirements – the report argues there is an increasingly developed market of investors who are interested in investing in these structures. For example, there is now an impact investment fund which is dedicated to the purpose of investing into ‘Payments for Outcomes’ Funds (The Results Fund).
- Can be practically delivered – ‘Payments for Outcomes’ Funds are still a relatively new investment innovation and can take a considerable time to develop. However, as the costs funded by the ‘Payments for Outcomes’ Fund would be approximately 8–12% of the property acquisition costs, initially a Fund of just £5–10m would be required to complement the first phase of the linked Social Property Fund discussed further below. This could focus on an initial cohort, and coalition of willing commissioners and providers which could then be further expanded and replicated.

There are a number of more detailed issues which would need to be addressed in the next phase of development of such a structure, which are dealt with in the *Winterbourne View and Social Investment* report.

Social Property Fund

The purpose of this element of the structure would be to give further impetus to the supply of specialized housing, in a scenario where providers were significantly scaling up activity from current levels.

The fund would acquire properties, and cover all acquisition costs and any refurbishment to bring them up to an agreed specification as set out in a Framework Agreement, but not very specialist adaptations necessary for individual tenants, which would be separately covered by the ‘Payments for Outcomes’ Fund described above. The fund would lease the properties it acquired to an initially small but inclusive group of approved providers with the relationship managed through the Framework Agreement. The financial return to investors would be based on the fund being paid Local Housing Allowance rates (or variations thereon) for rental but would also include capital gain on the property (if any).



The report authors believe that this structure:

- Meets the needs of the sector to help individuals – the report authors found a general unwillingness or inability from many providers to take on significant levels of debt. Another recurring theme is that complete reliance on a pure private capital model for housing may drive provision models back to the scale and perverse incentives that have arguably helped create the “Winterbourne View problem”. It is therefore necessary to think towards a social investment structure which bridges this gap. A property fund makes a clear distinction between the providers of investment capital to fund property assets, the users of those assets, and the providers of support (even if the last two may be the same in many cases). It is also an inherently “open” structure which can provide a diverse range of housing and support providers with access to those assets on appropriate terms.
- Makes best use of Government support – a fund structure should not require government guarantees of the investment vehicle or additional subsidies. It would seek to offer investors a risk adjusted return on their investment as a market based solution to the capital need of this initiative. However, it could be seeded by initial investment from identified Government funding sources which would provide initial impetus and encourage private sector investment.
- Fits with reasonable investor requirements – a property fund is a transparent and recognizable structure for investors. It can take initial “seed” investment from a small number of initial founding investors (including Government) and use this to attract further investment, potentially up to large amounts (£100–300m) which would be very difficult for individual service providers to raise on their own balance sheets.

- Can be practically delivered – there are established models for property funds which can be delivered within reasonable budgets and timing, and which can move from initial smaller scale structures to larger scale structures in due course. By avoiding direct Government guarantees and subsidy, and by dealing with specialist property adaptations through the linked ‘Payment for Outcomes Fund’, it is also inherently scalable to address large scale capital needs for the sector.

There are a number of more detailed issues which would need to be addressed in the next phase of development of such a structure which are dealt with in the *Winterbourne View and Social Investment* report.

