Evaluation of Building the Right Support

Stakeholder feedback report

July 2018

Document Title	Evaluation of Building the Right Support: Stakeholder feedback report
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Executive Summary

This is the executive summary of a report produced as part of the evaluation of Building the Right Support (BRS). BRS aims to improve quality of life, care and outcomes for people with a learning disability, autism or both who display behaviour that challenges services. The evaluation is being undertaken by the Strategy Unit, ICF, BILD, and the University of Birmingham.

In commissioning the evaluation, NHS England (NHSE) required an evaluation focused primarily on what is / not working in relation to BRS, and why. As a result, the evaluation aims to produce findings and support the process of translating them into improved practice. More information about the study, which began in December 2016 and ends in July 2019, can be found here.

This summary contains findings from the second round of interviews with national and regional stakeholders, carried out from February-April 2018. 41 interviews were undertaken with stakeholders from: the Transforming Care programme (as the main means of delivering BRS) and its partners; the broader sector concerned with care and support for people with a learning disability, autism or both and their families, including self-advocacy groups; and organisations representing care and support providers. A third round of stakeholder interviews will take place in April 2019, following the (scheduled) end of the programme.

Key lines of enquiry covered:

- The main achievements in implementing the vision set out in BRS and the national programme to date;
- Challenges encountered and how any of these have been overcome;
- What needs to change now to better meet the aims of BRS;
- Views on the likely achievements of the programme by March 2019 and whether these achievements are likely to be sustained;
- Learning and key messages for the programme team and local Transforming Care Partnerships (TCPs); and
- Implications for people and their families, stakeholder organisations and policy makers.

Findings presented here are drawn solely from these interviews.

Looking back: retrospective reflections from stakeholders

1. The BRS strategy is widely seen as having provided a clear statement of intent alongside an ambitious target

Nearly all stakeholders agreed that the direction and service model set out in BRS was right, and that BRS had made a contribution to generating a more consistent sense of purpose and direction. The strategy was also seen as providing a clear focus on the needs of an often overlooked – and frequently vulnerable – population. Stakeholders' views therefore focused mainly on the practicalities and speed of implementation, rather than taking issue with the direction of policy.

2. Stakeholders cited evidence of improvement, although progress is uneven

Overall, while interviewees considered that some progress towards the vision set out in BRS was being made, this was thought to be very unevenly distributed across the country, and that the results of establishing new partnerships and investing in new services had yet to be fully realised. Drawing partners together to define key elements of the model was cited as a further success.

3. Some stakeholders thought that more ought to be done locally and nationally to improve community-based support

Stakeholders ‘outside’ the programme found it harder to point to clear achievements in improving care and support in the community. Some felt that the aims of the programme were not being translated into a significant improvement in community support. Several stakeholders (not only those outside the programme) felt that as the programme had developed, an overemphasis on bed closure meant that longer-term transformation had not been given the priority that was originally envisaged.

4. The complexity of delivery has become clearer over time – as have additional needs

Interviewees noted that partnership working around the country has been varied. Some TCPs have made real progress; others are just starting out or are yet to take a system-wide approach to identifying needs and settling on solutions. Most stakeholders also reported that the process of delivery has revealed further needs. Groups cited included the increasing number of autistic people without a learning disability but with mental health conditions, and vulnerable women.

5. Cuts to social care budgets and rising demand form a challenging backdrop for the programme

With BRS being implemented following significant cuts in adult social care budgets, many stakeholders reported that it has been more difficult for some TCPs to adopt new ways of working. A small number of stakeholders also argued that commissioners have been reluctant / unable to invest in ‘upstream’ preventive services – and that essential activities with less obvious or immediate impacts, such as co-production, had not been prioritised. Many also reported a rise in demand for services due to the identification of more people with unmet needs in the community.

On the question of finance, some stakeholders reported that the costs of providing personalised and high quality support in community settings was at least equal to – if not more than – the savings from closing inpatient beds, once the costs of training or developing community infrastructure (services, homes) are factored in. Some stakeholders felt strongly that there were additional costs to social care from meeting the needs of people who had never previously been considered to come under the remit of these services.

6. A lack of skilled commissioners was highlighted as a limiting factor at local level

Nearly all stakeholders reported that the lack of experienced, specialist commissioners has been the biggest gap in implementing BRS. Many stakeholders, not only specialist providers, thought that without a stronger, more strategic engagement of providers at local and national level, it will be very difficult to move from a ‘case by case’ approach to commissioning.

7. Co-production is an essential part of BRS; interviewees argued for more focus on it

Many interviewees thought that the programme would have benefited from a stronger emphasis on defining ‘good co-production’: they wished to see more people and families included in setting priorities for change, and they wanted to the programme share more learning in this area.

8. More broadly, many saw culture change as the most important issue facing BRS

Many stakeholders thought that the scale of the cultural change needed had been underestimated – and that much more still needed to be done to develop a system-wide approach to ending reliance on institutional care. Programme stakeholders said that they had taken these concerns on board and were addressing this, by becoming more open to views from social care, and taking a more hands-on approach to driving change where local TCP partners could not, or were unwilling to, come together to deliver BRS on their own.

Looking forward: prospective views from stakeholders

1. BRS is not yet ‘business as usual’. The main call is to keep maintain focus

The most significant message from stakeholders – especially those ‘outside’ the programme team – was the need to maintain a focus on the needs of people and families. Interviewees making this point therefore suggested a need for national support and investment, whether the programme itself continues in a similar form or not. Some also saw an immediate need for clarity about what happens once the programme ends, so that progress does not slip.

2. Stakeholders wanted to see a continued focus on integrated working between health and social care

Many stakeholders wanted local partnership arrangements, based on a wider footprint, to be maintained – whether as part of Sustainability and Transformation Partnerships (STPs), or as stand-alone partnerships. They emphasised that planning at scale is starting to happen, but needed to develop further before the ‘spot purchase’ model of services can be ended. Pressures in social care funding also mean that there are disincentives to bringing about the risk sharing that is necessary for integrated care. Therefore some stakeholders also strongly expressed support for doing more nationally to bring about pooled budgets (between health and social care) wherever possible.

3. Children and young people, and people with autism, require specific attention

Many stakeholders wanted to see a much greater emphasis on the needs of children and young people and their families – to ensure that more resource is dedicated to preventing the ‘next generation’ of people developing more complex mental health conditions. Some also wanted to see a greater effort on making sure mental health services were equipped to help people with a learning disability or autism, and more generally, develop a consistent service model for autistic adults with complex needs.

4. Stakeholders had many ideas for improving the programme

Specific suggestions included investments in infrastructure for co-production; developing provider networks and ensuring that providers are more engaged; making shared decision making about discharge the norm; and closer working with the criminal justice system. In particular, it was thought to be important to assess the outcomes of Care and Treatment Reviews (CTRs) to measure the difference they are making to people’s quality of care and their quality of life.

5. Interviewees wanted the programme to communicate progress and share learning

Some stakeholders wanted to see the programme become more transparent and communicative (whilst, in some cases, acknowledging that things were improving). There were differences as to how this could be achieved. One stakeholder thought that the programme ought to be much more data driven; while self-advocates those that thought the programme ought to be more open with people and families; while providers wanted to see an approach that listened more to the expertise they had to offer. A small number of stakeholders also wanted to see more realism in relation to targets, and greater sharing of both successes and failures in order that others could learn.

Conclusions and recommendations

1. The focus on the people covered by BRS needs to continue

The programme is seen as having made a number of positive changes around cross-sectoral partnership working, admissions avoidance, changes to culture and the workforce, and developing community-based services. Therefore the broad approach taken by BRS ought to continue, be given the time and resources necessary in order to have an impact, and clarity ought to be provided as to whether the programme continues in its current form.

2. National policy should show how BRS will be delivered by STPs

The role for national policy is to show how delivery of BRS can continue given new local partnership arrangements. Partnerships similar to TCPs ought to be encouraged, with a view to commissioning consistent care and support in line with the BRS model. National policy should support and drive change that facilitates strategic planning for all people with a learning disability, autism or both (e.g. pooled budgets, provider support networks).

3. Developing commissioning skills and standards is key

There are too few commissioners able to take the broader view necessary to deliver the ambitions set out in BRS. National efforts should therefore focus on enabling health commissioners to learn from each other and from counterparts in social care, building on the guidance that is already being produced by the programme.

4. There should be a national focus on provider development

Commissioning skills are scarce; so too is specialist provision. A national programme or strategy to develop high quality providers is likely to be necessary. At least, providers should have a seat at the table in national policy making so their expertise informs the policy direction – and their representative organisations could be partners in implementing the next programme.

5. Monitoring should evolve a greater focus on outcomes and community support

The monitoring of Transforming Care should ‘keep some teeth’ but shift its emphasis towards the development of community services in line with the service model. Again, as performance management arrangements for STPs are established, there will be a route (and a moment) to reset national monitoring of local delivery.

6. Better partnerships with the criminal justice system are needed

Both nationally and locally, working with the criminal justice system to develop better forensic support (and prevention) should be a priority. Local systems need to be able to respond to signals from providers, families and the criminal justice system and plan support and prevention activities over the longer term.

7. Co-production will remain important, regardless of any future programme

Co-production takes time and specialist skills; its value is not always well understood or articulated; yet the solutions can only come from the people most affected. NHSE and its partners should therefore further consider the best way to support organisations engaged in co-production. This should be done independently of any decisions about the design of any future programme, since the requirement will be ongoing.

1 Introduction

This report has been produced as part of the evaluation of Building the Right Support (BRS). BRS aims to improve quality of life, care and outcomes for people with a learning disability, autism or both who display behaviour that challenges services. The evaluation is being undertaken by the Strategy Unit, ICF, BILD, and the University of Birmingham.

The evaluation was commissioned by NHS England (NHSE). The specification for the study set out a requirement for an evaluation focused primarily on the implementation of BRS: to examine what is / not working and why. As a result, the evaluation aims to take findings and support the process of translating them into improving practice. More information about the study, which began in December 2016 and ends in July 2019, can be found here.

The evaluation began with a scoping phase. The aim here was to understand BRS' purpose and ambitions, structures for delivery, history and context. This could then be used to focus the evaluation. Results from this work are contained in the 'Early Findings and Evaluation Framework' report (July 2017). That report identified three **priority themes** for the evaluation:

1. Community based support, prevention and early intervention;
2. Quality of life, co-production and empowerment; and
3. Collaborative systems and partnership working.

As well as establishing a thematic focus, the scoping phase of the study also set out the main approaches to evidence gathering. In summary, these approaches included:

- Case studies of ten Transforming Care Partnerships (TCPs);
- An eSurvey of all TCPs;
- Engagement with national groups to support co-production of the evaluation; and
- Interviews with national and regional stakeholders to BRS.

Each of these is being repeated over time, allowing the evaluation to track change.

1.1 This report

This report contains findings from the second round of interviews with national and regional stakeholders, carried out from February-April 2018. The findings are drawn exclusively from an analysis of 41 interviews undertaken with stakeholders from the Transforming Care programme (as the main means of delivering BRS) and its partners, and across the broader sector concerned with care and support for people with a learning disability, autism or both and their families, including self-advocacy groups and organisations representing a wide range of providers. The findings are relevant to a range of readers working in the NHS, social care and the voluntary sector.

This report is one of several from the evaluation. It concentrates solely on findings from the interviews and does not provide a full and thoroughgoing set of findings. Readers wanting further information are therefore referred to the other evaluation reports produced to date:

- A report bringing together the findings from the ten case studies of local TCPs (July 2018);
- The ten individual TCP case study reports; and
- Findings from the survey of all TCPs (February 2018).

Later outputs from the evaluation will also bring together all the findings of these different reports. These will include accessible outputs.

1.1.1 Method used; report structure

As noted above, one of the key tasks for the evaluation has been to carry out annual rounds of stakeholder interviews. These interviews allow the study to chart progress, provide a deeper understanding of the programme context as it changes, and to examine how learning from developments at both the local and national levels have informed policy. In more detail:

- The first round of stakeholder interviews took place in early 2017, focusing almost exclusively on stakeholders within NHSE and the programme partners at national level. The aim of these interviews was to understand the policy and its intentions. Findings were reported in the 'Early Findings and Evaluation Framework' report (July 2017);
- A second round of stakeholder interviews took place from February – April 2018. **These findings are reported here**. Interviews took place with a broad range of stakeholders and organisations, at both national and regional level (see below); and
- A third round of stakeholder interviews will take place in April 2019, following the (scheduled) end of the programme.

Interviewees were purposively sampled to gather a broad range of perspectives. The 41 stakeholders interviewed in the second round of stakeholder interviews are contained in Annex 2; they included:

- 28 stakeholders at the national level and 13 at regional level;
- 15 stakeholders from NHSE, including senior leaders of the programme, regional staff, Specialised Commissioning and 7 of the newly appointed regional housing leads;
- 5 stakeholders from local government partners – the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS), including some of the LGA regional leads;
- 4 stakeholders from other national partner organisations – Skills for Care (SfC), Health Education England (HEE), the Care Quality Commission (CQC) and the Department of Health and Social Care;
- 5 provider organisations, including providers from the voluntary and independent sectors, umbrella organisations, and those providing care and support for both children and young people and those providing both community and Assessment and Treatment Unit (ATU) services;
- 6 stakeholders primarily representing people with a learning disability, autism or both – including representatives of self-advocacy groups as well as organisations that also provide support; and

- 6 other stakeholders – covering a broad variety of professionals including clinicians, academics, and individuals involved in leading specialist projects on behalf of various stakeholders involved in Transforming Care.

The topic guide used in the interviews is contained in Annex 1. In summary, key lines of enquiry covered:

- The main achievements in implementing the vision set out in BRS and the national programme to date (with a focus on the three priority themes of the evaluation, as well as cross-cutting issues such as finance, housing and workforce);
- Challenges encountered and how any of these have been overcome;
- What needs to change now to better meet the aims of BRS;
- Views on the likely achievements of the programme by March 2019 and whether these achievements are likely to be sustained;
- Learning and key messages for the programme team and TCPs; and
- Broader implications for people and their families, stakeholder organisations and policy makers.

To aid the understanding of key messages arising from the diverse range of interviewees and the broad nature of these topics, we have presented findings in the following three-part structure:

- Retrospective. Views on the main achievements of BRS and reflections on the key success factors, challenges faced and the response to these from the programme and its stakeholders, including lessons drawn from experiences to date;
- Prospective. Looking forward, changes suggested now to the programme and broader policy, as well as looking at what could be done to enhance sustainability; and
- Conclusions and recommendations following from the above.

In presenting the findings we make extensive use of quotes from the interviewees, allowing them to ‘speak for themselves’ as far as possible.

2 Retrospective reflections

This section looks back at the delivery of BRS to date: looking at how and whether the Transforming Care programme (as the main means of implementing BRS) has led to improvements in people's care and support, and quality of life. It includes stakeholders' reflections on successes, challenges and responses to them, and main lessons arising.

The BRS strategy is widely seen as having provided a clear statement of intent alongside an ambitious target

Nearly all stakeholders agreed that the direction and service model set out in BRS was right. They saw BRS as defining a holistic approach to meeting an ambitious target for reducing dependence on inpatient units and enabling people to live better lives in the community. Views therefore focused mainly on the practicalities – and speed – of implementation, rather than taking issue with the direction of policy.

> *"I think that Building the Right Support is a great document … within that, we are starting to see the numbers decreasing out of hospital discharges … that's great, but, it's still very slow, and it needs to happen faster than it's actually happening."*

Self-advocate

Among stakeholders involved within in the programme, BRS was further viewed as having generated a shared sense of values and purpose across health and social care (seen as lacking previously in the earlier Joint Improvement Programme established shortly after the Winterbourne View scandal). It was also seen as providing a clear focus on the needs of an often overlooked – and frequently vulnerable – population.

> *"They've certainly mobilised…people know generally know what Transforming Care is, they know the objectives, they know the values that sit behind it – even if we're not seeing them fully implemented yet."*

National partner

> *"As a housing professional, because I come from the outside, it's been amazing to see so many committed people that really want to help people who – if we're being honest about it – have been forgotten about for a lot of years."*

NHSE stakeholder (housing advisor)

There is evidence that improvement is taking place, and that there is a greater focus on people's needs, although progress is uneven around the country

Overall, interviewees considered that some progress towards the vision set out in BRS was being made – although this was very unevenly distributed across the country, and that the results of establishing new partnerships and investing in new services had yet to be fully realised.

For example, some stakeholders stated that while progress was being made on avoiding admissions, the figures for inpatient beds were not yet on track to meet the ambitious target that was set.

> *“We know that there’s about 500 people who have been in hospital for more than five years who’ve gone home…that’s happened because of this programme. We know that we have got a gradual reduction in inpatient numbers, less than we’d anticipated, but it’s still double what it was before we started and it’s going in the right direction. That that kind of focus just wasn’t there before.”*

NHSE stakeholder

Drawing partners together to define key elements of the model was cited as a further success by stakeholders within the programme. Many interviewees from outside the programme also thought that the key elements of the service model set out by BRS were both necessary and correct – such as Care and Treatment Reviews (CTRs).

> *“The Care and Treatment Review process has helped as well … because it’s actually asked the question ‘have you got a plan for the future?’ and experts by experience and clinical experts now have knowledge of personalised planning and understand it … [and] at least people are looking at plans that are being made and saying that’s not good enough.”*

Voluntary sector support organisation

Some stakeholders also thought that the decision to encourage planning across a larger footprint than Clinical Commissioning Groups (CCGs) – through the TCP structures – was worthwhile, and that fostering relationships between partners in TCPs was necessary, to begin building up expertise. Implementing consistent models across a wider footprint, in line with the BRS strategy, was seen as leading to improvement.

> *“It’s definitely highlighted … the needs of a population that are increasingly becoming difficult to meet, and where it does work, where those TCPs have come together, I can see that they are developing services that are shared which needs to happen to be sustainable.”*

NHSE stakeholder (housing advisor)

> *“[Services] need to be commissioned on a more local level than the national one – but probably not a CCG [Clinical Commissioning Group] footprint because you’re not going to have the numbers, so that was a good decision. There probably wasn’t an acknowledgement of just how much knowledge and expertise would need to built up in those areas to deliver that.”*

Voluntary sector stakeholder

Some stakeholders further noted that the programme had attempted to establish novel solutions, such as the funding transfer agreements. They also stated that many of the most basic failings of the system at the start of the programme had now been addressed (for example, people that had been ‘forgotten about’ by commissioners):

> *“These are real people with real families and real lives. They were our citizens and we didn’t even know who they were sometimes.”*

Local government stakeholder

Some stakeholders thought that more ought to be done locally and nationally to improve community support and ensure that long-term change happens

Stakeholders ‘outside’ the programme found it harder to point to clear achievements to date in improving care and support in the community. Some saw this as resulting from the programme not communicating well; others saw it as evidence that the aims of the programme were not being translated into a significant improvement in community support around the country.

> *“It’s hard to be very positive about the outcomes because I haven’t really seen them. It doesn’t feel like it’s done enough to touch the power and economic issues at the heart of the problem.”*

Provider

Several stakeholders (not only those outside the programme) felt that as the programme had developed, an overemphasis on bed closure meant that longer-term transformation had not been given the priority that was originally envisaged. Providers and self-advocates held especially negative views on this point.

> *“[The programme] feels terribly heavy and panicky, and I’m not seeing a reflection of [the aims of Transforming Care and BRS] in terms of structures being built in communities, support being given to groups of families, self-advocacy groups being skilled and supported … to be part of the transformation … bed closure doesn’t necessarily equate to really skilled, supportive transformational work.”*

Self-advocate

Over time the challenge of delivery and the scale of the issues have become clearer. Stakeholders argued that there is a need to develop community support for autistic people, vulnerable women and children and young people in particular.

The scale of the challenge to implement BRS has become more apparent over time. Overall, most stakeholders viewed implementation as highly varied: with some TCP areas continuing to make progress, while others are just starting out or are yet to take a footprint-wide approach to identifying needs and settling on solutions.

> *“From our perspective, Local Authorities and CCGs are genuinely working together in those areas [where] they’re commissioning over the whole TCP area. That feels more strategic in the sense of relationships and planning. In those areas … [TCPs] come across as wanting to engage, and they’re wanting to listen to providers … So it’s felt very much more like, higher levels of engagement, higher levels of active listening, it hasn’t felt tokenistic … but in other areas, the TCP is irrelevant and Local Authorities and the CCGs just carry on as they used to with very little joined up thinking.”*

Provider

Most stakeholders also reported learning about (or much greater visibility of) major gaps in services across health and social care for key groups of people. Groups cited included the increasing number of autistic people without a learning disability but with mental health conditions, and vulnerable women.

> *"[Transforming Care] has shone a light on some issues that weren't so apparent before – like people living with autism in the absence of a learning disability. The numbers of people with autism that need additional support has been an eye opener for me."*

Local government stakeholder

> *"Getting women's services is like finding a needle in a haystack ... The women are often very self-harming, a lot are cutting and ingesting things and tying things round their neck … This is a different group we've got. These are people who do things that often the community teams have not been exposed to on a day to day basis up to now. And it can be really difficult for them then to construct a care plan for somebody who they've not had any real experience of managing…[for example] who might have a history of cutting herself, who might have had a history of being sexually abused as a child, that's some complications to manage in an ordinary house on an ordinary street with primary care supporting you, that's tough … I believe it's doable, but it's only doable under a certain set of circumstances and that's when you've got a robust community team."*

Clinician

In particular, the need to focus on care and support for children and young people, and preventing problems from arising in later life was thought to be very important. Many stakeholders argued that this is where the greatest differences can be made. Some stakeholders thought that the importance of the children and young people had yet to fully appreciated by commissioners:

> *"When children are admitted to hospital there's a false belief that they're safe, when they're actually in an unsafe environment. For a lot of people admitted to hospital aged 18 or under there's no transition planning, no thought given to their family or home – they're dumped there … People in agencies often talk about people with learning disabilities having to learn independent skills, but the average age for people to leave home these days is 27. We're expecting our most vulnerable young people be independent at 17 to 18 which is nonsense"*

Voluntary sector stakeholder

Other stakeholders recognised that more ought to be done to bring the adults' and children's policy agendas together, although progress was cited:

> *"DfE had just led on the huge SEND* [Special educational needs and disability] *transformation programme but there are lots of the values in that are the same as the values in Transforming Care. If we can support areas to see how they can join up this work we could reach better outcomes …I'm not sure we have a joined up policy perspective yet, but we're on a trajectory where we might get to it."*

NHS stakeholder

Cuts to social care budgets and rising demand form a challenging backdrop for the programme

With BRS being implemented following significant cuts in adult social care budgets, many stakeholders reported that it has been difficult for some TCPs to adopt new ways of working. A small number of stakeholders also argued that commissioners have been reluctant / unable to invest in ‘upstream’ preventive services – and that essential activities with less obvious or immediate impacts, such as co-production, had not been prioritised.

> *“[The gap in social care spending is] absolutely true…. When we look at the level we spend versus what other places in Europe spend on people per capita just as an average, we’d need an extra £10 billion in the system just to come up to a par … In 2017 the ADASS budget survey came back and for the first time adults of working age with disabilities, and particularly learning disabilities, were seen as a greater pressure than older people.”*
>
> Local government stakeholder

Many stakeholders also reported a rise in demand for services due to the identification of more people with unmet needs in the community (also see above) as well as addressing the needs of people being discharged from hospital. Again, some linked this to a lack of prevention or capacity (e.g. learning disability nurses in mainstream health roles).

On the question of finance, some stakeholders reported that the costs of providing personalised and high quality support in community settings was at least equal to – if not more than – the savings from closing inpatient beds, once the costs of training or developing community infrastructure (services, homes) are factored in. Coupled with delays in releasing funds from closing inpatient beds and the need to run both ‘old’ and ‘new’ services at once, some stakeholders felt strongly that there were additional costs to social care from meeting the needs of people who had never previously been considered to come under the remit of these services.

> *“Numbers have increased. People were working on ‘in two years can you get this number of people out of hospital’, but actually there were numbers that people weren’t aware of. I think that’s one of the massive challenges.”*
>
> Local government stakeholder

A small number of interviewees argued that despite the investment made by NHSE and others, the overall resources put into the system were less than for previous ‘campus closure’ programmes, and yet the people remaining in hospital have more complex needs than those targeted by previous efforts.

> *“Building the Right Support, unlike the other two programmes, didn’t have to me a clear route to money. It’s talked about but we’ve not to date seen any money move across, the financial transfer arrangements are still not clear, and the other programmes – although they weren’t awash with cash – did have money to help.”*
>
> Clinician

> *“The programme resources are relatively small, they are not going to change the world, they are just to recruit a few people to help manage the process.”*
>
> NHSE stakeholder

A lack of skilled commissioners was highlighted as a significant limiting factor at local level

In the view of nearly all stakeholders, the lack of experienced, specialist commissioners with the skills to understand how to commission personalised care and support at scale has been the biggest gap in implementing BRS.

> *"For me the real thing that I have picked up is that the lack of knowledge and expertise amongst commissioners. Particularly health commissioners. That's the biggest issue I think for the whole programme, is that often commissioning for people with learning disabilities is given to the most junior member of the commissioning team."*

National partner

Many stakeholders, not only specialist providers, thought that without a stronger, more strategic engagement of providers at local and national level, it will be very difficult to move from a 'case by case' approach to commissioning. They stated that collaborative approaches that include providers need to be a clear expectation of TCPs: but that commissioners often do not have the understanding of how to take initiative, or make their case with cautious procurement departments.

> *"There's one fundamental issue. So, basically, the people we're talking about have very complex needs and typically need bespoke services designed for them. In order to do that, you need to do several things, you need to plan at least a year ahead … Now, to me that's pretty basic but a lot of commissioners and a lot of care managers really struggle because they can't get out of a spot placement mentality… it's [only] occasionally you come across a dynamic commissioner who's got a can do attitude … They're pretty rare frankly."*

Provider

> *"Health [CCGs] are a little bit less mature in their understanding of commissioning [than social care]. They still have quite a procurement-led approach and it hinders them, because they don't invest enough in asset-based commissioning, relationship-based commissioning."*

Academic partner organisation

There is also recognition that while co-production is an essential part of BRS, more emphasis on it is needed

Many interviewees thought that the programme would have benefited from a stronger emphasis on defining good co-production – and taking steps to ensure that TCPs and commissioners are supporting it. Some thought that stronger co-production would have meant that families would have been more included in setting priorities for change (perhaps, as a few stakeholders pointed out, leading to a greater emphasis on supporting families with children and young people at an earlier stage in the programme).

> *"Co-production is really hard to do well because you have got to surrender ego in the early stages. You have got to be willing to really take on board other people's perspectives, and that means sometimes you've got to go back and fight other people's corners with your managers. I don't think*

> *that happens unless you give people time, space and support and they are really determined to make it work."*

Academic partner organisation

Many stakeholders (providers, voluntary sector, self-advocates) thought that while the programme had the right intentions around co-production, there was a need for the programme to share more learning in this area. Some thought that the whole programme infrastructure needed to model and invest in a more co-produced approach to developing solutions, for example pointing to the approach developed under Valuing People:

> *"You had the partnership board, you had the national forum, they had regional forums, you've had the national families' forum and they were contributing too … Now that doesn't happen because the funding is cut."*

Self-advocate

More broadly, many stakeholders argued that the most important issue is that of culture

Many stakeholders thought that the scale of the cultural change needed had been underestimated – and that much more still needed to be done to develop a system-wide approach to ending reliance on institutional care as a way of dealing with people with complex needs. Some described this as developing a mindset that enabled strategic planning across multiple agencies – providers in particular.

> "*We had places like Dorset, Cornwall, Buckinghamshire with single figures in secure care. Hardly anyone. And then you had places like Kent and Medway, Sussex, Hampshire, where you had fifty or sixty people … what that represents is a different culture and there may be very different reasons why those cultures prevail … The kinds of things that will make a difference to this group of people are … access to specialist and forensic care, so people have got a strong understanding and good working relationships with the criminal justice system, so people can anticipate and plan for the behaviours that might lead to trouble …but there is very little discussion about that at the moment.*"

NHSE stakeholder

Programme stakeholders said that they had taken these concerns on board and were addressing this. They also stated that they had learned that the programme needed to be more open to views from social care – and take a more hands-on approach to driving change where local TCP partners could not, or were unwilling to, come together to deliver BRS on their own. In making these points, interviewees noted recent changes to employ housing advisors, setting up virtual support teams in the LGA, clarify the guidance on funding flows, and fund work into market shaping.

A small number of stakeholders also then made a case for a more nationally led and 'direct' approach to change. They suggested (for example) sending in specialist change teams, and ensuring that there were consequences for poor commissioning / ownership of the challenge across a TCP. Some stakeholders wanted to see the elements of the BRS service model set out as minimum standards, with monitoring focused on the 'developing community services' side of BRS.

> *“People are still finding pockets of good practice and promoting them, which is great. However, what about the areas where it’s not happening? There doesn’t seem to be any, as I say, there’s no minimum standard. There’s no: ‘in every area, you can, at least, expect this’. It’s a bit: ‘well, this is what we think you should do and if you do it, great. But if you don’t, there are no particular consequences’.”*
>
> Self-advocate

3 Prospective views

This section looks forward, presenting stakeholders' views on changes to the programme and broader policy environment, as well as considering what could be done to enhance sustainability.

BRS is not yet 'business as usual'. The main call is to keep the policy focus in this area

The most significant message from stakeholders – especially those 'outside' the programme team – was the need to maintain a focus on the needs of the people and families. This view seemed to be animated by a sense that progress made under BRS would 'slip back' without a continued push.

Interviewees making this point therefore suggested a need for national support and investment (especially to continue to develop community support, community teams and providers, build local relationships, and capital funding), whether the programme itself continues in a similar form or not.

Some stakeholders saw an immediate need for clarity about what happens next once the programme ends. They worried that without a clear policy steer, less developed TCPs would revert to, or keep outdated ways of working (e.g. staying reliant on 'locked rehab' units to manage people with complex needs, in place of decommissioned ATUs).

> *"I think we do have a good service model that we will repeatedly come back to; I think it has helped to mobilise the good providers to come together to get their voices heard a little bit more ... in some areas barriers have been broken down and they will continue to do great things, but ultimately if we don't tackle, as Jim Mansell would have put it, institutionalisation via the back door, as long as we've got these places, they will get full because they always do."*

Academic partner organisation

A significant minority of stakeholders wanted to see national efforts continue to evolve towards a model that is led equally by social care as much as by the NHS. Senior stakeholders within the programme team thought that this change was now taking place and that there was now a much better understanding of the role of social care in implementing BRS.

> *"I think there are plenty of extremely good, passionate social care providers out there who could actually deliver really good quality care and support to probably 80% of those people that are currently in those hospitals … they don't have a strong enough voice, it's getting better, their voice is getting better in the programme … there's a lot more social care voices being heard."*

National partner organisation

On a related point, many stakeholders wanted to see a shift in the emphasis of monitoring towards measuring the progress of community services and the implementation of the service model – signalling a change in emphasis towards developing community support and ensuring that commissioners 'do the right thing'.

> *"Beating people up over a target ... which misses the point, we want to transform care, closing a bed doesn't count as transforming care, it just means we're managing someone's needs in a different location."*

NHSE stakeholder

A small number of interviewees then extended this point into considering sanctions. They wanted to see TCPs that failed to commission support and care in line with the BRS model face consequences for not doing so. One interviewee suggested that new legal mechanisms, such as a 'right to challenge' where local services were not sufficiently personalised, might ultimately be necessary.

> *"There should be an expectation that if a commissioner continues to spend money doing the same things, they don't get it [the money] anymore. That's a failure."*

Provider

Stakeholders wanted to see a continued focus on integrated working between health and social care

Many stakeholders wanted local partnership arrangements, based on a wider footprint, to be maintained – whether absorbed into Sustainability and Transformation Partnerships (STPs) with Transforming Care as a dedicated sub group, or as stand-alone partnerships. They emphasised that planning at scale is starting to happen, but needed to develop further before the 'spot purchase' model of services can be ended.

> *"A lot of the people we're trying to help and serve are people that have got particularly tricky situations, particular needs around accommodation and doing that on an individual level isn't necessarily financially sustainable in the long term … [personalisation and doing things at scale are] not necessarily mutually exclusive, especially when there's a need for new build [housing] and sharing that resource across TCPs."*

NHSE stakeholder (housing advisor)

Some stakeholders also strongly expressed support for doing much more to bring about pooled budgets (between health and social care) or risk sharing wherever possible, noting that TCPs still had a wide variety of arrangements.

> *"Local Authorities in particular don't have a cat's chance in hell of meeting the needs of this population with their current funding arrangements. So whether that means pooled budgets, or risk shares or those kind of things with the local NHS, which does have more resource … the answer to help health and social care communities move forwards."*

NHSE stakeholder

Some stakeholders also noted that they had not seen much change in providing people with more control over their support at an individual / personal level. They cited little change in people affected by BRS holding their own personal budget as an example.

Lastly, senior stakeholders in the programme said that they were pursuing a more balanced approach to leadership of the policy as a whole – moving from being NHS-led to more of a balanced partnership with social care, modelling integrated working. For example, in future programmes the NHS might fund the LGA or

ADASS more so they could provide more hands-on expertise and provide more visible leadership locally.

The needs of children and young people, and people with autism, require specific attention

More broadly, many stakeholders wanted to see a much greater emphasis on the needs of children and young people and their families – to ensure that more resource is dedicated to preventing the 'next generation' of people developing more complex mental health conditions, and to ensure that inpatient care does not become the 'norm' for them.

> *"I would work, work, work at making sure young people with a learning disability or autism – especially where it overlays with mental illness or personality disorder – and make it easy for them to get help and overcome those issues … the amount of stories you hear from families where they're saying we were asking for help for ten years, and eventually some really terrible thing happened, and they got arrested, or they got admitted to hospital, or sectioned – and now they're getting help, and we're really grateful for the help, but we could have avoided this … that's basically the default setting for almost every person I deal with and their families."*

NHSE stakeholder

Some stakeholders also wanted to see a greater effort on making sure mental health services were properly equipped to help people with a learning disability or autism, and more generally, develop a consistent service model for autistic adults with complex needs. This was felt not to sit anywhere in current NHS commissioned services, with significant variability as to what is available in different areas of the country. While autistic people's needs are recognised by the programme, stakeholders raising this point considered that TCPs (and the wider NHS) needed more help in developing new forms of support.

> *"Autism is really firmly embedded in [the second version of the CTR guidance], the question in there, for every person coming to a CTR, 'do you consider that this person might be autistic as well' … So that was really positive, that the guidance has been updated in that way, and I hope that it's a legacy of the programme too … [But TCPs] they're crying out … 'we just don't know how to do it for autistic people'. So, it's, again, the model is right, implementation has not been quite there."*

Voluntary sector stakeholder

Stakeholders had many ideas for improving the programme in the short- to medium-term

Specific ideas proposed by individual stakeholders for addressing some of the challenges identified in the previous section of this report included:

- Investing in regional and national infrastructure for co-production, so that there was an expectation that local areas would support groups, self-advocates and families;

- Actions to develop a more asset-based approach to local commissioning, so that families and communities are seen as part of the solution when care and support is being commissioned;
- Developing provider networks and more mechanisms to provide implementation support – to build greater collaboration and (ultimately) resilience;
- Continuing with national work to support TCPs to do market shaping, engage with providers and develop more collaborative approaches to commissioning – supported by stronger controls on private hospitals opening speculatively (i.e. without a clearly defined local need);
- Ensuring that shared decision making about discharge is a firm (or even legally enforceable) expectation – so that clinicians do not have to bear the full professional responsibility for discharging people who are hospitalised 'in their own interest';
- Closer working with the criminal justice system to develop initiatives such as 'police passports' or diversion schemes. (A few stakeholders wanted to see prisoners serving long sentences taken out of the target population for BRS; a few others strongly disagreed as labelling such people as 'too hard to help' might lead to a disincentive to develop support to stop people from coming into contact with the criminal justice system in the first place); and
- Ensuring that strong arrangements are in place to quality control small, supported living units (which do not currently have to register individually under CQC rules).

CTRs were a specific focus for several interviewees. A particular point made by some stakeholders was that while 'blue light' meetings and CTRs were happening, their quality was variable. To address this, they suggested that work needed to be done nationally and locally to systematically assess the outcomes of CTRs – this would enable the whole sector to understand at what outcomes had been achieved, how admissions had been avoided, or discharges sustained.

> *"People have had reviews and plans saying we should be looking towards discharging this person and getting them out into the community, with the reviews in place for some time, but this hasn't translated into actual new support arrangements."*
>
> Provider

> *"I'm not seeing a huge improvement in imagination when it comes to the recommendations in CTRs. I think it's a fantastic model ... when there are good Care and Treatment Reviews they are geared to conversation and challenge, but I don't know about the outcomes."*
>
> Self-advocate

And, on a related point, a small number of stakeholders saw a need to make sure that individual ‘life planning’ is brought into all CTRs - so that the process takes people’s broader preferences and longer term aims into account.

> *“Those kind of person centred approaches [such as individual life planning] that focus on good plans, on anticipating difficulties and responding to that … and making sure that support arrangements address that, they work, and the level of complexity doesn’t matter, it’s the focus on the individual and the planning around that the delivers the outcome.”*
>
> NHSE stakeholder

The social care workforce is a concern for stakeholders

Concerns were shared about the future too, with many stakeholders mentioning the social care and support worker workforce. They thought that this workforce needed much greater attention in national policy. Issues raised here were broad, complex and without obvious solution. They including recruitment, pay, careers and the way that social care is valued by society and policy makers (relative to the NHS) at play as factors that framed stakeholders’ concerns.

> *“We’re expecting care and support workers to do everything from challenge GPs about, over-medication of the people that they’re supporting through to being able to respond appropriately when somebody is distressed and their behaviours may become violent, aggressive, challenging etc. But that’s not really sustainable at minimum wage and so I think there still is more work to do on the maturity of and the stratification of our work with the market.”*
>
> NHSE stakeholder

Aligning education policy aims with health and social care was seen as important for addressing the rise in unmet need

A small number of stakeholders expressed concerns that education policy is ‘running counter’ to the holistic, inclusion-based approach championed by BRS. Those making this point characterised education as becoming less inclusive of children with mental health conditions, or those whose behaviour is labelled as challenging.

> *“[Special schools] are full for the first time, and it is particularly where there are behaviours that challenge and where there are mental health problems. Those seem to be the areas that are leading to those children and young people being excluded or placements breaking down and they’re coming over to our sector in large numbers.”*
>
> Provider

> *"I would ask for a lot more attention to be placed to education, and how people are included … while they still have clear rights to an education, from very early childhood through to adulthood … educating families alongside children and professionals to try and understand more and feel more networked from very early on, because of the isolation. Families get into fight mode very early, because it's not joined up ... if I could do something magic tomorrow, I would invest a lot of money in … national, regional, local networks of families and self-advocates working together."*
>
> Self-advocate

While not visible to stakeholders at local level or outside the programme, interviewees from within the programme considered that partnerships with the Department for Education (DfE) are strong and that national partnerships are now in place.

The programme should be more open and transparent with learning

Lastly, some stakeholders wanted to see the programme become more transparent and communicative (whilst, in some cases, acknowledging that things were improving). There were differences as to how this could be achieved. One stakeholder thought that the programme ought to be much more data driven; while self-advocates those that thought the programme ought to be more open with people and families; while providers wanted to see an approach that listened more to the expertise they had to offer.

A small number of stakeholders also wanted to see more realism and greater sharing of what has been learned. They thought that this would go some way to showing people and families that their views were being heard.

> *"It does feel that some of the culture problems we've got in these TCPs go right up to the top…we still have a tendency for NHS England to be 'it's about beds, it's about discharge, it's about procurement' … they don't have a good approach to building relationships, sustainable change, role modelled at the top … For me the biggest barrier is that we've got to stop saying that the programme is going to end – these ridiculous statements that 900 people are going to be discharged from hospital this year just … disengages those that are trying to work really hard on this … the families know it's not possible."*
>
> Academic partner organisation

4 Conclusions and recommendations

The following section highlights the main conclusions and recommendations arising from the findings presented above. As well as providing additional support for some of the actions that are now being taken by the programme, recommendations also point towards longer term changes for policy makers to consider. They can also form a basis for developing further questions for the next phase of evaluation.

The focus on the people covered by BRS should continue

Many stakeholders are concerned that the gains made are fragile and that the issue may ‘fall off’ local agendas as the focus provided by the current programme comes to an end. The programme is seen as having made a number of positive changes around cross-sectoral partnership working, admissions avoidance, changes to culture and the workforce, and developing community based services. Yet BRS is not ‘business as usual’ and much remains to be done to fulfil its ambitions.

These actions need to continue and intensify in focus. They also need to be given the time and resource to help make sure that they have an impact. On this point, NHSE and partners need to provide clarity as to whether the programme continues in its current form.

National policy should show how BRS will be delivered by STPs

During the lifetime of the programme, the NHS – and its partners in social care and local government more broadly – has re-organised into new structures (STPs) for local planning and delivery. In several ways this will be helpful to the ‘BRS agenda’ in that:

- BRS had to create its own structures through TCPs. In many ways, these partnerships were proto-STPs in that the direction of travel for STPs is for greater cooperation and integration – between health and social care, between commissioners and providers – recognising the benefits of partnership in providing integrated care;
- STPs operate at level of geography and population such that commissioners can be more strategic (and specialist – see below);
- STPs have / are evolving infrastructure – alongside visible senior leadership – that can oversee local delivery; and
- One of the fundamental questions STPs face is what needs to be done at the STP level (rather than national or sub-STP). ‘Delivery of BRS’ would be a suitable response.

Yet in other ways this change of environment presents a risk to the structures and relationships established by TCPs. The role for national policy is therefore to show how delivery of BRS should proceed in (or at least alongside) these new arrangements. No matter how planning footprints may change, partnership structures should continue to be encouraged, with a view to commissioning consistent care and support in line with the BRS model. National policy should support and drive change that facilitates strategic planning for all people with a learning disability, autism or both (e.g. pooled budgets, provider support networks).

Developing commissioning skills and standards is key

Commissioning capability appears to be a limiting factor. There are too few commissioners able to take the broader view necessary to deliver the ambitions set out in BRS. National efforts should therefore focus on enabling health commissioners to learn from each other and from counterparts in social care. National guidance is already in development. This should be followed up with skills support (such as mentoring programmes, formal training / qualifications, etc) as well as directions to local partners to invest in people that can specialise in personalised approaches to commissioning. Again, the move to STPs ought to be helpful given the opportunity to commission over a larger population and therefore to specialise.

There is a national role for provider development

Commissioning skills are scarce; so too is specialist provision. A national programme or strategy to develop high quality providers may well be necessary given that local markets (and local efforts to make them) are limited in scale and scope. At least, providers should have a seat at the table in national policy making so their expertise informs the policy direction – and their representative organisations could be partners in implementing the next programme.

National monitoring should evolve a greater focus on outcomes and the development of the community support in the BRS model

The monitoring of Transforming Care should 'keep some teeth' but shift its emphasis towards the development of community services. Ensuring that the outcomes of CTRs (and Care and Education Treatment Reviews) are better understood will be important here, for instance by providing tools and resources for TCPs to undertake a systematic analysis of important outcomes, e.g. whether readmissions have happened, whether people had a choice of home and a stable support package, are closer to friends and family, have had access to a personal budget and a life plan, been re-enabled over time (with support reducing accordingly), etc. A suggested national approach would be to use the infrastructure of the Learning Disabilities Mortality Review (LeDeR) as a model, with local reviewers feeding information upwards for analysis. Again, as performance management arrangements for STPs are established, there will be a route (and a moment) to reset national monitoring of local delivery.

Better partnerships with the criminal justice system are needed

Both nationally and locally, working with the criminal justice system to develop better forensic support (and prevention) should be a priority. Local systems need to be able to respond to signals from providers, families and the criminal justice system and plan support and prevention activities over the longer term.

Co-production will remain important, regardless of the exact shape of any future programme

Co-production is not easy to define or deliver. It takes time and specialist skills; its value is not always well understood or articulated; and there will be constant tensions to balance in achieving constructive challenge – not least in an area of service with such a difficult history. Yet it is clear (in policy at least) that making people and families part of the solution is necessary, to ensure that solutions come from the people most affected.

NHSE and its partners should therefore consider the best way to support organisations engaged in co-production. This should be done independently of any decisions about the design of any future programme, since the requirement will be ongoing.

Annex 1 Summary of topic guide

1. Please describe your role and your involvement with the NHS / LGA / ADASS Learning Disability programme and the Building the Right Support strategy
2. What are the main achievements of the national Learning Disability programme to date – particularly in respect of the key elements of the *Building the Right Support* strategy?
3. What have been the key success factors for making these changes happen?
4. What challenges have been encountered by the programme to date?
5. What needs to change now in order to better meet the aims of the programme?
6. What do you think that the programme (including TCPs) will have achieved by 2019?
7. In your view, are these achievements likely to be sustained?
8. What have you (and your organisation) learned from the programme about how care and support can be transformed?
9. What national and local support (and programme infrastructure) might be needed after 2019 to ensure that improvements can continue to be made?
10. What policy changes would support further improvements after the programme ends?
11. Do you have any further comments / are there any topics you would like to raise that I haven't asked you about?

Annex 2 List of stakeholders interviewed

Name	Organisation	Title
Alex Fox	Shared Lives Plus	CEO
Andrew Kyle	NHSE	Regional Housing Lead
Catherine Nolan	LGA	LGA TC Regional Adviser (West Midlands)
Claire Dorer	NASS	CEO
Dan Scorer	Mencap	Head of Policy
Dave Nuttall	Department of Health & Social Care	Deputy Director, Dementia and Disabilities
Deb Moore	St Andrews Healthcare	Learning Disability Nurse
Denise Needleman, Jo Hogg and Sam Sly	I'm Out of Here Ltd	Directors
Di Domenico	NHSE	Personalisation Lead
Fred Grand	NHSE	Regional Housing Lead
Gary Bourlet	Learning Disability England	Co-founder
Gavin Thistlethwaite	NHSE (Specialised Commissioning)	Programme Lead, TC South region
Gill Leng	NHSE	Regional Housing Lead
Helen Laverty	Nottingham University	Learning disability nurse
Helen Toker Lester	ADASS	Transforming Care and Learning Disability Lead
Jane Bellwood	NHSE	Regional Housing Lead
Jean O'Hara	NHSE	National clinical director
Jill Crook	NHSE	TC Nurse lead, South region
Jim Thomas	Skills for Care	Programme Head, Workforce Innovation
John Hier	NHSE	Regional Housing Lead

Julie Higgins	NHSE	Programme Lead
Margaret Kitching	NHSE	TC Nurse lead, North region
Peter Kinsey	Care Management Group Ltd	CEO, formerly Care England
Philippa Hughes	NHSE	Regional Housing Lead
Ray James	NHSE	National Director
Ruth Northway	University of South Wales	Professor of Nursing
Sarah Broadhurst	Institute for Public Care, Oxford Brookes University	Market shaping expert
Scott Watkin	SeeAbility	Self-advocate
Steve Scown	Dimensions / VODG	CEO (and chair of VODG)
Sue Gale	LGA	Assistant Director - Transforming Care
Sue North	NHSE	NHSE CYP lead
Theresa Joyce	CQC	National Professinal Advisor, Learning Disability
Tim Devanney	HEE	Head of specialist programmes
Tim Nicolls	The National Autistic Society	Policy Manager
Troy Jones	LGA	LGA TC Regional Adviser (London)
Vicky Raphael	Inclusion East	Director
Victoria Whittaker Stokes	LGA	LGA TC Regional Adviser (East Midlands and Yorkshire & The Humber)
Viv Cooper	Challenging Behaviour Foundation	Chief executive
Wendy Hicks	NHSE	Regional Housing Lead