Evaluation of Building the Right Support

Phase 4 Summary report of learning from the evaluation

September 2019

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Contents

1 Introduction to this report

This short report summarises the learning from the evaluation of Building the Right Support (BRS). It outlines the key findings from all the evaluation research undertaken from December 2016 to March 2019, and concludes with ideas for national and local policy makers to consider, to build on the progress made to date.

The aim is to show how learning from the evaluation can inform both local and national responses to the NHS Long Term Plan (LTP) and Implementation Framework, as well as the recently published Learning Disability Improvement Standards for NHS Trusts.

The evaluation was undertaken by the Strategy Unit, ICF, BILD, and the University of Birmingham. It was commissioned by NHS England on behalf of their partnership with the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS). The data collection and analysis focused on the local implementation of the national programme to improve care and support in the community for people with a learning disability, autism or both; providing findings to support the process of translating learning into practice.

All the interim reports produced by the evaluation have been published are here and the final reports are here.

1.1 Purpose of the evaluation

Phases 1 and 2 of the evaluation (2016-17) focused on the implementation of the BRS plan, which aimed to improve quality of life, care and outcomes for people with a learning disability, autism or both who display behaviour that challenges services – and ensure that support and care is closer to home. BRS was part of the wider Transforming Care agenda. It was published in 2015 by NHS England, the LGA and ADASS.

In phases 3 and 4 of the evaluation (2018-19), the evaluation has shifted focus to respond to developments in policy. The evaluation gathered evidence about positive practice locally; and focused on gathering more data about the experiences of people and families at local level. Findings from the evaluation provided important insights to help shape future plans (see NHS England's response to the findings in the form of 'You Said, We Did') as well as the LTP itself. The final outputs from the evaluation include: a report on examples of promising local approaches; a report on the views of people that are less heard in policy making; as well as slide packs summarising key findings and local approaches.

The dissemination of evaluation findings can be used to support local areas to develop plans and strategies to deliver the commitments set out in the LTP; and will inform collaboration between people and families, the NHS, local authorities, and providers as part of Integrated Care Systems (ICSs).

We will also produce accessible outputs to share these findings.

1.2 Thematic framework

A thematic framework was developed to structure the evidence gathering and analysis, agreed with the evaluation steering group as capturing the core elements of BRS.

These key themes are:

- Developing community provision through partnership working;
- Developing the workforce in the community;
- Care and support for children and young people;
- Housing;
- Finance;
- Personalisation;
- Co-production with people and families; and
- Sustainability and the future development of work arising from BRS and Transforming Care (an overarching / cross-cutting theme embedded within the others).

1.3 Approaches to gathering evidence

The main approaches used by the evaluation to gather evidence were:

- Case studies of ten Transforming Care Partnerships (TCPs) who are responsible for leading the implementation of BRS locally – including interviews and focus groups with professionals, people and families. There were two rounds of evidence gathering with case study TCPs (in 2017 and 2018-19), to follow progress over time. For further details on positive practice examples from the case studies and the findings, see the Phase 2 case studies report and Phase 3 case studies report;
- An online survey of frontline professionals, people and families about their views of their TCPs. This was conducted in November 2017 and the findings can be found here;
- Engagement with national groups to support co-production of the evaluation throughout the duration of the evaluation, including the evaluation team's expert panel of advisors from representing stakeholder organisations (including those working with people and families). This also included a rapid review of evidence concerning the views of people; and
- Interviews with national and regional stakeholders to BRS. These took place in two rounds (in late 2016 and early 2018). The findings can be found here.

This report draws together findings from all the research undertaken, with a focus on the most recent findings.

2 Key findings from the evaluation

This section summaries the key findings from the evaluation under each of the themes. As well as the main findings, the relevant commitments in current policy are described with a summary of the promising local approaches that we found (see 1.3). More detail on the promising practice examples and local approaches can be found in the Phase 3 case studies report.

2.1 Developing community provision through partnership working

Key findings

Important progress has been made towards improving community provision. This has been in the context of a very challenging period for social care funding and increasing demand for care and support, especially to meet the needs of people with autism and co-existing mental health conditions whose needs were previously overlooked.

In order to continue developing and improving community provision, the need to strengthen commissioning of care and support has been widely recognised – including in the LTP Implementation Framework. The evaluation found that the most effective local commissioners had the skills and time to co-produce services; and were able work effectively across health, social care and housing to personalise care and support at the individual level.

Many TCPs such as Dorset and Greater Manchester found it necessary to improve their commissioning capabilities and would like to invest more in this (for example, so they can better monitor the quality and outcomes of Care and Treatment Reviews (CTRs)). Evidence from both the case studies and surveys shows consensus that there are significant gaps in local provider markets in relation to support for people with complex needs (including children and young people, and people with autism); those commissioners that have been able to think creatively and use frameworks in a way that can spur innovation have been more likely to meet some of those gaps in care and support.

Where supportive infrastructure was already in place – such as joint commissioning teams or an existing LDPB to hold commissioners to account, together with a habit of close working and strong relationships among commissioners – TCPs seem to have been better placed to navigate the wider challenges for BRS. These include aligning health and social care budgets, investing in prevention, building community capacity in the health and social care workforce and their local provider market, and co-producing change (e.g. with a local Learning Disability / Autism Partnership Board) – in addition to enabling people to move from inpatient care into their own homes in the community.

The 2017 evaluation survey showed that TCPs are thought to have added value by improving partnership working, leadership and setting local

priorities across a system. 66% of respondents agreed that their TCP was helping in improve the quality of care and support. It is expected that learning from working together as a TCP will inform future partnership arrangements within the new Integrated Care Systems (ICSs) at local level.

Relationship with the commitments of the LTP

The LTP emphasises the need for local systems to have a strong understanding of the needs of people with a learning disability or autism; and increasing investment in intensive support. Alongside investment in specialist services in the community, there will be investment in training all NHS staff so that all services make reasonable adjustments. The Improvement Standards also (re)emphasise the need for local areas to take a rights-based approach to care and support, including the need for investing in co-production so that people, families and carers are involved in the planning and evaluation of new services that are commissioned.

In terms of the national support offer, local systems will be supported to grow and incentivise their provider market and further support will also be provided to help local areas to use dynamic support registers effectively, as well as map their existing provision against the national model and best practice.

Commitments in the LTP (normal text) and Implementation Framework (*italic*)

- Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives.
- By 2023/24, a ‘digital flag’ in the patient record will ensure staff know a patient has a learning disability or autism.
- Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) will be expected to make sure all local healthcare providers are making reasonable adjustments to support people with a learning disability or autism.
- National learning disability improvement standards will be implemented and will apply to all services funded by the NHS … By 2023/24, all care commissioned by the NHS will need to meet the Learning Disability Improvement Standards.
- By March 2023/24, inpatient provision will have reduced to less than half of 2015 levels (on a like for like basis and taking into account population growth) and, for every one million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit.
- Increased investment in intensive, crisis and forensic community support will also enable more people to receive personalised care in the community, closer to home, and reduce preventable admissions to inpatient services [including] seven-day specialist multidisciplinary service and crisis care.
- All areas of the country will implement and be monitored against a ’12-point discharge plan’ to ensure discharges are timely and effective.
- *Systems must ensure that they understand their local unmet need, gaps in care, including local health inequalities …System investment should identify what*

community provision is in place for intensive, crisis and forensic community support.

Local approaches

Case study TCPs had made progress with developing and joining up their commissioning capabilities across health and social care. Examples included:

- Establishing or continuing with integrated commissioning teams (as in Hertfordshire), ensuring that health and social care spend is more joined up;
- Commissioning intensive support teams and crisis services (as in Surrey), including housing in the community, to help avoid admissions;
- Commissioning specialist support teams for offending / risky behaviour;
- Using risk registers for people needing care and support, together with regular multi-disciplinary team (MDT) meetings (involving specialist or community learning disability services, or both, as well as other local TCP partners) to review admissions and care and support provision; and
- Developing joint assessment processes and personalised care and support planning to give people, families, commissioners and care and support providers a more holistic, shared view of an individual's needs and wishes.

Some case study TCPs such as Dorset had also worked closely with providers, people and families to develop improved procurement frameworks for care and support for people with the most complex needs.

This was often coupled with co-producing the overall framework for commissioning care and support, and engaging local organisations representing people and families in monitoring the quality of the outcomes. In addition, some TCPs such as Surrey prompted providers to work together in supporting each other and working more collaboratively.

2.2 Developing the workforce in the community

Key findings

Developing the workforce has been a key challenge and has been the subject of increasing attention, as more case study TCPs gained a better picture of the needs of their whole population and began to establish services such as intensive support in the community. Progress has been made – particularly in the latter half of the national programme as more TCPs have been producing workforce plans for their local systems.

There is still an urgent need to continue to build both a specialist workforce in the community that can support people with complex needs and their families / carers to live the lives they wish to lead in the community; but also to build the skills, values, awareness and confidence that more general

services need (whether in community learning disability teams, general practice, mental health, pharmacy), in order to enable people to stay in the community and work in more person-centred ways. Planning for a workforce that can meet the varied needs of people with autism is also an important challenge.

Many case study TCPs encountered challenges in recruiting, retaining and training staff – from specialist health professionals to support workers. TCPs learned from the challenges they encountered – for example, at least one TCP (Dorset) commissioned a new service only for the lack of a viable workforce to make commissioners stop and rethink their plans. Pragmatic solutions were developed, including: using new frameworks to raise rates for support workers who provide care and support to people with complex needs; commissioning services across boundaries in order to make the most of the existing workforce; deploying specialist expertise to build bridges between different professional teams and support more generalist teams; and, training a wide variety of professionals to give more of them the capability to support CTRs).

Although many TCPs began by rolling out Positive Behaviour Support (PBS) training to support workers and other staff, it is now more widely recognised that this is not the only solution that is needed. Building new forms of care and support must go in tandem with addressing considerations about retaining support workers; providing effective supervision and support to them; developing viable career pathways that value support workers; ensuring that services take account of the availability of support workers in more remote locations; the ability of support workers to travel; and, enabling people and families to have meaningful choice about which people and organisations support them. Over time, we also saw increasing recognition of the role that family carers can play if they are considered an essential part of the workforce.

Some staff in case study TCPs expressed concerns that specialist teams developed through BRS were overstretched and had become unable to provide some of the wider capacity-building tasks they were originally intended to undertake. Reported reasons were both a shortage of specialist clinicians, but also concerns about the extent to which such services would be resourced sustainably in the longer term. Commissioner capability and continuity was also cited by NHS stakeholders locally, with many learning disability commissioners having multiple roles. Those involved reflected on the challenges of working to deliver a much more personalised approach to care than is typical for most other areas they worked in.

In addition (as evidenced in the national stakeholder interviews undertaken for the evaluation in 2018), challenges remain in relation to the whole social care workforce that must be addressed as part of wider reforms to social care. The concerns cited included recruitment, pay, careers and the way that social care is valued by society and policy makers (lower, relative to the NHS).

Relationship with the commitments of the LTP

Growing and developing the workforce is key to delivering the aims of the LTP around improving care and support and continuing to invest in specialist multidisciplinary services in the community. As the findings of the evaluation show, workforce considerations need to be addressed together with strengthening commissioning, growing the provider market, and developing better community provision.

There is a strong emphasis in the Improvement Standards on workforce as a key topic, including requirements for Trusts to know about the unique needs of people with learning disabilities, autism or both; recruiting the right staff in the right numbers; staff training on the needs of people with a learning disability and autism (including supporting people with challenging needs, human rights and mental capacity); developing workforce plans that mitigate the shortage of qualified practitioners; and appointing a designated Trust lead for learning disabilities, whose role will be to provide leadership and ensure that people are being supported and engaged.

Importantly, the national support offer for the LTP will also include support for partners and providers to implement the NHS Learning Disability Employment Pledge, so that more people with a learning disability and autism can be employed by their local NHS and thus enhancing the system roles of experts by experience.

Commitments in the LTP (normal text) and Implementation Framework (*italic*)

- NHS staff will receive information and training on supporting people with a learning disability and/or autism.
- *All STPs and ICSs will have a named senior responsible officer to oversee local implementation of Long Term Plan ambitions for individuals with learning disabilities, autism or both, and their families.*

Local approaches

Case study TCPs had made progress with developing the workforce across health and social care. Key examples included:

- Setting-up various models of PBS training programmes to upskill a wide range of professionals – and spreading that training throughout the provider workforce, as an investment in support workers and their organisations (as in Outer North East London);
- Training for family carers, self-advocates and self-advocacy groups;
- Employing specialists (e.g. with an understanding of working with people with autism) to work with Mental Health Teams, CAMHS and others to ensure that reasonable adjustments were made and bring about more equal access to health services;
- Setting-up professional or clinical senates, or broader thematic communities of practice, to bring different interests and specialisms together and solve problems, as seen in Greater Manchester; and

- Pursuing innovative schemes to improve recruitment and retention, such as apprenticeship schemes for nurses or support workers, or 'retire and return' schemes.

2.3 Care and support for children and young people

Key findings

At the outset of BRS, many TCPs chose to take an initial focus on the needs of adults with a learning disability, autism or both. This was reflected in the survey responses from TCPs in 2017, where several responses highlighted the lack of prominence given to children and young people in broader TCP agendas, and the need for greater alignment between the children's and adults' services.

Both local and national stakeholders thought that more needed to be done to bring adults' and children's services together locally, to ensure that there are early intervention and prevention services in place to prevent crises and so that families are supported earlier. The importance of access to support in childhood – and ensuring that schools and education also adhere to the key principles of inclusion / reasonable adjustments and personalisation emphasised in BRS for health and social care – were also mentioned. Concerns were expressed that more ought to be done to monitor out-of-area education, care and support and make sure it was of high quality and joined up to transition plans locally. This learning has spurred case study TCPs, in the latter half of the programme, to make improvements and implement a range of approaches to ensure that children and young people with a learning disability, autism, or both have equal access to mainstream services; and that investments and forward planning focus on transitions. There was also evidence of investment in crisis and intensive support services, building on promotion of the 'Ealing model'[1] and local investments in avoiding long-term admissions to inpatient care. NHS England has also invested in the Accelerator programme to drive forward improvement and share good practice (Greater Manchester, a case study TCP for the evaluation, has benefited from this support).

At the time of the phase 3 research, some case study TCPs were also starting to address the gaps in care and support for children with autism specifically (and identifying children who need support from health and social care). Others were exploring ways to integrate services or commissioning in order to make sure that local SEND offers join-up with the Transforming Care agenda and wider activities. Joining-up adults' and children's services and improving Care and Education Treatment Reviews (CETRs) have become increasingly important for case study TCPs.

Relationship with the commitments of the LTP

The LTP emphasises the importance of support for children and young people and meeting current gaps in care. There is a commitment to reduce

[1] See this information leaflet and the paper by Sholl, C et al (2014)

waiting times and the Implementation Framework requires local systems, as part of their system-wide plans, to develop local offers on SEND and autism for young people and their families. This is coupled with national investment in keyworkers to support children and young people who are in mental health inpatient units. Further investment will be made available to local systems to roll out this service more widely in the coming years.

Work will also take place as part of the national support offer to review CETR policies, while the Learning Disability Improvement Standards aim to ensure that Trusts comply with the national policies and requirements for conducting effective CETRs.

Commitments in the LTP (normal text) and Implementation Framework (*italic*)

- Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives.
- [The NHS will] work with the Department for Education and local authorities to improve their awareness of, and support for, children and young people with learning disabilities, autism or both.
- Over the next three years, autism diagnosis will be included alongside work with children and young people's mental health services to test and implement the most effective ways to reduce waiting times for specialist services.
- By 2023/24 children and young people with a learning disability, autism or both with the most complex needs will have a designated keyworker.
- For children and young people, no more than 12 to 15 children with a learning disability, autism or both per million, will be cared for in an inpatient services.
- [The NHS] will work with the CQC to implement recommendations on restricting the use of seclusion, long-term segregation and restraint for all patients in inpatient settings, particularly for children and young people.

Local approaches

The evaluation found several examples of work where progress had been made to address the care and support needs of children and young people. These included:

- Strategies for children and young people's wellbeing that are inclusive of the needs of those with a learning disability, autism, or both – this is the focus of Greater Manchester's Accelerator programme;
- Investments in co-production, so that children and young people are engaged in shaping those supports and outcomes that matter most to them – in Dorset this was funded by the local authority;
- There were an increasing number of new community services set-up to provide support and training for families and early intervention, together with commissioning of crisis services (as in Surrey), as well as short breaks services and therapeutic support for young people and their families to avoid admissions.

Some case study TCPs were also aiming to move towards a more 'all-age' approach to commissioning strategy that plans around the needs of the whole population from childhood to old age. This would enable them to potentially overcome longstanding issues about linking up children's and adult services.

2.4 Housing

Key findings

Developing strategic housing plans that meet the needs of people and families has been a key area of focus for TCPs, but also an important challenge. It was an area where many NHS (CCG) commissioners had to upskill rapidly as, typically, many TCP NHS stakeholders lacked specific expertise in commissioning housing as part of personalised care and support. In the evaluation's initial case study visits and the survey, relatively few respondents thought that the TCP had yet made a difference. NHS stakeholders felt that influencing the decisions made predominantly by local authorities and housing providers was difficult. Access to capital funding was also identified as a central issue. In particular, stakeholders said that it was challenging to join-up various capital funding sources with differing conditions, while meeting Care Quality Commission (CQC) requirements and also working with providers to develop housing that was affordable and sufficiently personalised.

In the latter half of the programme, NHS England and the Local Government Association provided regional housing advisers to address these issues directly. They offered expertise in the development of housing plans and help with accessing capital funding, so that more TCPs could make the progress achieved by others (such as Devon) in using capital to develop new provision.

There is now widespread recognition across TCPs that housing plans need to be clearly linked to a strong understanding of population need – at the present time and in the future. This is necessary so that local system leaders can consider: which existing housing can be adapted or brought up to standard; where new developments are needed; and where there are opportunities to make an investment. Housing plans also need to take account of choice and personalisation, and the different ways in which tenancies and home ownership might be supported. Lastly, plans must take account of the local workforce and access to health and specialist services that people and families need.

Many TCPs continue to find it challenging to develop the skills needed to create personalised housing options that can be delivered on time, while at the same time doing so in a way that makes the most effective use of limited resources (money and workforce). Professionals contributing to the evaluation highlighted how working closely and sharing risk across health and social care is essential for success.

The most effective local housing plans have addressed the wider needs of all people with a learning disability, autism, or both, taking account of the

future needs of children and young people for supported living; and looking at the wider investment case for homes, including all the potential sources of capital funding for different kinds of developments.

Relationship with the commitments of the LTP

The LTP Implementation Framework states that targeted funding will be available providing continued capital funding for the development of new housing options and suitable accommodation in the community.

Commitments in the LTP (normal text) and Implementation Framework (*italic*)

- *[NHS England will] Provide capital investment for 2019/20 and 2020/21 to support the development of new housing options and suitable accommodation in the community.*

Local approaches

There have been a number of examples of positive practice from which local systems can learn. These include:

- Highly integrated approaches to commissioning health and social care – exemplified by Hertfordshire, where commissioning expertise has been built up and where there is strong engagement of providers in the planning around capital funds;
- Mapping exercises looking at supply and demand (as in Outer North East London or Surrey) – for example, making registers of voids (empty properties out of use) and local properties belonging to local authorities and the NHS which could be redeveloped, and mapping that to predicted local need as revealed by dynamic support registers and other sources of local information;
- Ensuring that homes are developed in a flexible way, and can be made more easily suitable for other residents when they need to be; and
- Co-producing housing plans, so that everyone involved knows how to meet the needs of different people and in a more person-centred way (for example, so that disabled young people have the same social opportunities as any other young people).

2.5 Finance

Key findings

Ensuring that money can follow people as they move from inpatient care to living in the community remains a challenge for TCPs, including reaching agreement between health and social care commissioners as to how the costs of care and support in the community are met.

Many TCP stakeholders remain uncertain as to whether the true costs of care and support in the community, and the infrastructure required to support

it, are met by transfers from inpatient care. Some local and national stakeholders felt that transferring ring-fenced budgets to meet the costs of community provision for people leaving long-term inpatient care would be a logical progression from current policy on funding transfers.

Nevertheless, case study TCPs have been making progress in addressing the financial challenges identified by this evaluation during the first years of their operation, such as the higher costs faced by some commissioners when people are discharged from hospital to home. In some cases, local commissioners such as those in Hertfordshire were able to build on a history of joint commissioning, integrating health and social care or pooling budgets.

However, other TCPs have made slow progress with establishing more formal joint commissioning arrangements. Feedback from local and national stakeholders suggested that, in part, this is because of severe cost pressures in social care more generally (and some participating CCGs were in financial special measures, compounding the challenge). Participants reported how they were waiting for a policy steer from the forthcoming Government Green Paper on social care to help them resolve the issues relating to reaching agreement on how funding is transferred from inpatient care to new community provision, or how costs are shared between health and social care. It is notable that Greater Manchester seems to have benefited from bringing all health and social care spending together under one umbrella.

Some TCPs are beginning to look at the longer-term cost implications for sustaining services locally while managing growing demand. For example Surrey is exploring whether cost savings have arisen over the longer-term as a result of re-enablement in the community – and whether numbers of support workers for every individual can be reduced over time, following discharge.

Relationship with the commitments of the LTP

The LTP emphasises the importance of local systems working together as ICSs to plan investments in their local plans. The Implementation Framework goes on to explain that funding to deliver the improvements set out in the LTP will be provided through CCG allocations and additional service development funding, distributed to all systems, which includes agreed transfers to cover specialised services, community service investment and for TCPs. Providers may also hold budgets to develop new services and improve local care and support.

Commitments in the LTP (normal text) and Implementation Framework (*italic*)

- Drawing on learning from the New Care Models in tertiary mental health services, local providers will be able to take control of budgets to reduce avoidable admissions, enable shorter lengths of stay and end out of area placements.
- *Where appropriate, specialised mental health services and learning disability and autism services will be managed through NHS-led provider collaboratives over the next five years. NHS-led provider collaboratives will become the vehicle*

for rolling-out specialist community forensic care … NHS-led provider collaboratives will be able to reinvest savings they make on improving local services and pathways.

- *System investment should identify what community provision is in place for intensive, crisis and forensic community support.*

Local approaches

Examples of work that TCPs have undertaken to enable more effective financing of care and support, and integrate health and social care funding include:

- Enabling single assessments (e.g. as in Devon) so that people are not assessed in different ways in relation to the same needs;
- Developing new ways of distributing funding between health and social care (e.g. fully integrated commissioning in Hertfordshire; or more integrated strategic commissioning in the context of Devolution in Greater Manchester, where decisions about how to spend the c£6bn total are taken at the regional level);
- Investing in prevention and early intervention, with the expectation that both health and social care will make savings; and
- Shared risk agreements or 'virtual pools' between health and social care commissioners, as in Dorset.

2.6 Personalisation

Key findings

The evaluation found evidence that, over time, both commissioners and providers had focused on personalising services and improving the planning of care and support to meet individuals' needs.

However, most case study TCPs did not yet appear to have a systematic approach to promoting and using tools such as personal health budgets (PHBs) or individual life planning. Addressing this gap in the future will make more personalised care and support possible for people and families.

Relationship with the commitments of the LTP

Personalisation is a key thread running through the LTP and the Implementation Framework, as well as the Improvement Standards.

Increasing the uptake of PHBs is a key goal for national policy. The Implementation Framework states that support for local systems to implement PHBs, in line with the NHS Comprehensive Model for Personalised Care, and social prescribing will be made available. This will include a new Institute for Personalised Care and a national network to share good practice and foster collaboration.

Commitments in the LTP (normal text) and Implementation Framework (*italic*)

- Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives.
- Where possible, people with a learning disability, autism or both will be enabled to have a Personal Health Budget (PHB).
- *Systems will be expected to set out how they will use the funding available to them to implement the six components of the NHS Comprehensive Model for Personalised Care as set out in Universal Personalised Care. Regional teams will support systems to develop local trajectories in line with the national ambition in the Long Term Plan, including their shares of social prescribing activity and personal health budget take up.*

Local approaches

Examples include:

- Developing a more personalised approach to commissioning, where people have a genuine choice over who they live with and who supports them, underpinned by a life plan and provider involvement with the person and their family well in advance of the discharge, as seen in Devon.

2.7 Co-production with people and families

Key findings

Many TCPs had made significant progress with co-production over the length of the evaluation. Nonetheless, in many cases the strongest examples were found when there was a longer history of local infrastructure and supportive system leadership, which could make sure that TCP plans were made with the active engagement of experts by experience.

There were a wide range of approaches to co-production at a strategic level: there was no common approach but there were shared key principles of: openness; the willingness to enable people and families to identify problems, set priorities and develop their own solutions; and investing in enabling people to take part (for example, by preparing agendas and questions in advance of meetings). In this way, when co-production is made an integral part of the work of the TCP, and given the time and resources necessary, care and support is more likely to be developed as set out in Building the right support.

Stakeholders emphasised that co-production can be challenging and can take time to bear fruit. However, people working in those local systems where there had been investment in co-production generally thought that they had been able to make better commissioning decisions based on a shared understanding of what was possible and achievable.

Relationship with the commitments of the LTP

The LTP and Implementation Framework emphasise co-production throughout, in respect of both adults and children and young people. People and families should be actively engaged in the design of new services, evaluating and checking the quality of care and support provided, and holding local providers to account with making reasonable adjustments.

The Improvement Standards make this approach even more explicit, placing a requirement on Trusts to show they engage people, families and carers in all aspects of planning and evaluating care and treatment. People with a learning disability, autism or both should be involved in staff recruitment and know if things are going wrong. Relevant services should be co-designed – from the review of services and pathways through to involvement in strategic decision making. People should also be informed of their rights throughout. Lastly, people and families should be rewarded for work they do in reviewing services or contributing to service improvement.

Commitments in the LTP (normal text) and Implementation Framework (*italic*)

- *Systems should involve people with lived experience and their families in checking the quality of care, support and treatment, and set out how they will ensure all local services make reasonable adjustments for people with learning disabilities, autism or both when they need it.*
- *When drawing up plans, systems can draw on the Ask Listen Do Framework to learn from, and improve the experiences of people with a learning disability, autism or both.*

Local approaches

Examples of work that TCPs have undertaken to enable a more co-produced approach include:

- Providing dedicated resources to fund co-production and self-advocacy groups, empowering them to take part in the design and delivery of care and support, as seen in Dorset;
- Involving people and families in the design, procurement and delivery of new services to meet gaps that they have identified e.g. a hub of expertise in autism for training professionals, or assessing potential providers on a new provider framework;
- Employing Experts by Experience to undertake a range of tasks (e.g. in Lincolnshire), from participating in CTRs to training other staff;
- Using ‘family charters’ or documents such as ‘Things you must know about me’ which help to provide ground rules for how providers work with individuals and families, or how C(E)TRs should be framed around the needs of the person and their family;
- Setting up ‘confirm and challenge’ groups as in Greater Manchester, or using Learning Disability Partnership Boards (LDPBs), to oversee the

development of care and support and take decisions about the agenda and priorities for future work; and

- Setting up working groups under the TCP or LDPB umbrella to lead on different sections of the TCP plan (as seen in Dorset), where self-advocates are integrated into a decision-making team (for example, thematic groups such as ‘Being Healthy’ or ‘Staying Safe’).

3 Ideas for the future

Using the findings from the evaluation, this section provides ideas that national or local policy makers may want to consider, in the context of the LTP. The evaluation team developed these points in conjunction with expert advisors representing stakeholder organisations (including those working with people and families).

3.1 Developing community provision through partnership working

- There should be an emphasis both nationally and locally on achieving fully integrated commissioning, spanning housing and community support.
- Commissioning plans should reflect the national emphasis on personalisation, giving priority to tools such as PHBs, personal budgets, individual service funds and personalised care and support planning across the whole life course (not just when a new 'package of care' is being sought). Family carers should also be considered as part of care and support plans for people in the community.
- Local and national policy should continue to focus on commissioner skills so that they are able to employ creativity in their approaches to meeting local need, rather than simply purely procure services for individuals. Retaining commissioners who can develop a specialism in this area is also important.
- Commissioners should improve collaboration with (and among) key providers that deliver, or might be able to deliver, care for people so that the whole system is able to support them better. There should be a clear expectation that providers are engaged and involved locally: they need to know the 'pipeline' for future demand so that they can plan; they also need to be able to have open discussions with commissioners about varying care and support when needs change.
- Frameworks for buying care and support locally should be able to facilitate the use of personal health budgets, and allow for higher rates to be paid for supporting people with complex needs that reflect the greater experience required.
- Setting and monitoring quality standards for community support should be a priority for local partners; these should be co-produced and led by people and families. The focus on quality should also include the analysis of outcomes from C(E)TRs, so that a comprehensive understanding of this feeds into future service planning.
- At a national level, quality standards ought to be established for commissioning (similar to the national Learning Disability Improvement Standards for Trusts); and further investment in provider development should be encouraged to spur innovation and meet some of the gaps reported locally.

3.2 Developing the workforce in the community

- There is a clear need for workforce strategies and implementation planning (nationally and locally) that include social care as well as health. Building on the Learning Disability Improvement Standards, a workforce strategy should clearly define what multiagency professionals and capacity per population are required for learning disability / autism teams and support teams working in the community.
- A system-wide approach to tackling the challenges in the social care workforce is required. This includes ensuring that career progression opportunities are available to tackle recruitment and retention issues in social care; and that social care apprenticeships include specialist learning disability and autism options, as requested by employers.
- Ensuring that providers have access to a wide range of relevant training is also central to achieving the more mature provider market that is required in each local system by the LTP, to deliver effective care and support for people with the most complex needs. This will require continued investment.
- Mandatory learning disability and autism training should be implemented in every local system as soon as is practical, so that all NHS and social care staff nationwide see this as a core skill – in line with the key aims of the LTP.
- Lastly, workforce strategies, both nationally and locally, should also emphasise that relevant training should also be made available to families and carers. Evidence from the case studies shows that where families and carers are better able to advocate for their own needs and where they are supported to be at the centre of a person's support network, crises and breakdowns can be avoided or better managed.

3.3 Care and support for children and young people

- The emphasis in the LTP on children and young people confirms the importance of early support and intervention so that exclusions from school, crisis points and admissions do not constitute a threshold for intervention.
- Further integration of education, health and social care services for children and young people with learning disabilities or autism is required – and areas must increase the focus and incentives for inclusion and reasonable adjustments in schools, education and health services. The support offer for the LTP envisages further work between NHS England, the Department for Education and the Local Government Association to raise awareness of the needs in this area.
- Schools and families should be able to access support from intensive support teams where there is a risk of care and support breaking down, as well as accessing training as part of personalised care and support where needed (including training on PBS).
- Commissioning for children with complex needs should be improved to reduce reliance on institutions a long way from the family home – building

on the commitment to keyworkers in the LTP to improve oversight of such provision and planning for discharge.

- More research is needed, to establish a clear picture of future demand and therefore the investment required both nationally and locally. There is a clear sense locally from TCPs that demand is increasing and that the 'numbers are changing' – there needs to be greater understanding of the patterns and what is driving the need so the demand can be better managed.

3.4 Housing

- Capital investment should continue to be made available nationally and locally, to provide the investment needed in good local housing stock for a range of purposes – both for ongoing living, as well as care and support in a crisis to minimise inpatient admissions and delays to discharge.
- The NHS and local authorities need to work more closely together to develop more integrated approaches to commissioning housing – not only around individual developments for people with multiple needs, but looking at how the whole housing stock and planning processes more generally can consider the needs of people with a learning disability and autism.

3.5 Finance

- Drive and support at the most senior levels for further integration across the system is key, and this will be an essential feature of ICSs. It is important that joint budgets and risk sharing (around integrated commissioning) are consistently put in place; and further national direction and guidance to enable this to happen may be necessary – for example, to introduce financial incentives (and addressing the financial disincentives) to keep people in the community.
- Those who have been in an Assessment and Treatment Unit (ATU) for over a year should have a ring-fenced budget (this could be via a personal budget) for at least 2 years after discharge.
- It will be important to develop further the business case for providing the right support, in the right place at the right time compared to institutional models of care. This could form part of the strategic commissioning function envisaged in the support offer from NHSE around the implementation of the LTP.

3.6 Personalisation

- The main consideration in this area is for local systems to give greater priority to personalisation and ensuring that opportunities to personalise care and support are delivered. Universal personalised care and the comprehensive model should be used to guide how care and support can be delivered in a much more person centred way.

3.7 Co-production with people and families

- The emphasis on the necessity for, and added value of, co-production should continue. This requires people having meaningful control of the agenda – including investment in the infrastructure for co-production; enabling people and families to set priorities and shape action locally and nationally.
- National stakeholders can help. For example, at the national level, the CQC could ensure that the experiences of people and families, and their lengths of stay, are taken into account in their inspections of inpatient care.
- The extent to which personal health budgets and personalised care and support planning help to lead to change should be assessed. More broadly, people and families must have a role in monitoring the quality of care and support via co-production and co-design (see section 2.7) to drive a focus on system-wide personalisation.

3.8 Cross-cutting considerations

The following are ideas for action that should be taken across Government:

- NHS England should publish an action plan in response to the ideas outlined in this section (as a 'You said, We did…' document).
- The Social Care green paper that sets out social care reform and better integration of health and social care funding must be published in 2019.
- Cross-department working must improve, to ensure that strategic ownership of the national programme includes all relevant parties (e.g. DfE, DHSC, NHSE, ADASS, LGA, HEE, S4C). The focus should be on getting a more consistent policy approach to making reasonable adjustments and taking action to ensure children with a learning disability and autism are supported from early childhood.
- Those overseeing ICSs should ensure that they make learning disability and autism a clear priority. As the evaluation showed, TCP-type structures are important for oversight and joint planning; and with their multi-agency membership the new ICSs can, and should, be setting goals that will help with the wider social context for improving the rights (and health) of people with a learning disability and autism, for example setting goals and accountability for supporting people with a learning disability into employment.
- Carry out further study and invest in exploring what savings accrue across education, health and social care over the longer-term following through investments in community provision and prevention.
- Continue to ensure that local authorities and social care are driving the shared agenda as much as NHS. This is important not just for buy-in but, crucially, achieving long-term results.

- Among stakeholders external to the national programme, there is a significant concern that the focus of BRS on closing inpatient beds and transforming community services may be lost with the inception of the LTP and ICSs. In response to the recent Panorama documentary, it is necessary to continue reemphasising the national commitment to these goals, and scaling up action on eliminating dependence on long-term hospital care.