Evaluation of Building the Right Support

What matters most for improving care and support: a report on the views of people that are less listened to in current policy

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Document Title	What matters most for improving care and support: a report on the views of people that are less listened to in current policy (Final)
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Background

This report has been produced as part of phase 3 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. BRS was published in 2015 by NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS).

The evaluation is being undertaken by the Strategy Unit, ICF, BILD, and the University of Birmingham. The findings from the study to date, which began in December 2016 and ends in July 2019, can be found here. The evaluation was commissioned by NHS England to focus primarily on the implementation of BRS, examining what works, what does not work and why.

In early 2019 a new Long Term Plan (LTP) for the NHS[1] was published which builds upon the ambitions and achievements of BRS. Findings from the evaluation helped shape these plans. Phase 3 of the evaluation shifted its focus to gathering evidence to support local systems to plan and implement the commitments set out in the LTP.

About this report

This report focuses on what people and families say about what matters most for improving care and support, so that all voices can be equally heard. The focus is on the views of people that are typically overlooked in policy making. These groups were identified by experts by experience and stakeholders representing people and families, and include:

- Children and young people and their families / carers;
- People living a long way from home (e.g. in Assessment and Treatment Units or other residential settings);
- People who have been recently discharged from hospital;
- Autistic people;
- People from Black and Minority Ethnic groups; and
- People with the most complex needs.

This report is a learning resource, providing insights that can inform local systems' approaches to ensure that people can fully participate in decisions about care and support.

The report addresses the following questions:

- What people and families want the most, as new approaches to care and support in the community are developed;
- What people and families think of the current model, and what is / is not working well for them; and

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[1] NHS England (2018), The NHS Long Term Plan: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/

- What are the barriers to being listened to, and what are the actions would make a difference for people and families.

In order to do this, the evaluation team reviewed recent academic studies, policy reports and case studies, in which people and families were asked about their experiences and views on care and support. 24 sources were reviewed, including 16 that provide commentary or reference to Transforming Care and / or BRS.

Primary research was also commissioned from *Inclusion North*, a voluntary sector organisation focused on supporting people and families with co-production and personalisation. In February 2019, *Inclusion North* convened two focus groups of people and families with relevant experience of BRS. All of the participants were trained as experts by experience and had been regularly involved in co-producing care and support, and facilitating shared decision making as advocates, advisers or chairs of Care (and Education) Treatment Reviews (C(E)TRs).

The evaluation team would like to thank all the people with lived experience and stakeholder organisations that contributed to the production of this report.

Key findings

The things that are important to people and families include:

- **Living in the community**: people's self esteem and confidence increases when they live in their community and can exercise choice and control over their day-to-day lives. This includes the ability to develop and maintain friendships, and relationships with family and the wider community that go beyond their staff team.
- **Personalisation:** people are experts in their own lives and have the right to be listened to and make decisions about their lives and their own individual support plan to help them live the lives they wish. If people are treated as equal partners and experts, they are more likely to be able to commission their own support, for example through personal health budgets.
- **Care (and Education) Treatment Reviews** provide an opportunity to put these values into practice. They need to be well planned so that people and families can attend, together with the right information and reasonable adjustments so they can take part. The quality of the conversations are vital, and the wishes of people and families should be respected and acted on. C(E)TRs work better when education services and family are also involved. Independent advocacy is also important.
- **Co-production**: working with people and communities as equals in decision-making about the nature of care, support and services. High quality co-production requires resources to support people so that they can express their views effectively and influence the ways that services are delivered. People and families need information, support and reasonable adjustments.

What steps can improve personalisation?

- Everyone can make decisions about their own care and support and has a right to be listened to – including children and young people, people with the most complex needs and people who do not have many or no words.
- People and families should be provided with all the information they need, in the ways that they need it, so they can make their own decisions – including support

from independent advocates and experts by experience who understand their needs and wishes.

- Families are also experts by experience and their views need to be listened to and their support needs taken into account.
- People and families need better support at home (not only specialist support, but also support to maintain and develop relationships around them), built around a person-centred support / life plan so more people can continue to live in the community. Relationships with friends and community should be valued. Personal health budgets can be a way to make this happen.
- Personalised housing is important and should be part of people's plans – it should be treated from staffing of support and requires its own focus.

What steps can improve co-production?

- Commissioning and accountability need to be improved. The commissioning of care and support for people requires several distinct skills, the most important being the ability to shift the balance of power.
- People and families need information and reasonable adjustments in order to take part, and experts by experience need to be supported and resourced in order to contribute as equals.
- Develop creative approaches for children and young people, people with the most complex needs and people who don't have many words.
- Reducing stigma and raising awareness and visibility of learning disability and autism is still very important.

1 Introduction to this report

This report has been produced as part of phase 3 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. BRS was published in 2015 by NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS).

The evaluation is being undertaken by the Strategy Unit, ICF, BILD, and the University of Birmingham. The findings from the study to date, which began in December 2016 and ends in July 2019, can be found here. The evaluation was commissioned by NHS England to focus primarily on the implementation of BRS, examining what works, what does not work and why.

In early 2019 a new Long Term Plan (LTP) for the NHS[2] was published which builds upon the ambitions and achievements of BRS. Findings from the evaluation helped shape these plans. Phase 3 of the evaluation shifted its focus to gathering evidence to support local systems to plan and implement the commitments set out in the LTP.

1.1 Aims of this report

In line with the key principles of the BRS service model, the evaluation team engaged with and sought the views of people with a learning disability, autism or both, their families and representative organisations at key points during the evaluation. We asked them about the challenges of co-producing a major change to the system in a way that enables everyone to be heard and listened to – so that their expertise can inform the agenda locally and nationally.

BRS aimed to improve the lives of those people with the greatest need – people who are living in hospital inappropriately because of a lack of high quality care and support in the community. In our initial engagement, it became clear that many of the voices of those who are the intended beneficiaries of this policy may rarely be listened to and their views may be overlooked in the design of new approaches to care and support. Therefore, Transforming Care Partnerships (TCPs) and Integrated Care Systems (ICSs) may not be able to effectively co-design services for everyone.

As a consequence of this insight, it was agreed with the NHS England / LGA / ADASS Evaluation Steering Group that the evaluation team should undertake a piece of work with the following objectives, to find out more about groups of people that are typically ‘less heard’, seeking the views of those people and families to understand:

- What people and families want the most, as new approaches to care and support in the community are developed;

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[2] NHS England (2018), The NHS Long Term Plan: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/

- What people and families think of the current model, and what is / is not working well for them; and
- What are the barriers to being listened to, and what are the actions would make a difference for people and families.

This report sets out insights to inform local systems' approaches to ensure that all groups are listened to, so they can fully participate in decisions about care and support. This can be via co-production (working with people and communities as equals in decision-making about the nature of care, support and services) or personalisation (people have choice and control of their own care and support)[3].

1.2 Method and approach

In the first half of 2018, the evaluation team engaged with key stakeholders to determine which groups of people and families were being overlooked.

The evaluation team looked at the current evidence base regarding the views of those people and families – with a particular focus on literature relating to people's experiences of Transforming Care and BRS.

The evaluation team spoke to representatives of the following stakeholder organisations and sought feedback at meetings of the following groups:

- The NHS Learning Disability and Autism Advisory Group and the NHS Learning Disability and Autism Engagement Team, as well as relevant topic experts at NHS England;
- The Empowerment Steering Group, a panel of people, family members who are experts by experience in relation to BRS, convened by the LGA;
- The evaluation team's expert reference panel of academic and practice experts, experts by experience and representatives of people with a learning disability or autism;
- National organisations representing people with a learning disability or autism; and
- Voluntary sector organisations that support the people affected by the core aim of BRS (i.e. reducing dependence on inpatient care).

Based on their feedback, the evaluation team decided to focus on the following groups:

- Children and young people and their families / carers;
- People living a long way from home (e.g. in Assessment and Treatment Units or other residential settings);
- People who have been recently discharged from hospital;
- Autistic people;
- People from Black and Minority Ethnic groups; and

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[3] See Whaley, J., Domenico, D. and Alltimes, J. (2019), "*Shifting the balance of power*", in Advances in Mental Health and Intellectual Disabilities, Vol. 13 No. 1, pp. 3-14.

- People with the most complex needs.

The stakeholders that the evaluation team spoke to during this scoping stage of the work identified several sources of existing information, including academic studies, policy reports and case studies, in which people and families were asked about their experiences and views on care and support. In this literature, certain groups were covered more extensively than others; for instance, several reports looked at the experiences of children and young people, but there was comparatively fewer papers relating to the other groups.

As a result, the evaluation team carried out the following tasks:

1. A review of this existing body of literature on the views of people and families, as suggested by the stakeholders. 24 sources were reviewed, including 16 that provide commentary or reference to Transforming Care and / or BRS.
2. Research to address the gaps in relation to insights gained from the literature, by speaking directly to experts by experience. The evaluation team commissioned *Inclusion North*, a voluntary sector organisation, as a research partner. As a result, in February 2019, *Inclusion North* convened two focus groups of people and families with relevant experience of BRS. All of the participants were trained as experts by experience and had been regularly involved in co-producing care and support, and facilitating shared decision making as advocates, advisers or chairs of Care (and Education) Treatment Reviews (C(E)TRs).

The evaluation team would like to thank all the people with lived experience and stakeholder organisations that contributed to the production of this report.

1.3 Content and structure of this report

The insights gathered from this work described above are presented in two stand-alone chapters corresponding to the two main tasks.

Each chapter is structured around key considerations for TCPs and ICSs, as they develop their local delivery plans to meet the commitments of the NHS LTP.

As a targeted literature review and primary research exercise, it should be highlighted that the evaluation team do not claim that this represents an exhaustive or representative list of considerations that ought to be taken into account when carrying out co-production with all the ‘less listened to’ groups of people and families.

As a whole, the content of this report should provide useful reading for local systems seeking to understand what people and families value, and how they can ensure that all voices are equally heard.

2 Review of existing literature relating to the experiences and views of people and families

The first two sections of this chapter show what the existing literature tells us about what people and families value the most, before discussing their views on current care and support arrangements and the gaps and barriers that are important to them, so that all voices can be equally heard.

In the last section, there are key considerations for what works, in the view of people and families, so care and support can be more effectively co-produced. These should be helpful for local systems in developing their delivery plans that will deliver on the commitments in the NHS LTP.

2.1 Background to the review

Relevant groups that may be less listened to in the context of BRS were identified as (but not limited to):

- Children and young people and their families / carers;
- People living a long way from home (e.g. in Assessment and Treatment Units);
- People who have been recently discharged from hospital;
- Autistic people;
- People from Black and Minority Ethnic groups; and
- People with the most complex needs.

The literature that was reviewed includes academic and policy literature, case studies and reports produced by self-advocacy and representative groups.

Recent literature (i.e. that produced since the inception of BRS in 2015) was identified by expert stakeholders. The evaluation team also identified additional relevant material already in the public domain. Within that body of work, the evaluation team focused on identifying those sources that described how people's experiences of care and support has changed (particularly if it related to Transforming Care or BRS), and what they highlighted as being really important for them and their loved ones to have a good quality of life.

Recent literature / reports that looked at people's experiences of taking part in decision-making at both the strategic level (co-production) and individual level (personalisation) – and the barriers that people encounter to being heard – were also particularly relevant and were included.

In total, 24 sources were reviewed, including 16 that provide commentary or reference to Transforming Care and / or BRS. Some of the sources look at Transforming Care specifically; for example, the National Autistic Society and Mencap[4] interviewed families of individuals in, or at risk of being in,

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[4] Transforming Care: our stories Learning from families' experiences to transform care for people on the autism spectrum, with a learning disability or both (NAS, 2017)

inpatient care with the objective of developing recommendations to enable NHSE, commissioners, the CQC, providers and relevant professionals to deliver on their commitments. Other sources did not focus as directly on BRS, but referred to the national programme, stating that their findings will be useful for TCP boards. The remaining sources do not mention Transforming Care or BRS, however, they undoubtedly draw attention to the issues experienced by the groups identified above, and so have been included in the review.

2.2 What do people and families value?

Living in the community

The most important message from the literature was that people who move out of hospital, and who are able to exercise choice and control over their care and support, gain self-esteem and become more confident in taking decisions. A study by Head et al. (2017) looked at the experiences of individuals with a learning disability who moved out of hospital as a result of Transforming Care[5]. Overall, the study makes clear that moving out of hospital has been beneficial as people feel more valued by wider society: with control over their day-to-day decisions, individuals took pride in doing things for themselves. Instead of being thinking of themselves as a 'patient' in the hospital setting, individuals took on a new identity as a "person in the community" (Head et al 2017, 5), and developed positive self-images and self-esteem over time as the result of a process of adaptation.

Care and Education Treatment Reviews

There was also strong evidence that C(E)TRs are valued by people and families and thought to be a critical part of the discharge process. For example, in a short case study produced by NHS England looking at how Transforming Care was working for children and young people in Hertfordshire, positive feedback on CETRs was received from parents, with one saying that she had moved from feeling alone and unheard to actively participating in planning for her child[6]. In general, it was thought that C(E)TRs promote coordination between hospitals and community support to improve discharges. In order to be effective, however, it was often noted that the quality of the conversations with people is even more important than the paperwork, suggesting that there is still room for improvement (as recognised in the LTP national support offer to implement the LTP, which commits to a national review of C(E)TR policies). It is also worth noting that none of the families interviewed in the literature had experienced C(E)TRs in a crisis prior to admission, so their use to avoid hospital admission or

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[5] Head et al (2017) Transforming identities through Transforming Care: How people with learning disabilities experience moving out of hospital. https://onlinelibrary.wiley.com/doi/epdf/10.1111/bld.12213

[6] https://www.england.nhs.uk/learning-disabilities/about/resources/caretransformed/hertfordshire-making-transforming-care-work-for-children-and-young-people/

manage the risks resulting from an admission might be a focus for improvement.

Personalisation

The BRS strategy (2015)[7] focused on ensuring that children, young people and adults with a learning disability, autism or both have the same rights and opportunities as anyone else to live satisfying and valued lives – including a home within their community, the ability to develop and maintain relationships, and the support they need to live healthy safe and rewarding lives. A key theme of BRS is the idea of person-centred approaches, supported by personalised care and support plans: “that is to put the individual at the centre of their own care and support arrangements. This recognises that individuals are the experts in their own lives and have their own ideas about how they want to be supported and how they want to live their lives” (Whaley et al 2019,4)[8].

The literature emphasises that personalised care and support should be based on each person’s wishes and aspirations (see, for example research[9] undertaken with children and young people aged 4-15 years old by Gore and Money (2016)) and an understanding of individuals’ own personal “emotional, social and physical needs” as highlighted in a report by the Council for Disabled Children looking at Transforming Care and autistic people specifically[10].

The importance of including families in therapeutic approaches to prevention and avoiding admission to / facilitating discharge from institutional care was emphasised in the literature also – for example the use of Positive Behavioural Support (PBS) when it is tailored to the needs of each family, and building their skills. This was highlighted in a person’s story from NHS England which looked at how Transforming Care helped to bring a child, aged ten at the time, back home to Cornwall[11]. The benefits of a strong multidisciplinary team around him, together with a resourceful provider that understood how to meet the child’s needs, were highlighted within the report.

The power of language to oppress or empower has also been noted (Whaley et al 2019), and in moving to a social model of disability, services should pay attention to not defining people by their vulnerabilities or their disability, and stop using jargon and using wording that dehumanises people by reducing them to their conditions. If people are treated as equal partners and experts, they are more likely to be able to commission their own support, for example through personal health budgets.

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[7] https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

[8] Whaley, J., Domenico, D. and Alltimes, J. (2019), "*Shifting the balance of power*", in Advances in Mental Health and Intellectual Disabilities, Vol. 13 No. 1, pp. 3-14.

[9] http://www.challengingbehaviour.org.uk/learning-disability-assets/makingsensetogetherworkshoppresentation1016.pdf

[10] Barriers to Participation: A Transforming Care Partners Resource

[11] https://www.england.nhs.uk/learning-disabilities/about/resources/caretransformed/making-transforming-care-work/

2.3 What have been the experiences of people and families?

Poor commissioning has let people down

The lack of high quality local care and support was a problem identified consistently across sources with, for instance, families of individuals in inpatient care agreeing that this is the “biggest challenge facing Transforming Care” (p.5).[12] Interviewees in various sources called for more specialist community-based services in line with the national model set out in BRS, and also for discharge plans to be scrutinised to avoid delays and ensure plans are acted upon. Delays in discharging people were sometimes attributed to a lack of clarity over accountability, with clinical decisions and funding decisions seemingly not joined up, in people’s experience.

Housing was a particular issue identified in the literature. In a report released in 2018 by the Voluntary Organisations Disability Group (VODG), the experiences of 27 people from London who have been in inpatient settings for over five years were explored[13]. A key need of this group of people was bespoke housing in the community setting, able to support a range of care and support needs. This includes people who want to live communally, people who may want independent self-contained flats with access to communal space, through to people who wish to live alone.

Lack of personalisation with children and young people (and people more generally)

BRS aimed to improve personalisation by recommending that people with a learning disability, autism or both and their families should be involved in designing their own personalised care and support plans. This is in line with the recommendation in a recent report produced by the Challenging Behaviour Foundation and Mencap (2016) which promotes good practice in keeping families in touch with children and young people when the latter are living away from home[14]. The involvement of children and young people in decision-making about their care and support is enshrined in law[15]; however, many sources stated that there was a gap in meaningful consultation with children and young people with severe learning disabilities (see for example Challenging Behaviour Foundation, 2017[16]).

There are also professional assumptions that children and young people will not be able to understand complex problems due to their age, or if they are

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[12] Transforming Care: our stories Learning from families’ experiences to transform care for people on the autism spectrum, with a learning disability or both

[13] https://www.vodg.org.uk/publications/transforming-care-the-challenges-and-solutions/

[14] Keeping In Touch With Home: How To Help Children And Young People With Learning Disabilities And Their Families Keep In Touch When They Are Living Away From Home. http://pavingtheway.works/project/wp-content/uploads/2016/07/Keeping-in-touch-with-home-web-version.pdf

[15] Mental Capacity Act 2005; Section 19 of the Children and Families Act 2014; outlined in The Special Educational Needs and Disability (SEND) Code of Practice (2015); The Mental Health Act Code of Practice (2015); the Care Act (2014)

[16] http://www.challengingbehaviour.org.uk/learning-disability-assets/challengewinter2017.pdf

displaying behaviour that challenges, or have the most complex needs. These negative assumptions about people's ability to participate are also highlighted in Whaley et a (2019). The 2018 Challenging Behaviour Foundation and Mencap report[17] criticises the false perception that a child cannot participate in decision-making; one young person was quoted as saying: "I wasn't really [given opportunities to speak]. At the end of the meeting they said "is there anything that you've got to say" (p.3). Moreover, the same report states that the experiences of children and young people show that they are not being listened to at all: *"they phrase it like you do have a decision but you really don't"* (Mencap 2018, 3). Such experiences where people are not being listened to – and therefore cannot co-design their own care and support – are also cited in respect of other people and groups in the literature, in different parts of their journeys through the care and support 'system'.

Expertise of families is often overlooked

An important point echoed across numerous sources is that, despite the expertise of families and their wealth of knowledge, their views are often overlooked. Moreover, many families felt that they were expected to have detailed knowledge of support services that were available; and found that it was extremely difficult to bring decision-makers together to receive the support they required, resulting in some families launching public campaigns. Families and carers of people with autism also reported similar experiences according to the Learning Disability and Autism Advisory Group, stating that they felt they were expected to understand autism and local pathways in order to receive support, with GPs looking to them to say 'what do you want me to do?', as opposed to educating them on what provisions are available[18].

People and families are not provided with key information or support

A related point made in some sources is that a lack of information or support can lead to an imbalance of power in interactions between people and families on the one hand, and professionals on the other. In research carried out by Carol Robinson (NDTI) and Jacqui Shurlock (CBF) looking at BRS specifically, it was found that there was a lack of knowledge about personal budgets[19], even though it was felt by families that this would make a positive difference. Similarly, despite BRS saying that independent advocacy should always be available under Transforming Care, the experiences of families showed that it often was not obtainable[20].

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[17] Barriers to Participation: A Transforming Care Partners Resource (2018)

[18] Focus on Autism. You Said, We Did. NHS England Learning Disability and Autism Advisory Group – 18 May 2017

[19] Building the Right Support for Children: Learning lessons from the field work with parents, children and young people, commissioners and providers

[20] Transforming Care: our stories Learning from families' experiences to transform care for people on the autism spectrum, with a learning disability or both

People who find communication difficult or who present with behaviour that challenges are more likely to be excluded from decision making about themselves

People who do not have many or no words were perceived as difficult to include in decision-making in their care and support and assumptions were made about their views. For example, this is reflected in the experiences of a family who criticised an advocate appointed to represent their daughter, who was reported to have said "'I can't find out what she thinks about it because she can't speak"[21]. A report for the Challenging Behaviour Foundation and Mencap (2016) looked at the difficulties experienced by families and carers of children and young people (aged 0-25) living in a variety of settings away from home, including residential schools, children's homes, care homes, support living, and Assessment and Treatment Units[22]. As well as the time taken travelling to meet their children and the financial costs visiting their child, the unsupportive attitudes shown by some staff were also highlighted, with individuals displaying behaviour that challenges facing heightened exclusion from decision-making. Families argued that services had failed to recognise that people's behaviour is a form of communication in itself, and a way for a child with complex needs to express an unmet need.

Care and support has to work for people with autism, too

The importance of treating people with autism as individuals with their own personal "emotional, social and physical needs" (p.8) is emphasised by the Council for Disabled Children [23]. Some people with autism and their families thought that people with autism get a poor quality of care and support and that their needs are poorly understood by services. Other issues that impact on the health of people with autism include a lack of employment opportunities,[24] loneliness and mental health problems[25]. As almost two in five people covered by Transforming Care have autism, and almost half of these people do not have a learning disability, put simply: "if Transforming Care does not work for autistic people, it will not work" (p 29)[26].

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[21] CBF and Mencap (2015) Valuing the views of children with a learning disability Engaging with children and young people with severe or profound and multiple learning disabilities. Available online at: http://www.challengingbehaviour.org.uk/learning-disability-assets/valuingtheviewsofchildrenwithalearningdisability.pdf [Accessed 17 July 2018]

[22] Keeping In Touch With Home: How To Help Children And Young People With Learning Disabilities And Their Families Keep In Touch When They Are Living Away From Home. http://pavingtheway.works/project/wp-content/uploads/2016/07/Keeping-in-touch-with-home-web-version.pdf

[23] Barriers to Participation: A Transforming Care Partners Resource

[24] http://www.fixers.org.uk/news/16797-11208/autistic-teens-speak-out.php

[25] https://www.england.nhs.uk/wp-content/uploads/2018/03/focus-on-autism-1-plain-english.pdf

[26] Transforming Care: our stories Learning from families' experiences to transform care for people on the autism spectrum, with a learning disability or both

2.4 What would work better, in the view of people and families?

Being supported at home

Children and young people stated that the one place they feel fully safe and supported was at home – for example, as reported by Fixers (a group of young people with autism) [27]. Numerous sources indicate that living away from home is one factor in limiting people's ability to effectively have their voice heard and participate in decision-making, and so reduces their quality of care. There is a great deal of evidence (see 2.2) that being enabled to live in the community, and stay close to home, has many health and wellbeing benefits for people, supporting the aims articulated in the LTP.

Focusing on having a life – and making strong relationships with friends and the community

An important aspect of personalisation is the ability to develop and maintain relationships (Whaley at al 2019). This includes not only relationships with staff teams[28] but also friends and the community too. As the 'You Said, We Did' document produced by the NHS England Learning Disability and Autism Advisory Group in 2018 states, people need care and support in forming friendships and making a house a home[29].

The 'So What, What Next?' project was commissioned by the LGA[30]. The project aims recognise that more needs to be done to foster community links, which it sought to do for a small number of people with a learning disability or autism who were leaving hospital. Importantly, this work shows that Transforming Care work does not stop when someone is discharged. The project supported people in becoming active citizens, developing relationships in the community with people outside of the staff and people they live with, building peoples' confidence, and helping them to "have dreams and really shine!" (p.3). The project enabled the participants to be aspirational and pursue their interests, such as Jamie "who loves walking and the outdoors and could make a great conservation volunteer" (p.6). The report emphasised that it can be difficult for someone who has spent a long time in hospital or prison to know how to live a good life and what community resources and opportunities are available, which sometimes involves creating links with people outside of services, such as local conservation volunteer groups as in Jamie's case. The report recommends more aspirational support places less emphasis on reducing risks to the extent that service put up barriers to the realisation of "creative and consistent support [which people] need to reach [their] dreams" (p.13).

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[27] http://www.fixers.org.uk/news/16797-11208/autistic-teens-speak-out.php

[28] Head et al (2017) Transforming identities through Transforming Care: How people with learning disabilities experience moving out of hospital. https://onlinelibrary.wiley.com/doi/epdf/10.1111/bld.12213

[29] You Said, We Did - Transforming care evaluation: NHS England Learning Disability and Autism Advisory Group

[30] The So What, What Next? Project: Report June 2018 – Aidan email (not published online yet)

Developing a creative approach to communication

The need for a more creative approach to communication with people who don't have many words was highlighted throughout many sources. Among the examples of interest cited in the report by the Challenging Behaviour Foundation and Mencap (2015) were: uses of assistive technology; the use of a 'Learner Voice Coordinator' who ensures young people are involved in decision-making, who sometimes challenges other staff members to make sure this occurs; and training on reading the behaviour and responses of children with the most complex needs. The potential of technology, such as videos and audio recordings to encourage people with learning disabilities and autism to be involved in decision-making was also echoed by the Council for Disabled Children (2018), as it means people can be included even if they are unable to attend a formal meeting about their care and support[31].

'Involve Me' was a three-year project run by Mencap and BILD (2017) with the goal of involving children and young people with the most complex needs in decision-making[32]. The project emphasised the importance of "appreciating the uniqueness of each individual and of finding the best way of communicating with each person" (p.4). The project found that participants had had gained in confidence, this will directly and indirectly influence services and policy – in line with the ambition of "shifting power from services to the people they support." (p.12). Fostering meaningful communication between individuals and staff also has the wider benefit of improving job satisfaction for staff who were enthusiastic about adopting innovative communication approaches to improve care provided.

Increasing awareness and reducing stigma around autism is vital for engaging some communities

There seems to be lack of literature on the care and support needs of ethnic minority people with a learning disability or autism and their families. However, the National Institute for Health Research (NIHR) is funding one study (see Fox, Aabe et al 2017)[33] that is working with families who have migrated from Somalia to the UK. The project explored how autism is seen and understood in the Somali community and typically, challenging issues can include perceptions of autism (there is no Somali word for autism; some parents delay seeking help); navigating the system (disbelief arising from lack of own language information and knowledge of autism or mental health conditions); and lack of support (speech therapy, short breaks). Therefore, increasing awareness of autism through better information and communication, and working to reduce stigma, would seem to be important actions to take.

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[31] Barriers to Participation: A Transforming Care Partners Resource

[32] https://www.mencap.org.uk/sites/default/files/2017-05/Involve%20me%20evaluation%20report.pdf

[33] Fox, F., Aabe, N., Turner, K., Redwood, S., and Rai, D. (2017). ' "It was like walking without knowing where I was going":A Qualitative Study of Autism in a UK Somali Migrant Community', J Autism Dev Disord (2017) 47:305–315

2.5 Resources to support engagement

NHSE has a wide range of resources available to support effective personalisation and coproduction that ensures the involvement of all voices in both the planning of care and support that meets all individuals' needs, and strategic planning.

For resources on personalisation see:

- NHS England introduction to personalised care planning
- NHS England resources from the Personalised Care Group on personalised care, including resources on the Comprehensive Model and universal offer, shared decision making and personalised care planning.
- NHS England pages on personal health budgets, including the legal right for people with a learning disability who are eligible for NHS Continuing Healthcare to have a personal health budget Etc.

For resources on coproduction see:

- NHS England guide to Involving people with a learning disability, autistic people and family carers
- NHS England resources on making information and the words we use accessible
- Ask Listen Do - resources to help people give feedback, raise concerns and make complaints in health, care and education
- Local Government Association guide to Co-production in Transforming Care

3 Main findings of focus groups with experts by experience participating in C(E)TRs

Inclusion North organised and facilitated two workshops with experts by experience:

- In Darlington on 27th February 2019; and
- In Leeds on 28th February 2019.

Expert Advisers from Inclusion North's Expert Adviser Hub were invited to attend the workshops; and the invitation was also sent to external contacts to share with relevant individuals.

Seven people attended the two workshops in total and one self-advocate completed the online questionnaire with support. There was a mixture of attendees, each with their own lived experience of a learning disability or autism including family members; all had experience of attending Care and Treatment Reviews (C(E)TRs) as independent Expert Advisers.

The workshops began by presenting the background and vision of BRS; this enabled the facilitator to bring context to the session and highlight the priorities. The aims of each session were to capture feedback about:

- What is working well;
- What could be better; and
- People's views on how things can be improved.

The reader should note that the bullet points represent the views of these experts by experience.

3.1 What is working well?

C(E)TR's are achieving good outcomes for some people

- It is good that C(E)TRs are in place to find out if the person is safe and cared for – although the outcomes are not always positive
- When people with different views are enabled to communicate, it gives a more rounded picture
- It is good when the experts by experience can make use of their personal lived experience too (especially around autism)
- Professionals ought to be held responsible if there are any stoppages and people not discharged. C(E)TRs work best when actions are identified and owned.
- C(E)TRs can make things happen, e.g.:
  - phone calls can be made there and then
  - mostly there are good chairs for C(E)TRs now, perhaps three quarters of the time
  - participants can review what services or supports are available

  - review of medication can take place / be arranged
  - provides opportunities for participants to develop skills.

Input from education has been a positive experience in some areas

- Experience is that “education” has been a strong presence in CETRs.
- When the family attends, the review goes better. We use the speaker phone to include them also enables participation. Young person will also engage on the telephone. They sometimes find it better than being in a group with lots of people and questions.
- In some areas e.g. Redcar & Cleveland the local authority education budget is supporting the Parent / Carer forum. The parent / carer forum is a way for families to come together and discuss how to support their family members with their learning disability or autism.

Expert Advisers’ (people with lived experience) involvement in C(E)TR’s has been positive

- There is support for experts to attend C(E)TRs.
- It is helpful for people and families to see a familiar face, this helps people feel comfortable when they see an expert by experience attend a review.
- Experts learn by attending reviews – how to challenge a panel, building a rapport with others so it is easier to challenge.
- Works when everyone is well prepared and value the inputs of people with lived experience.

Expert advisers have noticed improvements in their local care and support in the community

- There are more services for people when they are discharged, including 24 hour services.
- There are bespoke housing units where people can live a good life and where each person can choose their own teams.
- Working closely with people and with commissioners to make sure that places to live are long-term, not short term ‘placements’.
- Providers are robust and act with greater integrity than in the past.
- There will be a safe place in the community where someone can go when they go to in crisis to prevent going admission to hospital.
- Community CTRs seem to be improving – there is more work going on in relation to prevention.

3.2 What is not working so well?

The experts’ local Transforming Care programmes seem to have had little involvement from people with a learning disability or autism and families

- Experts did not seem to be aware of Transforming Care – some have been to meetings where there were many professionals but very few family members or people with lived experience (and thus the involvement was tokenistic).
- Experts do not feel valued or respected – when people are not paid for their inputs, professionals do not value them.
- There is not much sharing of information from TCP Boards. There is a much more equal relationship between people and professionals, and a better flow of information at the Learning Disability Partnership Boards.

There is still a lack of suitable services

- The desired care and support is not always available when people in hospital or the community need it.
- Staffing is an issue: if there are no staff able to support people in the community provider, a person cannot be discharged.
- Needs assessments are not taking place when they need to.
- Health support for young people with a mental health condition through CAMHS is time limited.
- There is little knowledge about the number of children with autism who are being educated at home, and their families have no support.
- Still instances where a person’s health deteriorates due to services being withdrawn or support being reduced, leading to a crisis and admission.
- Late diagnosis of autism is having an impact – people are admitted to mental health hospitals and then struggle to receive the right support
- Lack of transition / planning between children’s and adults’ services.
- Experts would like to see more of an emphasis on human rights – the environments where care and support might have changed but that does not mean anything if rights are not respected.
- Examples of this are that services do not always meet the needs of the person but the needs of the service – people cannot go out or do things at times when staff are not available (e.g. in the evenings) – this limits people’s involvement in their community. There are also staff who are poorly trained and the use of restraint has increased.

In some areas there seems to be little or no partnership working with people and families

- Where there isn’t a Learning Disability Partnership Board information is not being shared – the boards brought people together. Experts were not aware of any particularly good examples of co-production happening locally.

Poor planning and delivery of C(E)TRs

- Local commissioners of health and social care are often not the chairs of C(E)TR’s – so experts queried who was responsible for decision making.
- Sometimes the right decision makers do not attend C(E)TRs, and they end inconclusively with disputes about funding – perhaps one in five out of every C(E)TRs ends unsuccessfully in this way (usually linked to the question of where people live and which commissioner assumes responsibility.
- C(E)TRs do not go well when there is no information when people arrive; it would be better if profiles of people were provided in advance e.g. information about diagnosis, family, last C(E)TR. If the paperwork is not done, reviews are problematic.
- Shorter C(E)TR’s are happening – not following the guidance. Times can also vary or be rescheduled so as to make it difficult for experts to attend (poor planning).
- Panels do not always get a report of recommendations so they can be signed off – having a report means that everyone knows what was discussed and is sure all relevant information has been captured.
- There is a ‘My CTR Planner’ but it is sometimes not used.
- At CETRs, there is sometimes confusion over who can give consent and how the young person’s best interests can be considered and by whom.
- Sometimes experts are restricted from talking to people, or are told they are not well enough to attend. Professionals may also take a restrictive view on who can be involved in, or be invited to C(E)TRs.
- Lastly, experts commented that for people who are hospitalised, recommendations do not seem to be actioned and they do not know why. For example, it is sometimes agreed at review that a person should get a new staff team because relationships are poor / they do not get on, but this is then not actioned.

3.3 Ideas for improvement

Person-centred reviews

- People need continuity of service, and a nominated person who coordinates actions.
- Power differences have to be reduced via readily accessible information for C(E)TR participants, and more equal representation of families and people with lived experience. Phone access to C(E)TRs is not always offered either, which would help some people and families to take part.
- People need to be supported better to be involved in their review – i.e. with use of ‘My CTR Planner’.

- Families need support, information and access to advocacy too. People and families need to know their rights, about what a C(E)TR is and how to request one. They are usually not aware they can do this.

Reasonable adjustments are needed

- C(E)TRs must be in accessible venues – thinking, for example, about bus routes and wheelchair accessibility is important.
- Review times and places should be arranged around the person so that they can attend – experts gave examples of when a review was arranged for a person when it was their day to access the community (go out), so they chose not to attend their review.
- If meetings are offered in the evenings, more families might be able to attend. Family and carer commitments are often not considered and diaries are managed around the needs of professionals, rather than people
- Notes should be provided in a way that is accessible to all participants, no matter what their background knowledge.
- Advocacy services should not be connected to the provider and be focused entirely on respecting the person's rights.

Experts wanted to develop new ways for people and families to get involved and be supported

- There has to be commitment to involving people in a meaningful way – where true co-production means that people's involvement is valued and therefore enabled.
- Support for families could include peer support, more information about the Care Act and signposting to useful services (resource packs) such as support that will help keep people safe or help in the event of a crisis.

Experts wanted more prevention and personalisation

- There ought to be more preventative types of services including therapeutic / creative services.
- People need to be given more creative options for how they can receive support, for example:
  - Direct payments – support that is right for the person
  - Shared Lives – looking at different ways that a person can be supported in the community

Experts wanted training for schools, providers, and health and social care professionals

- Staff need training to support people, for example Positive Behavioural Support (PBS) as the use of restraint has increased.
- Staff need to be able to manage transition; better support for children, young people and their families.

Experts also thought that statutory C(E)TR guidance would be better

- This would then make the process mandatory and lead to a better likelihood of the policy guidance being adhered to. This would mean that:
    - People themselves would be more likely to take part and be supported.
    - Panels would be more likely to consider issues important to the person – such as their housing or staff team.
    - There might be better provision of information and consistent offers of independent advocacy.
    - Participants would be better prepared for reviews.
    - People and families being aware of their rights, including the right to request a review.