### **Evaluation of Building** the Right Support

Survey Results, December 2017

### **Final Report**

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### **Summary of headline findings**





- An electronic survey was undertaken as part of the evaluation of Building the Right Support. The survey ran
  in November 2017 and will be repeated later in 2018. It gathered views on how well Transforming Care
  Partnerships (TCPs) are functioning. This is a short summary of the main findings.
- There was a good response from all four NHSE regions, including commissioners and providers, NHS and local authority staff.
- Views of TCPs are generally positive 66% of respondents agreed that their TCP is helping to improve the quality of care and support.
- There was agreement that TCPs had resulted in better health services, in particular by making improvements to care and support for people at high risk of admission to hospital.
- Respondents were more likely to disagree, or were more unsure about, whether TCPs had made a difference to wider aspects of people's quality of life, e.g. housing, leisure or employment.
- TCPs are thought to have added value by improving partnership working, leadership and setting local priorities. Improving funding alignment and local workforce skills remain areas to focus on.
- Qualitative feedback supports the notion that health services have improved and that both people and providers are more involved in co-producing care and support, in spite of ongoing challenges in integrating budgets, and releasing funding into housing and new models of community support.
- We did not find many noteworthy differences among responses from the various professional and organisational groups, or between regions, or fast track/non-fast track TCPs.
- We also produced an easy read version of the survey, but this did not work as intended. We will be looking to engage people in different ways in the next phase of the evaluation.



### Introduction



### NHSE and its partners commissioned this survey to understand stakeholders' views on the progress of Transforming Care Partnerships (TCPs) and the national strategy for *Building the Right Support*

As part of the <u>evaluation</u> of the national programme to transform care for people with a **learning, disability, autism or both**, <u>The Strategy Unit</u> at Midlands and Lancashire NHS CSU, <u>ICF</u> (a health research and consultancy company); the <u>British Institute for Learning Disabilities</u> (BILD) and the <u>University of Birmingham</u> produced a survey for everyone involved in TCPs.

- The survey provides an overall view of the programme in November 2017, and explores stakeholders' views of their local TCPs' progress in addressing the key themes identified through the evaluation with a particular focus on what people think about changes in care and support as a result of working together as a TCP. These themes are:
  - > Community-based support, prevention and early intervention
  - > Quality of life, co-production and empowerment
  - > Collaborative systems and partnership working
- The same themes are being examined in greater depth in the ten case studies of TCPs that are taking place in early 2018 – so the survey can also reveal whether key findings from the case study sites are typical of the programme as a whole.



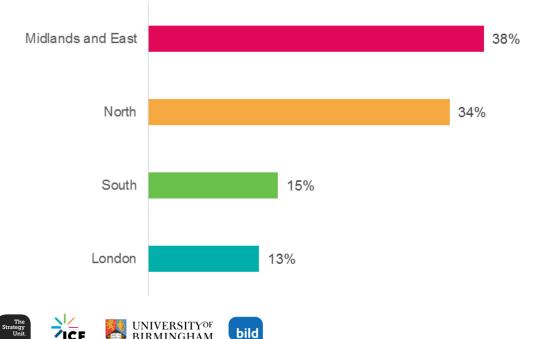
## This survey used snowball sampling to reach all groups with a view about their local TCP

- The survey (and an easy-read survey, analysed separately) was designed by the evaluation team. In developing the easy read version of the survey, we also sought feedback from experts by experience (BILD; the evaluation's expert reference panel; the Empowerment Steering Group; the Mencap/Challenging Behaviour Foundation families group; various members of the NHSE Learning Disability Network) as well as experts from the evaluation's steering group representing NHSE, LGA and ADASS. The evaluation team would like to thank all people who gave their time to contribute to the survey, including those that used it to share their feedback.
- The survey was aimed at everyone who might have a view about their local TCP, including: TCP SROs and leaders; directors of adult social services and children's services; all commissioners, providers, clinicians and staff involved in improving the quality of care and support – whether in health, social care, housing or education; as well as people with a learning disability, autism or both; their family members and carers; and experts by experience; .
- The respondents were reached by using a snowballing method as a central list of everyone who was involved with the TCPs was not available. Respondents were informed about the survey via established NHS and LGA programme communication channels in the first instance (with explicit backing of senior NHSE staff), supported by communications with a wide range of local NHS, independent and voluntary sector organisations. The survey was also sent by email to the Senior Responsible Officer (SRO) in every TCP. Respondents were encouraged to share the survey widely. Respondents were told that their feedback would be anonymised, such that individual TCP results would not be reported.



### We analysed 232 survey responses from 45 TCPs

- Responses were received from all NHS regions, with the largest share of responses from the Midlands and East region.
- The number of responses per TCP ranged from none to 24 (the greatest number of respondents commented on the Cumbria and the North East TCP).
- Three TCPs did not provide any usable information. There were no responses that could be analysed for Bedfordshire, Luton and Milton Keynes; Gloucestershire; or Somerset (as only incomplete responses were received).
- We looked for differences between broadly defined groups (by NHS region, 'fast track' status, funding received; commissioner / provider; NHS / local authority; and 'health' / 'community / non-health' groups).



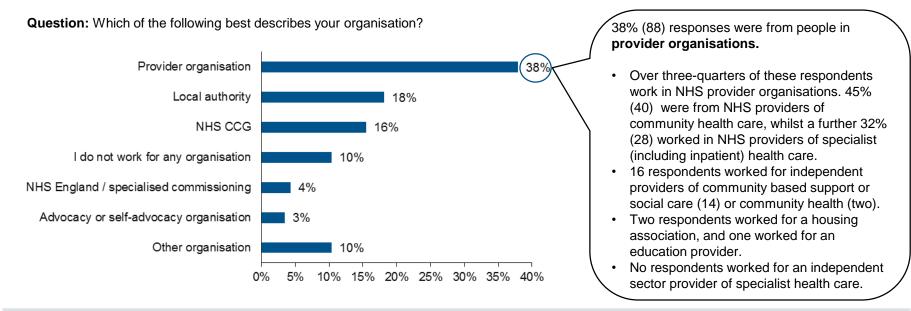
#### Responses by region

- We received 400 responses to the survey, of which 58% (232) contained substantive data (i.e. information other than basic data about the respondent).
- There were responses from 45 (out of 48) TCPs. The number of responses and profile of respondents varied by TCP. In general, Fast Track sites and geographically larger TCPs returned the highest numbers of responses.
- 86% of respondents (200) said they worked with people with a learning disability, autism or both; whilst 18% (42) respondents stated they were also/either a family member or carer of a person with a learning disability, autism or both. Seven respondents said they have a learning disability, autism or both.

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### **Respondents worked in many different organisations**

### Respondents worked in a broad range of organisations, with a notable proportion of responses from providers of health care (either in the community or specialist).



Overall, 49% of respondents (114) stated that they worked in the NHS (provider or commissioner), while 18% (42) were from local authorities.

**Respondents were asked to select any categories which best described their working role, as well as to indicate their main role in their TCP.** Overall, over a quarter of respondents (28%, 75) were clinicians and 16% (43) were commissioners. 7% (15) were TCP Senior Responsible Officers (SROs) or deputies, while four respondents stated they were Directors of Adult Social Services or Children's Services. 12% (27 respondents) said they were experts by experience. 16% of all respondents (37) gave a free text response to describe their role rather than choosing a category – this included managers and leads of local TCP programmes, parents and carers, and those working in other services. We were able to look for differences between broadly defined groups (by NHS region, 'fast track' status, funding received; commissioner / provider; NHS / local authority; and 'health' / 'community / non-health' groups).

**Respondents were also asked if they wished to comment on a certain group's experiences rather than the whole population.** Most respondents (43%, 100) chose to comment on the experience of everyone that their TCP worked with, but 41% (96) said they were commenting on adults only; 6% (15) said family members and carers only; 5% (11) said children and young people only; whilst 4% (ten) respondents said they wanted to comment only about people with autism who don't have a learning disability. This means that overall, the feedback in the report mainly relates to TCPs performance as a whole or their work with adults; no robust conclusions can be drawn about their specific work with children and young people or people with autism – although some of the qualitative responses relate to these groups. We have highlighted some key learning in Annex 1.



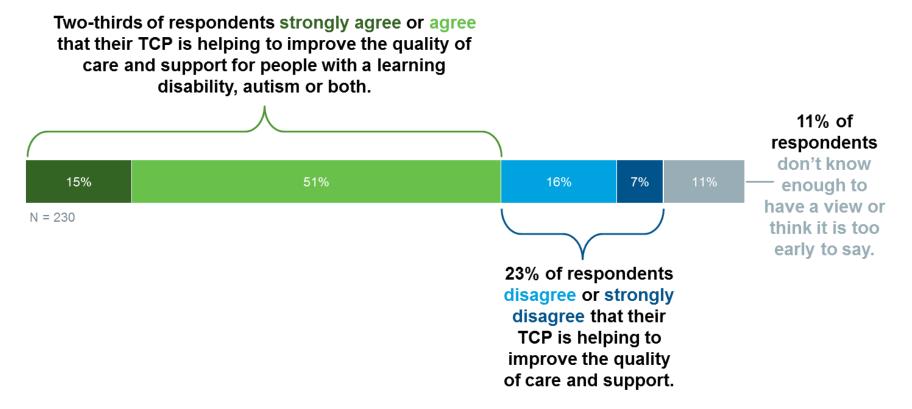
### **Survey findings**



## Overall, TCPs are thought to be improving the quality of care and support

Respondents were asked if their TCP is helping to improve the quality of care and support for people with learning disabilities, autism or both. The majority (66%, 152) agreed or strongly agreed that their TCP is helping to improve the quality of care and support.

Question: Overall, the TCP is helping to improve the quality of care and support for people with a learning disability, autism or both. Do you ...?





### Overall, TCPs are thought to be improving the quality of care and support

#### Further analysis of the responses showed:

- Respondents working with/for people with a learning disability were twice as likely to agree or strongly agree that their TCP is improving the quality of care and support compared to respondents with lived experience (72% and 37% respectively).
- NHS commissioners were more likely to take a more positive view than other groups (26% of them strongly agree that TCPs are helping to improve the quality of care and support, compared to 15% of LA staff thinking the same).
- We did not find any noteworthy differences in the responses between different NHS regions or between professional groups (such as differences between commissioners / providers; local authority / NHS).

"Bringing in ... autistic and LD EbEs [experts by experience with a learning disability] as part of the TCP team has transformed the service"

Expert by experience and commissioner, NHS CCG, Midlands region

"People are leading more fulfilling lives ... People are being understood and HEARD!" Service Manager, Independent provider of community support, North

"The effectiveness of community Care and Treatment Reviews in building bridges between health and social care and ultimately keeping people safe in the community"

Commissioner and co-lead, Children and Young People's Steering Group, NHS CCG, Midlands region

#### "Transforming Care is there facing the challenges head on"

Clinician and family member, NHS provider of specialist health services, North region

"Messages are being shared within health and social care about the agenda and priorities"

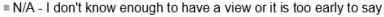
Clinician, NHS community provider, South region



### Most respondents think TCPs are having a positive impact on health services and care, but fewer think that they have made much difference to the wider agenda

Over half of all respondents agreed or strongly agreed that TCPs had improved care and support for people at high risk of admission to hospital (60%, 136); enabled fewer people to be admitted to hospitals and ATUs (53%, 120); and enabled people to be supported closer to home (52%, 120). However, less than a quarter of respondents agreed or strongly agreed that improvements had been made in support or access to education and employment opportunities (19%, 44); quality of local housing (21%, 48); and access to leisure and enjoyment opportunities (25%, 56).

17%		43%	1:	3 <mark>%</mark> 11%	16%
15%	38%		15%	8%	23%
10%	42%		20%	8%	20%
12%	39%		17%	11%	20%
8%	41%		21%	5%	25%
1%	38%	2	0% 9	%	29%
7%	34%		25%	10%	23%
5%	35%	219	6 7%		31%
5%	32%	22%	14	%	28%
<u></u> 2% 269	%	30%	14%	6	28%
4% 20%	6	28%	13%		34%
4% 17%	30	%	20%		29%
15%	28%		17%		35%



Improved care and support for people at high risk of admission to hospital (N = 226)

- Enabled fewer people to be admitted to hospitals or assessment and treatment units (ATUs) (N = 227)
  - Enabled people to be supported closer to home (N = 229)
- Improved care and support for people being discharged from hospital so people don't stay longer than they need to (N = 229)
  - Improved people's overall quality of life (N = 228)
  - Improved support for families and carers (N = 228)
- Given people more choice and control over the way their care and support needs are met (N = 229)
  - Enabled people to maintain stronger relationships with families and friends (N = 229)
- Improved the care and support that people get from mainstream health services (N = 229)
  - Enabled people to choose where they live and who they live with (N = 229)
    - Improved opportunities for leisure and enjoyment (N = 225)
    - Improved the quality and accessibility of local housing (N = 228)

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- Improved support for, and access to, education and employment opportunities (N = 229)
  - Disagree Strongly disagree
  - Strongly agree



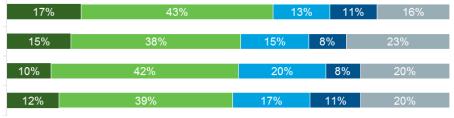
### Top achievements: the views of respondents

Improved care and support for people at high risk of admission to hospital (N = 226)

Enabled fewer people to be admitted to hospitals or assessment and treatment units (ATUs) (N = 227)

Enabled people to be supported closer to home (N = 229)

Improved care and support for people being discharged from hospital so people don't stay longer than they need to (N = 229)



Strongly agree = Agree = Disagree = Strongly disagree = N/A - I don't know enough to have a view or it is too early to say

There was strong agreement amongst respondents about TCPs resulting in improvements to care and support for people at high risk of admission to hospital, and those being discharged on time from hospital.

- NHS commissioners and those who were not from fast track TCPs generally expressed stronger agreement that improvements were made to the care and support for those at risk of admission to hospital and those being discharged from hospital, compared to respondents from local authorities and respondents from fast track sites respectively.
- Respondents with lived experience of a learning disability, autism or both were twice as likely to strongly agree that TCPs had improved care and support for people at high risk of admission to hospital (26% compared to 12% of respondents respectively).
- There was no noticeable difference in views when we looked at respondents' region, level of engagement or whether respondents had a particular role in the TCP.

#### There was also strong agreement among respondents that TCPs had enabled fewer people to be admitted to hospitals or ATUs, as well as for people to be supported closer to home.

- Respondents who said they were highly engaged in their TCPs were less sure about whether or not TCPs had enabled fewer people to be admitted to hospitals or ATUs and be supported closer to home.
- Nearly three-quarters (73%, 11 respondents) of those responding as independent or public providers of community-based support or social care, or as an education or housing association provider, agreed or strongly agreed that TCPs had enabled fewer admissions to hospitals or ATUs, compared to half of those responding as NHS or independent providers of community or specialist health care (52%, 27).
- NHS commissioners tended to agree more strongly that there were fewer admissions and more support closer to home as a result of TCPs, compared to respondents from local authorities.

### **Top achievements: qualitative feedback**

When asked about the greatest successes of their local TCP, respondents tended to focus on the development of community services, successes in discharging people from hospital, changes in culture (working across agencies and bringing agencies together), and increased co-production in commissioning or service development. In particular, respondents often mentioned the positive effects of Care and Treatment Reviews (CTRs), the development of risk registers, new workforce roles and the benefits of integrated working. Some typical comments are shown below. Please see Annex 1 for more detail.

"The 2 CTR managers - 1 for young people and 1 for adults have made a big difference in holding meaningful and valuable CTR/CETRs"

Clinician, NHS CCG, Midlands region

"Governance has significantly improved meaning that in some cases responsibility is focussed at a more appropriate level in the structure" Commissioner, NHS CCG, North region

"Development of joint working at a frontline level across health and social care teams has been part of the local success; developing strong collaboration in ensuring those at risk of admission are supported appropriately and that when admissions are necessary, discharging planning starts immediately. This is under pinned by the embedding of care and treatment reviews across all ages"

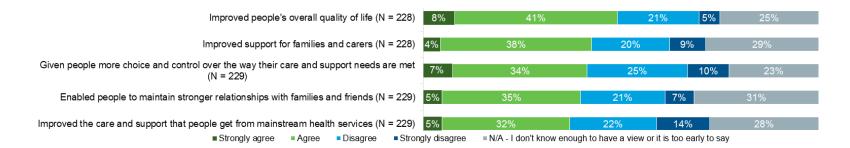
Commissioner, Local authority, South region

"The partners have worked collaboratively and in partnership to agree how to bid for and utilise transformational funding to deliver real change to the local service model, as well as deliver real training and development to the local workforce" TCP programme manager, NHS CCG, Midlands region "Embracing of Positive Behaviour Support as a strategy across the county" Clinician, NHS provider of specialist health services, Midlands region



### Moderate achievements: the views of respondents

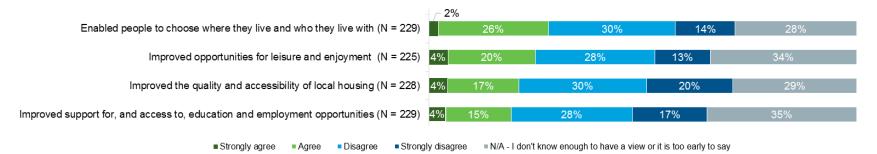
There was partial agreement amongst respondents that changes were being made to: improve people's overall quality of life; enhance support for families and carers; increase people's choice and control of their care and support needs; strengthen relationships with families and friends; and to improve care and support from mainstream health services. However, there were also more respondents who thought that it was too early to say or who did not know if their TCP had made any difference.



- Respondents from TCPs receiving transformation funding were slightly more likely to agree (48%, 49 respondents) that improvements had been made to people's overall quality of life compared to TCPs that did not receive funding (35%, 28). No differences were seen according to organisation, job role or engagement with the TCP.
- Respondents with lived experience of a learning disability, autism or both were more likely to agree or strongly agree that TCPs had improved the care and support people get from mainstream health services (47%, 71) compared to those working with / for people with a learning disability, autism or both (35%, 54).
- Respondents who were hardly engaged with TCPs expressed less strong agreement overall, compared to those highly engaged with TCPs.



### Areas for improvement: the views of respondents



## Respondents were more likely to disagree or strongly disagree, or were more unsure about, whether TCPs had generated any achievements relating to housing, including enabling people to choose where they live and who they live with, as well as improving the quality and accessibility of local housing.

 Commissioners were more likely to strongly agree or agree that TCPs had improved the quality and accessibility of local housing; a quarter of them strongly agreed or agreed compared to 14% of providers who agreed with this statement

Over three-quarters of respondents disagreed or strongly disagreed, or were more unsure about, achievements relating to the wider aspects of improving people's quality of life in the community – opportunities for leisure and enjoyment, as well as support for/access to education and employment opportunities.

- Respondents from non-fast track sites were more likely to strongly agree or agree that there were improved
  opportunities for leisure/enjoyment and education/employment than those from fast track sites.
- Respondents who were commissioners in local authorities were more likely to strongly agree there were
  improvements in these areas, whilst no health commissioners expressed strong agreement in relation to these two
  statements. Overall, however, similarly low proportions of respondents thought that TCPs had led to improvements
  locally.



### Areas for improvement: qualitative feedback

When asked about the greatest challenges in their local TCP, respondents tended to focus on shortcomings across the system that were leading to poor outcomes, particularly for people with forensic needs. Many respondents pointed out barriers with funding, legal problems, difficulties with housing and providers, and poor communication or oversight arrangements, both within TCPs and between TCPs and NHS England. However some respondents also mentioned a lack of (or belated) focus on the wider aspects of Transforming Care, such as improving services for children and young people. Some typical comments are shown below. Please see Annex 1 for more detail.

"Long waiting list for Mental Health support not involving advocacy within meetings -people being unaware of Care Act 2014 responsibilities and upholding these. " Worker in advocacy organisation, Midlands region

"[Challenges are] evaluating and identifying transition costs prior to moves ... understanding that transitions are supported best by involving the person particularly in matching staff"

Director of operations, Independent provider of community

"Gaining senior leadership support for the TCP across health and social care systems. particularly in respect of children and young people. There needs to be a greater push from the TCP team to dedicate some time to the children and young people's agenda, especially in terms of gaining recognition and support from social care leadership and having better representation on the TCP board"

Children's health services commissioner. NHS CCG. Midlands region

"Lack of provider services in the locality with necessary skills to support people in their own homes in the community [and] no local specialist in-patient [ATU] beds should an admission be necessary"

#### "Tendency of CQC to approve large (30+) community residences"

Clinician, NHS provider of community health care and support, North region

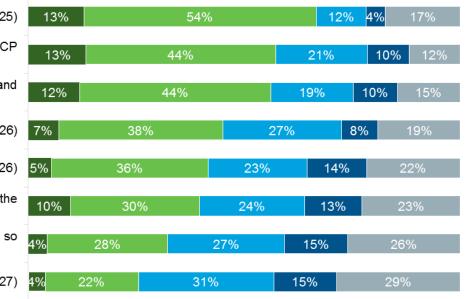
Clinician, NHS provider of community health care and support, North region

"The TCP need time and less pressure on numbers from NHSE so we can focus on quality as well as quantity" Chief executive of advocacy organisation and expert by experience, North



# TCPs have provided focus, leadership, and better partnership working – while workforce and aligning funding were thought to need more attention

Respondents were asked about changes that have been made as a result of the work of their local TCPs. Over two thirds of respondents (67%, 150 respondents) agreed or strongly agreed that clear priorities for action had been set across their TCP, while over half of all respondents also agreed or strongly agreed that changes had been made to improve partnership working (57%, 130) and provide leadership (56%, 127) to improve and transform care and support across the TCP area. On the other hand, respondents tended to disagree that the TCP had improved the skills of the local care and support provider workforce (42%, 94) or the alignment of health and social care funding (46%, 98). We did not find any noteworthy differences in the responses between different NHS regions or between groups.



N/A - I don't know enough to have a view or it is too early to say

Set clear priorities for action across the TCP (N = 225)

- Created a realistic plan for transforming care and support (N = 226)
  - Improved local commissioning of care and support (N = 226)
- Improved the quality of specialist heath care / intensive support in the community (N = 227)
- Improved skills among the workforce in local providers of care and support, so they can support people to live in the community (N = 226)
  - Improved the alignment of health and social care funding (N = 227)
  - Strongly agree Agree Disagree
- Strongly disagree



Improved partnership working on improving care and support across the TCP area (N = 227)

Provided leadership for transforming care and support across the health and social care system (N = 226)

## TCPs have added value compared to previous arrangements, but findings are mixed

Respondents were asked to rate the extent to which TCPs have made a difference, compared to the situation in place before, where "1" corresponded to no difference at all and "5" reflected that the TCP had definitely made a difference. On average, respondents tended to think that TCPs had made the biggest impact on improving decision making and the pace of transformation; fewer respondents felt that duplication of effort had reduced.

Decision making between partners is better than it would otherwise have been (N = 207)

Care and support have been transformed sooner than they would otherwise have been (N = 207)

There is better sharing of data and information to improve people's care and support (N = 208)

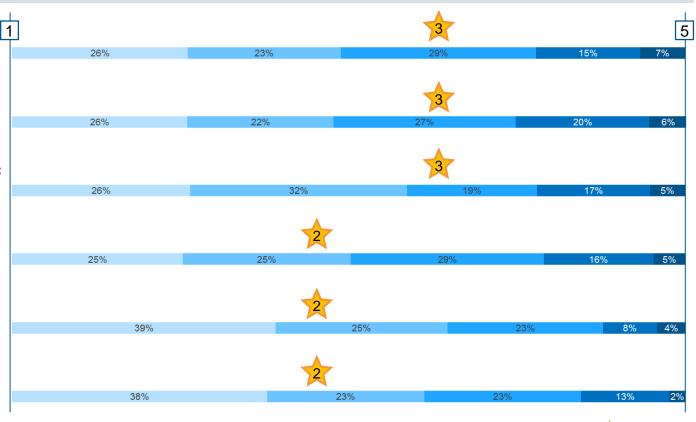
Each partner has a clearer idea of what it must do to transform care and support than they would otherwise (N = 209)

People and their families are driving the changes more than they would otherwise have been (N = 212)

There is less duplication of time and effort among local partners when arranging care and support for people (N = 206)

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★ = Average

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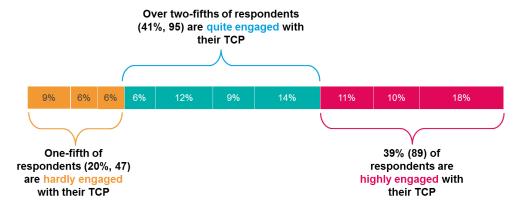
## Even when respondents didn't have a particular role in their local TCP, most still felt engaged

Respondents were asked to state how engaged they were with their local TCP, and whether they had a particular role in the TCP structure.

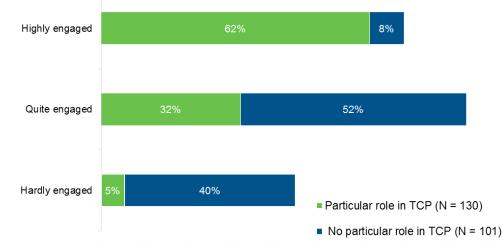
Nearly half of all respondents (44%, 101) said they did not have a particular role in the TCP. Respondents who had a role in the TCP had a diverse range of responsibilities. 15 respondents stated they were TCP SROs, while 18% (42) of respondents stated they had another role within the TCP Board/leadership, and a further 18% (42) stated that they had a particular role within local structures or partnerships. Additionally, 14% (32) of respondents said they were a representative of people with a learning disability, autism or both.

- Nearly two-thirds of respondents with a particular role in their TCP stated they were highly engaged.
- In contrast, 40% of those without a particular role in their TCP stated they were hardly engaged; although 5% of respondents who did have a particular role in their TCP also said that they were hardly engaged in it.

**Question:** On a scale of 1-10, where 1 is 'hardly engaged at all' and 10 is 'deeply engaged', how engaged would you say you are with the TCP?



**Cross-tabulation:** What is your main role in the TCP? How engaged would you say you are with the TCP?





### **Easy Read Survey**



### Introduction

An easy-read, accessible survey was also distributed using the snowball method. This contained questions which mostly had qualitative (open-ended) response options.

**Note:** This element of the survey did not work as intended. Despite the best efforts of the evaluation team and everyone involved in co-producing and distributing the survey, it did not produce useful evaluative evidence. What follows should therefore be treated with extreme caution and should not be used to inform evaluative assessments of the programme. The evaluation team and steering group will not repeat this element of the study and will use a different method to gain the views of people and families.

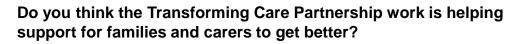
- There were 32 responses to the easy read survey, of which 19 (59%) were complete and 13 (41%) were partial (i.e. containing some limited information).
- Of these, nearly three-quarters (72%, 23 respondents) reported they were people with a learning disability without autism (the others were either people with autism or both), and less than a third (31%, 10 respondents) were a family member or unpaid carer.
- Exactly half of all respondents (16 respondents) worked for people with a learning disability, autism or both. This included nurses, therapists and healthcare assistants as well as volunteers.
- Four responses to the survey were sent from a group.
- Three respondents had been involved in the work their TCP was doing; 22 respondents reported not being involved, while one respondent did not know. However, ten respondents said they were involved in writing their TCP's plan (compared to 14 not involved). A number of those involved in the work of their TCP attended a range of meetings or forums (such as local engagement meetings) or sat on relevant boards. Many respondents who did work for their TCP stated that this was because they were not aware of the work that their TCP was doing.
- Seven respondents said that their TCP was including children and young people, as well as people with autism who don't have a learning disability, in their work. Furthermore, eight respondents said that the families of children, young people and adults with a learning disability, autism or both were also being included by their TCP in its work.

### **Main Findings: Summary**

Do you think your Transforming Care Partnership is improving the care and support that people get, so that they have better lives?

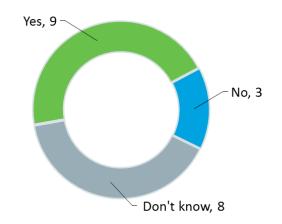
Nine respondents said that their TCP is improving care and support so that people have better lives.

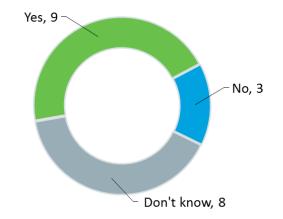
One reflection was that TCPs have led to a more coherent strategy, whilst another respondent suggested that continuing to listen to those with a lived experience of parents and careers who are supporting those with learning disabilities, autism or both, is important in being able to highlight areas of improvement to current services.



Nine respondents said that their TCP work is helping support for families and carers to get better.

Further improvements in this area were suggested, including: giving families and carers more of a voice, sharing more information with them and the continued promotion of local services.







### **Main Findings: Summary**

### Do you think the Transforming Care Partnership work has improved things for you?

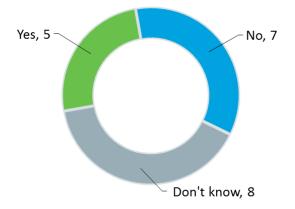
Five respondents said that their TCP has improved things for them. For example, one respondent suggested that the partnership element gets people working together and gives people targets to meet, which means that communication is better.

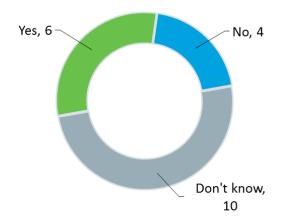
#### Is your Transforming Care Partnership telling people how it is improving the care and support available in your local area?

Six respondents said that their TCP is telling people how it is improving the care and support in the local area.

Suggestions for improving the way TCPs told people about their work included:

- Easy-read newsletters and accessible information promoted on social media, posters, newspapers and the radio;
- More events, including workshops
- Information in local health centres, local groups, hospitals and education settings, and further work with charity organisations.







## Annex 1 – Analysis of qualitative responses in the survey



### Introduction

This Annex focuses on more detailed analysis of the qualitative responses to several questions, where respondents were asked to give short examples of:

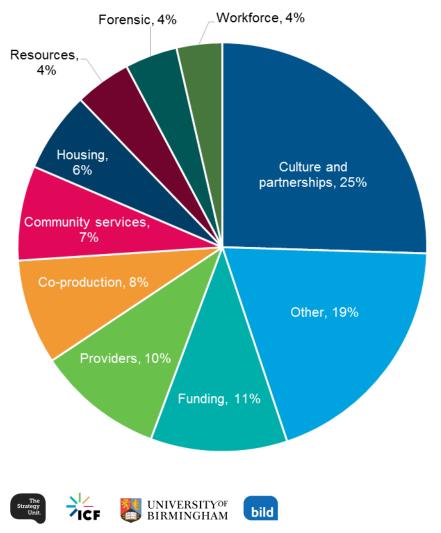
- Greatest challenges for their TCP
- Greatest successes for their TCP
- Support needed from NHSE and partner organisations
- Who has been a key change agent in their TCP
- Good practice in relation to the three key topics identified by the evaluation:
  - Community based services to support people with learning disabilities, autism or both
  - > Working together with people with a learning disability, autism or both and their families
  - Collaborative working between organisations in supporting people with a learning disability, autism or both and their families

Where possible, the research team attempted to group all the responses according to their main theme, to identify the main issues raised. This applies in particular to the responses relating to the challenges, successes and support needs of TCPs. Therefore, the percentages denoting different groups of responses should be treated as indicative and a result of the research team's interpretation of each response, and the relative importance of different themes emerging from the data, rather than as quantifiable measures of respondents' feedback.



### What have been the greatest challenges for your TCP?

The research team grouped all the responses according to their main theme, to identify the main issues raised. Our findings are shown here:



- **Culture and partnerships**: responses about the relationships established among TCP partners and/ or NHSE.
- **Funding:** responses about financial pressures, a lack of funding more generally, or specific issues with funding individual care packages or flows of funding from health to social care.
- **Providers:** responses about the need for an adequate supply of resilient, appropriately skilled providers, to support people living in the community.
- **Co-production:** responses relating to the challenge of engaging people with a learning disability and/ or autism in the TCP and decision-making processes.
- **Community services**: responses about issues with the availability of places in the community or barriers in finding suitable local services.
- **Housing**: responses relating to housing more generally as well as challenges related to the availability of affordable housing for people with complex individual needs.
- **Workforce:** responses relating to workforce availability and skills, including issues with recruitment.
- **Resources**: responses about resources in a less specific sense than finance or workforce alone, e.g. capacity constraints or lack of resources in the community.
- Forensic and legal restrictions: responses about poor planning, lack of information from NHSE on inpatients with legal restrictions, or complexities related to coordinating care and support for these people.
- Other: responses that did not fit easily into any other group or with a cross-cutting rationale or impact, such as communication issues across the partnership, geographic diversity, inappropriate discharges, or the perceived lack of inclusion of people with autism or Asperger's.

### **Challenges relating to culture and partnerships**

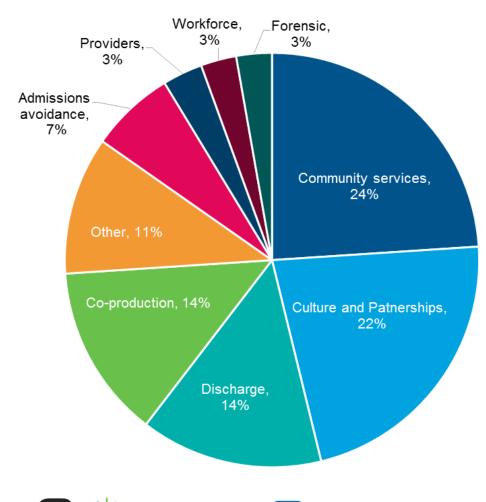
	children and Young People's	"Too much time wasted seeking to collaborate across areas without clear evidence that this will improve outcomes." Local commissioner, Local authority, London region	
	4	ee to a shared strategy in more than outline	

- 25% of responses mentioned challenges related to culture and partnerships.
- The need to act strategically and build stronger partnerships by ensuring engagement across the TCP was frequently
  mentioned by respondents. The need for a shared strategy at the TCP level, and to avoid individual teams acting in isolation,
  was noted. One respondent called for a "clear vision and aims that are translatable to actions", with several highlighting the
  need for more strategic clarity.
- Several respondents stated that services for children and young people must feature more prominently on TCP agendas, pointing to a lack of integration with children's services.
- There were several mentions of CCGs and LAs not working together well, and the need for improved communications between the TCP board and external partners, such as existing forums for local engagement of people with a learning disability.
- The need for a cultural shift was also noted a couple of times, such as the need to alter perceptions that hospital based care is not the only answer to managing behaviour that challenges services; a view thought to be held by health, social care and third sector staff, as well as some families.
- Some respondents thought NHSE could do better to promote better partnership working, pointing variously to a perceived lack of understanding of local authorities or a lack of information about the needs of inpatients.



### What have been the greatest successes for your TCP?

The research team grouped all the responses according to their main theme, to identify the main issues raised. Our findings are shown here:



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- **Community services**: responses about improvements in community support, including mentions of CTRs and Intensive Support Teams.
- **Culture and partnerships**: responses about improvements in partnerships and working together.
- **Co-production:** responses about strengthening the engagement of people and families in designing services and individual care and support.
- **Discharge:** responses related to successes in discharging people from hospital.
- Admissions avoidance: responses related to successes in preventing people being admitted to hospital.
- **Providers:** responses about improvements in working with the local provider market e.g. upskilling, working to deliver bespoke care and support, securing housing options were all highlighted.
- Forensic and legal restrictions: responses about successes in managing people in less restrictive ways.
- **Workforce**: responses about the skills, enthusiasm or improvements in supporting people.
- **Other:** diverse responses highlighted, among other things, the help provided by NHSE, sharing of data and working on needs analyses.

### **Successes relating to community services**

<b>"Development of communi- enhanced community tean</b> Deputy Chair of TCP Board,	ity solutions including n arrangements." , NHS CCG, Midlands region	"The effectiveness of comm Reviews in building bridges social care and ultimately ke community." Children's commissioner, NHS	eeping people safe in the
	<i>"</i> Setting the principle of care as clos		

- 24% of responses perceived the development of community services as a success.
- Many responses identified the development of high quality community services, including provision of "appropriate accommodation" within the community (thereby avoiding out of area placements). This was seen by a couple of respondents as leading to "low reliance on assessment and treatment units".
- The benefits of Care and Treatment Reviews (CTRs) were frequently mentioned in responses: for example, one
  respondent noted that this reduces admissions; while another stated that employing two CTR managers, one for young
  people and another for adults, has "made a big difference in holding meaningful and valuable CTR/CETRs" [Care,
  Education and Treatment Reviews].
- The development of Positive Behaviour Support (PBS) in services was praised multiple times in responses.
- Numerous respondents praised the establishment or expansion of community Intensive Support Teams (ISTs), which a couple of responses noted as assisting in admissions avoidance.



### Successes related to culture and partnerships

"That Transforming Care is there facing the challenges

head on."

Clinician and family member, NHS provider of specialist services, North region

"The partners have worked collaboratively and in partnership to agree how to bid for and utilise transformational funding to deliver real change to the local service model, as well as deliver real training and development to the local workforce."

TCP programme manager, CCG, Midlands region

<sup>4</sup>The development of joint working at a frontline level across health and social care teams has been part of **T** the local success; developing strong collaboration in ensuring those at risk of admission are supported appropriately and that when admissions are necessary, discharging planning starts immediately."

Commissioner, Local authority, South region

- 22% of responses referring to greatest successes were about improvements to partnership working.
- There was wide appreciation for effective partnership working, which has occurred as a result of more collaboration, ٠ joint working and problem solving, and sharing knowledge and expertise between relevant stakeholders and services. One respondent said there was now a "better shared vision between services".
- Several responses highlighted increased collaboration between health and social care, whilst a few responses also ٠ cited more alignment and understanding across children's and adults' services.
- Financial benefits of TCPs were mentioned several times; such as the sense that TCPs are working towards "financial ٠ transparency and cooperation", including pointing to the setting up of joint funding agreements and the availability of funding for pilot activity to meet the aims of BRS.
- Other successes arising from TCPs were also mentioned, such as the advantages of establishing response group ٠ meetings or the successful identification of leads for different strands of activity. Getting different stakeholders together (e.g. commissioners and clinicians) was thought to be a positive development.
- Senior level engagement, and raising the profile of the Transforming Care agenda across the NHS and local ٠ authorities, were also notable successes mentioned by respondents.



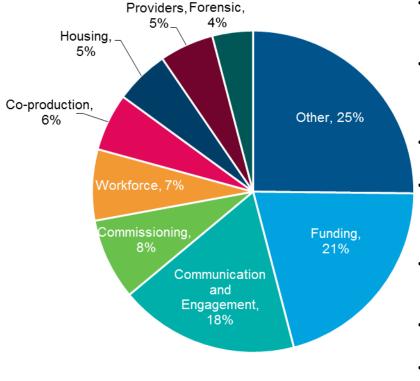
## Respondents identified several catalysts or change agents for making progress in their TCP

- Respondents identified a diverse range of individual roles and organisations that they regarded as being important in driving forward change. They included:
  - Commissioners (e.g. local CCG, local authorities, local partnership bodies, transformation boards)
  - TCP programme managers or SROs
  - Providers including independent community providers and NHS Trusts
  - Clinical staff
  - NHS England
  - Advocacy organisations and experts by experience both local and national (e.g. Challenging Behaviour Foundation)
  - Local MP



## What support, if any, does your TCP need from national organisations such as NHS England and its partners?

The research team grouped all the responses according to their main theme, to identify the main issues raised. Our findings are shown here:



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- **Funding:** responses about the need for access to funding or improving funding flows.
- **Communication and engagement**: responses calling for better communication, more engagement, or clearer guidance from NHSE and its partners.
- **Commissioning**: responses suggesting improvements to the way that local and national commissioners work together, and greater sensitivity to local needs and differences.
- **Workforce**: responses pointing to a need for support with workforce development and training to ensure good quality staff; many respondents wanted action to be taken to support local partners by focusing on support workers' pay and conditions.
- **Co-production:** responses encouraging national partners to keep listening to feedback from parents and carers, and people with lived experience.
- **Providers**: responses relating to holding new and existing providers to account for quality so they perform well, and calls for more support in creating the conditions needed to attract high quality providers into the market.
- **Housing:** responses calling for more of a strategic focus on housing and understanding of needs at the national level, as well as more funding to develop housing in local communities.
- **Forensic**: responses highlighting a need for support to develop clearer forensic pathways in the community.
- **Other**: varied responses focusing on other support needs, including calls for greater recognition of local needs, a focus on quality rather than bed reduction targets, and greater inclusion / recognition for people with autism and behaviour that challenges (but no learning disability).

### Support needs related to funding

"Resources to allow the wo increased the work load of	rk to be done properly - TC has hugely clinicians etc with no financial support - this r areas of work that there is no longer
has then impacted on a capacity to do"	der of specialist services, North region
Service manager, NHS provi	

"Acceptance that the overall change programme is not cost neutral and requires recurrent investment as well as 'one off capital' investment" SRO, NHS CCG, South region

"Funding! Most funding has required matched funding from CCG and this is not happening in my area meaning initiatives eg the clinical services are very keen to start around transforming care e.g. enhanced provision, forensic provision, proactive work and training are not possible or stretched within existing already minimal resources which means change is slow despite clinical services very keen to influence and support this agenda."

Clinician, NHS community provider, South region

- 21% of responses related to a need for greater support with funding or financial flows.
- The need to find more money in the system to address long term investment in community services was often mentioned.
- Issues surrounding the flows of funding were also stated multiple times; for instance, one SRO respondent called for "easier access to funding streams", whilst a couple of responses requested more straightforward transfer of funds as people move out of Specialist Commissioning services into local services. Respondents also mentioned the need for further guidance and/ or support from NHSE, such as the perceived need for a clear strategy, or help with identifying TCPs that are "struggling to implement transforming care" due to financial issues or limitations.
- Some responses mentioned the difficulties experienced due to the need to double fund inpatient services and a transition to new models of care: i.e. the more support was needed to meet the challenge "to develop an enhanced community service to prevent unnecessary admissions before releasing funds from inappropriate inpatient placements".
- Some other respondents also mentioned support to break down boundaries between what is funded by health and what is funded by local authorities, including calls for a greater push on joining up or pooling health and social care budgets.



### Support needs related to communication & engagement

models of care to	Clarity about what good looks like and preferred insure that we are working towards the same goals - between spec comms and community services." ity provider, North region	"Clear measurable actions to the priorities that make a meaningful difference to people with a learning disabil Clinician, NHS community provider, South region	a lity"
	"For our TCP, I feel they have really struggled in the minimal change to date. They would benefit from as on track in their vision and ways of working. This h noticeable already." <i>Clinician, NHS community provider, South region</i>	ssistance from NHSE to help them get back	

- 18% of responses related to communication and engagement.
- On the whole, responses in this category related to calls for more guidance from NHSE and clarity on processes, although
  responses were not always specific as to what clarity was most needed. Among more specific responses, one called for more
  guidance on the needs of young people with a learning disability, autism or both and how to include them in a risk register.
- Numerous respondents noted the need for increased information sharing between stakeholders and clear examples of good
  practice to support local efforts.
- Some responses related to engagement with NHSE, for example, one respondent stated that NHSE need to listen to an "overall narrative" rather than "granular detail" which was considered to be unhelpful to operational leaders and duplicative. Another respondent asked for less frequent reporting and monitoring.
- The desire to strengthen partnership working was echoed by multiple respondents. This included calls for more joint working (e.g. for people with a learning disability funded by NHS continuing healthcare), to bring related work streams together, to improve engagement with all stakeholders more generally, or more specifically to develop the LA role or strengthen the "social care voice".



## Examples of good practice from local TCPs: Community based services

"Intensive Community Assessment and Treatment Team - rapid response, short term advice and interventions for those experiencing an increase in emotional and/ or behavioural difficulties in a community setting; to reduce admissions to inpatient services." Advocate, Self-advocacy organisation, Midlands region

"Developing an enhanced support service (from an existing small challenging behaviour service) in [TCP] focusing on the transforming care cohort and people red/ amber on the risk register requiring a more intensive/ enhanced community response with a view to preventing placement breakdown/ hospital admission and offering more specialist proactive approaches re: transition back to area."

Clinician, NHS community provider, South region

- Good practice examples were varied. Many responses discussed specific new roles (for example, relating to PBS, improving support for people with autism, admissions avoidance). New roles were sometimes linked to the release of funding associated with Transforming Care, such as one description of a "creative practitioner post used with [section] 117 funding to support people in community to not go back into hospital".
- Other examples related to the expansion of community services, for example, the "development of an integrated community team for people with learning disabilities", as well as crisis intervention teams or projects, or community hubs to integrate health and social care. There were also many enhancements to existing services, such as 24/7 access. Intensive support teams and transition teams in particular were mentioned many times as good practice: responses mentioned the ability of these teams to offer an out of hours service, prevent admission and facilitate early discharge.
- Partnership working was also frequently cited as good practice, such as increased engagement of relevant stakeholders or the involvement of local advocacy groups.
- Supporting and upskilling providers was also mentioned, with a couple of respondents praising the expertise of providers with a track record of PBS.
- Some responses also highlighted the stories of individuals with a learning disability and / or autism who had been supported effectively (see the example overleaf).



# Example of one person's story and the organisational background highlighted as good practice

"For one person in particular we who has personality disorder and LD we have worked hard to understand, listen, and most importantly respond in the right way to her, using the principles of PBS [positive behaviour support], linking in with the personality disorder hub and her CPN [community psychiatric nurse].

This coordinated approach has resulted in the person being taken off her CTO [community treatment order] (the first time in almost 30 years!!!!), with a reduction in the use of PRN [psychotropic medication] and self harming behaviours. The person is now in her second year of community living - she has a cat whom she adores, and gives her purpose and a focus in her life. She goes out independently, has a part time job at our area office and is training to become a quality checker within our Organisation"

Service Manager, Independent community provider, North region



## **Examples of good practice from local TCPs:** effective co-production

"Calling meetings looking at what the pe disability wants and what their family wa a meeting with parents."	
a meeting with parents." Clinician, NHS provider of community heat	[[] Caro, ma

"Commissioning a robust advocacy service that reaches out to service users and their families, and helps to engage them at all forums relating to discharge planning and choosing a new community based placement to live in such as CTRs, CPAs, discharge/transition meetings etc." TCP programme manager, NHS CCG, Midlands region

"We were the first CCG to employ an actually autistic EbE [expert by experience] nearly 3 years ago. It is a permanent post, and they are still in place. We now employ two EbEs with a learning disability as well. The three EbEs provide in work training to the whole department, and also work with families of inpatients or people who are in danger of going in to hospital."

Clinician, Expert by experience and commissioner, NHS CCG, Midlands region

- The increased involvement of families in designing care and support was often mentioned in the responses. For example, one respondent felt that working with families "allows for the best ways of ensuring the right provision for our clients and allows for continuity of history and care".
- People's involvement in the design and delivery of services was also mentioned several times for example: taking part in CTRs which led to improved care and support; designing a new pathway for people with behaviour that challenges; or the establishment of co-production groups to monitor the TCP.
- Many responses highlighted the benefits of people with a learning disability, autism or both attending meetings and being involved in boards (such as the involvement of carer groups for children and young people in one TCP board).
- Various attempts to elicit feedback directly from people with lived experience were noted, for example one respondent said that ٠ their TCP carried out a survey with family carers of individuals with behaviour that challenges.
- Partnerships with local advocacy groups were cited numerous times as a means to involve people with lived experience.
- Employment positions for people with lived experience, resulting from the TCP, were highlighted by some respondents. These included experts by experience, expert advisers, and Board chairs.
- Furthermore, wider research projects exploring co-production were also mentioned, as well as the benefits of multi-disciplinary approaches (for example the social care teams and NHS teams working collectively to ensure good quality support).



# Examples of good practice from local TCPs: collaborative working

"Joint steering group with commissioners, NHS and social care for our extended Intensive Support Team pilot enables us to share concerns and problem-solve jointly." Clinician, NHS provider of community health services, Midlands region "Joint commissioning of a community based urgent respite service that can accommodate people who are going into crisis at short notice. The CCGs and Local Authorities worked closely together to design a service that does not aim to replace an acute assessment/treatment unit, but aims to offer a positive alternative for people who do not need a hospital admission. the service spec, procurement and evaluation of bids was also undertaken in partnership with the community assessment and treatment team, who will work in partnership with the service."

Clinician and TCP programme manager, NHS CCG, Midlands region

- Many responses referenced the increased opportunities presented by multi-agency delivery or joint commissioning meetings, TCP working groups and co-production events, or joint working within a community learning disability team – helping to bring together the different perspectives of NHS and social care staff; providers and commissioners; and local advocacy groups, families and carers together with professionals.
- In particular, some responses mentioned the successful development of pooled budgets or similar integrated arrangements focused on the needs of people with behaviour that challenges services, for example: "Section 75 agreement with risk share; pooled fund; community hubs providing health and social care so people can access services closer to home".
- Other examples of collaborative working focused on better relationships between providers and statutory services, for example: "We have an excellent relationship with the local behaviour team in [local TCP] ... The team feel supported and listened to by the NHS behaviour team; they have monthly reviews and are very responsive. As a result [one individual] has lived successfully in the community for 3 years without a re-admission. We could not have achieved this without the support of the behaviour team".
- Other responses referenced mechanisms for sharing learning, for example around PBS training or use of action learning.
- The development of new teams was also mentioned by some as a result of collaborative working. One respondent mentioned Shared Lives Plus as an example: "Shared Lives is [a] service that can support people with complex needs to live well in their local communities. There is a pilot site [here] and as part of the programme we have engaged with the Transforming Care Partnership Board to raise awareness of Shared Lives"
- Among other responses, one specifically mentioned joint working around the development of a local risk register, while another mentioned the benefit of mindfulness training in helping to address people's mental health needs.



## Annex 2 – Additional Findings – Questions for Senior Managers in TCPs



## Introduction

We also asked 11 questions to senior managers only about whether or not their TCP had carried out specific actions in respect of improving care and support for people with behaviour that challenges services. These questions focused on:

- Market shaping and communicating with providers
- Housing strategies
- Investment in community forensic services and intensive support teams (ISTs)

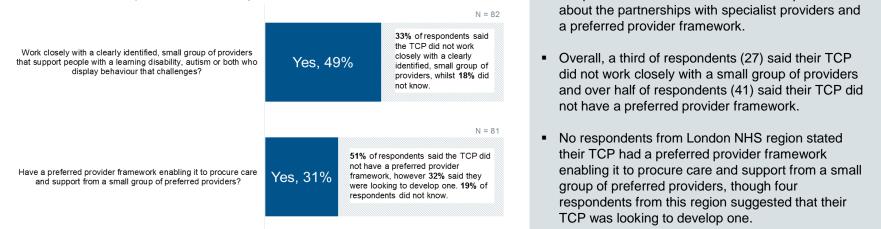
In total, respondents from 32 different TCPs provided answers; 57% (47) of respondents answered at least one of these questions and 43% (35) of people answered all of them.

Responses were provided by chief executive or equivalents, commissioners and/ or commissioning managers, finance managers and service managers, including 12 SROs and two DASSs.

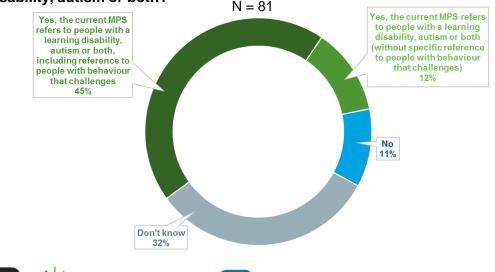


# Many TCPs still do not have a preferred provider framework or a market position statement specific to the BRS population

#### Question: Does your Transforming Care Partnership...



## Does the TCP, or do councils, have a market position statement that addresses the needs of people with a learning disability, autism or both?



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 Respondents from 32 TCPs also answered this question.

Respondents from 32 TCPs answered questions

- Over half of respondents (57%, 46) said their TCP has a market position statement which either refers to people with a learning disability, autism or both, either with specific reference to behaviour that challenges (45%, 36) or without (12%, 10).
- Eleven respondents from the Midlands NHS region stated their TCP refers to people with a learning disability, autism or both, including reference to people with behaviour that challenges, compared to two respondents from the London NHS region and three respondents from the South NHS region.

# Planned activities to stimulate the market included the use of provider events and forums, and frameworks

Senior managers were asked about what plans were in place at the TCP level to further develop relationships with providers, to better meet the needs of people with a learning disability, autism or both. We received **42 usable responses** reflecting a variety of different plans and challenges. The following two slides give an indication of the diverse responses received.

The most common action mentioned by senior managers was the **use of events**, **provider forums and continual engagement to improve communication** with their local market:

- "Provider forum and provider engagement events and targeted dialogue with good providers with a history of meeting the needs of complex people in the community" NHS commissioner
- "We have an on-going programme of meetings with providers to explain need, listen to ideas from the market and so shape the development of new services or shape re-design of existing ones" *LA commissioner*
- "The TCP has a market development workstream and has engaged with housing and support providers across the partnership through a range of TCP events. This will continue especially as cross partnership support develops. This has also introduced new providers and partners to local areas and enhanced overall LD provision" LA commissioner

Other answers highlighted the value of having a clear **strategy for commissioning care and support** for people with a learning disability, and translating this into **plans and frameworks** that apply to providers. A few answers related to PBS specifically:

- "Plan to get a clear understanding of needs of cohort and use this as basis for developing a range of plans with providers including workforce, training, housing etc" NHS Commissioning Lead
- "Outcomes Based Commissioning Framework with lead provider/contractor role. Expected in 18/19. Contract with Providers to be part of this model in driving improved outcomes" NHS SRO
- "The use of [a] specialist provider with expertise in autism and evidenced track record of Positive Behaviour Support has been commissioned on a case by case basis to provide time defined in-reach into families that are at risk of breakdown and or where the son/daughter was at risk of hospital admission. This intensive and bespoke support initially evolved from a creative response to a CTR Development of a micro commissioning process to develop appropriate providers who have expertise in supporting people with behaviours that challenge" LA commissioner

### The challenges in relation to market development are diverse

Senior managers raised a number of challenges connected with establishing framework contracts and creating productive working relationships with providers. A number of responses highlighted issues connected with geography; otherwise, responses were diverse and the challenges identified were varied in their nature.

Some answers highlighted **geographical / boundary issues** - the differences within TCPs at local authority level, or cross-STP working:

- "There is joint working across specific areas within the TCP to share information about providers, commission jointly where it makes sense and to develop joint frameworks where it makes sense. This it sometimes better with 1 or 2 other areas rather than the whole TCP. Local provider relationships (at a local authority level) remain important and providers value local approaches as well as TCP wide approaches where this makes sense to improve outcomes" *LA commissioner*
- "No current overall TCP market position statement. Each council has a market position statement and or relationship with the market. Can only comment on my councils MPS which does make reference to learning disability and autism" DASS and SRO
- "This is being considered ... however the geographic footprint is large and decision making is slow ... Whilst the TCP needs to consider the whole area, exemplars should be considered and worked up across the footprint to reduce delays" *Service* manager, NHS provider
- "We will continue to use our provider forums, and with our health provider. We are exploring how we can best provide community forensic support with regional colleagues but are aware [we] may need a different approach than STP footprint as 3 services (with 3 STPs) is not likely to be helpful" *Local authority SRO*

Other issues highlighted the problems arising from a **lack of** communication or engagement:

- "[Having lead providers] ... and then a framework of smaller ones. The problem for us ... is that we don't know whether we will be included and so it has lead to uncertainty" Service manager, independent sector community provider
- "... more emphasis should be on providers and housing. CCG is also under a lot of pressure from NHSE to discharge Patients to community settings, however there is no where suitable for more complex service users to go" *Clinician, NHS CCG*
- "Some areas have good framework contracts and there have been some "Provider" events organised but I'm not clear to what advantage. Some CCG areas work closely with their MHFT providers which creates small pockets of improvement. There appears to be little region wide improvement strategy being pursued by the MHFTs. There is little incentive for FT providers to fully engage as there is little money to support any significant development of community provision and they are faced with cuts to income with the bed closure initiative leaving them in a void as far as any business strategy planning is concerned" NHS commissioner

# Respondents think TCPs need a clearer understanding of the local housing needs in the future

Question: Do you agree that ...



Less than half of respondents (44%, 33) strongly agree or agree that there is good engagement of local authority housing teams or an integrated approach to housing teams in their TCP

#### Respondents were evenly split on whether there had been additional investment in better homes

Question: Do you agree that ...



Exactly half of respondents (50%, 37) strongly agree or agree that there has been additional investment in better homes for people with a learning disability, autism or both

Respondents were also asked if their TCP has a clear understanding of the housing developments / units required over the next five years to meet the needs of people with a learning disability, autism or both. Twelve respondents said that they were clear about what is required to ensure that those who are in hospital can have a home that meets their needs. Further, nearly a quarter of respondents (24%, 19) stated that their TCP was clear about what is required so that both people who are in hospital, as well as those at risk of admission to hospital, can have a home that meets their needs. However, 35% (28) of respondents said their TCP did not have a clear understanding of the housing developments / units required to meet needs over the next five years, whilst 26% (21) of respondents did not know.



# Responses suggested numerous challenges and solutions to delivering better housing

Senior managers were asked about **what else could be done to improve TCPs' understanding of housing needs**, to better plan for people that are leaving hospital or at risk of admission. We received **44 usable responses**.

Several responses highlighted the need for **more mapping and gap analysis**, with some of them highlighting a need for **better communication about the needs of people who are being discharged**, from NHSE and Specialist Commissioning in particular:

- "Although there is agreement across the local health & social care economy, housing needs are currently assessed & provided on an individual basis. Analysis of existing housing stock & access to emergency temporary accommodation is required" NHS commissioner
- "The planning for people in Spec Comm beds. We know and understand the housing needs of most of our residents living in the community at present, or in short term CCG treatment beds, but the pathways for people out of Spec Comm are not yet clear" LA SRO
- "There is limited information from NHSE on the needs of those people in secure hospitals to enable us to plan for what support and services they may need on discharge. This is difficult as it takes 1-2 years to procure and plan a good discharge and it is difficult to understand what a person's needs may be in a community environment if they have been in a secure service for prolonged periods" LA Commissioner and head of service
- "A greater understanding of the needs and risks of service users coming out of long stay institutions. There has been difficulties finding suitable properties in suitable areas to manage risk safely and safety nets [such as] relapse prevention services are slow to be put in place to aid relapse support and manage risk of readmission" Service manager, NHS provider

Other answers highlighted a need for **longer term planning and learning**, based on co-production with people and staff.

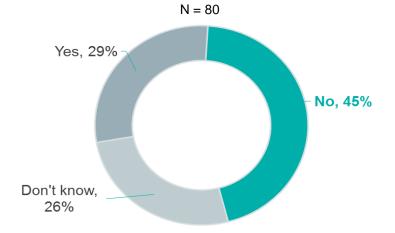
- "We need a period of reflection and review we know that long-stay 'hospital' placements are not the answer for people and we also know that smaller placements do not work for those with the most acute needs if the staff become burnt-out or cannot be easily rotated. Small bespoke cluster models, if operated well and with the correct level of scrutiny may help to repatriate those people with the most challenging needs and also prevent future use of out of area placements" Service manager, NHS provider
- "This is an area that needs a lot of attention in terms of long terms planning the next 20 years - and a better understanding of the [TCP] demographic .... What is the indicative data telling us about Autism / ADHD type (2)? What is the profile of PMLD coming through into adulthood and the demographic relating to older people with LD - over 70 & 80?" LA SRO
- "Commissioners with greater knowledge of customer need and challenges of service delivery [are needed]. Overly bureaucratic approach is taken that is distant from customers. No visible co production which is very poor indeed" LA commissioner

**Integration** – locally and nationally – was also mentioned as a must-do by a number of respondents:

- "Significant [work[ needs to be done to bring local authorities on board and to share the financial risks. Simply apply pressure to commissioners from NHSE is ... a heavy handed approach that is bullying ... CCGs CANNOT write housing strategies when housing sits with local authorities" NHS Commissioner
- "More work is needed with a greater joint commitment from services to provide enough suitable housing options. Lack of accommodation is the greatest cause that I see for hospital admission or move to unsuitable restrictive residential care" NHS Commissioner



## Communication with the market for care, support and housing can be improved, so that providers have a clear understanding of need and can plan strategically



Overall, 45% of respondents from 32 TCPs felt that the TCP is not communicating clearly with the market for care, support, and housing, so that providers have a clear understanding of need and are able to plan strategically.

In the qualitative comments, many responses focused on the need for TCPs to **communicate simply**, **regularly and clearly with their providers** and develop better processes for engaging them, as well as **greater integration** – usually in combination with more strategic planning for support and housing needs across all the partners. "[I need] Someone to explain it [the TCP's commissioning intentions for housing] clearly rather then in a complex way. I have been to 2 information sessions and sort of understand it - but feel not really knowing the detail and how it will affect us and service users."

Independent sector provider of community support, Midlands region

"[To improve communication we need to be] Developing comprehensive needs assessment of inpatients and those at risk of admission/in residential school placements and sharing this with providers"

Commissioner, NHS CCG, London region

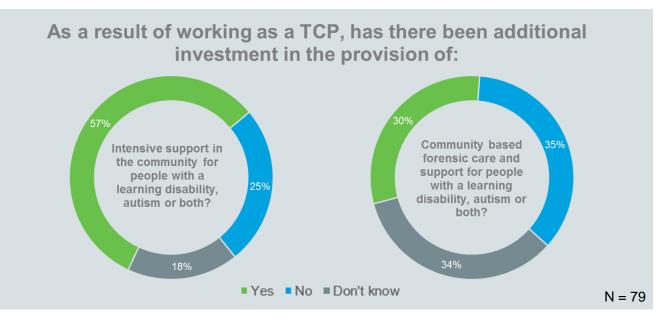
"A greater understanding of the needs and risks of service users coming out of long stay institutions [is needed]. There has been difficulties finding suitable properties in suitable areas to manage risk safely ... There are difficulties with housing association and purses of money to support those people who may need to live alone due to risk."

Service manager, NHS provider of specialist health care, North region



# Respondents were more likely to report that additional investment has gone to intensive support and housing, rather than community-based forensic care and support

Respondents were also asked if there was additional investment in the provision of support and care.



In the qualitative comments, typical responses related to:

- The short-term funding and challenging funding position behind some of the efforts to develop crisis support and intensive support for people with forensic needs (e.g. small-scale pilots making it difficult to prove a sustainable impact)
- Differences in the nature of the investment (some responses alluded to successful investment of transformation funds; other responses highlighted difficulties in accessing funds such as dowries; elsewhere investment appears to be limited to funding PBS training)
- Efforts being hampered by a lack of integration and joined-up thinking (e.g. no pooled budget arrangements)
- Many responses said that the development of local solutions to improving community based forensic care and support was still in development, with an uncertain funding environment



# Annex 3 – Survey questions used



## About you and / or your organisation

#### 1) Which TCP are you commenting on?\*

#### 2) Which of the following applies to you? (Please tick all that apply)\*

- [] I am a person with a learning disability, autism or both
- [] I am a family member or carer for a person with a learning disability, autism or both
- [] I work with / for people with a learning disability, autism or both

#### 3) Which of the following best describes your organisation?\*

- () Local authority
- () Advocacy or self-advocacy organisation
- () NHS CCG
- () NHS England / specialised commissioning
- () Provider organisation including NHS, independent or voluntary sector
- () Criminal justice / police
- () Other organisation: \_
- () I do not work for any organisation

#### 4) Which of the following best describes the provider organisation you work for?\*

- () NHS provider of specialist health care e.g. inpatient services
- () Independent sector provider of specialist health care e.g. inpatient services
- () NHS provider of community health care
- () Independent sector provider of community health care
- () Public sector provider of community based support or social care
- () Independent sector provider of community based support or social care
- () Education provider
- () Housing association

#### 5) Which of the following best describes your working role? (Please tick any that apply)\*

- [] Expert by experience e.g. a person who has lived experience of the services being looked at as part
- of the TCP work
- [] Advocate for people with a learning disability, autism or both
- [] Chief executive or equivalent
- [] Director of Adult Social Services
- [] Director of Children's Services
- [] Social worker or Care manager
- [] Clinician (including allied health professionals)
- [] Commissioner / commissioning manager
- [] Finance manager
- [] Service manager
- [] Care and support navigator
- [] Support worker providing care and support to people
- [] None of the above (please describe): \_

#### 6) What is your main role in the TCP?\*

- () A representative of people with a learning disability, autism or both
- () Senior Responsible Officer (SRO) or deputy
- () Other role within the TCP board / leadership. Please state your role:

() Other role within local structures or partnerships (e.g. TCP sub group, learning disability or autism partnership board). Please state your role () I do not have a particular role in the TCP

7) On a scale of 1-10, where 1 is 'hardly engaged at all' and 10 is 'deeply engaged', how engaged would you say you are with the TCP? Click on the scale to answer.\*

#### 8) Are you responding to this survey:\*

- () On behalf of my organisation
- () As an individual

## 9) If your experience or work mainly relates to a particular group of people, whose experience do you wish to comment on?\*

- () N/A I am commenting on the Transforming Care work as a whole () Adults only
- () Children and young people only
- () People with autism who don't have learning disability
- () Family members and carers only

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## **Effectiveness of your Transforming Care Partnership**

10) Overall, the TCP is helping to improve the quality of care and support for people with a learning disability, autism or both. Do you:\*

- () Strongly agree
- () Agree
- () Disagree
- () Strongly disagree
- () N/A I don't know enough to have a view or it is too early to say



## What has your local TCP achieved?

11) Thinking about the Transforming Care Partnership, to what extent do you think its work has enabled the following results to be achieved?

	Strongly agree	Agree	Disagree	Strongly disagree	N/A - Don't know or too early to say
Improved people's overall quality of life					
Improved support for families and carers					
Given people more choice and control over the way their care and support needs are met					
Enabled people to maintain stronger relationships with families and friends					
Enabled people to be supported closer to home					
Improved the quality and accessibility of local housing					
Enabled people to choose where they live and who they live with					
Improved the care and support that people get from mainstream health services					
Improved support for, and access to, education and employment opportunities					
Improved opportunities for leisure and enjoyment					
Improved care and support for people at high risk of admission to hospital					
Improved care and support for people being discharged from hospital so people don't stay longer than they need to					
Enabled fewer people to be admitted to hospitals or assessment and treatment units (ATUs)					

#### 12) Thinking about the Transforming Care Partnership, to what extent do you think its work has enabled the following changes to be made?

	Strongly agree	Agree	Disagree	Strongly disagree	N/A - Don't know or too early to say
Set clear priorities for action across the TCP					
Created a realistic plan for transforming care and support					
Provided leadership for transforming care and support across the health and social care system					
Improved partnership working on improving care and support across the TCP area					
Improved the alignment of health and social care funding					
Improved local commissioning of care and support					
Improved skills among the workforce in local providers of care and support, so they can support people to live in the community					
Improved the quality of specialist heath care / intensive support in the community					





## The difference made by coming together as a TCP

## 13) What, if any, difference has coming together as a TCP made - compared to the situation before the TCP was in place?

Select the number of stars to indicate how much of a difference has been made. To remove your answer, please click "X".

- · Care and support have been transformed sooner than they would otherwise have been
- Each partner has a clearer idea of what it must do to transform care and support than they would otherwise
- · Decision making between partners is better than it would otherwise have been
- People and their families are driving the changes more than they would otherwise have been
- There is less duplication of time and effort among local partners when arranging care and support for people
- There is better sharing of data and information to improve people's care and support

#### 14) What have been the greatest challenges for your TCP? Please list up to two examples

15) What have been the greatest successes for your TCP? Please list up to two examples

16) What support, if any, does your TCP need from national organisations such as NHS England and its partners so you can improve the lives of people with a learning disability, autism or both? Or what changes should be made so TCPs are better able to provide evidence of successful improvement? Please list up to two examples.

17) In your view, has any particular organisation or person been a key change agent for ensuring progress happens in the TCP?

18) Please state the name of the organisation or the role of the person you have in mind (please do not use individual names):\*



## **Approach to Transforming Care and Support**

19) Does the TCP work closely with a clearly identified, small group of providers that support people with a learning disability, autism or both who display behaviour that challenges?

- () Yes
- ( ) No
- () Don't know

## 20) Does the TCP have a preferred provider framework enabling it to procure care and support from a small group of preferred providers?

() Yes

- () No, but we are looking to develop one
- () No, and we have no current plans to develop one

() Don't know

21) Does the TCP or councils have a market position statement that addresses the needs of people with a learning disability, autism or both?

() Yes, the current MPS refers to people with a learning disability, autism or both, including reference to people with behaviour that challenges

() Yes, the current MPS refers to people with a learning disability, autism or both (without specific reference to people with behaviour that challenges)

( ) No

() Don't know

22) What plans does the TCP have to further develop relationships with providers, to better meet the needs of people with a learning disability, autism or both? Highlight (if relevant) any different approaches taken between different localities within your TCP.

23) Does the TCP have a clear understanding of the housing developments / units required over the next five years to meet the needs of people with a learning disability, autism or both?

() Yes, we are clear about what is required so that both people who are in hospital, as well as those at risk of admission to hospital, can have a home that meets their needs

() Yes, we are clear about what is required so those who are in hospital can have a home that meets their needs

( ) No

() Don't know



## **Approach to Transforming Care and Support**

24) What else could be done to improve the TCP's understanding of the steps required to ensure that suitable housing is in place for people with a learning disability, autism or both, who are currently in hospital, or who are at risk of admission to hospital?

25) In your view, is the TCP communicating clearly with the market for care, support, and housing, so that providers have a clear understanding of need and are able to plan strategically?

() Yes

() No

() Don't know

#### 26) What more could be done to improve this flow of communication?

#### 27) To what extent do you agree with the following statements?

- · There is good engagement of local authority housing teams within the TCP
- There is an integrated approach in housing teams to addressing the needs of people with a learning disability, autism or both
- There has been additional investment in better homes for people with a learning disability, autism or both

## 28) As a result of working as a TCP, has there been additional investment in the provision of intensive support in the community for people with a learning disability, autism or both?

() Yes

() No

() Don't know

29) As a result of working as a TCP, has there been additional investment in the provision of community based forensic care and support for people with a learning disability, autism or both?

() Yes

( ) No

() Don't know



## Good practice in your local area

## 30) We are interested in good practice. For each of the topics below, please summarise up to three examples of good practice that the TCP in your area has stimulated or developed.

- · Community based services to support people with learning disabilities, autism or both
- · Working together with people with a learning disability, autism or both and their families
- Collaborative working between organisations in supporting people with a learning disability, autism or both and their families

#### 31) Please write any other comments here for the national evaluation team

