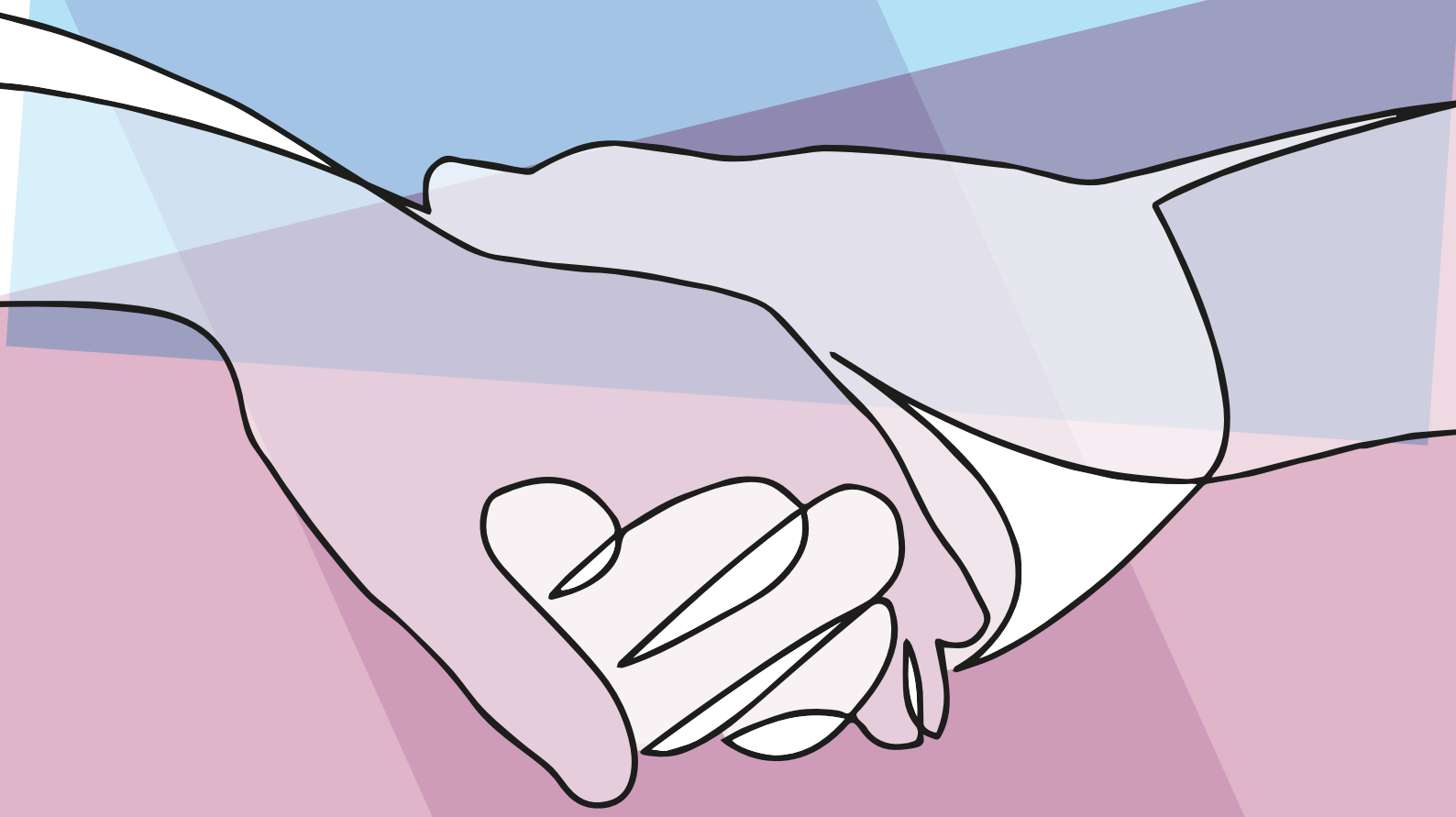
NEW DIALOGUES
DECEMBER 2020

Directors of adass adult social services



Transforming care

How can progress be improved?

New Dialogues is a series of think pieces supported by the partners of ADASS

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AS THINGS STAND

It is nine years since the abuse of people with learning disabilities or autism or both at Winterbourne View came to light. The government responded by pledging that everyone inappropriately placed in institutions would be moved to community settings. Subsequent targets for progress in achieving this have not been met[1]. The latest NHS figures available at the time of writing this report show 2,100 people in this group were receiving inpatient care commissioned by NHS England at the end of August 2020[2]. During that month, 80 people were admitted to hospital and 105 were discharged. The average length of stay for people who remained in hospital in August was more than five and a half years, with one in ten inpatients having been in hospital for ten years or more.

Since the beginning of lockdown in March, the numbers of people in inpatient beds has remained largely static. While the challenges posed by the pandemic must be considered a significant factor in hampering attempts to reduce numbers in recent months, figures show slow progress in achieving net reductions has continued over a prolonged period. This is despite integrated arrangements, which involve NHS England commissioners, clinical commissioning groups (CCGs) and local government through Transforming Care Partnerships (TCPs), having time to embed new and more streamlined approaches under the Building the Right Support plan announced in 2015[3].

The government said in October 2017 that the total number of patients with a learning disability or autism or both receiving inpatient care had fallen by 14% to 2,445 since March 2015. A target was then set to reduce numbers further to between 35-50% by March 2019. However, the figures for this month showed the number of inpatients had only reduced by a further 8% to 2,260. The NHS Long Term Plan published last year has now delayed the target for a 50% inpatient bed reduction to 2023-24.[4]

Meanwhile, evidence of the mistreatment of patients in specialist hospitals continues to emerge. Last year undercover filming by the BBC's Panorama showed abuse at Whorlton Hall in County Durham[5]. In September this year, Essex Police launched an investigation into reports of abuse at the Yew Trees hospital in Essex run by Cygnet Health Care[6]. Additionally, the use of restrictive interventions continues to rise in treatment settings, with a 45% increase from 3,045 instances in May 2019 to 5,520 in May 2020[7].

Earlier this year, the Equality and Human Rights Commission launched a legal challenge against the Secretary of State for Health and Social Care over a failure to move people with learning disabilities or autism or both out of inappropriate settings[8].

This discussion paper is sponsored by housing association Home Group, which last year started providing adapted community accommodation and care support teams for people with complex needs leaving inpatient treatment settings. The paper aims to highlight local government and housing provider perspectives on the challenges in the current Transforming Care system and complements a previous Home Group briefing paper, which explores views on barriers to progress from within the NHS, councils and providers.

"We probably do not have effective systems to enable those transitions to really benefit the individual as opposed to saying whose pocket is it going to come out of."

TRANSFORMING CARE PARTNERSHIPS

The ambition set out in the Building the Right Support plan was to significantly increase the pace of systemic change by shifting funding from inpatient services to community support though a new financial framework. This aimed to encourage TCPs to reach agreement on how to invest the money available across local systems to facilitate discharges from hospital and reduce admissions. However, the limited progress in reducing the numbers of

people receiving inpatient care suggests these arrangements have not been consistently effective.

Feedback from one area that piloted Transforming Care reflected that the funding the partnership received was very helpful and supported the development of services which made the community offer more robust. This included increased capacity of specialist health and care workers and the development of unplanned care beds to prevent people being admitted to hospital. This initially allowed some money to be made available for commissioning care packages and accommodation but, now the initial investment has ended, funding constraints across organisations and an ongoing lack of clarity over how money should move through the local system is hindering the TCP's progress. The Council felt that the lack of clarity around a longer term funding transfer agreement (FTA) is obstructing the development of future commissioning options. The change in governmental steer about the focus on a transfer of 'dowries' for those who met specific conditions to directly fund support packages, to a the use of FTAs based on the numbers of net reductions with a negotiable local approach to dowries, has impacted on the ability to reach a resolution locally. Feedback from authorities suggested the underpinning premise that a move from hospital to community would reduce the cost of packages and shift monies from health to local authorities has not fully materialised. The council said the requirement of NHS organisations to focus on reduction targets "makes it harder to share and see [funding] as a joint resource" and "did not necessarily enable the right people to leave in patient settings as it was about the numbers rather than outcomes". "We understand and share the principle of preventing admission, but the idea of the money trickling down from bed closures has not really happened and that makes it tricky for all partners," a Commissioning Manager says. "The strategic agreement is there; it is just how we finance it does not add up."

Moira Wilson, Co-Lead on Learning Disabilities for Association of Directors of Adult Social Services, says the process of implementing a FTA by TCP's has been difficult in some areas. She highlights that the two sources of health funding - from both NHS specialist commissioning and CCGs - created complications, particularly when responsibility for an individual was transferred from the former to the latter. "You can see there are all sorts of opportunities for things to go wrong," she adds. But Ms Wilson says a move away from FTA guidance focused predominantly on dowries could help to improve the process by encouraging system partners to focus more broadly on the funding needed for all people with learning disabilities or autism or both who need community support.

Stephen Chandler, ADASS Vice-President and Corporate Director of Adult Services at Oxfordshire County Council, says developing collaboration and agreement on finances in his area has been aided by shifting the focus away from dowries. "The thing that helped us was not the people who came with a dowry, but rather the people who did not have a dowry, then saying 'you haven't got the money for this, neither have I' and focusing on how to make this work," he says. But Mr Chandler admits his council is still solely paying for expensive care packages of up to £9,000 a week as agreeing who qualifies for funding through NHS continuing health care is difficult. "I am having good constructive conversations with the CCG in Oxfordshire, but we have not reached an agreed way forward yet," he says.

PROVIDER PERSPECTIVES

Offering a provider perspective on TCP's, Home Group executive director Rachael Byrne says she does not believe current arrangements have generally worked well. Ms Byrne cites one example of experiencing at first hand "difficult arguments" between a CCG and a council over responsibility for an individual in hospital, rather than a collective focus on that person's needs. "The current funding challenges facing the local authority can act as a disincentive for efficient discharge into community-based care as this delays the need for the local authority to take responsibility for this," she says. Ms Byrne adds that this friction over money and control exists in other areas and the

process needs streamlining to address "a mire in the middle" between hospital care and appropriate community alternatives.

Jeremy Porteus, chief executive Housing LIN, a network of housing, health and social care professionals, says there remains a "high probability" of blockages as discharging individuals is subject to transitions through health and social care systems. "We probably do not have effective systems to enable those transitions to really benefit the individual as opposed to saying whose pocket is it going to come out of," he says. "I am sure there are many parents or carers who despair about that."

THE HOUSING CHALLENGE

Providing an adequate level of specialist accommodation is clearly key to reducing inpatient care and improving quality of life. However, the high costs and levels of financial risk involved can act as a deterrent to development. A shortfall in supply of suitable accommodation in some localities is also said to drive up the level of out-of-area placements, creating the risk of individuals becoming disconnected from their families.

Mr Chandler says every decision about housing is also a decision about care and support, and getting accommodation right is the "first thing" that contributes to improving an individual's wellbeing and behaviour. But he adds housing providers are often not involved early enough in discussions on discharge plans and case management. "People will say 'we know what we want, now we need to find a housing provider'", Mr Chandler says. "I would ask why they did not talk about housing and accommodation needs right at the beginning?" Ms Byrne agrees, saying a lack of acknowledgement of housing providers' expertise at an early stage in the process causes avoidable delays, particularly as care providers often struggle to find a suitable housing provider. This, she says, can result in people being placed in inappropriate accommodation which is either institutional in character or inadequate for their needs, leaving them vulnerable to reaching crisis and being readmitted to hospital.

> *"Every decision about housing is also a decision about care and support"*

Home Group's investment model for this type of housing involves receiving government grant to build specialist accommodation or adapt existing stock. Ms Byrne says this aspect of the housing benefit process is complex as it's a very detailed exercise for each customer who will have different requirements for their overall rent and service charges. Whilst there is a definition of rent, it's often applied differently by local teams. This takes time, often up to six months.

A Commissioning Manager says that when individuals do not have their own tenancies, they are more vulnerable to being moved or readmitted to an institutional setting when a provider cannot deliver adequate support. "If people have got their own tenancy, they can stay at home and you would get a different care provider in and it gives people more security," they say. "The more secure tenancies people have got, the less likely they are to be thrown into crisis."

Ms Wilson says the long lead-in time for development means all housing providers need certainty about future revenue, but adds the complexity of commissioning specialist housing for people with challenging behaviour can be underestimated. Therefore, TCP's should establish strong partnerships with housing providers to utilise their expertise in finance and delivery as early as possible. This view is echoed by Mr Porteus, who says increasing involvement of housing experts would improve plans for the short and long term. "It should be a mix of looking strategically at the demand side and what breadth of housing choices are in that locality, as well as looking very specifically at the case management and the blockages being put in place to support someone being transferred," he adds.

Mr Porteus says a clear commitment by organisations on investment in the "TCP economy" and a sustainable local housing offer are key to forging effective alliances. "These are provider organisations which want to have stewardship locally and be seen to have 30 to 40 years investment in supported living, as opposed to just building a house and moving on because somebody is going to buy the company out," he adds.

Mr Chandler says mutual commitment between housing providers and commissioners will not only improve the process of successful discharge, but also build resilience to meet future demand. "You need a provider that is prepared to stand up alongside you when things are getting really difficult," he adds. "They need to be really committed to this group of people. As part of the commitment you need to recognise the cost of keeping that accommodation to the standard it needs to be, as well as physical adaptions there need to be to start with."

THE IMPACT OF REGULATION

The Care Quality Commission has adopted a presumption that community care settings for this cohort of people will usually accommodate six people or less. Ms Wilson says that, while hospitals must not be replaced with another form of institutional care, this must be balanced with the investment risk which means some providers seek to achieve more economies of scale through some higher occupancy on single sites. "The supported living model or extra care support is the preferred option but good quality modern accommodation which gives people independence and their own front door so they have choice of who comes in and out of their house may not always have to be single person," she says. "That is when we need local discussions about who the people are that need accommodation and how we can get good quality discussions going at a local level between social care, housing providers, the CQC and the NHS to come up with local person centred solutions."

CAPITAL FUNDING

As part of the new financial framework under Building the Right Support, NHS England made an initial £15m in capital funding available to TCPs, pitched as a key component to effective delivery of community care options. However, accessing this funding for development has proved a challenge in some areas.

One council identified that it had been "on a five-year journey" working to get approval for capital funding for bespoke accommodation for people with the most challenging behaviour. They describe a complex and constantly shifting process, with regular changes to the rules and guidance requiring information to be reproduced in many forms. "It has involved hundreds of hours of work by commissioners, finance, legal and planning to get this money," the council said.

Mr Chandler admits he has also found accessing this capital funding problematic. "My experience of working with NHSE on capital, particularly dowry capital, is extremely challenging because it is too distant, it needs to be locally driven," he says. "Getting a decision made quickly is really difficult."

Despite existing challenges in accessing capital, Mr Porteus sounds a note of optimism about the government's recent announcement of just under £12bn for affordable housing, 10% of which has been set aside for supported housing. "I am encouraged that at a system level there is leverage from capital to create solutions," he says. "How you then deliver those solutions to ensure the right people get them is the tricky pathway that TCPs and their partners need to work out."

THE MOST COMPLEX NEEDS

The fact that the most recent NHS figures show the average length of stay for people in hospital was more than five and a half years illustrates current arrangements have broadly struggled to find alternative settings for those individuals with the most complex needs and challenging behaviour, particularly as their circumstances have also led to them becoming institutionalised.

Ms Wilson says that, while establishing support for these people is particularly "tricky", an approach to discharge plans and commissioning focused on a "risk averse" medical model may also be hindering progress on reducing numbers and limiting opportunities to improve behaviour and wellbeing. "Some people may be receiving a high level of care in a hospital and then the consultant will say this person, because of the risk to themselves and to others, needs two to one or three to one staffing," she says. "But I have had feedback from some local authority social workers who say once the person is settled, we have been able to reduce their care plan significantly because they are no longer having to be supported in a very close way."

One Commissioning Manager says their TCP was able to discharge people at the lower end of need "some time ago", but a challenge remains to find community placements for those at high risk to themselves or others who are currently in secure beds but deemed ready for discharge. They add the partnership is looking to collaborate with their providers

on new service models as there is a view that some of these people are not ready to move into existing models of community provision. The commissioner said: "There are also a lot of people now who have Asperger's or autism who would really benefit from being in single person settings, but none of our secure or locked rehab services operate on a single accommodation basis. We need to be looking at that model and how we start to step people down and get them better ready." Commissioners identified that it is difficult to formulate a model of community care for those with the most challenging behaviour as the level of need could result in a requirement to effectively create "a single person prison in the community", which would not normally be considered within a local authority remit. "There are some very specialist services that are outside of what anybody would normally deem community provision," they say. "While we recognise that a person does not need treatment anymore, is a community offer not necessarily the right offer and how do we manage that?" The commissioners added that the challenges in establishing support for this group of people is "a big reason why we have reached the point of the numbers being stuck".

Mr Chandler agrees there is "an overreliance and dependency on the medical model" within the Transforming Care system. He believes too much responsibility for making decisions placed on one clinician, the Registered Medical Officer (RMO) who is usually a psychiatrist, leads to a reluctance to accept a degree of risk. Mr Chandler cites an example of one individual with complex needs who "pushed the boundaries of everything we did" and would repeatedly be picked up by the police or attend A&E. "I had conversations with the press, the NHS and the police and said we must need to give this young man a real chance," he says. "Too often as a society we are often not prepared to recognise that some of the most complex individuals have the same right as anybody else to live in our communities."

"We need local discussions about who the people are that need accommodation and how we can get good quality discussions going at a local level between social care, housing providers, the CQC and the NHS to come up with local person centred solutions."

Mr Chandler adds that some providers "who claim to be experts" often struggle to maintain support for people with challenging behaviour. But he says a flexible approach to commissioning is key. "You need to commission in a way that gives the provider the flexibility and assurance that when they are struggling you are not going to pull the plug," he says. "You have got to have that flexibility and relationship with you provider and I'm not sure that all councils and the NHS have done that."

THE WORKFORCE CHALLENGE

Mr Chandler says the significant workforce challenges faced by care providers adds to the complexity of ensuring a consistency of support that prevents people reaching crisis. He says maintaining capacity can be "a battle" for providers, with many experiencing high turnover of staff due to the demands of the job and low levels of pay.

Another commissioner identified that this challenge is a legacy of the financial constraints across the system. "The ability to have a well-skilled, well-paid, well-supported workforce when funding is being squeezed is difficult and we know the workforce is hard to find," they say. "We do pay enhanced rates for a lot of these services but there is still a long way to go and we experience a lot of churn in our residential care placements where we pay quite a lot of money for people, but services cannot always manage the complexity."

LOOKING LONG TERM

The NHS Long Term Plan could potentially alter the dynamic of Transforming Care arrangements. On people with learning disabilities or autism or both, the plan states NHS will "support local systems to take greater control of how budgets are managed" and "local providers will be able to take control of budgets to reduce hospital admissions".

Ms Wilson says it has been difficult to sustain social care involvement in some TCPs as councils also need to focus on the higher numbers of people who were not part of Transforming Care. But she adds that is "changing positively" due to the Long Term Plan. "It may be easier for local authorities to see that it is not just about that small group of people who are categorised as the Transforming Care cohort, it is about a long-term plan for people with disabilities or autism or both," Ms Wilson says. "That has probably helped strengthened the partnership arrangements."

However, one manager voiced concern that the health focus of the Long Term Plan could result in "all the energy and focus being on meeting targets and not seeing the bigger picture".

Mr Chandler says he fears the current focus on developing Integrated Care

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Systems under the Long Term Plan could lead to medical models being further embedded in TCPs, putting the influence of councils at risk. "Local authorities are best placed to lead for this group of people, even though a lot of them will be subject to NHS care and support," he says.

LEADERSHIP

Mr Porteus says making significant progress on reducing inpatient care relies on "getting the culture right" in local systems so there is a focus on the rights of the individual. "We need to think beyond what the fabric of the housing is to the other more person-centred issues that need to be put in place," he says. "We need to hard-wire a culture around creating better multi-disciplinary working, but at the same time consider the opportunities to create better spaces and places for people with learning disabilities or autism or both to live, including where technology can play its part."

Mr Chandler says there must be a shared goal to join up and coordinate care and support around the individual, but currently leadership nationally and locally "is not providing a clear, assertive and ambitious narrative" about how society and systems support people who have the most complex of needs. "Commissioning leadership, medical leadership and broader system leadership does not focus on what is best for the individual," he says. "It is about being constantly ambitious for that person, ambitious for them to be independent, ambitious to manage the challenges and ambitious to overcome whatever causes the deterioration in health and behaviours."

RECOMMENDATIONS FOR CHANGE

- **A clear collective understanding must be established on how funding for Transforming Care will move down from the government and through CCGs and local authorities. This would help streamline the discharge process and ensure individuals receive appropriate community-based support**
- **Current housing rights for people in care settings should be reviewed to strengthen the right to live at home, to remain at home following a change of care needs, and to be discharged home after a spell in hospital.**
- **Specific housing support programmes should be funded and developed to enable radical improvements to the current NHS Plans for Transforming Care, Mental Health crises support, and tackling homelessness and rough sleeping. Housing is a key determinant for better care, and equality.**
- **Housing and care providers should be directly involved in discussions on the process of hospital discharges at the earliest opportunity. Their expertise would speed up the process by enabling more flexible commissioning to ensure individuals are supported through the transition from institutional settings. Provider input would also help create more sustainable options to meet specific needs in the long term**
- **The process of securing NHS England capital funding should be more accessible and efficient, with clarity on eligibility criteria and the progress of applications. This would increase investment in the variety and profile of care options while contributing to a reduction in the need for inpatient care, particularly for those with the most challenging behaviour**
- **Funding available to local areas should be increased to help address the serious workforce challenge across the current system. Financial constraints across organisations is contributing to keeping pay low and maintaining a skills gap which results in high rates of staff turnover. This seriously undermines both the capacity and quality of care**

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