

Transforming Care – improving care and support for people with a learning disability and/or autism who display behaviour that challenges

Purpose of report

For information.

Summary

This report provides an update on the Transforming Care programme; the programme is due to finish in March 2019 and aims to improve services and support for people with a learning disability and/or autism who display behaviour that challenges, enabling them live ordinary lives in the community. It is an all age programme. The programme of work developed in response to the abuse scandal of people with a learning disability at Winterbourne View hospital. The Local Government Association is one of a number of national delivery partners, including NHS England. The vision underpinning the programme of work sets out what system partners are seeking to achieve for people with a learning disability and/or autism:

“Children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life.”

Local delivery is through 48 Transforming Care Partnerships (TCPs) across England - collaborations of CCGs, NHSE, local authorities and other partners; each have produced a 3-year transformation plan (March 2016-March 2019) aimed at supporting a reduced reliance on inpatient services through the development of community services.

Recommendation

Members of the Community Wellbeing Board are invited to note and comment on the update on the Transforming Care programme.

Action

Officers to continue to support this programme activity and will support close working

Contact officer: Jane Alltimes
Position: Senior Adviser
Email: jane.alltimes@local.gov.uk

Transforming Care – improving care and support for people with a learning disability and/or autism who display behaviour that challenges

Background

1. Origins of the programme; The 3 year Transforming Care programme aims to improve services and support for children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.
2. The programme of work developed in response to the abuse scandal of people with a learning disability at Winterbourne View hospital. The Local Government Association is one of a number of national delivery partners (along with NHS England, the Department of Health, the Association of Directors of Adult Social Services, the Care Quality Commission and Health Education England).
3. The investigations post-Winterbourne found that many people are inappropriately placed in hospital provision, in some cases effectively living in inpatient settings – far away from their local communities, families and friends – and with little or no planned focus on discharge.
4. The focus of the Transforming Care programme is on bolstering community capacity, thereby significantly reducing the numbers of people with a learning disability and/or autism reliant on inpatient settings. The challenge for local commissioners is as much about preventing new admissions to inpatient care by providing alternative care and support in the community (with a focus on early intervention and prevention) as it is about discharging those individuals currently in hospital.
5. For those who continue to need hospital treatment, there is a commitment to this being as close to home as possible, of a high quality, and focused on independence and recovery so that people do not stay in hospital for longer than necessary.
6. There is a focus on “shifting the balance of power” from more paternalistic services which are ‘doing to’ rather than ‘working with’ people in recognition that individuals, their families and carers are experts in their own lives and should have choice and control over the services they receive.
7. The underpinning national service model (October 2015) sets out a vision for services and support that are personalised and asset-based, recognising and valuing people’s aspirations and strengths and the contribution they can make to their local communities. The model is structured around nine principles seen from the point of view of a person with a learning disability and/or autism:

- 7.1. I have a good and meaningful everyday life.
 - 7.2. My care and support is person-centred, planned, proactive and coordinated.
 - 7.3. I have choice and control over how my health and care needs are met.
 - 7.4. My family and paid support and care staff get the help they need to support me to live in the community.
 - 7.5. I have a choice about where I live and who I live with.
 - 7.6. I get good care and support from mainstream health services.
 - 7.7. I can access specialist health and social care support in the community.
 - 7.8. If I need it, I get support to stay out of trouble
 - 7.9. If I am admitted for assessment and treatment in a hospital setting because my health needs can't be met in the community, it is high-quality and I don't stay there longer than I need to.
8. There are an estimated 24,000 people with a learning disability and/or autism (who display behaviour that challenges) in the community who are at risk of being admitted to an inpatient setting without the right support. This number is likely to be significantly higher when taking into account those people who end up in secure hospitals having been diverted from the criminal justice system.
9. As of November 2017, there were 2,465 people with a learning disability and/or autism in a hospital setting for behaviour that challenges/a mental health condition, including secure settings as part of a youth/criminal justice pathway. Of these 2,465 people, 880 have been in hospital for five years or more (36 per cent of the total inpatient population).
10. Programme aims; The programme has four key aims;
- 10.1. A better community infrastructure resulting in a substantial reduction in the number of children, young people and adults with a learning disability and/or autism who display behaviour that challenges, placed in inpatient settings;
 - 10.2. Prevention of people living in inpatient services and a reduction in length of stay for those people admitted to an inpatient facility;
 - 10.3. Better quality of care and support for children, young people and adults with a learning disability and/or autism who display behaviours that challenge; and
 - 10.4. Better quality of life for children, young people and adults with a learning disability and/or autism who display behaviours that challenge.

11. Delivery; NHSE have a particular focus on supporting TCPs to meet their trajectories based on the ambitions set out in the national policy document, “*Building the right support*”; that is;
 - 11.1. A reduction of 45 – 65 per cent of CCG-commissioned inpatient capacity;
 - 11.2. A reduction of 25 – 40 per cent of NHS England-commissioned capacity.
12. However, the focus must also be on ensuring the development of high quality services and support in the community; both specialist and ‘reasonably adjusted’ mainstream services that are able to meet the needs of people with a learning disability and/or autism, and enable community participation.
13. 48 Transforming Care Partnerships (TCPs) (collaborations of CCGs, NHSE, Local authorities and other partners) have been established across the country (by March 2016); each have produced a three year transformation plan (April 2016 – March 2019) setting out how they will achieve the aims outlined above.

Issues

14. Progress has been slower than anticipated; however, the numbers of people with a learning disability and/or autism in hospital settings are gradually reducing and we are seeing many positive examples of people being supported to move out of hospital into community settings with highly personalised and bespoke arrangements around them. **See appendix 1 for some examples.**
15. The population of people in hospital is not static (e.g. people are admitted, and others discharged), so looking only at ‘net’ change in the numbers of people in hospital can be misleading. We know, for example, that over the course of the programme 500 people who had been identified as having lengths of stay in hospital of over five years (at the start of the programme) have now been discharged from hospital and are living in the community.
16. This is likely to be as a result of a combination of things, including the development and ‘embedding’ of new community-based services. In the first year of the programme 21 new community services had opened; focusing on putting in place intensive support and community forensic capacity aimed at supporting transitions from hospital, as well as preventing admissions.
17. Transformation requires a multi-agency response, including across health, social care and housing as well as with criminal justice system partners and both adult and children’s services. Solutions for children and young people remains of significant importance to the programme, both because of evidence of service gaps and because this should also help to reduce adult demand for inpatient facilities.

18. For the LGA, our key priority areas of work for 2018-19, based on the key challenges being raised by local authority partners, are:
- 18.1. Funding - ensuring the money moves with the person out of hospital and enables support to be provided in a different way in the community (see below section for more on funding);
 - 18.2. Housing – we have appointed seven regional LGA senior advisers to support TCPs to develop and implement housing plans, and support a joined up approach to housing with local authority housing teams;
 - 18.3. Mobilising a high quality care and support market – supporting provider markets with the skills and expertise to support this group of people; the relatively small number of people within the Transforming Care ‘population’ means that working across larger footprints is required.
19. In addition, the LGA remains focused on supporting the sharing of good practice and innovative approaches amongst TCP partners relating to the provision of high quality and person-centred approaches to care and support which recognise individual and community assets. To support this approach we created and facilitate the empowerment steering group, ensuring the voices of people with lived experience are informing the work. The empowerment group have recently commissioned the ‘*So what, what next?*’ project to support individuals to be a part of their communities as active citizens, promoting progression, growth in independence and the development of natural supports. Members of the empowerment group are all people with a learning disability and/or autism, or family members, who have spent long lengths of time in inpatient provision but who are now leading good lives in the community.
20. It is worth noting that , whilst the Transforming Care population is a relatively small number of people within the wider learning disability and autism population, they represent a highly heterogeneous group – e.g. from those known to services who may self-injurious or aggressive behaviour unrelated to any mental health condition, to those people who may have been diverted to secure hospital settings from the criminal justice system – often not known or in receipt of services until coming into contact with the criminal justice system – and perhaps not even getting a diagnosis until admission to hospital. Some will have been in hospital for many years, not having been discharged when NHS campuses or long-stay hospitals were closed. This range of people provides additional complexity to achieving the transformation required.
21. Going Forwards: The LGA has established a strong team to discharge its responsibilities as a partner. The team consists of an assistant director, a senior adviser, and part time advisers on housing with support for each local government region.

22. Based on the priority areas outlined above, we will continue to influence the national programme activity ensuring the voice of local government is informing the work, including through governance arrangements. As part of this, we have established and are co-chairing a national finance group to support progress around the financial flows.
23. Our regional support to TCP local authorities and partners is based on a sector led improvement approach, through the sharing of good practice and peer support.
24. Of note to members is workstream activity relating to possible hospital site closures. As the numbers of people needing hospital provision falls, fewer beds in some hospital provision will need to be commissioned in the future. NHSE/CCG commissioners are clarifying with providers what kind of hospital services they do not think they will continue to need going forward. It will be up to providers to decide how they respond to these commissioning plans. In some cases, providers will respond by changing the services they offer, including potentially closing some hospital services and offering more services in the community. We are already seeing providers take these decisions, and expect more to follow in the coming months.
25. Importantly, whilst this activity reflects positive progress in achieving less reliance on hospital provision, we are also aware that this may not be an easy time for those individuals impacted as well as providers of hospital care, staff and suppliers in the areas where those services are located. We are continuing to support this programme activity and will support close working with individuals and families to manage any transitions from hospital into the community.
26. Resources
 - 26.1. Transforming Care: Councillor's briefing:
<https://www.local.gov.uk/sites/default/files/documents/transforming-care-council-ee2.pdf>
 - 26.2. Transforming Care: 'Must Know' guide:
<https://www.local.gov.uk/sites/default/files/documents/transforming-care-must-kn-3e0.pdf>
 - 26.3. Empowerment steering group: <https://www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/transforming-care/empowerment>

Financial Implications

27. The national policy document, "Building the right support" (BRS) set out that: *"Local transforming care partnerships will be asked to use the total sum of money they spend as a whole system on people with a learning disability and/or autism to deliver care in a*

different way that achieves better results... this includes shifting money from some services (such as inpatient care) into others (such as community health services or packages of support)".

28. To support TCPs to deliver this, NHSE made available £30 million transformation funding (to be match funded by CCGs) to support double running costs; as well as £100 million capital funding for housing/accommodation projects.
29. BRS set out a commitment to provide “dowry” payments for long stay patients – i.e. money for social care costs to follow the individual into the community at point of discharge. To enable this to happen, NHS England’s specialised commissioning budget has been aligned with Transforming Care Partnerships and an underpinning Funding Transfer Agreement is being developed to shift resources from NHSE-funded provision into local systems.
30. However, there remain ongoing challenges for local authorities in meeting the costs of individuals who are moving out of inpatient provision into community settings – many of whom require expensive packages of support. Despite the ‘mechanisms’ in place to support the flow of money from health to social care, local authorities have continued to report difficulties with the process, as well as in truly “joint” decision-making relating to the transformation required.
31. The LGA’s focus is therefore on supporting the development of TCP financial plans which clearly set out the scale of the funding requirements, the transitional costs required and the local arrangements supporting the funding flows; we are supporting the development of risk-share approaches that seek to ensure no one partner is disadvantaged by the arrangements.

Implications for Wales

32. The Transforming Care programme is an England-wide programme, and there are therefore no distinct implications for Wales. However, some of those patients in English inpatient facilities may be from Wales and may be wanting to return to community settings in Wales on discharge from hospital.

Next Steps

33. Members of the Community Wellbeing Board are invited to note and comment on the update on the Transforming Care programme.

Appendices

34. Appendix 1 - **examples of positive moves from hospital to the community**

Appendix 1 – examples of positive moves from hospital to the community

Josh's story

Josh was diagnosed with severe autism at the age of two and began seriously self-harming around the age of 11. He was placed into specialist inpatient provision in Birmingham but this meant his parents faced a 500 mile round trip to visit him from their home in Cornwall. Josh remained in hospital in Birmingham for a number of years, far away from his parents and siblings.

Josh is now back living in a specially adapted house near his parents. The house was adapted structurally to meet Josh's needs, including open plan light and spacious areas, and easy access to the garden.

The house fixtures and fittings were also designed around Josh's needs, for example no sharp corners that Josh could bang his head on. Josh's care and support team were specially recruited and his care plan carefully developed to meet his unique and individual needs. The joint health and social care funding will help ensure more children like Josh get the help they need in more suitable ways. Josh has an education, health and care package that means he gets tailored support to do the things that keep him well and happy. He goes to school for a few hours a day, is able to go for long walks on the beach which is nearby, and is now able to see his family regularly, spending time with his siblings and extended family.

Josh's dad Phil said: *"Physically and emotionally he's so much better, he sounds better and is eating better. His self-harming has improved and when people see photos of him they say 'look at the sparkle in his eyes'"*.

James' story

James, 58, who is originally from the North Somerset area, has moderate learning difficulties and at times his behaviour can be extremely challenging, requiring a high level of supportive care and assistance with his daily routine. He has received support in two different hospitals (Dec 2011-April 2013 – April 2013-Aug 2016) both miles away from his home town.

Local partners worked together to purchase and equip a bungalow for James, far closer to his home area in Somerset. They put together a staff team to support him during the day and night. James had input into how his new home would be furnished and it was decorated to fit in with the things James likes. Professionals took into account what he would like to do when living there.

In August 2016, after over 5 years in hospital. James was able to move into his new home. He has settled in well. He has been able to regain a certain level of independence and is learning new skills to better look after himself. He makes his own breakfast and drinks and enjoys being able to get out for walks in the local area.

James also has an interest in wildlife; James and his staff team are now in the process of developing a garden with bird boxes so that he can enjoy the wildlife up close.