

# Transforming care



How do you know you are doing everything you can to safeguard and promote the wellbeing of people of all ages with learning disabilities and/or autism who display behaviour that challenges, including those with a mental health condition?

## Key messages

Too many people are still living in hospitals who should be living in the community. As a lead member responsible for promoting the welfare of the most vulnerable people in your area, you can use your leadership role to ensure that this issue remains an urgent priority for your council and your local partners.

The Transforming Care programme is based on the assumption that children, young people and adults with a learning disability and/or autism with behaviours described as challenging have the right to live satisfying and valued lives, and to be treated with dignity and respect. They should have a home within their community, be able to develop and maintain relationships, and get the support they need for a life that is healthy, safe and rewarding.

You can help make change happen by:

- Asking your director and staff how council and other services are linking together to make sure that people aren't admitted to hospital inappropriately or spending too long there.
- Working with other relevant portfolio holders such as those with responsibility for housing and children and young people's services to ask what is being done across the council to make sure that the needs of this group of people are considered by all relevant services.
- Making sure it is kept on the table as a crucial issue by your health and wellbeing board (HWB). Your HWB should actively oversee progress on the Transforming Care Plan developed by the Transforming Care Partnership (TCP) for your area. Ensure you know who, from your own area, are members of the TCP and which people with learning disabilities or autism it is established to support.
- Ensuring your TCP have a process for rigorous scrutiny of new referrals to settings like assessment and treatment units and are working to ensure that as soon as someone is admitted to hospital, a plan is developed for how and when they can leave.
- Enabling local strategies and plans (such as the Joint Strategic Needs Assessment (JSNA), Health and Wellbeing Strategy, learning disability strategy and Children's Plan) to be influenced by people with learning disabilities and/or autism, including those with behaviour described as challenging, their family members and wider support networks; and that progress, obstacles and solutions to them are shared with local people.
- Working with Local Healthwatch and other voluntary and community sector organisations and local advocacy services to ensure individuals and their families are engaged in transformation of their services.
- Working with your Health and Overview Scrutiny Committee to ensure progress is happening at pace and scale.
- Making sure that serious and urgent consideration is given by NHS and council commissioners to pooling budgets for learning disability services to join up care pathways and long-term provision. Demarcation of funding responsibilities may sometimes get in the way of people receiving appropriate care and support. This issue should be part of discussions about integrated care and use of the Better Care Fund (BCF).
- Acting as a champion for people with a learning disability and/or autism and ensuring local commissioning and services are shaped by the views of children, young people and adults with a learning disability and their families and/or carers.

## Why you need to know

Unfortunately, we, as a society, still have some way to go to transform services for this very vulnerable group of people. For a minority of people with a learning disability and/or autism, national and local government have recognised that we have been and remain too reliant on:

- inappropriate inpatient placements, with too many people placed in hospitals, and staying there for long periods of time, often far away from their families, often because the right option is not available locally
- inappropriate models of care and support, which are not personalised and which do not allow people to be close to their families or local services
- poor care standards, with too many examples of poor quality care, and too much reliance on restraint.

People with a learning disability and/or autism who display behaviour that challenges are a highly diverse group. Some have a mental health problem which may result in them displaying behaviour that challenges. Some, often with severe learning disabilities, display self-injurious or aggressive behaviour unrelated to any mental health condition. Some display behaviour which can lead to contact with the criminal justice system. Some have been in hospital for many years, not having been discharged when NHS campuses or long-stay hospitals were closed. The new services and support we put in place to support them in the community need to reflect that diversity. It is vital that the quality of the services are of a very high standard and that they are personalised to meet the specific needs of the individual and enable them to have the most fulfilling life possible. Planning for these services should start from childhood to ensure that sufficient and appropriate services are in place to meet people's needs well in advance of them reaching adulthood.

## The Transforming Care Programme

Following the exposure by the BBC of the abuse of people with learning disabilities that took place at Winterbourne View Hospital, the Government set out in a Concordat its pledge to work with others, including NHS and local government commissioners, to transform care and support for all children, young people and adults with learning disabilities and/or autism who display behaviour that challenges.

Progress was initially slower than hoped in reducing the number of people in inpatient settings and increasing the number receiving good quality care and support in the community. Although hundreds were transferred out of inpatient care, the numbers admitted remained higher than the numbers transferred out. To make more and urgent progress on this issue, the LGA and five delivery partners (including NHS England, the Department of Health, the Association of Directors of Adult Social Services (ADASS), the Care Quality Commission and Health Education England) have developed the Transforming Care Programme. This renewed approach brings key local delivery partners together with shared governance structures to improve community services for this group and reduce the numbers in inpatient care, with a view to making significant progress by 2019.

The programme includes people of all ages with a learning disability and those with autism who do not have a learning disability, as well as those with both a learning disability and autism. There are approximately 2,600 people in this group who are inpatients and an estimated 24,000 people in the community who are at risk of being admitted to hospital without the right support. 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. There is a focus on shifting the

balance of power from more paternalistic services which are 'doing to' towards those that 'work 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.

As part of its commitment to improving the care of people with learning disabilities, NHS England has developed Care and Treatment Reviews (CTRs) for people who are at risk of admission or currently in receipt of specialist learning disability or mental health inpatient services and are the commissioning responsibility of NHS England or a CCG. Each CTR review involves the commissioner of that service and two expert advisors – an individual or family member with experience of learning disability services (an 'expert by experience') and an independent clinician as well as those who are providing the current care of the person whose care and treatment is being reviewed. The CTR asks four questions:

- Is the person safe?
- Are they getting good care?
- Do they have a plan in place for their future?
- Can their care and treatment be provided in the community?

Following the CTR, the review team makes recommendations, with follow-up checks to ensure the activity is being delivered. Individuals and anyone involved in their care have a 'right to request' a CTR if they are concerned about their care and treatment in a specialist hospital setting.

In October 2015, LGA, ADASS and NHS England published Building the right support, a national plan to reduce inpatient provision and enhance community capacity for people with a learning disability and/or autism who display behaviour that challenges. Forty eight Transforming Care Partnerships (TCPs) have been established, covering all areas in England. This means that each TCP is likely to include several councils and CCGs. They

each have a board which may differ from area to area in the details of its set-up. Each TCP is responsible for developing a three year 'transformation plan' to March 2019 and each has a Senior Responsible Officer (SRO) responsible for ensuring the transformation plan is implemented.

To support TCPs a service model was also published in October 2015 to describe 'what good looks like' in services and support. The model is structured around nine principles seen from the point of view of a person with a learning disability and/or autism:

- I have a good and meaningful everyday life.
- My care and support is person-centred, planned, proactive and coordinated.
- I have choice and control over how my health and care needs are met.
- My family and paid support and care staff get the help they need to support me to live in the community.
- I have a choice about where I live and who I live with.
- I get good care and support from mainstream health services.
- I can access specialist health and social care support in the community.
- If I need it, I get support to stay out of trouble.
- 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.

## Questions to consider

Do you understand how commissioning works for care and support for people with behaviour described as challenging and how some people have ended up with long stays in secure hospitals or assessment and treatment units?

In your council's area, has there been a review of the care of all people with learning disabilities or autism in inpatient beds and a personal care plan agreed for each individual based around their and their families' needs and agreed outcomes?

Do you and your HWB know how many people whose ordinary homes are in your area are in hospital assessment and treatment centres or similar placements, who is responsible for commissioning and monitoring their care and how much it costs?

Are the needs of people in this group included in your JSNA and other relevant strategic plans (eg your Children and Young People's Plan, your learning disability strategy and your CCG's Commissioning Intentions)? Is there a joined up approach to local commissioning for this group?

How can you support individuals, their families and carers in being heard when shaping services? Do you know if there are sufficient levels of accessible and good quality advocacy support for individuals and families? Are you in contact with any families in your area?

What role do people with learning disabilities and autism, their families and carers play in overseeing implementation of the TCP action plan and what is happening in your own area?

Do you understand the role of the TCP for your area? Do you know who the SRO is and how to contact her or him? Are other elected members (eg those with responsibility for children's services and health) sufficiently briefed to understand the role of the TCP?

What is the governance framework for monitoring and reporting progress in your council's area on your TCP's action plan?

How do you keep up to date with their actions and with the numbers moving in and out of inpatient care? How are they reported to and monitored by the HWB?

How do you work with councillor colleagues to ensure there are joined up health and social care services for children 0-25 years with learning disabilities and autism?

How can you work with NHS clinical colleagues to ensure that physical conditions and illnesses experienced by people with behaviour that challenges are identified and treated appropriately? (Some instances of challenging behaviour have been traced to physical problems, such as toothache, which could easily have been treated).

What are you and NHS partners doing to ensure that providers of care and support demonstrate that they are capable of meeting the needs of people who show behaviour that challenges, that they can provide positive behaviour support and that they can provide the right environment and skilled staff?

How are you and your NHS and housing partners working with providers to develop rapid expansion and improvement in community provision, including intensive support services, to enable the transfer of people from inpatient facilities? What transitional arrangements are in place while community provision is being expanded?

Do you understand the role of your children's and adults safeguarding boards in this agenda? Are you satisfied that the links between these boards and other relevant bodies such as the HWB are the right ones and that between them they have effective early warning systems for picking up possible cases of abuse?

How is your workforce planning taking account of the need for appropriate training and skills development which involves people who do or will use services and their families?

## Useful links

Department of Health (2012), Winterbourne View Review – Concordat: Programme of Action: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213217/Concordat.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf)

LGA/ADASS/NHS England (2015), Building the right support (the national plan for transforming care): <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

LGA/ADASS/NHS England (2015), Service model for transforming care: <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

You can find out more about your local TCP, such as which councils and CCGs it includes, as well as how to contact its SRO at: <https://www.england.nhs.uk/learningdisabilities/tcp/contact/>

Information about Care and Treatment Reviews: <https://www.england.nhs.uk/learningdisabilities/ctr/>

More information on the Transforming Care Programme, and useful resources for councils: [www.local.gov.uk/transforming-care](http://www.local.gov.uk/transforming-care)



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