

A place I call home:

responding to Winterbourne View



How do you know you are doing everything you can to promote the wellbeing of people with learning disabilities and/or autism who have a mental health condition or behaviour that challenges?

Key messages

Watch the BBC Panorama programme that exposed the abuse that took place at Winterbourne View Hospital and read the serious case review and the Department of Health's review, 'Transforming Care, and Concordat: Programme of Action' reports that followed it. Use your leadership role to ensure that this issue remains a priority for your council and your local partners.

Ensure your Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategy prioritise person-centred care at home and in the community for people with learning disabilities and/or autism who have a mental health condition or behaviour that challenges? Ensure that the issue is treated with a sense of urgency by all partners and kept on the table by your health and wellbeing board.

Support the development of local strategic plans that ensure rigorous scrutiny of new referrals to settings like assessment and treatment units and a process of discharge planning that is in place on admission and constantly reviewed.

Commissioners and providers should plan from day one of admission to in-patient services for the person to move back to the community.

Ensure that demarcation of funding responsibilities does not get in the way of people receiving appropriate care. Specifically, ensure that serious and urgent consideration is given by NHS and council commissioners to pooling budgets for learning disability and housing services to join up care pathways and long-term provision. Ensure this issue is part of discussions about use of the Better Care Fund (BCF).

Work with providers and housing to ensure there is a rapid expansion and improvement in community-based provision to enable the transfer of people from in-patient facilities and ensure that transitional arrangements are in place while this is done.

Develop a relationship with the Local Area Team (LAT) of NHS England. Local plans for improved care for the Winterbourne View cohort will need to be closely connected to and supported by NHS England area commissioning plans to ensure the future specialist provision supports local capacity and expertise according to the needs and wishes of local people.

A representative of the LAT sits on your health and wellbeing board. This should provide an opportunity to develop relationships and to discuss the issues and progress being made.

Ensure there are local plans to develop local services to permanently reduce the reliance on inpatient care or the use of other restrictive settings for all ages.

This will include building local capacity to minimise the risk and impact of a crisis by providing effective person-focused crisis intervention and positive behaviour support.

You will need to work with colleagues leading on children's services to ensure that the approach includes planning for the individual from childhood for children and young people who are and will be referred into services in the future.

Ensure that local action is influenced by people with learning disabilities and autism, their family members and wider support networks and that progress and challenges are shared with local people.

Your local Healthwatch and other voluntary and community sector organisations and your local advocacy services may be able reach out to service users and families.

Ensure there is a local transparent system to monitor progress towards the objectives identified in the Winterbourne View review and the Joint Improvement Programme. Local commissioners are regularly asked by the Improvement Programme team to provide information on their current position.

The information provided may enable you to assess where your local partners are in terms of the development of strategic local area plans, care packages and discharge plans for the individuals in your communities. You can also look monitor how progress is being achieved in your area via the [quarterly data](#) issued from NHS England.

Why you need to know

On 31 May 2011, a BBC Panorama television programme showed people with a learning disability being subjected to extreme, criminal abuse by staff at Winterbourne view private assessment and treatment centre. The patients were abused both physically and emotionally.

Following the programme, the Department of Health carried out a full review into what happened at Winterbourne View and what lessons could be learned about how people with behaviour that challenges are and should be supported.

Eleven members of staff who abused patient at Winterbourne View were sentenced for criminal acts. Most of the patients had been placed there under the Mental Health Act (known as 'being sectioned' or 'sectioning').

Most were placed far away from their homes in crisis situations in what was intended to be a short-term arrangement for a few weeks or months. However, the average length of stay at Winterbourne View was 19 months and it was not unusual for patients to be there for more than three years, at an average cost of £3,500 per week.

The serious case review and the Department of Health review, 'Transforming Care', found that South Gloucestershire council in whose area Winterbourne View was situated, the NHS commissioners, the Care Quality Commission, the Mental Health Act Commission and the police had all had information about Winterbourne View on which they should have taken further action, but didn't.

Families and other visitors had not been allowed access to the top floor wards and patients' bedrooms, offering little chance for outsiders to see daily routines at the hospital.

'Transforming Care' exposed wider concerns about how people with learning disabilities and/or autism who have mental health condition or behaviour that challenges were being treated in England:

- **Inappropriate placements** – too many people placed inappropriately in hospitals for assessment and treatment, and staying there for long periods, often far from their families, often because the right option is not available locally.
- **Inappropriate care models** – too few people experiencing personalised care that allows them to be in easy reach of their families, or their local services.
- **Poor care standards** – too many examples of poor quality care, and too much reliance on physical restraint.

The terrible abuse which took place at Winterbourne View and the findings of the Review have acted as a catalyst for cross-sector and cross-party agreement to fundamentally transform health and care services for people with learning disabilities and/or autism who have a mental health condition or behaviour that challenges.

A concordat and programme of action was endorsed in 2012 by a wide range of national government and voluntary sector organisations.

The Winterbourne View Joint Improvement Programme, jointly led by the Local Government Association and NHS England, has been established to support local partners across health and social care to work together in every locality to drive change so that individuals can be supported in their discharge from hospital to a safe and full life in the community.

Most local authorities and their health partners are taking a broad view and reviewing provision for people with learning disabilities and mental health problems more generally than just looking at the 'Winterbourne View cohort'.

The focus of the programme is on prevention and sustainability, with the aim of reducing reliance on inpatient care for this group and leading to a permanent and significant reduction in the numbers of people in places like Winterbourne View.

It can take several months or more to find the right accommodation and ensure all the necessary arrangements are in place to support someone who may have very complex needs.

Sometimes people may find it traumatic to move, even to somewhere that is a more appropriate setting than where they are now.

This means that discharge planning has to start from the earliest possible date, as soon as someone enters an assessment and treatment centre or hospital, and that planning should involve the patient or service user and their family as much and as early as possible.

Despite the best efforts of those involved, there is a consensus that the vision of fundamental change and improvement is not yet being achieved.

There remains a lack of appropriate provision, a system that does not work in a joined-up way or does not focus on supporting inpatients at assessment and treatment centres with behaviour that challenges to move on to the next stage of their lives.

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?

Do you know how many people from the Winterbourne View cohort 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?

Has a local action plan been agreed by all NHS and council partners to implement the Winterbourne View Concordat? What is the governance framework for monitoring and reporting progress on the action plan? What role do people with learning disabilities and autism, their families and carers play in overseeing implementation of the action plan?

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? Does this include accessible and good quality advocacy support for individuals and families? How are care plans monitored and issues reported to you and NHS partners?

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 in-patient 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? Are you satisfied that the links between these boards and other relevant bodies such as the health and wellbeing board 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), Transforming Care: A national response to Winterbourne View Hospital (Final report):

www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

Department of Health (2012), Winterbourne View Concordat: Programme of Action:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf

Department of Health (2013), Transforming Care: One year on:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/265752/Winterbourne_View_One_Year_On_Report.pdf

Website of the Winterbourne View Joint Improvement Programme with many resources and information:

www.local.gov.uk/place-i-call-home

Mencap and Challenging Behaviour Foundation, undated, Out of Sight: Stopping the neglect and abuse of people with a learning disability:

www.challengingbehaviour.org.uk/learning-disability-files/Out-of-Sight-Report.pdf

(Contains good explanation of 'behaviour that challenges', why it happens and why people get sent to assessment and treatment units and other institutional settings far away from home.)

NHS Confederation (2014), Health and wellbeing boards: leading local response to Winterbourne View:

www.nhsconfed.org/resources/2014/07/health-and-wellbeing-boards-leading-local-response-to-winterbourne-view

NHS England quarterly data on transfer dates for people with learning disabilities, autism and behaviour that challenges:

www.england.nhs.uk/2014/03/18/wvc-data/

Related 'Must Knows'

Personalisation: How do you know you are making progress in the Personalisation of adult social care?

The Care Act 2014: How do you know you are implementing the care and support reforms effectively?

Making it Real: How do you know you are playing a leadership role in working with service users to enable them to stay healthy and actively involved in their communities?



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