



National Audit Office

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## **Report**

by the Comptroller  
and Auditor General

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## **Department of Health**

# Local support for people with a learning disability

## Key facts

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**2,510**

people with a learning disability and/or autism in a mental health hospital (December 2016)

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**129,000**

adults aged 18 to 64 who use local authority learning disability support (2015-16)

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**£8bn**

estimated annual spend by government to support adults with a learning disability (2015-16)

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<b>2011</b>	exposure of abuse of people with a learning disability at Winterbourne View
<b>October 2015</b>	publication of <i>Building the Right Support</i> which introduced the Transforming Care programme to move people out of mental health hospitals into the community
<b>35% to 50%</b>	the programme partners' ambition to reduce beds by, in mental health hospitals for people with a learning disability by 2019
<b>5.8%</b>	employment rate of people with a learning disability in 2016
<b>11%</b>	reduction in the number of people with a learning disability and/or autism in mental health hospitals from October 2015 to December 2016
<b>60</b>	beds closed by December 2016 out of intended 136 bed closures by April 2017

# Summary

**1** A learning disability is generally defined as reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – that affects someone for their whole life.

**2** People with a learning disability have differing support needs. Many of the 930,000 adults with a learning disability in England may never use learning disability support services. There are 129,000 adults who receive local authority social care support. Of these, 28,000 live in residential care or nursing homes. A small proportion (around 2,500), of people with a learning disability and/or autism are in mental health hospitals, some with secure facilities. These people can be considered a danger to themselves or others and have behaviour that challenges services.

**3** The Department of Health (the Department) sets policy for adult learning disability services. Local authorities provide social care services and NHS England is responsible for meeting the health needs of people with a learning disability. The Department for Communities and Local Government sets finance policy for, and allocates funding to, local authorities.

**4** Depending on their support needs, activities to support people with a learning disability focus on increasing employment opportunities, getting people into settled accommodation, and giving them access to healthcare. Since 2012, following the abuse scandal at Winterbourne View the previous year, the Department has largely focused efforts on the approximately 2,500 people with a learning disability who are in mental health hospitals. Many of these people have been in hospitals for several years. The Department set out its commitment to transform the care of these people in *Building the Right Support* (2015), which is its national plan to reduce the number of beds for people with a learning disability in mental health hospitals by 35% to 50%.

**5** Moving people out of mental health hospitals is a considerable challenge. It cannot be done quickly or cheaply. As we noted in our previous report, efforts to do so date back to the 1980s, and is a difficult task which defies simple solutions.<sup>1</sup> It involves a number of complex and interrelated events, processes and services involving building community alternatives to head-off admission, minimising admissions and length of stay and discharging people to safe and supported locations with minimal readmissions. Unless all stakeholders work together it is unlikely that any individual element of effort will be successful or sustainable.

<sup>1</sup> Comptroller and Auditor General, Department of Health, *Care services for people with learning disabilities and challenging behaviour*, Session 2014-15, HC 1028, National Audit Office, February 2015.

## **Our report**

**6** This report examines how the NHS in England and local authorities seek to improve the lives of the 129,000 people aged 18 to 64 who use local authority learning disability support services (Part One). We also assess the setting up of the Transforming Care programme (the programme) which aims to move some of the 2,500 people with a learning disability and/or autism out of mental health hospitals (Part Two); and progress of the programme (Part Three). Our key questions are:

- How much does the government spend on supporting people with a learning disability?
- Is support improving outcomes?
- Has the Department made progress with its programme to provide community services and reduce mental health hospital beds for people with a learning disability?

## **Key findings**

### Supporting the learning disability population

**7 Central and local government spend £8 billion each year supporting adults with a learning disability.** Local authorities spend £4.61 billion supporting 129,000 adults (18 to 64) with a learning disability. Adults with a learning disability can access welfare benefits from the Department for Work & Pensions, which amounts to approximately £2.45 billion annually. The NHS also spends an estimated £0.93 billion on specialist learning disability health services (paragraph 1.6 and Figure 1).

**8 Local authority spending on learning disability services has increased.** In real terms, between 2010-11 and 2013-14 spending on adult social care fell by 8.4% while spending on learning disability services increased by 2.1%. The trend appears to be continuing with a reported increase of 3.5% in real terms between 2014-15 and 2015-16. Thirty-nine per cent of adult social care spend is on adults (18 to 64) with a learning disability and it is the second largest spend after older peoples' services (paragraphs 1.9, 1.10 and Figures 3, 5 and 6).

**9 The Department, NHS England and local authorities have limited measures to assess the quality and impact of health and social care support.** Most of the national measures focus on activity, rather than outcomes (paragraphs 1.13 to 1.19):

- The number of people with a learning disability having an annual health check increased between 2008-09 and 2014-15 from 27,011 to 124,785. Public Health England estimates that 23% of people who have a learning disability are registered with a GP as having a learning disability (paragraph 1.14).
- The proportion of people with a learning disability in paid employment has remained consistently low, and is currently 5.8%. There is considerable local variation, with some local authorities seeing employment rates of more than 15% (paragraphs 1.17, 1.18 and Figures 7 and 8).
- The proportion of people living in their own home or with family (settled accommodation) has increased from 70% in 2011-12 to 75% in 2015-16 (paragraph 1.16 and Figure 7).

Progress with the Transforming Care programme

**10 From 2012 to 2015, the Department's progress in moving people out of mental health hospitals and into the community was poor.** Following the Winterbourne View scandal, the Department, in 2012, committed to discharging inpatients with a learning disability and/or autism to their homes and communities where appropriate. Our report in 2015, *Care services for people with learning disabilities and challenging behaviour*, found that while the government had made progress in many of its commitments after Winterbourne View, it had not achieved its central goal of moving people with a learning disability out of mental health hospitals (paragraph 3.2).<sup>2</sup>

**11 In 2015, the Department and NHS England set up the Transforming Care programme to move people out of mental health hospitals more quickly.** The Department, with NHS England and national partners in the programme including the Local Government Association, and the Association of Directors of Adult Social Services, aim to build up community services, reduce inpatient provision and reduce the amount of time people with a learning disability and/or autism spend in inpatient care. Their ambition is to reduce the number of mental health hospital beds for people with a learning disability across England by 35% to 50% by 2019 and move people into the community where appropriate (paragraph 2.5).

<sup>2</sup> See footnote 1.

**12 The Department and NHS England have established a solid basis for the programme.** Governance arrangements bring together all the key partners who are responsible for specific areas of the programme and there is a ministerial assurance board and a decision-making delivery board. However, NHS England has few levers to influence the work of other stakeholders as none are part of NHS England's governance and accountability structure. The lack of levers is particularly relevant in the case of local authorities who are crucial to the success of the programme, making voluntary cooperation and coordination more important. Programme partners have quickly established 48 Transforming Care Partnerships as the main delivery bodies. These bring together local NHS teams and local authority social care teams. Since our last report, the quality of data in the data set has improved which will enable the programme partners to manage discharges more effectively and understand whether the programme is meeting its objectives. However, there is a second newer data set, published by NHS Digital, which indicates different numbers of patients. NHS England considers this newer data set to be less robust, less mature and needing development and so does not use it to monitor the programme. Our 2015 report highlighted the unsatisfactory situation of having two different unreconciled data sets and we are disappointed to find this problem again (paragraphs 2.6, 2.7, 2.12, 2.13, 2.14 and Figure 10).

**13 Early indications are that the programme is making progress in reducing the number of people in mental health hospitals.** Partnerships reduced the overall number of people in mental health hospitals by 11% from October 2015 to December 2016, which is in line with local plans. Patient numbers fell from 2,835 in October 2015 to 2,510 in December 2016, after adjusting for patients newly identified as being in mental health hospitals and having a learning disability (paragraph 3.29).

**14 Programme partners do not yet have confidence that Partnerships can close the planned number of beds by 2019.** NHS England has identified that between 900 and 1,300 beds will need to close by 2019. The majority of these closures will occur later in the programme as Partnerships only intend to close 136 beds by April 2017. By December 2016, 60 beds had closed. However, in January 2017, programme partners considered it likely that Partnerships would not deliver the required reduction in bed numbers by 2019. This was because of programme partners' concerns about the credibility of the Partnerships' plans for bed closures, a lack of community infrastructure and an inability to discharge patients. Programme partners have responded to these problems with a range of actions, which if implemented successfully, would increase the likelihood of reducing bed numbers. This indicates that the successful delivery of the programme's key objective may be more challenging than initial progress in reducing patient numbers suggests (paragraph 3.30).

**15 Programme partners must resolve a number of complex challenges if they are to achieve the ambition of a substantial shift away from reliance on inpatient care.** If programme partners achieve the ambition for reducing inpatient beds it is likely that the number of people admitted to inpatient care will reduce. However, reducing the number of inpatient beds does not deal directly with the problem of successfully getting long-stay patients out of inpatient care and into the community (paragraphs 3.4 and 3.5). We have identified four main barriers to progress:

- **One of the key mechanisms designed to manage the flow of patients into mental health hospitals is not working effectively.** The flow of people admitted to inpatient care needs to be reduced while the flow of people out into the community needs to increase. Partnerships have two key tools to help manage the flow of patients: ‘risk registers’ to identify people at risk of being admitted to a mental health hospital and mandatory care and treatment reviews which identify people in mental health hospitals who could be supported in the community. Care and treatment reviews are not taking place as needed. The number of people in mental health hospitals who have never had a care and treatment review has decreased, from 47% in January 2016 to 28% by December 2016. However, by December 2016, only 39% of people in mental health hospitals had had a review within the last six months, as required by NHS England’s policy. NHS England is consulting with people involved in reviews about how the review process could work better. It intends to produce a refreshed policy on reviews by the end of March 2017 (paragraphs 3.6 to 3.12).
- **Money is not yet being released from mental health hospitals quickly enough to help pay for extra community support.** Programme partners need money to follow patients as they are moved from mental health hospitals into community support. This means that beds, or in practice, whole wards or facilities need to close. Between £135 million and £195 million annually will need to be made available to pay for health and social care support in the community. NHS England has recognised that it will take time for money to move from hospitals to community support. It has provided £30 million revenue funding over three years, to be match funded by Partnerships, and £100 million of capital funding. These are only bridging funds though and in the longer term community support should be funded through ‘dowry payments’ for people who were in mental health hospitals for longer than five years as of April 2016 and by pooling budgets within Partnerships. However, these funding mechanisms have been poorly understood to date and are not yet working as intended. NHS England has been slow to resolve these problems. As of summer 2016, only one third of clinical commissioning groups had pooled their budgets with individual local authorities. In January 2017, NHS England agreed how dowry payments could move from NHS England to clinical commissioning groups using an established allocation process (paragraphs 3.13 to 3.20).

- **Partnerships are struggling to put in place appropriate accommodation quickly enough.** Providing specialist accommodation can take over 12 months. A small number of people have been delayed leaving hospital because there was not suitable accommodation in the community or in residential care homes. Programme partners are aware of the risk that accommodation in the community may not offer person-centred support and instead Partnerships and providers may favour large institution-type accommodation that offer economies of scale. This is contrary to the Department's statement of best practice which says that people should live in small community settings. Programme partners cannot mandate commissioners to follow this practice. Instead, Care Quality Commission's guidance and registration process is in line with this best practice and programme partners have stated their support of this approach. The Commission will seek to avoid registering large institution-type community housing, or former mental health hospitals re-badged as residential care homes (paragraphs 3.21 to 3.26).
- **Partnerships have not produced workforce plans for community provision.** The Department has tasked Health Education England and Skills for Care with working with Partnerships to develop workforce plans. However, they have noted that most Partnerships do not intend to produce workforce plans until 2019 which leaves no time to recruit and train people to provide community support against the deadline to reduce bed numbers by 2019 (paragraph 3.27).

**16 There has been limited progress in achieving the programme's other objectives.** One of the key aims of Transforming Care is that patients in mental health hospitals are closer to home. There has been little improvement since our report in February 2015, with just 20% of people in mental health hospitals 10 kilometres or less from home and 46% being 50 or more kilometres from home, as at November 2016.<sup>3</sup> There has been little improvement in the length of time people stay in mental health hospitals which is another objective. The average continuous length of stay has increased slightly since March 2015, and is almost five and a half years although this excludes people who have been discharged. This indicates that people discharged had lower than average lengths of stay (paragraphs 3.31 to 3.32, and Figures 20 and 21).

## **Conclusion on value for money**

**17** Central and local government spends some £8 billion on providing support for people with a learning disability, and spending by local authorities has increased in recent years. There have been some improvements, for example in the numbers of people with a learning disability in settled accommodation. However, as indicators do not measure quality of life, we cannot say with confidence that quality of life has improved.

3 See footnote 1.



**18** The Department, NHS England and partners have made good progress in creating a programme that aims to move people with a learning disability out of mental health hospitals, and into the community. Partnerships have reduced the number of people in mental health hospitals as planned so far. Programme partners consider it likely that the programme will not deliver the 35% to 50% reduction in bed numbers by 2019 and have responded with a range of actions that aim to increase the possibility of success. However, they have not yet put in place the necessary conditions such as community-based accommodation and support, a workforce with the right skills, and proven and timely ways to enable the funding to follow the patient. Unless solutions to these problems are successfully implemented, there is a risk that progress seen to date will not continue throughout the length of the programme. Therefore, the Department, and its programme partners, are not yet on track to achieve value for money through the programme to close hospital beds for people with a learning disability. Our recommendations provide areas for both the Department, national programme partners and Partnerships to address by 2019.

## **Recommendations**

### On the Transforming Care programme

- 19** The Department, NHS England, and programme partners where appropriate should:
- a** The refreshed policy on care and treatment reviews should require that reviews happen at the right time and involve the right people, and NHS England should assess whether the reviews lead to people being discharged into the community.
  - b** Ensure that there are effective and well-understood mechanisms to ensure that money follows the patient to where it is best needed, and can move quickly into paying for community support.
  - c** Ensure that Partnerships bring forward timetables to develop workforce plans to enable the workforce to be recruited and trained and to provide community support.
  - d** As we recommended two years ago, the government should improve its data on patient numbers. Programme partners need to develop a thorough understanding of why the two data sets have different patient numbers, in particular, why one shows a decrease in patient numbers and the other an increase. These two data sets should be reconciled.
  - e** Develop measures to assess the effectiveness of community capacity to prevent admissions into mental health hospitals.

### For the wider learning disability community

- f** Consult service users and carers on the value of its current measures, and revise and replace these as a result.