National Audit Office

Department of Health

Local support for people with a learning disability

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Local support for people with a learning disability

Report by the Comptroller and Auditor General

Ordered by the House of Commons
to be printed on 2 March 2017

This report has been prepared under Section 6 of the
National Audit Act 1983 for presentation to the House of
Commons in accordance with Section 9 of the Act

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Comptroller and Auditor General
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1 March 2017

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.

Contents

Key facts

2,510	129,000	£8bn
people with a learning disability and/or autism in a mental health hospital (December 2016)	adults aged 18 to 64 who use local authority learning disability support (2015-16)	estimated annual spend by government to support adults with a learning disability (2015-16)

2011	exposure of abuse of people with a learning disability at Winterbourne View
October 2015	publication of *Building the Right Support* which introduced the Transforming Care programme to move people out of mental health hospitals into the community
35% to 50%	the programme partners' ambition to reduce beds by, in mental health hospitals for people with a learning disability by 2019
5.8%	employment rate of people with a learning disability in 2016
11%	reduction in the number of people with a learning disability and/or autism in mental health hospitals from October 2015 to December 2016
60	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.[1] 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.

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1   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).[2]

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).

2   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.[3] 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.

Part One

Support to the wider learning disability population

1.1   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. In 2015, an estimated 1.1 million people in England had a learning disability. Of these, some 205,000 were children and 930,400 adults – around 830,000 of whom were aged 18 to 64.[4] This part of the report focuses on the 129,000 people with a learning disability aged 18 to 64 who use local authority learning disability support services.[5] Progress on the services for the small cohort of the population with a learning disability who may be considered to be at risk of harming themselves or others is in Parts Two and Three.

1.2   This part of the report sets out:

●   expenditure; and

●   outcomes of support that local authorities provide to adults with a learning disability.

1.3   According to Mencap, people with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people. People with certain specific conditions can have a learning disability too. For example, people with Down's syndrome and some people with autism have a learning disability. The level of support someone needs depends on the individual. For example, someone with a mild learning disability may only need support with things like getting a job. People with a severe learning disability or profound and multiple learning disabilities, will need more care and support with areas such as mobility, personal care and communication.

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4   Public Health England, *People with learning disabilities in England*, 2015, November 2016. Available at: www.improvinghealthandlives.org.uk

5   This figure is the number of people with a primary support reason of 'learning disability support' only. The total number of people with a learning disability receiving local authority support services will be greater.

Policy

1.4   Many aspects of support for people with a learning disability include other areas of government such as welfare benefits and human rights. Despite this, there is no current cross-government strategy for the learning disability population. The Department of Health (the Department) has the strategic lead for adult learning disability support. In 2001, it published its strategy, *Valuing people*, which aimed to improve the lives of people with a learning disability.[6] The strategy emphasised their rights as citizens, including being part of their community and to have choice and independence in their daily lives. In 2009, the Department published an updated strategy called *Valuing people now* which ran for three years and has not been replaced.[7] The latter outlined a limited cross-government approach on some aspects of supporting people with a learning disability. The Department has been considering how it can better align cross-government support for people with a learning disability.

1.5   Since 2012, in response to the Winterbourne View scandal the previous year, government has mostly focused on moving some of the 2,500 people with a learning disability out of mental health hospitals into the community, where appropriate. Therefore, the government's attention has mainly been on a small proportion of the learning disability community.

Expenditure on support for people with a learning disability

1.6   In the absence of national figures, we have estimated that central and local government spends approximately £8 billion each year supporting adults aged 18 to 64 with a learning disability. This figure is made-up of spending by local authorities who spend £4.61 billion, NHS which spends £0.93 billion (£675 million, by clinical commissioning groups, and £255 million by NHS England specialised commissioning teams who are responsible for secure facilities in mental health hospitals), and the Department for Work & Pensions who spend around £2.45 billion (**Figure 1** overleaf). There are sharp variations in average expenditure, depending on the extent of services provided (**Figure 2** on page 15).

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6   Department of Health, *Valuing people: a new strategy for learning disability for the 21st Century*, Cm 5086, March 2001.
7   Department of Health, *Valuing people now: a new three year strategy for people with learning disabilities,* January 2009.

Figure 1

Estimated gross total expenditure on learning disability services 2015-16

Government spends an estimated £8 billion annually supporting people with a learning disability

Local Authorities	Department for Work & Pensions
£4.61 billion	£2.45 billion
	NHS
	£0.93 billion
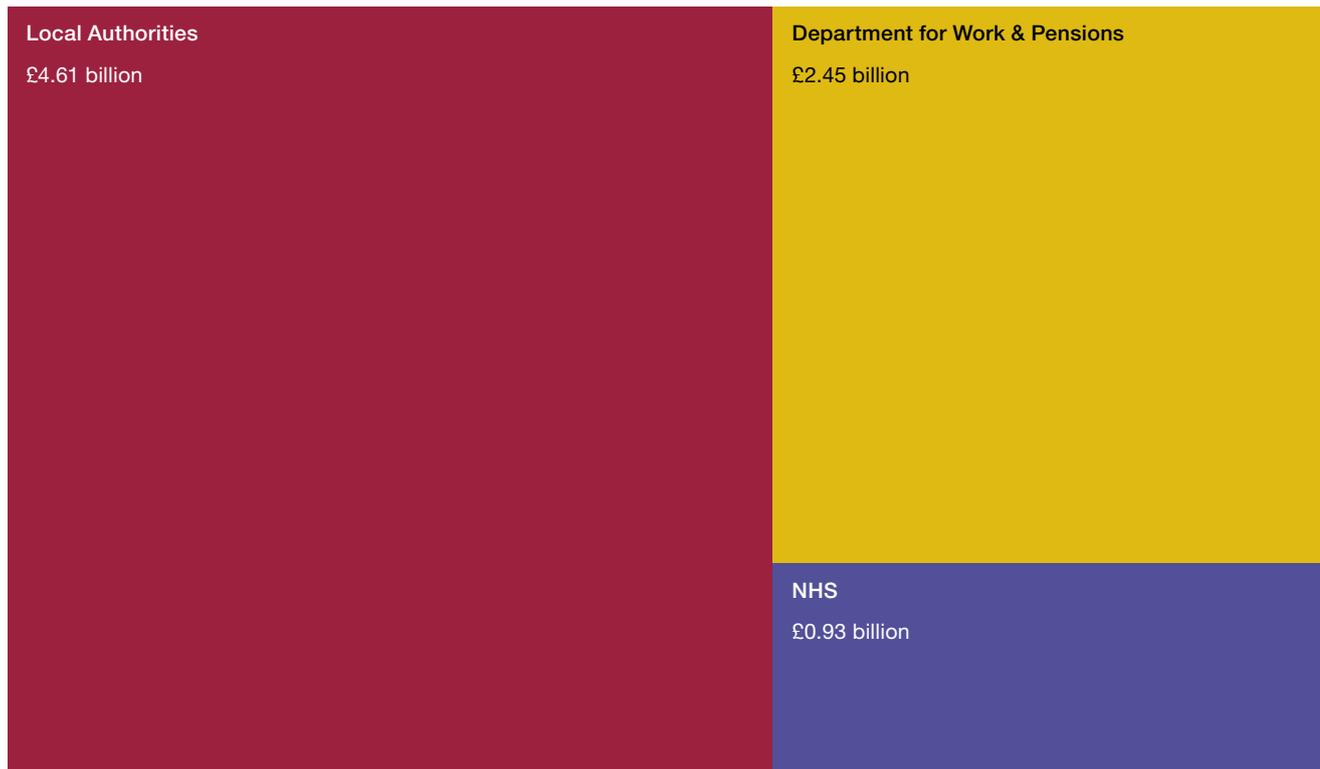
Note

1   Health expenditure does not include all patients with a learning disability accessing non specialist services. This expenditure may also include a small element of spend on children and adults over 65.

Source: National Audit Office analysis of data from NHS Digital, the Department for Work & Pensions and Department of Health

Local authority expenditure on social care support for people with a learning disability

1.7   Local authorities provided social care services for people with a learning disability at a cost of £4.61 billion in 2015-16. These services offer practical and personal help and support to enable someone to live as independently as possible. Spending on social care services makes up most of the annual expenditure. Only 16% (129,000 people) of people aged 18 to 64 with a learning disability access this support, as it is based on an assessment of need.

1.8   Local authorities also provide support for children and older adults, (aged 65 and over) with a learning disability. In 2015-16, local authorities spent £486 million, (net expenditure) on supporting older adults with a learning disability. In 2015-16, local authorities' budgets allocated £300 million to support all children with a disability. We cannot separately identify how much of this was spent on children with a learning disability.

Figure 2

Number of people with a learning disability and expenditure 2015-16

A small number of people with a learning disability incur the greatest cost to support

Number of people with a
learning disability

Average annual expenditure on supporting
a person with a learning disability

2,510

people in mental
health hospitals

£180,000

29,000

people in social
care residential
or nursing homes

£65,000

plus any additional specialist
health support

100,000

people receiving
social care support
in the community

£27,000

plus any specialist health support
and welfare benefits which people
may receive

700,000

people living in the
community and
accessing low level
support, eg receiving
an annual health check
from their GP, receiving
welfare benefits due to
their learning disability

Lowest cost

No unit cost data available but will be
limited to specialist health support
and/or welfare benefits

Notes

1   Figures have been rounded.

2   The figure for people in mental health hospitals is at December 2016.

Source: National Audit Office interpretation of data and information available from NHS Digital, Public Health England,
NHS England and Department for Work & Pensions

1.9 From 2010-11 to 2015-16, authorities' spending power decreased by 23.4%.[8] This affected spending on services, including adult social care, for which expenditure fell 8.4% between 2010-11 and 2013-14. Local authorities' net expenditure on learning disability services has not been as affected by these financial pressures and has increased. Between 2010-11 and 2013-14, net expenditure on learning disability services increased by 2.1% in real terms (**Figures 3** and **6** on page 20). The trend appears to be continuing: spending on learning disability services is reported to have increased by 3.5% in real terms between 2014-15 and 2015-16 (Figure 6).[9] The increase in spending on learning disability services is largely because the number of people with a learning disability that authorities support has increased slightly, while the numbers supported by adult social care services has not. Because of the high average cost of support for a person with a learning disability (**Figure 4** on page 18), a small change in the number of people supported can have a large impact on spend.

1.10 Support for people aged 18 to 64 with a learning disability is the second largest area of expenditure for authorities, after services for older people. While people with a learning disability make up 12% of the adults supported by authorities each year, they make up 39% of authorities' net expenditure (**Figure 5** on page 19).[10]

1.11 Continued pressures on authorities' budgets may have an adverse effect on services for people with a learning disability. Authorities face a 7.8% real-terms cut in spending power between 2015-16 and 2019-20.[11] The Association of Directors of Adult Social Services budget 2016 survey reported that authorities are considering cutting social care services. Nearly one-third of these cuts (where identified by type of service) will affect learning disability services.[12]

1.12 Health and social care teams often work together to provide support to people with a learning disability. The extent of joint working varies from area to area. Our survey of clinical commissioning groups showed that 82% of health and social care teams had joint working arrangements.[13] These were mostly for commissioning services.

The impact of support for people with a learning disability

1.13 The Department has limited measures to assess the quality and impact of health and social care support for people with a learning disability. Most measures count activity, rather than the improvement on people's lives.

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8   National Audit Office, *Overview 2015-16: local government*, November 2016.
9   The definitions and categories used in the data collected by NHS Digital from local authorities changed in 2014-15 and so is not directly comparable to that for previous years.
10 Net expenditure is the amount it costs authorities to provide services. This is the gross expenditure by local authorities minus client contributions and income.
11 See footnote 8.
12 Association of Directors of Adult Social Services, *ADASS budget survey 2016,* July 2016, available at: www.adass.org.uk
13 There was a 65% response rate to our survey.

Figure 3

Change in net expenditure, in real terms, on learning disability services compared to all adult social care between 2010-11 and 2013-14

Spend on learning disability services increased by 2.1% compared to an 8.4% reduction in total adult social care spend

Change in spend (%)

	2010-11	2011-12	2012-13	2013-14
● Learning Disability (aged 18 to 64)	0.0	1.3	0.4	2.1
● Total adult social care	0.0	-4.9	-7.7	-8.4
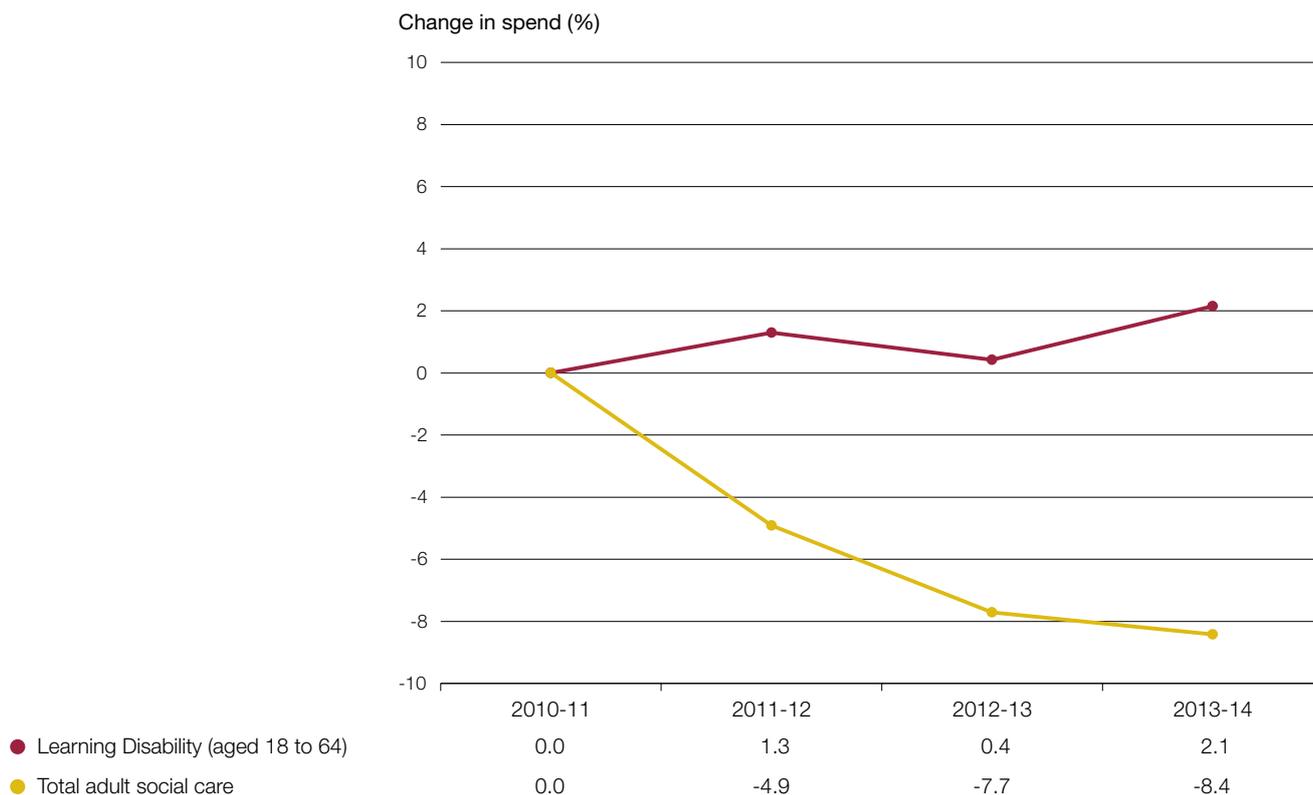
Notes

1   The definitions and categories used in the data collected by NHS Digital from local authorities changed in 2014-15.

2   Total adult social care expenditure includes learning disability spend.

3   Real terms expenditure has been calculated using 2013-14 prices.

4   Figures have been adjusted to include funding from the NHS for the provision of social care services that also benefit health, including funding specifically for the winter period.

5   Figures have been adjusted for 2010-11 to account for the transfer of some health funding to local authorities in 2011-12 as a result of *Valuing people now*.

Source: National Audit Office analysis of NHS Digital data

Figure 4

The average support costs per person for local authorities (2015-16)

The average annual support costs, per person are at least three time higher for learning disability services than for the other supported populations

Spend (£)
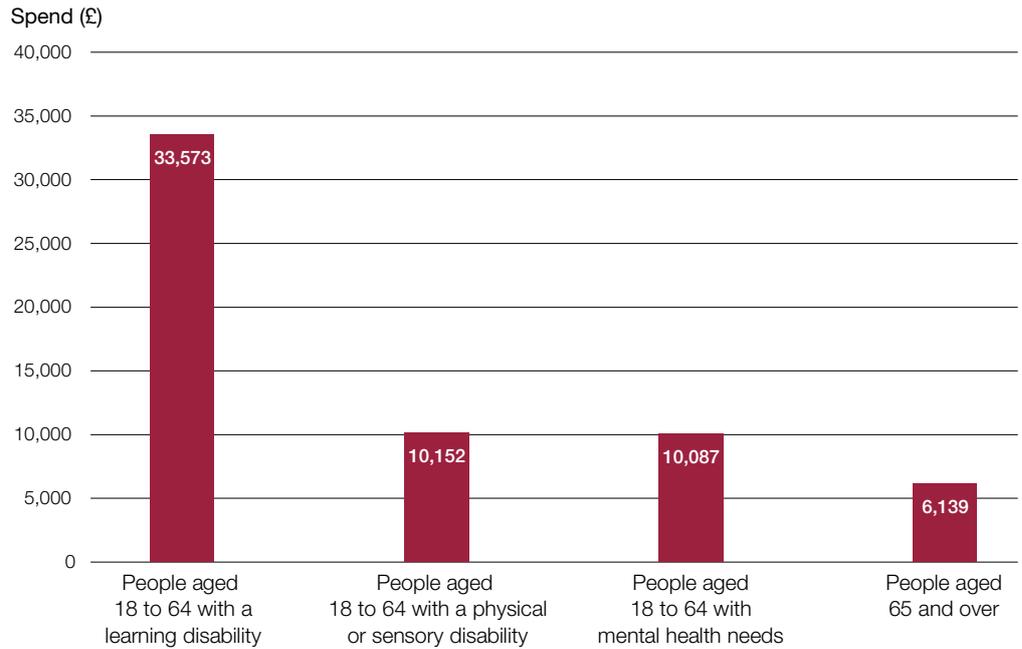
Note

1   People supported during the year.

Source: National Audit Office analysis of NHS Digital data

Figure 5

Breakdown of local authority net current expenditure and
number of people accessing social care support in 2015-16

Expenditure on people with a learning disability is high compared with the number of people supported

Percentage
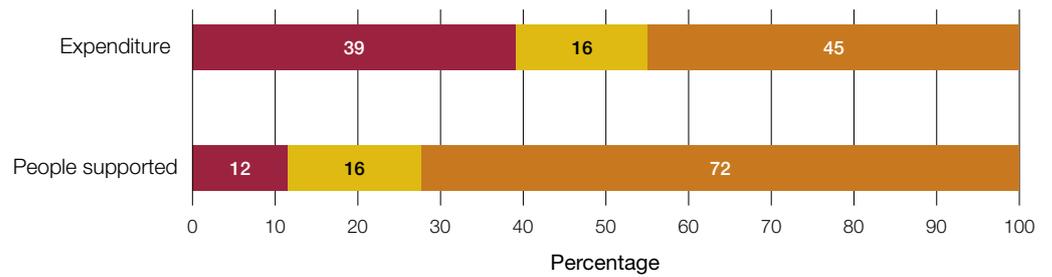
■ People aged 18 to 64 with a learning disability

■ Other people aged 18 to 64

■ People aged 65 and over

Notes

1   Expenditure includes all types of long and short-term support.

2   Number of people supporting during the year. Short-term support includes 'support to maximise independence' only.

3   There will be a small degree of double counting as the data shows activity during the year. Some people may receive
     long-term support following a short-term episode of support and others may have more than one long-term support
     episode during the year.

4   Other people aged 18 to 64 include people with a physical disability or sensory impairment, have a mental health
     problem or categorised as having a substance misuse problem/vulnerable.

Source: National Audit Office analysis of NHS Digital data

Figure 6

Breakdown of change in expenditure and number of people supported, 2010-11 to 2013-14 and 2014-15 to 2015-16

Both numbers of people with a learning disability supported, and expenditure on learning disability services have increased

Percentage change
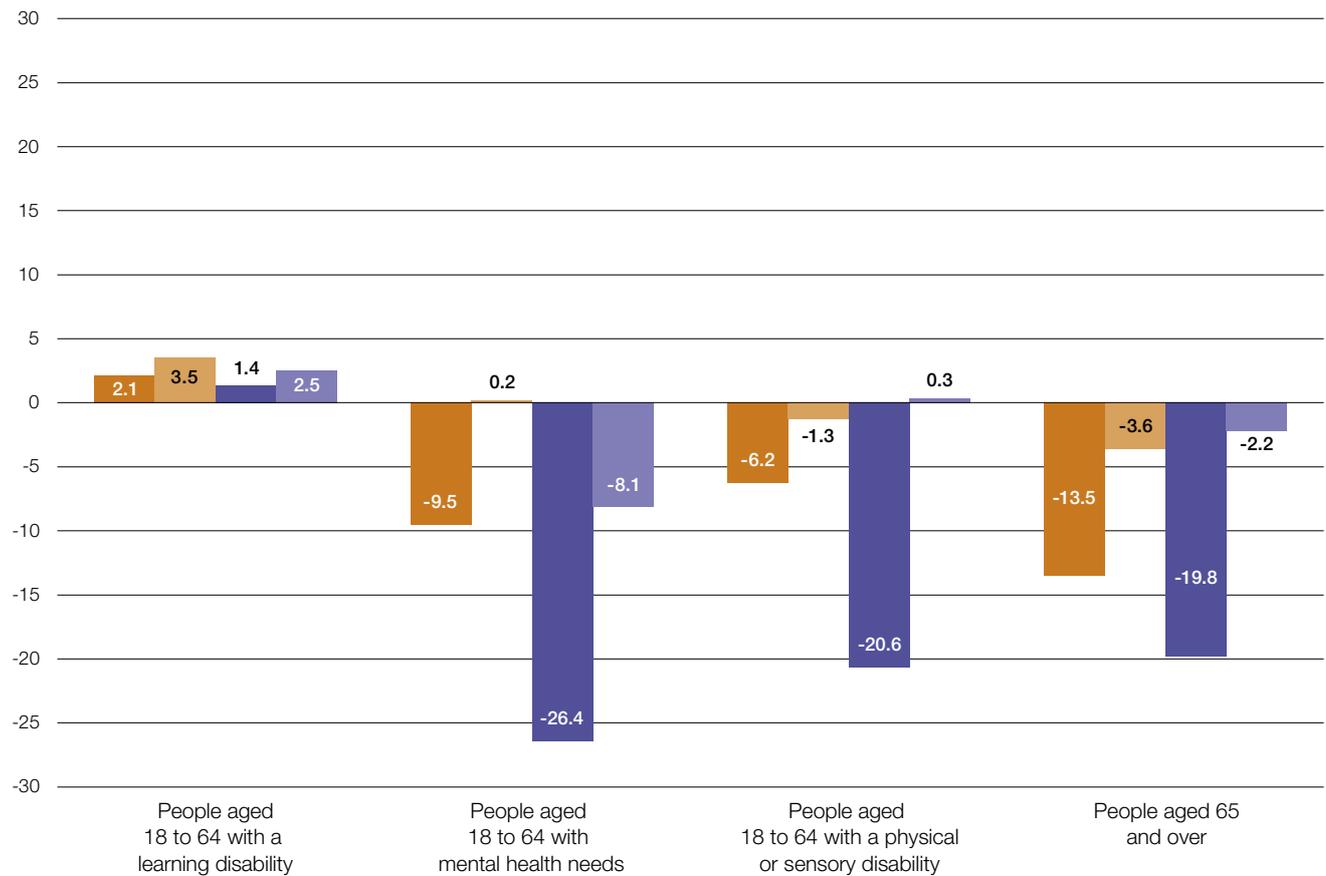
Percentage change in spend (2010-11 and 2013-14)

Percentage change in spend (2014-15 and 2015-16)

Percentage change in number of people (2010-11 and 2013-14)

Percentage change in number of people (2014-15 and 2015-16)

Notes

1   Number of people supported during the year.

2   2010-11 to 2013-14 real terms change in spend (2013-14 prices).

3   2014-15 to 2015-16 real terms change in spend (2015-16 prices).

Source: National Audit Office analysis of NHS Digital data

Healthcare outcomes

1.14 The health of people with a learning disability is monitored by the improving health and lives learning disabilities observatory in Public Health England. Even so, there are few indicators that show whether the health of people with a learning disability is improving. The Department monitors the number of people with a learning disability recorded on GP registers and whether they have had an annual health check. Both are optional for GPs who are given additional funds for having a register of patients who have a learning disability or doing health checks. The numbers of people having a health check has increased between 2008-09, and 2014-15: from 27,011 to 124,785.[14] More people with a learning disability (52% in 2014-15) had a health check than those without a learning disability aged 40 to 74 (46%).[15] The quality or content of health checks are not systematically validated. Public Health England estimates that 23% of people who have a learning disability are registered with a GP as having a learning disability. In 2008-09 there were 160,165 adults registered as having a learning disability on GP registers. This increased to 252,485 by 2014-15.[16]

1.15 The Department is working to improve mortality rates among people with a learning disability. People with a learning disability tend to die 20 years earlier on average (aged 58 to 60) than those without a learning disability. Mortality has improved since 2001, when, on average, people with a learning disability died aged 52 to 53. In June 2015, NHS England announced the introduction of the first national review of premature mortality of all deaths of people with a learning disability which will run for three years.

Social care outcomes

1.16 The Department has two measures of the effectiveness of learning disability social care services: the types of accommodation in which people live; and numbers of people in paid employment. The Department aims to increase the numbers of people in settled accommodation – in their own home or with family – to improve safety and quality of life. The proportion of people with a learning disability living in the community with family or with their own tenancy, has increased from 70% in 2011-12 to 75% in 2015-16 (**Figure 7** overleaf).

1.17 Employment rates for people with a learning disability receiving local authority support have remained persistently low, at around 6% to 7% (Figure 7). The employment rate for people with a mental health condition is similar at 6.7%. The Department recognises that this is poor. In 2014, the then Minister for Health stated that more needed to be done to increase the number of people with a learning disability into employment. There is no agreement on what would be a good rate of employment for people with a learning disability. Suitability for paid employment depends on the individual. Some people may prefer voluntary work and some may find certain types of work difficult to do because of the nature of their disability.

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14 This increase may be due in part because children aged 14 to 18 were included in the data set from 2014-15. See footnote 4.
15 This includes people with a learning disability over the age of 14. See footnote 4.
16 This increase may be due in part because children are included in the data set from 2014-15. See footnote 4.

Figure 7

Employment and accommodation of people with a learning disability
who receive local authority support

**There has been an improvement in the proportion of people with a learning disability living in their own home or
with their family while the proportion of people in paid employment remained stable**

Percentage of people with a learning disability
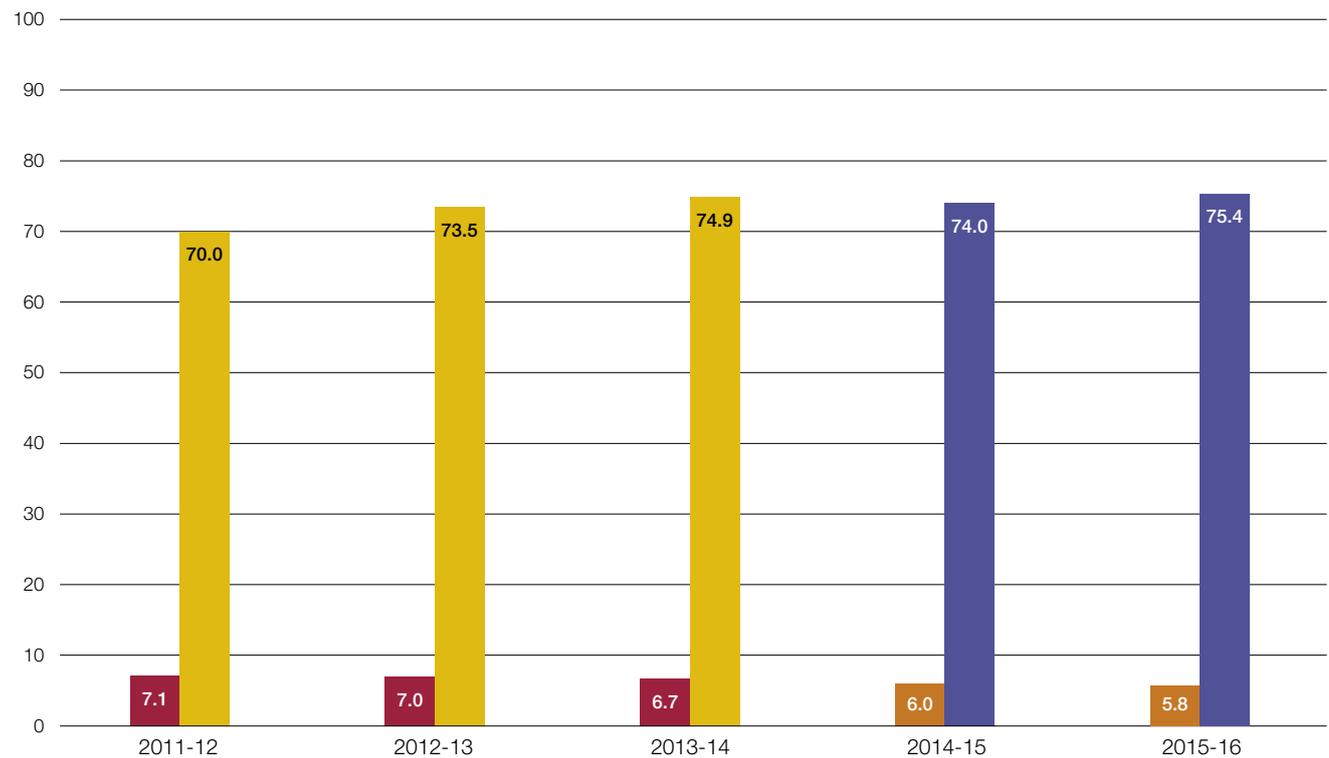
■ The proportion of people in paid employment
■ The proportion of people who live in their own home or with their family
■ The proportion of people in paid employment (amended measure)
■ The proportion of people who live in their own home or with their family (amended measure)

Note

1   The eligible population included in the data changed in 2014-15. This means that it is not possible to make direct comparisons over time.

Source: National Audit Office analysis of NHS Digital data

1.18 Employment rates vary locally with some authorities seeing more than 15% employment rates for people with a learning disability (**Figure 8**). Our analysis suggests that only a small amount of the variation is linked to the state of local labour markets. This suggests that there is an opportunity for those areas with lower employment rates to learn from those areas with higher rates. Over the next 18 months, the Department for Work & Pensions is testing an approach to work in partnership with local authorities to help get more people with a learning disability into employment.

Views of people who use support services

1.19 There is a limited national overview of the views of adults who use health and social care services. Local authorities carry out an annual survey to capture the views of people with a learning disability who use their specialist services. People with a learning disability are more satisfied with the social care services they receive compared with adults in other areas of social care. This may partly be explained by the survey design and collection method. For example, people with a learning disability were more likely to have help completing the survey from a social worker or carer.[17] We interviewed service users and carers as part of our study and found that their views on the support they receive to be mixed (**Figure 9** overleaf).

Figure 8

Employment rates of people with a learning disability across local authorities in 2015-16

There is variation among local authorities, ranging from 0.3% to 22.1%

Percentage in paid employment

Local authorities
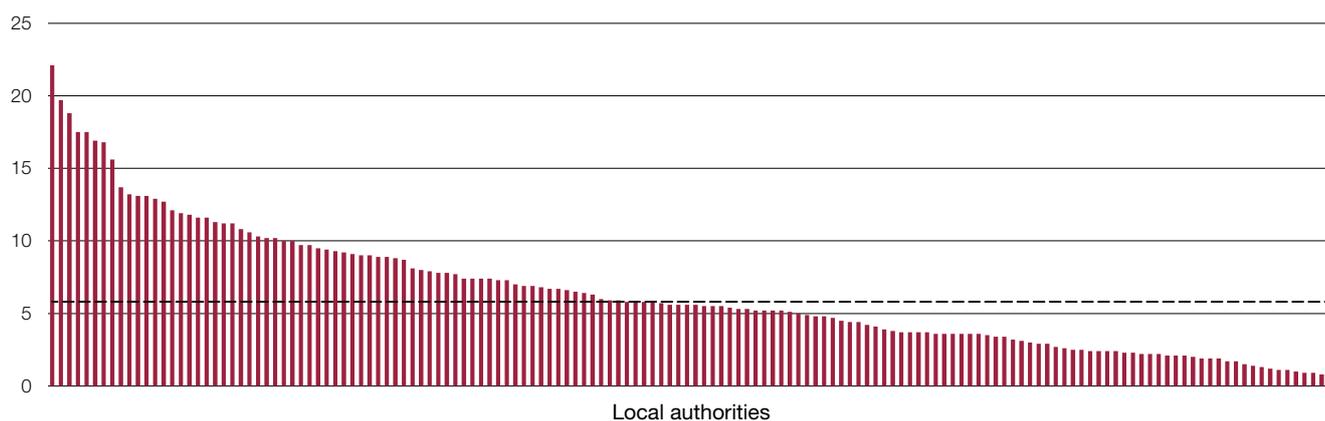
-- England average

Note

1   Adults aged 18 to 64 who receive long-term social care support.

Source: National Audit Office analysis of NHS Digital data

17   See footnote 4.

Figure 9

Views of people with a learning disability and carers

Views of service users and their carers are mixed

We asked service users and carers for their views on:

- day-to-day activities;
- their accommodation;
- provision of support;
- employment; and
- their healthcare.

Provision of support

- Service users and carers told us that good support can make a big difference to the quality of life and that people with profound learning disabilities can have active lives with the right support.
- Carers noted that a lack of support can leave people with nothing to do in the day.
- Many carers felt that there was not enough respite care.
- Some people who had been in mental health hospitals say it is possible for people with challenging behaviour to live in the community with the right support. They felt that it was better to be in the community if possible.
- There were very mixed views among carers about the quality of support staff. Some felt that they were caring and skilled. Others, including service users, noted problems with retention meant inconsistency with their carers.

Accommodation

- Most service users were positive about living in supported accommodation.
- Some told us that it was difficult to get the provider to make repairs to the property.

Healthcare

- Very mixed views from service users and carers. There was an even split between positive and negative.
- Carers regarded learning disability nurses in hospitals as good but are not in every hospital.
- Both service users and carers felt that some GPs do not understand the needs of people with a learning disability.

Carers' relationship with local authorities

- Many carers expressed frustration about their local authority.
- Many carers noted difficulty in getting help from local authorities, and felt that they had to fight to get anything.
- Many carers felt that local authority services had been cut because of lack of money.
- Some were positive about the support they got from their local authority, who they felt worked well with the family as a whole and understood their needs.

Day-to-day activities

- Service users noted that a lack of access to transport can limit what they do.
- They told us of the importance of support to do things such as swimming, and shopping.
- Some carers noted that there was no money left to spend on activities once accommodation was paid for.

Employment

- Most, but not all people had positive experiences of working.
- Some people had paid employment, others did voluntary work.
- Some felt the local authorities could do more to help them find work.
- Some felt employers could do more to understand people with a learning disability.
- One person noted that job search websites could be made more user friendly for people with a learning disability.

Source: National Audit Office interviews and focus groups with service users and carers

Part Two

Setting up the Transforming Care programme

2.1 This section looks at the Department of Health's (the Department), NHS England and other national partners' efforts to move people out of mental health hospitals and into the community. It examines:

- the Transforming Care programme's structures and governance; and

- data and monitoring.

Background

2.2 People with a learning disability may have behaviour that challenges services. According to Mencap, this behaviour can include tantrums, hitting or kicking other people, throwing things or people hurting themselves. Behaviour is considered challenging if it is harmful to the person and others around them, and if it stops the person achieving things in their daily life, such as making friends.

2.3 Historically, usually after a personal crisis event, admission to an assessment and treatment unit in a mental health hospital has been required for some people. For some people, these units are failing to assess and treat them, instead they have become a long-term care option. Patients remaining in them for several years, are becoming increasingly institutionalised.

2.4 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. It is a difficult task which defies simple solutions. 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.[18] Unless all stakeholders work together it is unlikely that any individual effort will be successful or sustainable.

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18 Comptroller and Auditor General, *Care services for people with learning disabilities and challenging behaviour*, Session 2014-15, HC 1028, National Audit Office, February 2015.

2.5 In 2015, the Department and NHS England set up the Transforming Care programme to move people out of mental health hospitals more quickly. At the Committee of Public Accounts hearing on our 2015 report, NHS England announced a programme of mental health hospital closures and committed to publishing more detailed proposals in the following months. NHS England set out its proposals in *Building the right support*, October 2015.[19] This strategy document described how NHS England and national partners 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 spend in inpatient care. They aim to reduce mental health hospital bed numbers across England by 35% to 50% by 2019 and move people into the community, where appropriate, through the provision of community services and new models of care.

The Transforming Care programme

Setting up the programme

2.6 Our previous reports have shown that the quality of project initiation is predictive of the success of the project.[20] To be successful, the programme needs strong governance involving key stakeholders. All stakeholders should be identified and brought into the programme, and roles and responsibilities clearly stated. The Department has mostly achieved this. The programme brings together key partners (see **Figure 10**). Programme partners have specific responsibilities, for example Health Education England is responsible for the workforce element. The Department only added the Department for Education, which has policy responsibility for children's services, to the programme from October 2016. Among others, the National Valuing Families Forum and the National Forum of People with Learning Disabilities currently provide users' views at the Transforming Care Assurance Board. The future participation of these forums is in doubt as the Department is considering stopping their funding. The Department recognises that it will need to find an alternative means of bringing the users' views in to the programme.

2.7 The programme has a ministerial assurance board, and a delivery board with representatives from stakeholders. The delivery board is a decision-making body. NHS England chairs the delivery board with the Association of Directors of Adult Social Services as vice chair. NHS England runs the central programme office. Success of the programme requires all programme partners to participate fully and have the capacity to play their respective roles. However, NHS England has few levers to influence the work of the 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. While local authority organisations such the Local Government Association and the Association of Directors of Adult Social Services are involved in the programme, local authorities are not accountable to these organisations.

19   NHS England, Association of Directors of Adult Social Services, the Local Government Association, *Building the right support,* October 2015, available at: www.england.nhs.uk
20   National Audit Office Guide, *Initiating Successful Projects*, December 2011.

Figure 10
Key stakeholders, their roles and accountability

Department of Health

Sets care policy, secures funding and is accountable to Parliament and the public for the performance of the programme

Department for Communities and Local Government

Sets local government finance and is accountable for the system that provides assurance that local authorities spend money with regularity, propriety and value for money

NHS England

Chairs the delivery board, heads the programme office, monitors progress and provides information and support

Transforming Care Partnerships

Forty-eight Partnerships, responsible for the delivery of the programme. Comprised of clinical commissioning groups, local authorities and NHS England Specialised Commissioning regional hubs

Local Government Association

Interface with, and support for, local authorities

Health Education England

Leads workforce element, helped by Skills for Care and Skills for Health

Clinical Commissioning Groups

Association of Directors of Adult Social Services

Interface with, and support for, local authorities

NHS England Specialised Commissioning

which commission specialist services

Care Quality Commission

Guidance and registration of care providers including residential care homes and inpatient facilities

Local Authorities

◻ Organisations involved in the programme

◻ Organisations not directly involved in the programme

→ Accountability flows

— No accountability

Source: National Audit Office

The local Partnerships

2.8 The programme relies heavily on delivery at local level. Therefore, it needs a structure to bring together health and social care teams who understand local needs and constraints. Programme partners have established a solid basis for delivering the programme locally. In October 2015, they set out the creation of 48 Transforming Care Partnerships (the Partnerships) as the main delivery bodies, bringing together local authorities and clinical commissioning groups, supported by four NHS England regional teams (**Figure 11**). Programme partners followed good practice by initially creating six pilot Partnerships. These aimed to represent different types of local conditions such as patient numbers, and urban/rural mix.

2.9 Ideally, programme partners would have exploited existing local relationships when they established the Partnerships. For some Partnerships, it is the first time that local authorities and clinical commissioning groups have worked together and it will take time for working arrangements and relationships to develop. The Partnerships were brought together before the 44 Sustainability and Transformation footprints, which were created in March 2016. Twenty-six of the 48 Transforming Care Partnerships do not match the geographical footprint of these new planning units.

2.10 As at national level, programme partners needed to engage all stakeholders and identify their role in local Partnerships. While roles are clear for clinical commissioning groups and local authorities, the role of NHS England specialist commissioning teams is unclear. The secure facilities that they commission represent half of the bed numbers so they are an important stakeholder. National representatives attend board meetings, but engagement with Partnerships varies at local level.

2.11 The 48 Partnerships began to come together after October 2015 and programme partners tasked them with producing plans detailing how they would reduce bed numbers in their areas and provide community support based on a national service model. Programme partners validated these plans in July 2016 and began monitoring Partnerships' progress as they moved from the planning stage into reducing bed numbers.

Figure 11

The Partnerships

There are 48 Partnerships across England

Transforming Care Partnership (TCP) number	TCP name	TCP number	TCP name
TCP01	South Worcestershire, Redditch, Bromsgrove and Wyre Forest	TCP24	Devon
TCP02	Hereford	TCP25	Kent and Medway
TCP03	Coventry, Rugby, South Warwickshire and Warwickshire North (Fast Track)	TCP26	Sussex
		TCP27	Surrey
		TCP28	Oxfordshire
		TCP29	Buckinghamshire
		TCP30	Berkshire
TCP04	Birmingham	TCP31	Hampshire and Isle of Wight
TCP05	Black Country	TCP32	Dorset
TCP06	Derbyshire	TCP33	Cheshire and Merseyside
TCP07	Nottinghamshire (Fast Track)	TCP34	Greater Manchester (Fast Track)
TCP08	Suffolk		
TCP09	Norfolk	TCP35	Lancashire (Fast Track)
TCP10	Cambridge and Peterborough	TCP36	Cumbria and NE (Fast Track)
TCP11	Essex	TCP37	North Yorkshire
TCP12	Bedford, Luton and Milton Keynes	TCP38	Barnsley, Wakefield, Kirklees, Huddersfield and Calderdale
TCP13	Hertfordshire (Fast Track)	TCP39	Bradford, Airedale, Wharfdale and Craven
TCP14	Northamptonshire		
TCP15	Lincolnshire	TCP40	Leeds
TCP16	Leicestershire	TCP41	Sheffield, Doncaster, Rotherham, N Lincs
TCP17	Shropshire	TCP42	East Riding and Hull
TCP18	Staffordshire	TCP43	London North West
TCP19	Gloucestershire	TCP44	Outer North East London
TCP20	Wiltshire and Swindon	TCP45	North, Central London
TCP21	Bristol, Bane and South Gloucestershire	TCP46	Inner North East London
TCP22	Somerset	TCP47	London South East
TCP23	Cornwall	TCP48	London South West
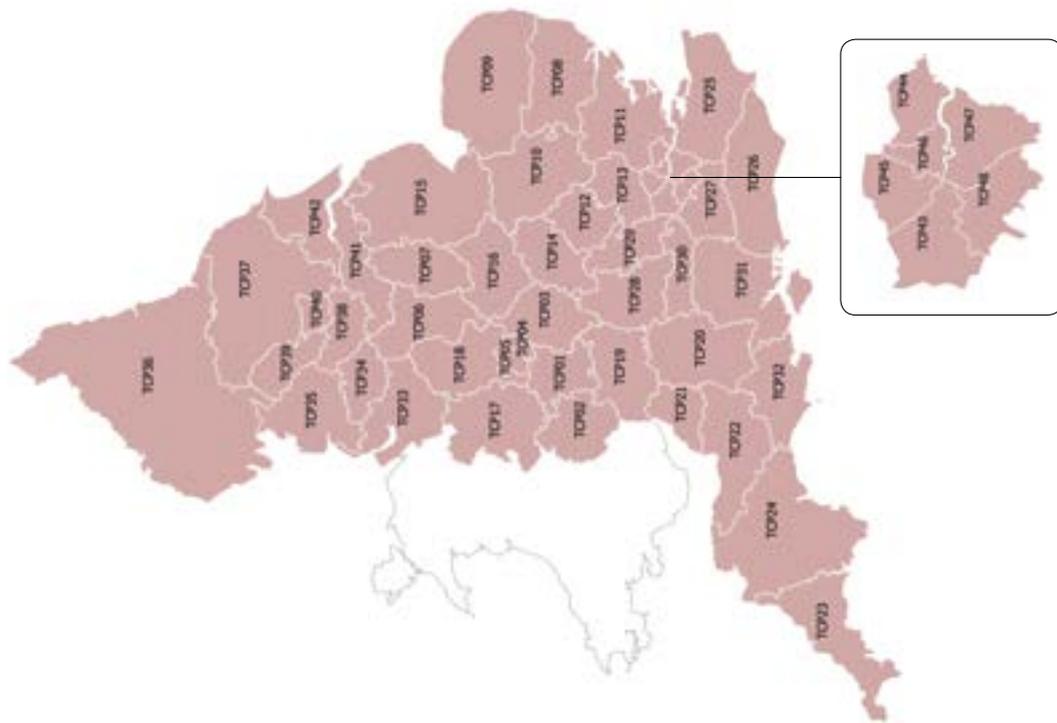
Source: Produced by the National Audit Office using data from NHS England

Data and monitoring

2.12 Our report on initiating successful projects noted that "projects that succeed have strong data systems, oversight of performance throughout the project…".[21] Our previous report in 2015 found poor quality data on patient numbers.[22] Since then, data quality has improved which will enable programme partners to manage discharges more effectively and understand whether the programme is meeting its objectives.

2.13 NHS England does not consider the current data it uses to monitor the programme to be a long-term solution and is planning for it to be incorporated into a newer, data set which monitors people using mental health services. This newer data set began reporting the number of people in mental health hospitals with a learning disability in May 2016. It reports a much higher number of people compared with the programme data set (3,805 people in November 2016 compared with 2,540 people in the programme data set at the same time). 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, where one data set reported that there were 2,577 people in mental health hospitals whereas another data set reported 3,250. We are disappointed to find this problem again.

2.14 NHS England told us that it considers the difference between the two current NHS data sets is mainly due to the inclusion in the newer data set of people who are only in hospital for a short length of time. NHS England is monitoring the difference between these two data sets, but there is no formal reconciliation between the two data sets. For our current analysis we are using the data tracked by the programme partners as it is based on submissions from Transforming Care Partnerships and the bed closure programme.

2.15 We would expect the programme's assurance and delivery boards to receive accurate, complete and realistic reports on the programme, and be committed to reviewing performance against plans. NHS England plays a key role in data collection and monitoring. Its monitoring is extensive with progress reports to the assurance board. However, not all Partnerships report progress in full. For example, in July 2016, just over one quarter of the 48 Partnerships did not submit progress reports and just a tenth in August 2016. This limits the value of the board's monitoring and oversight of the programme.

21   See footnote 20.
22   See footnote 18.

Part Three

Progress of the programme

3.1 This part of the report assesses progress to date. It examines:

- whether programme partners have established key mechanisms to reduce bed numbers; and

- progress in meeting the programme's objectives to reduce patient numbers, close beds, move people closer to home and reduce the length of time people stay in mental health hospitals.

Patient numbers

3.2 In 2012, following the Winterbourne View scandal, the Department of Health (the Department) committed to moving everyone with a learning disability and behaviour that challenges services, who would be better supported in the community, out of mental health hospitals by June 2014. Our report, *Care Services for people with learning disabilities and challenging behaviour* (February 2015), found that while the government had made progress in many of its commitments, it had not achieved its central goal of moving people with a learning disability out of mental health hospitals.[23]

3.3 There were 2,510 people with a learning disability and/or autism in some type of mental health hospital at December 2016 (**Figure 12** overleaf), 160 of whom were children under the age of 18 and 45 were over the age of 65.[24] Fifty-one per cent are in secure facilities commissioned by NHS England regional specialised commissioning teams. Twenty-four per cent of people in mental health hospitals overall are under restrictions by the Ministry of Justice and therefore not free to leave. Non-secure facilities are typically commissioned by local clinical commissioning groups.

23 Comptroller and Auditor General, *Care services for people with learning disabilities and challenging behaviour*, Session 2014-15, HC 1028, National Audit Office, February 2015.

24 The national service model states some of the needs of the people with a learning disability who are at risk of being admitted to a mental health hospital: NHS England, Association of Directors of Adult Social Services, and the Local Government Association: *Service model for commissioners of health and social care services*, October 2015, available at: www.england.nhs.uk

Figure 12

Numbers of people in different types of mental health hospitals

People are in a variety of mental health hospitals: both secure and non-secure

Mental health hospital security
level: Secure forensic

Mental health hospital security
level: General or Psychiatric
Intensive Care Unit

Secure

Non-secure

2,510

65

High secure inpatient
grave danger to the public

475

Medium secure inpatient
typically have a history of
serious offending

735

Low secure inpatient level of risk or
challenge meaning they cannot be
treated in an open mental health setting

1,235

Covers a range of different
types of inpatient beds
including specialist learning
disability units, generic
mental health, rehabilitation
beds and Psychiatric
Intensive Care Unit

Note
1   As of December 2016.

Source: National Audit Office analysis of NHS Digital data

Barriers to reducing bed numbers

3.4   If programme partners achieve the ambition to reduce 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. We have identified four
main barriers to progress:

●   One of the key mechanisms to manage the flow of people in and out of mental
health hospitals are not working effectively.

●   Money is not yet being released from mental health hospitals to help pay for
extra community support.

●   Partnerships are struggling to put in place appropriate community support
quickly enough.

●   Partnerships have not produced workforce plans.

3.5 While the structures for the programme are in place, without overcoming these barriers, Partnerships will struggle to meet the objectives of Transforming Care as these barriers represent several possible points of failure in the process to discharge someone into the community (**Figure 13**).

Figure 13
Managing the discharge process

There are several possible points of failure in managing the process to discharge someone into the community

Community

Person at risk of admission

Risk register

Supported to remain in the community

Pre-admittance care and treatment review

Conducted if person is at risk of immediate admission – intended to consider whether admission can be avoided

Mental health hospital

Post admission care and treatment review within 10 working days of admission

Care and treatment reviews every six months

Community

What needs to be in the community

Skilled workforce

Funding

Sufficient local accommodation

Source: National Audit Office

Managing patient flows

3.6 Managing patient flows is key to reducing the number of beds in mental health hospitals. The flow of people admitted needs to be reduced while flow of people out into the community needs to increase. Programme partners need assurance that Partnerships know who is at risk of being admitted and are able to manage their support to prevent admission, and identify people in mental health hospitals who can be supported in the community. Partnerships have two key tools to help manage the flow of patients: 'risk registers' and care and treatment reviews. However, care and treatment reviews are not taking place as needed.

Risk registers

3.7 Programme partners have tasked Partnerships with producing risk registers to identify people who are at risk of being admitted to a mental health hospital. This aims to provide people with the most appropriate support to help prevent admissions. NHS England monitors Partnerships' compliance. As of February 2017, it reported that 36 out of 48 partnerships had risk registers in place.

3.8 Risk registers do not identify all people at risk or waiting to be admitted into mental health hospitals. Data are particularly poor on people in the criminal justice system and on children about to enter the adult system. There is no separate measure of the capacity of community services to support people at risk of future admissions into mental health hospitals.

Care and treatment reviews

3.9 To prevent unnecessary admissions and move people out of mental health hospitals as quickly as appropriate, in October 2014, NHS England introduced care and treatment reviews.[25] These became mandatory in October 2015. NHS England has stipulated that all people with a learning disability in mental health hospitals, subject to giving consent, should:

● have a review just before or just after admittance to assess whether they could be supported better in the community; with

● a review every six months thereafter to assess whether they are ready to move to the community.

---

25 People entering secure mental health hospitals from court or prison do not need to have a care and treatment review before admission.

3.10 Without care and treatment reviews, the process to discharge people and get them appropriate support in the community cannot work to best effect. In February 2017, NHS England reported that a sizeable number of care and treatment reviews are not happening as needed, due to:

- patients are not giving consent;

- the administrative burden affecting the time taken to organise the review; and

- high numbers of cancellations caused by changes in the availability of clinical staff.

The programme does not have reliable data to monitor compliance with the care and treatment review policy for admissions. In December 2016, 63% of people admitted that month did not have a pre or post admission review, although this number may be lower as it includes people transferred from another facility where they may have already had a review (**Figure 14** overleaf). In January 2016, 47% of people in a mental health hospital had never had a review. This had decreased to 28% by December 2016. NHS England's policy is for everyone in a mental health hospital, subject to consent, to have a review every six months. In January 2016, 29% of people in mental health hospitals had a review within the past six months, and 39% of people by December 2016 (**Figure 15** on page 37).

3.11 We would expect NHS England to monitor the effectiveness of reviews as a tool to help move people into the community. However, it does not monitor the numbers of people who moved into the community after their review, just those who are ready to move. It started to report to the delivery board the numbers of people who avoided being admitted into mental health hospitals as a result of reviews from January 2017. It has reported that, from January to December 2016, those people who had a review before being admitted to a hospital, the review concluded that 71% did not need to be admitted. However, NHS England has concluded that this indicates a gap between current performance and what it may expect otherwise. NHS England is also consulting with people involved in reviews, including people with a learning disability, their carers and health and social care professionals about how the review process could work better. It will also consider the frequency of the reviews for people in secure facilities. It intends to produce a refreshed policy on reviews by the end of March 2017.

3.12 In our discussions with families and patients, some told us that care and treatment reviews were a good starting point. However, they told us that they did not understand how care and treatment reviews would lead to a discharge or which organisation was responsible for the discharge process from the mental health hospital to the community. Without a single point of contact able to effect change and coordinate resources, families found the process of discharge from mental health hospitals to be incomprehensible and emotionally draining. The programme has an 'empowerment group' which consists of people who have been in mental health hospitals and their families. This group discusses issues such as care and treatment reviews.

Figure 14

Proportion of care and treatment reviews of newly admitted patients

The majority of people admitted are not having a pre or post admission review

Percentage of admissions
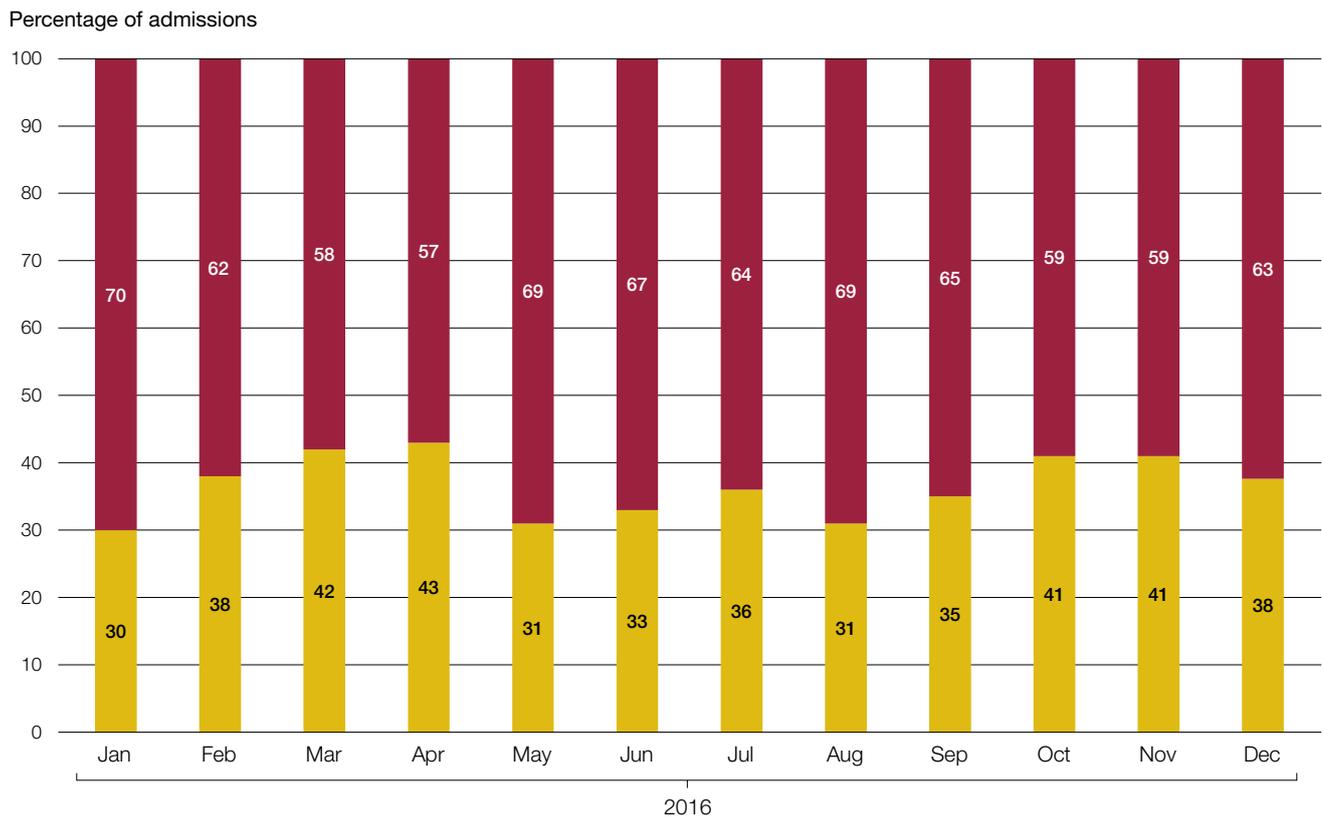
■ No pre or post admission review   ■ Pre or post admission review

Notes

1   Published data of admissions per month, rounded to the nearest five.

2   Due to rounding December data equals 101%.

3   Count of admissions includes people who have been transferred.

Source: National Audit Office analysis of NHS Digital data

Figure 15
Timing of most recent care and treatment review for people in a mental health hospital

There are decreasing numbers of people who have never had a care and treatment review

Percentage of people in mental health hospitals

Month	No review	Over six months ago	Within the last six months
Jan	47	24	29
Feb	42	23	35
Mar	40	24	36
Apr	39	25	36
May	35	29	36
Jun	33	33	36
Jul	32	36	33
Aug	30	37	32
Sep	30	37	34
Oct	30	36	34
Nov	28	34	38
Dec	28	34	39

2016
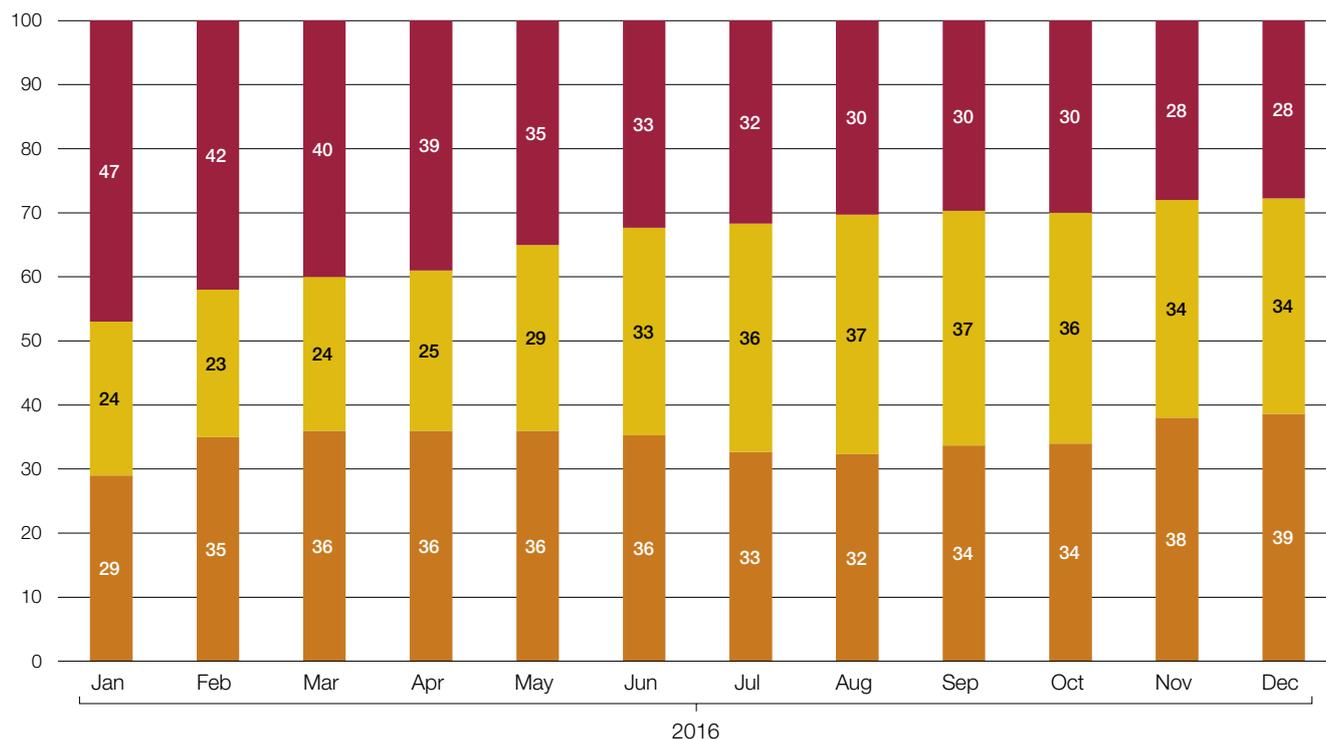
- ■ No review
- ■ Over six months ago
- ■ Within the last six months

Notes
1 Due to rounding not all months equal 100%.
2 Based on data from the end of each month (not subject to revisions).

Source: National Audit Official analysis of NHS Digital data

Paying for community support

3.13 Successful programmes need adequate funding. Money needs to be in the right place at the right time and to follow the patient. To reduce bed numbers, funding needs to be available to pay for health and social care support in the community, by moving with the patient, out of NHS funded mental health hospitals. This is a basic premise of the programme.

3.14 For the majority of people in mental health hospitals it costs up to £3,500 per person per week (on average some £180,000 per person per year) to provide care in a mental health hospital. In some cases, costs exceed £5,000 per week, with a small number of families telling us their child's care cost £11,000 per week (**Figure 16**). At the start of the programme, in October 2015, NHS England estimated the cost of support in the community to be £150,000 per patient per year and that 900 to 1,300 beds will close during the programme. Therefore, between at least £135 million and £195 million must be moved from mental health hospitals to provide community support. Unless money is released from mental health hospitals, this will be an unfunded pressure on local authorities and clinical commissioning groups.

Figure 16
Cost of providing support in mental health hospitals

For most people it costs up to £3,500 per week to support the majority of people with a learning disability in secure and non-secure mental health hospitals

Percentage of people with a learning disability
broken down by average weekly cost

- Less than £2,500
- £2,500 to £3,499
- £3,500 to £4,499
- More than £4,499
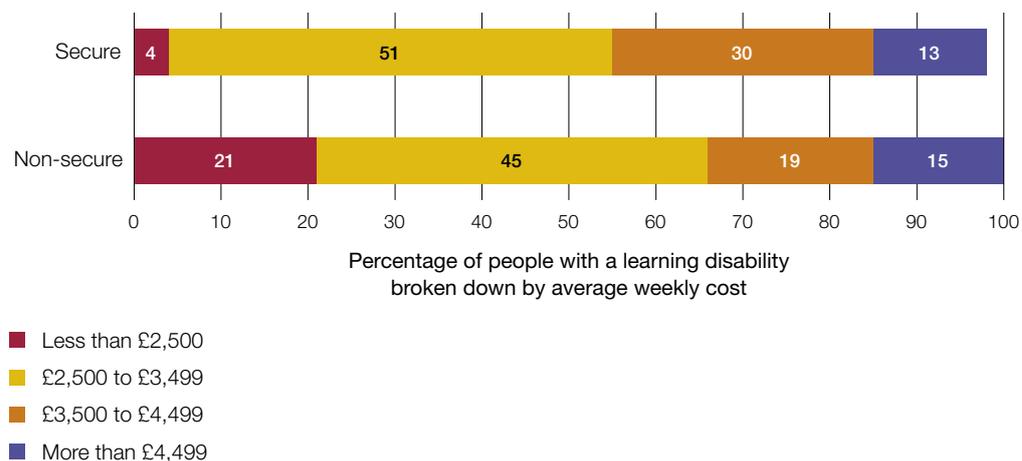
Notes
1   Data from September 2015. Includes patients from Scotland and Wales and short stay patients.

2   Percentage values as reported by NHS Digital. Secure does not equal 100%.

3   Totals may not sum to 100% due to rounding.

Source: National Audit Office analysis of NHS Digital data

Transformation funding

3.15 The programme's financial guidance states that the costs of the new model of care would be met from current spending on health and social care services. To release the money currently spent in mental health hospitals, it is likely that not just individual beds, but whole wards or facilities will need to close, depending on the contract by which the beds were commissioned. For people with more complex needs, up front investment will be needed to get support ready for them when they are discharged. NHS England has recognised that it will take time for money to move from hospitals to community support. To help in the short term, it has provided bridging funds of £30 million to Partnerships over three years, to be match funded by receiving Partnerships. This aims to support moving money into community support. Some £6 million over three years has been allocated to Calderstones hospital in Lancashire, leaving £8 million per year for the 48 Partnerships. Demand outstripped supply for the first year of funding, with Partnerships' bids exceeding £80 million. NHS England allocated funding to 30 Partnerships prioritising the most realistic plans and the most beds closing. However, the funding must be spent within the financial year and was not allocated until the summer of 2016, restricting Partnerships' ability to plan closures in a timely fashion and provide adequate community support for people discharged.

3.16 NHS England has also released £100 million of capital funding over five years, an increase on the initial amount of £15 million announced in *Building the Right Support*. The first £20.4 million has been allocated for 2016-17 but there were delays in allocating funding and programme partners are aware that Partnerships may not be able to spend their funding within the financial year. NHS England estimates that Partnerships have spent £680,000 by January 2017 and some £9 million will remain unspent by the end of 2016-17. Programme partners are concerned that any delays in spending will impact on the provision of community housing. Programme partners are also aware that there is a lack of understanding among Partnerships about how to apply for capital funding. They are exploring options on how to improve the process.

Moving money with the patient

3.17 To sustain the programme in the longer term, money needs to move from paying for mental health hospitals beds or other services for people with a learning disability, to paying for health and social care support in the community. There are two ways that the money could move from mental health hospitals. Both are problematic and programme partners have been slow to resolve the problems.

3.18 The first way to move money is through 'dowry payments'. These should cover the costs of people who have been in mental health hospitals for longer than five years on 1 April 2016. There are 900 patients potentially covered by dowry payments, nearly one-third of the total inpatient population. Programme partners have produced guidance on dowry payments. Although 105 people eligible for these payments were discharged between April 2016 and December 2016, there is poor understanding about how these payments will work in practice.

3.19 Throughout 2016, there was no agreement on how dowry payments would work for patients in secure facilities. NHS England estimates that 24 patients in secure facilities eligible for a dowry will have been discharged in 2016-17. In January 2017, NHS England agreed how money would move through shifts in funding between NHS England specialised commissioning, who are responsible for secure facilities, and clinical commissioning groups, who are responsible for non-secure mental health hospitals and health-related community support. This will use an established NHS England allocation process. This is a positive move, but not without difficulties:

- It will take time to implement. Money will first need to be released by closing beds in secure facilities before more money can then be allocated to clinical commissioning groups. There have been significant delays in releasing money in the first year of the programme. Only £1 million of an estimated £10.8 million of savings from closing beds in secure facilities in 2016-17 had been made by January 2017.

- It does not deal with how money will move from clinical commissioning groups to local authorities. The normal mechanism would be through a pooled budget. However, as of summer 2016, only one third of clinical commissioning groups had pooled their budgets with individual local authorities.[26]

3.20 Programme partners intend that pooling or aligning budgets for learning disability services within Partnerships will enable money to move from clinical commissioning groups to local authorities. Pooling budgets means that the local NHS and local authorities will have a single pot of money to support patients and will thus avoid unnecessary bureaucracy over where health care ends and social care starts. The Department and NHS England have not mandated this, but instead have encouraged it. Pooled budgets may not be suitable for all areas but without them, there are currently no mechanisms to move money with patients from NHS England to local authorities, other than dowry payments for long stay patients. NHS England's review of Partnerships' progress in September 2016 identified that failure to move money with the patient is leading to delays in providing community support.

Providing accommodation in the community

3.21 The Department has stated that best practice for supporting people in the community is:

"People with challenging behaviour benefit from personalised care, not large congregate settings. Best practice is for children, young people and adults to live in small local community-based settings".[27]

and

"… where possible, the focus should be on supporting people to live in their own homes".[28]

26   Taken from our survey of clinical commissioning groups. See Appendix Two.
27   Department of Health, *Transforming Care: a national response to Winterbourne View Hospital*, December 2012.
28   See footnote 24.

3.22 Programme partners need to ensure that Partnerships provide or commission suitable accommodation that meets stated departmental best practice in place before people are discharged. Providing specialist accommodation can take over 12 months so Partnerships need to plan in advance. NHS England estimates that 2,400 people will need new living accommodation which includes people already in mental health hospitals and those who will be admitted during the programme. Partnerships are struggling to put in place appropriate community accommodation quickly enough, partly because the money is not moving with the patient. A small proportion of people have been delayed leaving hospital to date because there was not suitable accommodation in the community or in residential care homes.

3.23 People are discharged into a variety of settings, including the family home, supported accommodation and residential care homes. Few settings are directly provided by local authorities, meaning that Partnerships will need to establish guidelines, support or controls for providers of accommodation to ensure that all types of accommodation align with best practice. Residential care homes are the most common type of accommodation but are not in line with the aim of supporting people in their own home (**Figure 17**). Programme partners are concerned that this is because of a lack of suitable community accommodation.

Figure 17
Destination after leaving mental health hospitals

Over one-third of people go to a residential care home when they leave mental health hospitals
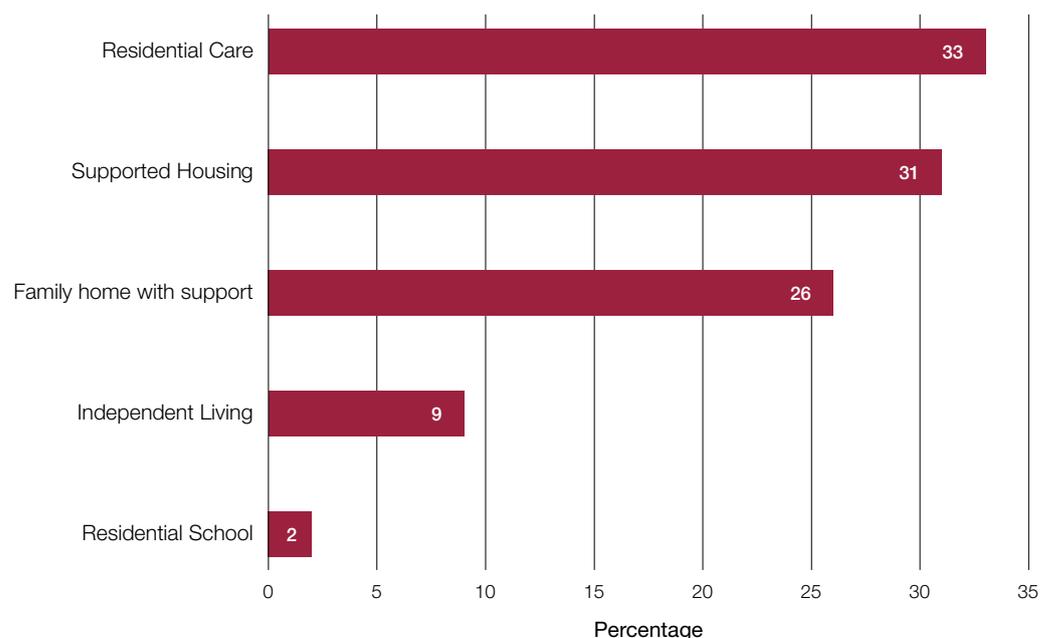
Notes
1   Destinations of people discharged into the community October 2015 – September 2016.
2   Does not equal 100% due to rounding.

Source: National Audit Office analysis of NHS Digital data

3.24 Programme partners are aware of the risk that community support may not offer the person-centred support envisaged 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.

3.25 Programme partners cannot mandate commissioners to follow this practice. Instead, the 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 aims to avoid registering large institution-type community housing, or former mental health hospitals re-badged as residential care homes. Between January and September 2016, it had 'proposed to refuse' 11 applications as the proposed service did not meet the criteria of small local community-based settings.

3.26 The Care Quality Commission has also noted that commissioners feel pressured to move people out of hospital, even though in many cases, appropriate community housing is not available. The pressure to reduce bed numbers, combined with delays in providing suitable community accommodation and support services may lead to people living in inappropriate institution-type housing or staying in mental health hospitals. In December 2016, programme partners published guidance for local Partnerships on housing. This guidance makes clear that capital funding available under the programme will only be awarded to projects that are in line with the Department's stated best practice.[29] The provision of accommodation may also be affected by changes to the application of the local housing allowance rate. These changes are due to be introduced in 2019 but providers told us that they are concerned about difficulties securing the capital funding for new supported housing schemes because of uncertainty about future revenue funding. NHS England considers that the risk posed by the Local Housing Allowance is limiting supply of supported housing, and that this problem is particularly acute for the programme and being able to move people out of mental health hospitals.

Workforce planning

3.27 As well as providing appropriate accommodation, programme partners need to ensure that Partnerships have the right people, with the right skills in the right place to provide support in the community. This support includes care workers, specialist learning disability nurses and psychiatrists. Programme partners and Partnerships need to take into account the lead times for recruiting and training staff, particularly for more specialist staff. The Department has tasked Health Education England and Skills for Care, and Skills for Health with working with Partnerships to develop workforce plans, as well as developing training. Both organisations have noted varied levels of engagement with Partnerships. Partnerships have been slow to develop workforce plans that will set out how they will develop the workforce. Most Partnerships are aiming to deliver their workforce plans in 2019 which leaves no time for providers to recruit and train their workforce to meet the ambition to close beds by 2019. Skills for Care estimate that only 8% of the social care workforce is with local authorities, and therefore it is important that Partnerships work with providers in producing their workforce plans.[30]

Progress to date

Changes in patient numbers

3.28 Understanding the Partnerships' achievement to date is difficult because of changes in the baseline of patient numbers. Our last report was published in February 2015 and a month later, in March 2015, NHS England calculated that there were 2,395 people in mental health hospitals. In October 2015, when the programme was launched, NHS England calculated that there were 2,620 people in mental health hospitals. Nearly a year later, in December 2016, there were 2,510 people in mental health hospitals giving an impression that Partnerships have only made a slight reduction in the numbers of people in mental health hospitals. However, through ongoing checks on data, local areas have identified an additional 215 people who were not in the original October 2015 patient count but should have been. Therefore, Partnerships will need to discharge more patients than they originally planned to reduce bed numbers to within the ambition. An important indicator for the safe discharge of people from mental health hospitals is the rate of readmissions. Discharging people too early or without the right support, may result in readmissions. Our 2015 report found that NHS England did not monitor readmissions. However, under the programme, NHS England's data teams now collate data on readmissions, which is a positive development. The number of readmissions fluctuated during 2016. On average, one in four people admitted had previously been in hospital within the last 12 months.

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30   Skills for Care, *The size and structure of the adult social care sector and workforce in England*, 2016, available at: www.nmds-sc-online.org.uk

Reducing numbers of people in mental health hospitals

3.29 Including the additional patients identified, Partnerships reduced the overall number of people in mental health hospitals by 11% from October 2015 to December 2016 which is broadly within the ambition (**Figure 18**).[31] Patient numbers fell from 2,835 in October 2015 to 2,510 in December 2016. The numbers of admissions is slightly lower than the number of discharges (**Figure 19** on page 46). NHS England uses the programme data set which it considers to be more robust. If patient numbers are taken from the newer data set, which is not the one used by the programme, then patient numbers are increasing.[32] This indicates that the number of people in mental health hospitals has increased from 3,110 in May 2016 to 3,805 in November 2016. NHS England told us it considers the increase in patient numbers is highly likely to be due to changes in the numbers of providers submitting data to the newer data set.

Reducing bed numbers

3.30 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. In summer 2016, most stakeholders we spoke to locally and nationally noted that the ambition for bed reductions and timescales for delivery were ambitious and unlikely to be achieved. NHS England has identified that between 900 and 1,300 beds will need to close over the programme. 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, the programme partners' continued concerns about the realism of reducing beds by 2019 indicates that successful delivery of the programme's key aim to reduce bed numbers may be more challenging that initial progress in reducing patient numbers suggests. NHS England started to monitor the numbers of beds closed from January 2017 but does not have a national profile of when and where beds will close as the programme progresses. It is starting to collate this information.

31 Patient numbers are retrospectively adjusted each month.
32 Mental Health Services data set.

Figure 18

Numbers of people in mental health hospitals

The number of people in mental health hospitals has reduced

Number of people

- Original October
- Revised figures
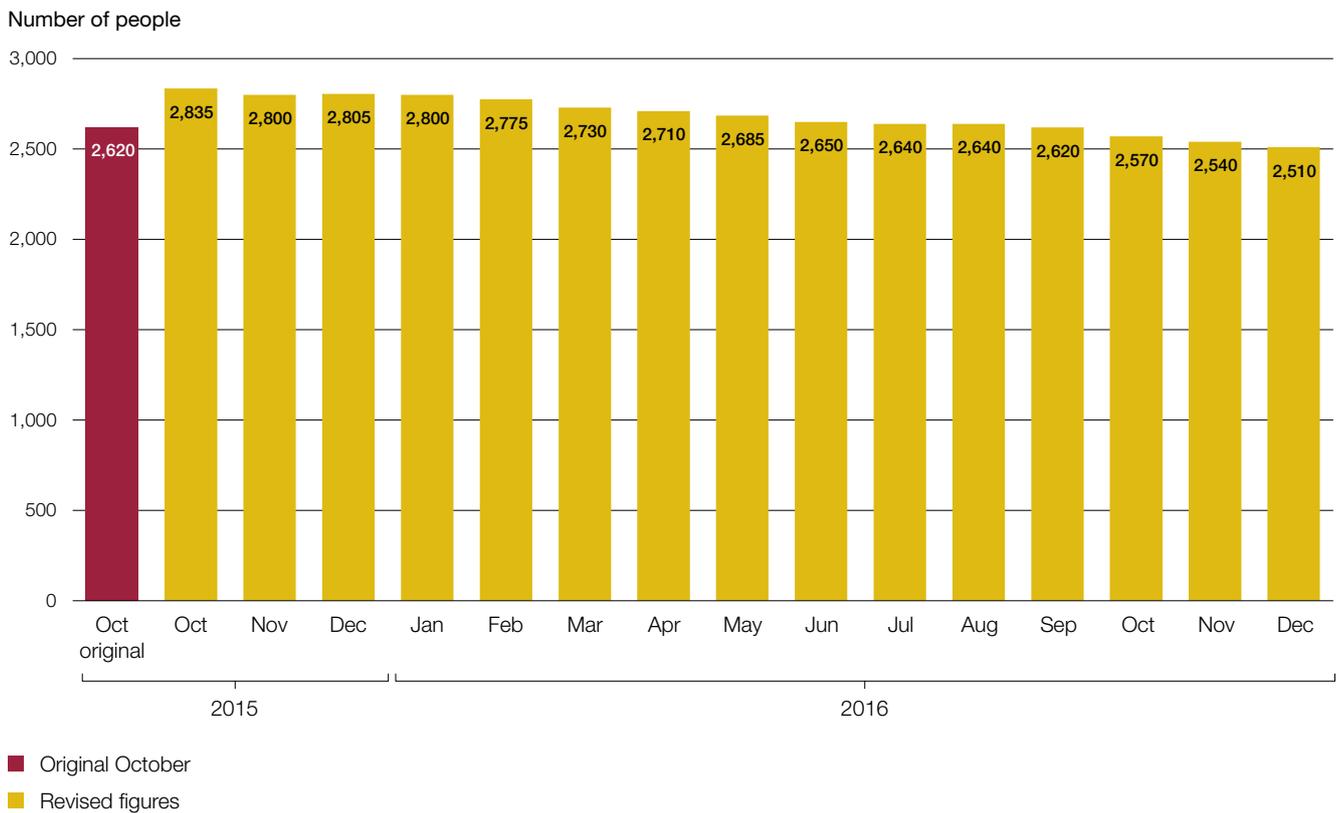
Note

1   The Assuring Transformation data set transferred to NHS Digital in February 2015. The chart shows the original count of people in mental health hospitals in October 2015 and the revised counts each month based on data at the end of December 2016.

Source: National Audit Office analysis of NHS Digital data

Figure 19

Admissions and discharges from mental health hospitals

Discharges slightly outnumber admissions

Number of people each month
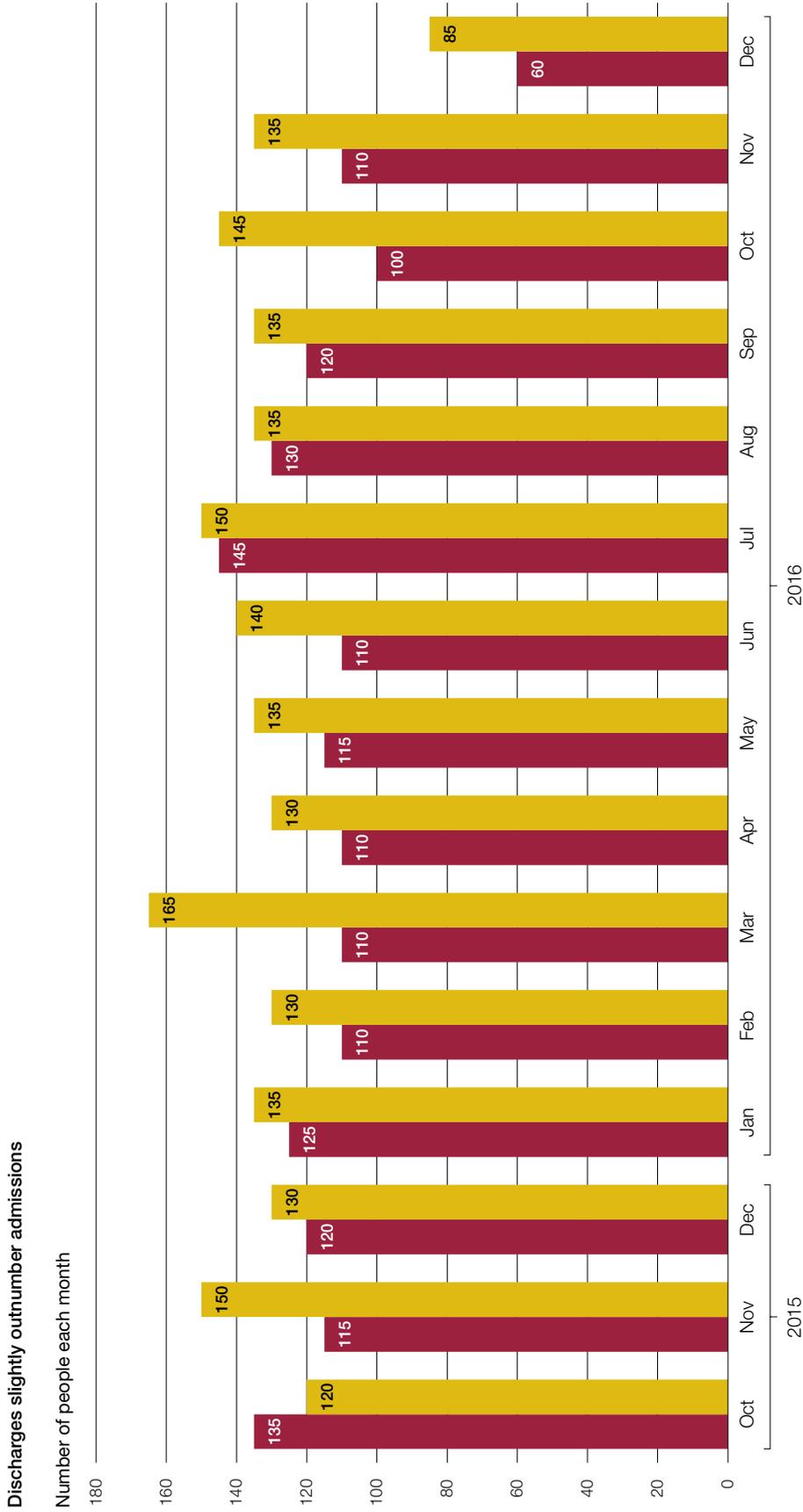
■ Admissions
■ Discharges

Notes

1 Based on revised December 2016 figures.

2 Discharges to other settings includes three categories: no transfer planned, patient died and other.

3 The number of admissions includes readmissions.

Source: National Audit Office analysis of NHS Digital data

Progress with other objectives

3.31 There is limited progress in the programme's other objectives. One of the key aims of Transforming Care is that patients in mental health hospitals will be moved to a hospital closer to home. There has been little improvement since our last report,[33] 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 (**Figure 20**).

3.32 Another key objective is to minimise the length of stay in mental health hospitals. Our report in February 2015, using the limited data available, found that the average continuous length of stay was six years and nine months. NHS England started to publish length of stay data in March 2015 but only for people who are still in hospital and excludes people who have been discharged. At this time, it found that average length of stay was just over five years. While the number of people who were in hospital for more than five years reduced from 930 people in March 2015 to 890 people in December 2016, the average length of stay for people still in hospital increased to almost five and a half years, indicating that people discharged had lower than average lengths of stay (**Figure 21** overleaf).

Figure 20
Distance from home of people in mental health hospitals

Distance from home remains unchanged

	Up to 10km	10 to 20km	20 to 50km	50 to 100km	100km or more
December 2015	20	12	23	21	24
November 2016	20	13	22	21	25
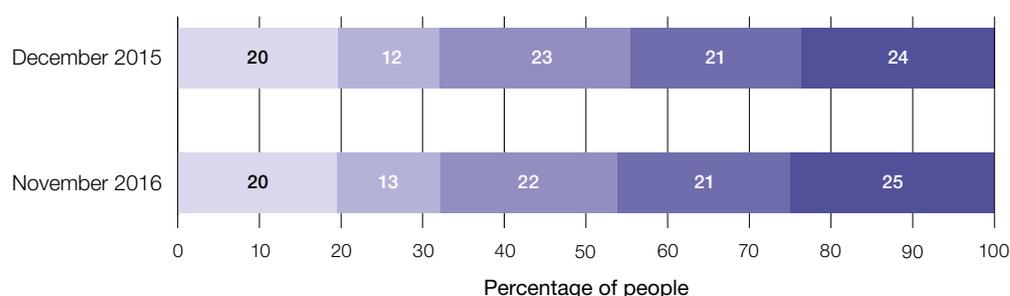
■ Up to 10km
■ 10 to 20km
■ 20 to 50km
■ 50 to 100km
■ 100km or more

Notes
1   Data as at December 2015 and November 2016.
2   Percentages have been calculated based on rounded data. November 2016 equals 101%.
3   People whose home is recorded as unknown have been excluded from this analysis. In December 2015 this was for 9% of people in hospital, and in November 2016 this was 16%.

Source: National Audit Office

33   See footnote 23.

Figure 21

Change in average length of stay

Average length of stay increased

Average length of stay in years
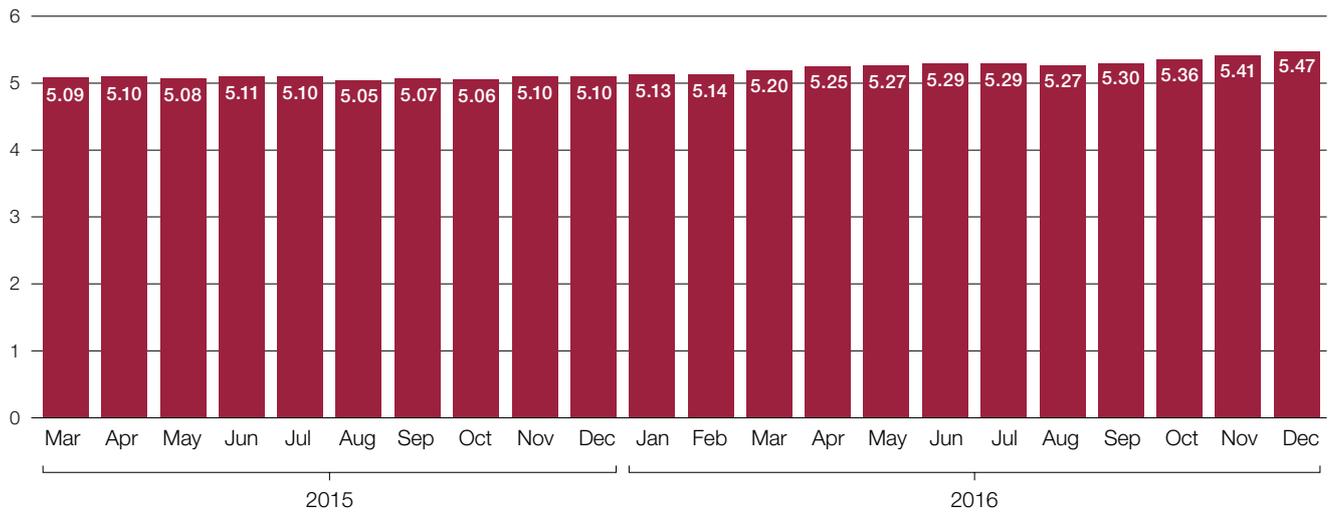
Notes

1   Total length of stay, which includes transfers from other mental health hospitals.

2   The length of stay relates to people still in mental health hospitals at the end of each month, and therefore excludes people who have been discharged.

Source: National Audit Office analysis of NHS Digital data

Appendix One

Our audit approach

1   This study examines whether health and social care support people for with a learning disability impacts on the quality of their lives. It also reviews progress by the Department of Health and NHS England in moving people with a learning disability and/or autism out of mental health hospitals into the community. We reviewed:

- Learning disability population data.

- The types of support provided to people with a learning disability.

- Government expenditure on supporting people with a learning disability, including Department for Work & Pensions expenditure on benefits, NHS England expenditure on healthcare, and local authority expenditure on social care services.

- Trends in local authorities' spending on adult social care and how this compares with local authority spending on learning disability services.

- Trends in healthcare outcomes: GP registers and GP annual health checks.

- Trends in social care outcomes: employment and settled accommodation.

- The governance of the Transforming Care programme and creation of the Partnerships.

- The Assuring Transformation data set on patient numbers, admissions, discharges and transfers, destination after discharge, numbers and frequency of care and treatment reviews.

- NHS England milestone monitoring on Partnerships' progress.

- Transforming Care programme financial arrangements, financial guidance and cost of hospital and community support.

2   In reviewing these issues, we applied an analytical framework with evaluative criteria, to consider what arrangements would be optimal for implementing a successful programme to move people out of mental health hospitals into the community and manage patient flows. By 'optimal' we mean the most desirable possible, while acknowledging expressed or implied constraints. We adapted a National Audit Office framework on initiating successful projects and good programme management to consider whether arrangements being put in place to manage the programme met good practice.

3   Our audit approach is summarised in **Figure 22** overleaf. Our evidence base is described in Appendix Two.

Figure 22

Our audit approach

The objective of government	The main objectives for the Transforming Care programme are: ● to reduce numbers of beds in mental health hospitals; ● to move people out of mental health hospitals into the community when appropriate; ● people who are in mental health hospitals should be close to home and family; and ● that the wider learning disability population has control over their lives, with employment and educational opportunities, have choice over what they do during the day, and have better health and improved access to housing.

How this will be achieved	The Department of Health has launched the Transforming Care programme, which aims to reduce bed numbers in mental health hospitals by 35% to 50%. National programme partners have created 48 local Partnerships formed of health and social care teams, who, supported by NHS England and other stakeholders will reduce bed numbers and provide good quality community support. The Department and the programme partners largely focus on the 2,510 people who are in mental health hospitals rather than the wider learning disability community.

Our evaluative criteria	How is money being spent on people with a learning disability?	Is the support provided to people with a learning disability improving outcomes?	Has the Department made progress with its programme to provide community services and reduce mental health hospitals beds for people with a learning disability?

Our evidence (see Appendix Two for details)	We estimated government expenditure on people with a learning disability by: ● calculating benefits from DWP; ● calculating local authorities spend using statutory data returns from NHS digital; ● calculating health spend from the Departmental general ledgers and statutory data returns; and ● using the learning disability census as the source for the learning disability population statistics.	We assessed the impact of support on outcomes by: ● conducting interviews with the Department; ● interviews and focus groups with carers, interviews with people with a learning disability; ● case study visits to local authorities and clinical commissioning groups; and ● reviewing outcomes data.	We evaluated the Department's progress with the Transforming Care programme by: ● conducting interviews with the Department and key stakeholders in the programme; ● case study visits to local authorities and clinical commissioning groups; ● survey of clinical commissioning groups; and ● evaluating the assuring transformation data set.

Our conclusions	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. 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 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 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.

Appendix Two

Our evidence base

1   We reached our conclusions based on work from July to September 2016. To understand support to the wider learning disability community and to help us assess the progress of the Transforming Care programme, we interviewed key stakeholders in the Department of Health, NHS England, the Local Government Association, the Association of Directors of Adult Social Services, Health Education England, Skills for Care, NHS Specialised Commissioning, the Care Quality Commission, the Department for Communities and Local Government, and the Department for Work & Pensions.

2   We went on six case study visits to local authorities and clinical commissioning groups. We interviewed key members of staff involved in the Transforming Care programme and involved in providing support to the wider learning disability community. These included local authority directors of adult social care services, local authority and NHS England commissioners, the heads of learning disability teams, social care workers and specialist practitioners such as learning disability nurses, health facilitators and data performance managers. We visited: Islington, Central Bedfordshire, York City, Plymouth, Salford, and West Sussex.

3   To capture the views of people with a learning disability who use local health and social care services, we interviewed and held focus groups with carers and people with a learning disability during our six case study visits. We also met with families and people with a learning disability and behaviour that challenges services at an event discussing the Transforming Care programme. We met with representatives from the National Valuing Families Forum and the Challenging Behaviour Foundation.

4   We engaged with third sector providers to gain their views on our proposed scope of the study. We convened a panel of experts including providers, charities and academics and held a panel discussion with providers from Care England.

5   We conducted a census of clinical commissioning groups to ask about joint financial arrangements and joint working. The response rate was 65%.

6   We reviewed key documents, including reports by the improving health and lives learning disability observatory, *Valuing people* and *Valuing people now*, the draft learning disability action plan, and minutes and papers of the National Learning Disability Board.

7   In addition to the work discussed, to assess progress with the Transforming Care programme we reviewed key programme documents including:

- Milestone reports.

- Assurance and delivery board minutes and papers.

- Programme progress reports (such as the 'dashboard').

- Programme guidance.

- Programme risk registers.

- We analysed the Assuring Transformation data set which are the key metrics for the programme.

8   We set out our data analysis including financial analysis in Appendix Three.

Appendix Three

Data

1   We used a number of different data sources to estimate expenditure on people with a learning disability aged 18 to 64. **Figure 23** overleaf sets out the data sources we used, our approach and our assessment of any limitations.

2   In 2014-15, the adult social care activity and expenditure data local authorities have a statutory responsibility to provide changed. These changes included replacing the categorisation of people who use services to reflect their primary reason for support eg memory and cognition and defining services as either short or long term. This same data is used to compile the measures included in the Adult Social Care Outcomes Framework.

3   In our data for people with a learning disability supported by the local authority we include people with a primary support reason of 'learning disability support'. A person whose primary support reason is recorded as 'physical support' will not be included, even if their secondary support reason is 'learning disability support'.

4   As a result of these changes it is not possible to make direct comparisons over time. Where we have shown this data in the same figure we have made this clear by showing it as two different time series. In part one we have compared different groups of people using local authority social care support services. We have based these on primary support reasons. For people with a learning disability this means that only people with a primary support reason of 'learning disability support' will be included in our learning disability category. Someone who has a 'learning disability support' as a secondary support reason will be included in another group, eg people aged 18 to 64.

5   The definition of eligibility for the Transforming Care programme is people with a learning disability and/or autism. As of December 2016, 17% of people in a mental health hospital, who came under the programme had autism and 23% had a learning disability and autism.

Figure 23

Expenditure estimate

Area	Source(s)		Approach and limitations
Local authority expenditure	1	NHS Digital Adult Social Care Finance Return 2015-16, gross expenditure on people aged 18 to 64 with a learning disability. Expenditure was comprised of spend on nursing and residential care, support in the community and short-term support.	This expenditure is taken from statutory data, which is subject to validation and it is our specified age range.
Health expenditure	1	Financial information from the clinical commissioning group ledgers for 2015-16 was used to identify spend on learning disability community support including continuing healthcare, specialist teams and health checks.	It was not possible to identify all clinical commissioning group spend on people aged 18 to 64 with a learning disability due to the descriptors used in the clinical commissioning group ledgers. We selected only lines that were clearly identified as being specifically related to learning disability spend and, where possible, to adults aged 18 to 64. A small proportion of spend will relate to children aged 14 to 18 with regard to health checks.
	2	To estimate expenditure by clinical commissioning groups on mental health hospital beds we used the cost per bed from the Learning Disability Census in 2015 multiplied by the number of inpatients.	Our estimate of clinical commissioning group spend on mental health hospital beds is based on slightly older and snapshot data.
	3	We used NHS England specialised commissioning expenditure on secure mental health hospital care for people with a learning disability 2015-16.	Some of the expenditure for mental health hospitals will include spend on people aged under 18 and over 65, however, this only equates to 8% of the population.
			Our estimate of health expenditure is limited to community based specialist learning disability support and mental health hospital stays.
Department for Work & Pensions	1	Data on personal independence payments and disability living allowance was provided by the Department for Work & Pensions extracted from Stat-Xplore for May 2016.	Data covers people aged 18 to 64 with the exception of women aged 61 to 64 years.
	2	Figures for employment support allowance were provided by the Department for Work & Pensions for July 2016.	Annual expenditure was extrapolated from monthly data from slightly different time periods and covers Scotland and Wales.
	3	Data on housing benefit (from end of 2015) published in the supported accommodation review in November 2016 was used to estimate spend on housing benefit for people with a learning disability in supported accommodation.	People with a learning disability may also receive other benefits not recorded here, eg housing benefit for their own home.
		This information is based on claimants identified with 'learning disability global'.	

Source: National Audit Office analysis of local authority, health and Department for Work & Pensions data