

Inpatient Admissions of People with Learning Disabilities and/or Autistic People and Attempts to Transform Care in England



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Accessible Summary and Key Findings

The UK government policy of *Building the Right Support* in England was launched in 2015 as part of Transforming Care. Transforming Care is the policy agenda set up to get people out of inpatient hospitals after the scandal at Winterbourne View.

This report looks at Transforming Care and *Building the Right Support* and gives an overview of what we think has worked and what has not worked.

It takes information from Transforming Care Implementation Plans, Freedom of Information requests, Assuring Transformation data about the numbers of people in in-patient hospitals and information from evaluations commissioned by NHS England.

The government set a target to reduce by over a third the number of people with learning disabilities people in hospitals, by March 2019. This target has not been met.

The government and NHS England have said that the number of people in in-patient hospitals has gone down by almost 20%. We think this is wrong and the number of people in in-patient hospitals has actually gone down by 14%.

Local health and social care partnerships asked the government for over £85 million so that they could change the way they are doing things and get people out of hospital.

Most of them did not get the money that they asked for. We think that this had a negative effect on their ability to implement *Building the Right Support*.

In the evaluations commissioned by NHS England people said that *Building the Right Support* is a good policy with lots of positive parts to it, but that there had been some difficulties in making it work.

People with learning disabilities and autistic people and their families who have had a Care and Treatment Review or a Care, Education and Treatment Review have told us that they made a difference and that the changes that had been made to them in 2017 were an improvement.

We believe that the government and NHS England have not yet done enough to put people with learning disabilities and autistic people and their families in charge of Transforming Care and that they also underestimated the amount of work involved.

At the end of the report we point out that Transforming Care and *Building the Right Support* are not mentioned in the NHS Long Term Plan 2019 and that the new commitment to reduce unnecessary hospital admissions for people with learning disabilities and autistic people is disappointingly low in ambition.

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1 An Introduction to Transforming Care

Many of the 930,000 adults with learning disabilities in England may never use specialist health and social care services¹. There are 147,915 adults who receive local authority social care support, a fifth (33,140) of whom live in residential care or nursing homes². Around 2,600 (2%), of people with learning disabilities are in long stay NHS and private hospital beds in specialist units, some of which are secure facilities. People with learning disabilities are more likely to experience a long stay in hospital than people without a learning disability³.

On 31st May 2011 the BBC television programme *[Panorama's Undercover Care: The Abuse Exposed](#)* was broadcast. The programme was an undercover investigation of a specialist hospital for people with learning disabilities and/or autism, Winterbourne View, which revealed to the public wilful abuse and neglect from staff towards people detained under the [Mental Health Act 1983](#) or [Mental Capacity Act 2005](#) for the purposes of care and treatment. It would lead to the prosecution and conviction of 11 members of staff, the closure of Winterbourne View Hospital and a flurry of activity on the part of the UK government to try and establish why the abuse had happened and how it could be prevented from happening in the future. This also brought into the light that an unknown number of people (in the thousands) were detained in these units (both NHS and private sector), sometimes for decades. People detained in the units were also found to be experiencing seclusion, restraint, assault and antipsychotic medication rather than effective support to help people move on⁴ at a cost of over £477 million a year⁵.

In 2012 the government conducted an inquiry that would lead to the publication of [Transforming Care: A National Response to Winterbourne View Hospital](#) which was jointly published with a [Concordat: Programme of Action](#). Fifty-one organisations signed up to support the Concordat, however the government did not ask the agencies who were responsible for commissioning or providing inpatient beds to do so. As a result clinical commissioning groups, local authorities and mental health hospitals were not asked to sign up to the Concordat. The Concordat outlined a number of objectives which centred around one key commitment, that by 1st June 2014 everyone with a learning disability who would

¹ <https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england-2015>

² <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2017-18> <https://www.nao.org.uk/wp-content/uploads/2017/03/Local-support-for-people-with-a-learning-disability.pdf>

³ <https://www.emeraldinsight.com/doi/full/10.1108/TLDR-02-2017-0010>

⁴ http://wp.lancs.ac.uk/cedr/files/2016/10/7_day_report_digital-1.pdf

⁵ <http://wp.lancs.ac.uk/cedr/7daysofaction2017/>

be better supported in the community would be moved out of hospital and for the beds to be closed⁶.

The programme failed in its ambition to keep people with learning disabilities out of hospital, accepting in its 2014 report [Winterbourne View – Time for Change](#) that:

“we make it too hard for stakeholders across the system to make change happen, and too easy to continue with the status quo. And we do not give enough power or support to the people most eager and best placed to make things change – starting with people with learning disabilities and/or autism themselves and their families” (p.9)

Key recommendations from the Transforming Care and Commissioning steering group were that:

- The government should draw up a Charter of Rights for people with learning disabilities and/or autism and their families, and it should underpin all commissioning.
- People with learning disabilities and/or autism should be given a ‘right to challenge’ their admission or continued placement in inpatient care.
- NHS England should extend the right to have a personal budget (or personal health budget) to more people with learning disabilities and/or autism, along with support to manage those budgets.
- The government should look at ways to protect an individual’s home tenancy when they are admitted to hospital, so that people do not lose their homes on admission and end up needing to find new suitable accommodation to enable discharge.
- The government and NHS England should force the pace on commissioning by requiring local commissioners to follow a mandatory framework.
- Community-based providers should be given a ‘right to propose alternatives’ to inpatient care.
- The commissioning framework should be accompanied by a by a closure programme of inappropriate institutional inpatient facilities, driven by tougher registration requirements, local closure plans, and leadership by NHS England.
- Health Education England, Skills for Care, Skills for Health and partners should develop as a priority a national workforce ‘Academy’ in this field, building on the work already started by Professors Allen and Hastings and colleagues.
- A ‘Life in the Community’ Social Investment Fund should be established to facilitate transitions out of inpatient facilities and build capacity in community-based services.

⁶https://webarchive.nationalarchives.gov.uk/20130124041359/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_080128.pdf

- Action on the recommendations above should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level.

Reporting on their analysis of the impact of the programme of action in 2015, the National Audit Office (NAO)⁷ observed that the central objective had been missed, and that there remained 2,600 people detained in inpatient beds as of September 2014, 83% of whom were sectioned under the Mental Health Act. The NAO findings were:

- The government underestimated the complexity and level of challenge involved in meeting its commitments.
- In December 2012, when agreeing the Concordat, the scope and the quality of data on patients with learning disabilities was poor.
- The government left it to mental health hospitals, NHS commissioners, and local authorities to decide how to meet the commitments.
- As funding did not follow the patient, there was no financial incentive for local areas to bring patients home.
- Only 73 of the 3,250 people in the 2013 census had been clinically assessed as posing such a risk to themselves, or others, that they needed to be in a high security hospital.
- NHS England lacks adequate and reliable data to monitor progress.

In October 2015, the UK Department of Health published *Building the Right Support*⁸ which provided a framework for the development of community service alternatives to hospital admissions, to support achievement of the ambitions Transforming Care Programme. The Transforming Care Programme⁹ aimed to reduce the number of people who were admitted to hospital, and to close hundreds of beds across England. The programme also included the establishment of 48 area-based Transforming Care Partnerships¹⁰ (TCPs), made up of Clinical Commissioning Groups (CCG), Local Authorities and other local stakeholders. *Building the Right Support* introduced a new National Service Model which was intended to be used as guidance to support local TCPs to meet a 45-65% reduction in capacity of hospital beds arranged by local commissioners, the Clinical Commissioning Groups, and a 25-40% reduction in the number of nationally arranged NHS England (NHSE) beds. The objective was that this would result in a reduction of the number of people inappropriately

⁷ <https://www.nao.org.uk/report/care-services-for-people-with-learning-disabilities-and-challenging-behaviour/>

⁸ <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

⁹ <https://www.england.nhs.uk/learning-disabilities/care/>

¹⁰ <https://www.england.nhs.uk/learning-disabilities/tcp/>

in inpatient beds from the 2,600 reported by the NAO to between 1,300 – 1,700 by March 2019.

In 2017, the NAO produced a further report¹¹ on progress in transforming local support for people with learning disabilities which observed that as of December 2016, an 11% reduction had been achieved in the number of people in mental health hospitals against the target of a 35-50% reduction and 60 NHSE commissioned beds had been decommissioned against a target of 136. The NAO findings on progress with the Transforming Care Programme was:

- From 2012 to 2015, the Department's progress in moving people out of mental health hospitals and into the community was poor.
- In 2015, the Department and NHS England set up the Transforming Care programme to move people out of mental health hospitals more quickly.
- Early indications are that the programme was making progress in reducing the number of people in mental health hospitals, noting an 11% reduction from 2,835 in October 2015 to 2,510 December 2016¹².
- Programme partners did not yet have confidence that Partnerships can close the planned number of beds by 2019. NHS England had identified that between 900 and 1,300 beds would need to close by 2019. By December 2016, 60 beds had closed and as of April 2017, TCPs only intended to close 136 beds by April 2017.

The NAO report recommended a number of areas of complexity which would need to be resolved to achieve the ambition of the Transforming Care Programme:

- The flow of people admitted to inpatient care needed to be reduced while the flow of people out into the community needed to increase.
- Money was not being released quickly enough from hospitals to invest in community models of support.
- Local TCPs were struggling to secure new models of accommodation and housing support.
- Local TCPs had not produced plans to mobilise a community based workforce.

¹¹ <https://www.nao.org.uk/wp-content/uploads/2017/03/Local-support-for-people-with-a-learning-disability.pdf>

¹² It is unclear why in the 2017 report the NAO used 2,835 as the baseline from which to calculate the 11% reduction, given the figure of 2,600 which was previously reported by the NAO in their 2015 report on the Transforming Care Programme. If the baseline of 2,600 had been used, the reduction would be 3.5% rather than the 11% reduction claimed.

- There had been little progress in meeting wider objectives, with just 20% of people in hospitals ten kilometres or less and 46% in hospitals over 50 kilometres from their home.

The NAO once again emphasised the centrality of good quality data to underpinning efforts to transform care:

“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.” (p.11)

In January 2019, NHS England published the Long Term Plan for the NHS in England¹³. Chapter Three of the NHS Long Term Plan focused on further progress in care quality and outcomes, including a section on learning disability and autism (paragraphs 3.31-3.36). The plan did not reference Transforming Care or *Building the Right Support*, however it did reflect on key commitments stating in paragraph 3.34 that:

“Since 2015, the number of people in inpatient care has reduced by almost a fifth and around 63598 people who had been in hospital for over five years were supported to move to the community.” (p.53)

New commitments were made that:

- Local systems would take greater control over budgets to reduce avoidable admissions, enable shorter lengths of stay and end out of area placements.
- people with a learning disabilities, autism or both will be enabled to have a personal health budget (PHBs).
- By March 2023/24, inpatient provision will have reduced to less than half of 2015 levels (on a like for like basis and taking into account population growth) and, for every one million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit. For children and young people, no more than 12 to 15 children with a learning disability, autism or both per million, will be cared for in an inpatient facility.

On Wednesday 22nd May 2019, the BBC broadcast a second Panorama programme expose of the experiences of people with learning disabilities and autistic people at the so called "secure mental health hospital", [Whorlton Hall](#). The programme coincided with the publication of the [third annual report on the Learning Disabilities Mortality Review](#)

¹³ <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>

[programme in England](#), which reported finding that women with learning disabilities died 27 years earlier; men 23 years, when compared to the general population. The Care Quality Commission in England also published in the same week a report on their [interim findings from their review of the use of restrictive interventions in places that provide care for people with mental health problems, a learning disability and/or autism](#). The CQC had visited 35 wards, and reviewed care and support for 39 people who had experienced segregation, a high proportion of whom were autistic. The CQC reported finding staff lacked necessary training and skills to support people who were being secluded, and in seven out of ten cases had given up trying to reintegrate the person back from seclusion onto main wards.

2 Transforming Care: Building the Right Support (2016-2019)

The programme of activity introduced by *Building the Right Support* consisted of a number of key elements.

A National Service Model

The National Service Model¹⁴ for *Building the Right Support* had nine components, or principles, which should form the basis of a local offer for people with learning disabilities and/or autistic people and their families:

1. A good and meaningful everyday life
2. Person-centred, planned, proactive and coordinated care
3. Choice and control
4. Support from and for their families/carers as well as paid support and care staff
5. Housing
6. Mainstream NHS services
7. Specialist health and social care support in the community
8. Support to stay out of trouble
9. Treatment in a hospital setting for no longer than they need it.

The idea being that with the right services in place people would not need to go into inpatient hospitals.

A New Financial Framework

Whilst there was no new money available to support Transforming Care, it was intended that the development of a national service model would be helped by what was called a new financial framework¹⁵ whereby Local Authorities, CCGs and NHS England specialist commissioners would use funding that paid for hospital admission to fund community services. It was estimated that the closure of hospital beds would release “hundreds of millions of pounds” (para 4.42) to reinvest in the community.

Care and Treatment Reviews

Since 2015, Care and Treatment Reviews¹⁶ (CTRs) have been taking place. Care and Treatment Reviews are carried out by a panel including one representative of the person

¹⁴ <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

¹⁵ <https://www.england.nhs.uk/learningdisabilities/wp-content/uploads/sites/34/2016/01/finance-gas.pdf>

¹⁶ <https://www.england.nhs.uk/learning-disabilities/care/ctr/>

and ask questions about what could be done to avoid an admission to hospital or to help someone home who was inappropriately detained. After criticism of the implementation of CTRs by the Public Accounts Committee, who observed that by December 2016 reviews had only taken place with 39% of people with learning disabilities in mental health hospitals and that senior clinicians were not engaging in the CTR process¹⁷, a number of changes were made to the CTR Policy and Guidance including the creation of Care, Education and Treatment Reviews for children and young people.

Transforming Care Partnerships

In order to support the delivery of *Building the Right Support* at a local level 48 area-based Transforming Care Partnerships (TCPs) were set up in April 2016. Their objective was to bring together commissioners and providers from across different agencies, at a scale that would help to prevent duplication and support the development of the infrastructure required to improve support in the community. Once they were established, they were required to draw up implementation plans outlining how they were going to deliver the objectives set out in *Building the Right Support*.

The Transforming Care implementation plans outlined how the 48 Transforming Care Partnerships would implement *Building the Right Support*. Each Partnership was instructed to consult widely in drawing up its plan and show how it intended to implement the National Service Plan in its local area, adapting it to the needs of the local community and making full use of existing systems and services. It is unclear to what extent each TCP area complied with the duty to consult.

Building the Right Support Objectives

Building the Right Support set out a number of objectives for NHS England and the 48 local Transforming Care Partnerships. The first was that each TCP should have the National Service Model in place by the end of March 2019, this quite specific objective was accompanied by the slightly vaguer expectation that partnerships would *make progress on three outcomes*

1. Reduced reliance on inpatient services (closing hospital services and strengthening support in the community)
2. Improved quality of life for people in inpatient and community settings
3. Improved quality of care for people in inpatient and community settings

(BRS, p36)

¹⁷ <https://publications.parliament.uk/pa/cm201617/cmselect/cmpubacc/1038/103805.htm>

However, ultimately, NHS England and the Department of Health and Social Care determined that the success or failure of Transforming Care / *Building the Right Support* would be measured by the policy's ability to reduce the number of people detained for assessment and treatment in inpatient hospitals, setting the following targets:

"at a minimum, 45 – 65% of CCG commissioned inpatient capacity will be closed, and 25 – 40% of NHS England-commissioned capacity will close, with the bulk of change in secure care expected to occur in low-secure provision. Overall, 35% - 50% of inpatient provision will be closing nationally with alternative care provided in the community. The change will be even more significant in those areas of the country currently more reliant on inpatient care. In three years we would expect to need hospital care for only 1,300-1,700 people where now we cater for 2,600. This will free up money which can then be reinvested into community services, following upfront investment" (BRS, p6).

3 Has the number of people with learning disabilities and/or autistic people in inpatient units reduced?

The [Long Term Plan for the NHS in England](#), published in 2019, states that “Since 2015, the number of people in inpatient care has reduced by almost a fifth and around 635 people who had been in hospital for over five years were supported to move to the community.” (para 3.34, p.53)

How many people were in hospital at the start of Transforming Care?

In February 2016, a month before the start of the Transforming Care Programme, there were 2,650¹⁸ people receiving inpatient care.

Where do we find the information about Transforming Care?

There are two main sources of information about Transforming Care. The Assuring Transformation and the National Mental Health Services Data Sets. The Assuring Transformation data set, which NHS Digital assumed responsibility for in January 2015, reports on the number of people with learning disabilities and autistic people in hospital to ensure that the public awareness of delivery of the NHS commitments in the Winterbourne View Concordat are transparent and robust. In September 2014, rather than revising Assuring Transformation, the scope of the Mental Health Services data set was expanded to include contact with people with learning disabilities and autistic people in the return¹⁹. The Mental Health Services Data Set aims to provide up to date information about the numbers of people using services, spending time in psychiatric hospitals and subject to the Mental Health Act (MHA).

Both data sets have continued to be collected and reported on during the Transforming Care Programme. They report different numbers of people with learning disabilities and autistic people experiencing inpatient stays with the Assuring Transformation data set reducing, whilst the Mental Health Services Data Set shows an increasing inpatient population (see Figure 1).

¹⁸ <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/learning-disability-statistics-annual-overview-england-2015-2016>

¹⁹ <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set/mental-health-and-learning-disabilities-statistics-mhlds-monthly-reports>

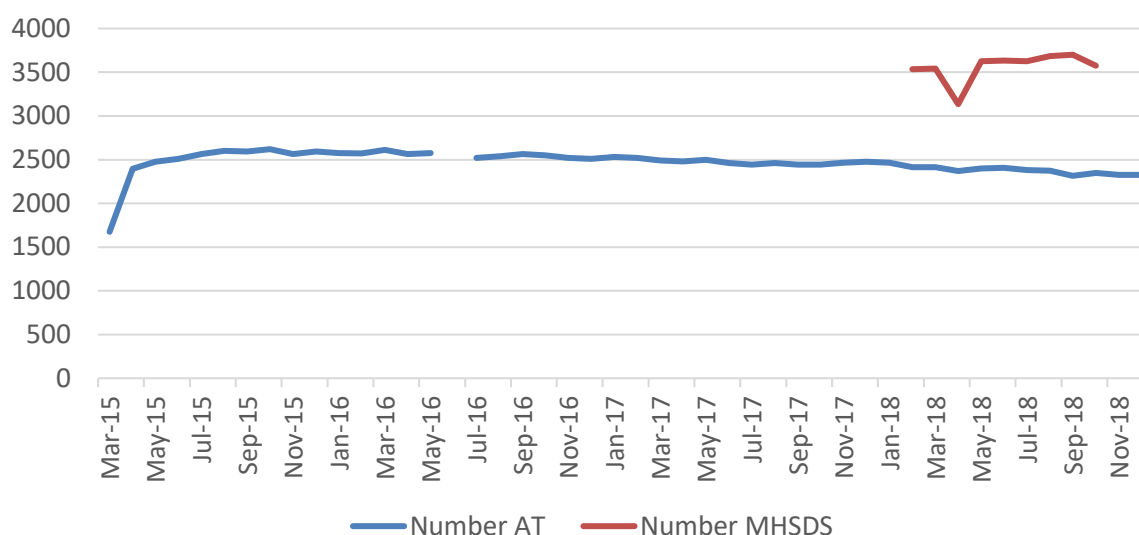


Figure 1 showing the number of people reported as being in patient units by Assuring Transformation (AT) and the Mental Health Services Data Set (MHSDS)

Accepting that 2,600 people in inpatient units was the baseline for Transforming Care:

- NHS Digital provisional Assuring Transformation statistics release 17 January 2019²⁰, reported that there were 2,305 people in inpatient beds as of the end of December 2018, which would be an 11% reduction in the number of people in inpatient units. However, the Mental Health Services Data Set reported that as of the end of October 2018 there were 3,575 people in inpatient beds.

“For every one million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit.” (NHS Long Term Plan para 3.34)

At the start of Transforming Care, in April 2016, 48 Transforming Care Partnerships produced plans²¹ in which they reported a baseline inpatient rate of 53 per million GP Registered Population in April 2016 (see Figure 2). To achieve a rate of 30 per million GP registered population by March 2023/24 would require a 43% reduction in the number of people detained in inpatient units from the April 2016 rate.

²⁰ <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/provisional-statistics-at-january-2019-mhsds-november-2018-final>

²¹ <https://www.emeraldinsight.com/doi/abs/10.1108/TLDR-02-2017-0010>

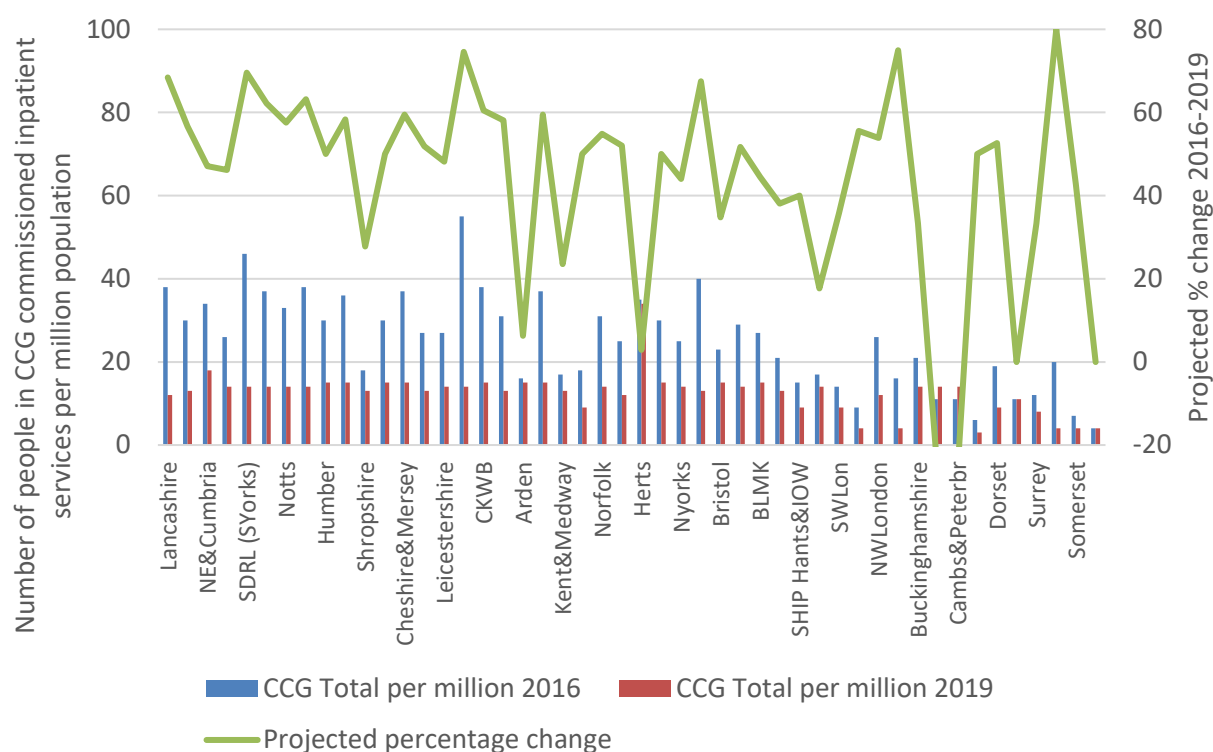


Figure 2 Inpatient rates per million people registered with GPs by TCP area, the column in blue is the baseline reported by the 48 TCPs in 2016, the column in red is the 2019 TCP target in keeping with Building the Right Support, the green line is the projected percentile change required

The 48 TCPs each submitted in April 2016 a forecast target which, if their plans were fully supported and resourced by NHS England and partners, they believed they could achieve by March 2019. The average TCP target inpatient rate per million GP registered population was 31.

The Mental Health Services Data Set includes information about how long some people have been in hospital. It showed that half of people reported on had been in hospital for over a year, and 15% had been in hospital for more than five years (see Figure 3²²).

²² MHSDS LDA 45 - Hospital spells open at the end of the RP

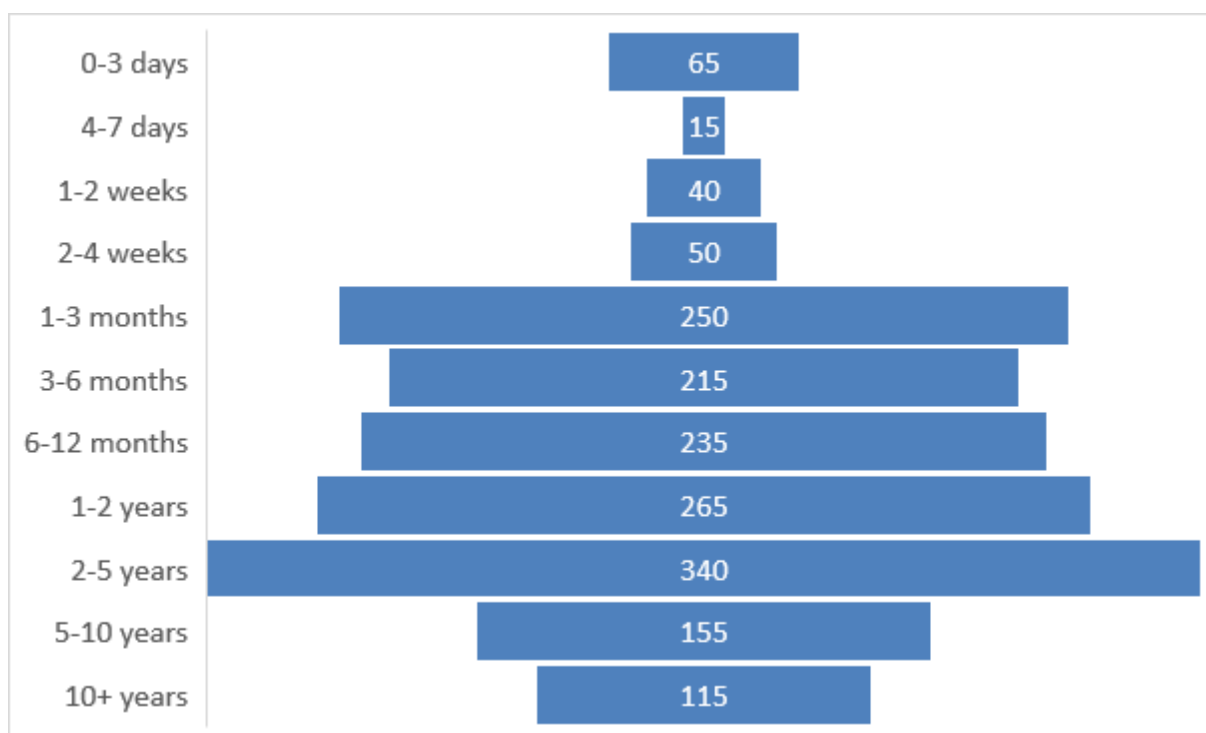


Figure 3 Length of stay for people in hospital who were reported by providers as being present at the end of the November 2018 in the MHSDS

For the TCP areas, this equates to an inpatient rate per million GP registered population of 35. There are rates of variation in performance between TCP areas shown in Figure 2 which are not explainable by population prevalence, which is consistent with our previously reported findings²³.

²³ <https://www.emeraldinsight.com/doi/full/10.1108/TLDR-02-2017-0010>

Has the number of inpatient beds for people with learning disabilities reduced?

“By March 2023/24, inpatient provision will have reduced to less than half of 2015 levels (on a like for like basis and taking into account population growth) and, for every one million adults” (NHS Long Term Plan para 3.34)

Since the early 1980s, there has been a sustained programme of closing NHS Trust provided specialist beds for people with learning disabilities (see Figure 4).

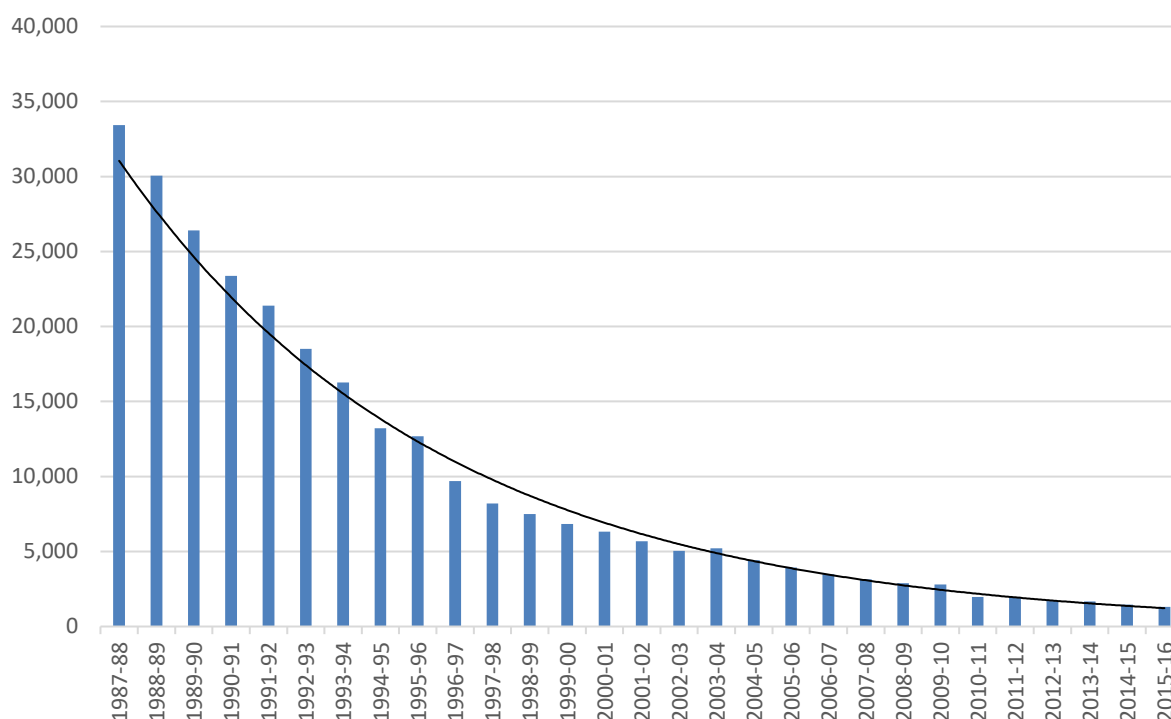


Figure 4 NHS Trust provided specialist learning disability beds since 1987²⁴

At the start of the Transforming Care Programme in April 2016, there were 1,248 NHS Trust provided specialist beds for learning disabilities, occupied by 913 people (an occupancy rate of 73.5%). As of December 2018, the number of beds available had reduced by a fifth (20%) down to 997. These beds were occupied by 766 people, a 16% reduction (occupancy rate of 76.8%).

²⁴ Data taken from KH03 collection from all NHS organisations that operate consultant-led beds open overnight or day only. Changes to the way data is collected mean only Q4 data provided from 2010/11. More information: <https://www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-and-occupancy/>

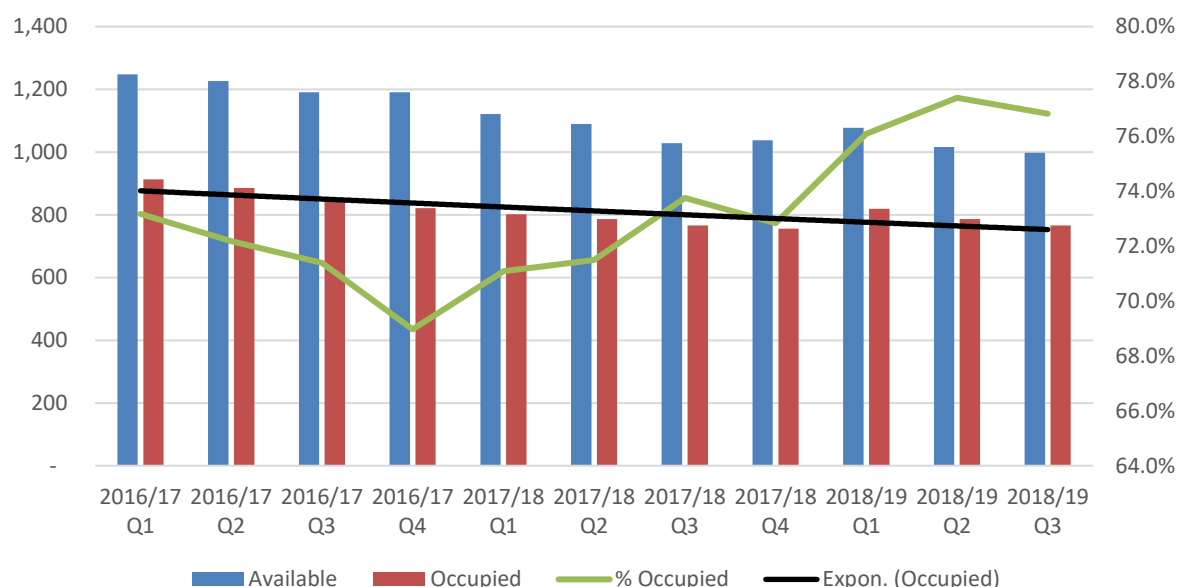


Figure 5 NHS England specialist learning disability beds 2016 - 2019²⁵, the blue column shows the number of beds available, the red column shows the number of beds occupied, and green line shows the percentage occupancy rate

In addition to the NHS Trust provided beds, there is also an expansive and expanding private (independent) sector market of mental health hospitals supplying additional capacity to health commissioners. Glover and Olson (2012) found that in 2006, a fifth (20%) of people with learning disabilities in specialist mental health units were being treated in private hospitals. By 2015 the proportion of people who were in ATUs within the independent sector had increased to 46%²⁶

To try and understand how the number of private sector beds may impact on the total number of beds available in the system which people with learning disabilities and/or autistic people may be detained in, for the purposes of assessment, care and treatment, analysis was undertaken on the Care Quality Commission locations registered for assessment, care and treatment for people with learning disabilities and people detained under the Mental Health Act 1983. These private sector beds can be registered with the Care Quality Commission for a number of different population groups, so the number of registered beds does not necessarily reflect the number of people with learning disabilities and autistic people in these locations.

²⁵ <https://www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-and-occupancy/bed-data-overnight/>

²⁶ <http://wp.lancs.ac.uk/cedr/files/2017/06/A-Trade-in-People-CeDR-2017-1.pdf>

We found 164 registered locations, owned by 19 independent sector Brands (see Table 1) who were registered with the CCG to provide assessment, care and treatment for adults detained under the Mental Health Act (100 locations) or whose registration included learning disabilities (64 locations) as one of the named population groups the provider supported. The 19 Brands were operating through 46 named providers who managed 164 locations providing 6,006 registered beds for adults and a further 300 beds for children and young people's mental health services (CAMHS).

Table 1 Brands of Independent Sector Providers of CQC Registered Assessment, Care and Treatment of people with learning disabilities and people detained under the Mental Health Act

Brand name	Number of CQC registered locations	% of all locations
Acadia	46	28%
Alternative Futures Group	6	4%
Arcadia	1	1%
Barchester Healthcare	2	1%
Bramley Health	2	1%
Cambian Healthcare Limited	1	1%
Careline Lifestyles	2	1%
CareTech Community Services	1	1%
Cygnet Health Care	45	27%
Danshell	8	5%
Disabilities Trust	1	1%
Elysium Healthcare	26	16%
Equilibrium Healthcare Group	1	1%
Four Seasons	8	5%
Inmind Healthcare Group	4	2%
Jeesal Group	1	1%
Making Space	1	1%
St Andrew's Healthcare	4	2%
Turning Point	4	2%
Total	164	

The Mental Health Services Data Set does not include comprehensive information about people with learning disabilities and autistic people who are resident in these independent hospitals as most of the providers do not yet report into NHS Digital. We found that as of the end of November 2018, there were 71 providers who submitted information of which only 14 were independent providers.

As of March 2019, there were 3,659 NHS Trust specialist beds and independent sector beds registered with the CQC to provide assessment, care and treatment for adults with learning disabilities at a rate of 68.7 per million adult population. In addition, there were a further 3,344 independent sector beds where a person with learning disabilities and/or autistic person subject to section of the Mental Health Act 1983 could potentially be detained for the purposes of care and treatment. This is a combined total potential position of 7,003 beds, a rate of 131.5 beds per million adult population²⁷.

Given the size of the independent sector bed base, it is insufficient to measure whether or not the size and shape of inpatient patient provision has transformed based solely on the number of NHS Trust specialist learning disabilities beds available. A data development and research agenda, which seeks to further improve understanding of the likelihood of a person with learning disabilities and/or autistic person to be admitted into a location registered with the CQC for the purposes of assessment, care and treatment of adults sectioned under the Mental Health Act, is required to enable increased confidence that there is a recognised, transparent baseline from which to assess the inpatient capacity in England and ensure accountability of delivery by 2023/24 of commitments made in the NHS Long Term Plan.

Has the length of time people stay in inpatient units reduced?

The Assuring Transformation and Mental Health Services Data Set published January 2019 reported that 1,335 people (57%) had a total length of stay in inpatient units of over two years. This compared with, of those in hospital at the end of July 2018, where 1,390 people (58%) had a total length of stay of over two years.

²⁷<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/july2017>

4 Has Transforming Care Building the Right Support achieved its objectives?

Once established the Transforming Care Partnerships developed implementation plans, most of which were published in the Spring or Summer of 2016. They were of varying quality, although a good many showed evidence of a significant amount of work, careful planning and of wide consultation within local communities.

In the NHS Long Term Plan, NHS England claim that “*Since 2015, the number of people in inpatient care has reduced by almost a fifth*”. We have tried to recreate the calculation so that we can validate it. *Building the Right Support*²⁸ stated that there were 2,600 people in hospital (p6), however the final Assuring Transformation reports that the number of people in hospital was 2,885 in March 2015. As of December 2018, Assuring Transformation provisionally reports that there were 2,325 people in hospital, 560 less people, a reduction of 19.41%, “*almost a fifth*”.

The problem with this approach is that it is likely to significantly overestimate the rate of progress that has been achieved. It is highly likely that 2,325 as a “provisional” figure will change and increase as additional people become known to commissioners. To try and validate a more accurate figure, we also compared the final number of people reported as being in hospital in March 2018 (2,495) with the final number of people in hospital in March 2015 (2,885). This way of working it out gives us a 13.5% reduction as there were 390 fewer people in hospital by March 2018. Allowing for improved data quality, we think that the rate of progress in reducing the number of people with learning disabilities and autistic people who are inappropriately in hospital is more likely to be around 14% rather than the 20% claimed by NHS England.

Why hasn't *Building the Right Support* delivered the outcomes that it promised?

The Transforming Care Partnerships do not seem to have developed the impetus that was hoped for. The early efforts and optimism that is reflected in many of the plans was not sustained, possibly because of the inability to realise the anticipated hundreds of millions of pounds of money envisaged in the new financial framework. Whilst the number of NHS Trust provided specialist learning disability beds has reduced, the number of beds in the independent/private sector was not well enough understood at the start of Transforming Care and remains an insufficiently well scoped significant contributor to the bed base. Given the number and cost of private sector beds, we have previously reported that the average fee per week is in the region of £3,564²⁹ per person (p6), it is not appropriate that

²⁸ <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

²⁹ http://wp.lancs.ac.uk/cedr/files/2016/10/7_day_report_digital-1.pdf

only 14 providers report into the Mental Health Services Data Set. As long as this practice is allowed to continue, progress in reducing the number of people inappropriately in hospital and releasing the money committed to detain them for investment in community alternatives will remain impeded.

Reducing the number of people in inpatient hospitals is not just about developing systems that will help to get people out of hospital, it is about having support in people's everyday lives. Some of that support may be about responses to crisis, but much more needs to be focused simply on support to help people to live their everyday lives. However, as long as Transforming Care remains a professional led programme, it will remain focused on prioritising professional concerns. Financial balances, patient flows, compliance with compiling registers of people in the community who are deemed by professional to be at risk. If Transforming Care is to make a paradigm shift in focus and impact, Transforming Care version 0.3 will need to make a transformational shift in understanding of who should be leading the programme. It is our strongly held view, that any future work to reduce the number of people with learning disabilities and autistic people in long stay beds (of all types, private, NHS, residential, nursing, mental health hospital) must be led by people with learning disabilities and autistic people, their families and peer advocates.



Figure 6 Location of Specialist Independent Hospitals, by the number of beds provided, registered with the CQC for assessment and treatment of people with learning disabilities and/or autistic people³⁰

³⁰ CQC database of registered providers extract accessed, <https://www.cqc.org.uk/file/258838> 1 March 2019

In this report we argue that the national policy, Transforming Care, has not met its goal of achieving profound and radical change which would reduce by over a third the number of people with learning disabilities and autistic people who are inappropriately in hospital due to a failure to position people with learning disabilities and autistic people and their families as leaders of the national programme.



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