



Health & Social Care  
Information Centre

# Learning Disabilities Census Report

**England, 30 September 2013**

**Published 13 December 2013**

This product may be of interest to the Department of Health, the Care Quality Commission and Public Health England. It will also be of interest to commissioners and providers of in-patient and community-based services for people with learning disabilities and/or autistic spectrum disorder (including Asperger's Syndrome). Charities and third sector organisations with a focus on people with learning disabilities, and/or autistic spectrum disorder (including Asperger's Syndrome), as well as service users themselves, and their family and friends, may also find this product useful.

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<b>Version:</b>	<b>V1.0</b>
<b>Date of publication</b>	<b>13 December 2013</b>

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## Executive Summary

This report presents initial findings from the 2013 Learning Disability Census. Data were collected via the Health and Social Care Information Centre (HSCIC) on behalf of the Department of Health, the Care Quality Commission, Public Health England and NHS England.

The principal aim of the Census is to deliver action 17 in 'Transforming Care: A national response to Winterbourne View Hospital'<sup>1</sup> - "an audit of current services for people with challenging behaviour to take a snapshot of provision, numbers of out of area placements and lengths of stay".

The Learning Disability Census provides an individual record-level snapshot of inpatients with learning disabilities, autistic spectrum disorder and/or behaviour that challenges, and the services they receive, for service users who were inpatients in NHS and independent services at midnight on 30 September 2013. The census will be re-run on 30 September 2014.

These statistics are important as they present definitive and comprehensive information about the population size, characteristics, and experience of care, of people whose treatment, care and support needs may be similar to those treated in Winterbourne View. The Learning Disability Census collected a range of information about this group of service users and their treatment environment, including demographics, ward characteristics and information relating to out of area placements and lengths of stay. A full list of the data items collected is published on the HSCIC website<sup>2</sup>.

This initial publication reports on a key subset of data collected in the Learning Disability Census, covering: demographic characteristics of service users (age, gender and ethnic group), health-care provider, area of residence and ward stay, distance between residence and ward stay, length of ward stay, service type, and security level of ward.

As this report focuses on a subset of the data collected, the HSCIC are considering undertaking more comprehensive analysis of the 2013 Learning Disability Census, which would include data items relating to experience of care, legal status, and ward conditions. The 2014 Learning Disability Census is expected to measure changes in the number of service users receiving inpatient treatment and care, and is expected to be supported by the inclusion of data for people with learning disabilities within the Mental Health and Learning Disabilities Data Set effective from April 2014.

This is the first time this information has been collected in this format and presents a significant opportunity to undertake longer term monitoring of change and outcomes realisation beyond the 2014 Learning Disability Census. These statistics are intended to help inform improvements in the provision of inpatient and community-based care for people with learning disabilities, autistic spectrum disorders, and/or behaviour that challenges and will be of interest to mental health professionals as well as service users, their families and representative organisations.

Taken in conjunction with development of monthly data submissions from NHS and independent sector providers, the Learning Disability Census marks a significant progression in enabling the transformation of care for people with learning disabilities currently receiving inpatient provision.

## Key facts

Responses from 104 provider organisations were received on behalf of 3,250 service users who met the inclusion criteria for the 2013 Learning Disability Census:

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<sup>1</sup> Transforming Care: A national response to Winterbourne View Hospital:  
<https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>

<sup>2</sup> <http://www.hscic.gov.uk/ldcensus>.

- Around three in four service users (74.6%) were male and one in four (25.4%) were female. Most service users (2,994 or 92.1%) were adults of working age (18-64); few (185 or 5.7%) were aged under 18 and very few (71 or 2.2%) were aged 65 and over. The ethnic group composition of service users was broadly in line with the general population of England<sup>3</sup>.
- Six in ten service users (60.0% or 1,949) had been inpatients for a year or more and around one in six (17.6% or 572) had been inpatients for five years or more. Inpatients admitted in the three months before the Census comprised about a fifth of all service users (18.5% or 601 people). Length of inpatient stay varied with age:
  - Service users aged under 18 were proportionally more likely to have been inpatients for three months or less (45.4% or 84) than service users overall, whilst the comparable proportions of working age adults (16.9% or 506) and adults aged 65 and over (15.5% or 11) were broadly in line with the all-ages proportion.
  - For service users aged 65 and over, around four in ten (38.0% or 27) had been inpatients for five years or more, around twice the proportion of all inpatients. Proportionally fewer service users aged under 18 had been inpatients for five years or more (7.6% or 14). For working age adults, the proportion who were inpatients for five years or more (17.7% or 531) was similar to the proportion of all inpatients.
- Just under one in five inpatients (18.2% or 570) were staying in wards located 100km or more (as the crow flies) from their residential postcode. About the same proportion (19.6% or 612) stayed in wards within 10km of their residential postcode; a further 7.7% (240 people) were resident in hospital, with the same postcode recorded for both residence and hospital. Substantial regional inequalities were found in the distances travelled for inpatient care:
  - More than half of service users resident in the South West (52.6%) were inpatients in wards located 100km or more from their postcode of residence, compared with 8.8% of service users resident in the North East.
  - Around four in ten service users resident in London (39.0 %) received inpatient care within 10km of their residential postcode (and had a postcode of residence separate from their ward stay), compared with around one in ten in the South East (10.5%).
- Most service users (76.3% or 2,481) were inpatients in wards predominantly providing services for people with learning disabilities. A further one in five (20.1%, or 653) were inpatients in mental health wards. The remainder (3.6% or 116) were inpatients on wards predominantly providing some other service. Ward stays in wards designed primarily for people with learning disabilities were substantially below the national proportion in Yorkshire and The Humber (62.2%), London (59.7%), and the South West (40.5%). As a region, the South West had the highest proportion of inpatients staying in mental health wards (45.6%) and in other wards (13.9%).
- Around three in four service users (75.1%) in England (where the postcode of ward stay was known) were inpatients within a fifth (31) of England's 152 local authorities. Almost half (49.5%) were staying in just 12 local authorities. The concentration of most inpatients in a small proportion of local authorities contributes to inequalities in provision seen at regional level:
  - The South West, the South East and Yorkshire and The Humber were the highest 'net exporters' of service users, having seventy or more service users with a postcode of residence within the region than were receiving care in the region.
  - The East Midlands and the East of England were the highest 'net importers' of service users, having one hundred or more service users that were receiving care within the region than had a postcode of residence within the region.
- Maintaining contacts with family, friends, advocates and commissioners helps ensure that inpatient stays remain suitable for service users' needs. Overall, providers could not supply a valid residential postcode for 910 people (28.0% of inpatients). Nine providers submitted more than seven in ten (71.6%) of the 910 records received without a valid residential postcode. Some providers were unable to supply valid residential postcodes for most of their inpatients.

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<sup>3</sup> The 2011 Census for England and Wales: <http://www.ons.gov.uk/ons/guide-method/census/2011/index.html>

## Introduction

This report presents initial findings from the Learning Disability Census. This Census collected record-level information about service users with a learning disability, autistic spectrum disorder (including Asperger's syndrome) and/or behaviour that challenges, who were inpatients at midnight on 30 September 2013. This report provides analysis and statistical commentary on the following key topics covered by the Learning Disability Census:

- Profile of service users;
- Ward service, security level and length of stay;
- Service users by region, local authority, and distance between residence and ward stay;
- Profile of providers.

Appendix 1 to this document describes the methodology for the Learning Disability Census. Appendix 2 lists the reference data tables on which this report is based: these are provided in accompanying spreadsheets as part of this release. Appendix 3 provides further information and resources.

A data quality statement accompanies this publication and can be downloaded from the main publication page for this report: <http://www.hscic.gov.uk/pubs/ldcensusrep1213>.

The Learning Disability Census collected information about a wider range of topics related to service users' experience of inpatient care than are covered in this initial report. A full list of the data items collected is published on the HSCIC website<sup>4</sup>.

It is expected that further analysis of the Learning Disability Census will be conducted with a view to publishing additional findings in Spring/Summer 2014. It is anticipated that this further reporting will include service users' experience of care (in particular, the frequency of restraint or incidents) as well as providing more detailed geographic analysis (where possible).

These statistics are intended to help inform improvements in the provision of inpatient and community-based care for people with learning disabilities, autistic spectrum disorders, and/or behaviour that challenges and will be of interest to mental health professionals as well as service users, their families and representative organisations.

## Background

The BBC One Panorama programme "Undercover Care: The Abuse Exposed"<sup>5</sup> alerted viewers in May 2011 to the mistreatment and assault of adults with learning disabilities and autistic spectrum disorder within Winterbourne View Hospital. There followed a Serious Case Review conducted by South Gloucestershire Adult Safeguarding Board<sup>6</sup> and a series of publications by the Department of Health.<sup>7</sup>

The Department of Health developed a change programme designed to address the transformation of care and support for people who have learning disabilities or autistic spectrum disorder who may also have mental health needs or behaviours considered challenging.

The Learning Disability Census was commissioned as one of 63 initiatives identified within 'Transforming Care: A national response to Winterbourne View Hospital' ('Transforming Care') in response to the abuse at

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<sup>4</sup> <http://www.hscic.gov.uk/ldcensus>.

<sup>5</sup> <http://www.bbc.co.uk/programmes/b011pwt6>

<sup>6</sup> <http://www.southglos.gov.uk/Pages/Article%20Pages/Community%20Care%20-%20Housing/Older%20and%20disabled%20people/Winterbourne-View-11204.aspx>

<sup>7</sup> <https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>

Winterbourne View Hospital. The signatories to the Department of Health 'Winterbourne View Review Concordat: Programme of Action'<sup>8</sup> ('Concordat') committed to a change programme in order to transform health and care services and in so doing improve the quality of the care offered to children, young people and adults with learning disabilities, autistic spectrum disorder and/or behaviour that challenges, to ensure better care outcomes for them.

Concordat actions are intended to lead to a reduction in hospital placements for this group of people by 1<sup>st</sup> June 2014.

The delivery of this census will:

- Highlight issues with the quality of care that people are receiving;
- Quantify the extent to which people are using services for protracted periods;
- Establish how many people are receiving services at distance from their home or usual communities;
- Respond to, and support delivery of, the commitment to review care and support movement to more appropriate settings where necessary by definitively identifying service users at a single point in time.

Several of the actions identified within 'Transforming Care' and 'Concordat' are expected to benefit from being informed by findings of this census. The information developed through the census will be of interest to professionals working with people who have a learning disability, those meeting mental health needs in both NHS and independent sector provision, commissioners and providers of services as well as service users, their families and representative organisations.

The census sought to collect information from all providers of mental health services in England which provided services to inpatients with a learning disability. They may also have one or more of:

- An autistic spectrum disorder;
- Mental health needs;
- Behaviours that challenge.

The Learning Disability Census included service users from other home countries who were in receipt of services within England on census date.

The range of inpatient environments within the scope of the census included

- High, medium and low secure forensic wards;
- Acute admission beds within specialised learning disability units;
- Acute admission beds within generic mental health settings;
- Forensic rehabilitation beds;
- Complex continuing care and rehabilitation beds;
- Other beds including those for specialist neuropsychiatric conditions.

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<sup>8</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213217/Concordat.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf)

## Initial Findings

The Learning Disability Census is a count of people with learning disabilities and/or autistic spectrum disorders (including Asperger's Syndrome) and/or behaviour that challenges<sup>9</sup> occupying CQC-registered inpatient beds for mental and/or behavioural healthcare as of midnight on 30<sup>th</sup> September 2013. It collects a wide range of information about service users experience of care.

Service users were included in the Census if they were on leave on the Census date, with a bed held open for them. Service providers were instructed not to include:

- People in accommodation not registered with the Care Quality Commission (CQC) as hospital beds;
- People in beds for physical health care;
- People who do not have either learning disabilities or autistic spectrum disorders.

Out-patients and people receiving community-based services were not in scope for the Census.

Responses to the Learning Disability Census were submitted by 104 provider organisations<sup>10</sup> on behalf of 3,313 people. Of these, 3,250 responses were made on behalf of people who met the inclusion criteria for the Learning Disability Census.<sup>11</sup> This level of response is broadly in line with the response to the CQC's Count Me In 2010, which found that 3,376 service users with learning disabilities were receiving inpatient services in England as of 31 March 2010. Time-series analysis of Count Me In 2010 data showed that the number of people with learning disabilities receiving inpatient services was decreasing over time, from 4,435 in 2006 to 3,376 in 2010<sup>12</sup>.

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<sup>9</sup> The Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability gives the following definition of behaviour that challenges "Challenging behaviour is a socially constructed, descriptive concept that has no diagnostic significance. It can range from pica, smearing and self-injury in a person with a profound learning disability, to unlawful killing in someone with a mild learning disability and forensic issues." Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability, "People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services", (Faculty Report FR/ID/03, July 2013), 9.  
<http://www.rcpsych.ac.uk/pdf/FR%20ID%2003%20for%20website.pdf>

<sup>10</sup> See Table 11 or the reference data tables. Two independent providers (Anselm Clinics and Alpha Hospitals) submitted data under multiple codes. These multiple codes are reported separately in table 11 of the reference data tables (with an explanatory footnote), as this table is based on the provider codes submitted by providers. For purposes of analysis, data submitted by one provider under multiple codes is combined within this report.

<sup>11</sup> The remaining 63 responses (1.9% of all responses received) were made on behalf of people who did not meet the inclusion criteria for the Learning Disability Census. This could be because they did not have a learning disability or an autistic spectrum disorder, because they were in hospital to meet a physical health care need (rather than for mental and/or behavioural health care), or because they were admitted to inpatient care after the census date of 30 September 2013. These responses are excluded from all analysis presented in this report.

<sup>12</sup> 'Count Me In' was a census of inpatients and patients on supervised Community Treatment Orders in mental health and learning disability services, which was conducted annually from 2005 to 2010. Whilst its scope was therefore considerably broader than the Learning Disability Census, it reported on service users with learning disabilities as a sub-group. Care Quality Commission, "Count Me In 2010", [http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-mental-health/carequalitycommission/155293count\\_me\\_in\\_2010\\_final\\_tagged.pdf](http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-mental-health/carequalitycommission/155293count_me_in_2010_final_tagged.pdf), pp. 34-39.

## Profile of service users

### Gender

Around three in four service users (74.6% or 2,424 people) were male and one in four (25.4% or 824 people) were female (see figure 1).

### Age

The age composition of service users differs substantially from that of the general population of England<sup>13</sup>:

- Around one in twenty (5.7% or 185 people) service users were aged under 18, much lower than the comparable proportion of England's general population (21.4%)
- More than nine in ten (92.1% or 2,994 people) service users were aged 18-64, substantially higher than the comparable proportion England-wide (61.7%)
- Very few service users (2.2% or 71 people) were aged 65 and over, much lower than the comparable proportion for England (16.9%).

Several factors may contribute to these differences in age composition between the population of service users and the general population. Among very young children, only severe learning disabilities are likely to be apparent, which may partly account for the low proportion of children among service users<sup>14</sup>. The low proportion of service users aged 65 and over may reflect lower life expectancy: people with a learning disability recorded on their death certificate have been observed to have a median age of death of 57 years; whilst for those without the median age of death was 81 years, a gap of more than twenty years.<sup>15</sup>

Estimates of life expectancy produced for the "Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)" suggested a smaller, but still large, gap in life expectancy between those with learning disabilities and the general population:

"The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died."<sup>16</sup>

Few differences were observed between the age composition of male and female service users (see Learning Disability Census reference data tables, 2013 table 2).

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<sup>13</sup>Population figures for England are taken from the ONS Mid-2012 Population Estimates: England; estimated resident population by single year of age and sex. This is available as a download from:

<http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-319259>.

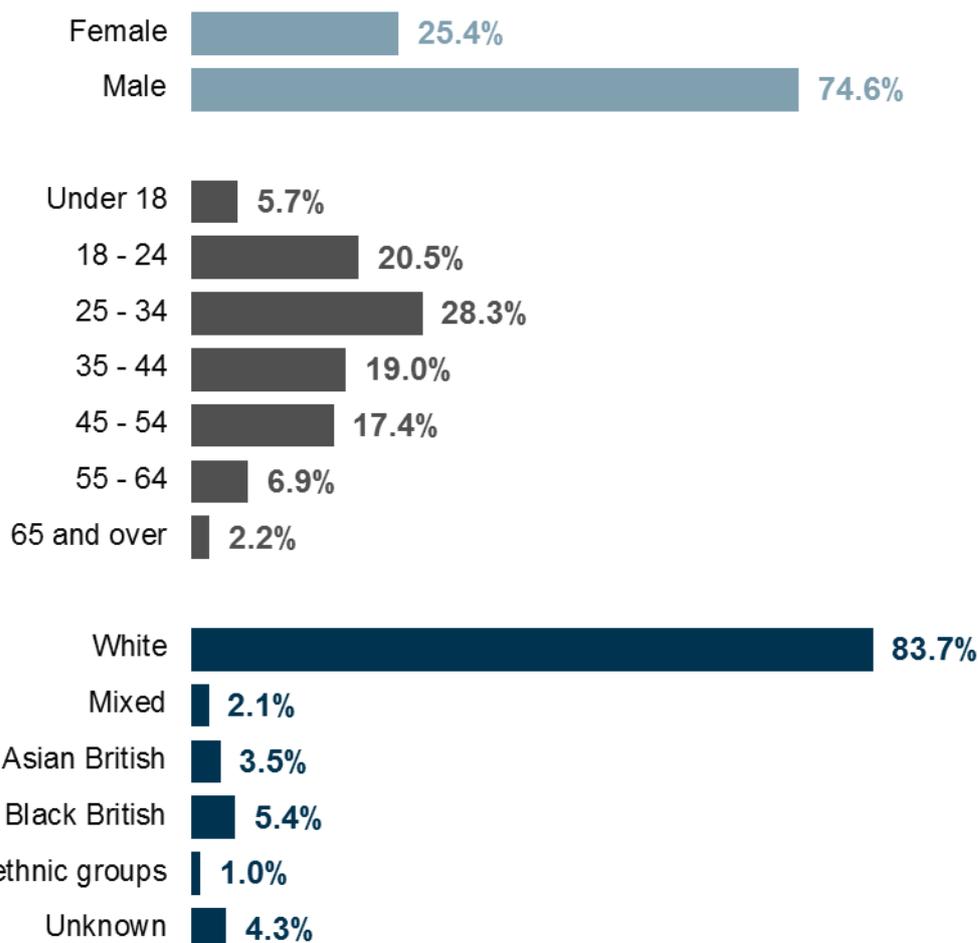
<sup>14</sup> Eric Emerson et al. "People with Learning Disabilities in England, 2011", (Improving Health and Lives: Learning Disability Observatory, 2012), p.3 <http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&fv=18581> .

<sup>15</sup>Emerson et al note that gap in life expectancy gap needs to be interpreted with caution, as learning disabilities may only be recorded on a death certificate when the doctor issuing the certificate considers that such a disability was a direct or indirect cause of death. Eric Emerson et al. "People with Learning Disabilities in England, 2012", (Improving Health and Lives: Learning Disability Observatory, 2013), p.5,

[http://www.improvinghealthandlives.org.uk/publications/1185/People\\_with\\_Learning\\_Disabilities\\_in\\_England\\_2012](http://www.improvinghealthandlives.org.uk/publications/1185/People_with_Learning_Disabilities_in_England_2012).

<sup>16</sup> Pauline Heslop et al, "Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report", (University of Bristol, 2013), p.2, <http://www.bris.ac.uk/cipold/fullfinalreport.pdf> .

**Figure 1: Gender, age, and ethnic group composition of service users**



Base: All service users (3,250)

Data source: Tables 2 and 3 of the Learning Disability Census reference data tables, 2013.

### Ethnic group

The ethnic group composition of service users was broadly in line with that of England's general population, though the proportion of Asian or Asian British service users (3.5%) was lower than the comparable proportion (7.1%) in the 2011 Census.<sup>17</sup> The ethnic group composition of service users varied slightly with gender, with a higher proportion of women (84.8%) than men (77.6%) being categorised as White British (see Learning Disability Census reference data tables, 2013 table 3). This difference may be due in part to better recording of ethnic group category for female service users than male service users. Ethnic group data was recorded as 'not stated' or 'not known' for 4.3% of all service users (139 people), with the proportion of records recorded as 'not stated' or 'unknown' being higher among male service users (5.1%) than female service users (1.8%). Other differences in ethnic group composition by gender were small.

<sup>17</sup>The 2011 Census uses slightly different ethnic group categories than the Learning Disability Census (which uses the NHS data dictionary categories, taken from the 2001 Census). The 2011 Census grouped Chinese respondents in the 'Asian or Asian British' category, and introduced 'Arab' as a category within 'Other ethnic groups.' For comparison purposes, we have mapped 2011 Census categories back onto the 2001 categories where possible (i.e. people within the 'Chinese' category are moved to the 'Other ethnic groups' category rather than being counted within the 'Asian or Asian British' category and 'Arab' is removed from the 'Other ethnic groups' category). ONS, "2011 Census: Ethnic group, local authorities in the United Kingdom (KS201UK)" (October, 2013). The 2011 Census for England and Wales: <http://www.ons.gov.uk/ons/guide-method/census/2011/index.html>.

## Ward service, security level and length of stay

### Ward service type

Around three in four service users (76.3% or 2,481 people) were staying in wards that predominantly provided services for people with learning disabilities. A further one in five service users (20.1%, or 653 people) were staying in mental health wards. The remaining service users (3.6% or 116 people) were staying in wards that predominantly provided some other type of service (see Learning Disability Census reference data tables, 2013 tables 12-14).

The distribution of service users by ward service type varied with the region of ward stay (see Learning Disability Census reference data tables, 2013 table 6). The South West had the smallest proportion of service users receiving care in wards primarily providing learning disability services (40.5%), much lower than the overall proportion (76.3%). This region also had the highest proportion of service users receiving inpatient care in mental health wards (45.6%), as well as the highest proportion (13.9%) receiving treatment in wards primarily providing some other type of service. The proportion of inpatients staying in wards that primarily provided learning disability services in London (59.7%) and Yorkshire and The Humber (62.2%) was also comparatively low, with both regions having relatively high proportions of inpatients in mental health wards (36.0% and 37.0% respectively).

Service users aged under 18 (30.3%) or 65 and over (28.2%) were more likely to be inpatients in a ward primarily providing mental health services than were service users overall (20.1%), but differences in ward service type by age band were generally small (see Learning Disability Census reference data tables, 2013 table 12).

### Ward security level

Overall, more than four in ten service users (45.2%, or 1,470 people) were inpatients in general (non-secure) wards and more than one in three (36.8%, or 1,195 people) were staying in low secure wards. Around one in seven service users (15.8%, or 512 people) were in medium secure wards; few (2.2% or 73 people) were inpatients in high secure wards (see Learning Disability Census reference data tables, 2013 tables 8 and 12-14). The majority of inpatients staying in high secure wards were located in the East Midlands (84.9%).

Service users aged under 18 (67.0%) or 65 and over (69.0%) were proportionally more likely to be inpatients in general (non-secure) wards than service users overall (45.2%). Around one in ten of those aged under 18 (11.4%) were staying in low secure wards, lower than the all-ages proportion (36.8%). Very few service users aged 65 and over were inpatients in medium secure or high secure wards (see Learning Disability Census reference data tables, 2013 table 12).

Proportionally more men (22.0%) than women (6.3%) were inpatients in medium secure or high secure wards. A higher proportion of women (55.3%) than men (41.7%) were in general (non-secure) wards (see Learning Disability Census reference data tables, 2013 table 13).

### Length of stay

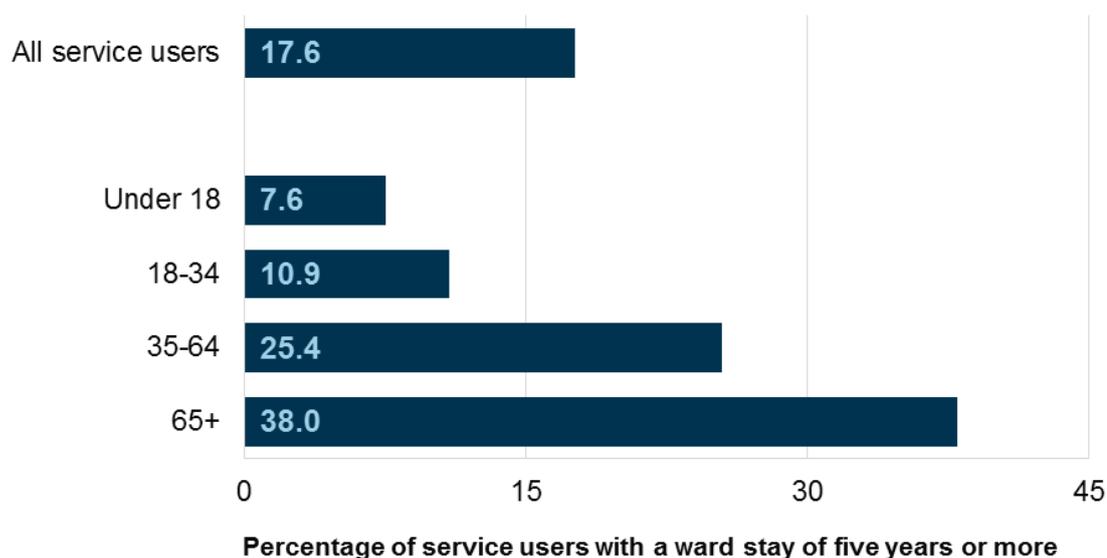
Close to one in five service users (18.5%, or 601 people) had a ward stay of less than three months (see Learning Disability Census reference data tables, 2013 tables 12-14). Six in ten service users (60.0%, or 1,949 people) had a ward stay of one year or longer, with around one in six service users (17.6% or 572 people) having been an inpatient in their current ward for five years or more. Length of stay varied with age, with service users aged under 18 proportionally more likely to have been inpatients for three months or less (45.4%) than service users overall (18.5%).

The proportion of inpatients with ward stays of five years or more increases with age (see figure 2):

- Among service users aged under 18, around than one in fourteen (7.6%) had been inpatients for five years or more.

- Over a third of service users aged 65 and over (38.0%) had been inpatients for five years or more, around the twice the proportion of all service users (17.6%).

Figure 2: Service users with a ward stay of five years or more by broad age band



Base: All service users (3,250)

Data source: Table 12 of the Learning Disability Census reference data tables, 2013.

## Service users by region, local authority, and distance between residence and ward stay

This section of the publication focuses on the geographic distribution of service users by residence and location of inpatient stay (including information about distance between their postcode of residence and ward stay). As this information is derived from the postcodes of service users' residence and ward stay, this section also includes a brief analysis of the data quality and completeness of the postcode data supplied by providers.

### Data quality and completeness for postcode data

Providers were asked to supply service users' postcode of residence to support analysis of distance between address of residence and ward stay (as well as other geographically derived variables such as local authority of residence). Of the records submitted on behalf of the 3,250 people who met the inclusion criteria for the Learning Disability Census, more than one in four (28.0% or 910) originally had a postcode of residence that did not exist, or a 'ZZ99' postcode indicating that the postcode of residence was unknown. Whilst there are some valid reasons for a provider to be unable to supply a service user's postcode of residence (for example, if the service user was homeless prior to admission, or of no fixed abode, or had never had a residential address), this overall proportion is high.

As part of the HSCIC's data cleansing process, NHS number tracing was used to locate a last known postcode of residence for service users, where the field entry supplied by providers was invalid or indicated that the service user's former residence was unknown. This process reduced the proportion of all Learning Disability Census records<sup>18</sup> with 'ZZ99' postcodes from 25.0% to 0.6% (whilst the proportion of invalid postcodes decreased from 3.0% to 1.6%).<sup>19</sup> NHS number tracing sometimes gave service users' postcodes of residence as the hospital postcode of their ward stay, but this does not account for most of the

<sup>18</sup> 3,313 records, including the 63 records subsequently excluded as they did not meet the inclusion criteria.

<sup>19</sup> See the data quality statement for this publication for more information.

improvement in data quality. The number of service users with the same postcode of residence and hospital increased from 147 to 233 after NHS number tracing (see the data quality statement report accompanying this publication for further information).

### Service users with an unknown residential postcode

Sixty-one out of 104 providers submitted 'other' ('ZZ99') or 'invalid' residential postcodes for at least one of the 3,250 service users who met the inclusion criteria for the 2013 Learning Disability Census. Most (71.6%) of the 'other' or 'invalid' postcodes of residence submitted, however, were supplied by nine providers (see table 1 below, which shows the providers that submitted returns with the highest number of service users with no known postcode of residence).

**Table 1: Service users with 'unknown' postcodes of residence by providers<sup>a</sup>**

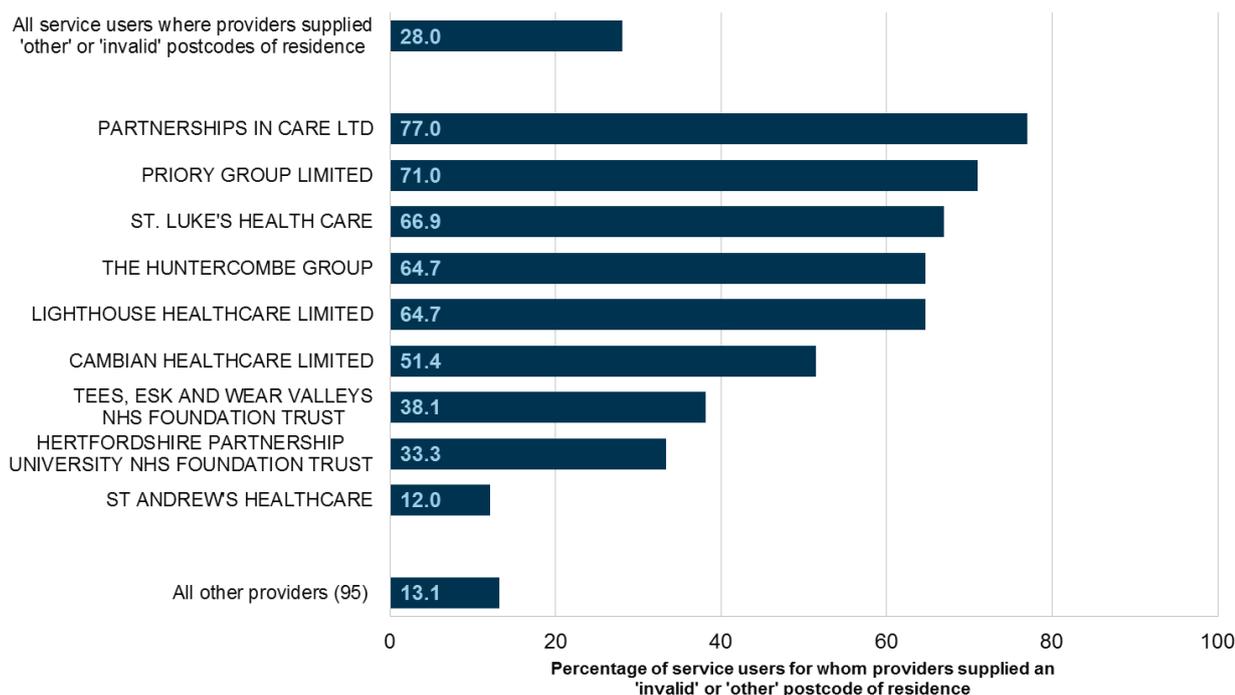
England		numbers / percentages	
		Service users	
		no.	%
<b>All service users where providers supplied 'other' or 'invalid' postcodes of residence</b>		<b>910</b>	<b>100.0</b>
<b>Provider code</b>	<b>Provider name</b>		
NMV	PARTNERSHIPS IN CARE LTD	174	19.1
NV2	THE HUNTERCOMBE GROUP	110	12.1
NR6	ST. LUKE'S HEALTH CARE	93	10.2
NES	LIGHTHOUSE HEALTHCARE LIMITED	66	7.3
RX3	TEES, ESK AND WEAR VALLEYS NHS FOUNDATION TRUST	61	6.7
NTN	PRIORY GROUP LIMITED	44	4.8
RWR	HERTFORDSHIRE PARTNERSHIP UNIVERSITY NHS FOUNDATION TRUST	39	4.3
NTT	CAMBIAN HEALTHCARE LIMITED	36	4.0
NYA	ST ANDREW'S HEALTHCARE	29	3.2
<b>All other providers (95)</b>		<b>258</b>	<b>28.4</b>

Data source: Learning Disability Census 2013.

<sup>a</sup>Providers with 20 or more unknown postcodes are listed individually.

Partnerships in Care Ltd supplied the largest number of 'other' ('ZZ99') and 'invalid' postcodes (174), accounting for around one in five (19.1%) of those submitted: they were unable to supply a valid postcode for more than three in four (77.0%) of their 226 service users (see Learning Disability Census reference data tables, 2013 table 11, and figure 3). The Priory Group Limited were unable to supply valid postcodes for a similar proportion (71.0%) of their service users. A further three providers (St. Luke's Healthcare, The Huntercombe Group and Lighthouse Healthcare Limited) were unable to supply a valid postcode for more than six in ten of their service users. Tees, Esk and Wear Valleys NHS Foundation Trust were unable to supply postcode of residence for close to four in ten (38.1% or 61) of their service users, and Hertfordshire were unable to do so for a third (33.3% or 39) of their service users. Whilst St. Andrew's Healthcare was unable to supply a valid postcode for 29 of its 241 service users, the proportion of service users for which it was unable to supply valid postcodes (12.0%) was in line with that of most other providers rather than (13.1%).

**Figure 3: Service users with 'invalid' or 'other' ('ZZ99') postcodes by selected providers<sup>a</sup>**



Data source: Data Quality analysis and table 11, Learning Disability Census reference tables, 2013.

<sup>a</sup>The nine providers with 20 or more unknown postcodes (See table 1 above) of the 'invalid' and 'other' postcodes supplied are presented separately; other providers are grouped together as 'All other providers'.

Base: All service users (3,250)

### Service users with the same address of residence and ward stay

Following data cleansing, postcode data for both residence and ward stay were available for 3,129 service users. Of this group, 240 service users (7.7%) had the same postcode (or a different postcode covering the same hospital)<sup>20</sup> recorded for both their residence and ward stay. Analysis of this group by region (see Learning Disability Census reference data tables, 2013 table 9) shows that:

- Around four in ten (40.4%, or 97 people) were inpatients in wards located in the East of England, with smaller proportions staying in wards in the South East (14.2%, or 34 people), the East Midlands (11.3%, or 27 people) and the West Midlands (9.2%, or 22 people);
- London (4.2% or 10 people), Yorkshire and The Humber (3.8% or 9 people) and the South West (2.1% or 5 people) accounted for an even smaller proportion of service users with the same postcode of residence and ward stay.

Most service users with the same postcode of residence and ward had long ward stays. Around seven in ten service users (71.3%, or 171 people) had a length of stay of two years or more; more than one in four (27.5% or 66 people) had a length of stay of ten years or more (see Learning Disability Census reference data tables, 2013 table 15).

More than four in ten service users with the same postcode of residence and ward stay (41.3%, or 99 people) were living in general (non-secure) wards; a similar proportion (42.1%, or 101 people) were in low secure wards. The remaining service users (16.7% or 40 people) were in medium secure wards (see Learning Disability Census reference data tables, 2013 table 14).

<sup>20</sup> Nine service users had a postcode of residence which differed from their postcode of hospital stay, but the distance between postcodes calculated was 0 metres. Further analysis showed that this was because the same hospital had been allocated multiple postcodes.

## Region of residence and ward stay

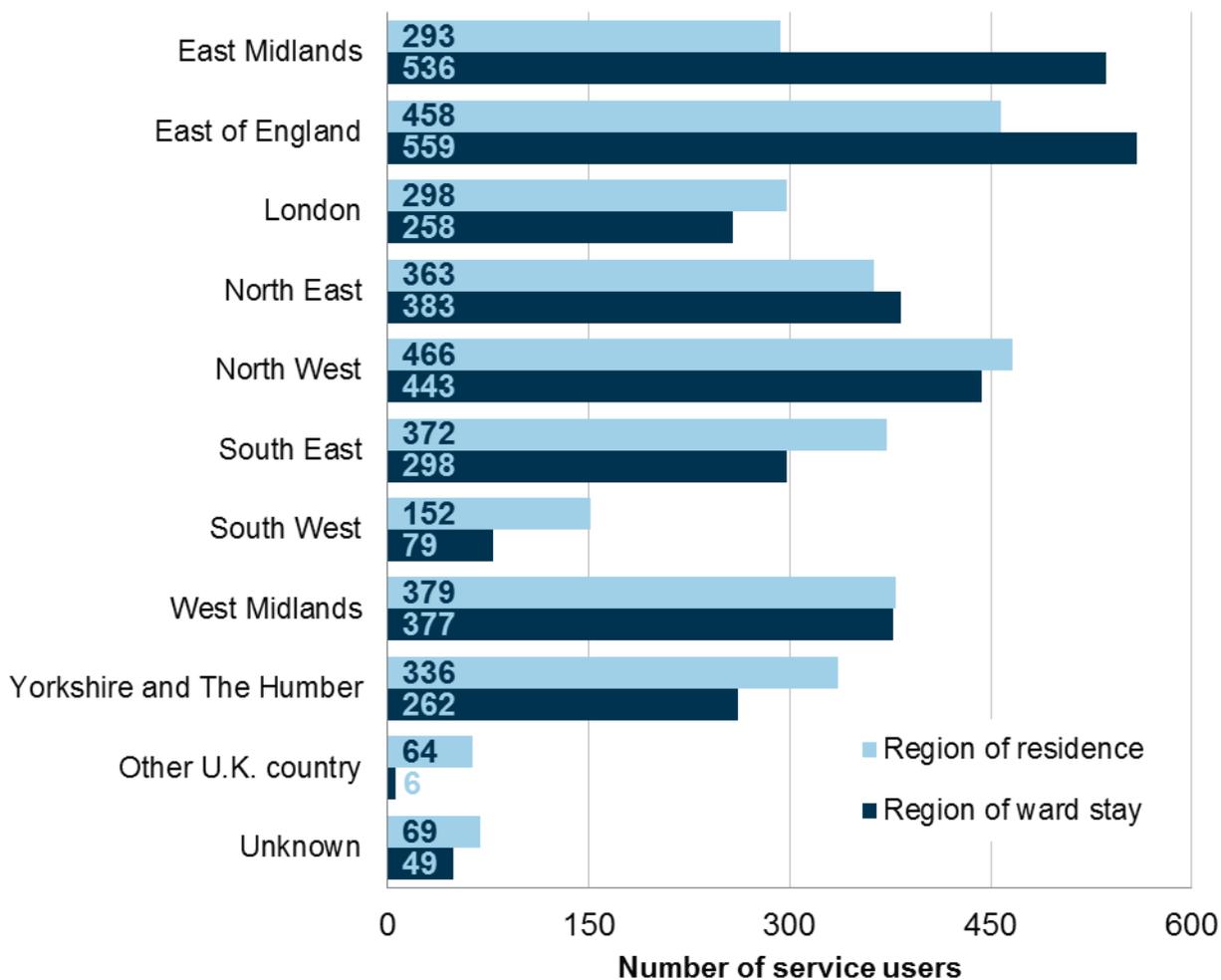
Analysis of service users by region of residence and ward stay shows that substantial regional imbalances exist in the provision of inpatient services for people with learning disabilities (see figure 4 below). Overall, the East Midlands, the East of England and the North East were net destinations for inpatient ward stays:

- The East of England had the largest number of service users receiving inpatient care (559 people or 17.2% of all service users), substantially higher than the number of service users with a postcode of residence in the region (458 people, or 14.1% of all service users);
- The East Midlands had the largest net difference (243 people) between the number of service users receiving inpatient care (536 people, or 16.5% of all service users) and the number of service users with a postcode of residence in the region (293, or 9.0% of all service users).

Other regions had substantially fewer service users receiving inpatient services than service users with a postcode of residence within the region:

- The South West provided ward stays for 79 service users (2.4% of all service users), but almost twice this number (152 people or 4.7% of all service users) had a postcode of residence within the region;
- The South East, Yorkshire and The Humber and the South West all had seventy or more service users with a postcode of residence in the region than were receiving inpatient care within the region.

**Figure 4: Service users by region of residence and region of ward stay**



Base: All service users (3,250)

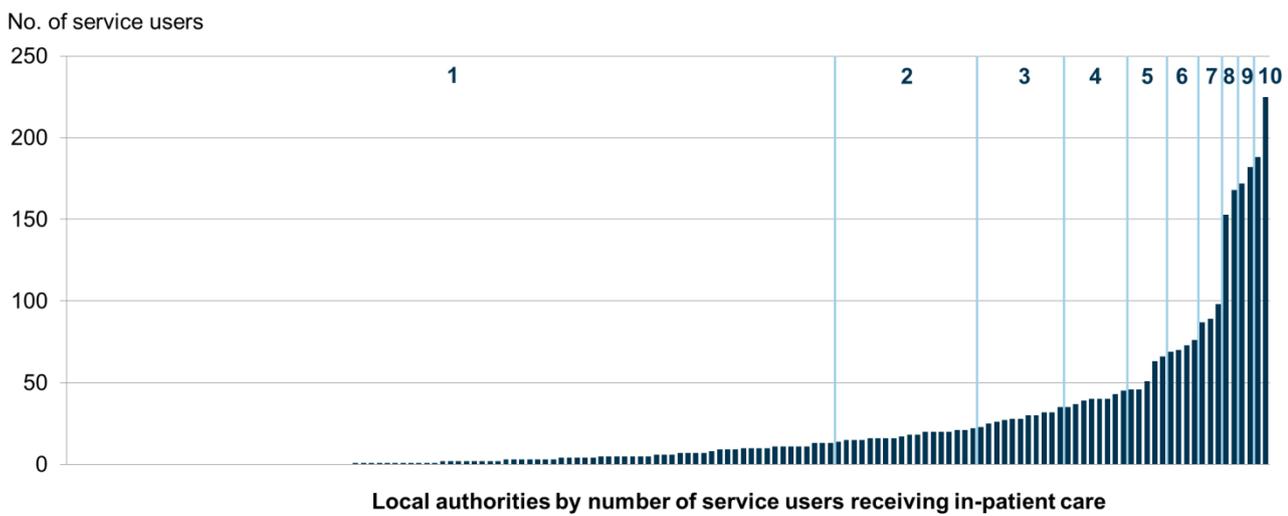
Data source: Table 1 of the Learning Disability Census reference data tables, 2013.

More detailed analysis at local authority level shows that inpatient service provision was concentrated in a relatively small number of local authorities (see figure 5). Of the 152 local authorities in England:

- Around one in four (23.7% or 36 local authorities) had no service users receiving inpatient care;
- Around one in three (32.2% or 49 local authorities) had between 1 and 9 service users (inclusive);
- Around one in four (23.7% or 36 local authorities) had between 10 and 29 service users (inclusive);
- Around one in five (20.4% or 31 local authorities) had 30 or more service users receiving inpatient care. This group of local authorities accounted for about three in four (75.1%) of all inpatients with a known local authority of ward stay in England.

Around three in four service users (75.1%) in England (where the postcode of ward stay was known) were inpatients within a fifth (31) of England's 152 local authorities. Almost half (49.5%) were staying in just 12 local authorities.<sup>21</sup>

**Figure 5: Distribution of service users in deciles<sup>a</sup> by local authority of ward stay**



Base: All service users with a known local authority of ward stay in England (3,195)  
 Data source: Table 10 of the Learning Disability Census reference data tables, 2013.

<sup>a</sup>Each decile represents approximately a tenth of all service users.

As may be expected, given the concentration of inpatients in a relatively small number of local authorities, large differences between the number of service users resident in a local authority and the number receiving inpatient care are found in some localities. Table 2 shows that Northamptonshire, Lancashire, Northumberland and Nottinghamshire all had at least 100 more service users with ward stays in their locality than service users with a postcode of residence in their locality.<sup>22</sup>

<sup>21</sup>The local authority of ward stay was unknown for 49 service users, as providers submitted invalid postcodes for the location of the hospital. A further six service users had a ward stay in another U.K. country and are excluded from this analysis.

<sup>22</sup>Some service users have the same address of residence as of ward stay.

**Table 2: Service users by local authority of residence and ward stay, for selected local authorities<sup>a</sup>**

		<i>numbers</i>		
		Service users by local authority of:		
		Residence <sup>3</sup>	Ward stay <sup>4</sup>	Difference between ward stay and residence
LA Code	LA Name			
504	Northamptonshire	44	188	144
323	Lancashire	92	225	133
104	Northumberland	64	168	104
511	Nottinghamshire	80	182	102
410	Solihull	16	87	71
620	Essex	106	172	66
607	Norfolk	100	153	53
506	Derbyshire	32	63	31
720	Bromley	16	45	29
112	Middlesbrough	48	76	28
322	Warrington	22	43	21
723	Enfield	15	35	20
219	York	11	28	17
704	Hackney	7	23	16
812	Hampshire	50	66	16
413	Staffordshire	84	98	14
614	Bracknell Forest	2	16	14
213	Wakefield	27	40	13
512	Nottingham	15	27	12
625	Bedford	15	26	11
205	Doncaster	30	40	10

Data source: Table 10, Learning Disability Census reference tables, 2013

<sup>a</sup>Table 2 shows local authorities where ten or more service users overall are receiving inpatient care than are resident in the local authority area.

### Distance between location of residence and ward stay

'Transforming Care' noted that people requiring inpatient services should be treated locally wherever possible, as sending people out of their local area can weaken their existing relationships with family and friends, damage continuity of care, and result in people being placed in settings that are unfamiliar and stressful.<sup>23</sup>

Of the 3,250 service users who were included in for the Learning Disability Census, distance (as the crow flies) between postcode of residence and ward stay was calculable for 3,129 service users.<sup>24</sup>

<sup>23</sup> Department of Health, "Transforming care; a national response to Winterbourne View Hospital" (Department of Health, 2013), [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf), 20.

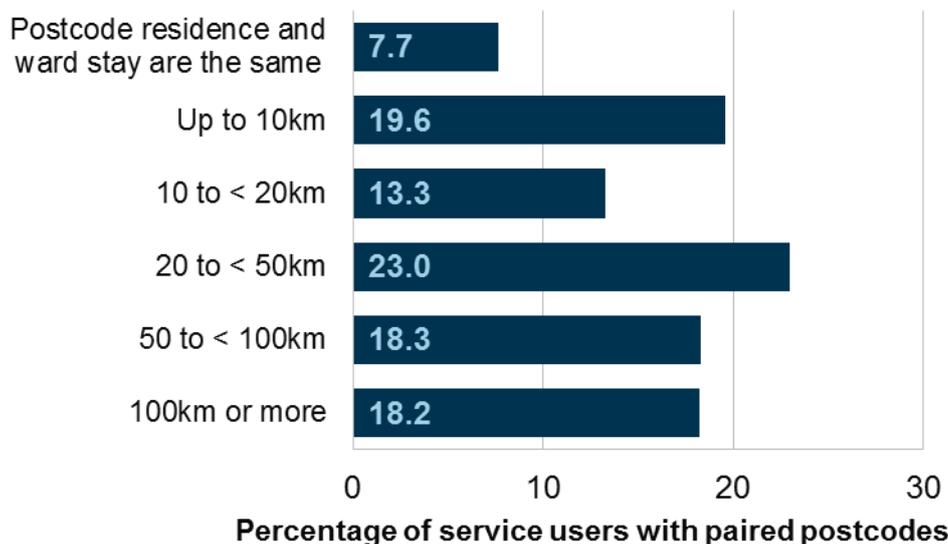
<sup>24</sup> As noted earlier in this report, providers were unable to supply a postcode of residence for a substantial proportion of service users (28.0% or 910 service users). NHS number tracing enabled identification of a last known address (which in some cases was the same as the hospital address) for 841 service users. In addition, providers did not supply a valid hospital postcode for 49 service users. In this report, distance between service users' postcode of residence and ward stay was calculated 'as the crow flies'. Distances data presented in this publication should therefore be treated as indicative, rather than definitive: users will be aware that actual shortest travel routes along road or rail networks are likely to cover substantially longer distances. HSCIC is considering improvements to its methodology for distance calculation, which would take account of transport networks.

Analysis of the distance between postcode of residence and ward stay for these service users (see figure 6) shows that:

- around one in five (19.6% or 612 people) were receiving inpatient care within 10km of their postcode of residence
- a further 13.3% (or 415 people) were staying in a ward 10km or more, but less than 20km, from their postcode of residence
- close to one in four (23.0% or 719 people) were staying in wards located 20km or more but less than 50km from their postcode of residence
- close to one in five (18.3% or 573 people) were staying in wards located 50km or more, but less than 100km, from their postcode of residence
- a similar proportion (18.2% or 570 people) were staying in wards located 100km or more from their postcode of residence.

The remaining 240 service users (7.7%) had the same postcode for both their residence and ward stay (see above for an overview of these service users).

**Figure 6: Service users by distance between residence and ward stay**



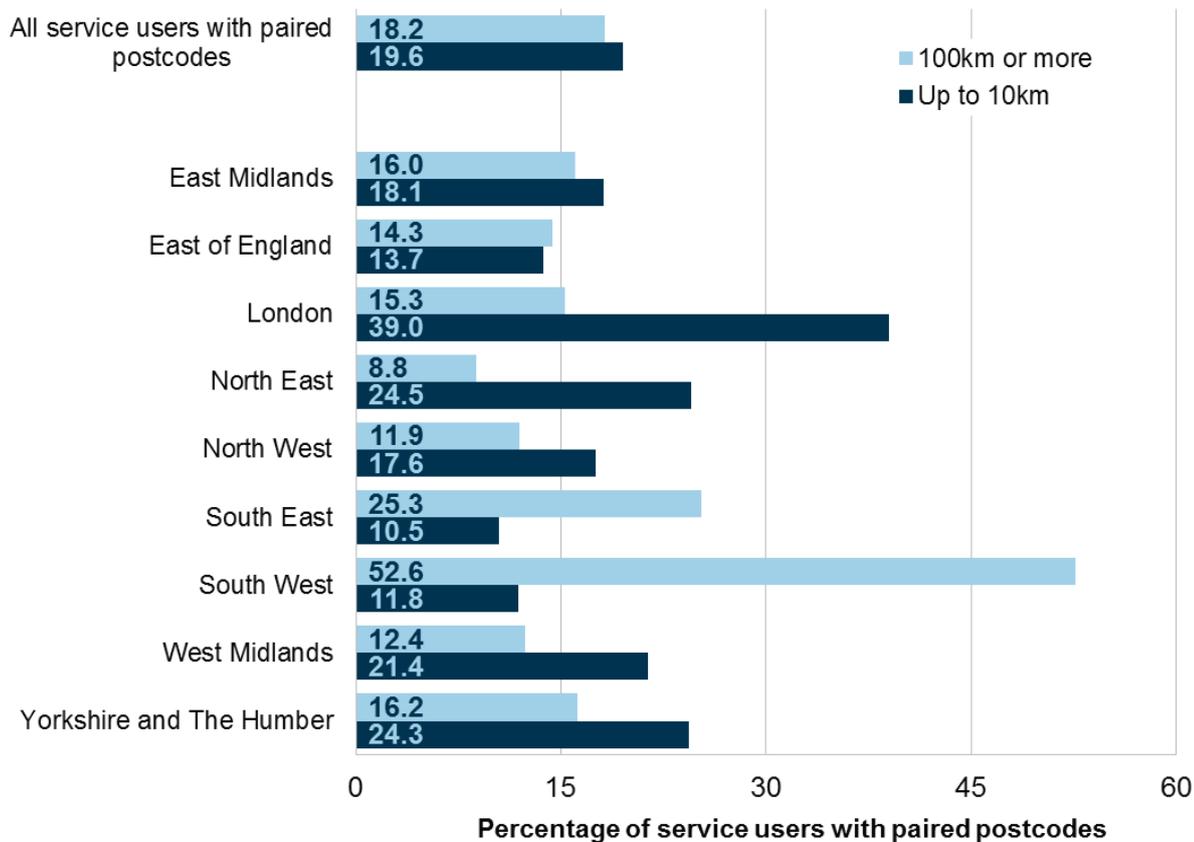
Base: All service users with paired postcodes (3,129)

Data source: Table 9 of the Learning Disability Census reference data tables, 2013.

Distance between service users' postcode of residence and ward stay varied considerably with their region of residence (see figure 7 and Learning Disability Census reference data tables, 2013 table 9).

- More than half of service users (52.6% or 80 people) resident in the South West were inpatients in wards located 100km or more from their postcode of residence, almost three times the national proportion (18.2%). The proportion of service users resident in the South East with inpatient stays located 100km or more from their postcode of residence (25.3% or 94 people) was also higher than the national proportion.
- Fewer than one in ten service users (8.8% or 29 people) resident in the North East were staying in wards 100km or more from their postcode of residence, well below the national proportion.
- Around four in ten service users (39.0% or 115 people) resident in London were staying in wards located within 10km of their postcode of residence and had a postcode of residence separate from that of their ward stay; this is about twice the national proportion (19.6% or 612 people). The South East had the lowest proportion of service users (10.5% or 39 people) staying in wards within 10km of their postcode of residence (and separate from postcode of ward stay).

**Figure 7: Service users by distance of inpatient care from postcode of residence<sup>a</sup>, by region of residence**



Data source: Table 9 of the Learning Disability Census reference data tables, 2013.

<sup>a</sup>Service users with the same postcode of residence and hospital are not included in the proportion with a ward stay of up to 10km from their postcode of residence, but are counted as ‘service users with paired postcodes’.

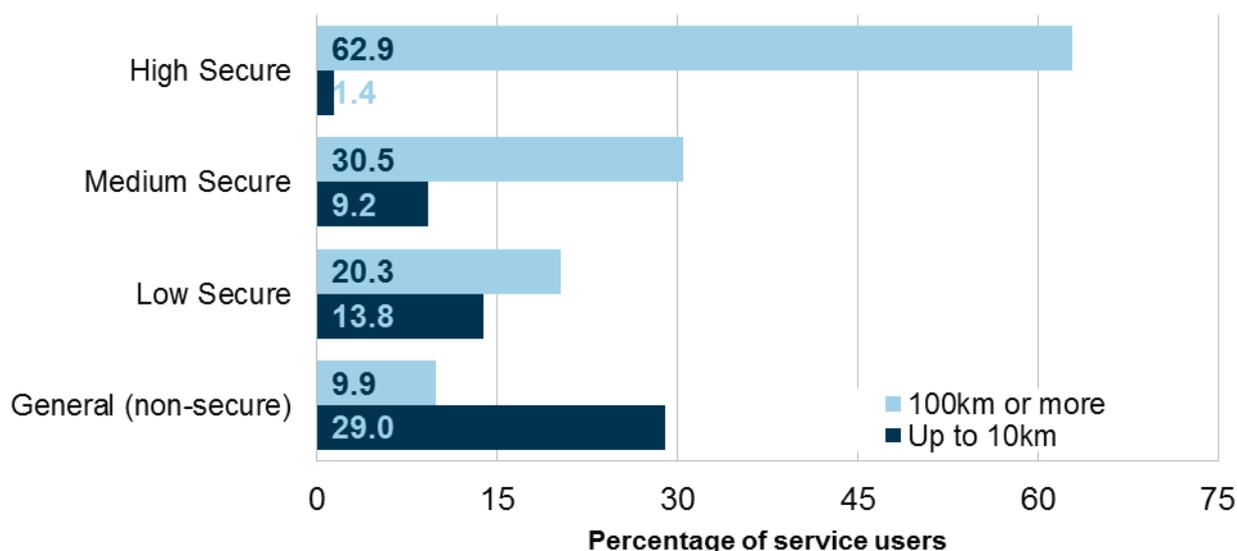
Base: All service users with paired postcodes (3,129)

Service users recently admitted for inpatient care were more likely than service users overall to stay in a ward nearby their postcode of residence (see Learning Disability Census reference data tables, 2013 table 15). Among those with a ward stay of up to three months, over one in three (36.4% or 212 service users) were located within 10km of their residential postcode (but not at the same postcode of residence as ward stay). Among those with a ward stay of five years or more, this proportion falls to around one in eight (12.0% or 66 service users).

Distance between service users’ postcode of residence and their ward stay increased with the security level of the ward (see figure 8 and Learning Disability Census reference data tables, 2013 table 14):

- Among service users staying in a general (non-secure) ward, 29.0% (or 404 people) had an inpatient stay within 10km of their postcode of residence. This proportion drops to 13.8% (161 people) among service users in low secure wards and 9.2% (46 people) among those in medium secure wards. Just 1.4% (1 person) of service users in high secure wards were located within 10km of their postcode of residence.
- Among service users staying in high secure wards, the highest proportion (62.9% or 44 people) were inpatients in wards located 100km or more from their postcode of residence. The proportion of service users staying in wards located 100km or more from their postcode of residence was 30.5% (152 people) among service users in medium secure wards, and 20.3% among service users in low secure wards. Around one in ten service users (9.9%, or 138 people) in a general (non-secure) ward were 100km or more from their postcode of residence.

**Figure 8: Service users by distance of inpatient care from postcode of residence<sup>a</sup>, by ward security level**



Data source: Table 14 of the Learning Disability Census reference data tables, 2013.

<sup>a</sup>Service users with the same postcode of residence and hospital are not included in the proportion with a ward stay of up to 10km from their postcode of residence, but are counted as ‘service users with paired postcodes’.

Base: All service users with paired postcodes (3,129)

## Provider profile

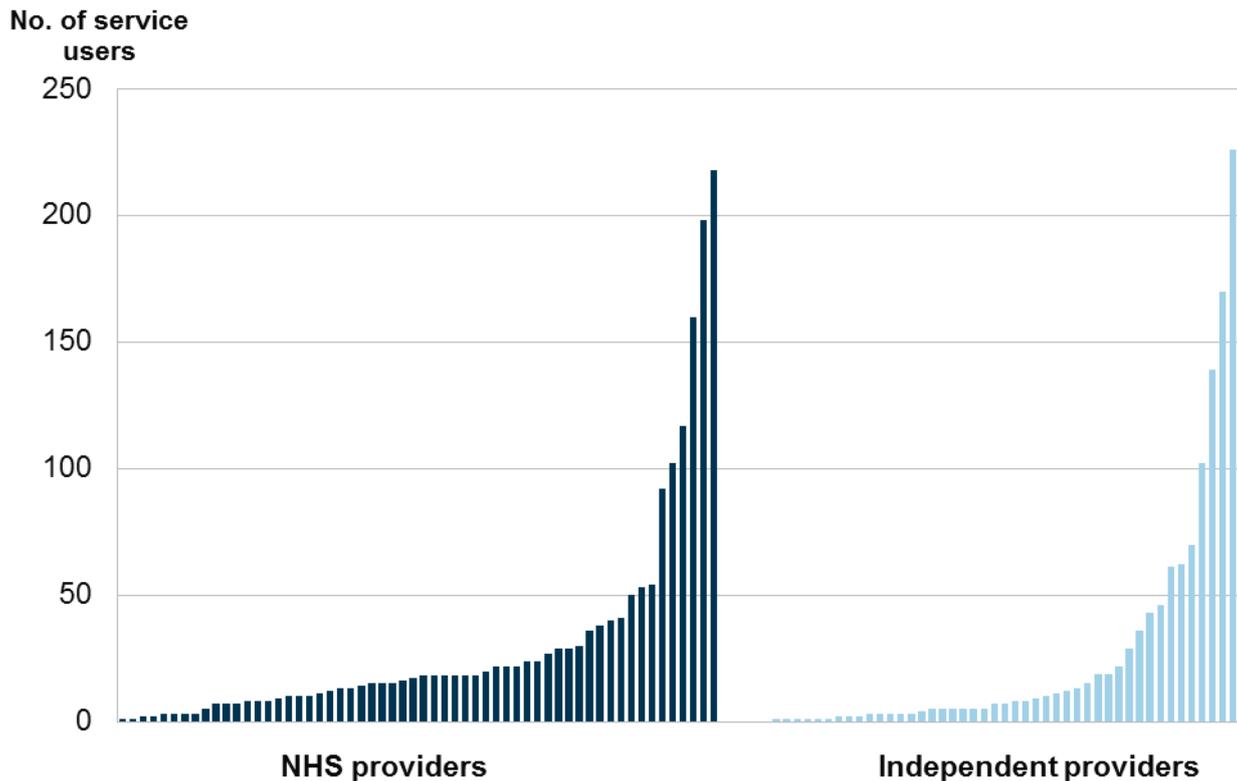
104 providers submitted data on behalf of the 3,250 service users who met the inclusion criteria for the Learning Disability Census (see table 11 of the Learning Disability Census reference data tables, 2013 tables):

- 58 NHS providers submitted data on behalf of 1,804 service users
- 46 Independent providers submitted data on behalf of 1,446 service users<sup>25</sup>.

Provision of inpatient services for people with learning disabilities was concentrated in a small number of providers. Overall, seventeen providers with 50 or more service users together accounted for 65.1% of all service users in the Learning Disability Census. Figure 9 shows that the distribution of service users by provider is similar for both NHS and Independent providers, with both sectors having a large proportion of providers with a relatively small number of inpatients and a small proportion with large numbers of service users.

<sup>25</sup> Two independent providers, Anselm Clinics, and Alpha Hospitals, submitted data under multiple provider codes (see table 11 of the reference data tables).

Figure 9: Distribution of service users by provider



Base: All service users with paired postcodes (3,250)

Data source: Table 11 of the Learning Disability Census reference data tables, 2013.

Two providers identified as having inpatients likely to be in-scope for the Learning Disability Census were not able to submit data during the allotted collection window. These providers were:

- Eden Healthcare
- Glencare Group.

# Appendices

## Appendix 1: Methodology

The Learning Disability Census provides an individual record-level snapshot of inpatients with learning disabilities, autistic spectrum disorder and/or behaviour that challenges, and the services they receive, for service users who were inpatients in NHS and independent services at midnight on 30 September 2013.

### Defining the population

Data were collected from providers on behalf of service users who:

- were staying in inpatient facilities providing assessment, treatment and care for mental health needs, learning disability needs and / or behavioural healthcare;
- have either Learning disabilities or an autistic spectrum disorder (including Asperger's Syndrome).

Providers were requested to submit data for service users that met these criteria, regardless of their age, ward security level, or status under the Mental Health Act. Providers were asked not to submit data on behalf of:

- people in accommodation not registered with the CQC as hospital beds;
- people occupying a hospital bed for physical health care;
- people who do not have either learning disabilities or autistic spectrum disorder.

### Identifying and engaging with providers

In order to ensure that service users meeting the inclusion criteria were counted in the Learning Disability Census, it was critical to develop a comprehensive list of service providers that potentially had inpatients who met the inclusion criteria. The HSCIC therefore collated a list of providers to be approached to take part in the Learning Disability Census from:

- The Care Quality Commission
- Inpatients Formally Detained in Hospitals Under the Mental Health Act 1983 and Patients Subject to Supervised Community Treatment, England - 2012-2013, Annual figures;<sup>26</sup>
- Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability;<sup>27</sup>

A direct mailing and a series of reminders were sent to these providers, inviting them to register and take part in the Learning Disability Census.

Potential providers were also invited to a series of engagement events, in five regional centres, in August – September 2013. 114 NHS and independent sector organisations attended these events. The Learning Disability Census engagement events offered an opportunity for provider organisations to register for the Census, receive and discuss information about its scope and purpose, and address practical issues about the data collection process and Census content. Discussion at these events was used to inform development of the Learning Disability Census question set, and produce Frequently Asked Questions (FAQs) for providers. Attendees were signposted to the Learning Disability Census webpages<sup>28</sup> developed by the HSCIC to enable providers to keep up-to-date with new versions of the Census questions, guidance and supporting documentation.

Overall, 104 providers submitted data (excluding nil returns) on behalf of the 3,250 service users who met the inclusion criteria for the Learning Disability Census (see table 11 of the reference data tables):

- 58 NHS providers submitted data on behalf of 1,804 service users

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<sup>26</sup> <http://www.hscic.gov.uk/catalogue/PUB12503>

<sup>27</sup> <http://www.rcpsych.ac.uk/pdf/FR%20ID%2003%20for%20website.pdf>

<sup>28</sup> <http://www.hscic.gov.uk/ldcensus>

- 46 Independent providers submitted data on behalf of 1,446 service users<sup>29</sup>.

## Census design

The Learning Disability Census was adapted from the 2010 “Count Me In” census<sup>30</sup>, which focused on inequalities by ethnic group in care for inpatients and patients on supervised community treatment in mental health and learning disability services in England and Wales. The Learning Disability Census 2013 focused specifically on service users with learning disabilities, and on aspects of service user experience (such as distance of inpatient stay from usual place of residence) identified as particularly relevant following the Winterbourne View Review. The final content of the Learning Disability Census was developed over several months, taking into account views from clinicians, expert users, and attendees at regional engagement events.

The Learning Disability Census covered the following topic areas:

- Patient registration information and demographics including full name, date of birth, NHS number, provider organisation code, address prior to admission, gender, age and ethnicity. Person identifiable data was used to support NHS number tracing to verify and improve data quality, as well as to create derived variables that are not personally identifiable (such as age bands, and distance between postcode of residence and ward stay). With the exception of postcode, person identifiable data was removed from the dataset used for analysis.
- Information on admission including legal status on admission, source of referral, reason for admission, receipt of treatment authorised without consent, type of disability. These data were collected to ensure that the range of needs associated to the need for treatment were sufficiently understood.
- Experience of care including information on the number and type of incidents within the care environment within the last three months. This information was considered important as an indicator that may help identify practices that effectively minimise interventions.
- Accommodation information: questions related to gender specificity of treatment environments.
- Location details including information on the location of the facility providing the treatment episode. This was considered important as it enabled derivation of the distance from usual residence to treatment to be calculated.
- Patient details: data requested included whether individuals had an authorised deprivation of liberty, the use of medication, details of review and care planning, and the cost of the treatment and care provided.

The Learning Disability Census 2013 was an individual-level data collection. As the Census will be repeated in 2014, this will enable analysis of outcomes for service users. In particular it will support analysis of the extent to which service users have moved out of inpatient settings, or into settings that are closer to their area of residence. Longitudinal analysis of changes in service users’ experience of care will also be possible.

## Data collection

The HSCIC’s Clinical Audit Platform was used to collect data for the Learning Disability Census. This is a secure data collection tool, which enabled batch uploads and submission of individual records through a secure web-based form (for providers with small numbers of in scope service users). Data validation was built into the collection tool, with providers being notified of records where validation errors were detected. The HSCIC Data Collection Team provided extensive support to providers in order to help them address registration and validation issues where necessary.

The data collection period ran from 1 October 2013 to 15 October 2013.

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<sup>29</sup> Two independent providers, Anselm Clinics, and Alpha Hospitals, submitted data under multiple provider codes (see table 11 of the reference data tables).

<sup>30</sup> [http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-mental-health/carequalitycommission/155293count\\_me\\_in\\_2010\\_final\\_tagged.pdf](http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-mental-health/carequalitycommission/155293count_me_in_2010_final_tagged.pdf)

Data cleansing was undertaken after the collection closed. Records were sent to the HSCIC Personal Demographics Service (PDS) for NHS number verification and to trace a last known postcode of residence where that supplied by providers was invalid or unknown. This tracing process considerably improved data quality for postcodes of residence, reducing the proportion of all Learning Disability Census records submitted by providers<sup>31</sup> that had 'ZZ99' postcodes from 25.0% (828 service users) to 0.6% (19 service users), whilst the proportion of invalid postcodes decreased from 3.0% (or 100 service users) to 1.6% (or 54 service users).<sup>32</sup>

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<sup>31</sup> These figures were produced before the report analyses and are based on 3,313 records which include the 63 records subsequently excluded as they did not meet the inclusion criteria.

<sup>32</sup> See the Data Quality Report for this publication for more information.

## Appendix 2: List of Tables (England level)

The following tables can be found in the supporting Excel document which can be found here – <http://www.hscic.gov.uk/pubs/ldcensusrep1213>

Table 1	Service users by region of residence and region of ward stay
Table 2	Service users by gender and age band
Table 3	Service users by gender and ethnic group
Table 4	Service users by broad age band, region of residence and region of ward stay
Table 5	Service users by gender, region of residence and region of ward stay
Table 6	Service users by service type, region of residence and region of ward stay
Table 7	Service users by length of stay, region of residence and region of ward stay
Table 8	Service users by ward security level, region of residence and region of ward stay
Table 9	Service users by distance from residence, region of residence and region of ward stay
Table 10	Service users by local authority of residence and local authority of ward stay
Table 11	Service users by provider
Table 12	Service users by age band, length of stay, service type and security level of ward
Table 13	Service users by gender, length of stay, service type, and security level of ward
Table 14	Service users by ward security level, length of stay, service type, and distance from residence
Table 15	Service users by distance from residence and length of stay

## Appendix 3: Related reading

### A3.1 HSCIC information

#### Historical versions of this publication:

There are no historical versions of this publication. 2013 is the first year that this has been undertaken and it is anticipated to be re-run on a further occasion in 2014.

Other documentation listed below concerning this publication can be found at:

<http://www.hscic.gov.uk/ldcensus>

- Letter introducing the Learning Disability Census and invitation to attend awareness events.
- Guidance notes
- Frequently asked questions
- Operational guidance
- Easy read leaflet
- Awareness event presentation slides
- User registration form

Press release

<http://www.hscic.gov.uk/article/3591/New-Learning-Disability-Census-deadline-approaches-for-mandatory-submissions>

#### Background documentation and resources concerning this publication:

Winterbourne View Hospital: Department of Health review and publications

<https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>

Winterbourne View Joint Improvement Programme

[http://www.local.gov.uk/web/guest/adult-social-care/-/journal\\_content/56/10180/3912043/ARTICLE](http://www.local.gov.uk/web/guest/adult-social-care/-/journal_content/56/10180/3912043/ARTICLE)

South Gloucestershire Safeguarding Adults Board Winterbourne View Hospital A Serious Case Review

<http://hosted.southglos.gov.uk/wv/report.pdf>

#### Suggested reading:

People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services: Faculty Report FR/ID/03 July 2013

<http://www.rcpsych.ac.uk/pdf/FR%20ID%2003%20for%20website.pdf>

This report gives background to the development of current in patient provision, / argues for a range of provision to meet complex needs and presents a reclassification of inpatient assessment and treatment options available.

Eric Emerson et al. "People with Learning Disabilities in England, 2012", (Improving Health and Lives: Learning Disability Observatory, 2013),

<http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&fv=18581>

The publication aims to provide a summary of information on the characteristics of people with learning disabilities, the services and supports they use as collected by numerous government departments.

Pauline Heslop et al, "Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report", (University of Bristol, 2013)  
<http://www.bris.ac.uk/cipold/fullfinalreport.pdf>

The Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) was tasked with investigating avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews of deaths. (Considering 247 deaths between 2010 and 2013). The aim was to review the patterns of care that people received in the period leading up to their deaths. It identified deficient health and social care provision.

Services for People with learning Disabilities and Challenging Behaviour or Mental Health Needs: Report Of A Project Group Chairman: Prof J L Mansell) Revised Edition October 2007  
[http://www.kent.ac.uk/tizard/research/research\\_projects/dh2007mansellreport.pdf](http://www.kent.ac.uk/tizard/research/research_projects/dh2007mansellreport.pdf)

The report recognised people with learning disabilities whose behaviour challenges are among those most at risk of services breaking down and the need to change the nature of commissioning to build and sustain the capacity to meet the needs of people in each area.

### **A3.2 Related statistics**

Care Quality Commission "Count Me In." Count Me In' was a census of inpatients and patients on supervised Community Treatment Orders in mental health and learning disability services, which was conducted annually from 2005 to 2010. Whilst its scope was considerably broader than the Learning Disability Census and focused on the Department of Health's five-year action plan for improving mental health services for Black and minority ethnic communities in England, it reported on service users with learning disabilities as a sub-group.  
[http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-mental-health/carequalitycommission/155293count\\_me\\_in\\_2010\\_final\\_tagged.pdf](http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-mental-health/carequalitycommission/155293count_me_in_2010_final_tagged.pdf)

**Published by the Health and Social Care Information Centre  
Part of the Government Statistical Service**

**Responsible Statistician**

**Claire Thompson**

Principal Information Analyst, Community and Mental Health team

ISBN 978-1-78386-046-3

This publication may be requested in large print or other formats.

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