

TLDR – Specialist inpatient services for people with learning disabilities across the countries of the UK

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## Abstract

### Purpose

This paper compares data from national censuses on specialist inpatient service use by people with learning disabilities across England, Scotland, Wales and Northern Ireland.

### Methodology

National statistics (England, Scotland, Wales, Northern Ireland) reporting inpatient service censuses including people with learning disabilities were accessed, with data extracted on trends over time, rate of service use, young people and length of stay.

### Findings

The number and rate of people with learning disabilities in specialist inpatient services varied across the UK: 230 people in Scotland (rate 4.88 per 100,000 population); 3250 people in England (5.48); 183 people in Wales (5.90); 144 people in Northern Ireland (7.82). The number of people in inpatient services in Northern Ireland halved over four years, in other areas reductions were modest. Between 5% and 8% of people in inpatient services were children/young people. Median length of stay in the person's current inpatient service varied: 19 months in England; 33 months in Scotland; 3-5 years in Northern Ireland.

### Implications

Different parts of the UK vary in the scale of their specialist inpatient services for people with learning disabilities. With the exception of Northern Ireland, which may still be in the last stages of completing a 'regular' deinstitutionalisation programme, strong policy prescriptions for substantial reductions in specialist inpatient services are currently only resulting in modest reductions.

### Originality

This paper is a first attempt to compare national concerning inpatient service statistics across the UK. With increasing divergence of health and social service systems, further comparative analyses of services for people with learning disabilities are needed.

## Introduction

Over the past 20 years, devolution across the four main constituent parts of the United Kingdom (England, Scotland, Wales and Northern Ireland) has resulted in increasing diversity in how health services are organised (Bevan et al. 2014). In England, health service commissioners are largely local (211 Clinical Commissioning Groups and 10 NHS England specialised commissioning hubs) and commission services from a market of a large number of (largely but not wholly NHS) health service providers. In Scotland and Wales, there is no division between service commissioners and service providers (Scotland has 14 regional health boards and seven special NHS boards; Wales has seven local health boards), with competition discouraged and health services generally provided by the NHS. In Northern Ireland there is still a commissioner/provider split, although competition is discouraged, and five local commissioning groups map on to five Health and Social Care Trusts integrating health and social care.

Although the different parts of the UK tackled large-scale deinstitutionalisation for people with learning disabilities in different ways and at different times (Emerson & Hatton 1994), all parts of the UK are now operating service systems where large-scale, long-stay NHS institutions are theoretically no longer in existence. There are still, however, people with learning disabilities in specialist inpatient services in all four parts of the UK, ostensibly for the time-limited specialist assessment and treatment of challenging behaviours, mental health problems, and/or offending behaviour.

The need for the volume of these specialist inpatient services has long been questioned (e.g. Mansell 2007), and in England a BBC Panorama programme uncovering abuse at one of these services, Winterbourne View, has resulted in repeated policy efforts to substantially reduce the number of inpatient places in England (NHS England et al. 2015). A similar policy direction has been specified in Northern Ireland (Northern Ireland Executive 2012), with Scottish policy (Scottish Government 2013) and Welsh policy (Welsh Government 2011) identifying the importance of the issue without explicitly stating a reduction in inpatient service numbers as a policy aim.

This paper describes available information from the four parts of the UK on the numbers of people with learning disabilities in inpatient services. Each part of the UK collects this information independently, at different times and using different criteria. All four parts of the UK have, however, conducted an inpatient census of people with learning disabilities in inpatient settings on at least two occasions between 2011 and 2015. While an inpatient census only provides a snapshot of inpatient services (it does not, for example, record the number of people with learning disabilities using inpatient services across a whole year) it can be a useful indicator of the volume of inpatient services and trends in inpatient services over time.

## Datasets

England: The Learning Disability Inpatient Census (see Health and Social Care Information Centre 2015) was conducted by gaining information from specialist inpatient service providers in England on people with learning disabilities and/or autism in their service on 30<sup>th</sup> September. This census includes people with learning disabilities in English inpatient services whose placements were commissioned from outside England (75 people in 2015), and did not include people with learning disabilities in inpatient services commissioned by English commissioners but placed outside England.

The learning disability census was conducted in 2013, 2014 and 2015, and there are no plans to repeat it in 2016.

Scotland: The Mental Health and Learning Disability Inpatient Bed Census (see Scottish Government 2015) was conducted by gaining information from health services in Scotland (Scottish NHS health service providers and information on people commissioned by Scottish health services but placed in either independent services or NHS services outside Scotland), including information on people with learning disabilities on 29<sup>th</sup> October 2014. Reference is made in the Scottish learning disability strategy (Scottish Government 2013) to numbers from previous inpatient censuses, which have been conducted every two years. There is a stated aim to repeat the census in 2016.

Wales: An annual census of patients in mental health hospitals and units in Wales with a learning disability (StatsWales 2015) is conducted on 31<sup>st</sup> March. This gives information on people with learning disabilities in NHS inpatient services in Wales, but does not include people with learning disabilities commissioned by Welsh health services in independent/3<sup>rd</sup> sector inpatient services or placed in inpatient services outside Wales. For 2015, a national CCSIW inspection report (Care and Social Services Inspectorate Wales 2016) provided additional information for the census date on the number of people with learning disabilities in independent sector hospitals commissioned by health services in Wales.

Northern Ireland: An annual Mental Illness and Learning Disability census, including people with learning disabilities in inpatient services in Northern Ireland (Northern Ireland Department of Health 2015), is conducted on 17<sup>th</sup> February. The census includes people resident in inpatient services but on home leave on the date of the census. This gives information on people with learning disabilities in inpatient services run by Health and Social Care Boards in Northern Ireland. It appears that there are no independent sector providers of specialist inpatient services for people with learning disabilities in Northern Ireland.

## Results

Table 1 reports the number of people with learning disabilities in specialist/mental health inpatient services across the four parts of the UK from 2011-2015, where census data are available. In England, the number of people in inpatient services dropped from 3,250 people in 2013 to 3,000 people in 2015, a 7% drop in two years. In Scotland, the number of people in inpatient services dropped from 272 people in 2012 to 230 people in 2014, a 15% drop in two years. In Wales, the number of people in Welsh NHS inpatient services increased from 118 people in 2011 to 130 people in 2015, a 10% increase in four years. However, given that an additional 53 people were identified in 2015 as being placed in inpatient services outwith Welsh NHS services, an overall trend in the number of people with learning disabilities in Wales placed in inpatient services cannot be calculated. In Northern Ireland, the number of people in learning disabilities in inpatient years dropped from 315 people in 2011 to 144 people in 2015, a drop of 54% in four years.

TABLE 1 ABOUT HERE

Table 2 below reports a range of data relating to the most recent census date for each part of the UK.

First, to take into account differences in population size across the four parts of the UK, Table 2 reports the number of people with learning disabilities in inpatient services as a rate per 100,000 of the total population (across all ages) (National Records of Scotland 2015, Northern Ireland Statistics and Research Agency 2016, Office for National Statistics 2016, Statistics for Wales 2016). Total population (all ages) was used as a consistent comparator; although the vast majority of people with learning disabilities in inpatient services are adults, there are some younger people in inpatient services in the four areas and threshold ages for adulthood in these statistics vary across the four parts of the UK.

Rates of people with learning disabilities in inpatient services varied across the four parts of the UK: 4.88 in Scotland, 5.48 in England, 5.90 in Wales and 7.82 in Northern Ireland. If expressed as rates per 100,000 adult general population (aged 16 years or over), the rates increase to: 5.18 in Scotland, 6.76 in England, 7.19 in Wales and 9.89 in Northern Ireland.

Second, Table 2 shows the percentage of people with learning disabilities in inpatient services who are children/young people, for three of the four parts of the UK where data were publicly reported. Threshold ages are slightly different for Wales (18 years or under) compared to England and Northern Ireland (under 18 years), with percentages varying from 5.5% (England) to 7.6% (Wales and Northern Ireland). Data specifically for people with learning disabilities was not publicly reported in Scotland, although overall numbers of children/young people in the mental health and learning disability census as a whole were low.

Finally, although reported very differently across three of the four parts of the UK where data were available, England, Scotland and Northern Ireland reported on the median length of stay of people with learning disabilities in their current inpatient service at the time of the census. In England this median was 19 months (1 year 7 months), in Scotland this median was 33 months (2 years 9 months) and in Northern Ireland this median was 3-5 years.

TABLE 2 ABOUT HERE

## Discussion

This paper attempts to provide some basis for comparing the number of people with learning disabilities in specialist inpatient services across the four constituent parts of the UK. Although there are differences in census methodologies and reach across the four parts of the UK, there are some useful findings to be drawn from this comparative analysis.

First, rates of people with learning disabilities being placed in inpatient services vary somewhat across parts of the UK. Scotland was the lowest at 4.88 per 100,000 total population, followed by England (5.48) and Wales (5.90). Although differences in these rates seem relatively small, they translate into substantial differences in the number of people in inpatient services. For example, at Scotland's rate, England would have 2,674 people in inpatient services, and at Wales' rate, England would have 3,232 people in inpatient services

Northern Ireland reported a much higher rate, at 7.82 per 100,000 total population. However, this is likely to be a consequence of Northern Ireland's inpatient population still including some people in

hospital services on a long-stay basis. For example, 20 people in inpatient services in Northern Ireland (14% of their total) had been in inpatient services for 30 years or more. Taking out this long-stay group results in rates of inpatient service usage (6.7 per 100,000) and median lengths of stay (2-3 years) that begin to look more like other parts of the UK.

This might also partly account for the rapid decrease of inpatient services in Northern Ireland compared to other parts of the UK – in effect Northern Ireland are completing ‘regular’ deinstitutionalisation, with reductions in inpatient places possibly slowing when only specialist inpatient services are left.

It is also worth noting that the lengths of stay reported here concern lengths of stay in their current inpatient service, rather than total length of stay in inpatient services if people are transferred between different inpatient services. Certainly in England the median length of continuous stay in inpatient services (861 days) is much longer than the median length of stay in the person’s current service (554 days) (Health and Social Care Information Centre 2015). A shorter median length of stay in a person’s current inpatient service may reflect a more unstable inpatient service system rather than shorter stays in inpatient services.

Despite very different sizes, health service systems and policy urgency, the four parts of the UK seem to be generally facing common issues. Small but important numbers of children/young people with learning disabilities are still being placed in specialist inpatient services, lengths of stay in inpatient services are frequently measured in years rather than months, and even in parts of the UK with a strong policy imperative to reduce inpatient services reductions are modest and far short of policy ambitions.

Methodologically, the scope and methodology of the censuses conducted across the UK vary, which must be borne in mind when making comparisons. Some of these differences in scope reflect the different health systems, for example in whether independent sector services are included or not (a seemingly much bigger issue in England than in other parts of the UK). However, greater consistency in scope across the four parts of the UK would be helpful in understanding how inpatient services are being used, particularly as people can be placed across national boundaries. For example, should the focus of a census be people placed in specialist learning disability inpatient services, or people with learning disabilities placed in specialist inpatient services (including mainstream mental health inpatient services)? Should the focus of a census be inpatient services within a geographical area (even if some people within them are placed there from other parts of the UK) or inpatient services paid for by health services in that part of the UK (including inpatient services in other parts of the UK)? Should the focus of a census be people with learning disabilities, or people with learning disabilities and/or autism? Should a census be able to track people placed in independent sector inpatient services?

Finally, it is worth noting that a census offers only a partial view of inpatient services for people with learning disabilities, and other methods of collecting data are needed to gain a more complete picture. More comparative analyses of the range of data available across the four parts of the UK concerning services for people with learning disabilities are needed to help identify policy and service organisational factors and levers associated with positive outcomes.

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Table 1: Number of people with learning disabilities in specialist/mental health inpatient services across the four parts of the UK: 2011-2015 (where data available)

Part of UK	Census scope	2011	2012	2013	2014	2015
England	NHS & independent sector inpatient services in England			3,250	3,230	3,000
Scotland	NHS Scotland services and people in services outwith NHS Scotland		272		230	
Wales	NHS providers in Wales only	118	133	130	120	130 +53 (independent sector or inpatient services outside Wales)
Northern Ireland	HSC services only (no independent sector inpatient provision in NI)	315	296	263	176	144

Table 2: Number and rate per 100,000 total population, percentage of young people, and median length of stay, of people with learning disabilities in inpatient services at most recent census date

Part of UK	Year of census	Total number of people in inpatient services at census date	Total population (all ages)	Rate per 100,000 total population of people with learning disabilities in inpatient services	Percentage of inpatient population who are children/young people	Median length of stay at time of census
England	2015	3,000	54,786,300	5.48	5.5% (165 people) aged under 18	19 months
Scotland	2014	230	5,347,600	4.88	n/a	33 months
Wales	2015	183	3,099,086	5.90	7.6% (14 people aged 18 or under, for the 130 people in Welsh NHS services)	n/a
Northern Ireland	2015	144	1,840,498	7.82	7.6% (11 people) aged under 18	3-5 years

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