

Final accepted version

TLDR – Living arrangements of adults with learning disabilities across the UK

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## Abstract

### Purpose

This paper compares data from national social care statistics on the living situations of people with learning disabilities across England, Scotland, Wales and Northern Ireland.

### Methodology

National social care statistics (England, Scotland, Wales, Northern Ireland) reporting the living situations of adults with learning disabilities (residential and nursing care, living with family, other forms of accommodation) were accessed, with data extracted on trends over time and rate of service use.

### Findings

There were substantial differences in the statistics collected across the UK. Overall, there were higher reported rates of adults with learning disabilities in residential/nursing accommodation in England than Scotland or Wales, but much lower reported rates of adults living in other forms of unsupported and supported accommodation and much lower reported rates of adults living with their families. In all three countries, trends over time suggest that reductions in residential care towards more independent living options may be stalling. In Northern Ireland reductions in currently extensive residential and nursing care services are continuing, unlike other parts of the UK.

### Implications

Despite similar policy ambitions across the four parts of the UK, statistics on the living situations of adults with learning disabilities report substantial differences.

### Originality

This paper is a first attempt to compare national social care statistics concerning the living situations of adults with learning disabilities 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 and social services are organised (Bevan et al. 2014). 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), the vast majority of adults with learning disabilities in the UK are now living outside institutions run by health services. Adults with learning disabilities are in a wide range of living situations, from residential and nursing care through supported living to tenancies and home ownership, with a large proportion of adults with learning disabilities still living with their families.

There are both similarities and differences in how social care is delivered across England, Scotland, Wales and Northern Ireland. Social care is commissioned (and provided to varying degrees) by 152 local authorities in England, 32 local authorities in Scotland, 22 local authorities in Wales, and 5 integrated Health and Social Care Trusts in Northern Ireland. There are also national and local variations in eligibility for social care support and funding. In all parts of the UK there have been substantial reductions in state funding for social care, although there have been substantial national and local variations in the extent and distribution of these reductions (see e.g. Hastings et al 2015).

Within the past 20 years, there have been major statements of policy concerning people with learning disabilities in England, Scotland, Wales and Northern Ireland. All these policy statements include similar key principles or values. In England, 'Valuing People Now', launched in 2009, is the most recent government strategy concerning people with learning disabilities (HM Government 2009). This restated the four fundamental principles of rights, independence, choice and inclusion in Valuing People (Department of Health 2001). In Scotland, the 'Keys To Life' strategy concerning people with learning disabilities was launched in 2013, with the four strategic aims of a healthy life, choice and control, independence, and active citizenship (Scottish Government 2013). The Welsh Government issued its most recent 'Statement on Policy and Practice for Adults with a Learning Disability in 2007 (Welsh Government 2007), with the four key aims of living healthy, productive and independent lives, choice and control, living connected lives in their community, and having the support of their community (see SSIA 2014). In Northern Ireland, the Bamford review of mental health and learning disability first published a report concerning people with learning disabilities in 2005 (Review of Mental Health and Learning Disability 2005; see Northern Ireland Executive 2012 for an update and action plan), with the key values of citizenship, social inclusion, empowerment, working together and individual support.

A previous paper (Hatton, 2016) compared statistics concerning people with learning disabilities in specialist inpatient services across England, Scotland, Wales and Northern Ireland, within the context of devolved differences in health services. This paper compares statistics concerning the living situations of much larger numbers of adults with learning disabilities who are either living with their families (most commonly parents) or living in various forms of accommodation funded by social care services.

## Datasets

England: NHS Digital publishes annual returns from 152 councils with adult social services responsibilities concerning social care for adults with learning disabilities (NHS Digital 2016). Adults are defined as aged 18 years or over, with some data only available for adults aged 18-64 years. There was a major change in social care data collection for 2014/15 onwards. The categories reported in this paper did not change, but the pool of people from which the data are drawn changed, from adults with learning disabilities known to councils up to 2013/14 to the smaller number of adults with learning disabilities receiving long-term social care support from 2014/15 onwards. This discontinuity needs to be borne in mind when interpreting trends over time from England. Specifically, this paper uses data from Table LTS001a for information on the number of adults with learning disabilities aged 18 or over in residential and nursing care. Data from Table LTS004 are used on the number of adults with learning disabilities aged 18-64 years: living with family/friends (short-term and long-term), in owner-occupied/shared ownership housing, in tenancies, in supported accommodation, in a shared lives arrangement, and in sheltered/extra care housing.

Scotland: The Scottish Commission for Learning Disability publishes annual returns from 32 local authorities concerning adults with learning disabilities known to local authorities (Scottish Commission for Learning Disability 2016). Adults are defined as aged 16 years or over. Specifically, this paper uses data on the number of adults with learning disabilities: living with family carers, in registered adult care homes, in mainstream accommodation (without support, with support, and where it is unknown if there is support or not), and in supported accommodation.

Wales: StatsWales publish annual returns from 22 local authorities concerning adults with learning disabilities on local authority registers (StatsWales 2016). Adults are defined as aged 16 or over. Specifically, this paper uses data on the number of adults with learning disabilities: in a community placement with parents/family, in residential accommodation (whether council or independent sector), in a community placement in their own home, and in a community placement in lodgings/supported living.

Northern Ireland: The Northern Ireland Department of Health publish annual returns from 5 Health and Social Care Trusts (health and social care provision is integrated in Northern Ireland) concerning adults with learning disabilities in contact with Trusts (Northern Ireland Department of Health 2016). Adults are defined as aged 16 years or over. Specifically, this paper uses data on the number of adults with learning disabilities in residential care and in nursing care. Data concerning other forms of accommodation for adults with learning disabilities are not available for Northern Ireland.

## Results

Table 1 reports the number of adults with learning disabilities in residential and/or nursing care across the four parts of the UK from 2010/11 to 2015/16, where data are available. In England, the number of adults in residential care and nursing care decreased from 2010/11 to 2013/14, then apparently increased in 2014/15 and stabilised to 2015/16. The discontinuity in data collection from 2013/14 to 2014/15 in England reduced the pool of adults with learning disabilities from whom statistics were reported, so it is difficult to interpret an increase associated with this discontinuity.

In Scotland and Wales, the number of adults with registered care homes or residential accommodation seemed fairly stable over time. In Northern Ireland, the number of adults in residential care has dropped steadily from 2010/11 to 2015/16, with numbers in nursing care fluctuating around a fairly stable level.

To take into account differences in population size across the four parts of the UK, the number of people with learning disabilities in residential/nursing care as a rate per 100,000 of the total population aged 15 years or more using mid-year 2015 population estimates for England, Scotland, Wales and Northern Ireland (Office for National Statistics 2016) was calculated. These comparisons must be treated with caution; for example the minimum age threshold is different for England than Scotland, Wales and Northern Ireland, and definitions of service types are also different across the UK.

In England in 2015/16, 67.5 adults with learning disabilities per 100,000 adult population were living in residential care, and a further 4.3 adults per 100,000 were living in nursing care.

In Scotland in 2014/15, 42.0 adults with learning disabilities per 100,000 adult population were living in registered adult care homes.

In Wales in 2015/16, 51.2 adults with learning disabilities per 100,000 adult population were living in residential accommodation.

In Northern Ireland in 2015/16, 39.3 adults with learning disabilities per 100,000 adult population were living in residential care, and a further 43.9 adults per 100,000 were living in nursing care.

TABLE 1 ABOUT HERE

Table 2 reports the number of adults with learning disabilities living in the most common various other types of accommodation across England, Scotland and Wales (no statistics are available for Northern Ireland) from 2010/11 to 2015/16, where data are available. The categories used to describe accommodation types are quite different across the UK. For England data are only available for adults with learning disabilities aged 18-64 years rather than including older adults, and data may be in some respects discontinuous from 2013/14 to 2014/15.

In England, the number of people in owner-occupied housing, tenancies, supported accommodation and to a certain degree shared lives arrangements all increased from 2010/11 to 2013/14. A drop from 2013/14 to 2014/15 may be partly a function of the change in data collection methods, as numbers in all these categories increase from 2014/15 to 2015/16. However, for some of these categories it seems unlikely that people in these forms of accommodation would not be getting long-term social care support, and hence excluded from the statistics from 2014/15 onwards. The number of adults with learning disabilities in sheltered/extra care housing increased continuously in England from 2010/11 to 2015/16.

In Scotland, the number of adults with learning disabilities in mainstream housing with no support decreased from 2011/12 to 2014/15, as the number of people living in mainstream housing with support and in mainstream housing where it was unknown if the person was getting support or not both increased over the same time period. Although the trend is less linear, the number of adults

with learning disabilities in Scotland living in supported accommodation also increased from 2011/12 to 2014/15.

In Wales, the number of adults with learning disabilities both living in their own home and living in lodgings/supported living steadily increased from 2010/11 to 2015/16.

In England in 2015/16: 6.1 adults with learning disabilities per 100,000 adult population were living in owner occupied/shared ownership housing, 35.0 adults per 100,000 had tenancies, 52.4 adults per 100,000 were living in supported accommodation, 6.9 adults per 100,000 had shared lives arrangements, and 2.4 adults per 100,000 were living in sheltered/extra care housing.

In Scotland in 2014/15, 151.4 adults with learning disabilities per 100,000 adult population were living in mainstream housing without support, 119.1 adults per 100,000 were living in mainstream housing with support, 76.8 adults per 100,000 were living in mainstream housing where the presence of support was not known, and 96.1 adults per 100,000 were living in supported accommodation.

In Wales in 2015/16, 60.7 adults with learning disabilities per 100,000 adult population were living in their own home, and 95.2 adults per 100,000 were living in lodgings/supported living.

TABLE 2 ABOUT HERE

Table 3 reports the number of adults with learning disabilities living with family/friends across England, Scotland and Wales (no statistics are available for Northern Ireland) from 2010/11 to 2015/16, where data are available. The categories used are slightly different across the UK, and for England data are only available for adults with learning disabilities aged 18-64 years rather than including older adults and data are in some respects discontinuous from 2013/14 to 2014/15.

In England, taking into account the discontinuity from 2013/14 to 2014/15, the number of adults with learning disabilities aged 18-64 years living with family/friends (whether in a settled arrangement or on a short-term basis) increased steadily over the time period. Almost all these adults (98.5%) were living with friends/family on a settled basis.

There were similar increases in Scotland for adults aged 16 years or over from 2011/12 to 2014/15, while there were no obvious trends in numbers in Wales for adults aged 16 years or over from 2010/11 to 2015/16. In both Scotland and Wales, the vast majority of these adults were aged 18-64 years (97.2% in Scotland, 98.1% in Wales) rather than 65 years or over.

In England in 2015/16, 97.8 adults with learning disabilities per 100,000 adult population were living in with family/friends on a settled or short-term basis.

In Scotland in 2014/15, 195.1 adults with learning disabilities per 100,000 adult population were living with a family carer.

In Wales in 2015/16, 203.5 adults with learning disabilities per 100,000 adult population were living with their parents/family.

TABLE 3 ABOUT HERE

For context, the total rates of adults with learning disabilities known to/using social services were calculated for each part of the UK, drawn from the same data sources as above.

In England in 2015/16, a total of 143,705 adults with learning disabilities (age 18 years or over) were receiving long-term social care support, a rate of 3.2 adults with learning disabilities per 1,000 age-matched general population.

In Scotland in 2014/15, a total of 27,218 adults with learning disabilities (aged 16 years or over) were known to local authorities, a rate of 6.1 adults with learning disabilities per 1,000 age-matched general population.

In Wales in 2015/16, a total of 14,729 adults with learning disabilities (aged 16 years or over) were on local authority registers, a rate of 4.7 adults with learning disabilities per 1,000 age-matched general population.

In Northern Ireland in 2015/16, a total of 7,921 adults with learning disabilities (aged 16 years or over) were in contact with Health and Social Care Trusts, a rate of 5.4 adults with learning disabilities per 1,000 age-matched general population.

## Discussion

This paper attempts to provide some basis for comparing the number of adults with learning disabilities living with their families or in various types of social care accommodation across the four constituent parts of the UK.

Comparisons across the four parts of the UK are difficult due to substantial differences in the data collected and reported across England, Scotland, Wales and Northern Ireland. These differences are likely to reflect increasingly divergent policies and service patterns relevant to adults with learning disabilities, and also to reflect when social care statistics were last revised. One obvious difference is that in England, social care statistics are only reported on those adults with learning disabilities getting long-term support from councils, rather than on adults with learning disabilities known to local authorities (not all of whom will be getting long-term support). Another obvious difference is that in Northern Ireland only statistics on adults with learning disabilities in residential and nursing care are reported.

Regarding residential and nursing care, trends across England, Scotland and Wales suggest that the number of adults with learning disabilities in these forms of accommodation is stabilising, with rates of people in residential care higher in England (67.5 per 100,000) than in Scotland (42.0 per 100,000) and Wales (51.2 per 100,000). In Northern Ireland, the rate of adults with learning disabilities is comparable (39.3 per 100,000) but the rate of adults in nursing care (43.9 per 100,000) is much higher than in England (4.3 per 100,000). However, in Northern Ireland the number of adults with learning disabilities in both residential and nursing care is continuing to steadily decrease, so this may reflect a process of service reconfiguration happening later in Northern Ireland than other parts of the UK.

In contrast, the number of adults with learning disabilities in other forms of accommodation steadily increased up to 2013/14 across England, Scotland and Wales. Interpretation beyond this date is difficult for England particularly, but there are tentative signs of supported accommodation/living/housing continuing to increase beyond this date while more independent housing options seem to be stabilising. Overall, substantially fewer adults with learning disabilities in England seem to be living in this range of housing options than in Wales or Scotland. For example, 52.4 per 100,000 adults with learning disabilities in England were living in supported accommodation, compared to 96.1 adults per 100,000 in supported accommodation in Scotland and 95.2 adults per 1,000 in lodgings/supported living in Wales. This difference can partly be accounted for by the restricted age range for England (18-64 years) compared to Scotland and Wales (16 years or over). However, in Wales only 15.6% of adults with learning disabilities in lodgings/supported living were aged 64 or over, so this difference in age range is unlikely to account for the difference. The number of adults with learning disabilities in supported accommodation in England in 2013/14 (when adults known to councils rather than just adults getting long-term social care support were included) was also lower than the number in 2015/16 (24,485 people vs 25,325 people) so the difference is also unlikely to be an artefact of changes to data collection in England in 2013/14.

Statistics for England also report a much lower rate of adults with learning disabilities living with family/friends (97.8 per 100,000) compared to Scotland (195.1 per 100,000) and Wales (203.5 per 100,000). Given the low numbers of adults with learning disabilities aged 65 years or more living with their families in Scotland and Wales, this difference is unlikely to be accounted for by the restricted age range in England compared to Scotland and Wales. In England, changing the pool from whom statistics are taken undoubtedly suppressed the number of adults with learning disabilities reported as living with family/friends (as many of these adults are presumably not getting long-term social care support), but even taking the 2013/14 data gives a rate (107.7 per 100,000) still far below Scotland and Wales.

Overall, social care statistics for England report lower rates of adults with learning disabilities (3.2 per 1,000 age-matched population) than Wales (4.7 per 1,000), Northern Ireland (5.4 per 1,000) and Scotland (6.1 per 1,000). This is unlikely to reflect differences in underlying rates of learning disability across the UK. These differences are more likely to be the result of: 1) a more restrictive definition of who counts in social care statistics in England, which is likely to exclude more adults with learning disabilities getting little or no social care support (particularly those living in unsupported accommodation or with families); 2) differences in past and current investment in local authority registers of people with learning disabilities; 3) differences in the extent of social care service provision for adults with learning disabilities. However, even the highest rate recorded in Scotland is still substantially below the rates reported in prevalence studies of 9.2 per 1,000 population in high-income countries (Maulik et al 2011).

Overall, statistics for England suggest higher rates of adults with learning disabilities in residential/nursing accommodation than Scotland or Wales, but much lower rates of adults living in other forms of unsupported and supported accommodation and much lower rates of adults living with their families. Some of these differences are likely to reflect the exclusion of more adults with learning disabilities from the statistics in England compared to Scotland and Wales. However, even taking this into account adults with learning disabilities in England are more likely to be in residential care and less likely to be in more independent or supported living options than adults in Scotland



and Wales. In all three countries, trends over time suggest that reductions in residential care towards more independent living options may be stalling. Data for Northern Ireland is restricted, but suggests that reductions in relatively extensive residential and nursing care living options are continuing, unlike other parts of the UK. A final point is that these trends in service provision over time across all four parts of the UK are highly unlikely to be keeping pace with the increasing number of adults with learning disabilities requiring social care (Emerson et al 2012).

It is hoped that this paper demonstrates both the limitations and the potential value of comparative analyses of services for people with learning disabilities across the four areas of the UK.

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Table 1: Number of people with learning disabilities in residential and nursing care across the four parts of the UK: 2010/11 to 2015/16 (where data available)

Part of UK		2010/ 11	2011/ 12	2012/ 13	2013/ 14	2014/ 15	2015/ 16
England	Residential care (age 18+)	34,565	34,275	33,095	32,345	33,010	32,625
	Nursing care (age 18+)	2,045	2,035	1,930	1,845	2,110	2,100
Scotland	Registered adult care home (age 16+)	n/a	1,866	2,001	1,964	2,020	n/a
Wales	Residential accommodation (age 16+)	1,407	1,431	1,437	1,439	1,473	1,413
Northern Ireland	Residential care (age 16+)	821	819	772	737	647	634
	Nursing care (age 16+)	718	737	750	779	719	709

Table 2: Number of people with learning disabilities in other forms of accommodation across England, Scotland and Wales: 2010/11 to 2015/16 (data not available for Northern Ireland)

Part of UK		2010/ 11	2011/ 12	2012/ 13	2013/ 14	2014/ 15	2015/ 16
England	Owner occupier/shared ownership (age 18-64)	2,340	2,885	2,640	3,755	2,570	2,940
	Tenant (age 18-64)	17,405	19,390	20,220	21,505	16,665	16,900
	Supported accommodation (age 18-64)	17,610	21,420	24,700	24,485	23,275	25,325
	Shared lives (age 18-64)	2,675	3,805	3,415	3,550	3,075	3,355
	Sheltered/extra care housing (age 18-64)	675	835	985	890	1,310	1,145
Scotland	Mainstream housing: no support (age 16+)	n/a	8,354	8,122	7,943	7,282	n/a
	Mainstream housing: with support (age 16+)	n/a	4,415	4,603	4,858	5,728	n/a
	Mainstream housing: support unknown (age 16+)	n/a	3,059	2,727	3,360	3,692	n/a
	Supported accomm (age 16+)	n/a	4,458	4,361	4,703	4,622	n/a
Wales	Live in own home (age 16+)	1,836	1,833	2,012	1,948	1,918	1,675
	Lodgings/ supported living (age 16+)	2,128	2,272	2,477	2,434	2,491	2,627

Table 3: Number of adults with learning disabilities living with family members across England, Scotland and Wales: 2010/11 to 2015/16 (data not available for Northern Ireland)

Part of UK		2010/ 11	2011/ 12	2012/ 13	2013/ 14	2014/ 15	2015/ 16
England	Settled mainstream housing with family/friends (age 18-64)	41,205	48,785	50,930	52,090	45,215	46,590
	Staying with family/friends in short term (age 18-64)	625	765	770	810	625	695
Scotland	Lives with family carer (age 16+)	n/a	8,489	9,142	9,299	9,386	n/a
Wales	Lives with parents/family (age 16+)	5,602	5,534	5,643	5,709	5,580	5,612

## Acknowledgements

The writing of this paper has been supported by Public Health England, as part of the work of the Public Health England Learning Disabilities Observatory. Views expressed in this paper are those of the author, and not necessarily those of Public Health England.