Final accepted version

TLDR – Day services and home care for adults with learning disabilities across the UK

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Abstract

Purpose

This paper compares data from national social care statistics on day services and home care for people with learning disabilities across England, Scotland, Wales and Northern Ireland.

Methodology

National social care statistics (England, Scotland, Wales, Northern Ireland) reporting the number of adults with learning disabilities accessing day services and home care, with data extracted on trends over time and rate of service use.

Findings

Regarding day services, despite some variations in definitions, the number of adults with learning disabilities in England, Scotland and Wales (but not Northern Ireland) using building-based day services decreased over time. Data from Scotland also indicate that adults with learning disabilities are spending less time in building-based day services, with alternative day opportunities not wholly compensating for the reduction in building-based day services. Regarding home care, there are broadly similar rates of usage across the four parts of the UK, with the number of adults with learning disabilities using home care now staying static or decreasing.

Implications

Similar policy ambitions across the four parts of the UK have resulted (with the exception of Northern Ireland) in similar trends in access to day services and home care.

Originality

This paper is a first attempt to compare national social care statistics concerning day services and home care for 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; Hatton 2016), 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 (Hatton 2017). Alongside these living arrangements, substantial numbers of adults with learning disabilities are getting some form of separate support during the day and may be getting home care support, which is the focus of this paper, the third in a series comparing services for adults with learning disabilities across the UK (see Hatton 2016, 2017).

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. A consistent theme in all these policy documents is day service ‘modernisation’, with the intention of reducing or replacing building-based day centres with more flexible, fulfilling and inclusive supported daytime activities, including access to further education and support to gain paid employment (Department of Health 2001; HM Government 2009; Northern Ireland Executive 2012; Review of Mental Health and Learning Disability 2005; Scottish Government 2013; Welsh Government 2007). In contrast, none of these policy statements set clear objectives for home or domiciliary care, although supported living and independent living situations, where people are most likely to be accessing home care, have been encouraged in policies across the UK, have until recently been increasing (Hatton, 2017). As well as policy, broader financial issues, particularly the impact of general reductions in social care expenditure (although services for people with learning disabilities may until recently have been relatively protected from these reductions; see e.g. Hatton et al., 2016), are likely to be a major influence on the provision of social care for adults with learning disabilities.

In practice, people with learning disabilities and their families (with whom many adults with learning disabilities are living, Hatton 2017) have experienced day service ‘modernisation’ as having both positive and negative impacts. Day centres could be sites of inflexible, unfulfilling time being served with little support for individuals to develop fulfilling lives in terms of being citizens of their local communities, but they could also be sites of predictable time spent in activities out of the house, with peers and friends. Reductions in time spent in building-based day services could result in daytime being spent more flexibly and productively within local communities, but at the same time could also result in less time being spent less predictably outside the person’s home, engaged in atomised activities in a restricted number of ‘safe havens’ within generally less than welcoming local communities (Power & Bartlett 2015). There is little research on how people with learning disabilities or family members experience home care.

Previous papers have compared statistics concerning people with learning disabilities across England, Scotland, Wales and Northern Ireland with respect to specialist inpatient services (Hatton 2016) and a wide range of living situations (Hatton, 2017). This paper compares statistics concerning day services and home care used by adults with learning disabilities across England, Scotland, Wales and Northern Ireland.

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. There was a major change in social care data collection for 2014/15 onwards, when information on the number of adults with learning disabilities getting day services and home care was discontinued. Up to this point data were available in the RAP dataset, Table P2F (see Hatton et al., 2016, for a detailed discussion of these data).

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 using day centres and the number of adults with learning disabilities using alternative day opportunities (these two categories are not mutually exclusive). Data on home care are published separately by the Scottish Government (Scottish Government, 2016) for adults with learning disabilities aged 18 years or over.

Wales: StatsWales publishes 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: getting day care, getting community support day care, and getting home care.

Northern Ireland: The Northern Ireland Department of Health publishes 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 2016a). Adults are defined as aged 16 years or over. Specifically, this paper uses data on the number of adults with learning disabilities using: adult training centres/social education centres/workshops; day centres. Whilst in other parts of the UK these would all be subsumed into one category of building-based day centre, the distinction made in Northern Ireland statistics is respected in this paper.

From 2013/14, the Northern Ireland Department of Health has also published data on the number of adults with learning disabilities aged 16 or over who are getting domiciliary care (Northern Ireland Department of Health 2016b).

Results

Table 1 reports the number of adults with learning disabilities using day services across the four parts of the UK from 2010/11 to 2015/16, where data are available.

In England the number of adults using day services dropped by 5.0% from 2010/11 to 2013/14, the last year for which data are available.

There was a similar trend for the number of adults using day centres in Scotland, with a drop of 4.7% from 2011/12 to 2014/15. The number of adults in Scotland getting alternative day opportunities rose sharply from 2011/12 to 2012/13, but has since dropped back in 2014/15 to 2011/12 levels. It is important to note that in Scotland these categories are not mutually exclusive; in 2014/15 2,422 adults with learning disabilities were both using a day centre and getting alternative day opportunities.

In Wales, the number of adults using day care also consistently dropped, by 5.5% from 2010/11 to 2014/15. In contrast, the number of adults in Wales using community support day care increased by 30.9% from 2010/11 to 2014/15.

In Northern Ireland, again the number of adults using Adult Training Centres/Social Education Centres/(sheltered) workshops almost halved (a decrease of 48.3%) from 2010/11 to 2015/16, although the number of adults using other forms of day centre sharply increased from 2010/11 to 2015/16 (an increase of 415.8%).

Overall, there seems to be a consistent drop in the number of adults with learning disabilities accessing building-based day centres across most parts of the UK, with the exception of Northern Ireland. In contrast, there are less consistent increases in the number of adults with learning disabilities accessing alternative daytime support options.

TABLE 1 ABOUT HERE

To take into account differences in population size across the four parts of the UK, the number of people with learning disabilities using day services 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 minimum age thresholds vary, and definitions of types of day service/day time support are also different across the UK.

In England in 2013/14, 102.5 adults with learning disabilities per 100,000 adult population were using a day service.

In Scotland in 2014/15, 108.6 adults with learning disabilities per 100,000 adult population were accessing a day centre, and 184.5 people were getting alternative opportunities during the day. Because these two categories are not mutually exclusive, overall in 2014/15 242.7 people per 100,000 population were accessing some form of support during the day.

In Wales in 2014/15, 88.7 adults with learning disabilities per 100,000 adult population were getting day care, and a further 83.4 adults per 100,000 population were getting community support day care.

In Northern Ireland in 2015/16, 98.7 adults with learning disabilities per 100,000 adult population were accessing an adult training centre/social education centre/workshop, and a further 114.1 adults per 100,000 were accessing day centres.

Although definitions of day services vary across the four parts of the UK, Northern Ireland appears to have the highest rate of adults with learning disabilities using building-based day centres, with Scotland, England then Wales having lower rates. Scotland and Wales also report substantial rates of adults with learning disabilities accessing alternative daytime support, with these statistics not collected in England and Northern Ireland.

The data above relate to the number of people using various forms of day service support, but do not provide any information on the extent of day service support accessed by adults with learning disabilities. For example, it would be possible for the number of people accessing day services to stay the same while the quantity of that support was cut from 5 days per week to 1 day per week. One part of the UK, Scotland, publishes statistics on the amount of time adults with learning disabilities spend in day centres and accessing alternative day opportunities. Table 2 presents this information for 2011/12 and 2014/15.

With respect to day centres in Scotland, Table 2 shows that overall the number of adults with learning disabilities using them reduced slightly from 2011/12 (5,481 people) to 2014/15 (5,222 people). The proportion of people accessing a day centre for less than 10 hours a week increased from 14.0% in 2011/12 to 24.8% in 2014/15.

With respect to alternative day opportunities in Scotland, Table 2 shows that overall the number of adults with learning disabilities was very similar in 2011/12 (8,867 people) and 2014/15 (8,875 people). At both time points, almost half of people did not have a specified amount of time spent in alternative day opportunities (49.8% of people in 2011/12; 46.6% of people in 2014/15); a further fifth of people were accessing these opportunities for less than 10 hours per week (19.3% of people in 2011/12; 21.5% in 2014/15).

Taken together, these data for Scotland suggest that building-based day centres are decreasing, both in the number of people accessing them at all but also in the amount of time each person spends at the building-based day centre. Alternative day opportunities, both in terms of number of people accessing them or the amount of time they spend, are remaining static over this time period. It is unknown whether similar trends are evident in other parts of the UK.

TABLE 2 ABOUT HERE

Table 3 reports the number of adults with learning disabilities getting home/domiciliary care support across England, Scotland, Wales and Northern Ireland from 2010/11 to 2015/16, where data are available.

In England there was an increase (6.7%) in the number of adults getting home care from 2010/11 to 2013/14 (no data are available after this date), a rate of 89.0 adults with learning disabilities per 100,000 population getting home care in 2013/14.

In Scotland, the number of adults with learning disabilities getting home care increased from 2010/11 to 2013/14, but has decreased from 2013/14 to 2015/16. In 2015/16, this was a rate of 93.1 adults with learning disabilities per 100,000 population getting home care.

In Wales, the number of adults with learning disabilities getting home care decreased from 2010/11 to 2014/15 (-5.5%), the last year for which data are available at the time of writing. In 2014/15, this was a rate of 88.7 adults with learning disabilities per 100,000 population getting home care.

Statistics concerning domiciliary care for adults with learning disabilities in Northern Ireland have been published since 2013/14 – numbers have stayed fairly stable between 2013/14 and 2015/16. In 2015/16, this was a rate of 77.9 adults with learning disabilities per 100,000 population getting domiciliary care.

TABLE 3 ABOUT HERE

Discussion

This paper attempts to provide some basis for comparing the number of adults with learning disabilities using day services and/or using home care across the four constituent parts of the UK.

Comparisons across the four parts of the UK are not straightforward due to differences in the data collected and reported across England, Scotland, Wales and Northern Ireland, and recent changes to statistics in England mean that these comparisons will not be possible in the future.

With respect to day services, England, Scotland and Wales seem to be following similar paths, with building-based day services steadily decreasing. These seem to be the continuation of longer term trends, pre-dating recent restrictions on health and social care spending. For example, the number of adults with learning disabilities in Scotland accessing day centres increased from 6,353 people in 1985 to a peak of 8,934 people in 1997, then declined to 7,693 people in 2001 (Scottish Executive, 2002) and 5,481 people in 2011/12. In England, the number of adults with learning disabilities using community-based day care increased from 23,200 people in 1969 to 56,720 people in 1994 (Mansell, 1997) and 58,020 people in 2005/06 (Hatton et al., 2016), declining to 52,150 people in 2010/11. In Wales, the number of adults with learning disabilities also dropped from 3,199 people in 2001/02 (StatsWales, 2016) to 2,589 people in 2010/11.

Data on alternative daytime support is limited to Scotland and Wales, and show fluctuating numbers of people accessing this type of support. The most complete data are available from Scotland, which suggests that, both in terms of the number of people accessing any form of day time support and the amount of time that people gain support during the day, alternatives to building-based day services are not replacing the shrinking building-based day service sector. Given extremely low and dropping employment rates for working age adults with learning disabilities in England (currently around 6% in England; Hatton et al., 2016), paid employment is unlikely to be replacing building-based day services either.

As with living situations for adults with learning disabilities (Hatton, 2017), day services for adults with learning disabilities in Northern Ireland are more likely to be ‘traditional’ in form, although policy directions are similar across the four constituent parts of the UK.

The number of adults with learning disabilities using home/domiciliary care is broadly similar across the four parts of the UK, with fluctuating levels but some signs of the number of people getting home care remaining static from 2013/14 onwards. In England and Wales, the number of adults with learning disabilities receiving home care is similar to the numbers of adults with learning disabilities in supported living/supported tenancy/home ownership living situations; in Scotland the number of people getting home care is substantially lower than the number of people in supported living/mainstream housing with support (cf. Hatton, 2017).

It is also unknown how much home care people are getting, and whether the quantity of home care people are getting is changing over time.

It is hoped that this series of three papers (Hatton 2016, 2017) 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. The different histories of the four parts of the UK seem important determinants both of the patterns of services used by adults with learning disabilities and how these services are framed in official statistics. Similar financial pressures on social and healthcare budgets and similar broad policy intentions across the four parts of the UK may be resulting in broadly similar directions of travel in the patterns of service provided, but there are substantial differences in how widely the net is cast in terms of eligibility for social care support. It is also unclear whether integrated health and social services (as in Northern Ireland) are making a radical difference in terms of access to services by adults with learning disabilities. Further, more detailed comparative analyses are needed to understand how finances, policy, and service organisation come together to influence what supports are available (or not) to adults with learning disabilities. Comparative work on how adults with learning disabilities and their families experience services within the context of their lives across the UK, is also urgently needed.

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Table 1: Number of people with learning disabilities in day services 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 (age 18+) | Day services | 52,150 | 51,710 | 51,300 | 49,555 | n/a | n/a |
| Scotland (age 16+) | Day centre | n/a | 5,481 | 5,287 | 5,368 | 5,222 | n/a |
| Alternative opportunities | n/a | 8,867 | 9,250 | 9,025 | 8,875 | n/a |
| Wales (age 18+) | Day Care | 2,589 | 2,471 | 2,548 | 2,493 | 2,446 | n/a |
| Community Support Day Care | 1,756 | 2,073 | 2,147 | 2,083 | 2,299 | n/a |
| Northern Ireland (age 16+) | Adult Training Centres, Social Education Centres, workshops | 2,842 | 1,710 | 1,736 | 1,549 | 1,594 | 1,468 |
| Day centres | 354 | 1,484 | 1,507 | 2,018 | 1,842 | 1,826 |

Table 2: Time spent at day centres and alternative day opportunities: 2011/12 vs 2014/15 (Scotland only)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Time spent | Day centres | | Alternative day opportunities | |
| 2011/12 | 2014/15 | 2012/13 | 2014/15 |
| <10 hours | 768 (14.0%) | 1,296 (24.8%) | 1,712 (19.3%) | 1,912 (21.5%) |
| 10 – 19.75 hours | 1,377 (25.1%) | 1,275 (24.4%) | 1,453 (16.4%) | 1,538 (17.3%) |
| 20 – 29.75 hours | 1,257 (22.9%) | 875 (16.8%) | 810 (9.1%) | 642 (7.2%) |
| 30+ hours | 982 (17.9%) | 871 (16.7%) | 478 (5.4%) | 645 (7.3%) |
| Time not specified | 1,097 (20.0%) | 905 (17.3%) | 4,415 (49.8%) | 4,138 (46.6%) |
| Total | 5,481 | 5,222 | 8,867 | 8,875 |

Table 3: Number of people with learning disabilities receiving home/domiciliary care: 2010/11 to 2015/16

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Part of UK | | 2010/ 11 | 2011/ 12 | 2012/ 13 | 2013/ 14 | 2014/ 15 | 2015/ 16 |
| England | Home care (age 18+) | 40,320 | 40,205 | 42,200 | 43,025 | n/a | n/a |
| Scotland | Home care (age 18+) | 4,270 | 4,590 | 4,330 | 4,950 | 4,860 | 4,480 |
| Wales | Home care (age 18+) | 2,589 | 2,471 | 2,548 | 2,493 | 2,446 | n/a |
| Northern Ireland | Domiciliary care (age 16+) | n/a | n/a | n/a | 1,232 | 1,236 | 1,258 |

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.