



Improving Health and Lives:
Learning Disabilities Observatory

Hospital Admissions That Should Not Happen

Admissions for Ambulatory Care Sensitive
Conditions for People with
Learning Disabilities in England

Gyles Glover, Felicity Evison



Supported by the Department of Health





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About the Authors

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EasyRead Summary

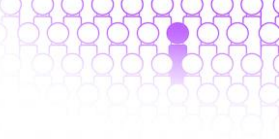


Sometimes people have to go into hospital as an emergency for problems that good care from community nurses and family doctors could have prevented.

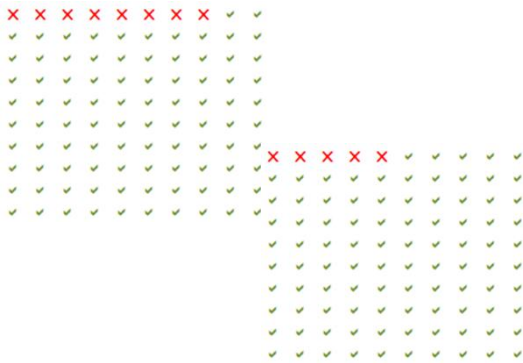


When this happens a lot, we should ask how good care is OUTSIDE hospital.

This report is about how often this happens for people with learning disability.



What we found.



For people with learning disabilities, about 8 out of every 100 admissions are emergencies that might be preventable.

For people who don't have learning disabilities, it is about 5 out of every hundred.



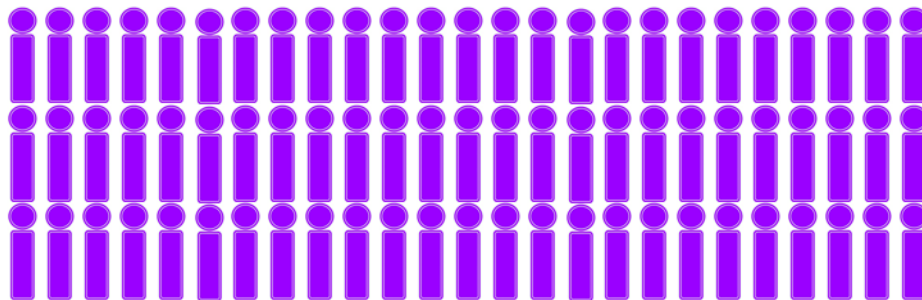
For people with learning disabilities this happens to adults of all ages.

For people who don't have learning disabilities, it is mainly a problem for older people.

The commonest cause for people with learning disabilities is convulsions and epilepsy.

At any time in England there are about 75 people with learning disability in hospital as an emergency for this reason.

This is 75 people





Other common causes for people with learning disabilities are constipation, diabetes and influenza/pneumonia.



Hospital admissions for emergencies that could usually be prevented are longer than other admissions.

This is the same for people with learning disabilities as for other people.

What health services should do



People who organise local health services should watch how often these admissions happen.



The NHS Information Centre could help. They could see which people family doctors think have learning disabilities.

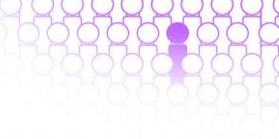
They could report how often these people go into hospital.



Hospitals should tell family doctors and community nurses when people with learning disabilities leave hospital.

If they think the problem could have been prevented. They should all think how to stop it happening again.

People with learning disabilities who are admitted to hospital as an emergency with convulsions and epilepsy should always see a specialist in neurology.



Introduction

What are ambulatory care sensitive conditions?

Ambulatory care sensitive conditions (ACSCs) have been defined as conditions which, given 'effective management' at the primary care level, should not normally result in an admission to hospital. They were first identified in a study of general hospital admissions in New York city in the United States by Billings and his co-workers.¹ Their interest was to explain the mechanisms underlying the higher observed rates of hospitalisation from areas characterised by lower socio-economic groups. Their hypothesis was that a lack of access to out-patient care was a key factor. So, using a Delphi approach, they derived a list of conditions for which, they considered, *"timely and effective outpatient care can help to reduce the risks of hospitalization by either preventing the onset of an illness or condition, controlling an acute episodic illness or condition, or managing a chronic disease or condition"*.

This original concept, that there are some conditions, which with reasonable access to ordinary primary or community-based care should usually not lead to hospitalisation has persisted. In the UK, two groups, the Kings Fund and Dr Foster Intelligence, have published particularly widely cited work in this area. The Kings Fund data briefing focussed mainly on the cost of emergency admission for ACSCs, identifying this as an outlay that could be saved.² The Doctor Foster briefing presented a broader perspective, emphasising also the nature of the community-based interventions likely to be required to achieve this.³ The latter report indicated that significant additional investment in community-based care would likely be required to achieve savings in hospital-based spending, but made the point that this would also likely lead to be better care. For some ACSCs likely to cause emergency admissions pre-emptive care is simple; influenza immunisation to reduce admissions for influenza pneumonia is the best example. For others, for example congestive heart failure, the action required to minimise hospitalisation is more complex and the extent to which admissions are preventable is less clear, although the desirability of better and more timely clinical control is obvious. In the NHS operating Framework for 2012/13 The Department of Health appears to follow the Dr Foster line. Unplanned admissions for chronic ambulatory care sensitive conditions are identified primarily as a care quality indicator under the heading 'enhancing quality of life for people with long term conditions'. Whilst good care is likely to reduce costs, their importance is not primarily as a cost saving mechanism.⁴

Billings' original list of conditions has been modified and updated. Many additions or alterations have been proposed. Purdy and her colleagues presented the list of 19 conditions most commonly used in the English NHS, which they attribute to Dr Foster and the NHS Institute for Innovation and Improvement.⁵ They also identified a range of studies in which additional conditions had been added to the list. They identified three broad

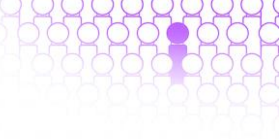


reasons why other researchers have done this: differences in the context of care outside hospital, the question of whether the focus is on the preventability of the conditions or of the admissions, and particular interests of the individual researchers. Our interest falls under the third category – what can patterns of emergency admissions for ACSCs tell us about community and primary healthcare for people with learning disabilities?

Many of the conditions identified as ACSCs are of particular importance in the health and health care of people with learning disabilities. Some, for example convulsions and epilepsy, are much more common among people with learning disabilities. Others, notably diabetes, are a little more common, but also raise particular management issues. A Canadian research group led by Balogh recently studied the extent to which this approach was relevant to the health and healthcare of people with learning disabilities. They demonstrated that admissions for many of the conditions recognised as ACSCs by the Canadian Institute for Health Information were more common in people with learning disabilities.^{6,7} After adjustment for age, sex, place of residence and, in some cases prevalence of relevant conditions, they found that people with learning disabilities were more likely to be hospitalised for ACSCs than people without. They also considered whether other conditions should be added to the list as having specific relevance for this group. Using a Delphi approach with a group of experts in the field of primary care for people with learning disabilities, they identified five relevant conditions. One of these (epilepsy) is already included among the 19 NHS conditions. The others were constipation, gastro-oesophageal reflux disease, osteoporosis and schizophrenia.

Box 1 provides the full list of conditions considered in this report. This comprises both the NHS set of 19 indicators and some additional indicators suggested by Balogh and his colleagues. Schizophrenia (suggested by Balogh) and depression (included in the NHS set) were omitted as the requirement for test of whether admissions should be included is both that they be for an appropriate condition and that they should be classed as emergencies. In English Hospital Episode Statistics, emergency (as opposed to elective) admissions are identified by a field called the 'admission mode'. Whilst this data item is completed for psychiatric admissions as well as for general medical, surgical and other admissions, psychiatric units appear to report it very idiosyncratically. Some district services report nearly all admissions as emergencies, others very few, and there is a pretty complete spectrum between these two poles. This makes this field effectively uninterpretable in psychiatric Hospital Episode Statistics data.

For a large proportion of the conditions considered, there are established issues in relation to greater prevalence or specific associations or complications for people with learning disabilities. Box 2 gives a brief synopsis of these associations with references.



Box 1. Conditions used and their broad category

Acute conditions	Chronic conditions	Immunisable conditions
Cellulitis	Angina	Influenza and pneumonia
Convulsions and epilepsy	Asthma	Other vaccine preventable conditions:
Dehydration and gastroenteritis	Chronic obstructive pulmonary disease	Tetanus
Dental conditions	Congestive heart failure	Diphtheria
Ear-nose-throat infections	Diabetes complications	Whooping cough
Gangrene	Hypertension	Acute Poliomyelitis
Pelvic inflammatory disease	Iron-deficiency anaemia	Measles
Perforated/bleeding ulcer	Nutritional deficiencies	Rubella
Pyelonephritis	Balogh additions:	Acute hepatitis B without hepatic coma
Balogh addition:	Gastro-oesophageal reflux disease	Chronic viral hepatitis B
Constipation	Osteoporosis	Mumps
		Haemophilus meningitis
		Rubella arthritis



Box 2. What is known about Ambulatory Care Sensitive Conditions in people with Learning Disabilities

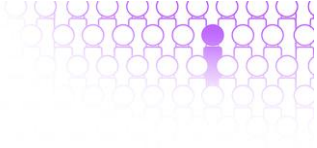
Acute conditions	Notes	References
Cellulitis	No results found	
Convulsions and Epilepsy	Epilepsy is roughly 20 times as common in people with learning disabilities, although there is evidence it may sometimes be over-diagnosed. Seizure control is often more difficult. Some anti-epilepsy drugs side effects have been found to include amongst others osteoporosis, depression and constipation.	8-13
Dehydration and gastroenteritis	A recent study in Manchester estimated that the prevalence of dysphagia (difficulty swallowing) was 8.5% in people with learning disabilities and that around two thirds of these had problems with drinking sufficient fluids to maintain health levels of hydration. A study from Glasgow also found dehydration associated with dysphagia; management of this reduced admissions for dehydration.	14 15
Dental conditions	People with learning disabilities are more likely than others to have untreated dental health problems including gum disease and dental caries. A Northern Ireland community study found people with Down's syndrome were particularly likely to have poor dental health. Access to dentistry may be a problem. A recent survey of specialist and non-specialist dentists in the UK found that whilst most respondents felt they were confident in treating people with learning disabilities, many had little experience and little knowledge of the key contemporary behaviour management techniques.	16-20
Ear Nose and Throat infections	A recent study on pre-school age children with Down's syndrome in Glasgow found that 37% of children with data recorded regarding annual visits to ear, nose and throat services had been listed as needing surgery by the age of five. Ear, nose and throat infections are known to occur frequently in children with Down syndrome and may lead to severe outcomes if left untreated.	21 22
Gangrene	No results found	
Pelvic Inflammatory Disease	No results found	



Box 2 What is known about Ambulatory Care Sensitive Conditions in people with Learning Disabilities (cont).

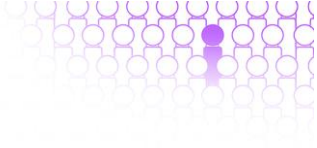
Perforated / bleeding ulcer	People with learning disabilities living in institutional settings are known to have high rates of <i>Helicobacter pylori</i> infection which causes peptic ulceration. This may also be associated with pica. This puts them at additional risk of both perforated ulceration and malignant disease of the stomach and duodenum.	23
Pyelonephritis	No results found	
Constipation	Constipation is common in people with learning disabilities, although often hard to diagnose. A recent Dutch study found that 70% of 215 people with severe learning disabilities had been constipated at least once during a three-month period. Straetmans et al found a treated prevalence of 20% in a group with learning disabilities, compared to 3% in a comparison group. A multi-centre European study estimated prevalence of constipation in people with learning disabilities at 26.5%. Constipation in people with learning disabilities is commonly a side effect of dysphagia or psychotropic medication, and may less commonly be associated with pica.	14 24-29

Chronic conditions	Notes	References
Angina	Known risk factors which are also more common in people with learning disabilities include obesity, lack of exercise and diabetes mellitus.	30-42
Asthma	There is some evidence that the prevalence of asthma may be higher in people with learning disabilities than in the general population. People who have learning disabilities who have also been diagnosed with asthma are more likely to smoke than people who have not been diagnosed ⁴³ . They are also more likely to visit their GP than people who have not been diagnosed with asthma. There is some evidence that being obese leads to higher odds of having asthma and the prevalence of obesity is known to be elevated in people with learning disabilities.	43-45
Chronic Obstructive Pulmonary Disease	Although Respiratory diseases have been identified as the most common immediate cause of death for people with learning disabilities, there has been little research into the co-morbid patterns of people with learning disabilities and COPD.	46 47



Box 2 What is known about Ambulatory Care Sensitive Conditions in people with Learning Disabilities (cont).

Congestive heart failure	See references for Angina (above) for general issues in relation heart disease.	
Diabetes complications	The prevalence of diabetes in people with learning disabilities has been reported to be higher than in those without. (9-11% vs. 4-6%). For type 2 (non-insulin dependent) diabetes, obesity is a major risk factor, and as previously mentioned above (see angina refs) the prevalence of obesity is higher in people with learning disabilities than in people without. Otherwise relatively independent people with learning disabilities may struggle to understand the management of diet and hypoglycaemic medication required in living with diabetes.	25 48
Hypertension		
Iron-deficiency anaemia	A high frequency of mild anaemia has been reported in a Japanese group of people institutionalised with learning disabilities.	49
Nutritional deficiencies		
Gastro-oesophageal reflux disease	Gastro-oesophageal reflux disease (GORD) occurs more frequently in people with learning disabilities than those without. Estimates of the prevalence of GORD in people with learning disabilities are around 10-15%, although known risk factors such as cerebral palsy, scoliosis and anticonvulsant drugs, may be associated with an increase in prevalence of 2 to 3 times. Estimates for people with severe learning disabilities living in institutions have been as high as 50%. Diagnosis may be difficult as heartburn (the most common symptom) is commonly not reported by people with learning disabilities. GORD may be associated with anaemia.	50-53
Osteoporosis	Osteoporosis is becoming more important in people with learning disabilities as their life expectancy increases. Risk may be increased by lack of vitamin D and use of anti-epileptic or some antipsychotic drugs. People with Down's syndrome may have an increased risk due to muscle hypotonia. People with learning disabilities may not report fractures or the associated pain associated leading to under-diagnosis of osteoporosis. Srikanth et al reviewed a number of studies showing that people with learning disabilities have lower bone mass density than others.	26 54-57



Box 2 What is known about Ambulatory Care Sensitive Conditions in people with Learning Disabilities (cont).

Vaccine preventable conditions	Notes	References
Influenza and pneumonia	Two studies of the 2009 H1N1 influenza strain demonstrated that children with intellectual disabilities and other pre-existing neurological conditions were at greater risk of death and severe complications including encephalopathy. A Dutch study indicated that response to administration of immunisations for this strain of influenza was also less likely to achieve a satisfactory immune response in people with severe motor and intellectual disabilities.	58-60

Aims of this study

Building on previous work our overall aim was to explore whether studying rates of unplanned (emergency) admissions for ACSCs could provide helpful evidence about patterns of community based health care for people with learning disabilities in England. This has not been studied before in this context.

Specifically we set out to identify individuals with learning disabilities appearing in hospitalisation records over a recent period in English admission statistics (Hospital Episode Statistics), and to look at the numbers of admissions they had overall, occurring in an unplanned way, and where the condition primarily causing the admission was an ACSC.

We aimed to look at:

- the number of admissions,
- the associated bed use, and
- which conditions were the most prominent causes.

We also wanted to look at how this varied:

- over time, and
- around the country.

As far as possible we wanted in all cases to compare people with and without learning disabilities.

We were looking for two types of conclusions: those applicable generally which could provide pointers to practice everywhere, and those which might be usefully applied as local performance indicators.



Data sources and methods


For the purposes of this study, we looked at four years of English Hospital Episode Statistics (HES) data; 2005 to 2009 inclusive. In almost all cases, this source collates information on every inpatient episode that someone has which was NHS funded. The exception is mental and behavioural healthcare, where NHS funded care in independent sector hospitals is not currently included.

An inpatient 'episode' for a patient is not quite the same as an admission. In the course of a single admission a patient may be transferred from one clinical specialty or consultant to another. This results in multiple 'episodes' being recorded, each documenting the care under one consultant. We looked only at records of 'admission episodes' – those which start with the patient being admitted to hospital, as opposed to being transferred from another consultant. The elements in HES records relevant to this study include:

- Personal identifiers (these are pseudo-anonymised in the HES dataset we have, so that we can identify multiple appearances of individuals, but our identifiers are unique to the North East Public Health Observatory and do not actually identify the people or link to any other datasets).
- Personal characteristics such as age and gender,
- PCT of residence,
- How the patient was admitted (for our purposes emergency or other),
- The primary reason for the episode (up to sixteen diagnoses are recorded coded in the tenth revision of the International Classification of Diseases (ICD-10), one of which is identified as the primary reason for the episode),
- The length of stay.

We identified people with learning disabilities in this dataset by looking at all the diagnoses ever given to each individual patient. First we made an un-duplicated list of personal identifiers. Then we went through all the diagnoses each had been given using the list of diagnoses developed for an earlier study of mortality in people with learning disabilities.⁶¹ This list is in four sub-categories: conditions usually associated with learning disabilities, sometimes associated, rarely associated, and conditions with a neurodegenerative element associated with learning disabilities. For this study we included people with any of these conditions. Thus our group will include some people with conditions such as cerebral palsy and hydrocephalus, which are only sometimes associated with learning disabilities whether or not the individuals actually had this complication. We also included anyone who had a HES episode recorded under the clinical specialty of psychiatry of learning disabilities.

We identified all admission episodes for people aged 18 and older at the time of admission. We coded each according to whether the person at some time had a diagnosis of learning



disability or an associated condition, whether admission was as an emergency, and whether it was for any of the ACSCs identified in the list in Box 1.

Most of our presentations are simple descriptive statistics of numbers and proportions of admissions. We were unable to calculate age-adjusted admission rates because there is currently no available source of age/sex specific population data for people with learning disabilities. For mapping we calculated crude admission rates for adults (aged 18 and over) with learning disabilities using estimates of the numbers of these in the population from general practitioners registers of adults with learning disabilities reported through the 2010/11 NHS Quality and Outcome Framework (QOF).⁶² We used 2010/11 in preference to selecting years corresponding to the HES data years because we believe these are the most reliable. QOF learning disabilities registers were introduced in 2006/7. Total numbers on the registers increased annually from 139,300 in 2006, to 188,819 in 2010/11, an overall 40% increase in four years. Our interpretation of this is that it reflects primarily more complete recording. Thus the most recent figure probably gives the best representation of the whole period.

Results

Numbers of admissions and bed days

In the four years we studied, there was an overall total of 52.6 million spells of hospitalisation, comprising 192.2 million days of in-patient care. 34.8% of admissions were as emergencies, 7.6% were for ACSCs and 4.9% were emergency admissions for ACSCs, the main focus of this study. Corresponding figures for bed days were 54.7% in emergency admissions, 13.3% in admissions for ACSCs and 11.4% in emergency admissions for ACSCs. Summary figures are shown in Table 1. The overall average number of bed days per admission for non-emergency admissions for non-ACSC causes was 2.53. On average, emergency admissions were 2.27 times this length, admissions for ACSCs were 2.54 times as long, and emergency admissions for ACSCs, 3.37 times as long.

We cannot compare population-based admission rates between people with and without learning disabilities with any precision, as we do not have comparable population statistics with the age and sex breakdown necessary to adjust for the age profile differences. However the figures shown in Table 1 allow some comparative conclusions. 1.3% of admissions involved a person who, at some stage in the four years had a diagnosis of learning disabilities or a related disorder. For every hundred of these, 43 were admitted as an emergency, 12 with an ACSC and 8 as an emergency with an ACSC. Corresponding numbers per 100 admissions of people without learning disability associated conditions were 35 admitted as an emergency, 8 admitted with an ACSC and 5 admitted as an emergency with an ACSC. Admissions for people with learning disability associated conditions lasted longer – on average 5.8 days per admission compared to 3.7 days for admissions for other people. However the impact of emergency mode of admission or ACSC primary diagnosis on stay length was smaller. For people in the learning disabilities group, non-emergency admissions on average lasted 4.9 days, emergency admissions 7.0 days, admissions for ACSCs 5.9 days and emergency admissions for ACSCs 7.3 days. For other people non-emergency admissions on average lasted 2.5 days, emergency admissions 5.7 days, admissions for ACSCs 6.5 days and emergency admissions for ACSCs 8.5 days.

Using our best estimate of the number of people aged 18 and over in the population of England with and without learning disabilities suggests the crude rate of emergency admissions for ACSCs is 76 admissions per 1000 per year for adults with learning disability-associated conditions. This is roughly five times the rate for other people (15 per 1000). If we were able to adjust this for age, the disparity would increase as a result of the younger age profile of the patients with learning disability-associated conditions. So this difference should be seen as a minimum.



For people without learning disabilities there was a downward trend in overall stay length. This fell by 11% overall (from 3.8 to 3.4 days), and by 17% (from 9.3 to 7.8 days) for emergency admissions for ACSCs. For people in the learning disabilities group the trend in stay-length for emergency admissions for ACSCs was similar (15% fall from 7.9 to 6.7 days).

Table 1. Admissions and in-patient bed days for people with and without learning disabilities or related condition, 2005/6 to 2008/9, by year; percentages as emergency, for ACSCs and as emergency for ACSCs.

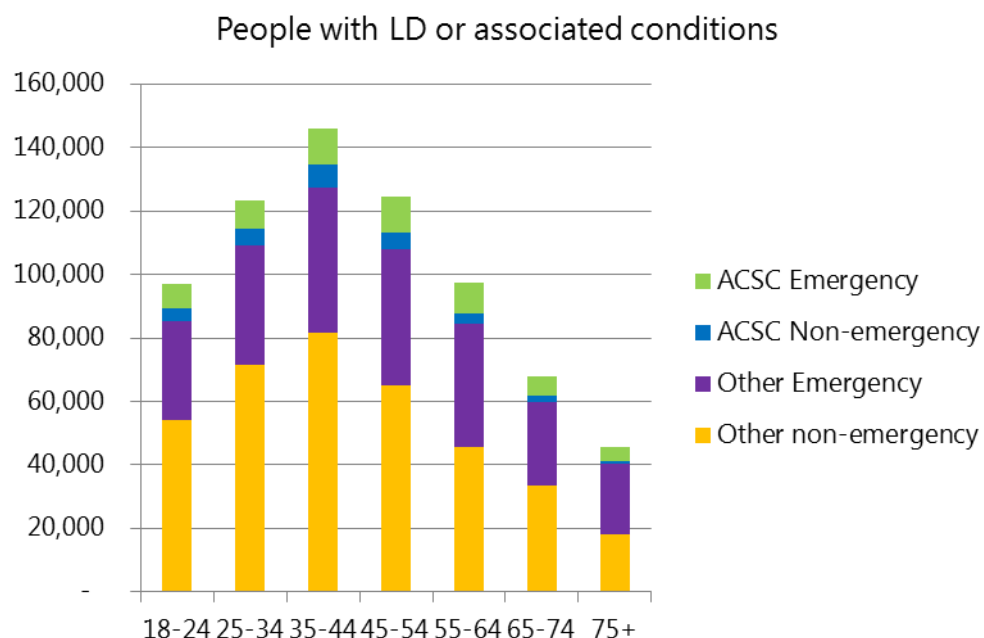
	Year	Admissions	% Emergency admissions	% ACSCs	% Emergency and ACSC
People with learning disabilities or related condition	2005/06	160,014	44.4% (1.24x)	11.9% (1.58x)	8.3% (1.65x)
	2006/07	170,582	42.6% (1.22x)	11.2% (1.61x)	7.5% (1.66x)
	2007/08	179,323	43.0% (1.27x)	12.2% (1.62x)	8.2% (1.75x)
	2008/09	191,618	43.7% (1.28x)	12.5% (1.58x)	8.6% (1.73x)
	<i>Total</i>	<i>701,537</i>	<i>43.4% (1.25x)</i>	<i>12.0% (1.60x)</i>	<i>8.2% (1.70x)</i>
People with no learning disabilities	2005/06	12,155,241	35.8%	7.5%	5.0%
	2006/07	12,587,309	34.9%	7.0%	4.5%
	2007/08	13,178,247	33.9%	7.5%	4.7%
	2008/09	14,016,964	34.1%	7.9%	5.0%
	<i>Total</i>	<i>51,937,761</i>	<i>34.7%</i>	<i>7.5%</i>	<i>4.8%</i>
	Year	Bed days	% in Emergency admissions	% for ACSCs	% in Emergency for ACSCs
People with learning disabilities or related condition	2005/06	840,001	57.5% (1.03x)	14.7% (1.03x)	12.5% (1.02x)
	2006/07	968,054	54.9% (1.00x)	11.4% (0.94x)	9.6% (0.93x)
	2007/08	1,105,967	50.4% (0.93x)	11.6% (0.86x)	9.7% (0.84x)
	2008/09	1,119,840	50.9% (0.94x)	11.6% (0.86x)	9.9% (0.87x)
	<i>Total</i>	<i>4,033,862</i>	<i>53.1% (0.97x)</i>	<i>12.2% (0.92x)</i>	<i>10.3% (0.91x)</i>
People with no learning disabilities	2005/06	46,340,620	55.9%	14.3%	12.2%
	2006/07	47,132,656	55.0%	12.1%	10.4%
	2007/08	47,047,588	54.2%	13.6%	11.5%
	2008/09	47,659,387	53.9%	13.4%	11.4%
	<i>Total</i>	<i>188,180,251</i>	<i>54.7%</i>	<i>13.3%</i>	<i>11.4%</i>

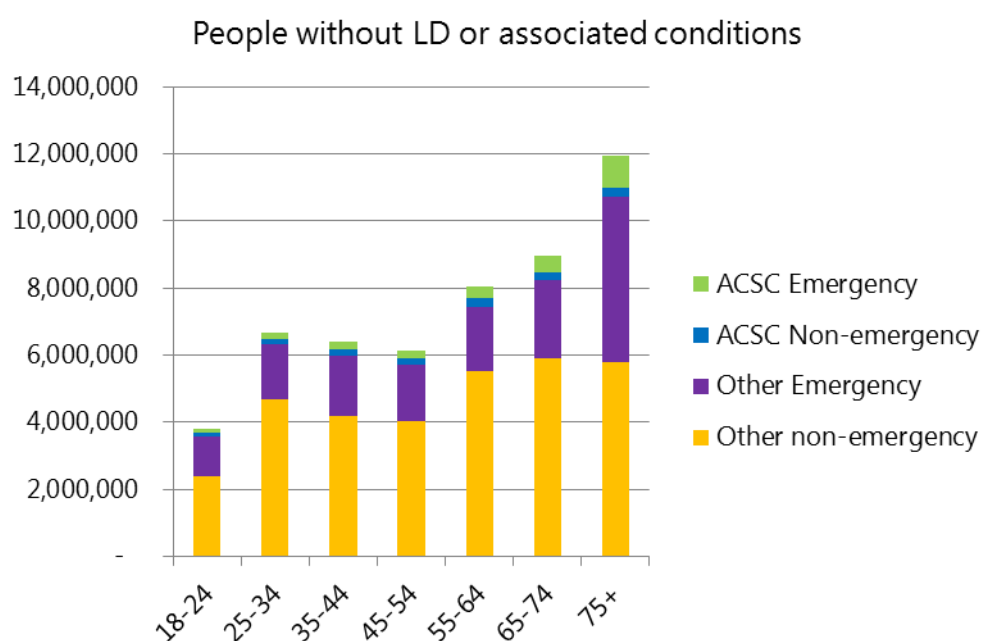
In the percentage columns, for people with LD, the ratio for people with LD to people without is shown in parentheses).

Figure 1 shows the age profile of patient admissions in each of the four emergency/non-emergency and ACSC/other causes categories. For people in the learning disabilities group the overall proportion of admissions which were as emergencies for ACSCs was fairly similar across the age bands, ranging from 6.7% at 25 to 34 to 10.1% in the oldest age group. For people without learning disabilities, by contrast, the proportion was low (less than 4%) in the groups up to age 54, but doubled to 8.2% in the oldest age group. This age group accounted for 23% of all admissions for those without learning disabilities.

The two charts in Figure 1 indicate the large difference in age profile between admissions of people with and without learning disabilities. These reflect differences in the population arising from the much higher mortality rates of people with learning disabilities. Admission numbers for the former rose with age-group in early adulthood, peaking in the group aged 35-44, which accounted for 21% of all admissions, before falling steadily at each older age group. For other people there was a slight peak in numbers in the two decades from age 24 to 44, probably at least in part attributable to maternity admissions, followed by a sharp rise in the oldest age groups.

Figure 1. Age distribution of admissions, distinguishing emergency /non-emergency and ACSC / other causes, for people with and without LD or associated conditions.






Conditions involved

The different age profile of patients in the learning disabilities and other groups suggests that the patterns of conditions given as the primary reason for admission would be likely to differ for this reason alone. To allow for this we have presented data on causes in three separate age bands, 18 to 34, 35 to 64 and 65 and over (Figure 2).

The most obvious difference between people in the learning disabilities and other groups was in the proportions of emergency ACSC admissions attributed to convulsions and epilepsy. This was much the most common reason for admission of people in the learning disabilities group in the two younger age bands. The share of ACSC admissions accounted for by this condition was four times as great for people in the learning disabilities group in comparison with others in all three of these broad age bands. Taking all age groups together, emergency admission for this condition accounted for 41% of all emergency ACSC admissions and 27% of bed days for people in the learning disabilities group – an average annual total of just under 6,000 admissions and just over 28,000 bed days, or 40 admissions and 187 bed days for every Primary Care Trust in England. This is of particular importance because of the key role of epilepsy and convulsions as a cause of death in people with learning disabilities.⁶¹ Emergency admissions for this indicate ineffective epileptic control and/or lack of adequate rescue medication plans.

Other causes, particularly in the two younger age groups all tended to have a lower proportionate significance for people in the learning disabilities group because they were



overshadowed numerically by convulsions. After allowing for this, a small number of conditions appeared to be particularly important for all age groups. These were diabetes, constipation and influenza/pneumonia. Angina, chronic obstructive pulmonary disease and congestive heart failure emerged as proportionately important causes of emergency ACSC admissions for people *without* learning disabilities at age 35 and over, but they figured less prominently for people in the learning disabilities group. For people with learning disabilities at these ages, dehydration and cellulitis emerged as important. ENT and dental infections, pyelonephritis and pelvic inflammatory disease were prominent in people without learning disabilities at younger age groups, but less prominent for those with.



Figure 2. Comparison of the causes of emergency admissions for ACSCs admissions for people with and without LD or associated conditions. Charts show the proportion of admissions and bed days attributable to each primary cause for specific age groups.

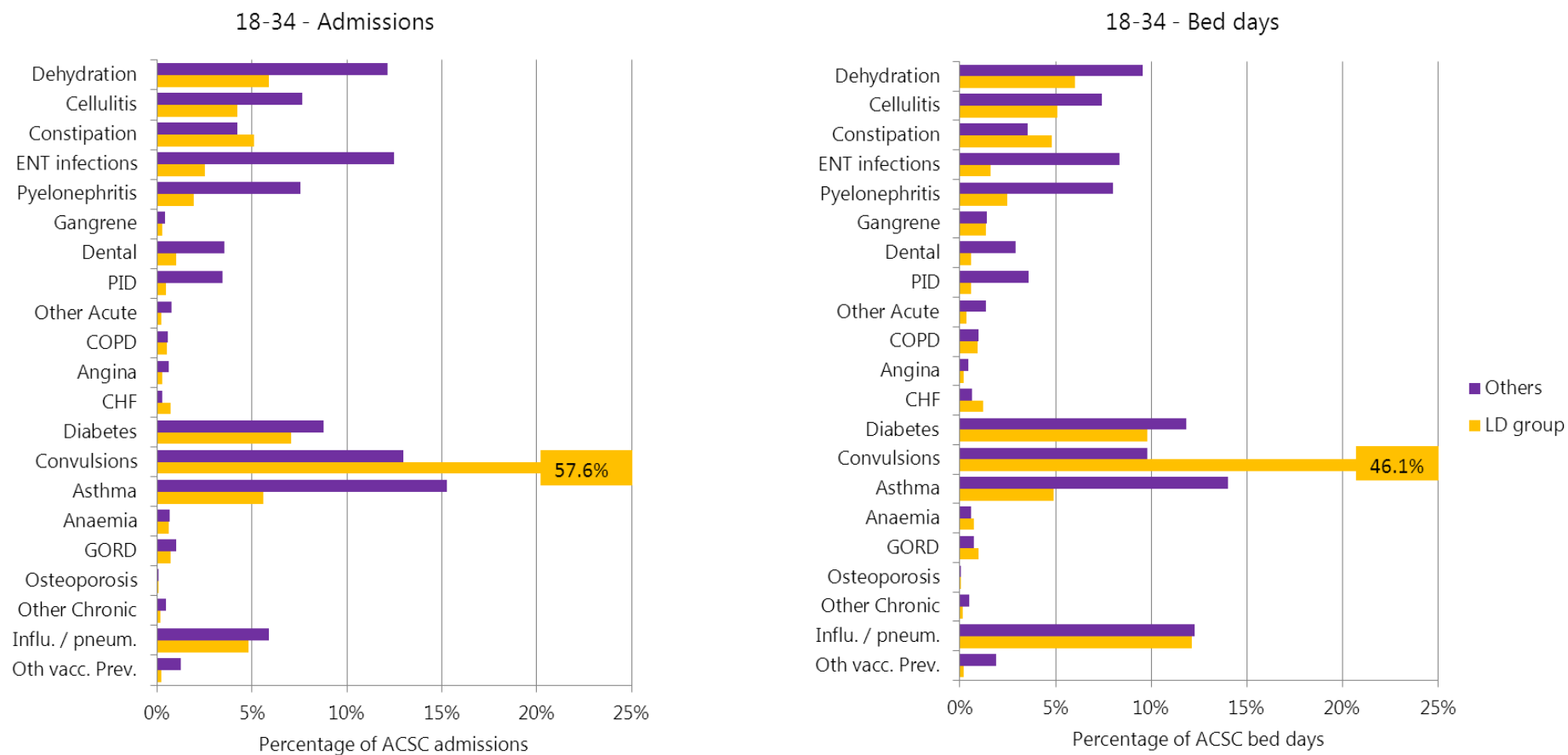
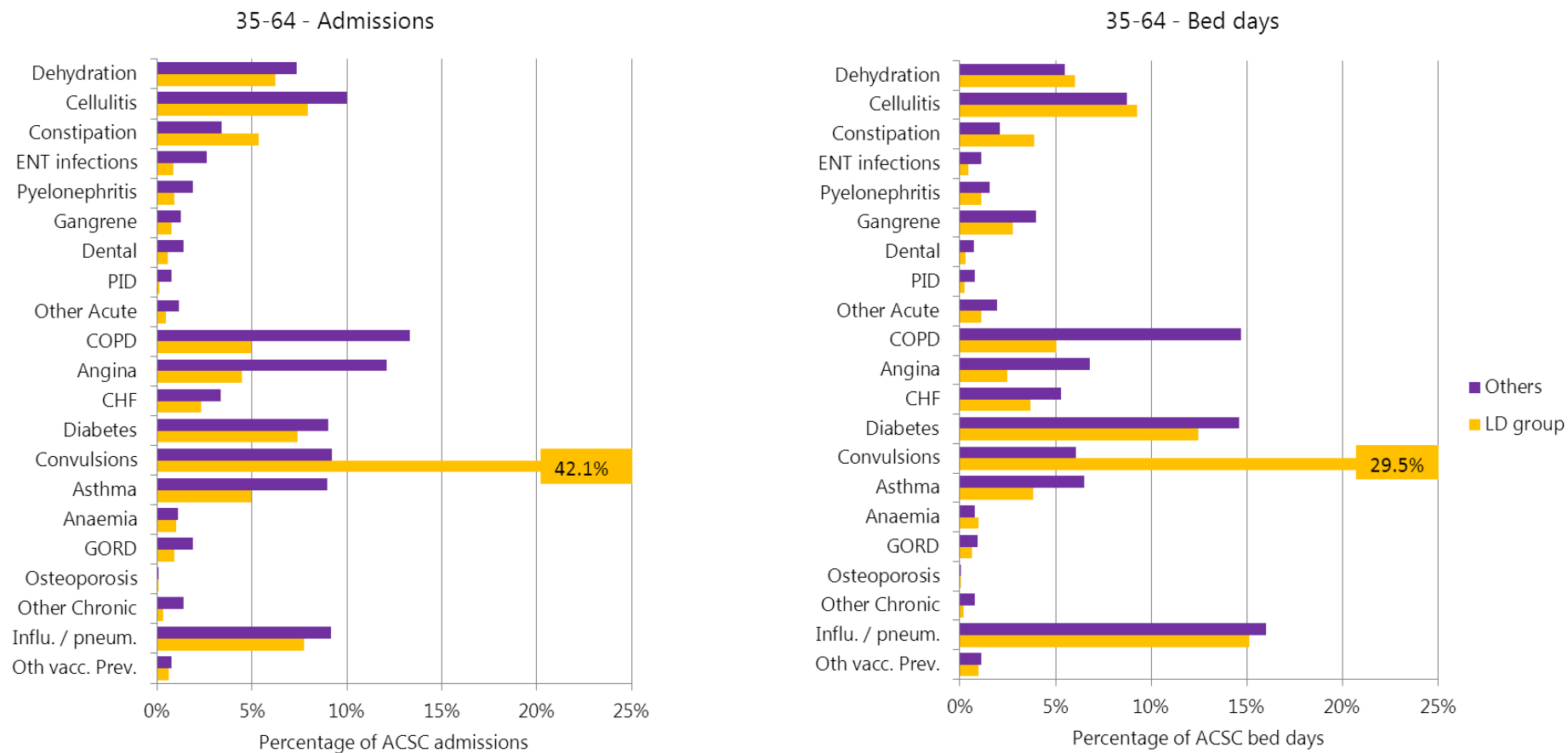




Figure 2 Comparison of the causes of emergency admissions for ACSCs admissions for people with and without LD or associated conditions (cont).



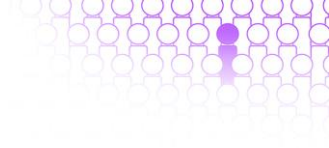
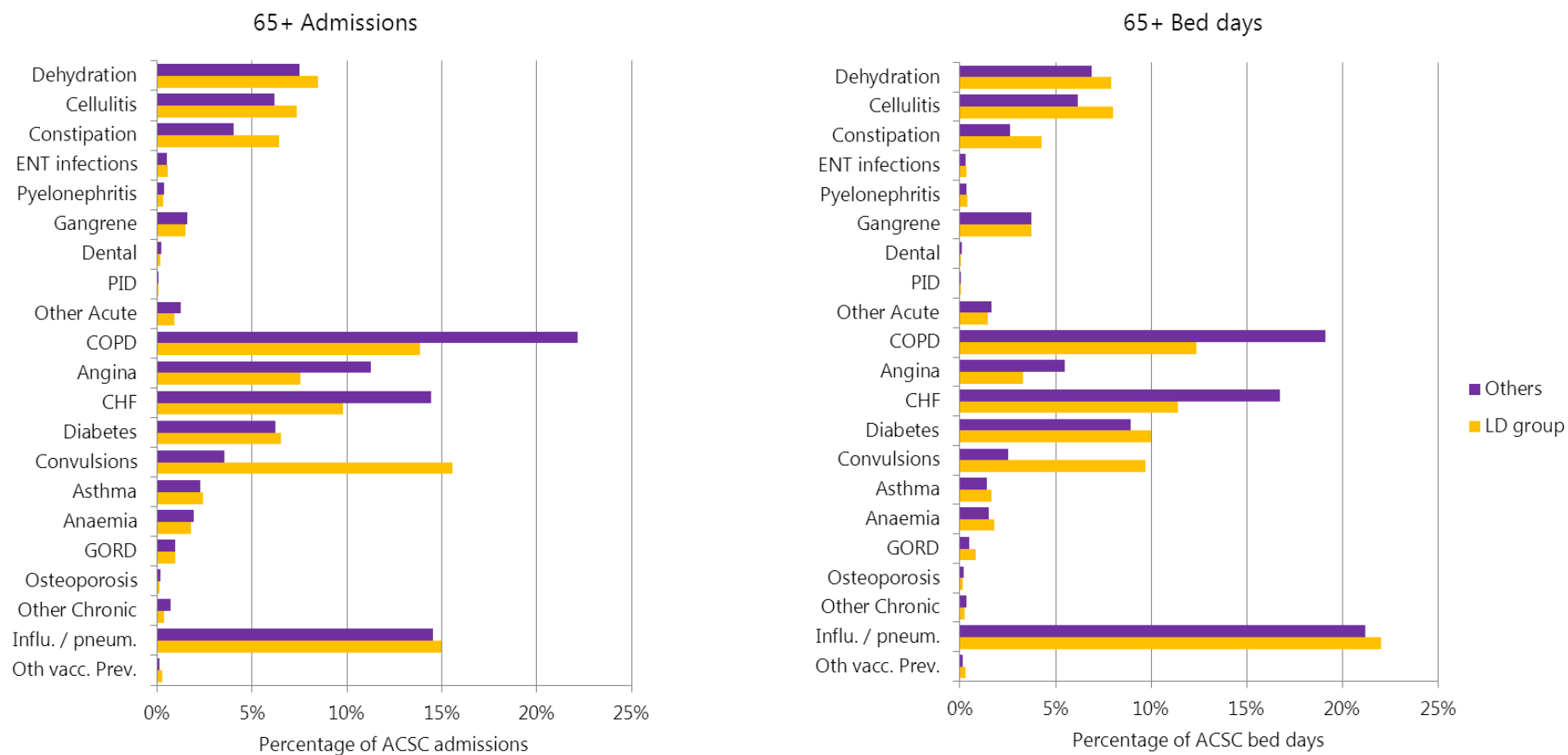
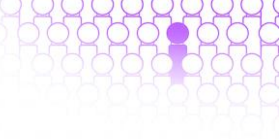


Figure 2 Comparison of the causes of emergency admissions for ACSCs admissions for people with and without LD or associated conditions (cont).





Changes over time

In thinking about changes in the pattern of emergency admissions for ACSCs over time, it is important to look at overall trends in admission numbers to provide context. The period we have studied was the period in which 'Payment by Results', a new tariff system for payment of NHS hospitals for the work they perform, was being introduced. This almost certainly led to some changes in the way admission and diagnostic data were recorded in Hospital Episode Statistics, which effectively became the billing system. Trends in this data source for this period are therefore hard to interpret. In Figure 3 we show overall trend patterns. Numbers of all admissions rose fairly steadily, though slightly faster for people in the learning disabilities group. This difference was apparent across both emergency and non-emergency admissions, and those for ACSCs and other causes. This could either indicate an actual increase in the number of people with learning disabilities being admitted, or a greater tendency to add sufficient additional diagnoses of co-morbid and complicating conditions for us to be able to identify them as in the learning disabilities group.^a


The increase in emergency admissions was smaller for both groups, more notably for people without learning disabilities. Numbers of admissions for ACSC conditions rose from 2006/7 (the second year of our data) onwards, but over the first year of the period we studied numbers remained level for people in the learning disabilities group and fell for other people. Numbers of emergency admissions for ACSCs fell for both groups in the first year, before rising steadily. It is not obvious what caused this discontinuity in the trends, but it indicates that trend findings should be treated with caution.

Table 2 shows the trend figures for emergency admissions for ACSCs for people in the learning disabilities and other groups. This table has a lot of gaps, because figures have only been included where these represent statistically significant movements from the baseline figure. This analysis is unsatisfactory, like those preceding it, in that it presents trends in numbers of admissions not age-adjusted rates.

For people in the learning disabilities group, convulsions and epilepsy were the cause most likely to show a significant trend as the initial number was by far the largest. This means that smaller proportionate changes would reach statistical significance. The pattern of the trend for people with learning disabilities was similar to that for people without (slight fall followed by greater increase).

Several conditions stood out as showing substantial and statistically significant increases for people in the learning disabilities group. These included cellulitis, dehydration, gangrene,

^a This would affect mainly people who were only admitted a small number of times. Where individuals had admissions throughout the period, if their learning disabilities was reported only in later years, we would have assumed it was present at all times.



pyelonephritis, anaemia, asthma, and COPD. In all cases the observed increase was greater for people in the learning disabilities group than for others, but the difference in the rate of increase between the groups in most cases was not great. This suggests that whilst we can be reasonably confident numbers rose, in view of the overall patterns described above, we probably cannot be confident they actually rose faster in the learning disabilities group than for others. Numbers of admissions for constipation showed a similar trend for people with and without learning disabilities.

Admissions for influenza / pneumonia rose particularly sharply. The rise showed a similar pattern in both groups but was again greater for people in the learning disabilities group. The period we studied includes the period in which there was high media coverage about "bird flu". However, this was largely over by 2008 so the rises seen in the 2008/09 admissions are unlikely to have been affected by this. The "swine flu" pandemic occurred in England after the end of our data window with the first cases described in the press in April 2009.

Thus to the extent that there were trends over time, they did not differ greatly between people with and without learning disabilities.



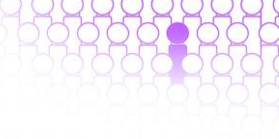
Figure 3. Overall trends in admission patterns for people with and without learning disabilities or associated condition diagnoses.



Numbers of admissions in each year are shown as a percentage of the number in 2005/6.

Table 2. Numbers of emergency admissions for ACSCs for people with and without learning disabilities by cause in the first year studied, and statistically significant percentage deviation from this in subsequent years. Numbers omitted where not significantly different from the baseline number.

Labels	No Learning disabilities				Learning disabilities or associated condition			
	Baseline	2006/07	2007/08	2008/09	Baseline	2006/07	2007/08	2008/09
All ACSC	609,981	-6.9%	+1.4%	+15.1%	13,285	-3.8%	+10.9%	+24.6%
Individual causes								
Acute								
Cellulitis	46,348	-3.9%		+9.2%	907			+21.5%
Constipation	23,705	-8.3%		+12.8%	775	-14.1%		+16.8%
Convulsions	39,093	-7.7%		+9.8%	5,747	-6.4%		+15.5%
Dehydration	46,142		+11.1%	+20.6%	840		+19.6%	+31.2%
Dental	5,495		+11.9%	+21.2%	83			
ENT infections	14,363		+13.0%	+16.4%	168			
Gangrene	7,421		+16.8%	+41.8%	91			+48.4%
PID	4,072	-10.1%			24			
Pyelonephritis	9,057		+13.7%	+30.3%	137			+42.3%
Other Acute	7,545	-13.5%	-8.8%	+4.7%	73			
Chronic								
Anaemia	9,467	-8.2%		+19.4%	131			+48.9%
Angina	72,080	-11.6%	-15.9%	-12.8%	548			
Asthma	36,722	-8.2%	-7.6%	+5.7%	617			+22.2%
CHF	61,946	-14.4%	-5.0%	+2.3%	443			
COPD	106,349	-8.1%	-3.8%	+14.0%	664		+17.3%	+45.9%
Diabetes	42,072	-4.7%	+12.0%	+29.5%	913		+26.8%	+19.1%
GORD	7,545		+5.9%	+11.4%	134			
Osteoporosis	742	-19.4%	-18.5%	-16.8%	3			
Other Chronic	5,562	-7.2%		+5.7%	45			
Vaccine preventable								
Influ. / pneum.	61,194		+25.8%	+61.3%	882		+39.3%	+93.5%
Oth vacc. Prev.	3,061	-23.8%	-21.0%		60			



Total bed use

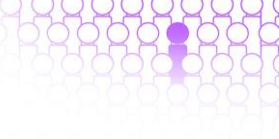
In Table 3 we show the extent of bed use arising from emergency admissions for ambulatory sensitive conditions. The table shows national figures. In the second column of numbers, total bed days have been divided by the number of days covered to give the number of beds occupied on an average day by people in the group specified. In total, the figure amounted to roughly two beds per PCT occupied by people in the learning disabilities group at any time. About a quarter (27%) of this was accounted for by people with poorly controlled epilepsy.

The admissions were surprisingly long. Over the whole period the average number of days per admission for all adult admissions taken together (including elective and emergency and ACSC and other causes) was 3.7. Emergency admissions for immunisable conditions (mainly influenza/pneumonia) were particularly long (14.2 days). People in the learning disabilities group accounted for just under 2% of all emergency bed days for ACSCs. The proportion was fractionally greater than 2%, for acute conditions and less for chronic and immunisable conditions, but approaching 13% for convulsions.

Table 3. Four measures of in-patient bed use by people in emergency admissions for ACSCs, comparing people with learning disabilities and related conditions with others, and giving breakdown for broad condition groups, 2004-2008.

	Cause Group	Average annual bed days	Beds on an average day	Proportion of bed days for LD	Average bed days per admission
People with learning disability or associated condition	Acute	25,942	71.0	2.0%	7.7
	Chronic	32,057	87.8	1.1%	8.4
	Convulsions	28,149	77.1	12.5%	4.7
	Immunisable	17,817	48.8	1.6%	14.2
	<i>Total</i>	<i>103,964</i>	<i>284.6</i>	<i>1.9%</i>	<i>7.2</i>
People with no learning disability	Acute	1,286,610	3522.5		7.5
	Chronic	2,795,915	7654.8		8.3
	Convulsions	196,705	538.5		5.0
	Immunisable	1,073,934	2940.3		13.9
	<i>Total</i>	<i>5,353,164</i>	<i>14656.2</i>		<i>8.6</i>

Table shows average annual bed days, beds on an average day, the proportion of bed days for people with learning disabilities and the average bed days per admission.



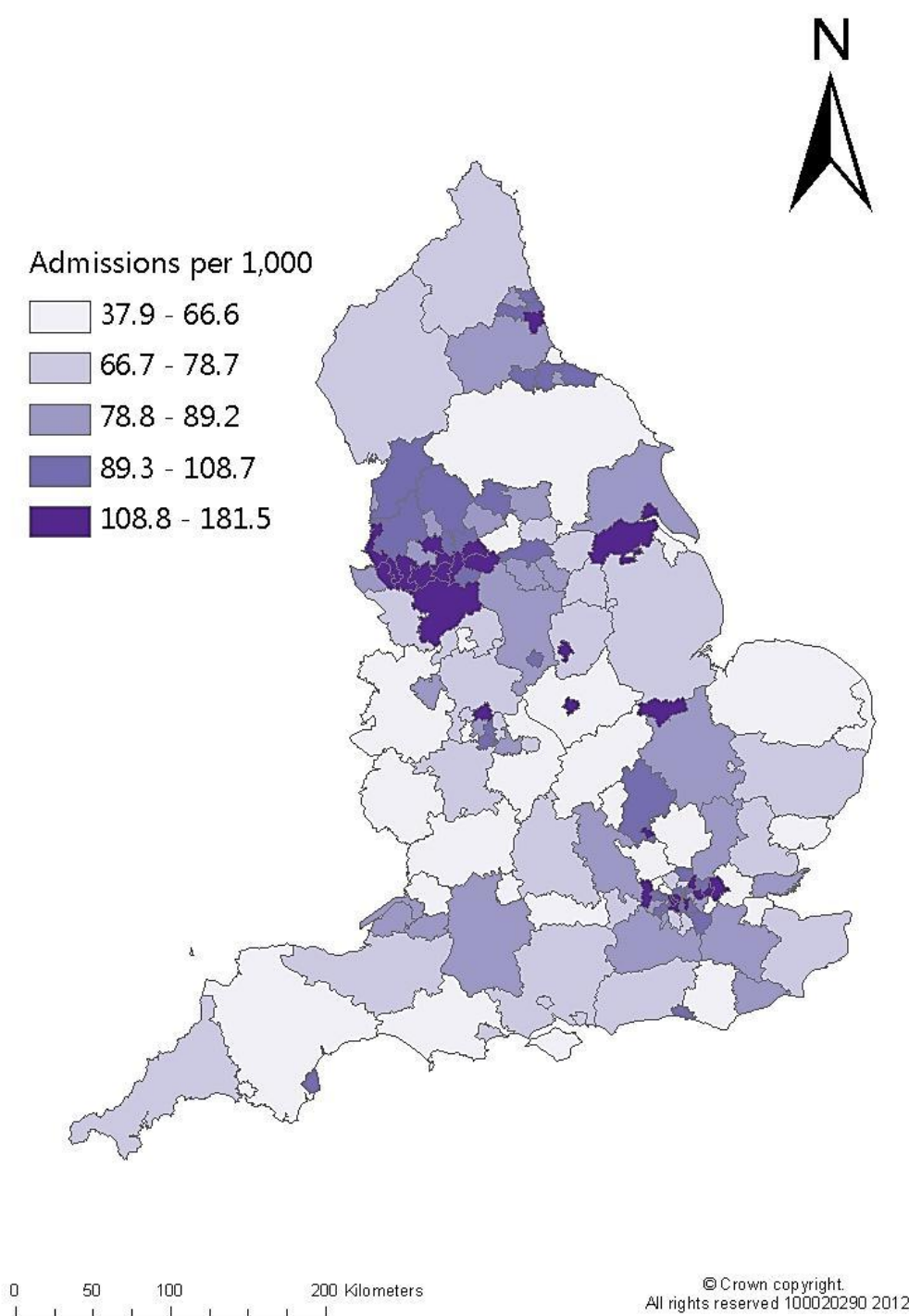
Variation around the country

We explored the variation in the frequency of these admissions around the country. Figure 4 shows a map of the rates per 1000 for people with learning disabilities known to General Practitioners. As above, this is unsatisfactory as the limited scope of our data did not allow us to make allowance for any differences there may be between areas in the age profile of people with learning disabilities.

Generally, urban areas had higher rates than rural ones. Leicestershire and Nottinghamshire, both predominantly rural counties in the centre of the map with distinct PCTs for their county towns, showed clear urban/rural differences. This may reflect greater accessibility of hospital facilities for people in the urban areas. An area comprising Greater Manchester and Merseyside, and extending into Central and Eastern Cheshire showed a notable cluster of areas with high rates.

The key problem in interpreting this map is that it is impossible to say whether the areas showing higher rates actually had higher admission rates. An alternative possibility is that they may simply have been better than other areas at recording co-morbid or complicating diagnoses. This would allow more complete identification of people with learning disabilities who were admitted to hospital. As the number in the population is from a separate source, this would give rates of admissions for both ACSC and other conditions which appeared higher but in reality were simply more accurate. In some cases this distinction could be apparent from local knowledge of hospital catchment areas. However we were not able to identify obvious examples.

Figure 4. Map showing PCT emergency admission rates for people in the learning disabilities group for all ambulatory care sensitive conditions





Discussion

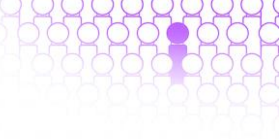
Reliability of the findings

There are two key problems with the data as we have used it; the problems with identifying people with learning disabilities and the lack of age/sex breakdowns for comparable population statistics, making normal epidemiological analyses impossible. We have drawn attention to the second problem repeatedly in the report and no further comment is needed here.

It is very unlikely that we have identified all individuals with learning disabilities being treated in hospitals. Our identification was dependent on key conditions being recorded as a comorbid diagnosis at some stage during people's admissions. To the extent identification was incomplete, our figures for people in our learning disabilities group will be under-estimates. We know from other work using this source that the completeness of recording of learning disabilities is highly variable. Individuals will commonly have learning disabilities diagnosis recorded for one admission but not another. This makes it likely that the chance of any individual with learning disabilities being identified will increase if they are admitted frequently, and be least if they are admitted only once. It is possible that the observation that individuals with learning disabilities have more frequent admissions arises in part from this bias. However it also seems possible that diagnostic recording may be better, and thus more complete, in the less pressured situation of non-emergency admissions. If this is the case, our figures may be under-estimating the scale of emergency admissions for ACSCs in people with learning disabilities.

It is also possible that our identification of individuals with learning disabilities may be selective. For example people with a relatively obvious cause, for example Down's syndrome, may be more likely to have had this recorded than people whose learning disabilities have no identifiable cause. If so, this could give a biased representation of the position for all people with learning disabilities. Again this would be likely to show a pattern of greater use of hospital care since many of the identifiable causes of learning disabilities are associated with other physical problems likely to lead to unusually frequent hospitalisation. However there is no reason why it should not lead to more emergency admissions for ACSCs as conceptually these are assumed to be largely avoidable.

Thus we cannot be sure that the individuals we have identified are representative of people with learning disabilities as a whole, though we think they are probably reasonably representative of people with severe or profound learning disabilities or those with evident syndromic causes such as Down syndrome. However, this does not make the findings worthless. We have identified a substantial group of largely inappropriate admissions occurring more than five times as commonly in our learning disabilities group as in other people. This indicates at least that the issue merits further scrutiny.



The substantive findings

We can confidently say that when people in our learning disabilities group were admitted to hospital, compared to other people, it was 25% more likely to be as an emergency, and 70% more likely to be as emergency and for an ACSC. This suggests that primary care for them was not as effective as it was for others.

Unlike people without learning disabilities, for this group, emergency admissions for ACSCs occurred across the adult age spectrum; they were not predominantly confined to older ages.

Whilst in most respects the profile of clinical conditions involved was similar at similar ages, one condition, convulsions and epilepsy, stood out as by far the most frequent cause for people in our learning disabilities group. This one cause accounted for more than 40% of all emergency admissions for ACSCs for people with learning disabilities – 6,000 admissions and 28,000 bed days per year. On an average day there will be 75 people with learning disabilities in hospital in England for this reason.

Other ACSCs which led to higher proportions of emergency admissions for people in our learning disabilities group at all ages were constipation, complications of diabetes and influenza/pneumonia.


Trend data were less easy to interpret; however, if anything, they suggest that the disparity between people with learning disabilities and others was growing not shrinking.

Emergency admissions for ACSCs were, on average, much longer than elective admissions for other causes. However, in this respect people in our learning disabilities group were no different from others.

Potential for future monitoring

A key conclusion must be that this area needs closer monitoring. We have not presented data comparing different areas in much detail because, as we have noted, given the weakness of the data source, we cannot tell whether the local variations that are apparent reflect differences in practice or record-keeping. However we can confidently say that we have identified differences which need explaining and which need to be monitored.

In any local area there is a straightforward approach to doing this. GPs and community learning disabilities teams should collaborate in developing a local register of people with learning disabilities, identifying their NHS numbers, age and gender. This should be done on the basis of requesting explicit consent from subjects and carers, and 'best interests' agreements where the individuals concerned are not able to understand. At a local level, this would permit proper epidemiological monitoring of condition-specific admission patterns.



This approach would also help ensure that hospitals and other secondary services become aware of people with learning disabilities in their care.

Nationally, this could be better done for statistical purposes in an anonymised way by the NHS Information Centre. Using their new constitution, from April 2013, they could use the mechanism of a General Practice Extraction System request to obtain NHS numbers for all patients that GPs have recorded as being on Quality and Outcome Framework Learning Disabilities registers. These could be used to add learning disabilities status marker to the anonymised sets of hospital use- and mortality data made available for analysis in the new national public health system, Public Health England. They could also be used to provide regular, and directly comparable, population data for adults with learning disabilities. This would transform our ability to see how good or bad hospital and other care is for this group of people.



Key messages

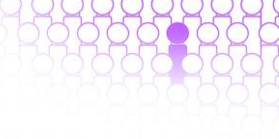
The point of ACSCs is that they are signals in one part of the system (hospital admissions) indicating potential weaknesses in others (primary care and long term condition managements). So who should do what about them? We believe there are four key messages which emerge from this report:

1. Nationally, ambulatory care sensitive condition admissions suggest weaknesses in primary care for people with learning disabilities. This means that locally PCTs and CCGs need to act to check whether and to what extent this is a problem in their area and to take necessary action to meet their statutory obligations to address it. At the very least, PCT Chief Executives/CCG leads and Directors of Public Health should correspond about the situation in their local area and this correspondence should be published, possibly as part of the Director of Public Health's Annual Report.
2. The most efficient way to produce usable statistics nationally, allowing national benchmarks to be produced would be for the NHS Information Centre to produce annotated hospital episode and mortality data sources for Public Health England.
3. In addition to monitoring, remedial action is needed. At the least, every in-patient unit caring for NHS patients should establish a routine Emergency ACSC notification to go with every discharge of a patient with learning disabilities admitted this way. This would advise the GP and the community learning disabilities team that a patient had been discharged with a condition suggestive of a requirement for review of their Health Action Plan.
4. In the specific situation of patients with learning disabilities and convulsions, emergency admissions should be seen as a danger warning signal. This event should trigger a review of the long term care of their epilepsy by a specialist neurologist.



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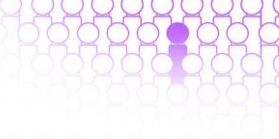
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List of abbreviations

PCT	Primary Care Trust
CCG	Clinical Commissioning Group
ACSC	Ambulatory Care Sensitive Condition
QOF	Quality and Outcomes Framework



Annex 1.

Table 1 Conditions, their ICD-10 codes, and any exceptions used as definition. Except for those identified as the Balogh group, these definitions are from the technical documentation provided by the NHS Institute for Innovation and Improvement.⁶³

Condition	ICD-10 Codes	Further notes
Influenza and Pneumonia	J10, J11, J13, J14, J153, J154, J157, J159, J168, J181 , J188	Exclude if D57 (sickle cell recorded)
Other Vaccine Preventable	A35, A36, A37, A80, B05, B06, B161, B169, B180, B181, B26, G000, M014	
Anaemia	D501, D508, D509	Primary diagnosis only
Angina	I20, I240, I248, I249	Primary diagnosis only and no surgical procedure carried out
Asthma	J45, J46	Primary diagnosis only
COPD	J41, J42, J43, J44 , J47	Primary diagnosis only, alternatively if J20 is primary diagnosis and any of codes listed are secondary
Congestive heart failure	I110, I50 , J81	Primary diagnosis only and none of procure codes K0, K1, K2, K3, K4, K50, K52, K55, K56, K57, K60, K61, K66, K67, K68, K69, K71
Diabetes complications	E100- E108, E110-E118, E120-E128, E130-E138, E140-E148	
Gastro-oesophageal reflux*	K21	Primary diagnosis only
Hypertension	I10 , I119	Primary diagnosis only and none of procedure codes: K0, K1, K2, K3, K4, K50, K52, K55- K57, K60, K61, K66-K69, K71
Nutritional deficiencies	E40, E41, E42, E43, E550 , E643	Primary diagnosis only
Osteoporosis*	M81	Primary diagnosis only
Cellulitis	L03, L04, L080, L088, L089, L88, L980	Primary diagnosis only and none of procedure codes: A, B, C, D, E, F, G, H, I, J, K, L, M, N, O, P, Q, R, S1, S2, S3, S41, S42, S43, S44, S45, S48, S49, T, V, W, X0, X1-X5

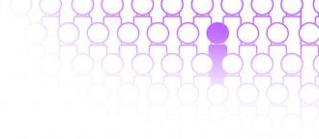


Table 1 cont. Conditions, their ICD-10 codes and any exceptions used as definition

Condition	ICD-10 Codes	Further notes
Constipation*	K590	Primary diagnosis only
Convulsions and epilepsy	G40, G41, R56 , O15	Primary diagnosis only
Dehydration and Gastroenteritis	E86, K522, K528, K529	Primary diagnosis only
Dental conditions	A690, K02, K03, K04, K05, K06, K08, K098, K099, K12 , K13	Primary diagnosis only
Ear, Nose and Throat infections	H66, H67, J02, J03, J06, J312	Primary diagnosis only
Gangrene	R02	
Pelvic inflammatory disease	N70, N73 or N74	Primary diagnosis only
Perforated/bleeding ulcer	K250- K252, K254-K256, K260-K262, K264-K266, K270-K272, K274-K276, K280-K282 , K284-K286	Primary diagnosis only
Pyelonephritis	N10, N11, N12, N136	Primary diagnosis only