

# Health and Care of People with Learning Disabilities

**2014-15**

Published 09 December 2016

Information on people with and without learning disabilities was collected from over half of GP practices in England, to identify potential differences in the treatment, health status, and outcomes of people with learning disabilities compared with the rest of the population. The purpose of this publication is to provide a comparable dataset to support and encourage further research into these areas and to facilitate discussions about these differences. This publication was produced in collaboration with Public Health England.

## Key findings

From the data collected, in 2014-15:



**51.2%**  
of registered patients in England were represented within this dataset



Obesity was **twice** as common in people aged 18-35 with learning disabilities

and being underweight was twice as common in patients over 64, compared with patients without learning disabilities



On average **18 year** lower life expectancy for females with learning disabilities

14 year lower life expectancy for males than the general population



**1 in 2** eligible females with learning disabilities received breast cancer screening

Over 2 in 3 eligible females without learning disabilities received breast cancer screening

Produced in collaboration with



Public Health England

Protecting and improving the nation's health

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## This is an Experimental Statistics publication



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NHS Digital and Public Health England have worked together to produce the Learning Disabilities Health and Care dataset, the richest resource of information on the health and care of patients with learning disabilities available to clinicians, carers, patients, researchers, commissioners, and the wider public.

## Overview

This is a preliminary report on a data collection designed to identify differences in the health and care of people with learning disabilities. It aims to present key findings at a national level and provide the technical context to enable researchers to undertake further work using the Clinical Commissioning Group (CCG) level data accompanying the publication.

The Learning Disability Health and Care (LDHC) National Programme is providing a wealth of detailed data which can be found on NHS Digital's website.<sup>1</sup> Further publications about how to use specific aspects of these data will be published by the Public Health England Learning Disabilities Observatory Team. This report is intended to provide an introduction to the work and the headline findings both about the national state of health and the extent of local variations. It includes information about the source of the data and aspects relating to its completeness.

The report presents headline findings at a national level only. Before using the accompanying CSV to undertake further analysis, it is very important that the Technical Notes are considered. Principal among these considerations is that the sample of GP practices in these data is not random.

Although this dataset represents a sample and not the entire population of registered patients in England, it closely mirrors its age and sex structure. Overall the population of patients represented in this dataset had a slightly younger profile than the England population, with 65.2 per cent falling into the age 0 to 49 bracket, compared to 64.7 per cent in the England population. There are 0.9 per cent more females than males in the England population, and this difference is slightly more marked in this dataset, with 1.1 per cent more females than males. The prevalence of learning disabilities was the same in both populations, at 0.4 per cent. These differences should be taken into account if scaling any calculations up to England population level.

## What is a Learning Disability?

This report describes the health of people who are recorded by their GP as having a learning disability. Learning disabilities are varied conditions, but are defined by three core criteria<sup>3</sup>:

- lower intellectual ability (usually defined as an Intelligence Quotient [IQ] of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood.

An IQ below 70 should not be used on its own to determine whether someone has a learning disability. The definition encompasses people with a broad range of disabilities. It includes adults with autism who also have learning disabilities, but not people with a higher-functioning autistic spectrum disorder who may be of average, or above average, intelligence. The definition does not include people who have a "learning difficulty", such as dyslexia or dyscalculia.

Learning disability was defined in the 2001 Government White Paper *Valuing People*<sup>4</sup> as the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- a reduced ability to cope independently (impaired social functioning)

- which started before adulthood (under the age of 18), with a lasting effect on development.

For many people, there is little difficulty in reaching a decision whether they have a learning disability or not. However, in those individuals where there is doubt about the diagnosis or the level of learning disability, referral to a multi-disciplinary specialist learning disability team (where available) may be necessary to assess the degree of disability and diagnose any underlying condition.

Since 2006-07, GPs in England have been asked to keep a register of people registered with them who have learning disabilities. The initial purpose of this register was to provide the basis for a list of individuals who should be targeted for an annual learning disability health check. However, the register has wider purposes for ensuring that appropriate consideration is given to key issues of communication, consent and the ability of the patient to follow recommended care plans by both primary care staff and secondary care services to which they may be referred.

Learning disability registers comprise the list of individuals registered with the GP practice for General Medical Services, who have a recorded diagnosis on their medical record. A few additional individuals have records in their GP case notes indicating that the GP considers it likely that they have learning disabilities or that they have a condition commonly associated with learning disabilities. These may take the form of formal disease codes or they may be text records or scanned letters from consultants. We were unable to collect data on any individual where their diagnosis was not coded in the medical record.

## Technical Notes

The following are important technical notes to consider when interpreting this report and the accompanying data:

- The GP practices that provided these data were not randomly distributed across the country, which has resulted in varying coverage across different geographical areas. This is expected to have little impact at national level but should be considered when making any comparisons at sub-national level.
- The definition of a learning disability encompasses people with a broad range of disabilities, and can be difficult to diagnose. Learning disability diagnoses may not be formally recorded on General Practice IT systems.
- Many charts in this report are given with 95 per cent confidence intervals. These indicate the range within which one would expect the true value to lie 95 per cent of the time. If two confidence intervals within a given statistic do not overlap, the difference between the two values is considered statistically significant. If the confidence intervals overlap, the significance of the difference between the values is not determined.
- Data recorded on General Practice IT systems may be an imperfect record of what the GP or other practice staff knew or thought, particularly where there is no contractual obligation to record information in a specified way and no particular benefit to the patient in recording information in a way that lends itself to subsequent statistical analysis.
- These data cannot account for cases where a GP deemed an action not to be in a patient's interests, where a patient refused treatment, or where activity was carried out outside the GP practice but recorded in the GP clinical system.
- These data do not demonstrate causality. The full context informing both clinical practice and data reporting behaviour must be considered prior to interpretation. For example: where patients with learning disabilities were not recorded as receiving the same treatment as patients without learning disabilities. This could be because they were more appropriately treated by a specialist outside the GP practice.
- The data reflect a snapshot, as at 31 March 2015, but were collected at various times throughout 2016. In the intervening time some GP practices closed or merged with other practices, and many patients will have changed their GP practice registration because they moved practice or changed GP. Therefore, these data collected present patient characteristics as being accurate at 31 March 2015 but *may* not attribute these patients to the CCG they were registered with at this time, which makes it difficult to directly compare with other CCG-level datasets.
- Mortality rates for people with learning disabilities may be understated in this report as the numbers of deaths do not include people whose learning disability was diagnosed during the year, people who were not registered with a GP practice as at 1 April 2014, and, in some cases, people who were registered with a different GP practice at the start of the year to the practice they were registered with when they died.

## 1. Coverage

Coverage is the proportion of the whole population included in this dataset. Overall, the number included comprises 51.2 per cent of patients registered with a GP in England (as at 1 April 2015).

There are two major gaps in the data. GP system suppliers play an important role, translating the specifications into code for their systems and managing the submission of queries to GP practice systems and collecting responses. The first notable gap in this extract is that data were not gathered from all GP practices. Not all practices using EMIS, INPS and Microtest have had their data collected and no practices using TPP have had their data collected, as demonstrated in Table 1:

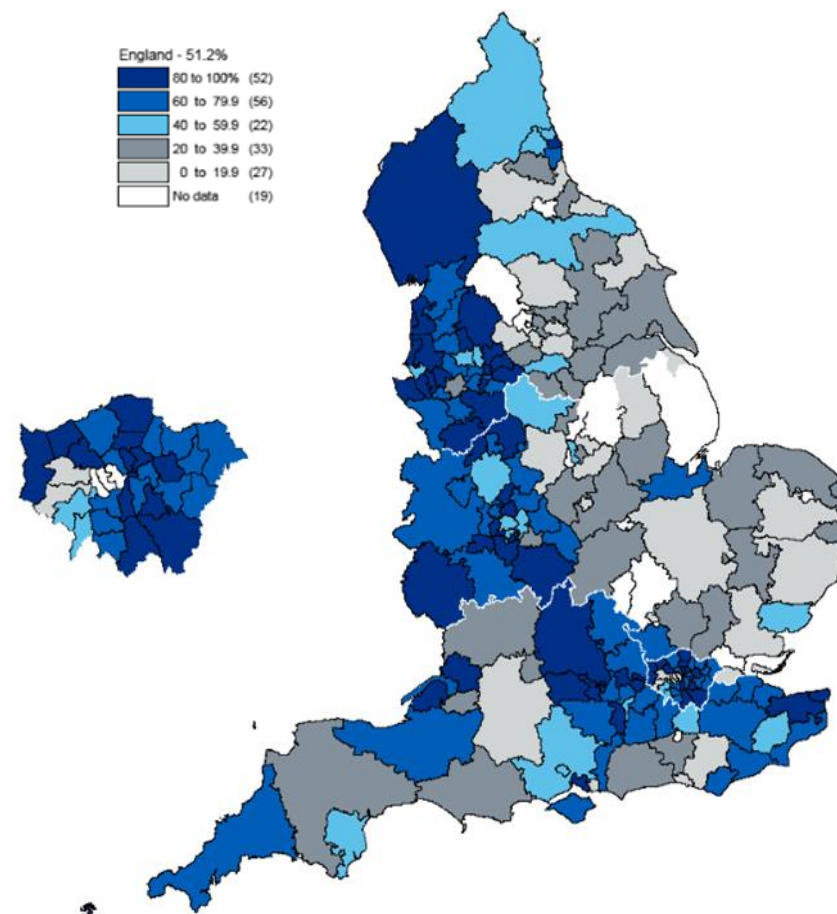
**Table 1. Practice coverage by system supplier, England, 2014-15**

	<u>Open Practices</u>	<u>Data Received</u>	<u>Coverage (%)</u>
EMIS	4,268	3,438	80.6
INPS	632	438	69.3
Microtest	91	61	67.0
TPP	2,618	0	0.0
Other	280	0	0.0
Total	7,889	3,937	49.9

The second gap arose because practices had to agree to participate in the data collection. Of the cohort of available practices (excluding TPP) 89.3 per cent of practices did so, 3.0 per cent declined, and 7.7 per cent did not respond.

As shown in Figure 1, coverage varied by CCG. 19 CCGs had no data included in the dataset. Of those CCGs with data, coverage varied from 1.3 per cent of registered patients (NHS Leicester City CCG) to 97.6 per cent of registered patients (NHS West Lancashire CCG). These deficiencies in coverage are unlikely to distort the findings of national analyses, yet it is important to consider them when analysing local variations. On average CCG areas have just under 40 GP practices, but they vary in size. In small CCGs where the coverage rate is also small, the GP practices collected may not be representative of the wider CCG. Coverage figures for all CCGs are shown here: [PowerBI Interactive Tool](#)

**Figure 1. Patient coverage by CCG, England, 2014-15**





## 2. Demography

### 2.1 Prevalence of Learning Disabilities

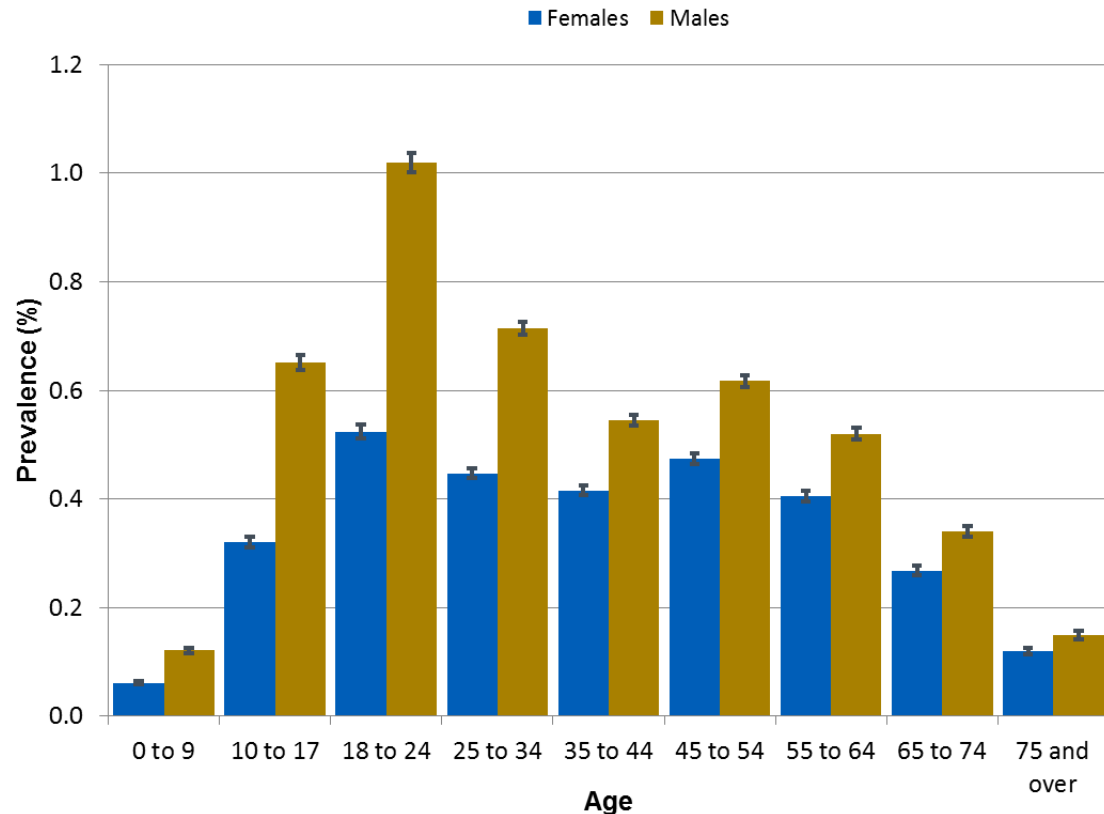
Knowing how many people there are with learning disabilities in the population, their age and sex profile and ideally more detail about their learning disability profile, is fundamental to planning and providing care services. This dataset provides national and local information about the demographic profile from the data that was collected. The age and sex profile of all people in England is very similar to the data within this sample dataset. Figure 2 shows the percentage of people with learning disabilities in each age group.

Overall, 0.44 per cent of the population were recorded as having a learning disability. This is the same as in the national Quality and Outcomes Framework (QOF) for the corresponding year.

Prevalence varied with sex and age. Diagnoses of learning disabilities were more commonly recorded in males (1 in 189 people, or 0.59 per cent) than females (1 in 286 people or 0.35 per cent). Males aged 18 to 24 had the highest recorded prevalence (1 in 98 people, or 1.0 per cent). Prevalence fell sharply over the age of 60 as a result of relatively early deaths.

Prevalence was very low in the youngest age group. This is assumed to be an underestimate as a learning disability is often not identified in many children until after they start school and may not be recorded by the GP until substantially later than this.

Figure 2. Learning disabilities prevalence (per cent) by age and sex, England, 2014-15



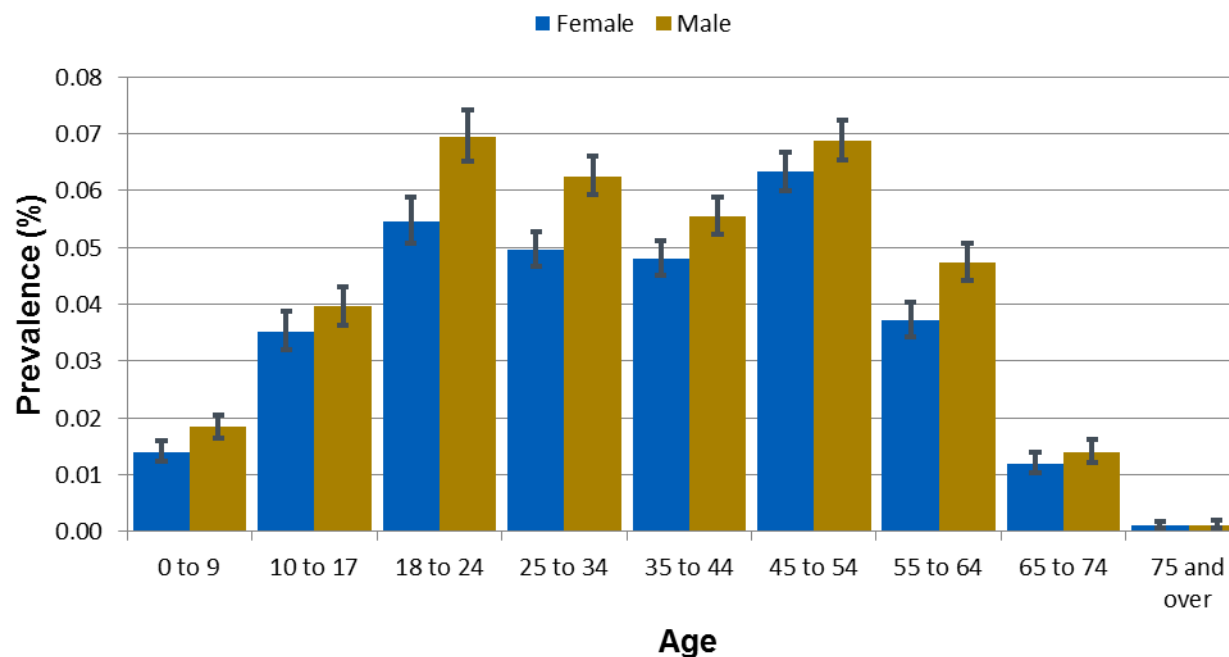
Prevalence of learning disabilities also varies between areas, with numbers at different CCGs ranging from half to double what would be expected if national age and sex prevalence rates applied (see standardised prevalence ratio of learning disabilities here: [PowerBI Interactive Tool](#)). The age profile of people with learning disabilities also varied.

## 2.2 Prevalence of Down syndrome

Down syndrome is a clearly recognisable and common cause of learning disability that results from having an extra copy chromosome 21. It occurs more commonly in children born to older mothers.<sup>5</sup>

In addition to learning disability, the syndrome includes a range of physical abnormalities including congenital heart disease, visual and auditory problems, and abnormalities of facial structures. People with Down syndrome have high rates of a number of types of illness but key issues in their care are their increased likelihood of developing thyroid deficiency and the high likelihood of developing Alzheimer-type dementia after the age of 40 years.

**Figure 3. Down syndrome and learning disabilities prevalence (per cent) by age and sex, England, 2014-15**



The overall prevalence rate of Down syndrome in England was 0.04 per cent. The rate rose steadily from 0.02 per cent in 0 to 9 year olds to 0.06 per cent in 18 to 24 year olds, peaking at 0.07 per cent in 45 to 54 year olds. Down syndrome was much less common in older ages with prevalence rates of less than 0.01 per cent and was more prevalent in males than females across all age groups. The frequency of Down syndrome in the adult population is changing as a result of two influences. Treatment of associated congenital heart defects at birth has substantially increased the proportion of people with Down syndrome who survive childhood. Ante-natal screening with termination of affected pregnancies has reduced the rate of children born with the condition. It is possible that a tendency of parents to have children at later ages may also have increased the number of babies conceived with Down syndrome. Identifying the numbers in this group is important as a result of their very specific care needs.

## 2.3 Mortality

Many research studies from the UK and other countries have reported high death rates among people with learning disabilities. The Confidential inquiry into premature deaths in people with learning disabilities<sup>6</sup> (CIPOLD) reviewed the events leading up to the deaths of 247 people with learning disabilities and concluded that “42% of deaths were considered to be premature”. Local monitoring of death rates for people with learning disabilities is difficult because the overall numbers of people, and therefore the numbers of deaths, are comparatively small. Research studies using local case registers have typically used data from a decade or more to allow statistically meaningful analysis. These data are the most detailed yet seen.

**Figure 4: Annual mortality rate (per cent) by age and sex for a) patients with a learning disability and b) England population, England, 2014-15**

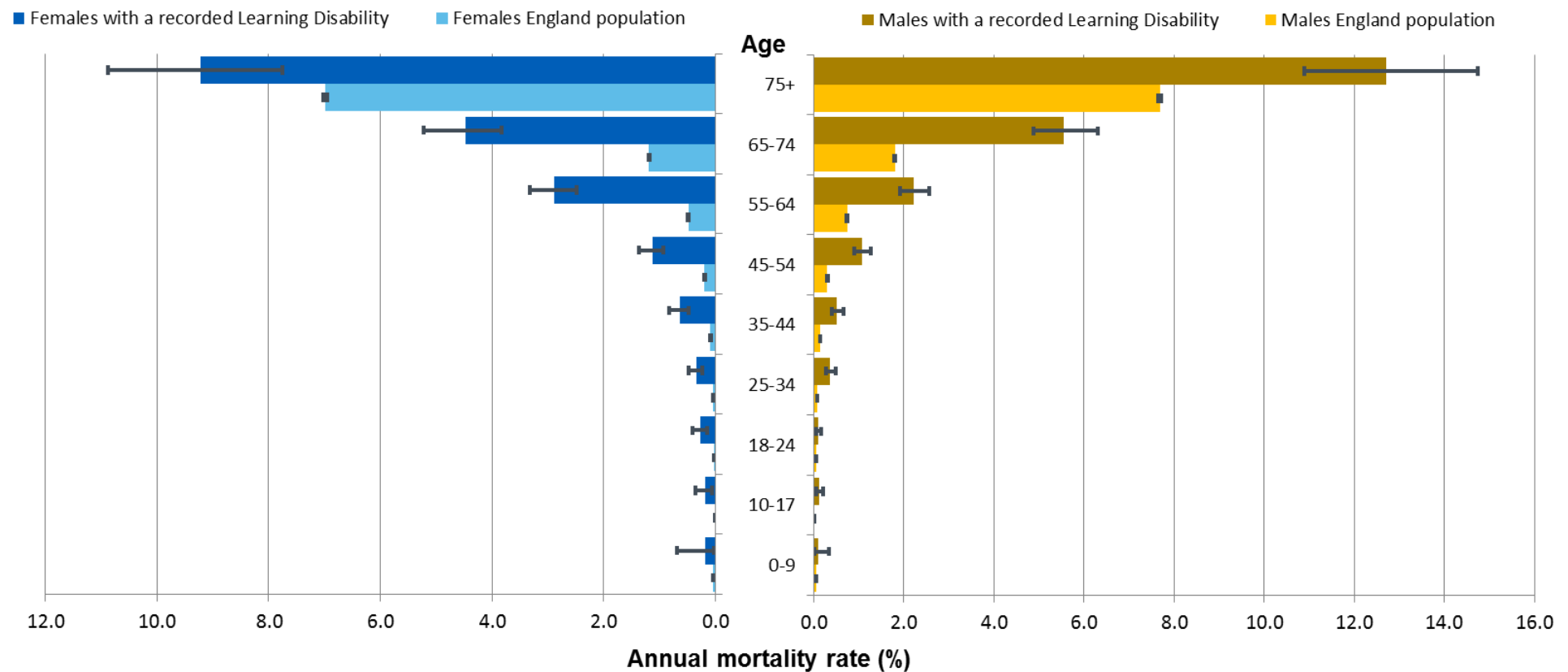


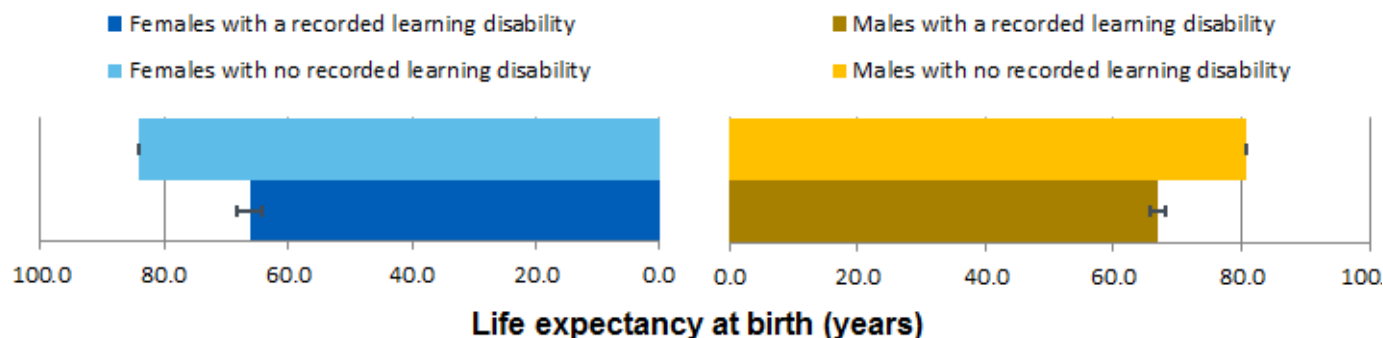
Figure 4 above shows the death rates for people with learning disabilities by age and sex group, comparing these with the general population death rates. Death rates were significantly higher for people with learning disabilities for both sexes, in every age group. The difference was proportionally greater in younger age groups, although not in the youngest. In England, the mortality rate for patients with a learning disability was 1.3 per cent.

An overall comparison of the death rate between people with learning disabilities and the general population requires adjustment for the different age and sex profile in the population. The Standardised Mortality Ratio (SMR) is the number of deaths in a group of people as a proportion of the number expected if they had the same age and sex specific death rates as the general population. The SMR for people with learning disabilities was 298.1 per cent (almost three times the expected number of deaths occurred). The SMR for people with learning disabilities was higher for females (333.0 per cent) than for males (274.8 per cent).

The SMR varied around the country. Regional figures were: London 2.7 (95 per cent confidence interval 2.3 to 3.0), South 2.7 (2.4 to 3.0), Midlands and East 3.1 (2.8 to 3.4), North 3.3 (3.1 to 3.6). Because the total number of deaths was relatively small, the confidence intervals are relatively wide; however the figures for the North and for the South and London do not overlap showing there are statistically significant differences. Similar differences are also seen in the SMR of the general population.

**Figure 5: Life expectancy at birth (years) by sex for a) patients with a learning disability and b) England population, England, 2014-15**

On average, females with learning disabilities have an 18 year lower life expectancy than the general population, and males have a 14 year lower life expectancy than the general population:



As the actual number of deaths of people with learning disabilities occurring in any year is low, the conclusions that can be drawn about individual CCGs on the basis of a year's data, which in many cases is substantially incomplete, are limited. These data could inform the choice for an initial measurement within the NHS Outcomes Framework 1.7: reducing premature mortality in people with learning disabilities.<sup>7</sup>

### 3. Health promotion

#### 3.1 Health checks

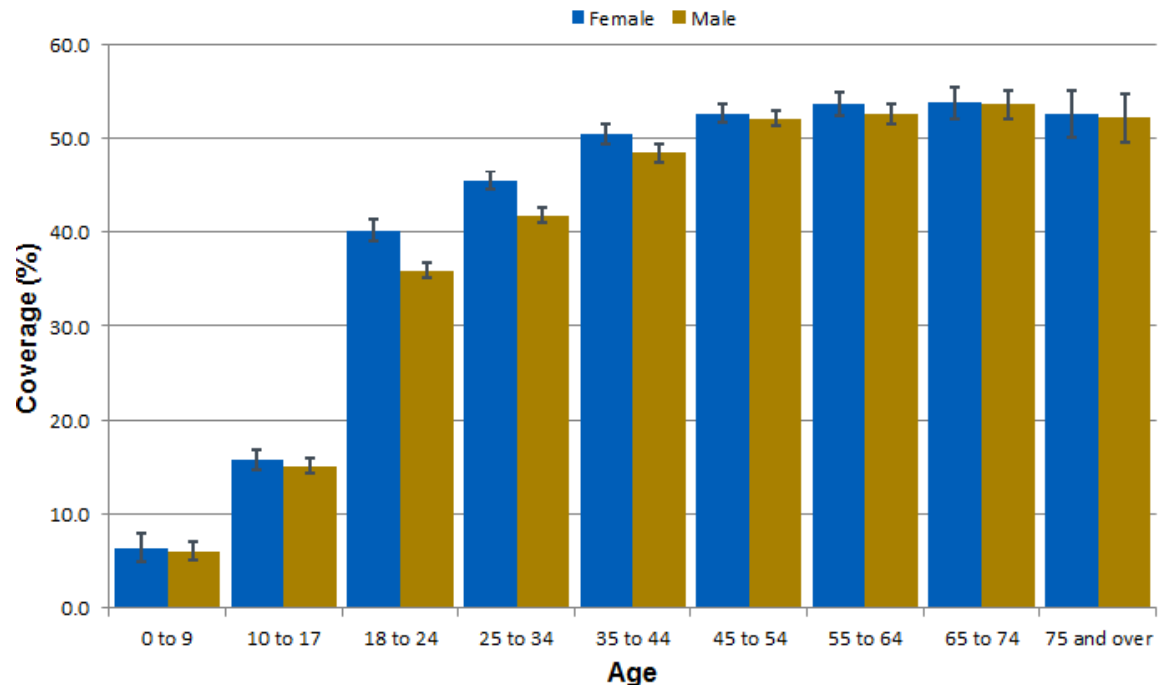
Annual learning disability health checks were introduced in 2008-09. They are a key recommended 'reasonable adjustment' in providing primary care for this group who may not be aware that their GP could help with emerging physical problems. They have been shown to identify many previously unsuspected, common, distressing and potentially treatable conditions.

These data give a clear picture of the extent to which people known to their GP to have a learning disability are getting annual health checks. Overall, 43.2 per cent of people known to their GP to have a learning disability had an annual health check between 1 April 2014 and 31 March 2015. Coverage was better in older age groups, reaching 50.0 per cent or higher in people aged 45 years or older. It was poorer in younger adults with less than 40.0 per cent of those under 25 years having a health check.

Coverage of the annual learning disability health check varied around the country: in comparison to the England average, 38.9 per cent of CCGs had a crude rate significantly lower and 34.2 per cent of CCGs had a crude rate significantly higher.

In some areas where coverage of the learning disability health check programme is low, this reflects GP practices decision not to offer this service to their patients.

**Figure 6. Proportion of patients with a learning disability who received a learning disability health check in the year (per cent) by age and sex, England, 2014-15**

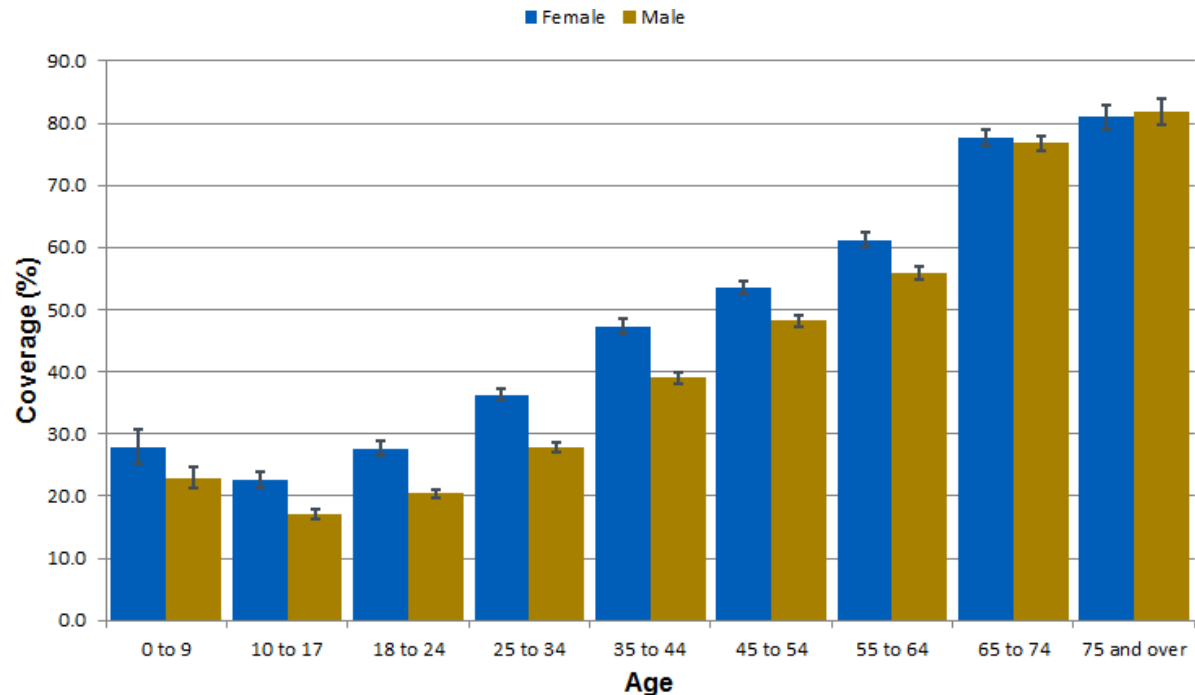


### 3.2 Influenza Immunisations

CIPOLD identified respiratory infections as a major cause of premature death in people with learning disabilities. Influenza pneumonia is also a major cause of potentially avoidable hospital admission for this group. CIPOLD recommended that the annual influenza immunisation programme was to be extended to cover all adults with a learning disability. This was implemented from the 2014-15 flu season. These figures show the coverage achieved in the first year of this expanded programme.

Overall, 40.8 per cent of people recognized by their GP as having a learning disability received a flu immunisation. Coverage increased steadily with age. In the youngest adult age group coverage was a little over 20.0 per cent. At ages 75 years or over, it reached 80.0 per cent.

**Figure 7. Proportion of patients with a learning disability who received a seasonal influenza immunisation (per cent) by age and sex, England, 2014-15**



In this first year of influenza immunisation for all people with learning disabilities there was confusion in GP practices about their eligibility for immunisation. Where patients are frightened of needles, the new nasal spray vaccine may provide a more acceptable alternative for them.

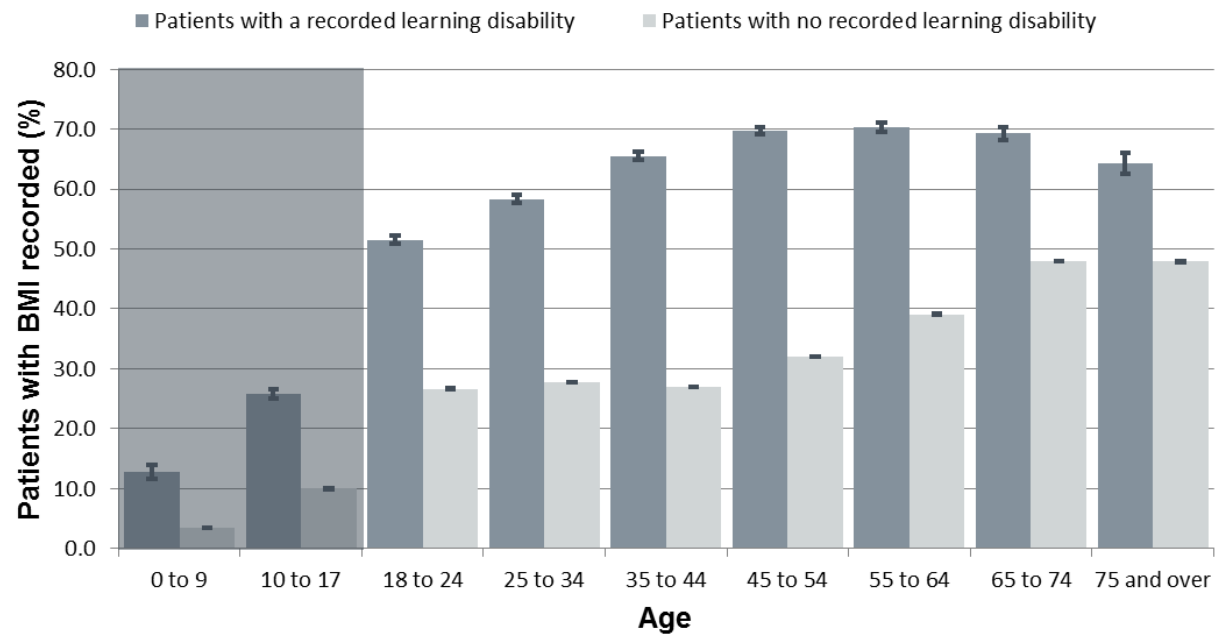
At England level, 40.8 per cent of patients with a learning disability received an immunisation against seasonal influenza in the period 1 September 2014 to 31 March 2015. Overall 46.4 per cent of females and 37.1 per cent of males, with a learning disability received an immunisation against seasonal influenza. Figure 7 demonstrates that seasonal influenza immunisations also varied by age. 24.2 per cent of CCGs had a crude rate for influenza immunisation significantly lower than the England figure; 26.3 per cent had a rate significantly higher.

### 3.3 Body Mass Index (BMI)

Obesity is a major public health problem in England. Obesity is associated with heart problems, maturity onset diabetes, mobility problems and many types of cancer. People with learning disabilities are more likely to be obese than the general population, as shown in these data. Possible reasons for obesity include lack of access to or information about healthy eating, lack of opportunities to take exercise and, in some cases, side effects of antipsychotic medication.

People with learning disabilities are also more likely than others to be underweight, as shown in these data. This can reflect under-nutrition, as a result of feeding problems, and can also be associated with difficulty in swallowing and / or needing help feeding. It is seen particularly in people with cerebral palsy and / or scoliosis. Under-nutrition is associated with diminished resistance to infections. To make sense of weight profiles, it is important to look at the proportion of people who have any weight measurement. This can give some indication of whether people have been weighed as a matter of routine or because there were specific concerns. The actual measurement collected was patient's Body Mass Index (BMI). This is the ratio of a patient's weight to the square of their height.

**Figure 8. Proportion of patients with a BMI recorded in the 15 months to 31 March 2015 (per cent) by age and learning disability status, England, 2014-15**



Due to the low proportion of patients aged less than 18 years who had a recorded BMI (as shown by the first two shaded age groups in Figure 8), these ages will be **excluded** from further analysis.

BMI categorisations are shown in Table 2.

In England, 58.1 per cent of patients with learning disabilities had a BMI assessment in the 15 months prior to 31 March 2015. In patients without a recorded learning disability, 28.3 per cent had a BMI assessment in the same period.

26.8 per cent of CCGs had a crude rate for patients with learning disabilities having had a BMI measurement significantly lower than the England figure; 30.0 per cent had a rate significantly higher.

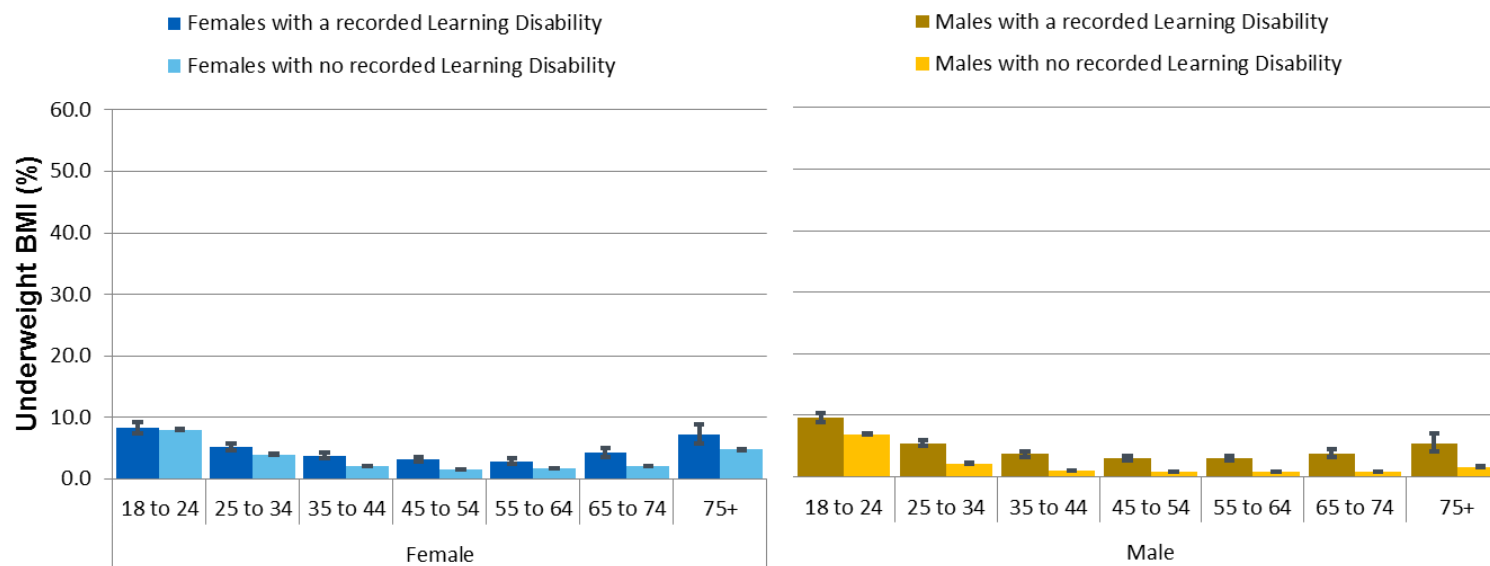
The following comparisons between patients with learning disabilities and patients without learning disabilities should be treated with caution. Patients with learning disabilities are more likely to undergo a BMI assessment as a matter of routine. A higher proportion of the measurements collected from patients without learning disabilities may have been taken as the result of a specific concern over their weight. The sample of patients without learning disabilities may therefore be biased towards patients with BMI measurements falling at the higher and lower ends of the spectrum. Comparable data taken from the Health Survey For England<sup>8</sup> support this. Resultantly, where the following charts indicate that patients with learning disabilities more often have a BMI of underweight or obese than patients without learning disabilities (as shown in Table 2 below), this is likely an underestimate of the true difference.

**Table 2. Proportion of patients aged 18+ in each BMI classification recorded in the 15 months to 31 March 2015 (per cent) by learning disability status, England, 2014-15**

BMI Chart		Patients aged 18+	
		Learning Disability	No Learning Disability
BMI less than 18.50	Underweight	4.6%	2.5%
BMI 18.50 - 24.99	Healthy weight	28.2%	33.6%
BMI 25.00 - 29.99	Overweight	28.5%	33.6%
BMI 30 or more	Obese	38.4%	30.1%



**Figure 9. Proportion of patients with an underweight BMI recorded in the 15 months to 31 March 2015 (per cent) by age, sex and learning disability status, England, 2014-15**

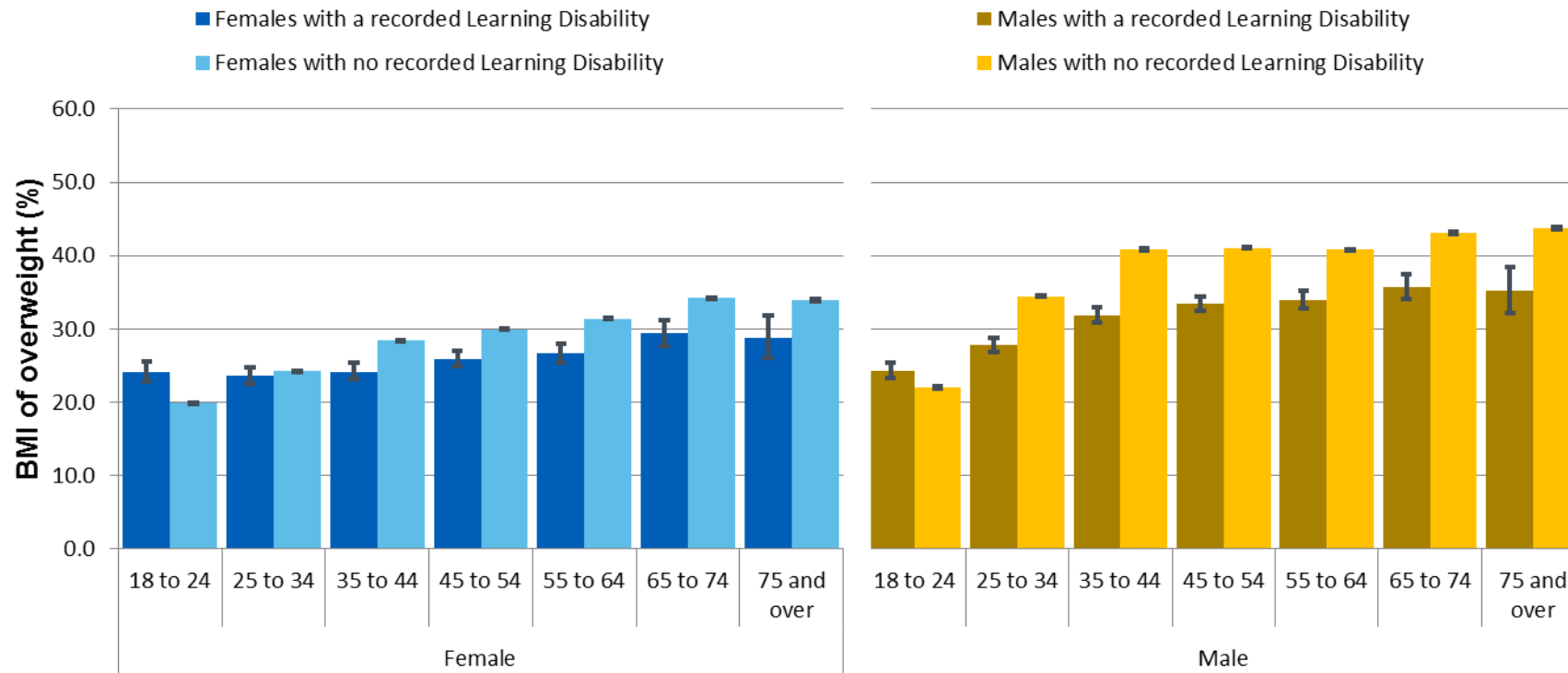


9.6 per cent of males aged 18 to 24 with learning disabilities were underweight compared to 6.9 per cent of males without learning disabilities. A BMI of underweight was least prevalent in males aged 45 to 54 and 55 to 64 with 3.0 per cent of people with learning disabilities and 0.8 per cent of those without learning disabilities in both age groups. The greatest difference in the proportion of those with an underweight BMI between males with and without learning disabilities was in those aged 75 and over with 5.4 per cent and 1.6 per cent of patients respectively.

In females, an underweight BMI was most prevalent in people aged 18 to 24 in both patients with and without learning disabilities with 8.3 per cent and 8.0 per cent respectively. Similarly to males, an underweight BMI was least common for females with learning disabilities aged 55 to 64 (2.9 per cent) and for females without learning disabilities between ages 45 and 54 (1.5 per cent). This varied relatively little around the country; 3.7 per cent of CCGs had a standardised prevalence ratio for adults for being underweight significantly lower than the England figure, 2.6 per cent had a ratio significantly higher.

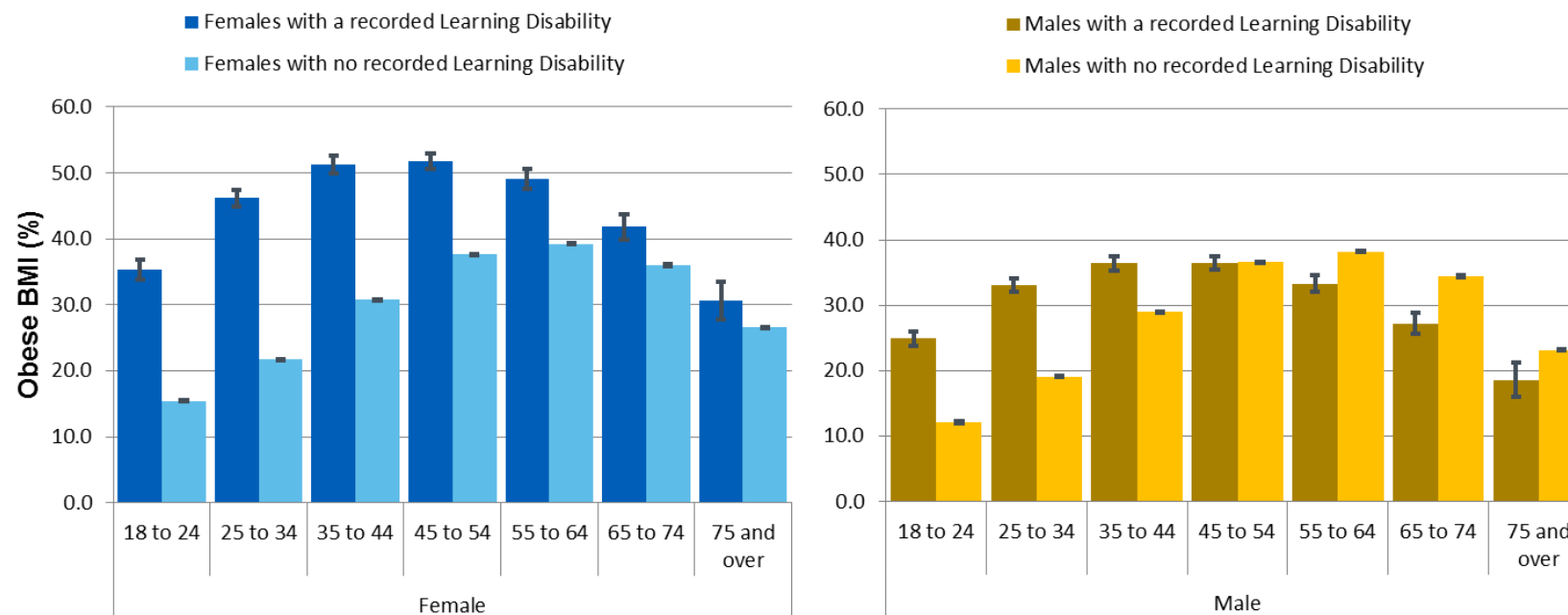
People with learning disabilities who are underweight need to have the reasons for this reviewed. Where this relates to feeding management, a range of remedial steps are available. The Learning Disabilities Observatory Team at Public Health England recently published a guide<sup>9</sup> to practical issues in weight management programmes for people with learning disabilities.

**Figure 10. Proportion of patients with an overweight BMI recorded in the 15 months to 31 March 2015 (per cent) by age, sex and learning disability status, England, 2014-15**



With the exception of people aged 18 to 24, an overweight BMI was less common in patients with a learning disability than those without. For patients with a learning disability an overweight BMI was most prevalent in people aged 65 to 74, with 29.3 per cent of females and 35.7 per cent of males. In patients without a recorded learning disability an overweight BMI was most common in females aged 65 to 74 with 34.2 per cent and males aged 75 and over with 43.7 per cent.

**Figure 11. Proportion of patients with an obese BMI recorded in the 15 months to 31 March 2015 (per cent) by age, sex and learning disability status, England, 2014-15**



35.4 per cent of females aged 18 to 24 with learning disabilities had a BMI of obese compared to 15.4 per cent of females without a learning disability. The proportion of females recorded as obese rose steadily, peaking in those with learning disabilities in ages 45 to 54 with 51.7 per cent and those without learning disabilities aged 55 to 64 with 39.2 per cent. Obesity was more prevalent in females with a learning disability than females without a learning disability in all age groups.

In males aged 18 to 44, obesity was more prevalent in those with a learning disability than people without; however from ages 45 and over this is reversed with obesity more common in males without a learning disability. Obesity was least prevalent in males without a learning disability in ages 18 to 24 with 12.1 per cent then rose steadily with age, peaking at 38.2 per cent in ages 55 to 64. In males aged 18 to 24 with a learning disability, 24.9 per cent were recorded as obese, gradually rising until ages 45 to 54 with 36.4 per cent before dropping to 18.5 per cent in ages 75 and over.

The spread in the rates of obesity in people with learning disabilities was smaller. 5.3 per cent of CCGs had a standardised prevalence ratio for adults for being obese significantly lower than the England figure; 2.6 per cent had a ratio significantly higher. 1.6 per cent of CCGs had a standardised prevalence ratio for adults for being overweight significantly lower than the England figure, 2.6 per cent had a ratio significantly higher.

## 4. Palliative Care

Palliative care is care provided to assist with pain and other types of distress from conditions that cannot be cured and usually where the person is likely to die within a few weeks or months. It is most commonly provided for people with terminal cancer but may be provided for other terminal conditions associated with pain or other types of physical distress. It is commonly provided by specialist organisations in dedicated hospices, general hospital and community settings but the overall numbers identified from national surveys<sup>10</sup> indicate that a larger number of people receive palliative care from primary care teams.

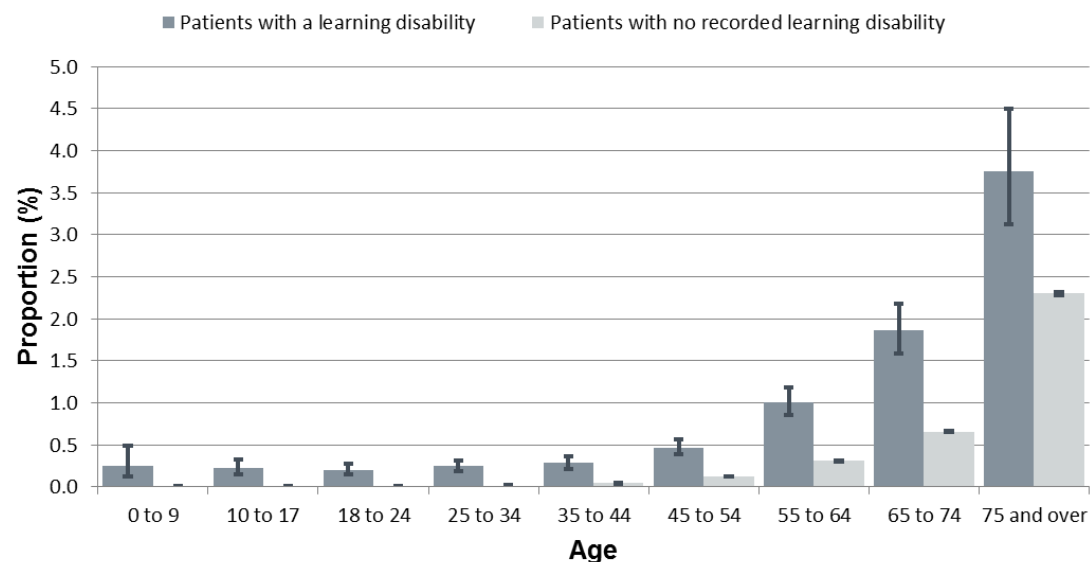
Palliative care in people with learning disabilities raises a number of specific issues, mostly related to the extent to which they understand what is happening to them and their capacity to communicate regarding their symptoms and the relief they are getting.

From the whole dataset, 702 individuals with learning disabilities were identified as currently receiving palliative care. They received palliative care at a younger age than people without learning disabilities (Figure 12). Numbers in local areas are too small to comment in detail, but clearly vary widely. In almost 30 per cent of CCGs no-one with learning disabilities was recorded as receiving palliative care.

In England, 0.6 per cent of patients with learning disabilities were registered as being in need of palliative care and support. This figure is 0.3 per cent in patients without learning disabilities.

CCGs could consider whether the specialist services providing palliative care in their area include staff familiar with the specific issues involved with people with learning disabilities.

**Figure 12. Proportion of patients registered as being in need of palliative care (per cent) by age and learning disability status, England, 2014-15**



## 5. Cancer

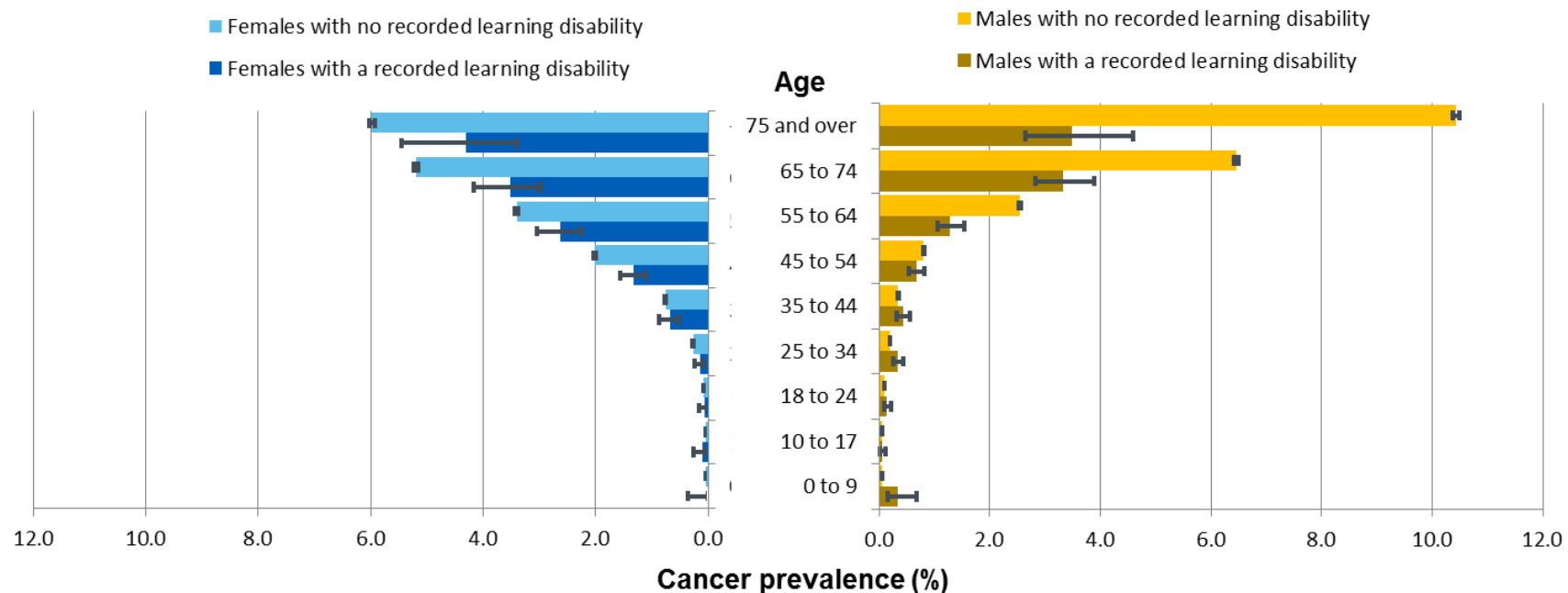
Which groups of people in the population are more or less affected by different types of cancer can be influenced by their levels of exposure to the different causal agents and by personal characteristics and lifestyle factors that speed or slow their progression. Some cancers can also be associated with specific genetic or chromosomal factors.

Obesity, alcohol consumption, lack of exercise, exposure to tobacco smoke, and infection with some sexually transmissible organisms are associated with common types of cancer. Most cancers are more common in older people; breast cancer is more common in females who do not have children. All these risk factors are differently distributed in people with learning disabilities. The chance of survival with cancer is helped by early diagnosis and prompt treatment. This is more likely in people who are well informed and alert to early warning signs and able to negotiate the health care system to initiate early investigation. People with learning disabilities may have more difficulty in these areas.

The data in this section gives a very broad measure of the number of people with and without learning disabilities who were recorded as having cancer. Its interpretation is complex as high figures may show many new cases or long survival of those diagnosed.

### 5.1 Cancer Prevalence

**Figure 13. Cancer prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



Overall rates of cancer are very low in children and young adults up to the age of 24 years and rise sharply with age after age 45 years.

The rate is significantly higher for people with learning disabilities aged under 35 years, probably reflecting cancers with special risk factors (for example: lymphoma in people with Down syndrome or brain or kidney cancers in people with tuberous sclerosis). Lower rates of smoking and alcohol consumption could possibly influence this, but later diagnosis with reduced survival after diagnosis may be important. Standardised prevalence ratios do not vary greatly between CCGs.

## 5.2 Cancer Screening

The three national cancer screening programmes raise different issues for people with Learning Disabilities:

- The colorectal cancer screening service sends kits for individuals to produce specimens of their faeces for testing for blood. Whether people with learning disabilities manage to obtain and send back usable specimens is likely to depend on whether a family carer or paid care staff are available to help.
- Cervical cancer screening is difficult for people whose capacity to understand and consent to the examination is limited. It is usually done by the patients' own GP.
- Breast cancer screening is likely to require specialist services to be provided in local areas, to anticipate and plan for the potential concerns of females with learning disabilities. This needs liaison with GP practices to identify who may require these specialist services.

The latest evidence<sup>22</sup> for England suggests that death rates from cervical or breast cancer in females with learning disabilities are not unusually high or low. However, death rates from colorectal cancer in people with learning disabilities are significantly higher than for others.

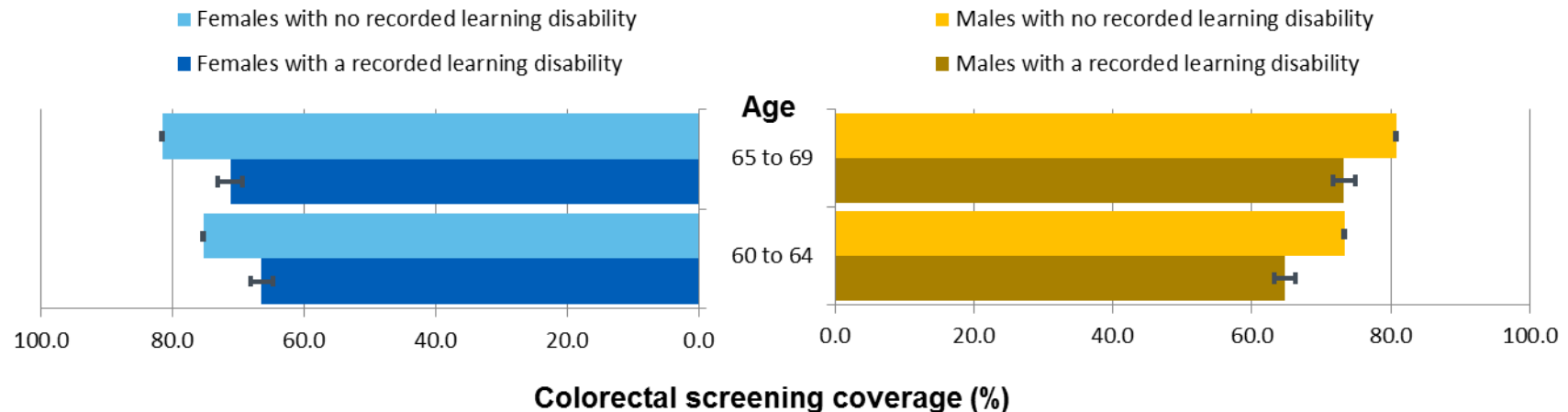
The measure shown in the cancer screening charts is the 'coverage'. This is the proportion of eligible people whose GP's notes record a satisfactory screening test sufficiently recently for them to be up-to-date with the programme. Findings are set out below for each of these three screening programmes. For cervical and breast cancer screening, coverage figures can be compared to national coverage figures published by NHS Digital.<sup>23, 24</sup> Overall screening coverage rates for cervical and breast cancer screening are similar to nationally reported programme monitoring figures. In all cases coverage was lower for people with learning disabilities.

Programme monitoring statistics published by NHS Digital<sup>23, 24</sup> show the national coverage of cervical cancer screening to have been 73.5 per cent in 2014-15 and coverage for breast cancer screening 75.4 per cent.

There is variation between CCGs for the different types of screening:

- 19.5 per cent of CCGs had a rate for colorectal cancer screening in eligible people significantly lower than the England figure and 22.6 per cent of CCGs had a rate significantly higher
- 10.5 per cent of CCGs had a rate for cervical cancer screening in eligible females significantly lower than the England figure and 12.6 per cent of CCGs had a rate significantly higher
- 14.7 per cent of CCGs had a rate for breast cancer screening in eligible females significantly lower than the England figure and 10.5 per cent of CCGs had a rate significantly higher.

**Figure 14. Proportion of patients receiving a colorectal screening (per cent) by age, sex and Learning Disability status, England, 2014-15**



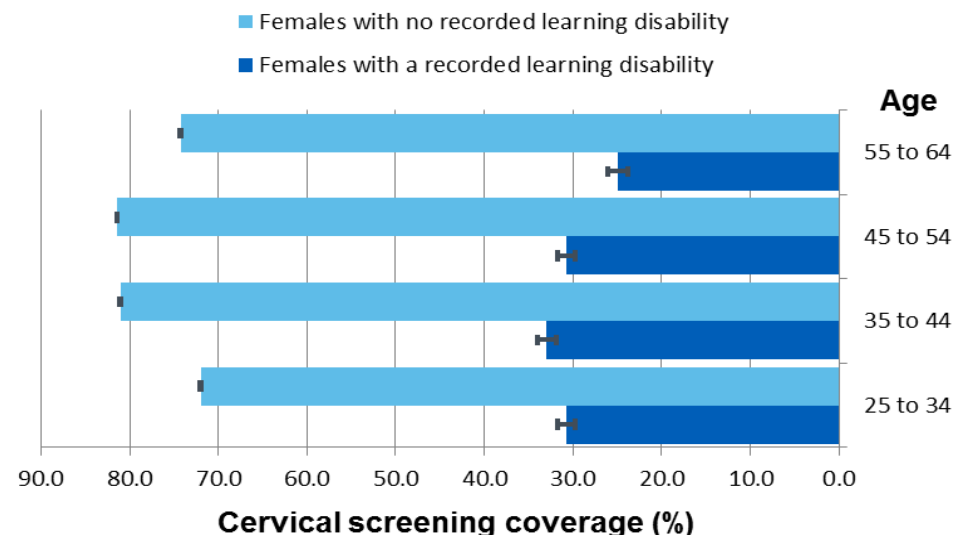
Colorectal screening is offered only when people reach the age of 60. At this stage a substantial proportion of people with learning disabilities will be being supported by paid care staff in residential care or supported living settings. Colorectal screening will unusually depend on this group providing assistance.

There are no official national statistics for colorectal cancer screening. These data showed an overall coverage for people without learning disabilities of 77.8 per cent. Coverage was slightly lower in males than in females and in the younger half of the eligible decade of life than the older. For people with learning disabilities, overall coverage was 68.6 per cent, with younger eligible people covered slightly less completely than older.

**Figure 15. Proportion of patients receiving a cervical cancer screening (per cent) by age and learning disability status, England, 2014-15**

Cervical screening coverage for females with learning disabilities was much lower than the non-learning disability population, with 30.2 per cent of eligible females being screened. As for females without learning disabilities, coverage fell a little in the oldest eligible age group (55 to 64 years). At this age 24.9 per cent of eligible females with learning disabilities had been screened in the previous five years, as compared to 74.2 per cent of eligible patients without learning disabilities.

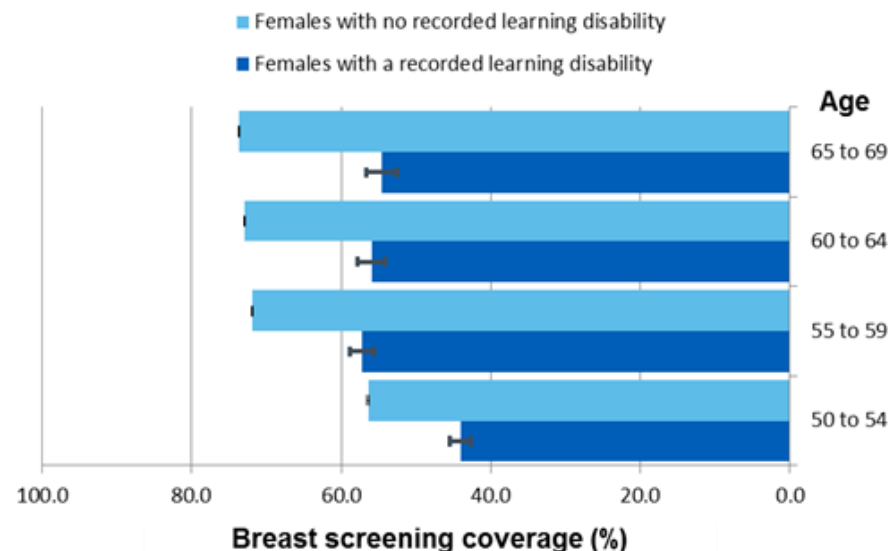
Statistics published by NHS Digital<sup>23</sup> show that screening coverage across all females aged 25 to 64 years, under the NHS Cervical Screening Programme, was 73.5 per cent as at 31 March 2015.



**Figure 16. Proportion of patients receiving a breast cancer screening (per cent) by age and Learning Disability status, England, 2014-15**

NHS Digital statistics<sup>24</sup> show the national coverage of breast cancer screening to have been 75.4 per cent for females aged 53 to 70 years. The coverage statistics within these data would be expected to give a slightly lower estimate of coverage as females aged 50 to 52 years were also included in the denominator and it is during this three year period that females are called for their first screening examination.

Overall coverage for females without learning disabilities was 67.9 per cent. It was lower at 56.4 per cent in the 50 to 54 year age band and rose from 71.9 per cent to 73.7 per cent in the three older five year age bands. Coverage for females with learning disabilities was consistently lower: 44.0 per cent at age 50 to 54, rising to 57.2 percent at 55 to 59 before dropping to 54.5 per cent at 65 to 69.

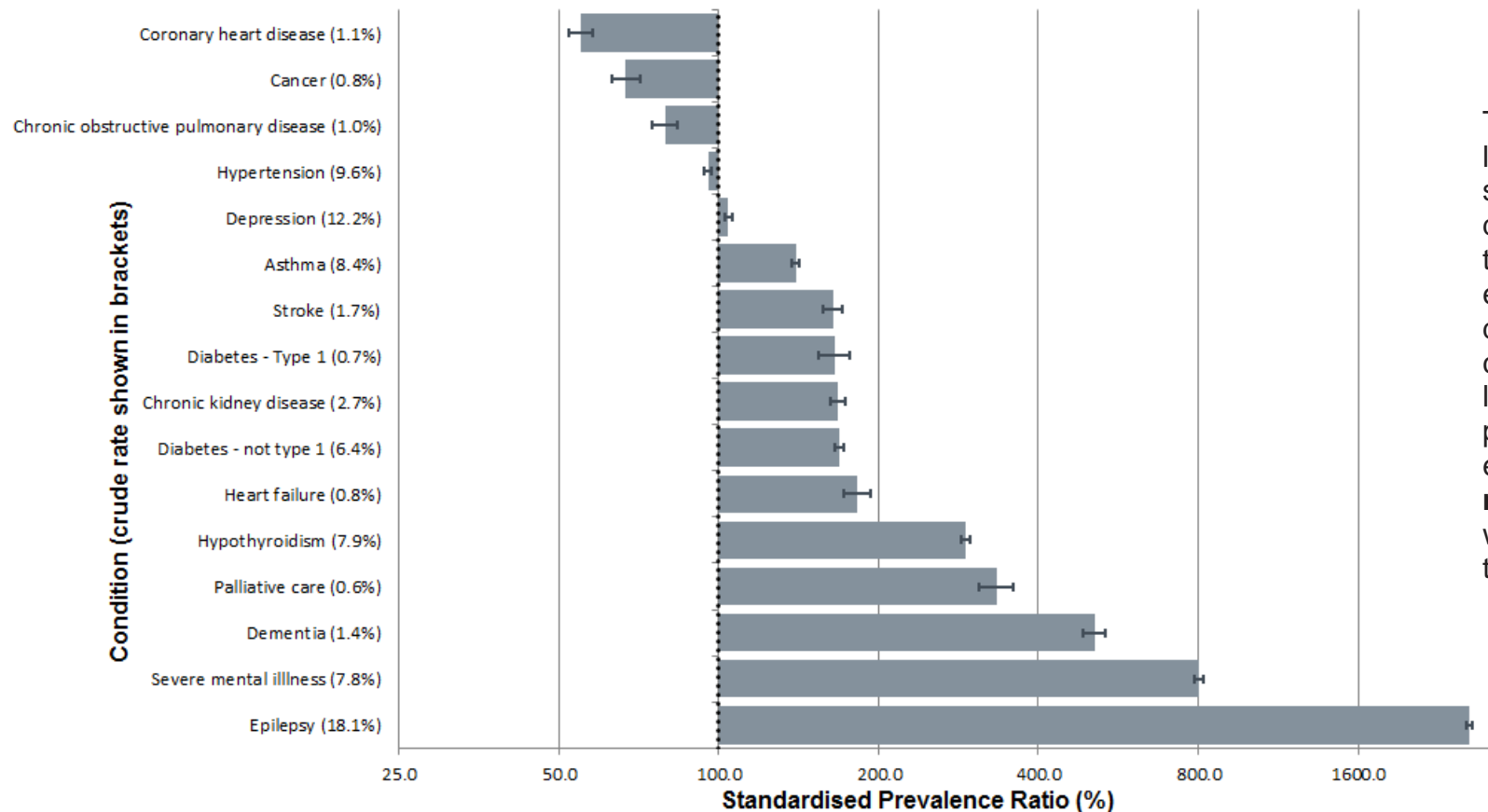




## 6. Disease Prevalence

The numbers on this page are standardised prevalence ratios. Most of the conditions described occur more frequently in older people and, as people with learning disabilities die younger, a smaller proportion of people with learning disabilities are in the older age groups. To make a valid comparison, the number of cases in people with learning disabilities is shown as a proportion of the number expected if the general population age and sex specific rates had been applied to them. A figure of 100 per cent (shown by the dotted black line) means the number seen is exactly the number expected from the general population. Numbers below 100 per cent mean that, allowing for the age and sex profile of people with learning disabilities, the condition is less common; numbers above 100 per cent mean it is more common. A figure of 200 per cent would mean the condition occurred twice as much as expected.

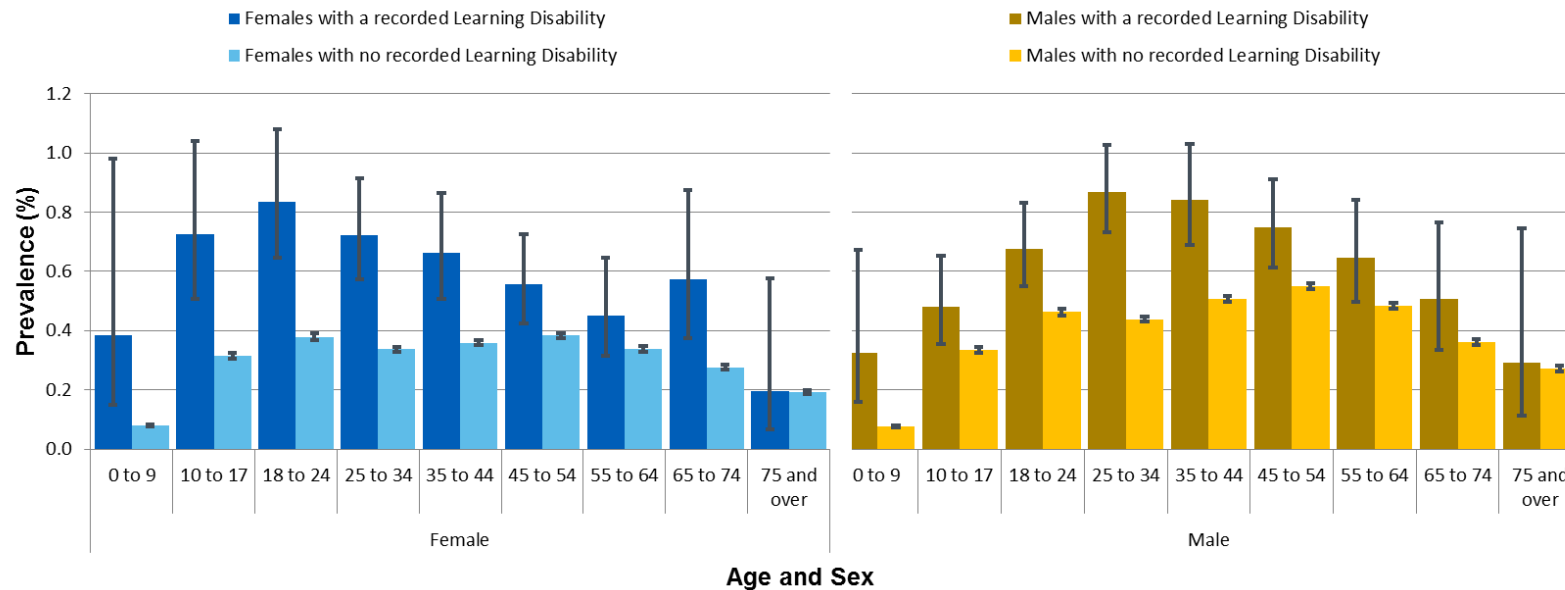
**Figure 17. Standardised prevalence ratio for patients with learning disabilities (per cent) by disease, England, 2014-15**



This chart shows data on a logarithmic scale in order to show increases and decreases in occurrence on the same scale. For example, coronary heart disease is almost half as common in people with learning disabilities than people without, and epilepsy is over 25 times **more** common in people with learning disabilities than people without.

## 6.1 Diabetes

Figure 18. Type 1 diabetes prevalence (per cent) by age, sex and learning disability status, England, 2014-15

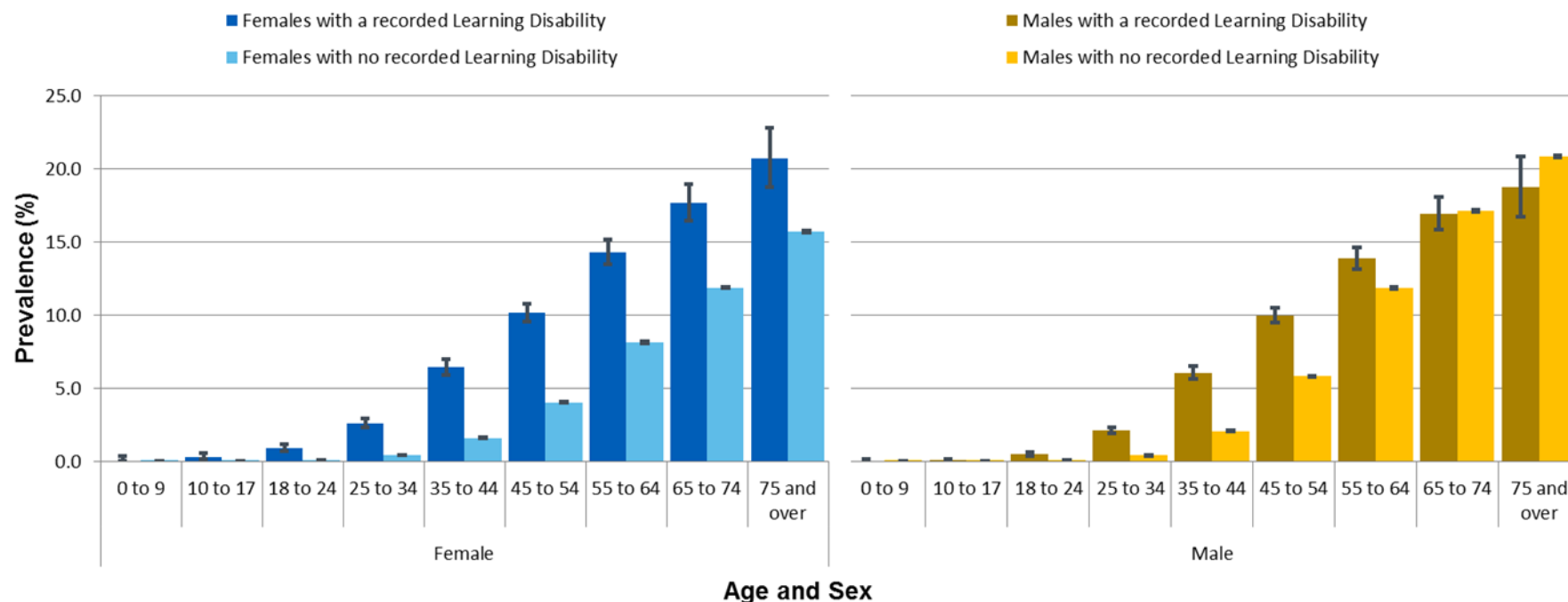


Both type 1 (insulin-dependent) diabetes and non-type 1 diabetes (much of which is caused by obesity) have important consequences for health. In both conditions blood sugar needs to be monitored and managed to minimise damage to blood vessels potentially causing heart attacks, strokes, peripheral vascular disease (with the risk of loss of limbs) and blindness from retinal damage. This is true for anyone with diabetes. Those who also have learning disabilities are likely to have more difficulty in managing diabetes.

Type 1 diabetes is known to be more common in people with Down syndrome. Non-type 1 diabetes is associated with obesity, which is more common in people with learning disabilities. It can also occur as a side effect of antipsychotic drugs which are widely prescribed people with learning disabilities. Type 1 diabetes is recorded in 0.67 per cent of people with learning disabilities and 0.35 per cent of people without. Allowing for age and sex profile differences there were 65.2 per cent more people with diabetes among those with learning disabilities than expected if the general population age and sex specific rates had applied. Although recorded rates varied substantially between CCGs, because the overall numbers were small, confidence intervals were wide and only two had rates that differed significantly from the national figure.

No CCGs had a standardised prevalence ratio for type 1 diabetes significantly lower than the England figure; 2.1 per cent had a ratio significantly higher.

**Figure 19. Non-type 1 diabetes prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



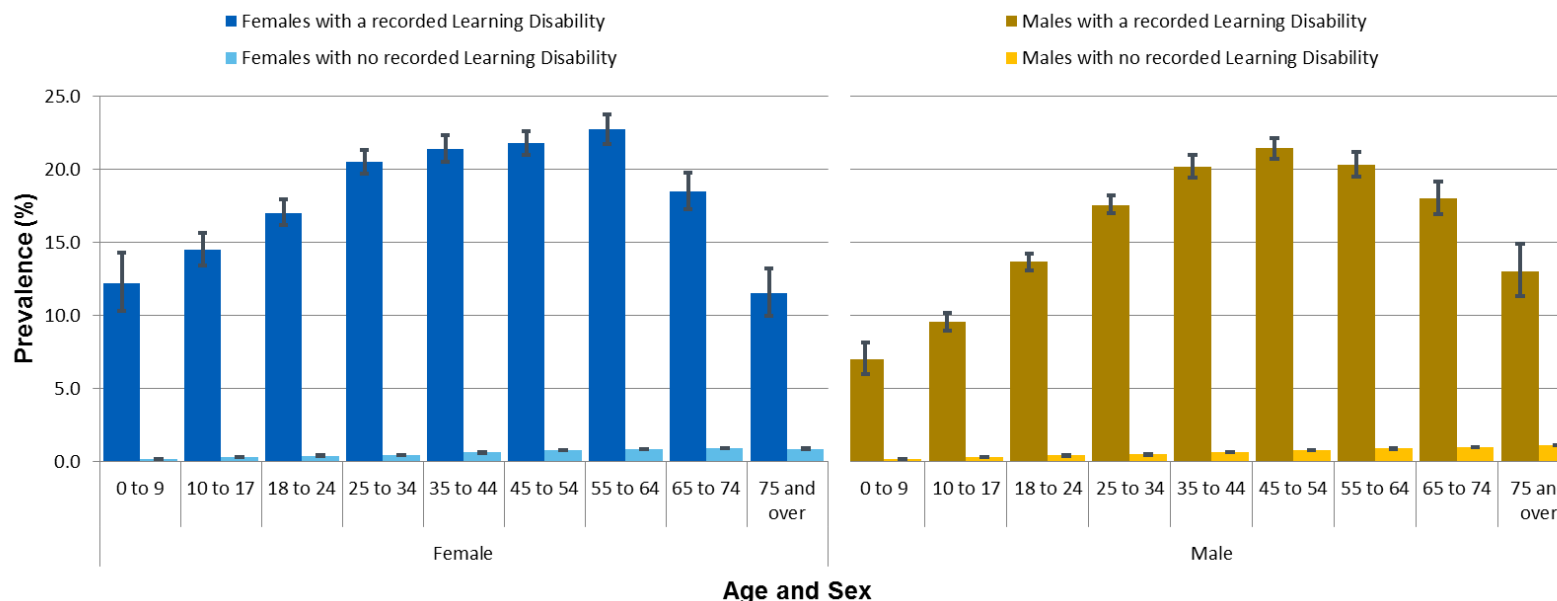
Non-type 1 was recorded in 6.5 per cent of people with learning disabilities and 4.8 per cent in those without. The difference in rates was greater in younger people of both sexes. Rates rose sharply in older males without learning disabilities, overtaking those for males with learning disabilities at ages over 65. Rates varied substantially around the country: 8.9 per cent of CCGs had a standardised prevalence ratio for non-type 1 diabetes significantly lower than the England figure and 10.5 per cent of CCGs had a ratio significantly higher.

The diabetes management data looks at the proportion of people with diagnosed diabetes who have had a blood test (HbA1c) measuring long term sugar control within the last 12 months. Despite the difficulty in doing blood tests with some people with learning disabilities, this aspect of diabetes management was satisfactorily completed in almost exactly the same proportion of diabetics with learning disabilities as diabetics without (91.7 per cent to 91.8 per cent, respectively). This comparison is not adjusted for age as this should not affect completeness of care processes.

## 6.2 Epilepsy

Epilepsy is well known to be common in people with learning disabilities, usually as an additional complication of the condition causing the learning disability. It can be more difficult to control than in people without learning disabilities. These data provide an extended picture of both the prevalence and the management of epilepsy in this group.

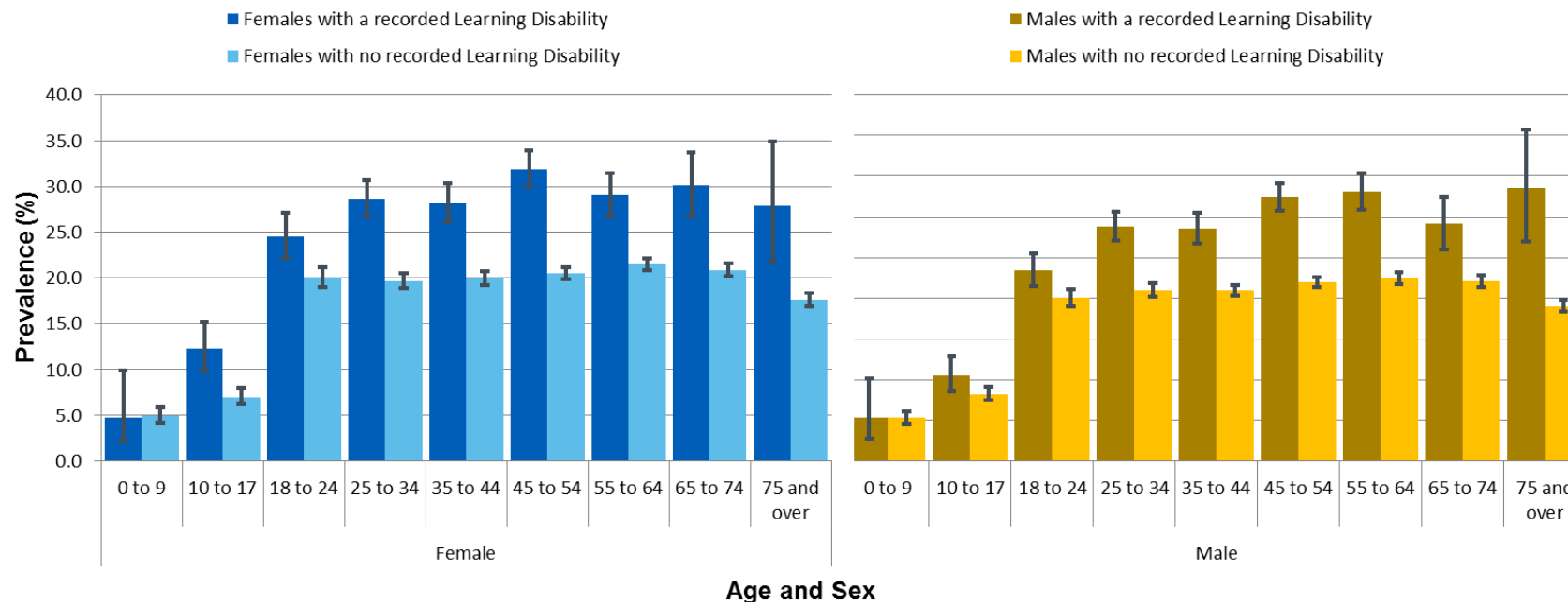
**Figure 20. Epilepsy prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



As expected, rates of epilepsy were significantly higher in people with learning disabilities. 18.1 per cent of people with learning disabilities were recorded as having epilepsy. The corresponding figure for people without learning disabilities was 0.60 per cent. For people without learning disabilities the rate rose with age almost in a straight line and, until the oldest age group, where the rate for females did not rise, there was no difference between the sexes. By contrast, in people with learning disabilities the rate rose with age until age 54 years and then fell for males; falling after age 64 years for females. Rates were substantially higher for females until age 35 years. Adjusting for the different age and sex profile, the number of people with learning disabilities diagnosed as having epilepsy was 25.9 times the figure expected if general population age and sex specific rates had applied.

Rates varied around the country to a moderate degree: 9.5 per cent of CCGs had a standardised prevalence ratio for epilepsy significantly lower than the England figure and 7.9 per cent of CCGs had a ratio significantly higher.

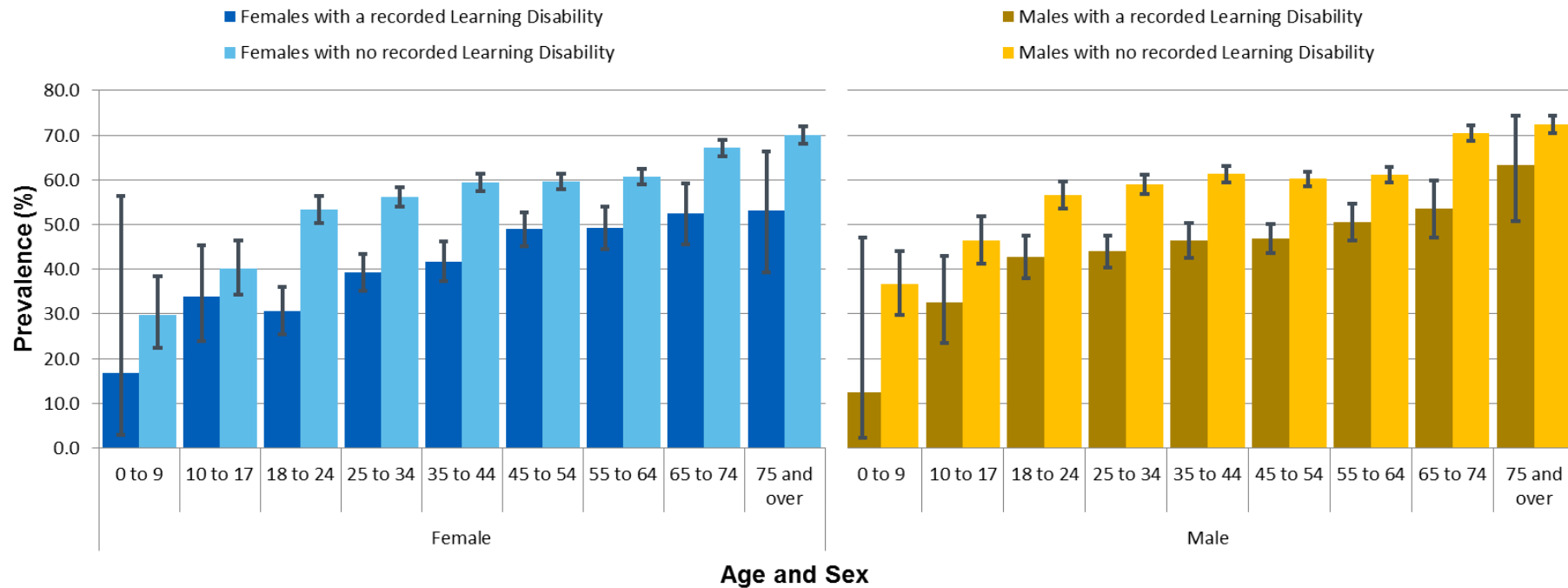
**Figure 21. Proportion of patients with epilepsy keeping a record of seizures by age, sex and learning disability status, England, 2014-15**



Of those patients identified as having a diagnosis of epilepsy, a certain proportion also had a record of the frequency of their seizures. This proportion, as shown in Figure in 21, was 27.9 per cent of those who had a learning disability and 19.6 per cent of those who did not. In both groups, rates were much lower for children and young people aged under 18 with epilepsy but reasonably consistent across adult age groups. There was large variation between areas. 25.3 per cent of CCGs had a significantly lower proportion of patients with a record of seizures than the overall England figure; 20.5 per cent were significantly higher. This may reflect primarily differences in local arrangement for epilepsy management.

The low proportion with a record of seizure frequency needs interpretation. This could possibly reflect the number for whom the GP was the person managing the epilepsy; Where this was being managed by a paediatrician, neurologist, or psychiatrist of learning disabilities, the seizure diary would likely have been discussed with them. These data suggest that a higher proportion of epilepsy sufferers with learning disabilities had their seizures managed by their GP. The low and different proportion of people for whom a seizure diary is recorded complicates interpretation of the pattern of recorded seizure free years.

**Figure 22. Proportion of patients with epilepsy keeping a record of seizures who have been seizure free for 12 months (per cent) by age, sex and learning disability status, England, 2014-15**



Of those patients above, identified as having epilepsy and a record of seizure frequency, a proportion were recorded as being seizure free for 12 months or more. This proportion was 45.3 per cent for people with a learning disability and 61.8 per cent for those without learning disabilities. Seizure control was worse in childhood for people without learning disabilities; it appeared to be much worse for children with learning disabilities but this is tentative as the confidence intervals are wide. In adult age groups seizure control rates were worse at all ages for people with Learning Disabilities. The gap closed somewhat in older age groups up to age 65 years, but then widened again. Rates of seizure free years varied relatively little around the country: 4.2 per cent of CCGs had a standardised prevalence ratio for epilepsy outcomes significantly lower than the England figure; 0.5 per cent of CCGs had a ratio significantly higher.

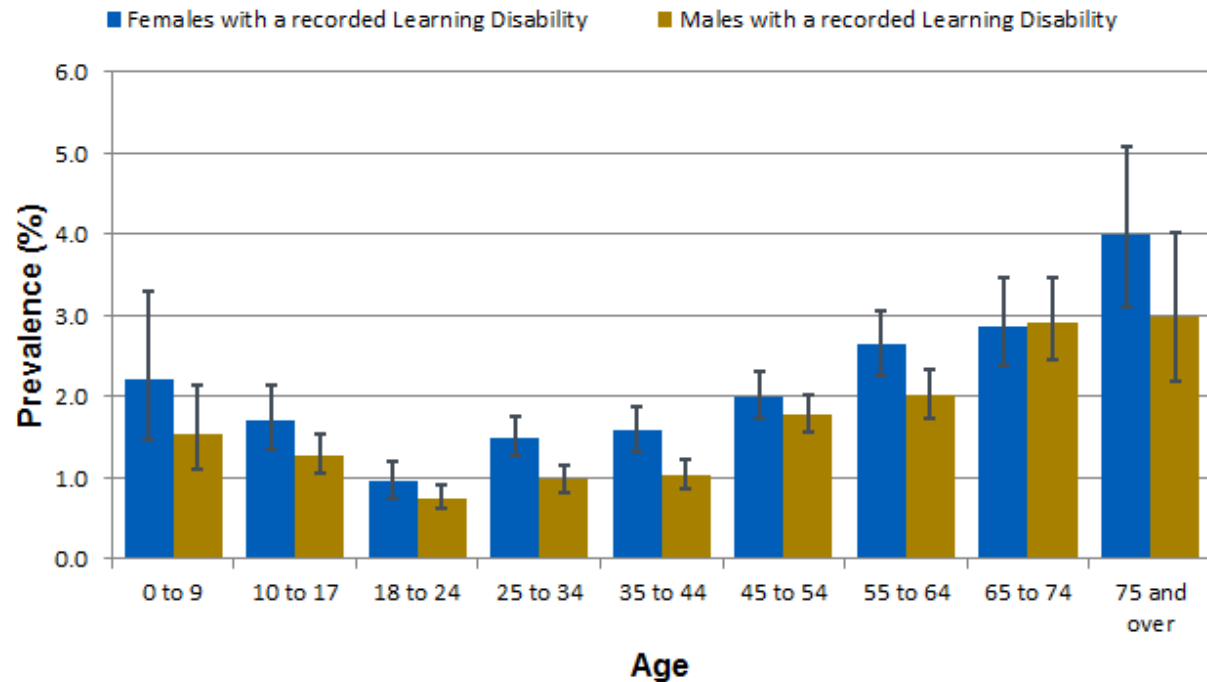
### 6.3 Constipation

Constipation is an important issue for people with learning disabilities. Lack of exercise, a diet low in fibre and side effects of antipsychotic medication combine to make this a frequent, and often severe, problem.

Constipation can be a cause of behavioural problems identified by carers and care staff as challenging. It has been identified as a common cause of avoidable emergency hospitalisations.

Constipation has not previously been defined for the purposes of QOF targets. The definitions used here were developed specially for the programme. They consider whether a person has a diagnosis of chronic constipation or faecal impaction, or evidence of prolonged treatment for constipation.

**Figure 23. Chronic constipation prevalence (per cent) in patients with a learning disability, by age and sex, England, 2014-15**



The overall rate of identified constipation was 1.6 per cent of people with learning disabilities. The rate rose with age through adult life from 18 to 24 years onwards. It was higher in females in all ages except for 65 to 74 years. Constipation prevalence data were only collected for patients with learning disabilities so no comparison of rates with those for people without learning disabilities is possible.

34.7 per cent of CCGs had a standardised prevalence ratio for constipation significantly lower than the England figure; 16.3 per cent had a ratio significantly higher.

The range of observed rates highlights the extent to which the problem is handled differently in different areas. In view of the importance of the topic this clearly merits careful study.

## 6.4 Dysphagia

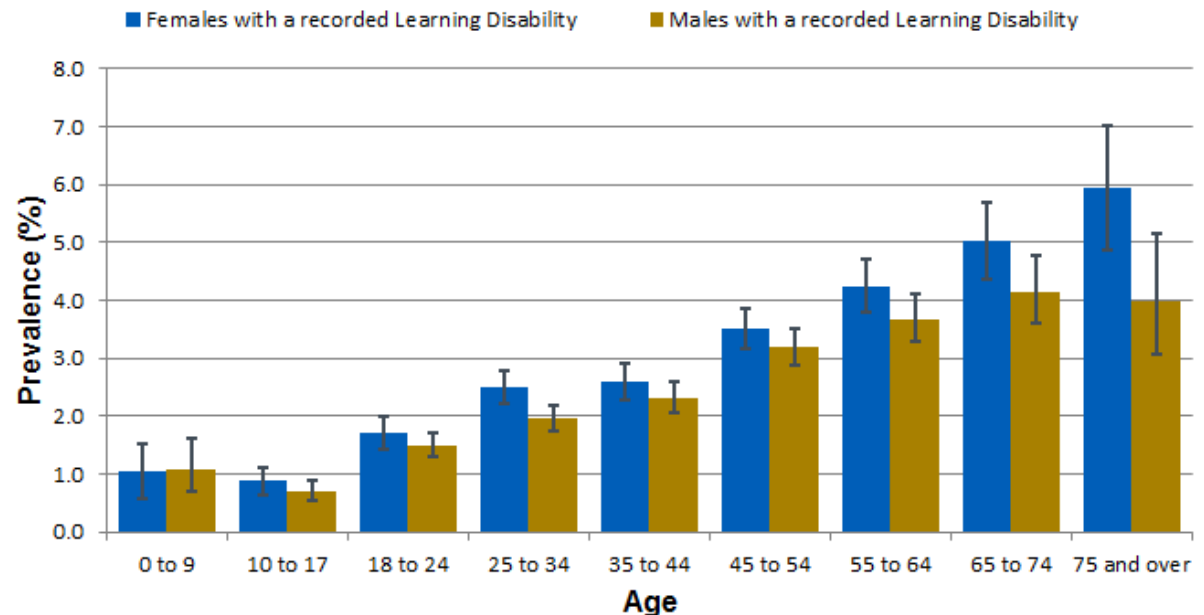
Dysphagia is an important condition which underlies choking, aspiration pneumonitis and underweight problems in people with learning disabilities. It can be caused by neurological abnormalities or some developmental abnormalities affecting the shape of the face and upper respiratory tract. The most thorough UK study<sup>25</sup> of the prevalence of dysphagia in people in touch with learning disability services suggested roughly 8.0 per cent have this problem to some extent. Its importance is that it underlies the high rates of hospitalisation and death for aspiration pneumonitis, is associated with risk of sudden death from choking and is associated with the malnutrition seen in people with learning disabilities who are underweight.

Dysphagia was recorded in 2.6 per cent of people with learning disabilities. The rate rose steadily from around 0.82 per cent in childhood to between 4.1 per cent and 6.0 per cent in the oldest age groups.

Rates of identification vary considerably between CCGs: 20.0 per cent of CCGs had a standardised prevalence ratio for dysphagia significantly lower than the England figure; 15.8 per cent had a ratio significantly higher.

Only the top 10.0 per cent of CCGs had overall rates of identified dysphagia above 4 per cent which is half of the estimated rate referenced above. These data suggest that dysphagia is widely under-recognised.

**Figure 24. Dysphagia prevalence in patients with a Learning Disability (per cent) by age and sex, England, 2014-15**



A wide range of approaches to managing dysphagia are possible. Assessment by GP and then a speech and language therapist are usually the first steps. A recent guideline<sup>26</sup> by the Royal College of General Practitioners provides practical advice.

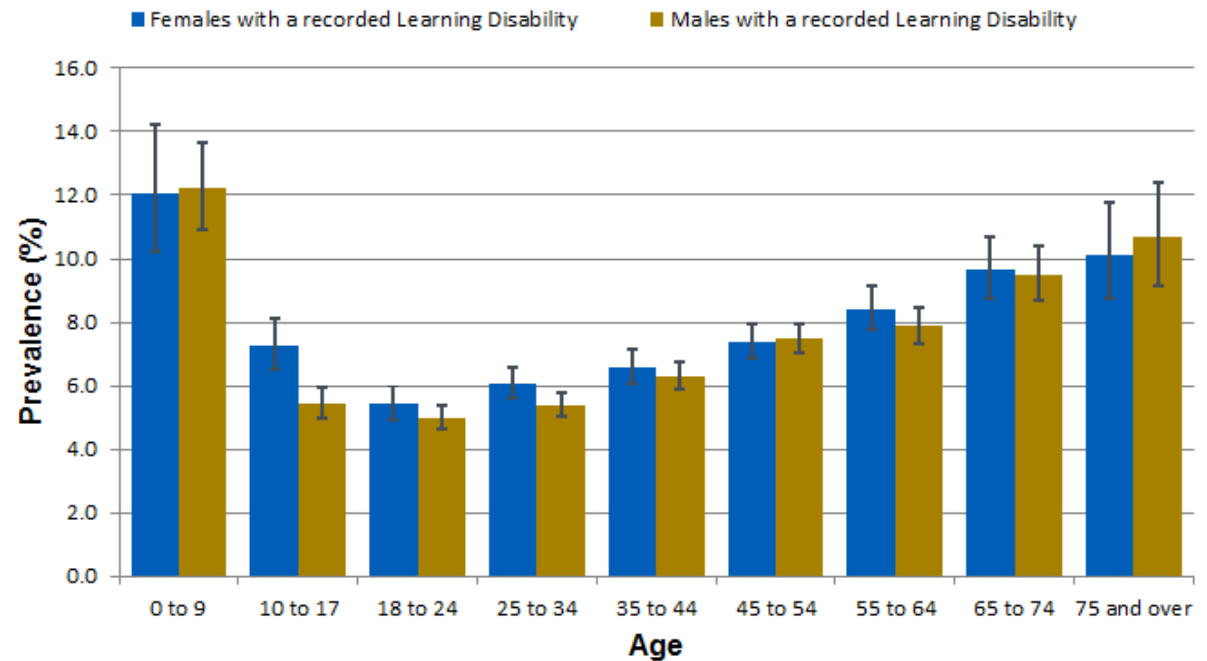


## 6.5 Gastric Oesophageal Reflux

Gastro-oesophageal reflux disease (GORD) is a distressing and painful condition caused by reflux of stomach acid into the oesophagus. It is common in people with learning disabilities, particularly those who have cerebral palsy or scoliosis or who are on treatment with anticonvulsant drugs or long term treatment with benzodiazepine drugs for other reasons.

In people with limited capacity for spoken communication it may give rise to challenging behavioural expressions.

**Figure 25. Gastric oesophageal reflux disease prevalence in patients with learning disabilities (per cent) by age and sex, England, 2014-15**



Overall 6.8 per cent of people with learning disabilities were recorded as having GORD. The rate rose with age from between 5 to 6 per cent in 18 to 34 year olds to between 9 to 11 per cent in people aged 65 years or over.

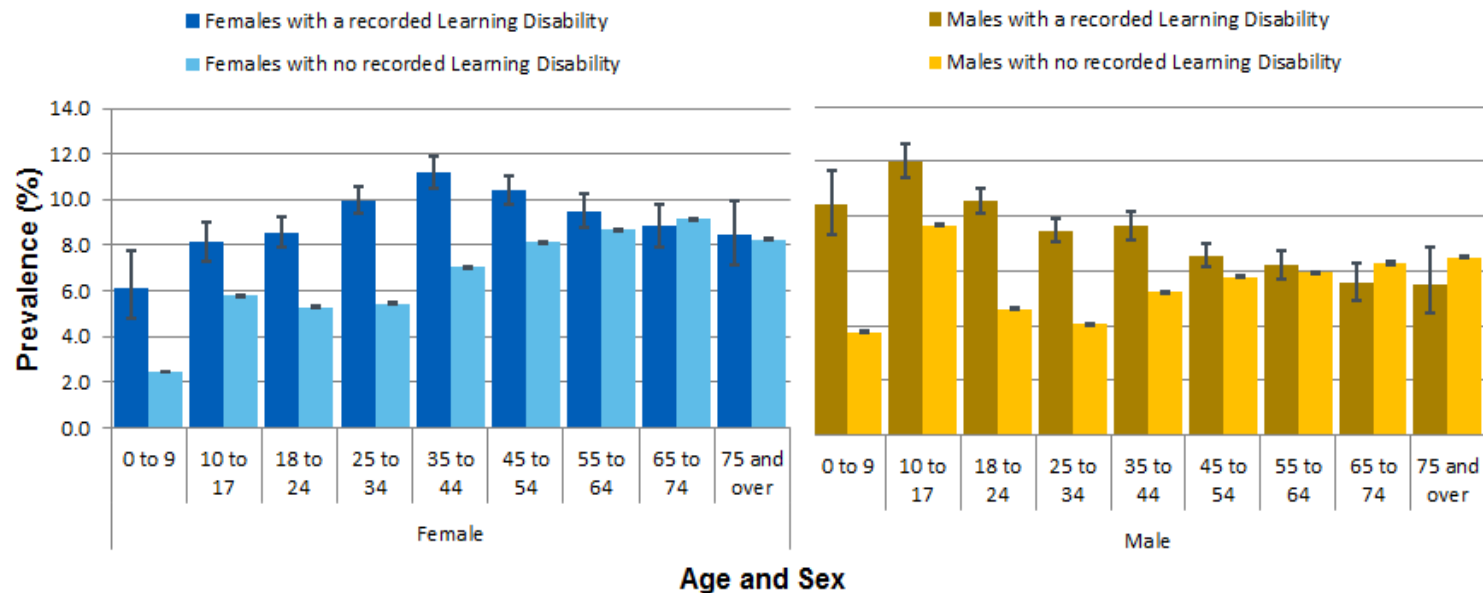
Variation between CCGs in diagnosed rates of GORD was moderate: 6.8 per cent of CCGs were recorded as having a rate of GORD in people with learning disabilities significantly lower than the national figure; 5.8 per cent were recorded as having a rate significantly higher.

## 6.6 Asthma

Asthma is a long term inflammatory condition of the airways which causes episodes of wheezing, coughing and shortness of breath as a result of small airway tubes going into spasm. Allergic reactions to specific allergens, such as grass, pollen or house dust, or to air pollutants can trigger episodes. Severe episodes can lead to acute difficulty in breathing. Treatment is by a range of drugs and by avoiding allergic triggers.

**Figure 26. Asthma prevalence (per cent) by age, sex and learning disability status, England, 2014-15**

8.4 per cent of people with learning disabilities and 6.0 per cent of those without had a diagnosis of asthma. Rates of asthma in people without learning disabilities showed a complex pattern with age and sex. In childhood, rates were higher for boys, peaking in the teenage years before dropping in young adult life. They rose again in middle age to plateau in old age.



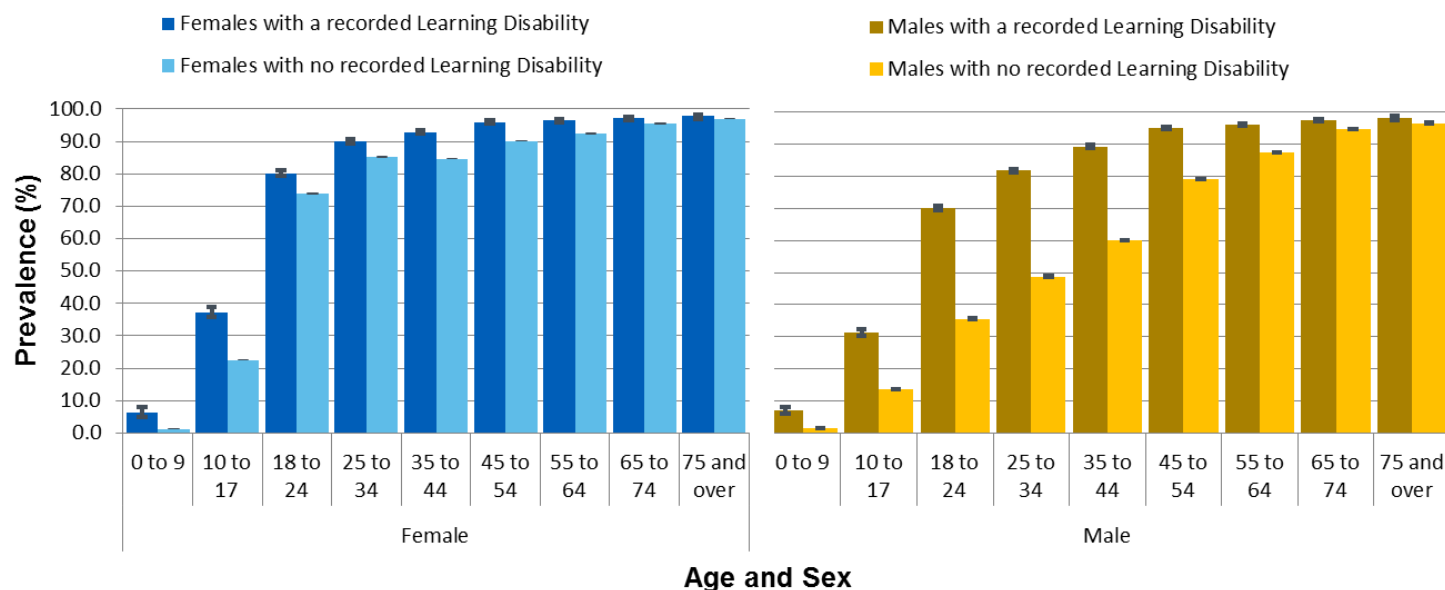
The late life rise was more pronounced in women. Rates for people with learning disabilities showed similar gender patterns, but were higher at each age group up to the late 50s. Above age 55 years, rates were not significantly different. Allowing for these age and sex related rate differences the number of people with learning disabilities diagnosed as having asthma was 39.6 per cent above expectation based on applying general population age and sex specific rates to the population with learning disabilities. There was moderate variation round the country: 5.8 per cent of CCGs had a standardised prevalence ratio for asthma significantly lower than the England figure; 5.3 per cent had a ratio significantly higher.

## 6.7 Blood Pressure and Hypertension

High blood pressure is an important risk factor for heart disease, strokes, kidney failure and other conditions. High blood pressure has no symptoms so regular monitoring is a normal part of ordinary primary health care. Monitoring blood pressure is a simple, non-invasive procedure, though may not be comfortable for people with learning disabilities.

The current QOF target, reflecting NICE assessments of required screening rates, is that blood pressure should be monitored every five years for all people aged 45 and older<sup>3</sup>. It should also be measured regularly, and usually more frequently for people with a range of other conditions. Blood pressure measurement is normally a component of the annual learning disability health check. The measurement here is the proportion of people with and without learning disabilities who have a measurement of their blood pressure within the last five years.

**Figure 27. Proportion of patients who have received a blood pressure measurement in the previous five years (per cent) by age, sex and Learning Disability status, England, 2014-15**

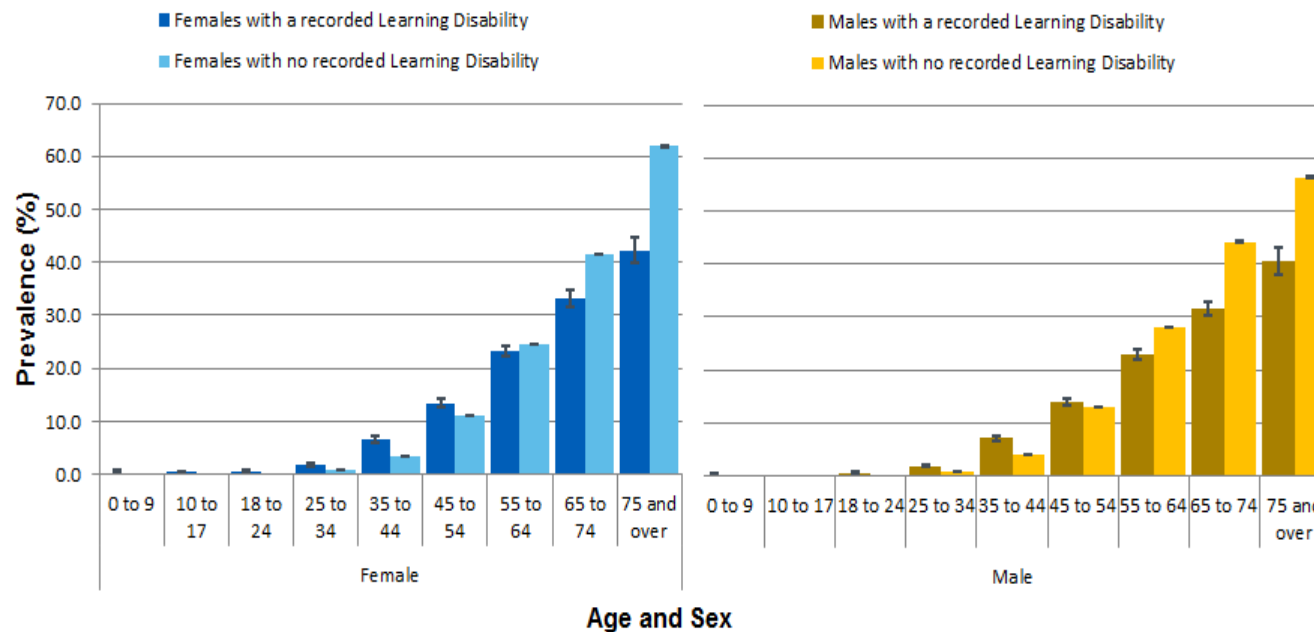


81.2 per cent of people with learning disabilities had had a blood pressure measurement in the previous five years. This was substantially more than the 64.3 per cent for people without learning disabilities. Rates varied with age. Above 45 years old, which is the age group used for reporting blood pressure performance in the QOF, 96.1 per cent of people with a learning disability and 90.4 per cent of those without had had a measurement.

For younger people without a learning disability there was a large difference between the sexes, with females significantly more likely to have had measurements. For younger people with learning disabilities there was no substantial difference. There was no substantial variation between CCGs.

Monitoring of blood pressure and management of hypertension are important. As reported above, people with learning disabilities have higher than average rates of strokes, diabetes and chronic kidney disease. All these make monitoring and, if necessary, management of blood pressure important.

**Figure 28. Hypertension prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



9.6 per cent of all people and 10.9 per cent of those aged 18 and over with learning disabilities had a diagnosis of hypertension; corresponding figures for people without a learning disability were substantially higher: 13.7 per cent of people and 17.4 per cent of those aged 18 and over.

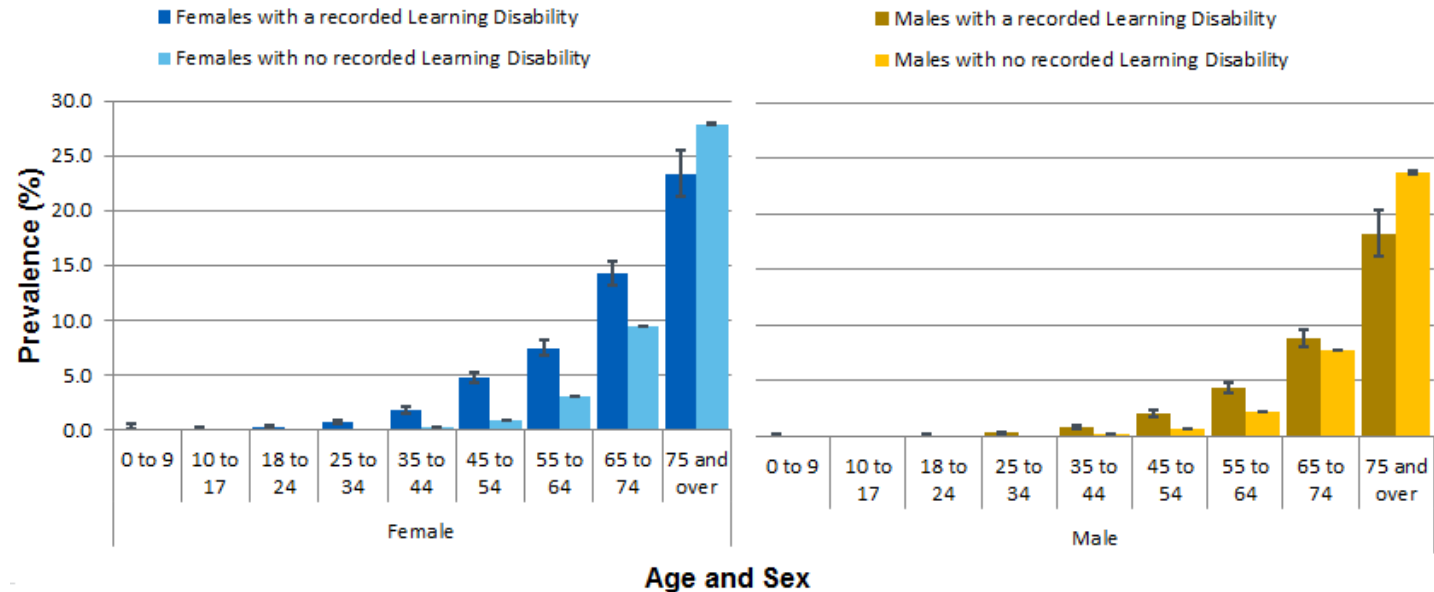
Hypertension was much more common in older people. At younger ages slightly higher proportions of people with learning disabilities had hypertension. This may reflect in part the difference in measurement coverage. Above age 55 years it was more common in people without learning disabilities. Overall, allowing for the difference in age and sex profile, 4.4 per cent fewer people with learning disability had hypertension than would be expected if the general population age and sex rates had applied.

7.4 per cent of CCGs had a standardised prevalence ratio for hypertension significantly lower than the England figure; 8.9 per cent of CCGs had a ratio significantly higher.

## 6.8 Chronic Kidney Disease

Chronic kidney disease is a slow progressive loss of capacity of the kidneys to perform their function of clearing various waste substances from the blood. In its most severe forms, patients without kidney dialysis or transplantation have a poor chance of survival. More mild forms are common and may have few symptoms beyond general un-wellness and possibly loss of appetite. Diabetes, high blood pressure and a range of other diseases affecting blood vessels can cause chronic kidney diseases, but in many cases there is no obvious cause. It is commonly diagnosed in blood tests at routine health checks. The importance of diagnosis at early stages is to ensure that possible underlying conditions are identified and controlled to reduce as far as possible the rate of progress.

**Figure 29. Chronic kidney disease (stages 3-5) prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



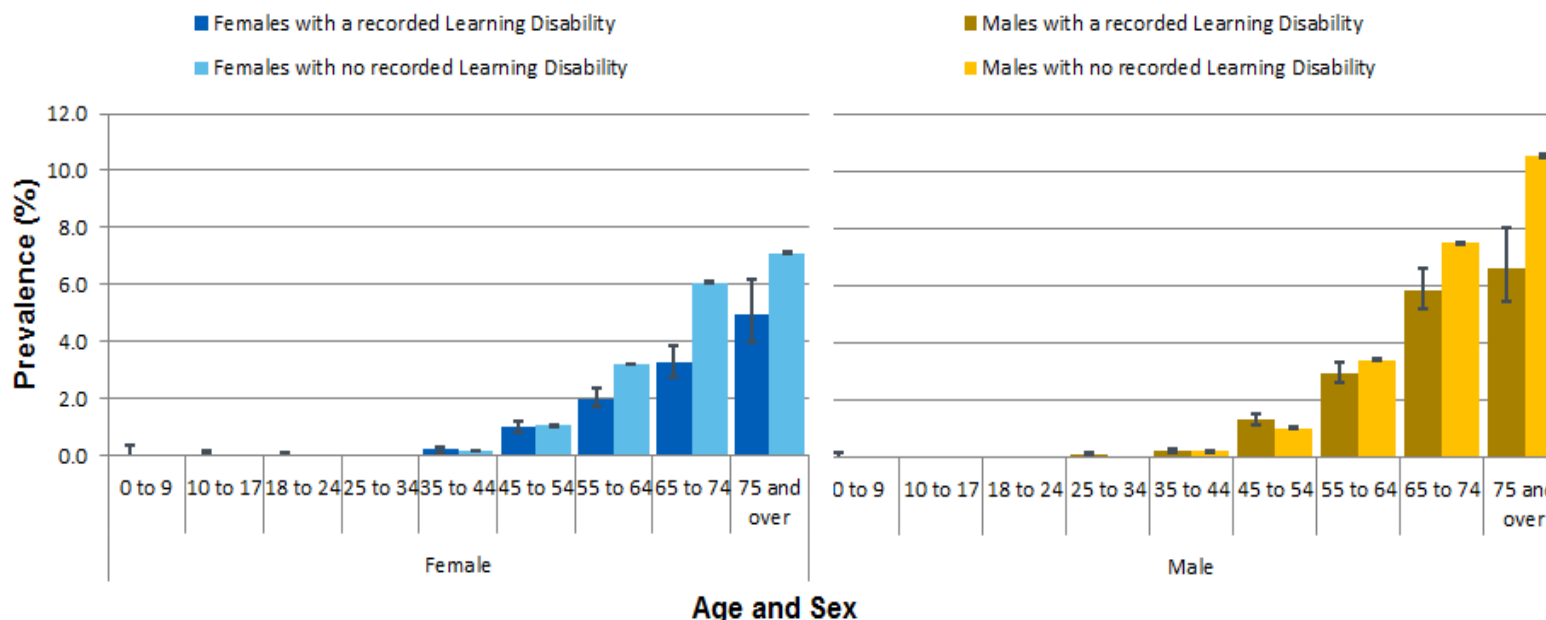
2.7 per cent of people with learning disabilities were recorded as having chronic kidney disease compared to 3.2 per cent of those without learning disabilities. In both people with and without learning disabilities, rates were higher in females than males and rose sharply with age. Rates for people with learning disabilities were higher than for others of the same gender and age group at all stages except the oldest group of each gender.

Adjusting for age and sex profile, there were 67.8 per cent more people with learning disabilities who had chronic kidney disease than would be expected if general population rates had applied. Rates for people with learning disabilities showed moderate variation around the country: 4.2 per cent of CCGs had a standardised prevalence ratio for chronic kidney disease significantly lower than the England figure; 5.8 per cent of CCGs had a ratio significantly higher.

## 6.9 Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) is a group of conditions caused mainly by exposure to smoke and other air pollutants. Symptoms are breathlessness and chronic productive cough. It is largely preventable but not reversible. As it worsens, particularly when exacerbated by acute respiratory infections, it can cause respiratory failure.

**Figure 30. Chronic obstructive pulmonary disease prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



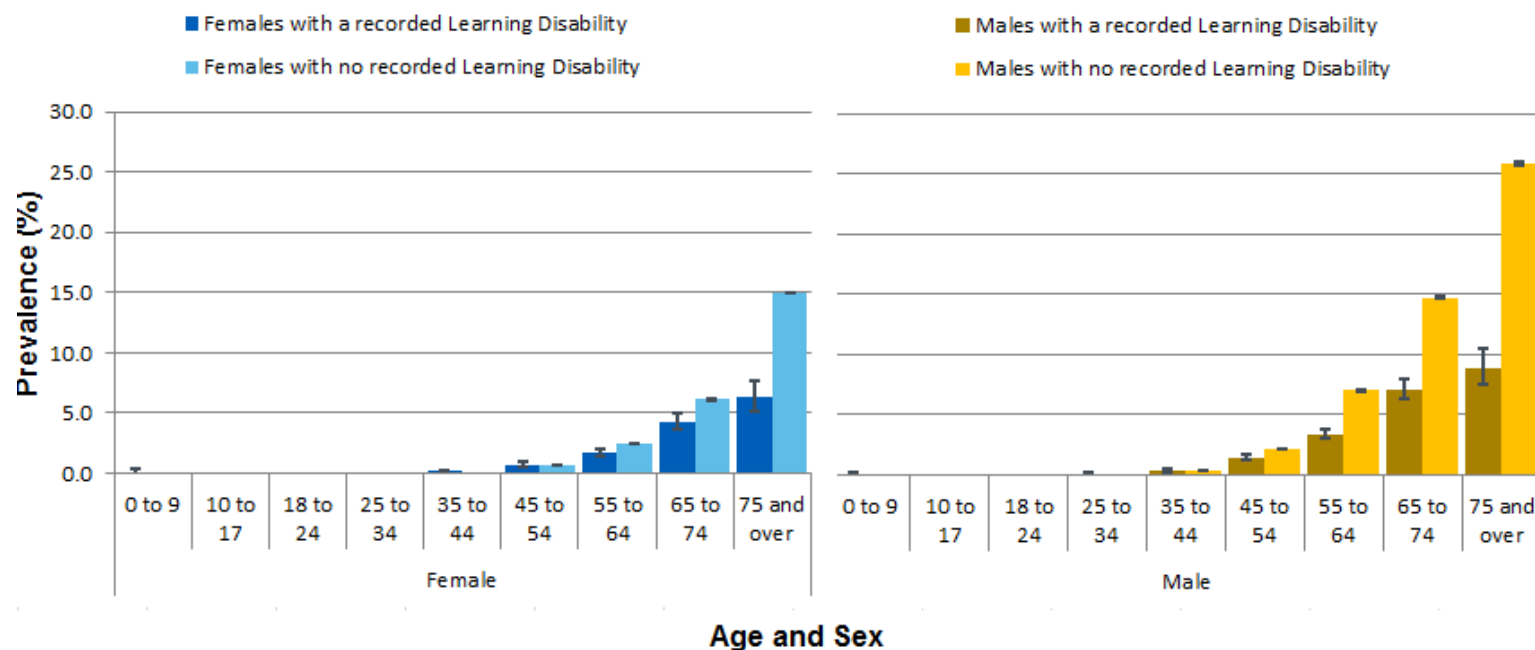
1.0 per cent of people with learning disabilities were recorded as having COPD, significantly fewer than the corresponding figure of 1.8 per cent for people without learning disabilities. Rates of COPD were lower in both groups until age 45 years, rising sharply in older age groups. Rates were higher in males than females and, in almost all cases, for each gender higher in people without learning disabilities than people with learning disabilities. Adjusting for the different age and sex profiles, there were 20.8 per cent fewer cases of COPD in people with learning disabilities than would have occurred if general population age and sex specific rates had applied to them.

While rates appeared to vary between CCGs, case numbers were low, which made statistical confidence intervals wide. 2.6 per cent of CCGs had a standardised prevalence ratio for COPD significantly lower than the England figure; 3.2 per cent of CCGs had a ratio significantly higher.

## 6.10 Coronary Heart Disease

Coronary heart disease is a major cause of death in both the general population and in people with learning disabilities. It is also a major cause of disability in older people. It develops with increasing age and its progress is speeded by smoking tobacco, diets high in saturated fat and lack of exercise. The major preventive intervention is lifestyle change.

**Figure 31. Coronary heart disease prevalence (per cent) by age, sex and learning disability status, England, 2014-15**

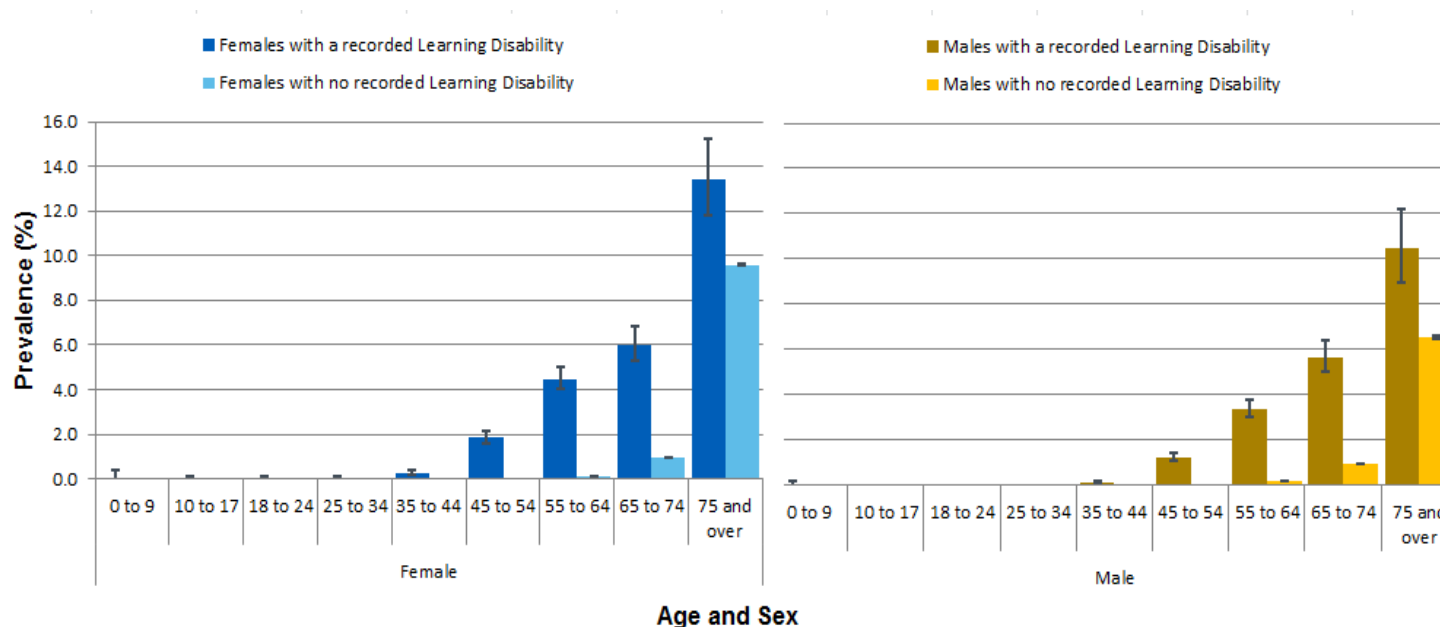


1.1 per cent of people with learning disabilities were recorded as having coronary heart disease, significantly fewer than the 3.2 per cent in people without learning disabilities. Rates were very low at ages younger than 45 years and rose sharply in older age groups. At the younger ages, whilst low, rates for people with learning disabilities were higher than for people without learning disabilities. Above the age of 45 years, rates were higher in people without a learning disability and this trend continued into the older age groups. Rates were higher for males than females at almost all ages and in both groups. After adjustment for differences in age and sex profile, the number of cases of coronary heart disease in people with learning disabilities was 55.0 per cent of what would be expected if general population age and sex specific rates had applied. 2.6 per cent of CCGs had a standardised prevalence ratio for coronary heart disease significantly lower than the England figure; 3.7 per cent of CCGs had a ratio significantly higher.

## 6.11 Dementia

The term 'Dementia' describes a number of conditions most commonly appearing in elderly people which involves progressive loss of brain tissue and with it memory and other intellectual functions. Dementia is known to be more common in people with learning disabilities. People with Down syndrome are particularly likely to develop Alzheimer-type dementia and do so at younger ages than others. Diagnosis of dementia in people with learning disabilities is made easier if baseline recordings of intellectual functioning have been made in earlier stages of adult life to which later levels of functioning can be compared. Early diagnosis makes it more likely that useful benefit can be obtained, at least for a period, from anti-dementia drugs.

**Figure 32. Dementia prevalence (per cent) by age, sex and learning disability status, 2014-15**



The rates of diagnosed dementia first exceeded 0.1 percent for people with learning disabilities in the 35 to 44 year age band, and rates rose sharply in older age groups. In people without learning disabilities this threshold was first exceeded in the 55 to 64 year age band, and, again, rates rose sharply in older age groups. Adjusting for age and sex profile, the number of people with learning disabilities diagnosed with dementia was 5.1 times the number expected if general population age and sex specific rates had applied.

Variation between CCGs was moderate: 3.7 per cent of CCGs were recorded as having a standardised prevalence ratio for dementia in people with learning disabilities significantly lower than the national figure; 6.8 per cent of CCGs were recorded as having a standardised ratio significantly higher.



**Figure 33. Dementia prevalence (per cent) by age and comorbidity of Down syndrome and/or learning disabilities, England, 2014-15**

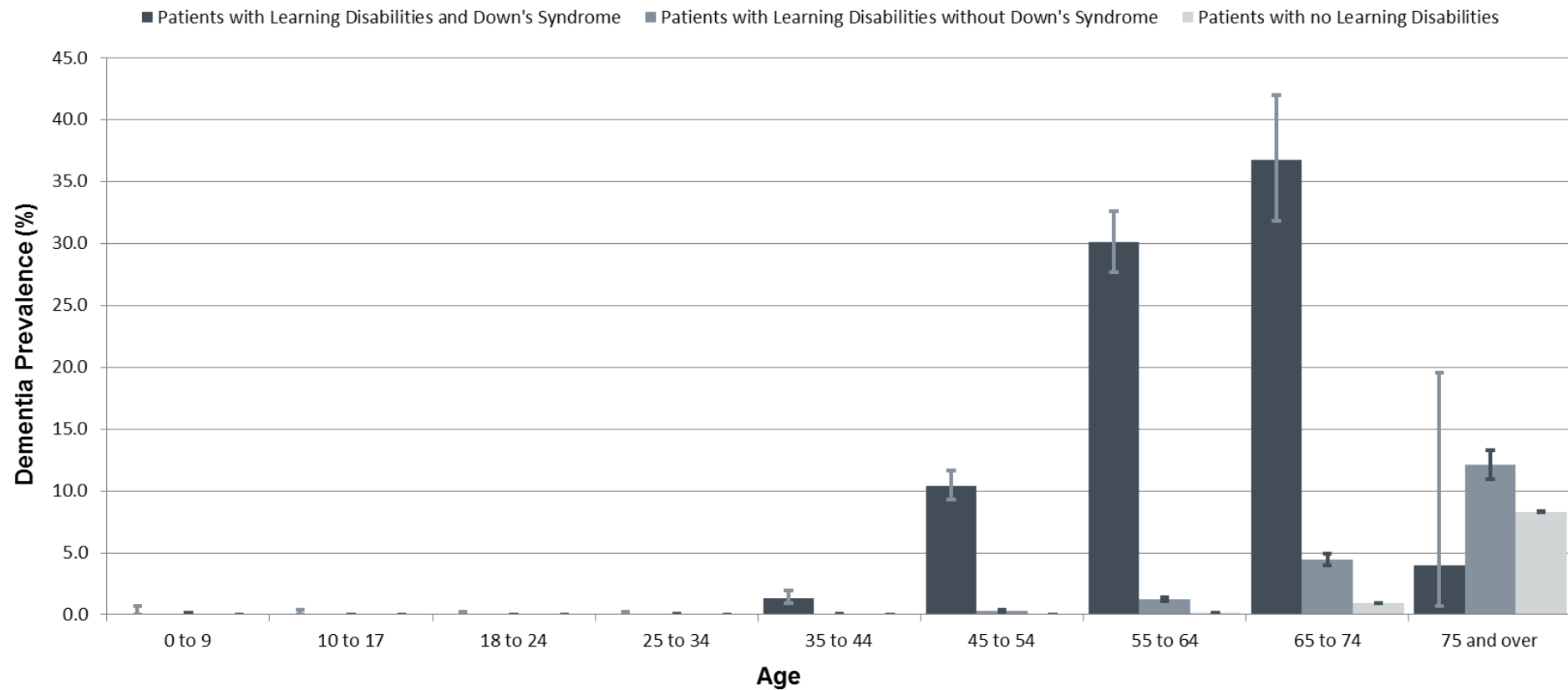


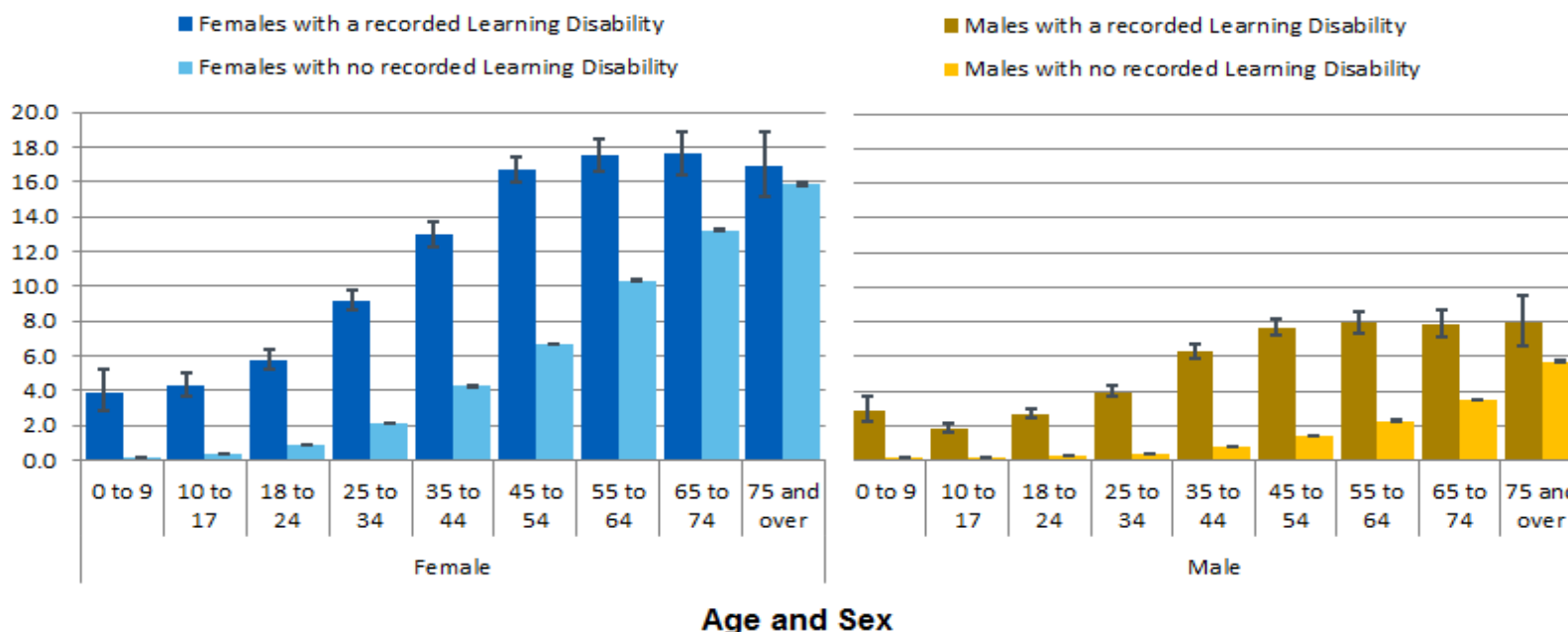
Figure 33 shows age specific rates of dementia for people without learning disabilities, and for those with learning disabilities (separated into those with Down syndrome and others). The figure shows clearly the earlier presentation and overall higher rates of dementia in people with Down syndrome. In the oldest age band the high rate of dementia in people with Down syndrome is less clear. This is because few people with Down syndrome survive to this age.

Diagnosing dementia in people with learning disabilities can be difficult because it depends on assessment of the level of deterioration of mental functioning from an initially low base. It is also important because treatable conditions such as hypothyroidism or depression may be mistaken for dementia. Early diagnosis is increasingly important as treatment with available anti-dementia drugs may improve patients' quality of life for a period.

## 6.12 Hypothyroidism

Undiagnosed thyroid insufficiency (hypothyroidism) in new-born infants can cause learning disabilities. Thyroid insufficiency is also a common feature of several conditions causing learning disabilities, particularly Down syndrome. Thyroid insufficiency can cause fatigue, weakness and skin problems, but also low mood and reduced memory capacity among many other symptoms. Onset is often gradual and commonly not noticed by people living closely with a sufferer. It is relatively easily treated with hormone replacement therapy. In people with associated syndromes, thyroid function screening is appropriate.

**Figure 34. Hypothyroidism prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



Rates of hypothyroidism were higher for females than males in both those with and without learning disabilities, but for those with learning disabilities the difference was smaller. Rates were a little more than twice as common in most adult age bands in comparison to more than four times as common for people without learning disabilities.

For people with learning disabilities, rates rose with age until the 45 to 54 year age group, above which they plateaued. For people without learning disabilities, the rise continued steadily with each successive age group. Adjusting for the different age and sex profiles, there were 2.9 times the rate of hypothyroidism in people with learning disabilities than would be expected had general population age and sex specific rates applied. 7.9 per cent of CCGs had a standardised prevalence ratio for hypothyroidism significantly lower than the England figure; 8.4 per cent of CCGs had a ratio significantly higher.

**Figure 35. Hypothyroidism prevalence (per cent) by age and comorbidity of Down syndrome and/or learning disabilities, England, 2014-15**

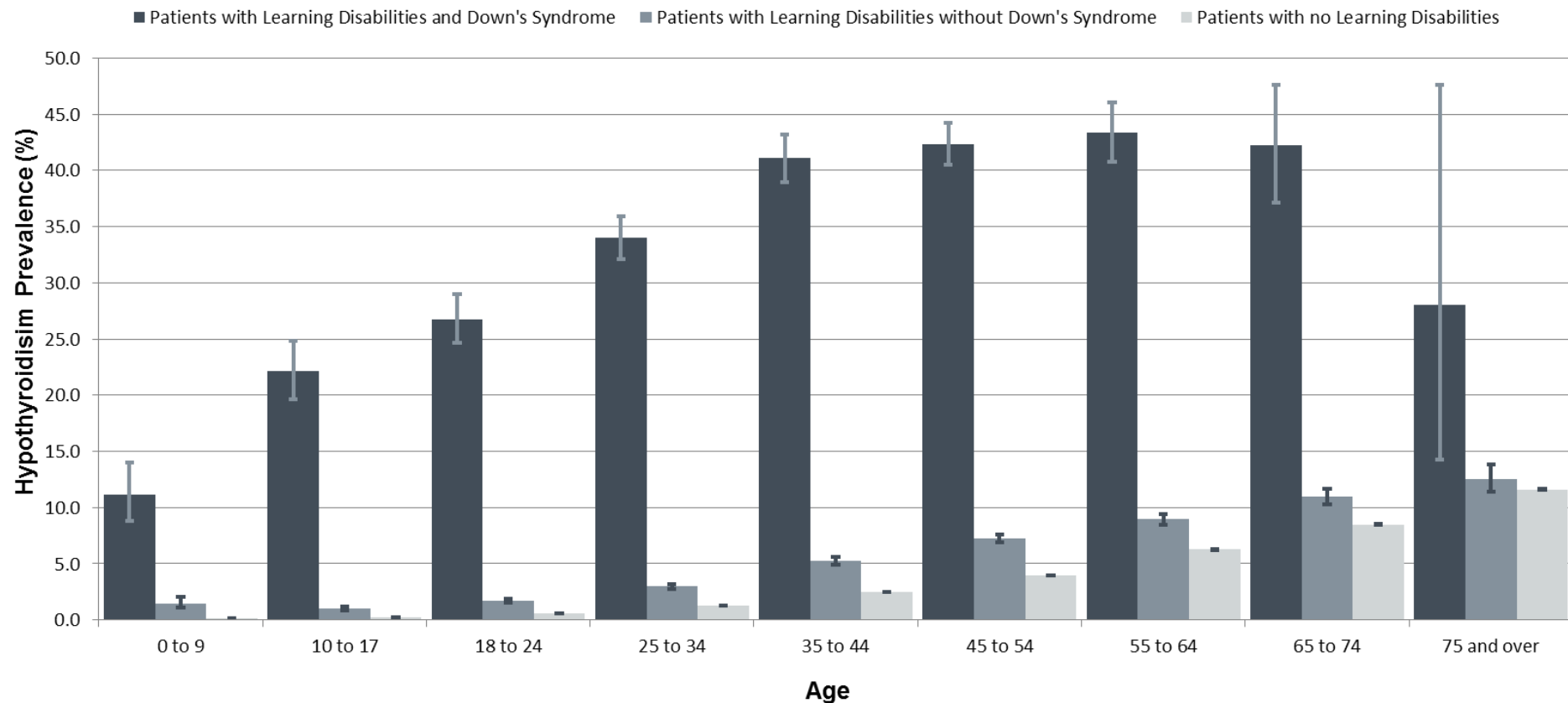


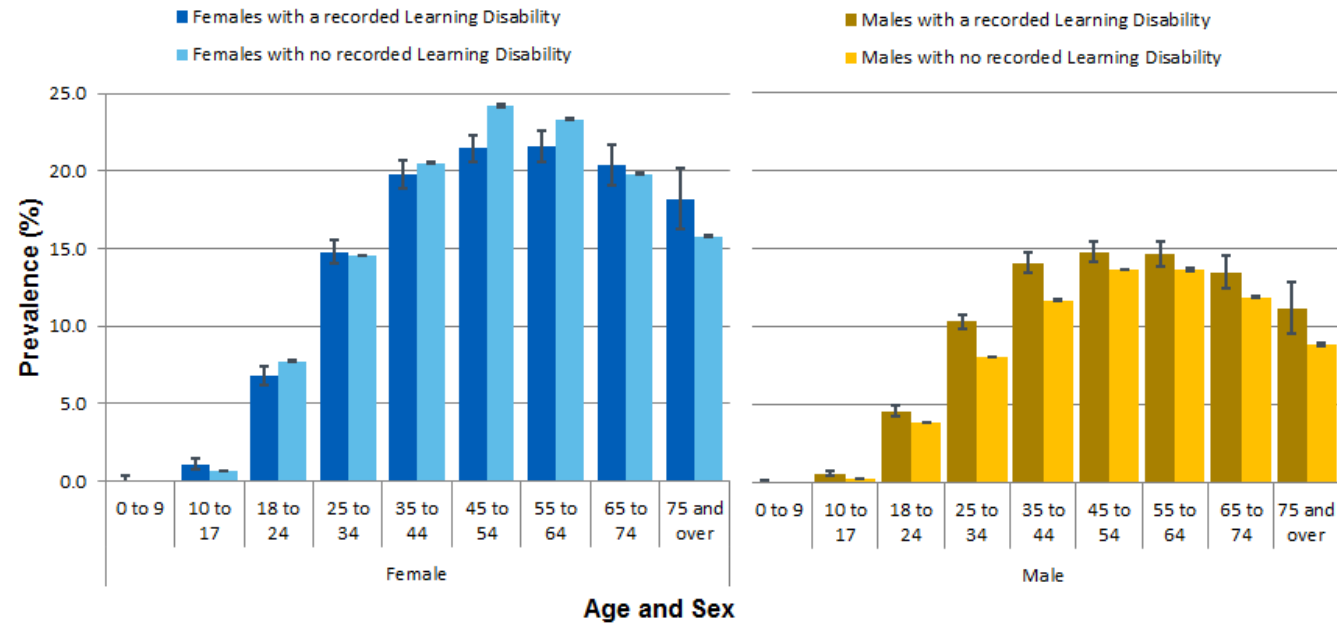
Figure 35 shows age specific rates of hypothyroidism for people without learning disabilities, and for those with learning disabilities (separated into those with Down syndrome and others). The higher rates in people with Down syndrome are clear. However, it is also apparent that people with learning disabilities but without Down syndrome also have significantly higher rates of hypothyroidism than people without learning disabilities in all but the oldest age group.

For context, 4.7 per cent of female patients with a learning disability also had a diagnosis of Down syndrome and Hypothyroidism. This figure was 2.5 per cent for males. 7.9 per cent of CCGs had a standardised prevalence ratio for hypothyroidism significantly lower than the England figure; 8.4 per cent of CCGs had a ratio significantly higher. 0.85 per cent of patients with a learning disability had a diagnosis of both Down syndrome and Dementia; this figure was 0.54 per cent for males.

## 6.13 Depression

Depression is a major and treatable cause of distress and disability for people with and without learning disabilities. In people with learning disabilities, particularly those with limited ability to communicate, it can be expressed in behavioural ways understood by carers or care staff as 'challenging'. This makes clarity about diagnosis particularly important.

**Figure 36. Depression prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



The overall rate of having a diagnosis of unresolved depression in adults with learning disabilities (13.9 per cent) was very similar to that for people without learning disabilities (14.5 per cent).

Rates for both groups rose with age until late middle age and then fell slightly in old age. Adjusting for the age and sex profile, the number of cases in people with learning disabilities was 4.3 per cent above the number expected if general population rates had applied. 14.2 per cent of CCGs had a standardised prevalence ratio for depression significantly lower than the England figure; 12.6 per cent of CCGs had a ratio significantly higher.

NICE guidelines on the treatment of depression<sup>27</sup> indicates that both medical and psychological approaches play an important role. Psychological approaches are increasingly being provided through the NHS Improving Access to Psychological Therapies programme<sup>28</sup>. These data provide some guidance about the numbers of people with learning disabilities likely to need treatment for depression in local areas.

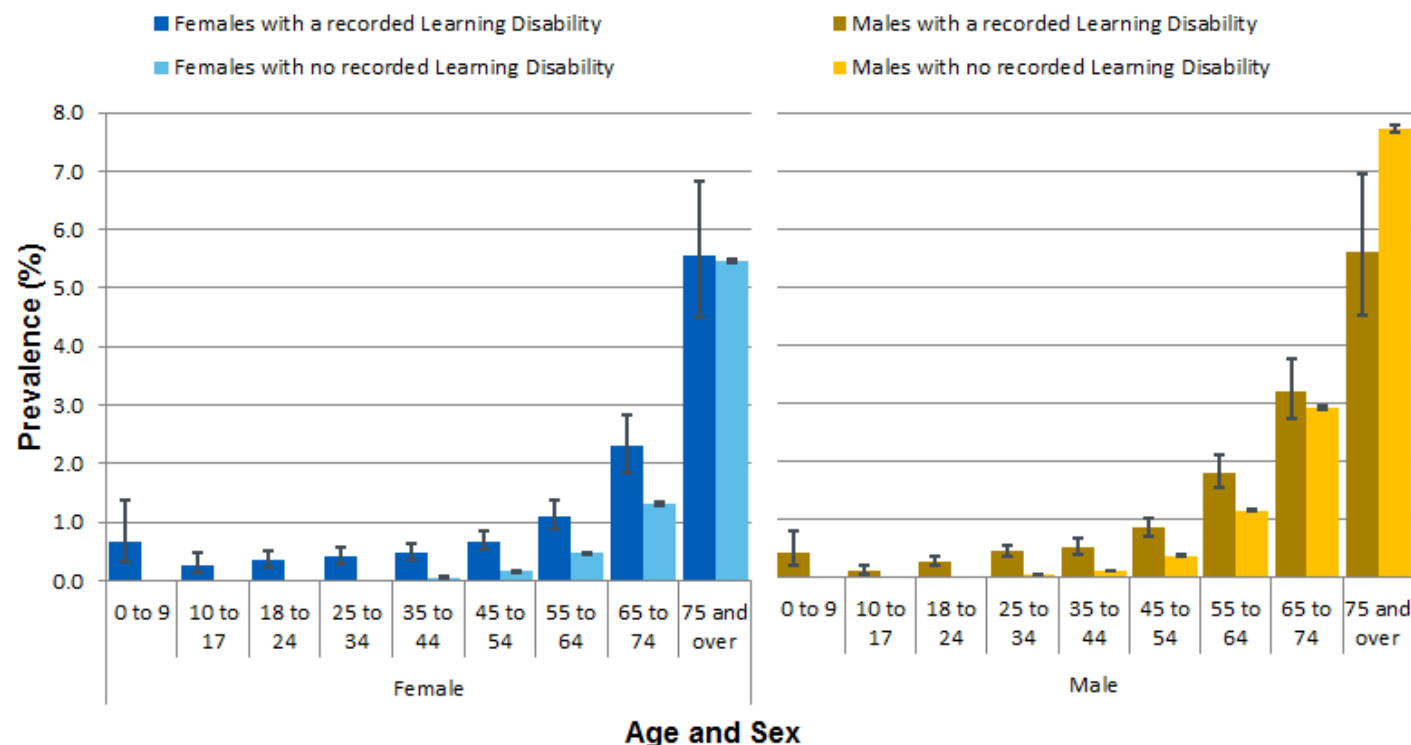
## 6.14 Heart Failure

Heart failure is the condition where as a result of damage (for example, a heart attack) or persistent overload (for example, as a result of hypertension) the heart is unable to sustain the burden of pumping blood as normally required.

It is a disabling and sometimes fatal condition, usually affecting older people.

It is specifically associated with some conditions causing learning disabilities and involving either abnormal development of the heart or progressive damage to the heart as a result of inherited metabolic disorders.

**Figure 37. Heart failure prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



0.85 per cent of people with learning disabilities and 0.83 per cent of people without were recorded as having heart failure. In all but the oldest age group, the rate for both sexes was higher in those with learning disabilities than those without learning disabilities, though these margins diminished as age group increased. The overall rate was almost evened up by a much higher rate in males without learning disabilities aged 75 years or over. Adjusting for the differing age and sex profile, the number of cases identified in people with learning disabilities was 82.6 per cent higher than would be expected if general population age and sex specific rates had applied.

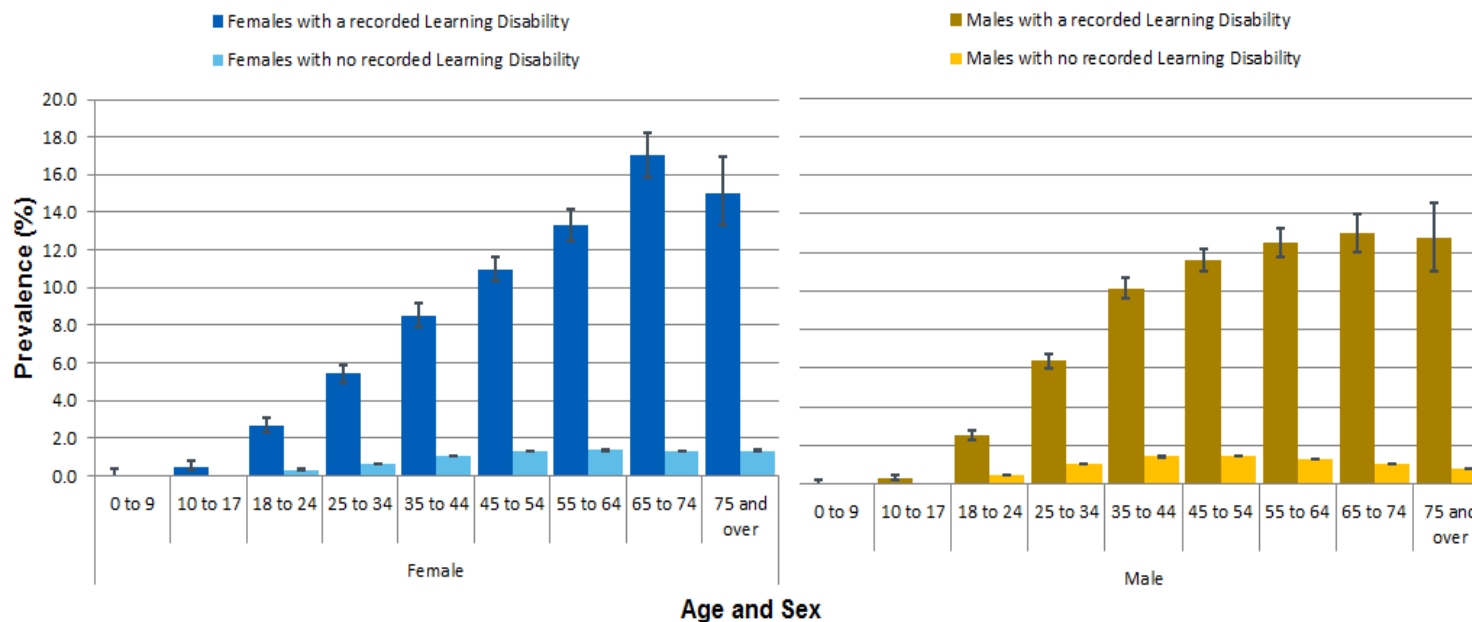
There was relatively little variation around the country: 1.6 per cent of CCGs had a standardised prevalence ratio for heart failure significantly lower than the England figure; 2.6 per cent of CCGs had a ratio significantly higher.

### 6.15 Severe Mental Illness

People with learning disabilities are known to suffer more commonly with severe mental illnesses including schizophrenia, bipolar disorder and other less well defined psychotic conditions. However, exactly how much more commonly is difficult to assess since diagnosis of these conditions is substantially more difficult, particularly in those with more severe learning disabilities and little or no ability to communicate verbally. In people without learning disabilities, psychotic disorders are relatively uncommon in childhood, appearing usually in adolescence or young adulthood.

Overall, GPs recorded 7.8 per cent of people with learning disabilities as having severe mental illnesses; 8.8 per cent in those aged 18 and over. This compared to 0.87 per cent of people without learning disabilities; 1.1 per cent in those aged 18 and over. Adjusting for age and sex profile, the number of people with learning disabilities recorded as having a severe mental illness was 7.9 times what would be expected if national general population age and sex specific rates applied. 15.3 per cent of CCGs had a standardised prevalence ratio for severe mental illness significantly lower than the England figure; 13.2 per cent of CCGs had a ratio significantly higher.

**Figure 38. Severe mental illness prevalence (per cent) by age, sex and learning disability status, England, 2014-15**

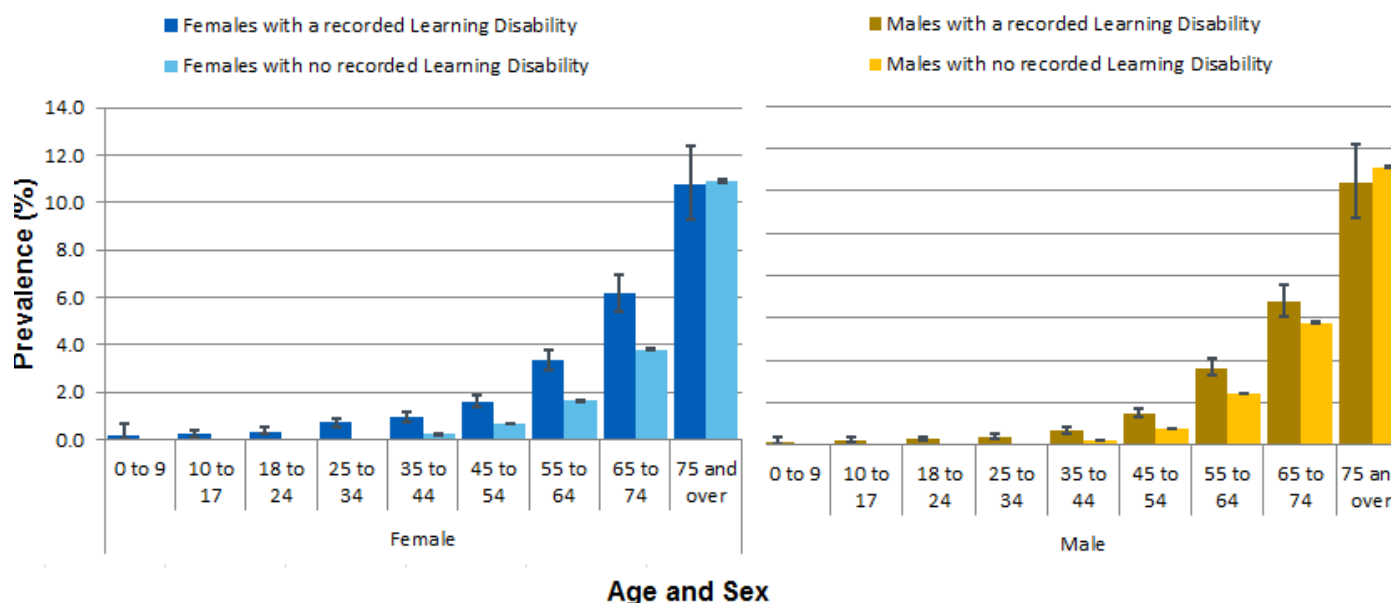


The large variability in the rates of severe mental illness strongly suggests that this is being under-diagnosed (and possibly under treated) in some areas and over-diagnosed in others. This is an important issue in clarifying the appropriateness of use of antipsychotic and anti-depressant medications. This is currently the subject of an NHS England programme<sup>29</sup>.

## 6.16 Stroke and Transient Ischaemic Attack

Strokes are sudden loss of the function of part of the brain as a result of damage or blockage in the blood vessel supplying it leading to death of small sections of brain tissue. Transient ischaemic attacks (TIAs) are brief loss of elements of brain function due to brief interruption of blood supply but recovering within minutes or hours. TIAs are often followed by strokes. Strokes are a leading cause both of death (the underlying cause of 7.8 per cent of all deaths and 5.9 per cent of deaths of people with learning disabilities in a recent study<sup>22</sup>) and of both physical and additional mental disability.

**Figure 39. Stroke and Transient Ischaemic Attack prevalence (per cent) by age, sex and learning disability status, England, 2014-15**



1.7 per cent of people with learning disabilities were recorded as having diagnoses of stroke or a TIA. The figure for people without learning disabilities was 1.7 per cent. These data show that strokes were roughly 10 times as common in people with learning disabilities up to the age of 34 years. Adjusting for the age and sex profile of the population with learning disabilities, the number recorded with this diagnosis was 64.1 per cent higher than would be expected if general population age and sex specific rates had applied. These figures did not vary greatly around the country: 4.2 per cent of CCGs had a standardised prevalence ratio for Stroke / TIA significantly lower than the England figure; 2.1 per cent of CCGs had a ratio significantly higher.

## 7. Technical annex

The data reported here are extracted from 'General Practice IT systems'. The data are collected at aggregate level, meaning the risk of re-identification is very low. Data are collected only for patients registered with the GP Practice for General Medical Services who meet specific criteria; for example: having congestive heart failure, being male, aged between 45 and 54 years and having a learning disability. The open data accompanying this report include total population numbers and numbers with key conditions, by age, sex, learning disability status and geographical area (CCG) of the GP practice. The full technical specification for the extract, including the lists of clinical codes specifying diagnoses are set out in the document: [Health care learning disabilities metadata](#).

All GP practices in England were asked to participate, which was deemed a relatively low-burden task. If they agreed and authorised the query, these data were read directly from their electronic systems by the GP system suppliers who supply and maintain them. GP practices were advised about the programme in the summer of 2015 and asked in April 2016 if they would agree to participate<sup>30</sup>. Local Directors of Public Health were asked to encourage those who did not respond. At a specified date, GP system suppliers ran the queries on the information systems of all the GP practices they supported that agreed to participate. This resulted in data being sent to NHS Digital's General Practice Extraction Service (GPES). **GPES collects information from general practice (GP) clinical systems in England and forms part of NHS Digital's GP Collections service.** NHS Digital grouped the data into aggregate totals for all the GP practices in each CCG. This report used this CCG aggregate level data file.

### 7.1 Body Mass Index Data

Only a minority of children and young people aged under 18 years had a BMI record. The proportion was higher for people with learning disabilities and in teenage years but even for people with learning disabilities aged 10 to 17 years it was less than 30 per cent. This suggests that people were being measured because there was concern about their weight. The profile is therefore unlikely to be representative of the population aged under 18 years as a whole.

In adults with learning disabilities the proportion with a BMI record rose above 50.0 per cent from age 18 to 24 years to 65.0 per cent at ages 25 to 34 years and up to 70.0 per cent at older ages before falling to 64.0 per cent for people aged 75 years or over. This reasonably high coverage probably reflects the learning disabilities health check programme. For people without learning disabilities, rates were below 30.0 per cent up to age 45 years, reached 40.0 per cent by age 55 to 64 years and approached 50.0 per cent for people aged 65 years or over. This reflects the fact that there is no universal screening programme which involves measuring the weight of adults until age 40 years, the point at which the adult NHS Health Check starts.

### 7.2 Demographic Data

Although this dataset represents a sample and not the entire population of registered patients in England, it closely mirrors its age and sex structure. Overall the population of patients represented in this dataset had a slightly younger profile than the England population, with 65.2 per cent falling into the age 0 to 49 year's bracket, compared to 64.7 per cent in the England population. There are 0.9 per cent more females than males in the England population, and this difference is slightly more marked in this dataset, with 1.1 per cent



more females than males. The prevalence of learning disabilities was the same in both populations, at 0.4 per cent. These differences should be taken into account if scaling any calculations up to England population level.

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