Herefordshire Council

Herefordshire Adult Learning Disabilities Needs Assessment

Version 1.0
Herefordshire Council Intelligence Unit

February 2018

CONTENTS

SUMMARY

Prevalence of Learning Disabilities

Recent Patterns

In 2015/16 there were 900 patients with LD in Herefordshire; this represents a prevalence of 0.60 per cent compared to a figure of 0.48 per cent for England and 0.51 per cent for the West Midlands.

Between 2009/10 and 2013/14 the number of adults with LD recorded on Herefordshire GP practice lists increased proportionally by 10.0 per cent; increases were also observed across England and the West Midlands, although the proportional increases were higher at 19.7 and 17.5 per cent respectively.

Locally, the number of LD cases shows some variability by age with the highest number of individuals between the ages of 18 and 44, which represented 49.2 per cent of all cases in 2015/16; similar patterns were evident nationally and regionally with this age group representing 49.9 and 48.7 per cent of LD cases across England and the West Midlands respectively[2].

However, the proportions of LD cases reported in Herefordshire in the <24 years cohort were significantly lower than those reported nationally and regionally, while the local proportion for cases in the 35 to 44 cohort was significantly higher than those for England and the West Midlands.

Comparison of 2015/16 adult LD prevalence data for Herefordshire with a comparator group of 12 nearest statistical neighbours indicates that the local prevalence (0.60 per cent) was significantly higher than that recorded in 5 out of the 12 nearest neighbours; the local figure was also significantly higher than the national and regional figures.

There are no reliable statistics characterising accurately how many people there are with learning disabilities across the UK - it has been estimated that the numbers on the GP registers represent only 23 per cent of adults with LD.

According to estimates there are an estimated 3,573 adult LD cases in Herefordshire in 2017, which represents a prevalence of 2.32 per cent.

When examining the prevalence there is a steady decline for total of LD cases with age from 2.70 per cent in the 18 – 24 cohort to 1.89 per cent in the 85+ group; a similar pattern is evident for moderate and severe cases.

Projected Trends

Over the 20 year period between 2015 and 2035 it is estimated that the number of all age registered LD cases in Herefordshire will increase from 976 to 1,019, which represents a proportional rise of 4.4 per cent; for adults the increase is from 900 to 934, a rise of 3.8 per cent.

It is predicted that by 2035 the numbers of LD cases in the majority of age groups will increase, particularly in those aged 70 and over with a predicted rise of 36.7 per cent for the 70 – 74 age group and 71.4 per cent for the 75+ cohort.

Although the number of LD cases are predicted to rise over this 20 year period the overall prevalence is predicted to fall, with the adult rate falling from 0.61 to 0.57 per cent.

A similar pattern is projected for the number of “whole population” adult LD cases in Herefordshire with numbers rising steadily from the 2017 estimate of 3,573 to 3,892 in 2035.

However, over this period the whole population adult LD prevalence is expected to show little change.

Health Issues

Cancer

In 2015/16 the overall cancer prevalence in people in Herefordshire with LD was 0.82 per cent which, while being lower than that for the county as a whole, the difference was not statistically significant; the local figure was similar to that for the West Midlands.

Coronary Heart Disease (CHD)

In 2015/16 the CHD prevalence in people in Herefordshire with LD was 1.13 per cent which was similar to both the national and regional figures.

The local prevalence of heart failure in individuals with LD was 0.82 per cent which, while being less than both the national and regional figures the differences were not statistically significant.

In 2015/16 the prevalence of hypertension in people with LD in Herefordshire was 11.8 per cent, a figure broadly similar to both the national and regional figures.

Respiratory Disease

In 2015/16 the prevalence of chronic obstructive pulmonary disease (COPD) in people in Herefordshire with LD was 0.92 per cent, a figure broadly similar to both the national and regional figures.

Obesity

In 2015/16 the prevalence of obesity in people with LD in Herefordshire was 23.9 per cent. The local prevalence was similar to the national figure and broadly similar to the regional *prevalence*

Diabetes

In 2015/16 the prevalence in Type 1 diabetes people in Herefordshire with LD was 0.71 per cent which was similar to both the national and regional figures.

For non-type 1 diabetes the local LD community prevalence was 8.20 per cent. While being higher than the national and regional figures the local prevalence was broadly similar to these figures.

Gastro Oesophageal Reflux Disease (GORD)

In 2015/16 the prevalence of GORD in those with LD in Herefordshire was 8.4 per cent. Although the local prevalence was higher than both the national and regional figures the differences were not statistically significant.

Neurological Problems

In 2015/16 the prevalence of epilepsy in people in Herefordshire with LD was 22.7 per cent which was approximately over thirty times that for the county as a whole (0.68 per cent). The local prevalence was significantly higher than both the national and regional figures.

Depression

In 2015/16 the prevalence of depression in people in Herefordshire with LD was 9.63 per cent which was approximately eight tenths of that for the county as a whole (12.1 per cent).

Health Check

In 2016/17 almost 62 per cent of LD patients in Herefordshire receiving an annual health check, a figure lower that recorded for England as a whole (67 per cent).

The local proportion of LD cases receiving an annual health check is higher than those recorded in the majority of nearest neighbour CCGs - it should be noted that all nearest neighbour figures were significantly lower than that recorded nationally.

Screening

In 2015/16 the local proportion of female patients aged 25 to 64 recorded on their GP's LD register and who were eligible for cervical cancer screening was 26.4 per cent, a similar to those recorded both nationally the regionally.

In Herefordshire the proportion of female LD patients aged 50 and 69 who received breast cancer screening was 50.9 per cent which was approximately three quarters of that for the county as a whole (69.6 per cent). While the local proportion was higher than both the national and regional figures the differences were not statistically significant

In 2015/16 the local proportion of LD patients aged 60 to 69 who were eligible for colorectal cancer screening was 83.5 per cent. Although higher than the national proportion the local figure was not statistically higher than that for the West Midlands.

Living

Long Term Support

In 2015/16 there were 590 Herefordshire adults received long term LD support, which represents a 9.4 per cent increase on the 2009/10 figure.

Of those receiving support in 2015/16 525 were aged between 18 and 64 and 65 were 65 and over. The total figure for 2015/16 represents 0 in Herefordshire.

At the end of 2015/16 a total of 555 adults receiving long term support, which represents 61.7 per cent of the 900 adults included on the LD register. Of these 500 had been in care for more than 12 months representing 90 per cent of individuals receiving long term LD support.

Accommodation

As of the end of March 2016 there were 130 adults with LD in residential accommodation across Herefordshire; of these 125 had been in care for more than 12 months representing 96 per cent of adults in residential accommodation.

Five adults with LD were in nursing accommodation at some point in 2015/16, all of which were aged between 18 and 64 and were resident at years end.

Of the 525 people aged 18-64 with LD who received long term care in Herefordshire in 2015/16 305 were recorded as living in settled accommodation, which represents 58 per cent of this cohort.

Supporting Carers

In 2015/16 there were 75 adults with LD in Herefordshire whose carer received direct support throughout the year while a further 30 carers received no direct support:

- 15 received direct payment,
- 5 received part direct payment,
- 10 received CASSR commissioned support,
- 15 received Information, advice and other universal services / signposting,
- 30 received respite or other forms of carer support delivered to the cared for person.

Employment

In 2015/16 there were 60 individuals with LD of working age (18-64) in paid employment in Herefordshire. Of these 10 were employed for 16 hours or more per week and 50 for less *than 16 hours a week.*

Safeguarding

In 2015/16 there were 170 section 42 LD safeguarding concerns in Herefordshire which resulted in 75 section 42 safeguarding enquiries.

Payments

In 2015/16 of a total of 365 Herefordshire adults with LD received long term support payments in Herefordshire; 305 were working of working age (18 – 64) and 60 were aged 65 and over. The most prevalent payment type was to individuals in residential accommodation with a total of 110 individuals receiving support.

Current Provision of Services

Providers – Community Services

[2]Gether NHS Foundation Trust - community services are commissioned from [2]Gether NHS Foundation Trust through the Community Learning Disability Team (CLDT).

Echo - an independent Herefordshire-based charity which runs a range of activities primarily for people with moderate or severe learning disabilities in a variety of community venues.

Aspire - a registered charity based in Hereford which provides support to individuals with LD. Services provided include residential care, support at home helping people to live independently and also helping individuals to undertake tasks such as shopping, volunteer and leisure activities.

Ategi - operates a Shared Lives Scheme in Herefordshire providing personal care for people who live in their homes.

Affinity Trust - (known as Score Community Opportunities in Herefordshire) is a registered charity providing support for people with learning disabilities providing day opportunities on weekdays.

Salters Hill - provide accommodation for people with LD, support people with LD to live in their own homes and encourage creative learning and encourage involvement in the community.

Providers – Residential Services

There are 36 establishments across Herefordshire which provide residential accommodation for adults with LD.

Of these all but one have a CQC rating of 'Good', with a single establishment rated as 'Requires Improvement'.

Over a third of these establishments are located in and around Hereford with others near Ross and in Leominster; there is only one located in the west of the county at Kington.

Expenditure

In 2015/16 the weekly unit cost of long term care for those with LD aged 18 – 64 in Herefordshire was £1,162 per week compared to £1,359 per week in England and £1,375 in the West Midlands. Between 2014/15 and 2015/16 the local unit cost fell proportionally by 2.73 per cent compared to an average increase of 4.37 in comparator areas and a 2.33 per cent increase nationally.

For individuals aged 65 and over the long term weekly unit cost for Herefordshire was £622 per week while the weekly figures for England and the West Midlands were £868 and £898 respectively.

The weekly unit cost of short term care for those with LD aged 18 – 64 in Herefordshire was £214 per week compared to the national figure of £494 per week and the regional figure of £531.

For individuals aged 65 and over the short term weekly unit cost for Herefordshire was £77 per week while the weekly figures for England and the West Midlands were £381 and £584 respectively.

In 2015/16 the total expenditure in Herefordshire for long and short term care combined was £18.48 million, which was made up of £16.45 million for those aged 18-64 and £2.04 million for those aged 65+. Of the overall expenditure £18.22 million was for long term care and £0.26 million for short term care.

Locally, the 2015/16 overall expenditure represented a 20.7 per cent fall on the figure for 2014/15 compared to the national and regional contexts where the overall expenditure on LD care increased by 3.7 and 7.6 per cent respectively.

INTRODUCTION

Scope

This Adult Learning Disability Integrated Needs Assessment was commissioned by Herefordshire Council to provide an overview of health and wellbeing issues affecting adults with learning disabilities living in Herefordshire and to outline levels of care and services currently provided. This document will inform the Learning Disability Strategy.

Definition

Historically, people with learning disabilities have been pushed into the background or institutionalised in care homes or health care settings. The majority of people with a learning disability however, are fully capable of living independent and fulfilling lives as long as the right support is provided. Over recent years a number of significant improvements have been made in the level of support and opportunities being made available to people with learning disabilities as part of a national push towards supporting people to live independently. However, inequalities still exist with people with learning disabilities being frequently excluded and remaining as some of the most disadvantaged people within our society. For this to change there needs to be better understanding of their distinctive needs1. It is important to treat each person as an individual, with specific strengths and abilities as well as needs, and a broad and detailed assessment may be needed.

Some people with learning disabilities live independently without much support, whereas those with more complex needs will require a range of additional support, in some instances this may take the form of 24 hour care. While people with autistic spectrum disorders (ASD) may also receive support through learning disability services their needs may be different to the requirements of those with learning disabilities. The amount of everyday support a person with a learning disability needs will depend mostly on the severity and nature of the disability.

'Learning disabilities' is currently a poorly defined term. It can have different meanings in different contexts (such as in education or medical settings) and have different interpretations by different professionals and lay people. Introduction of newer terminology such as 'intellectual disabilities' and 'specific learning disorder' which refer to a subset of learning disabilities further makes it difficult to define a clear workable definition of learning disabilities. Overall, "learning disabilities", can be considered an umbrella term that covers a range of neurological disorders in learning with varying degrees of severity that leads to impairment in social, intellectual and practical skills. Predecessor terms include: minimal brain damage and minimal brain dysfunction, and mental retardation (BILD, 2011)[1]. The most widely used term in the UK is, 'learning disability' and can be considered interchangeable with 'intellectual disability[1,2].

Definitions provided by Diagnostic and Statistical Manual of Mental Disorders – V (DSM-V), British Psychological Society (BPS), National Institute for Health and Care Excellence

[1]British Institute of Learning Disabilities, 2011, factsheet

[2] Learning Disabilities Needs Assessment, Fulfilling Lives for People with Learning Disabilities (2012), JSNA Hertfordshire, Damms & Nagaraj.

(NICE), and the government white paper on learning disabilities, 'Valuing People'[3] have common core features which can be used to define learning disabilities[4]:

- *Impaired Intelligence* - lower intellectual ability (usually an IQ of less than 70) which can significantly reduce ability to understand new or complex information in learning new skills;

- *Impaired Social Functioning* **-** significant impairment of social or adaptive functioning which can reduce ability to cope independently;

- *Neurodevelopmental* **-** onset in childhood, before the age of 18 years.

Impairment in social, intellectual and practical skills can be highly varied among individual cases. Underlying neurological conditions also plays a role in the severity of disability and how functional an individual will be. Some people with learning disabilities live independently without much support, but others may require 24 hour care to perform most daily living skills due to complex needs.

Diagnosis

In the past, diagnosis of a learning disability and understanding of a person's needs were based on IQ scores. Today the importance of a holistic approach is recognised with IQ testing forming only one small part of assessing someone's strengths and needs. The DSM-V emphasizes the use of both clinical assessment and standardised testing of intelligence when diagnosing learning disabilities. Assessments of adaptive function focus on how people can manage their daily living skills and what support they may need. This form of assessment is considered more useful in assessing the impact of any learning disability on a person than an intelligence test[5,6]. The Wechsler Adult Intelligence Scale (WAIS) fourth edition is the IQ classification commonly used and reported here[7].

Severity

In the UK, the terms "profound", "severe", "moderate" and "mild" are used to describe the severity of learning disabilities. However, there are no clear dividing lines between the groups. Further, there is no clear cut off point in the IQ scale between people with mild learning disabilities and the general population and the term borderline learning disability maybe used.

---

[3] Department of Health. Valuing people: a new strategy for learning disability for the 21st century. London: Department of Health; 2001. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

[4] The Challenging Behaviour Foundation, http://www.challengingbehaviour.org.uk/learning-disability-files/Formal-Definitions-of-Severe-Larning-Disability.pdf

[5] British Institute of Learning Disabilities, http://www.bild.org.uk/information/faqs/#What-are-the-possible-causes-of-a-persons-learning-disability

[6] Diagnostic and Statistical Manual of Mental Disorders, 2013, http://www.dsm5.org/Documents/Intellectual%20Disability%20Fact%20Sheet.pdf

[7] WAIS: Groth-Marnat, G. (2009). Handbook of psychological assessment. John Wiley & Sons.

Learning Disabilities can be grouped into four main levels of severity[8]:

- *Normal Learning* - children are meeting developmental milestones in emotional, cognitive, and physical health. IQs of 90-109 are considered average, whereas 80-89 is low average, and 70-79 is borderline; 69 and below is considered extremely low.

- *Mild Learning Disability* - likely to result in some learning difficulties at school. At this level, many adults will be able to work, maintain good relationships and contribute to society. Approximate IQ level 50-69.

- *Moderate Learning Disability* - likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills. Adults are likely to require varying degrees of support in order to live and work in the community. Approximate IQ level 35-49.

- *Severe Learning Disability* - likely to result in severe developmental delays and a continuous need for support throughout the life course. Approximate IQ level 20-34.

- *Profound and Multiple Learning Disabilities (PMLD)* - people with PMLD are likely to have the highest levels of care needs. They have great difficulty communicating and need high levels of support with most aspects of daily life. Many people with PMLD will have additional sensory (such as visual, hearing) or physical disabilities (movement impairments), complex health needs or mental health difficulties or autism or epilepsy. This is likely to result in severe limitations in self-care, communication and mobility and therefore requiring a high level of constant care and support. The combination of these needs and/or the lack of the right support may affect behaviour (Mencap, 2010)[9]. They will have IQ of less than 20 (considered a profound learning disability) (Department of Health, 2001)[4]. In relation to PMLD it is likely that individuals will have high support needs such as requiring 24-hour-a-day support with all aspects of their lives. Their needs are also complex, such as the range of medical conditions that they often experience. This is termed as *High Support or Complex Needs*

However, these terms do not help others to understand the specific issues that affect impact upon the lives of people with learning disabilities. This is because many people who do not have a profound learning disability could be described using these terms. For example, someone with a physical disability and communication impairment may be

[8] CDC: http://www.cdc.gov/ncbddd/actearly/milestones/index.html,

CDC: http://www.cdc.gov/ncbddd/childdevelopment/positiveparenting/adolescence2.html.

[9] Mencap Website https://www.mencap.org.uk/

described as having complex needs or high support needs but may have no impairment to their intellectual ability. As a result they may be confused with someone who has PMLD[10].

Causes of Learning Disabilities[11]

Learning disabilities are thought to be caused by something that affects the development of the brain. They may occur before birth (prenatally), during birth, or in early childhood. Learning disabilities can be caused by any one of a variety of factors, or by a combination. Sometimes the specific cause is not known.

Possible causes include the following:

- An inherited condition, meaning that certain genes passed from the parents affected the brain development: Fragile X;
- Chromosome abnormalities e.g. Down's syndrome or Turner syndrome;
- Complications during birth resulting in a lack of oxygen to the brain;
- A very premature birth;
- Mother's illness during pregnancy;
- The mother drinking during pregnancy, for example Foetal Alcohol Syndrome;
- A debilitating illness or injury in early childhood affecting brain development, for example a road traffic accident or child abuse;
- Contact with damaging material (e.g. radiation);
- Neglect, and/or a lack of mental stimulation early in life.

Further details on common neurological conditions which can cause learning disabilities are given in Table 1. https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/l/learning-disabilities

[10] PMLD factsheet: http://www.pmldnetwork.org/pmld%20definition%20factsheet%20-%20standard.pdf

[11] https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/l/learning-disabilities

Table 1: Common neurological conditions which can cause learning disabilities.[10]

Conditions known to cause learning disabilities		
Condition	**How does the condition affect someone?**	***Living with the condition***
Fragile X is a genetic condition tha affects both boys and girls, althoug boys are often more severely affect can cause a range of issues with language, emotions, attention, behaviour and social interaction ar the most common inherited cause learning disability. Of the people wi have Fragile X, nearly all boys will a learning disability but only a third girls. The learning disability could mild, moderate or severe, which wi affect the amount of support the pe needs day-to-day[7].	Someone with Fragile X might have short attention span, be easily distra act impulsively, feel restless, be very active, and have heightened senses no two people are the same. Many people with Fragile X might ac way that is similar to someone with autism, including avoiding eye conta feeling anxious in social situations, extreme shyness, enjoying familiar routines and hand flapping or hand	Most people with Fragile X will need support with their speech and langua and with social and emotional interac with others. Some people with Fragil also develop epilepsy, and a few hav autism. This may also have an impac the kind of support they need, both a child and as an adult. With the right support, it is possible for someone w Fragile X to lead a fulfilling life, in the they choose.
Down's syndrome: is a genetic condition. People with Down's syndrome will typically have some of learning disability and character physical features. There are some problems associated with Down's syndrome, such as heart problems difficulties with sight and hearing, these will not affect everyone with condition.	A person with Down's syndrome will some degree of learning disability, b level of ability will be different for eac individual. A child with Down's syndr might take longer than other children age to reach certain milestones and develop certain skills.	They may need ongoing support for different aspects of their life when the become an adult. As with other cond associated with learning disability, ev person with Down's syndrome is an individual and, with the right support opportunities, can lead a happy and fulfilling life.
William's syndrome is a rare genet condition. It occurs randomly and affects 1 in 18,000 people in the UK characterised by cardiovascular disease, developmental delay and learning disabilities. A child's developmental delay means they m take longer to learn how to walk, ta and develop other social skills.	People with William's syndrome are talkative and can be excessively frie	People with William's syndrome can develop physical and mental health problems later in life, including anxie depression.
Cerebral palsy is a physical conditi that affects movement, posture and ordination. It is usually diagnosed birth or in early childhood. Cerebra palsy is not a learning disability, bu some people with cerebral palsy m have a learning disability. Cerebral is usually caused by an injury to th brain before, during, or shortly afte birth, such as a lack of oxygen or illness.	Each individual with cerebral palsy v affected differently, and it can vary fr mild to severe. For some people, ce palsy will affect them physically, mak muscle movements more difficult. O may also be affected by seizures, ep or difficulties with speech and langua	

Other Learning Difficulties

'*Learning Difficulties' and 'Specific Learning Disabilities'*

Mencap and NICE differentiate 'learning disabilities' from 'learning difficulties' and 'specific learning difficulties'. 'Learning difficulties' and 'specific learning difficulties' do not affect intellectual ability and those diagnosed as such are not considered to have a general impairment in intelligence (NICE, NG1112). This means that a person can have difficulties in one or two areas of their learning, but manages well in other areas of their development. For example, a child can have a specific learning difficulty such as dyslexia, having difficulty in reading, writing or understanding what is said to them, but have no problem with learning skills in other areas of life. A child with a specific learning difficulty is as able as any other child, except in one or two areas of their learning. Often, a child will appear to understand, have good ideas, and join in storytelling and other activities, as much as other children, and better than some. Sometimes it can take years for adults to realise that a child has a specific difficulty. For instance, they may find it difficult to recognise letters, or to cope with numbers or reading13. Compared to other children, those with a specific learning difficulty are more likely to develop mental health problems such as anxiety, or have additional developmental disorders such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

Details of common learning difficulties are given in Table 2.

Table 2: Types of specific learning difficulties.

Dyslexia	**Difficulty processing language**	**Problems reading, writing, spelling, speaking**
Dyscalculia	Difficulty with maths	Problems doing math problems, understanding time, using money
Dysgraphia	Difficulty with writing	Problems with handwriting, spelling, organising ideas
Dyspraxia (sensory) integration disorder	Difficulty with fine motor skills	Problems with hand-eye coordination, balance, manual dexterity
Auditory processing disorder	Difficulty hearing differences between sounds	Problems with reading, comprehension, language
Visual processing disorders	Difficulty interpreting visual information	Problems with reading, maths, maps, charts, symbols, pictures

[12] NICE Guidelines on Learning disabilities.
https://www.nice.org.uk/guidance/ng11?unlid=202191859201610163616

[13] http://www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/generallearningdisability.aspx.

Autistic Spectrum Disorder

Autism is a lifelong condition. Someone may have mild, moderate or severe autism, so it is sometimes referred to as a spectrum, or Autism Spectrum Disorder (ASD)[14]. ASD is not a learning disability, but around half of people with ASD may also have a learning disability. They may receive support through learning disability services, however, they may have different types of support needs than people with learning disabilities will have. ASD is a developmental condition present from birth and last throughout life. These conditions are diagnosed by identifying Wings and Gould's (1979) 'triad' of behavioural impairments:

- Impaired social interaction;
- Impaired social communication;
- Impaired imagination.

The concept of the autistic 'spectrum' reflects how autism may occur in 'isolation' (e.g. Asperger syndrome or high-functioning autism) but can also occur in combination with learning difficulties/disabilities[14,15].

Attention Deficit Hyperactivity Disorder (ADHD)

ADHD itself is not considered a learning disability but is readily co-morbid with learning disability, with 45% of children with ADHD having an accompanying learning disability[16]. The DSM-V categorises ADHD under neurodevelopmental disorders group, similar to intellectual (learning) disabilities, but is considered a hyperkinetic disorder which affects self-regulation and executive function. The core symptoms of ADHD are:

- Hyperactivity;
- Impulsivity;
- And/or inattention.

These core features result in significant psychological, social, educational and occupational impairment, and persist over time16[17]. (The following website lists how ADHD clinical symptoms inhibit functioning http://www.helpforadd.com/2013/june.htm).

[14] https://www.mencap.org.uk/learning-disability-explained/conditions/autism-and-aspergers-syndrome

[15] https://ldaamerica.org/types-of-learning-disabilities/

[16] DuPaul, G. J., Gormley, M. J., & Laracy, S. D. (2012). *Comorbidity of LD and ADHD: Implications of DSM-5 for assessment and treatment.* Journal of Learning Disabilities, **46:** 34-51.

[17] NICE: NICE clinical guidelines on ADHD: https://www.nice.org.uk/guidance/CG72/chapter/Recommendations#treatment-for-children-and-young-people

Overlap between Autism and ADHD

Currently, ADHD and ASD are medically considered as separate disorders. However, there is significant co-morbidity between the disorders underpinned by genetic and neurobiological aspects which also overlap between the conditions. Further, similarity in symptoms can cause a child to be incorrectly diagnosed or labelled with one condition rather than the other. For example, children with autism who have language difficulties, can seem like they are not paying attention to directions, but it maybe that they do not understand the directions. Similarly, ADHD can affect social skills and they may avoid eye contact and resort to getting into other people's personal space.

Education

Learning disabilities interfere with learning basic skills such as reading, writing and/or math. They can also interfere with higher level skills such as organisation, time planning, abstract reasoning, long or short term memory and attention which means learning at school or in higher education will be challenging. A child with a general learning disability finds it more difficult to learn, understand and do things compared to other children of the same age. Like all children and young people, children with learning disabilities continue to progress and learn throughout their childhood, but more slowly.

In an educational context, children are described primarily has having special educational needs rather than learning difficulties or disabilities. A child or young person has special educational needs if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her. A child of compulsory school age or a young person has learning difficulties or disabilities if he or she:

(a) Has significantly greater difficulty in learning than the majority of others the same age;

(b) Has a disability which prevents him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.

A child who is identified as having special educational needs in school does not necessarily have a learning disability (or would not meet adult services criteria), and may not therefore go on to access statutory services in adulthood.

The different levels of learning difficulties experienced by a child are classified using the Department of Education categories produced by The Learning Disabilities Observatory (IHaL)[18]:

- *Moderate Learning Difficulty:* Quite often children with moderate learning difficulties find it hard to attempt new tasks alone and require individual pupil support, this is a result of low levels of self-esteem and low confidence in their own abilities to complete the task.
- *Severe Learning Difficulty*: School children with severe learning difficulties experience significant intellectual cognitive impairments which require a high level of support in school.
- *Profound Multiple Learning Difficulty*: School children with profound and multiple learning difficulties can often have more than one disability. These disabilities can be physical and sensory, but they will also have significant problems with learning. Most parents of children

[18] IHaL criteria: http://www.improvinghealthandlives.org.uk/numbers/sendata/detail

with profound and multiple learning difficulties find that residential schools offer the best support.

- *Autistic Spectrum Disorder:* School children with Autistic Spectrum Disorders can find changes to routine very unsettling. Pupils need to be informed and prepared in advance of any changes. Some get special support in mainstream school, and some attend specialist schools. Only certain levels of the Autistic Spectrum are given Statements of Special Needs.

Specific Learning Difficulty: Classroom Needs[19]

Children with specific learning disabilities often become angry and frustrated due to reading difficulties. Behavioural problems can be very common and if they don't get suitable help, the problems may get worse. Older children may become disillusioned, fail exams or get into serious trouble - both at school and outside.

Classroom issues tend to be underpinned with some common characteristics of specific learning disabilities, including:

- Memory difficulties;
- Organisational difficulties;
- Writing difficulties;
- Visual processing difficulties;
- Reading difficulties;
- Auditory processing difficulties;
- Time management difficulties;
- Sensory distraction: an inability to screen out extraneous visual or auditory stimuli;
- Sensory overload: a heightened sensitivity to visual stimuli and sound; an inability to cope with busy environments.

Characteristics of specific learning disabilities can lead to classroom issues for example:

- Specific difficulties can make lessons challenging for a child;
- They may struggle keeping up with classmates, and may come to see themselves as stupid, or no good;
- They may find it difficult to concentrate on lessons and, because they may not be able to follow them properly, they may complain of lessons being `boring';
- The child may search for other ways to pass the time and to succeed;

[19] British Dyslexia Society: http://www.bdadyslexia.org.uk/educator/what-are-specific-learning-difficulties#Dyslexia

- They may try to avoid doing schoolwork because they find it impossible to do it well.
- Doing badly in school can undermine their self-confidence. This can make it harder for the child to get along with other children and to keep friends.

Learning Disability Needs

Learning and Intellectual Needs

People with learning disabilities do not learn certain skills as quickly as other people and may therefore need extra help in certain aspects of their lives. The specific skills in question will depend upon the type of disability. People with mild learning disabilities may live alone, travel independently, and work. They may not require any support from their local authority, or may just need support in managing their finances. Other people may require more regular support to ensure their safety and health on a daily basis. Those with more severe or complex needs may need extensive, hour-to-hour help in performing basic skills, such as eating, dressing and washing.

With the right support people with learning disabilities can live full and meaningful lives. However, if this support is not provided they may face problems in gaining independence or a home of their own, in accessing leisure and recreation activities, and/or in developing friendships and relationships.

Social Impact of Learning Disabilities

People with learning disabilities can be more vulnerable than the general population to abuse and exploitation because of their relative:

- Limited ability to identify risky situations;
- Lack of understanding of the motivation of others;
- Communication difficulties;
- Poor social understanding;
- Vulnerability to being tricked, deceived or exploited by others;
- Propensity for being identified as ‘easy victims’ who will not report crimes to the authorities;
- Likelihood of living in high crime neighbourhoods.

The social impact of this emphasises the importance of safeguarding to protect people with learning disabilities from neglect and abuse. The Government White Paper ‘Valuing People’ set out a vision for the lives of people with learning disabilities. This was underpinned by four key principles; choice, independence, rights and inclusion. Each of these principles emphasised the importance of working in partnership with people with learning disabilities and also introduced a fifth value of collective responsibility.

Challenging Behaviour

People with a learning disability are more likely to display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and is used to indicate that although such behaviour is a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability

(for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating with other people).

Challenging behaviour is not a learning disability, but people with a disability are more likely to show challenging behaviour. This can be due to people having difficulty communicating and expressing frustrations. Challenging behaviour can also be a sign that something is wrong, like pain or discomfort that your child cannot express in another way. Challenging behaviour can also be a sign of wider problems, including with someone's mental health. This behaviour often results from the interaction between personal and environmental factors and includes aggression, self-injury, stereotypic behaviour, withdrawal, and disruptive or destructive behaviour. It can also include violence, arson or sexual abuse, and may bring the person into contact with the criminal justice system[9].

It is relatively common for people with a learning disability to develop behaviour that challenges, and more common for people with more severe disability. Prevalence rates are around 5–15% in educational, health or social care services for people with a learning disability, nationally. Rates are higher in teenagers and people in their early 20s, and in particular settings (for example, 30–40% in hospital settings). People with a learning disability who also have communication difficulties, developmental disorders (autism), sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges (NICE, NG11[12]).

What causes challenging behaviour?

Several factors are associated with challenging behaviours. These include; the environment, relationships, discomfort and frustration. People with a disability are more likely to show challenging behaviour as an attempt to express themselves[9].

Best Practices on the Care of People with Learning Disabilities.

Communicating Effectively Using Positive Behaviour Support (PBS)

Challenging behaviour can arise for many different reasons, dependent on the individual. It may be due to communication or interaction issues, because of pain or illness, environmental overstimulation or under-stimulation or sensory deficits. Positive behaviour support is understanding why the individual exhibits challenging behaviour ("triggers"), and addressing the issues to prevent further episodes of challenging behaviour. This assessment is also known as a functional behavioural assessment, and is used to create an individualised support plan. Positive behaviour support aims, through positive methods, to teach the individual new behaviours and enable them to achieve what they want to achieve[20, 21,22].

Positive behaviour support is a person centred approach rather than a “one size fits all” approach. It is used in different ways, according to the individual’s requirements, and is considered as a long-term management technique. It may involve changing environmental factors that may be the root

[20] http://www.nes.scot.nhs.uk/media/570730/pbs_interactive_final_nov_12.pdf

[21] http://www.aboutlearningdisabilities.co.uk/what-positive-behaviour-support.html

[22] https://www.nice.org.uk/guidance/ng11/documents/challenging-behaviour-and-learning-disabilities-draft-nice-guideline2

cause of the challenging behaviour, so that the person is able to live a more valued, fulfilled life with better access to services. Other examples of positive behaviour support are proactive and reactive strategies and the teaching of new competencies to aid communication and interaction. The basis is the removal of the triggers and any need for 'attention seeking' through challenging behaviour.

The Process

Evidence shows that prevention and reduction of challenging behaviour happens when there is support which:

- increases the individual's quality of life, inclusion and participation;
- defends and supports valued social roles;
- uses principles and procedures from behaviour analysis to assess and support behaviour change and other complementary, evidence-based approaches[23].

The process of PBS requires a functional assessment to plan interventions to change and manage behaviour. Stages involve:

1. Challenging behaviour (to think about the behaviour in terms of):
    - "appearance" – what the behaviour looks like;
    - "rate" - how often it occurs;
    - "severity" - how severe the behaviour is;
    - "duration" - how long it lasts.
2. Functions of the challenging behaviour (the reason the behaviour happens which will come under one of the following categories):
    - Social attention;
    - Escape/avoidance;
    - Tangible;
    - Sensory.

Behaviours can be rated using a traffic light system which helps to clarify the different stages of the behaviour:

- Green = calm & relaxed;
- Amber = anxious, aroused or distressed;
- Red = incident;

[23] http://www.skillsforcare.org.uk/Topics/Learning-disability/Positive-behavioural-support/Positive-behaviour-support.aspx

- Blue = calming down - but still need to be careful.

An individual's behaviour moves from 'typical behaviour' (green), to a level that indicates that problems are about to occur (amber) prior to the occurrence of the behaviour itself (red).

After the behaviour (blue) care must be taken to ensure that the person returns to the green phase. This format enables carers to more easily identify when they could intervene to prevent behaviour escalating into an episode of challenging behaviour[24].

[24] http://www.challengingbehaviour.org.uk/learning-disability-files/03---Positive-Behaviour-Support-Planning-Part-3-web-2014.pdf

LEGISLATION

Mental Capacity Act 2005

The primary purpose of the Mental Capacity Act 2005[25] is to promote and safeguard decision making within a legal framework by empowering people to make decisions for themselves wherever possible, and by protecting people who lack capacity by providing a flexible framework that places individuals at the heart of the decision-making process.

Disability and Equality Act 2010

Since the Disability and Equality Act 2010[26], disabled people have important rights of access to everyday services (Directgov). Service providers are now obliged to make reasonable adjustments to premises or to the way they provide services. Access to services is not only about physical access, it is about making services easier to use for everybody, for example longer appointment times and more accessible health promotion information [27].

The Care Act 2014

The Care Act 2014[28] came into effect on 1st April 2015 and represents the single biggest reform of social care legislation since the National Assistance Act 1948. It integrates and improves upon all previous legislation and incorporates accepted good practice as part of the legal framework and guidelines. The key focus of the act is the statutory principle of individual wellbeing and aims to achieve:

- Clearer and fairer care and support;
- Physical, mental and emotional wellbeing of both the individual needing care and their carer;
- Preventing, reducing and delaying the need for care and support;
- Putting people in control of their own care.

The Act specifically refers to the following areas for local councils:

- Duty to Promote Wellbeing and to undertake Prevention Activities - the Act gives a wide ranging and specific set of directives to promote wellbeing and to prevent, reduce and delay needs developing.
- Provide Information and Advice - it also a requirement of local authorities to offer comprehensive information and advice about local services to people who make inquiries therefore enabling them to make more informed decisions about the care for themselves and members of their family.

[25] https://www.legislation.gov.uk/ukpga/2005/9/contents

[26] https://www.gov.uk/definition-of-disability-under-equality-act-2010

[27] Available at: https://www.legislation.gov.uk/ukpga/2010/15

[28] Available at: http://www.legislation.gov.uk/uksi/2010/2128/contents/made

- Independent Advocacy - importantly for people with a learning disability, the act introduces a requirement to provide independent advocacy for those who need it.
- Safeguarding - for the first time, safeguarding of vulnerable adults is placed on a statutory footing; this is of particular importance for people with learning disability considering the number of high profile cases where people with learning disability have been the victims of serious crime, occasionally ending in loss of life.
- Diversity and Quality in the Care Market - a new duty for local authorities is to promote quality and diversity in the market of care; local authorities must act to ensure there are a variety of high quality providers who are able to meet the needs of local people.
- Integrating Services - the local authority has a duty to ensure that services are fully integrated and joined up i.e. health, housing, education and social care; this has implications for how commissioning is undertaken.

The Act also builds on other important standards which need to be taken into account when commissioning, notably the Human Rights Act 2004 and duties under the Equalities Act 2010, as well as duties to promote social value under the Public Services (Social Value) Act 2013 and to undertake Joint Strategic Needs Assessment (JSNA) under the Public Involvement in Health Act (2007).

Our Health, Our Care, Our Say.

'Our Health, Our Care, Our Say'[29] is a White Paper published in 2006 building on the Green Paper referred to above which sets out a new direction for the whole of the health and social care system and builds on the Green Paper Independence, Wellbeing and Choice referred to above. Although much of this is concerned with healthcare, there is a strong emphasis on choice and control through personalised services, self-assessment and people planning and managing their own services.

'Valuing People' and 'Valuing People Now'

The 'Valuing People' white paper published in 2001 formed the basis of the subsequent government paper 'Valuing People Now: A new three-year strategy for people with learning disabilities'[30] (published in 2009) with both representing key benchmark documents for the principles underpinning the provision of services for people with a learning disability foreshadowing, as they do, the era of personalisation, empowerment and choice.

'Valuing People' recognises that people with a learning disability are among the most vulnerable and socially excluded in our society. The strategy set out new opportunities for children and adults with a learning disability and their families and called for action to reduce health inequalities and discrimination. It has six priority areas:

- Disabled children and young people;

[29] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/272238/6737.pdf

[30] Valuing People Now. A new three year strategy for people with learning disabilities – Making it happen for everyone. Department of Health (2009). Available at: http://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf

- More choice and control for people with a learning disability;
- Supporting carers;
- Improving health for people with a learning disability;
- Housing, fulfilling lives and employment;
- Quality services.

'Valuing People Now' set out the Government's strategy for people with learning disabilities and responds to the main recommendations in 'Healthcare for All', which was an independent inquiry set up after the publication of 'Death by Indifference'.

In 2004 the charity Mencap launched "Treat Me Right", a major campaign aimed at improving the health care of people with learning disability. The basis of this was that people with learning disability have specific health problems attributable to their disability and they are more likely to have a lower income and less healthy lifestyle. The campaign exposed the unequal healthcare that people with a learning disability often receive from healthcare professionals and the report made clear that much work needed to be done within the NHS to ensure that people with a learning disability are treated decently and equally. As the study progressed, six parents with offspring who had died within the healthcare system came forward and described what had happened which culminated in the study 'Death by Indifference'[31] which was published in 2007. The main contentions within the report were:

- People with a learning disability are seen to be a low priority.
- Many healthcare professionals do not understand much about learning disability.
- Many healthcare professionals do not properly consult and involve the families and carers of people with a learning disability.
- Many healthcare professionals do not understand the law around capacity and consent to treatment.
- Health professionals rely inappropriately on their estimates of a person's quality of life.
- The complaints system within NHS services is often ineffectual, time-consuming and inaccessible.

The 'Death by Indifference' report prompted an independent inquiry into access to healthcare for people with learning disabilities, 'Healthcare for All'[32], which reported in 2008 and confirmed the findings 'Death by Indifference' and expanded the commentary in detail linking recommendations back to key legislation and policy. The report made 10 recommendations to improve the healthcare of people with learning disability:

[31] Death by indifference: 74 deaths and counting. A progress report 5 years on. Available at: https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf

[32] Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities. London: Department of Health. (2008). Available at: http://webarchive.nationalarchives.gov.uk/20130105064756/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf

- Improved training for those with responsibility for the provision and regulation.
- All healthcare organisations should ensure the collection of information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.
- Family and other carers should be involved as a matter of course as partners in the provision of treatment and care.
- The needs of people with learning disabilities and their carers should be identified and assessed by relevant authorities as part of their Joint Strategic Needs Assessment.
- A learning disabilities Public Health Observatory should be established which will raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of LD services.
- Core Standards for Better Health should be amended to include explicit reference to the requirement to make 'reasonable adjustments' to the provision and delivery of services for vulnerable groups, in accordance with the disability equality legislation.
- Inspectors and regulators of the health service should develop and extend their monitoring of the standard of general health services provided for people with learning disabilities in order to support appropriate, reasonable adjustments to general health services for adults and children with learning disabilities and their families.
- The Department of Health should direct relevant health care providers to secure general health services that make 'reasonable adjustments' for people with learning disabilities through a Directed Enhanced Service.
- It must be ensured that that the views and interests of people with learning disabilities and their carers are included in the planning and development of services and in decisions affecting the operation of services.
- Health care providers should demonstrate in routine public reports that they have effective systems in place to deliver effective, 'reasonably adjusted' health services for those people who happen to have a learning disability.

There were 11 key objectives detailed in 'Valuing People Now' which were enshrined within the four themes of Rights, Independence, Choice and Inclusion initially set out in 'Valuing People'. These are related to the Human Rights Act 1998 and the Disability Discrimination Act 1995 and are clearly linked to other documents referred to in this text and enshrined in the new Care Act 2014 which is also referred to in this section.

The objectives are:

- Maximising Opportunities for Disabled Children. In all areas of life including education, health and social care; whether with families or elsewhere.
- Transition into Adult Life. As young people move into adulthood, ensure continuity of care and support for the young person and their family and provide equality of opportunity in order

to enable as many young people as possible to participate in education, training and employment.

- Enable People to Have More Control Over Their Own Lives. This can be achieved by enabling people with learning disability to have as much choice and control as possible through advocacy and person centred planning (and by implication; personal budgets/direct payments) to planning the services they need.
- Supporting Carers. To increase the help and support carers receive from all local agencies in order to fulfil their caring role more effectively.
- Good Health. To enable people with learning disability to gain access to a health service designed to meet their individual needs.
- Housing. To enable people with learning disability to have greater choice and control over where and how they live.
- Fulfilling Lives. To enable people with learning disabilities to lead full and purposeful lives in communities and develop a range of friendships, activities and relationships.
- Moving into employment. To enable more people with learning disabilities to participate in as many forms of employment as possible and to make a contribution to the world of work. This might also include voluntary work.
- Quality. To ensure that all agencies provide a high quality, evidence based and continually improving quality of service which promotes both good outcomes and best value.
- Workforce and Planning. To make sure that all health and social care staff working with people with a learning disability are appropriately trained, skilled and qualified and to promote a better understanding of people with a learning disability.
- Partnership working. To promote a more fully integrated and holistic way of working between all agencies to ensure uniformity and consistency of quality and provision for people in the commissioning and delivery of services.

'Valuing People Now' goes on to reinforce the developing themes of Personalisation (individual Direct Payments) improved daytime activity, choice rights and housing as well as advocacy services.

Independence, Wellbeing and Choice

'Independence, Wellbeing and Choice'[33] was published by the Department of Health in March 2005, this was a government Green Paper setting out the vision for the future direction of social care for all adults of all age groups in England. The vision is one of:

- Greater independence through choice and control over the way people's needs are met. In effect this is referring to Personal Budgets and Direct Payments.
- Well planned (commissioned) and integrated care services.

[33] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/272101/6499.pdf

This Paper is explicitly set within the context of:

- Greater public expectation driven by consumer (public) choice.
- Changes in mobility with the breakdown of the traditional family ties and proximity and many more people living alone.
- The balance of risk between independence and protection.
- Changes in the population which will increase demand. People with learning disability are specifically referred to. At the time of the report there were an estimated 800,000 people with learning disability but, because of improvements in medical technology this was estimated to rise by a further 14% to over 900,000 by 2021. Moreover, premature death due to specific conditions associated with people with a learning disability has also been reduced, therefore people live longer.

In this document, the importance of outcomes is emphasised together with improved assessment and Direct Payments and Personal Budgets are seen as a way of achieving these. The role of the wider community is also emphasised, in particular, the role of carers. A whole chapter is devoted to strategic commissioning and community capacity building.

Transforming Care

In May 2011 the BBC Panorama programme showed the Winterbourne View documentary. Winterbourne View was a private hospital for specialist medical help for people with learning disability. Undercover live filming by a BBC reporter in the hospital showed residents/patients with learning disability being tortured and abused by the people who were employed to care for them. Several staff received prison sentences and the government initiated a nationwide programme of measures to ensure the safety and wellbeing of people with learning disabilities placed in Assessment and Treatment Units countrywide. This programme was updated as recently as June 2015 and the plan re-vitalised as the 'Transforming Care Programme'[34], advocating and monitoring the principles of proactive case management and planned repatriation to improve services for people with learning disabilities and/or autism, who display behaviour that challenges, including those with a mental health condition. The programme is designed to drive system-wide change and enable more people to live in the community, with the right support, and close to home. Led jointly by NHS England, the Association of Adult Social Services (ADASS), the Care Quality Commission (CQC), Local Government Association (LGA), Health Education England (HEE) and the Department of Health (DH), the Transforming Care programme focuses on the five key areas of:

- Empowering individuals;
- Right care, right place;
- Workforce;
- Regulation;
- Data.

[34] https://www.england.nhs.uk/learning-disabilities/care/

The plan builds on other transforming care work to strengthen individuals' rights; roll out care and treatment reviews across England, to reduce unnecessary hospital admissions and lengthy hospital stays; and test a new competency framework for staff, to ensure we have the right skills in the right place.

The Transforming Care programme is focusing on addressing long-standing issues to ensure sustainable change that will see:

- More choice for people and their families, and more say in their care.
- Providing more care in the community, with personalised support provided by multi-disciplinary health and care teams.
- More innovative services to give people a range of care options, with personal budgets, so that care meets individuals' needs.
- Providing early more intensive support for those who need it, so that people can stay in the community, close to home.
- Ensuring where there is a need for in-patient care that it is only for as long as it is needed.

Think Local, Act Personal

Think Local Act Personal (TLAP)[35] is a national partnership of more than 50 organisations committed to transforming health and social care through personalisation and community support. The partnership spans:

- Central and local government;
- The NHS;
- The provider sector;
- People with care and support needs, carers and family members with whom we engage via the National Co-production Advisory Group.

The work of the partnership is coordinated by a small core team with policy advisors responsible for pooling resources from different partnership members. This arrangement puts the partnership in the unique position of bringing together people who use services and carers with national organisations. The TLAP partnership is open to any national organisation not represented through one of the umbrella associations already involved, that is willing and able to make a specific commitment of support. It emphasises co-production at all levels with an emphasis on improved lives and independence with enhanced wellbeing and resilient communities (communities that are able to "rally round" and support people consistently, rather than just service provision. Personal budgets and Direct Payments are seen as part of this.

[35] https://www.thinklocalactpersonal.org.uk/

GOOD PRACTICE AND ORGANISATION OF SERVICES

Good Practice Guidance

It is evident that people with LD want to live in mainstream society and to do the things that most people take for granted such as studying, working, having relationships and friendships and joining in social and leisure activities. National policy reflects this and good practice should enshrine the need to provide services that support people to have healthy, meaningful and fulfilled lives. The central precept upon which services should be developed is that individuals with LD have the same rights and aspirations as other people and that in commissioning services a number of 'default positions' should be taken:

- A person must be assumed to have the mental capacity to make decisions about their care, unless it is established that they lack capacity for that specific decision - and all practicable steps should be taken to support them to make their own decisions.
- People's homes should be in the community, supported by local services.
- The starting point should be for mainstream services, which are expected to be available to all individuals, to support people with LD, making reasonable adjustments where necessary, with access to specialist multi-disciplinary community-based expertise as appropriate.

In 2015 NHS England, the Local Government Association (LGA), and the Association of Directors of Adult Social Services (ADASS) published a new draft national framework[36] designed to improve the care of people with learning disabilities, shifting services away from hospital care and towards community-based settings. The framework sets out nine overarching principles which define what 'good' services for people with learning disabilities and/or autism whose behaviour challenges should look like:

- Providing more proactive, preventative care, with better identification of people at risk and early intervention;
- Empowering people with a learning disability and/or autism, for instance through the expansion of personal budgets and personal health budgets and independent advocacy;
- Supporting families to care for their children at home, and the provision of high-quality social care with appropriate skills;
- Providing greater choice and security in housing;
- Ensuring access to activities and services that enable people with a learning disability and/or autism to lead a fulfilling, purposeful life (such as education, leisure);
- Ensuring access to mainstream health services (including mainstream mental health services in the community);
- Providing specialist multi-disciplinary support in the community, including intensively when necessary to avoid admission to hospital;

[36] Supporting people with a learning disability and / or autism who have a mental health condition or display behaviour that challenges. Available at: https://www.england.nhs.uk/wp-content/uploads/2015/07/ld-draft-serv-mod.pdf

- Ensuring that services aimed at keeping people out of trouble with the criminal justice system are able to address the needs of people with learning disabilities and/or autism, and that the right specialist services are in place in the community to support people with a learning disability and/or autism who pose a risk to others, and;
- Providing hospital services that are high-quality and assess, treat and discharge people with a learning disability as quickly as possible.

These principles are designed to underpin how local services are planned while allowing for local innovation reflecting differing local needs and circumstances, while ensuring consistency in terms of what patients and their families should be able to expect from local decision-makers.

Guidance is provided by the National Institute for Clinical Excellence (NICE) which covers interventions and support for children, young people and adults with a learning disability and behaviour that challenges[37]. It highlights the importance of understanding the cause of behaviour that challenges, and performing thorough assessments so that steps can be taken to help people change their behaviour and improve their quality of life. The guideline also covers support and intervention for family members or carers. The guideline includes recommendations on:

- general principles of care;
- support and interventions for family members or carers;
- early identification of the emergence of behaviour that challenges;
- assessment;
- psychological and environmental interventions;
- medication;
- interventions for coexisting health problems and sleep problems.

Organisation of Services

People with learning disabilities will have a need to access a range of health and social care services throughout their lives. While many will require only basic support others will need additional services, and a few will require a comprehensive range of services. In order to deliver the requirements of all GP lead primary care teams, secondary care mental health services and specialist learning disability services need to work closely together so that coordinated planning and provision is achieved. Planning ahead is essential so that individuals with LD have appropriate person centred plans for their current and future service needs. Planning will also allow care providers to proactively build capacity into the system to cope with future demand.

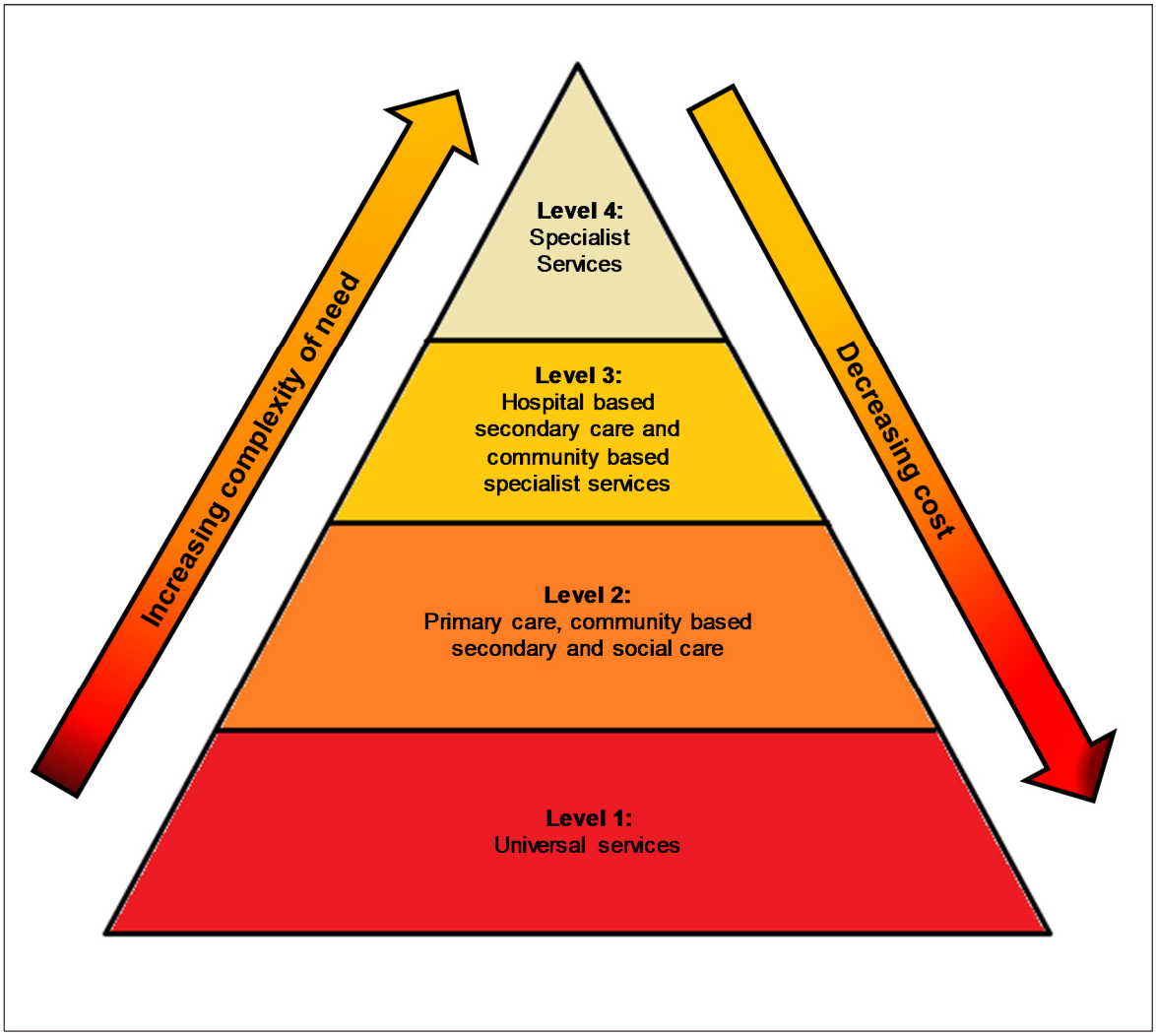
Services for people with LD should be organised in a tiered approach with increasing levels of care and intervention with increasing complexity of need as indicated in the pyramid of services and support (see Figure 1).

[37] Challenging Behaviour and Learning Disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guideline 11: Methods, evidence and recommendations. May 2015. Available at: https://www.nice.org.uk/guidance/ng11/evidence/full-guideline-pdf-2311243668

Level 1 - Universal Services

The difference between the number of registered and estimated number of adults with LD indicates that the majority of individuals live in the community with limited support with no social care. As discussed individuals with LD are at higher risk of many physical and mental health conditions, have fewer opportunities to work and often experience social deprivation. Supporting people with learning disabilities to lead healthy, meaningful lives and preventing the need for more intensive and expensive service provision requires Universal Services to be accessible which involves 'reasonable adjustments' to be made to the service to improve access for less able users. Universal Services are primarily focused on improving the health of the whole population of people with learning disabilities. Good access to housing, leisure, education, transport and employment are known to have a positive impact on mental health. It is a statutory requirement that public sector agencies make 'reasonable adjustments' to their practice that will make services as accessible to disabled individuals as for people without disabilities. All adults with LD will use universal services.

Figure 1: Pyramid of services and support for the organisation of LD services.



Level 2 - Targeted Services

As discussed, due to various factors such as increased deprivation, poorer life style behaviours and poor physical conditions, individuals with LD often have poorer health and die younger than other people. This is often exacerbated by poor understanding of physical changes and problems associated with poor health in those with LD, while the awareness of how to get help from health services is also an issue.

Individuals with LD must be able to access targeted mainstream health services provided by primary and community based secondary healthcare services in the same way as the general population. In primary care, this means regular health checks, advice and support on lifestyle factors such as diet, exercise, alcohol consumption and sexual health. Other services include health facilitation to improve access to primary care and health liaison to improve access to acute hospital based care. Training and support for carers should be made available. Improving access to psychological therapies is included at this level.

This again involves 'reasonable adjustments' to be made to services to meet individual users' needs and for providers to monitor the quality of the services provided to determine their adequacy and amend as appropriate. For individuals with LD this will commonly involve clear, simple and possibly repeated explanations of what is happening, and of treatments to be followed, helping with appointments and managing issues of consent.

Level 3 - Targeted Services

Other targeted services include social care and continuing health care funded services provided by Community Mental Health and Learning Disability teams who provide assessment, treatment and some on-going support for people with a moderate degree of mental health need (significant anxiety and depression, psychotic disorders, and cognitive impairment). These teams will have expertise in dealing with perceived behaviour problems associated with these conditions, as well as the whole range of learning disability and coexisting autism and ADHD. Services include assessment, treatment and some on-going support for people with a moderate degree of mental health need.

Level 4 - Specialist Services

Specialist services include hospital based secondary care and community based services such as those provided by Community Mental Health Teams and Community Learning Disability Teams. Services need to have expertise in dealing with people who are a severe risk to themselves and others, often with chronic severe treatment resistant mental illness, behaviour problems and offending behaviour. People with LD have the right to the same level of medical and nursing care as the general population. Consequently, services must make 'reasonable adjustments' as appropriate so that any diagnosis or treatment appreciates the individual's needs to ensure that the best possible health outcome is achieved. The strategy would be to incorporate greater integration, communication and information sharing between general hospital and learning disability services in identifying the individual's needs which will inform the care plan. Such a process, the 'Care Bundle' has been trialled in Wales[38] which has four key steps:

- Early recognition of patients who have learning disabilities.

[38] All Wales Care Bundle. Available at: https://www.ldw.org.uk/media/211979/all_wales_care_bundle.pdf

- Effective communication with patients, family members, carers and hospital staff.
- Patient-centred care planning.
- Effective review and discharges planning through multi-agency joint working.

It is perceived that the Care Bundle will achieve a number of benefits, including:

- Health services being more responsive to the individual needs of patients with learning disabilities.
- Improved clinical outcomes and experiences for patients and their carers.
- Length of admission more appropriate to the patient's clinical needs and more effective timely discharge.
- Improved joint working between statutory and third sector providers.
- Better communication and information sharing between stakeholders.

People with learning disabilities are a vulnerable population who have a significantly higher risk of developing mental health problems which can be overlooked or wrongly attributed to the learning disability itself. Proactive and preventive approaches are essential in relation to mental health problems to ensure timely detection, assessment and subsequent treatment of an individual, as delay can lead to progressive deterioration of mental health and behaviour. Any deterioration may result in the need for more intensive services over a longer period, often in a more restrictive and distant setting, which, as well as causing unnecessary suffering to the individual and their family, can increase costs significantly. It is also often difficult for people with learning disabilities to access generic and specialised mental health services[39]. Consequently:

- Reasonable adjustments are a legal requirement and should be put in place to enable access to all mainstream services where appropriate.
- Learning disability services should be provided alongside mainstream mental health services so that the skills and expertise from both services can be utilised in order to respond to individual need.
- There should be clarity with regard to commissioning arrangements between learning disability and mental health commissioners, with a presumption of accessing generic services wherever possible and there should be protocols setting out clear pathways between mainstream and specialist services.
- Where an individual lacks capacity and does not have a family to support them, the procedures of the Mental Capacity Act 2005 should be followed to ensure that decisions made are in her/his best interest and, if appropriate, an Independent Mental Capacity Advocate appointed.

[39] Guidance for commissioners of mental health services for people with learning disabilities. Joint Commissioning Panel for Mental Health, 2013. Available at: https://www.jcpmh.info/wp-content/uploads/jcpmh-learningdisabilities-guide.pdf

Community Learning Disability Teams. and the services they provide should be organised as fully inter-disciplinary team with sufficient capacity to deliver the following five functions required by commissioners for inclusion in commissioning service specifications, operational policies and reviews[40].

These are:

- Supporting positive access to and responses from mainstream services.
- Targeted work with individuals and services enabling others to provide effective person-centred support to people with learning disabilities and their families/carers.
- Specialist direct clinical therapeutic support for people with complex behavioural and health support needs.
- Responding positively and effectively to crisis presentations and urgent demands.
- Quality assurance and strategic service development in support of commissioners.

Individuals with LD who have come into contact with or may be at risk of coming into contact with the criminal justice system, should have access to the same services aimed at preventing or reducing anti-social or 'offending' behaviour as the rest of the population[41]. Often individuals with LD some of those people with a learning disability who end up in hospitals following contact with the criminal justice system have mild to moderate learning disabilities as well as having difficult backgrounds. In order to secure better outcomes for individuals there is a need to focus on reducing the likelihood of offending or reoffending from as early on as possible. Such an approach requires collaboration between services aimed at preventing or reducing anti-social or offending behaviour, community mental health and forensic services and specialist health and care services with specialist LD services providing advice and support to ensure they are able to deal effectively to people with LD.

The NHS Liaison and Diversion (L&D)[42] services identify people who have mental health, learning disability, substance misuse or other vulnerabilities when they first come into contact with the criminal justice system as suspects, defendants or offenders. The services aim to improve overall health outcomes for people and to support people in the reduction of re-offending. It also aims at timely identification of vulnerabilities in people which reduces the likelihood that they will reach a crisis-point and helps to ensure the right support can be put in place from the start.

[40] Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers. A Briefing Paper on Service Specifications and Best Practice for Professionals, NHS Commissioners, CQC and Providers of Community Learning Disabilities Health Team by the National LD Professional Senate. March 2015. Available at: https://www.bps.org.uk/system/files/user- files/DCP%20The%20Faculty%20for%20People%20with%20Intellectual%20Disabilities/public/national_ld_professional_senate_guidelines_for_cldt_specialist_health_services_final_3_march_2015_with_references.docx.

[41] The Bradley Report - Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system. April 2009 http://webarchive.nationalarchives.gov.uk/20130105193845/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_098698.pdf

[42] Liaison and Diversion Standard Service Specification 2013/14. Availalble at: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2014/04/ld-ser-spec-1314.pdf

The main things that L&D services do for the people they see are identification, screening, assessment and referral to other services. These are explained below:

- Identification - criminal justice agencies working at the Police and Courts stages of the pathway are trained to recognise possible signs of vulnerability in people when they first meet them. They then alert their local L&D service about the person.

- Screening - once someone is identified as having a potential vulnerability, the L&D practitioner can go through screening questions to identify the need, level of risk and urgency presented. It also helps determine whether further assessment is required.

- Assessment - using approved screening and assessment tools an L&D practitioner will undertake a more detailed assessment of the person's vulnerability. This provides more information on a person's needs and also whether they should be referred on for treatment or further support.

- Referral - the L&D practitioner may refer someone to appropriate mainstream health and social care services or other relevant interventions and support services that can help. A person is also supported to attend their first appointment with any new services and the outcomes of referrals are recorded. L&D services will also provide a route to treatment for people whose offending behaviour is linked to their illness or vulnerability.

The police, probation and the judiciary make decisions based on the evidence and information presented to them. L&D services record all information about a person's health needs and share these with relevant agencies so they can make informed decisions about case management, sentencing and disposal options.

It is likely that all people with LD will need to access level 1 and level 2 services, while only those with more severe LD and complex needs will also access level 3 and 4 services. Cost of care falls as less intensive services are used and independent living skills are gained by the individual receiving care and support.

DEMOGRAPHICS

The Office for National Statistics (ONS) publishes mid-year population estimates for local authorities each summer; the 2015 figures were released in June 2016.

Herefordshire is a predominantly rural county, with the 4th lowest population density in England. Between 2001 and 2015 the Herefordshire population increased from 174,900 to 188,300[43] which represents a 7.7 per cent increase compared to population growth of 11 per cent observed in England and Wales over the same period. If recent (last five years) demographic trends were to continue and nationally determined assumptions about future fertility, mortality and migration were to be realised, the total population of Herefordshire is likely to increase by 2 per cent from 188,300 in 2015 to 193,000 in 2020, and to 206,300 people by 2035, an increase of 9.6 per cent from 2015 (Table 3). This growth rate would be equivalent to an average annual increase of 0.48 per cent over this 20-year period, although this is lower than the projected annual rate of growth for England as a whole of 0.69 per cent[44].

Table 3: Estimated headline population figures for Herefordshire, mid-2015 to mid-2035.

Age group	2015	2020		2025		2030		2035	
		N	% change	N	% change	N	% change	N	% change
0-4	9,900	9,700	-2.0	9,800	-1.0	9,600	-3.0	9,500	-4.0
5-9	10,100	10,600	5.0	10,400	3.0	10,500	4.0	10,400	3.0
10-14	9,700	10,500	8.2	11,000	13.4	10,900	12.4	11,000	13.4
15-19	10,200	9,300	-8.8	10,100	-1.0	10,500	2.9	10,400	2.0
20-24	9,500	8,400	-11.6	7,700	-18.9	8,500	-10.5	8,800	-7.4
25-29	10,700	11,100	3.7	10,200	-4.7	9,500	-11.2	10,400	-2.8
30-34	10,300	11,300	9.7	11,700	13.6	10,800	4.9	10,200	-1.0
35-39	9,900	10,700	8.1	11,500	16.2	11,900	20.2	11,100	12.1
40-44	11,100	10,200	-8.1	10,900	-1.8	11,700	5.4	12,100	9.0
45-49	13,500	11,500	-14.8	10,500	-22.2	11,300	-16.3	12,100	-10.4
50-54	14,200	13,900	-2.1	12,000	-15.5	10,900	-23.2	11,700	-17.6
55-59	12,800	14,600	14.1	14,400	12.5	12,500	-2.3	11,400	-10.9
60-64	12,400	13,100	5.6	14,900	20.2	14,800	19.4	12,900	4.0
65-69	13,400	12,400	-7.5	13,100	-2.2	15,000	11.9	15,000	11.9
70-74	10,600	12,900	21.7	11,900	12.3	12,700	19.8	14,600	37.7
75-79	8,100	9,600	18.5	11,900	46.9	11,100	37.0	11,900	46.9
80-84	6,000	6,700	11.7	8,200	36.7	10,200	70.0	9,600	60.0
85-89	3,800	4,300	13.2	5,000	31.6	6,300	65.8	7,900	107.9
90+	2,100	2,500	19.0	3,100	47.6	4,000	90.5	5,300	152.4
All ages	188,300	193,300	2.7	198,300	5.3	202,700	7.6	206,300	9.6

Source: ONS

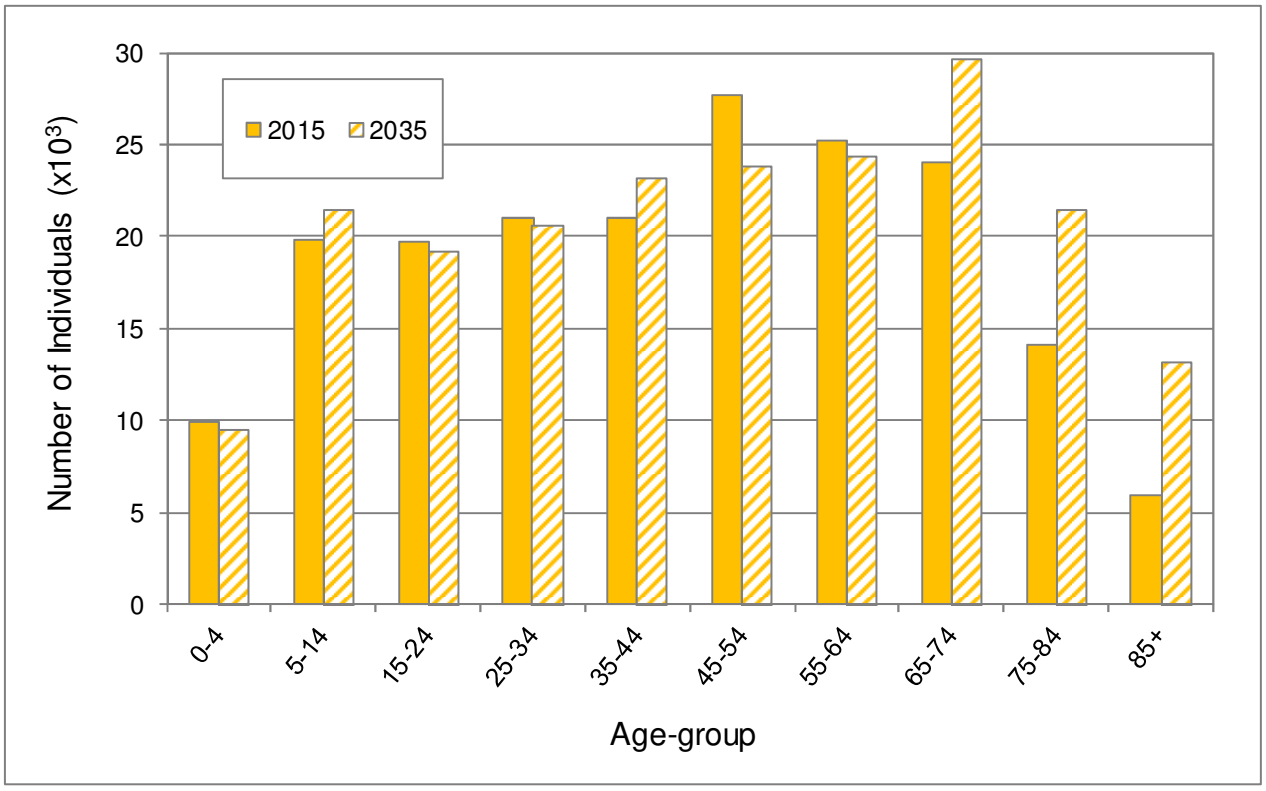
[43] Annual 2015 Mid-Year Population Estimates for the UK, Office for National Statistics © Crown Copyright.

[44] *The Population of Herefordshire, 2016*. Strategic Intelligence Team, Herefordshire Council.

Between 2015 and 2035 it is predicted that the number of individuals in Herefordshire aged 65 and over will increase appreciably from 44,000 to 64,300 (Figure 2), with these figures representing an increase from 23.4 to 31.1 per cent of the total population. Within this group increases of over 7,000 are predicted for those aged between 75 and 84 and those aged 85 and over. The number of individuals aged between 5 and 14 and those aged between 35 and 44 are also predicted to rise, although the changes in the proportions of the population represented by these groups are both less than 1 per cent.

Over this 20 year period the number of individuals aged between 45 and 54 are predicted to fall by almost 4,000 with a concomitant fall in proportion of the population from 14.7 to 11.5 per cent. Falls of between 400 and 900 in the number of individuals are predicted in other age groups, particularly in those aged under 35, although in the these age groups the predicted change in proportion of population are all less than 2 per cent.

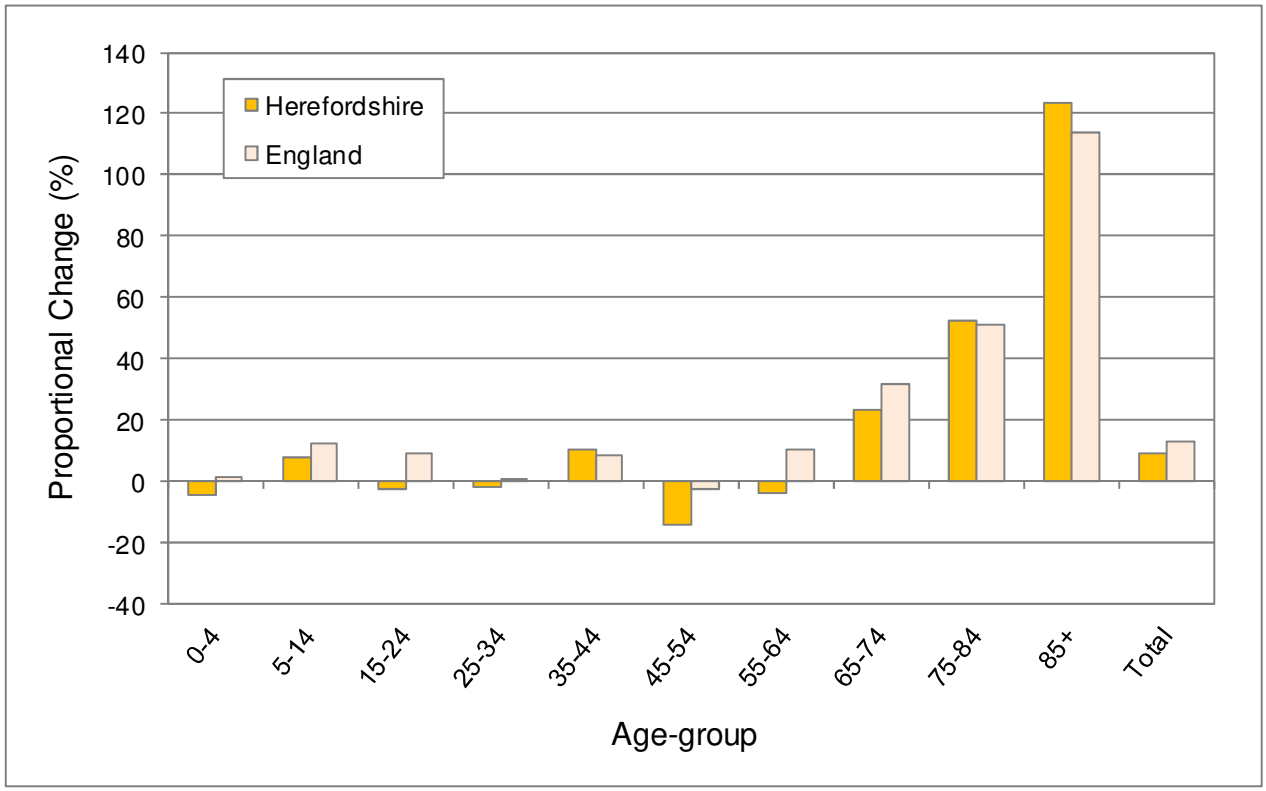
Figure 2: Number of individuals by age group in Herefordshire in 2015 and 2035.



Source: ONS

Between 2015 and 2035 the numbers of individuals in the majority of age groups in Herefordshire are predicted to fall, although in most cases the proportional changes are less than 5 per cent (Figure 3). This is at odds with the national pattern where small proportional increases are evident in the majority of age groups under 65 years of age. In all age groups at 65 years and over appreciable proportional increases are evident with the magnitude increasing with age, a pattern evident across England as a whole.

Figure 3: Proportional population change by age-group in relation to predicted population change in Herefordshire and England, 2015 and 2035.



Source: Intelligence Unit, Herefordshire Council

PREVALENCE OF LEARNING DISABILITIES

Age, Sex, Deprivation and Ethnic Group

It is understood that the prevalence of learning disabilities is associated with age, gender, ethnicity and deprivation as follows[45]:

- **Age -** Due to the reduced life expectancy of people with learning disabilities, learning disabilities are significantly more prevalent in younger adult age groups. As a result, areas with younger demographic profiles would be expected to have an increased number of adults with learning disabilities and autism.
- **Gender** - Of those known to services, learning disability appears to be more prevalent amongst men.
- **Ethnicity** - Severe learning disabilities are more common among the Pakistani and Bangladeshi community. As a result, areas with higher proportions of young Pakistani and Bangladeshi adults would be expected to have an increased number of adults with learning disabilities and autism.
- **Deprivation** - Learning disabilities are more common in poorer households and less severe learning disabilities are also more common in poorer communities. As a result, more socially deprived areas would be expected to have an increased number of adults with learning disabilities and autism. However, this effect may not be particularly pronounced as autism is less common among people with less severe learning disabilities.

Recent Patterns

Difference Between Known and True Prevalence (i.e. met and unmet need)

Although having a moderate or severe learning 'difficulty' does not always imply a learning 'disability', the likelihood is that for the majority of individuals this will be the case. Appreciable differences exist nationally between the estimated prevalence of moderate and severe learning difficulties in schools (around 24.5 per 1,000) and in adults who have learning disabilities (4.3 per 1,000). This would indicate that for instances where moderate or severe learning difficulties are identified in school many cases develop into adults with a learning disability which is unknown to their GP and other health services[27]. In the following discussion those adult LD cases known to the health services are referred to as 'registered patients' while the true prevalence is discussed in terms of the 'whole population'.

Registered Patients

"Registered Patients" refers to the number of patients recorded on their general practice's LD register. Data from NHS Digital[46] indicates that at the end of 2015/16 there were 976 patients across

[45] Emerson E, Baines S (2010). The Estimated Prevalence of Autism among Adults with Learning Disabilities in England: Improving Health and Lives, Learning Disabilities Observatory. http://www.improvinghealthandlives.org.uk/publications 2010

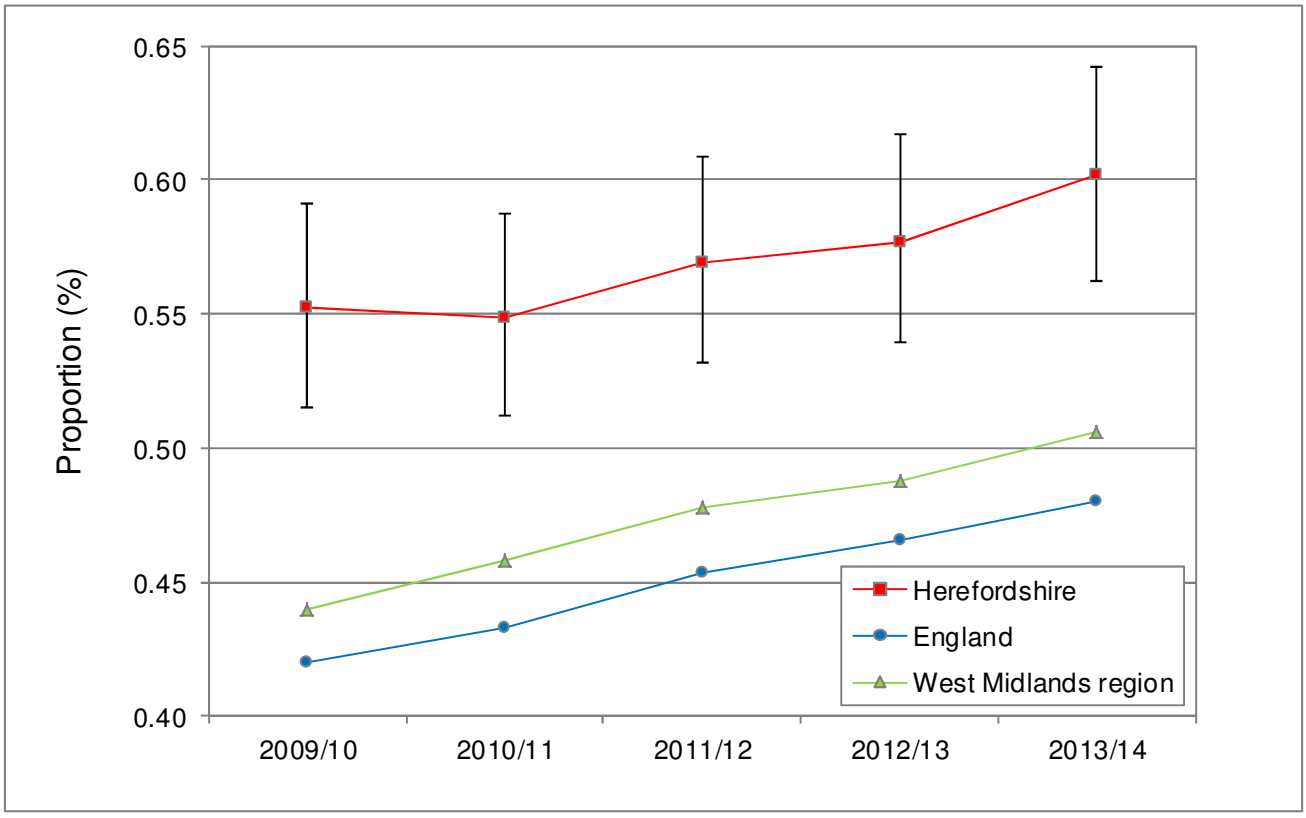
[46] Health and care of people with Learning Disabilities, Experimental Statistics, 2015-16. http://digital.nhs.uk/pubs/LD1516

Herefordshire recorded on their general practice's Learning Disabilities Register, as per the current QOF[47] definition, compared to 821 at the start of the period, which represents a proportional increase of 14.6 per cent over the year compared to 19.4 per cent increase observed nationally. The local end of year figure represents an all age LD prevalence of 0.52 per cent compared to a figure of 0.45 per cent for England and 0.50 for the West Midlands.

The number of adults (18+) with LD in Herefordshire and registered as such on Herefordshire GP practice lists was 900. This figure represents a local prevalence of0.60 per cent, while the figures for England and the West Midlands were 0.50 and 0.54 per cent respectively.

Between 2009/10 and 2013/14 the number of adults with LD recorded on GP practice lists in Herefordshire increased steadily from 808 to 889 which represents a 10.0 per cent rise; increases were also observed across England and the West Midlands, although the proportional increases were higher at 19.7 and 17.5 per cent respectively. These figures represent a steadily increasing prevalence at local, regional and national levels, although the local proportional increase in prevalence over this period (8.9 per cent) was lower than those observed nationally (14.2 per cent) and regionally (14.9 per cent) - (Figure 4). Throughout this period the local prevalence was significantly higher than those recorded in both England and the West Midlands.

Figure 4: Proportions of adult learning disability cases registered at GP practices in Herefordshire, England and the West Midlands, 2009/10 – 2013/14.



Source: PHE – Learning Disability Profiles

In 2015/16 the number of all age male LD cases in Herefordshire (584) represented 59.8 per cent of all cases, with females (392) representing 40.2 per cent (Figure 7); similar gender proportions were

[47] QOF – Quality and Outcomes Framework

also evident for those aged 18+. These patterns were consistent with those observed both nationally and regionally.

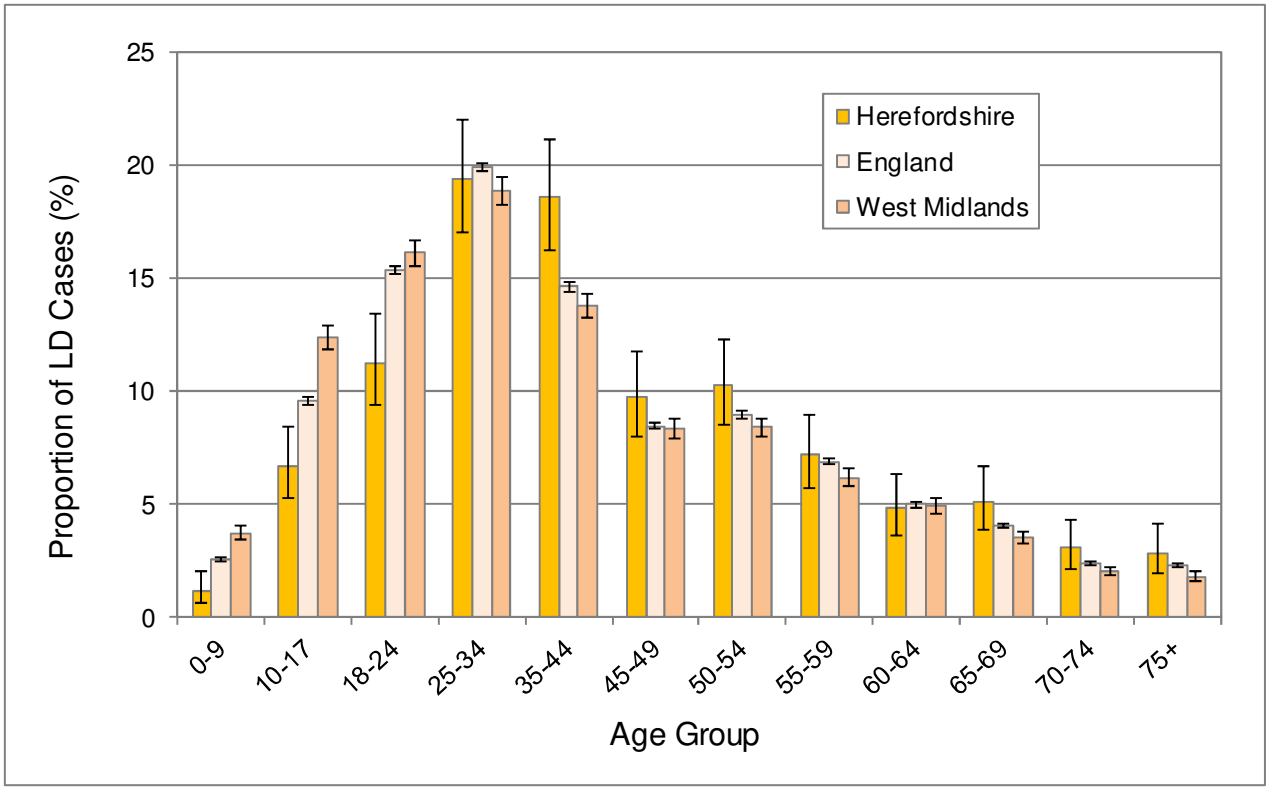
The number of LD cases shows some variability by age with the highest number of individuals between the ages of 18 and 44 (Figure 5), which represented 49.2 per cent of all cases in 2015/16; similar patterns were evident nationally and regionally with this age group representing 49.9 and 48.7 per cent of LD cases across England and the West Midlands respectively. However, the proportions of LD cases reported in Herefordshire in the age groups under 24 years were significantly lower than those reported nationally and regionally, while the local proportion for cases in the 35 to 44 cohort was significantly higher than those for England and the West Midlands.

When examining the crude rate for LD the Herefordshire rates for the age groups between 25 and 54 years are significantly higher than the corresponding national figures, while for those aged under 18 the local rates was significantly lower than those recorded for the West Midlands (Figure6). The all age overall crude rate for Herefordshire of 528 per 100,000 individuals was significantly higher than that for England (447 per 100,000) but broadly similar to that for the West Midlands (501 per 100,000). For adults (18+) the local crude rate of 598 per 100,000 was significantly higher than both the national (496 per 100,000) and regional (537 per 100,000) rates.

The prevalence of registered LD cases across Herefordshire GP practices in 2015/16 ranged from 0.16 per cent at Weobley to 0.81 per cent at Cantilupe and The Marches practices with a county average of 0.52 per cent (Figure 8). Compared to the England figure of 0.46 per cent 13 practices in Herefordshire had a prevalence higher than the national level, with eight being statistically significantly higher the England figure. When looking at LD prevalence across Herefordshire in 2015/16 it is evident that the highest levels occur in and around the City Locality[48] where five out of eight city surgeries reported figures higher than the county average, all of which were significantly higher than the national figure with the result that the City average was significantly higher than reported nationally (Figure 9); the figures for other three localities were broadly similar for that reported foe England overall. When plotting the prevalence at each practice geographically the pattern described above is evident with high levels occurring in Hereford with lower levels generally recorded in rural and semirural areas (Figure 5).

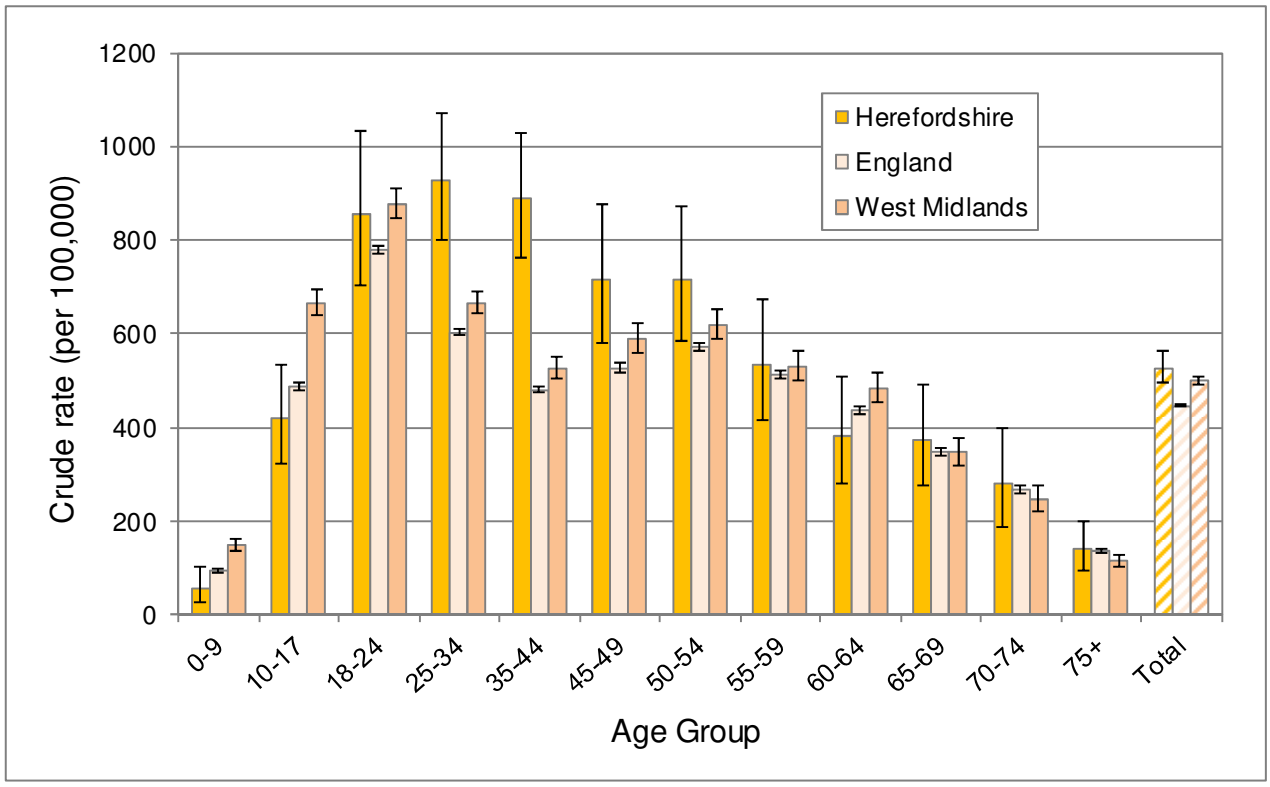
[48] CCG Localities – there are four designated localities based on GP practices around the county: City (Belmont, Cantilupe, Greyfriars, King Street, Moorfield, Quay House, Sarum House and Wargrave practices), North and West (Kington, Mortimer, The Marches, Weobley and Westfield Walk practices), East (Cradley, Colwall, Ledbury Market, Nunwell and St. Katherines practices) and South and West (Alton Street, Fownhope, Golden Valley, Kingstone, Much Birch and Pendeen practices).

Figure 5: Proportions of learning disability cases registered at GP practices by age group for Herefordshire, England and the West Midlands, 2015/16.



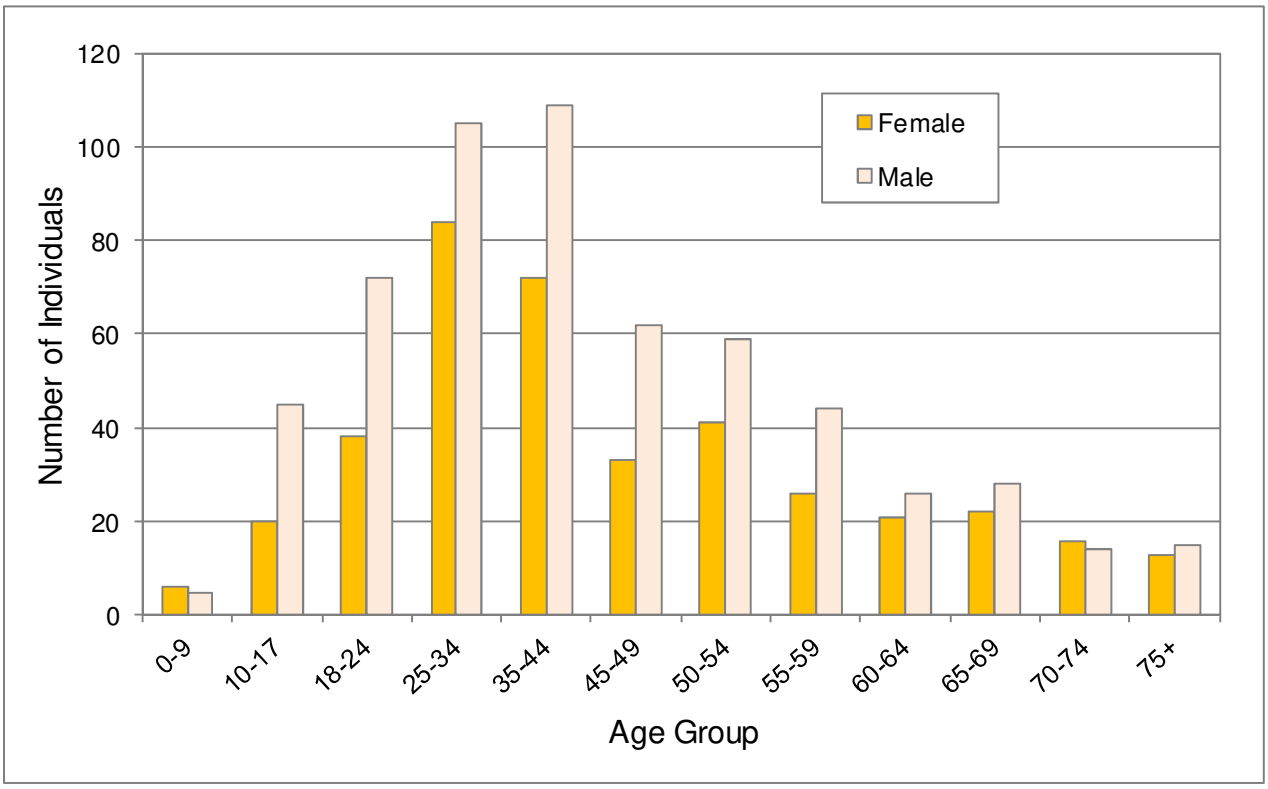
Source: NHS Digital - Health and care of people with Learning Disabilities, Experimental Statistics, 2015-16

Figure 6: Crude rate of learning disability cases registered at GP practices by age group for Herefordshire, England and the West Midlands, 2015/16.



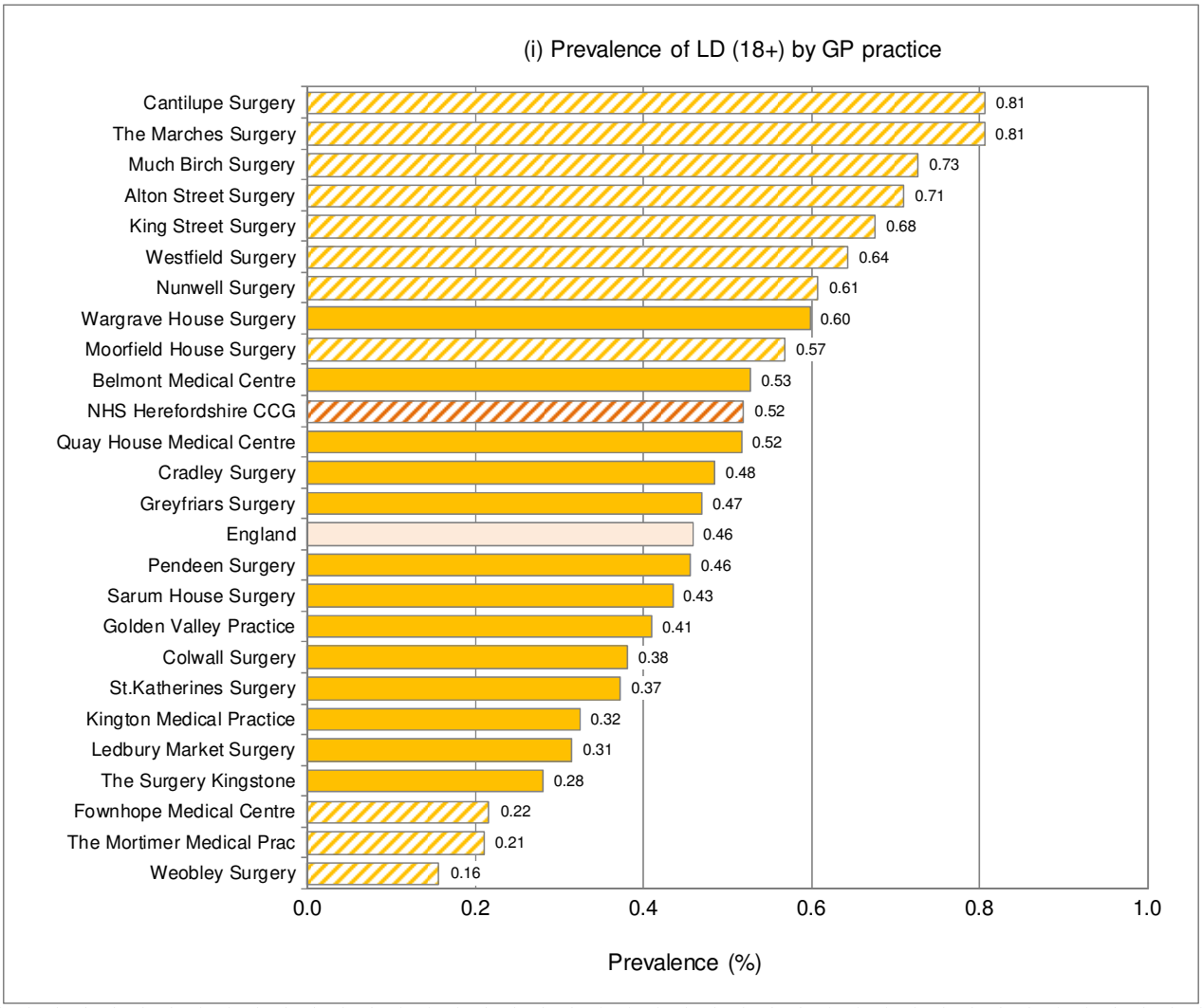
Source: Intelligence Unit, Herefordshire Council

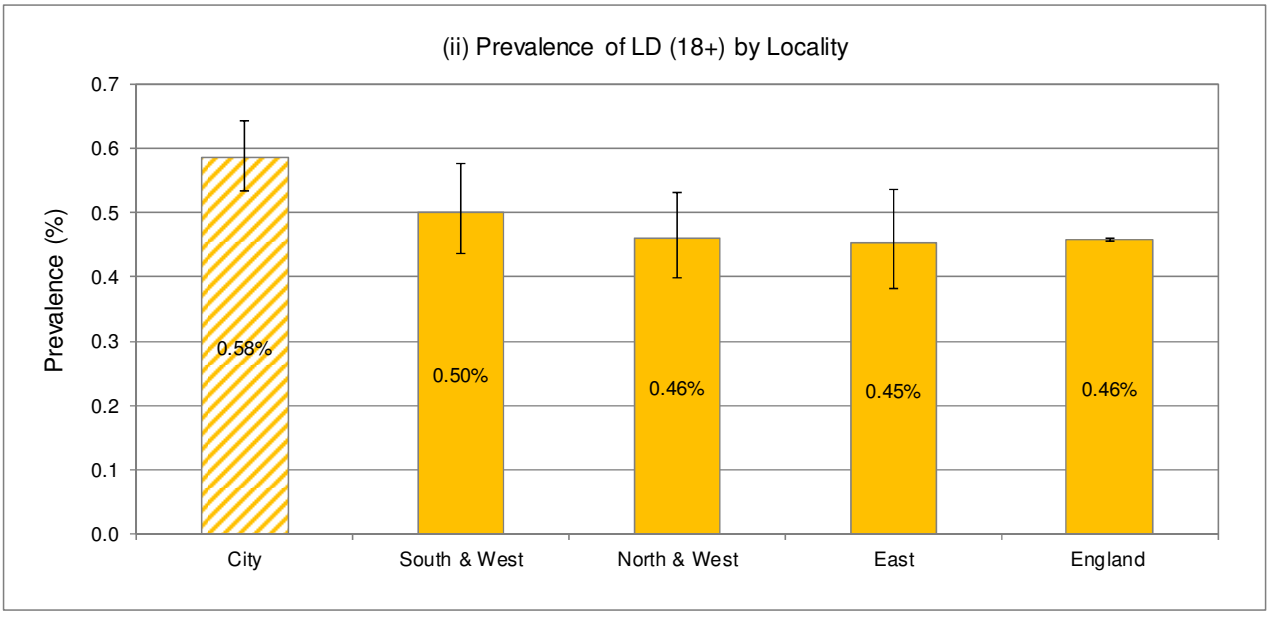
Figure 7: Number of learning disability cases registered at GP practices by age group and gender for Herefordshire, 2015/16.



Source: NHS Digital - Health and care of people with Learning Disabilities, Experimental Statistics, 2015-16

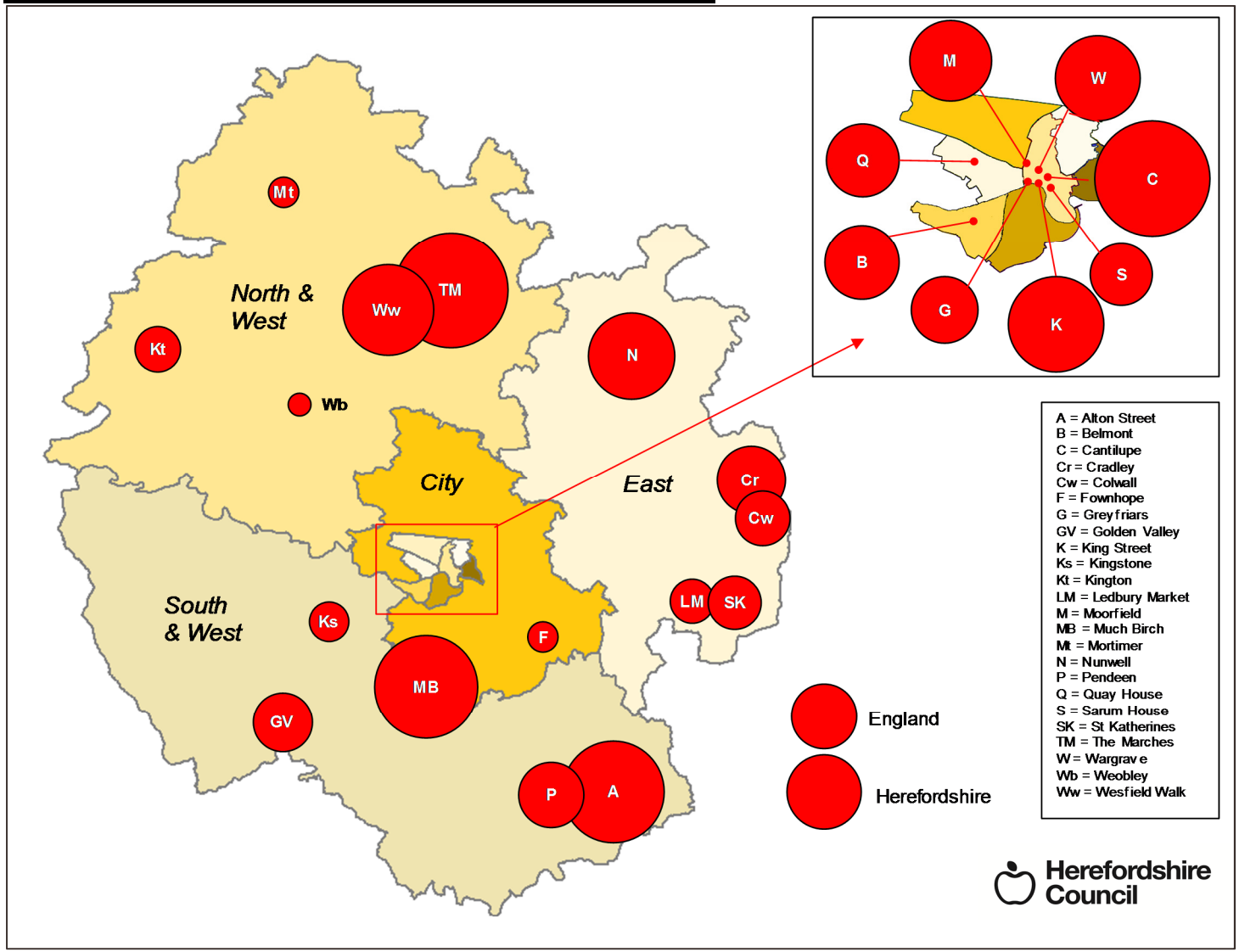
Figure 8: Prevalence of learning disability cases registered in Herefordshire GP practices, 2015/2016. (shaded bars = significantly different from England prevalence)





Source: PHE – National General Practice Profiles / Intelligence Unit, Herefordshire Council

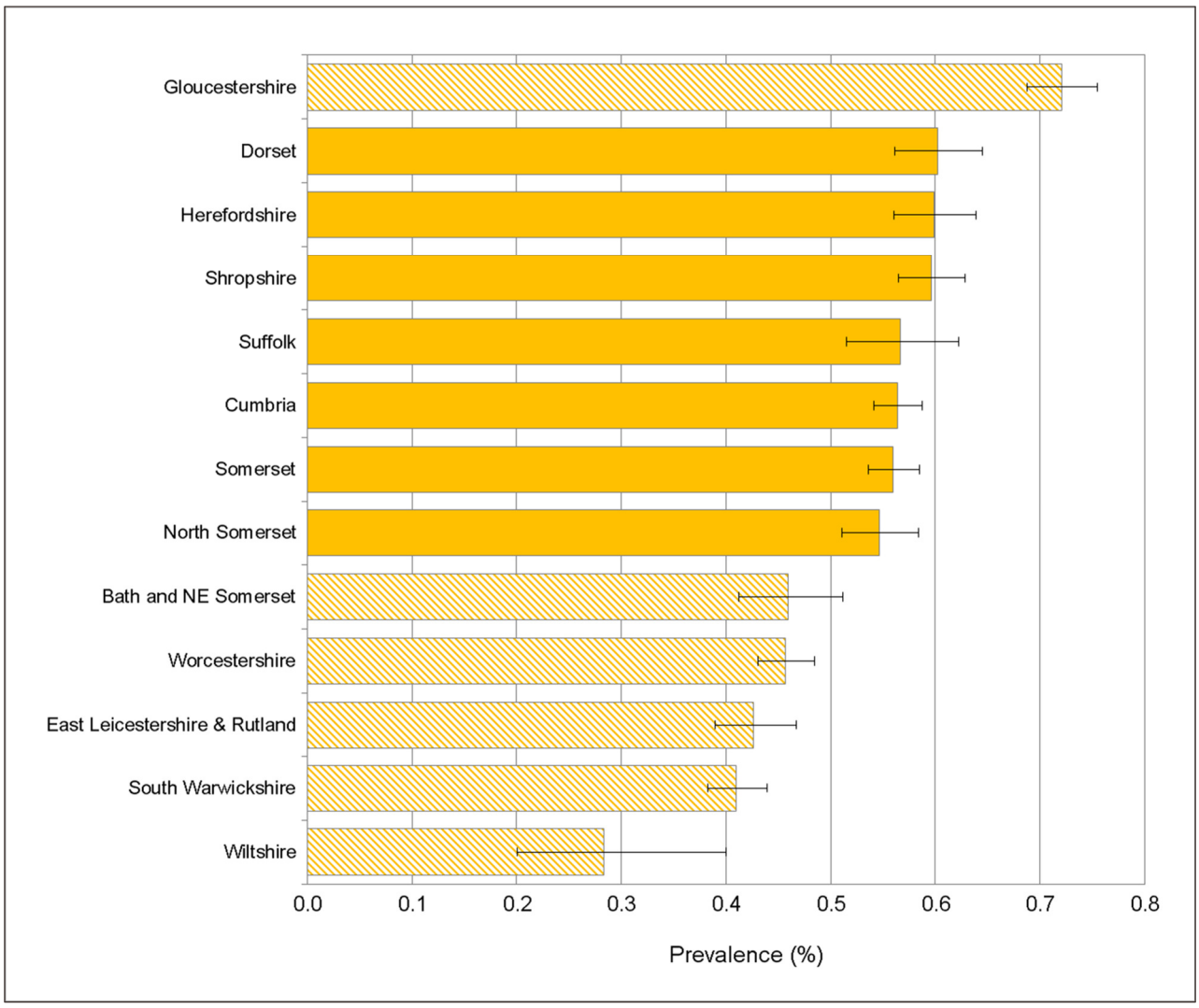
Figure 9: Spatial distribution of prevalence of learning disability cases registered in Herefordshire GP practices, 2015/2016 (circle size proportional to prevalence).



Source: PHE – National General Practice Profiles

The LD prevalence in Herefordshire in 2015/16 was compared with comparative data from 12 County Councils and Unitary Authorities identified as being those most similar (nearest neighbour) to Herefordshire as identified by the Chartered Institute of Public Finance and Accounting (CIPFA)[49]. The comparison of Herefordshire data with the comparator group is shown in Figure 10 which indicates that the local prevalence (0.60 per cent) was significantly higher than that recorded in 5 out of the 12 nearest neighbours; the local figure was also significantly higher than the national and regional figures.

Figure 10: Prevalence of learning disability cases registered in Herefordshire and comparator authorities, 2015/16. (shaded bars = significantly different from Herefordshire prevalence)



Source: NHS Digital - Health and care of people with Learning Disabilities, Experimental Statistics, 2015-16

[49] Nearest neighbours are determined with reference to a range of socio-economic factors such as population characteristics, employment profile, housing and mortality.

Whole Population Estimates

There are no reliable statistics characterising accurately how many people there are with learning disabilities across the UK. The discussion above is based on the number of patients recorded on their general practice's LD register. However, it is thought that this presents a considerable underestimation of the total numbers of LD, particularly for adults, due to the fact that while those with mild intellectual impairment and additional problems will come into contact with services and therefore be identified as having mild learning disabilities many individuals with mild intellectual impairment without such problems may not be identified as having LD. It has been estimated that the numbers on the GP registers represent only 23 per cent of adults with LD.[50]

Estimates and predictions of whole population LD prevalence are provided by Department of Health population estimation websites "Projected Adults Neds Services Information" – PANSI[51] and "Projecting Older People Population Information" - POPPI[52]. Predictions are based on estimated prevalence rates from a report by the Institute for Health Research, Lancaster University[53]. For 2017 the estimated number of adult LD cases is 3,573 which represents a prevalence of 2.32 per cent. POPPI and PANSI also provide information on the prevalence of moderate or severe LD cases of which it is estimated that there are 723 cases in Herefordshire, which represents 20.2 per cent of all adult LD cases; the prevalence of moderate and severe cases in 2017 is 0.47 per cent. Where severe cases are concerned there are currently estimated to be 155 in those aged between 18 and 64 in Herefordshire which represents 5.9 per cent of all adult LD cases and equated to a prevalence of 0.14 per cent.

The number of LD cases varies by age with a general increase with age evident with numbers rising from 343 in the 18 – 24 cohort to 639 in the 45 – 54 cohort; the numbers then fall with age with the lowest figure of 119 observed in the 85+ cohort (Figure 11). This pattern is also evident in the number of moderate and severe cases. When examining the prevalence for each age group there is a steady decline for total cases with age from 2.70 per cent in the 18 – 24 cohort to 1.89 per cent in the 85+ group; a similar pattern is evident for moderate and severe cases (Figure 12).

POPPI and PANSI data indicates that in 2017 there were 1,513 adults in Herefordshire diagnosed with autistic spectrum disorders. The number of cases in each age group show a similar pattern to LD overall with a general increase with age evident up to the 45 – 54 cohort where 267 cases were recorded, numbers then fall with age, although the lowest figure of 132 was observed in the 18 - 24 cohort (Figure 13).

---

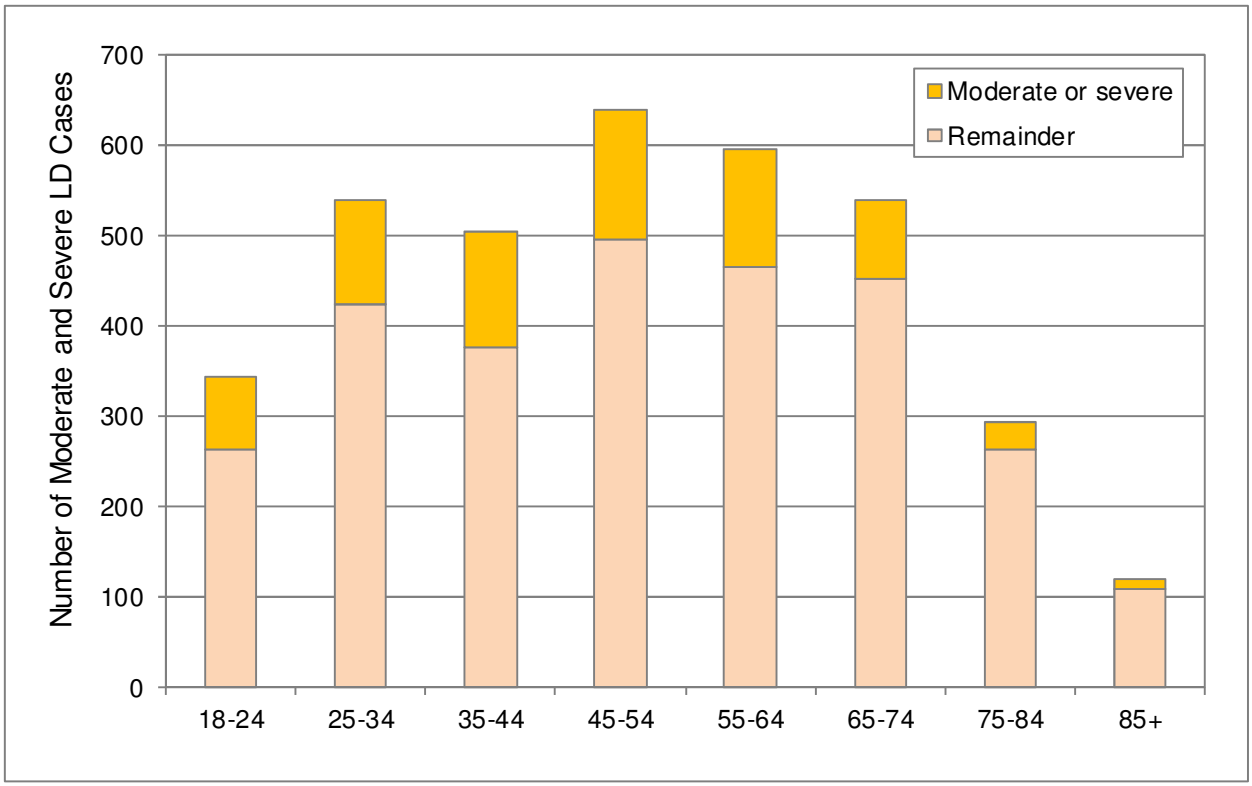
[50] *People with learning disabilities in England 2015: Main report*. PHE Learning Disabilities Observatory. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

[51] http://www.pansi.org.uk/index.php?&PHPSESSID=8utiofdcjgknam78skbctbmmd0&areaID=8

[52] http://www.poppi.org.uk/index.php?&PHPSESSID=8utiofdcjgknam78skbctbmmd0&areaID=8306&np=1

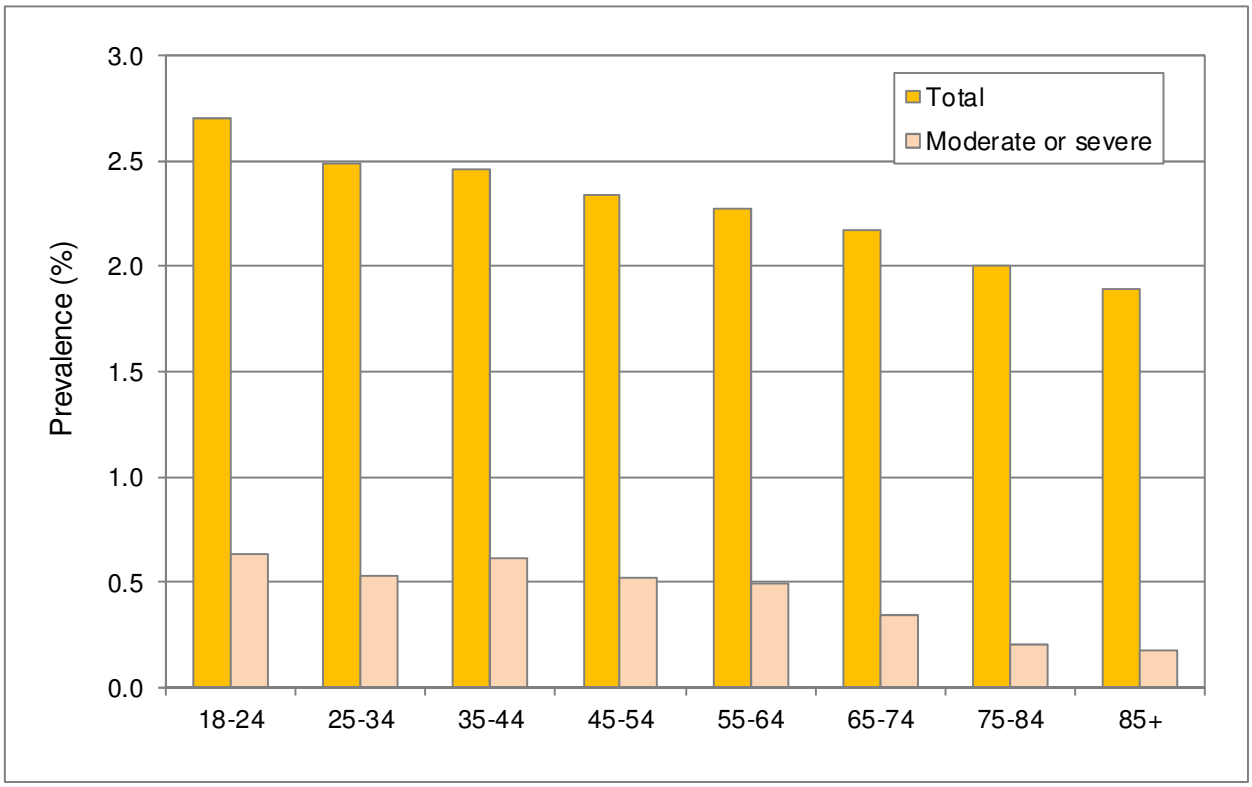
[53] Emerson, E. & Hatton, C. (2004). *Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England.* Institute for Health Research, Lancaster University

Figure 11: Number of all population adult learning disability cases and moderate or severe cases by age group in Herefordshire, 2017.



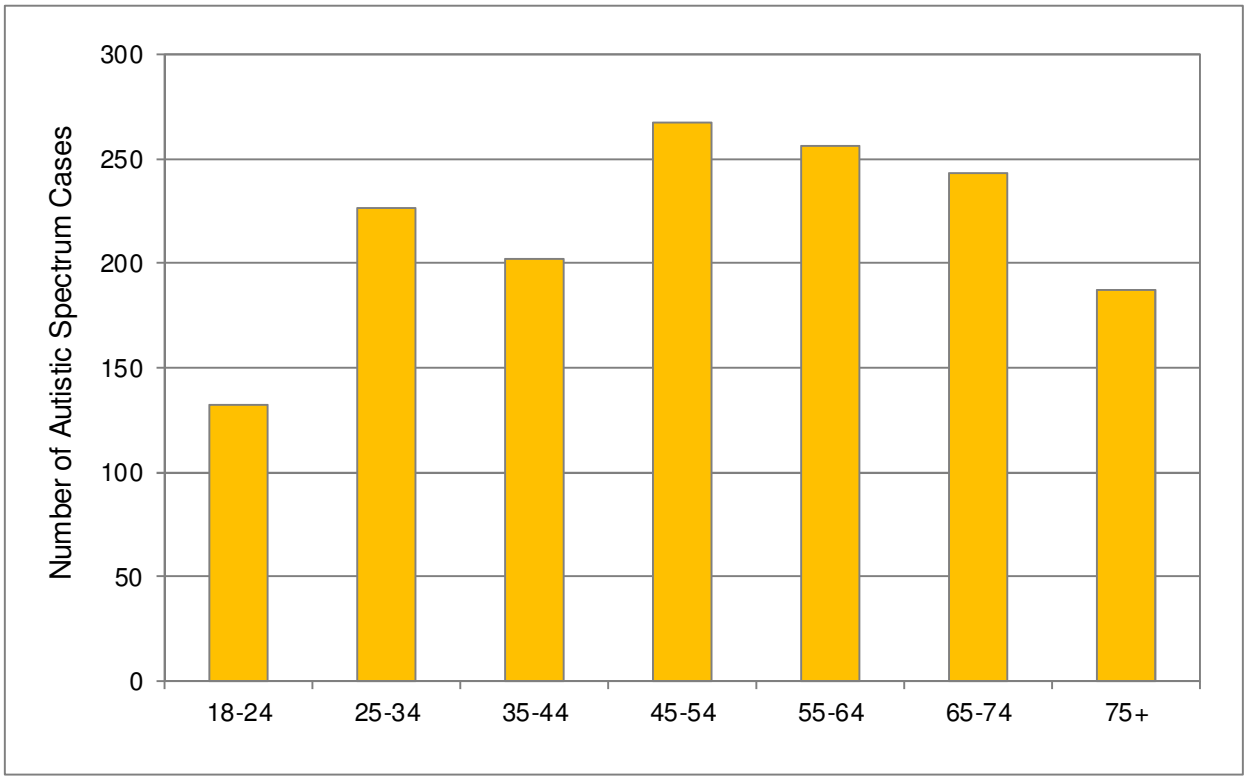
Source: POPPI & PANSI

Figure 12: Prevalence of all population adult learning disability cases and moderate or severe cases by age group in Herefordshire, 2017.



Source: POPPI & PANSI / Intelligence Unit, Herefordshire Council

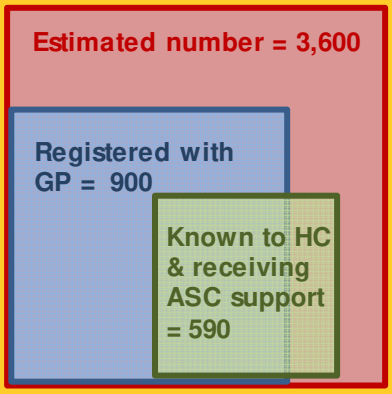
Figure 13: Prevalence of all population adult autistic spectrum cases by age group in Herefordshire, 2017.



Source: POPPI & PANSI

Observations

The identification of adults as having LD is poor in Herefordshire, reflecting both national and regional patterns. Better identification could be facilitated by all relevant clinicians, health workers and carers becoming more aware of LD, with a particular aim of improving the recording of adults with mild LD. An improvement in enumerating the number of adults with LD would aid accurate assessment of future demand and ensure that relevant services will be provided at the required level. Furthermore, future identification of those adults with LD who are not currently known to the Local Authority will aid the successful targeting of low level interventions which could help maintain their continued independence from statutory services.



In addition, there is currently no indication as to whether those recorded on GP LD registers correspond to those known to the local authority, and vice versa, resulting possible ambiguity in the data. Clear cross-referencing of these data between all relevant organisations would clarify this and provide a clearer picture of Herefordshire's adult LD community.

Projected Trends

In their work for the Department of Health CEDR highlighted three factors that are likely to lead to future increases in the age-specific LD prevalence rates for adults in England[46]:

- the increase in proportion of younger English adults who belong to South Asian minority ethnic communities;
- increased survival rates among young people with severe and complex disabilities;
- reduced mortality among older adults with learning disabilities.

By combining the effects of these changes with the effects of general demographic change CEDR estimated modest but sustained future growth in both the numbers of people with learning disabilities known to learning disability services.

Registered Cases

The figures for future population and the most recent LD prevalence data can be employed to provide estimates of future LD cases as registered on the general practice's Learning Disabilities Register. Over the 20 year period between 2015 and 2035 it is estimated that the number of all age registered LD cases will increase from 976 to 1,019, which represents a proportional rise of 4.4 per cent; for adults the increase is from 900 to 934, a rise of 3.8 per cent (Table 4). However, when considering age groups the proportional changes vary considerably. Overall, it is predicted that the numbers of individuals in the majority of age groups will increase, particularly in those 70 and over with rises by 2035 of 36.7 per cent for the 70 – 74 age group and 71.4 per cent for the 75+ cohort. However, for those between 45 and 49 and the numbers are predicted to fall by between 8.4 and 16.0 per cent by 2035.

Although the number of LD cases are predicted to rise over this 20 year period the overall prevalence is predicted to fall, with the all age figure falling from 0.52 to 0.49 per cent and the adult figure from 0.61 to 0.57 per cent (Figure 14).

Table 4: Estimated future numbers of registered learning disability cases by age group in Herefordshire.

Age group	2015	2020		2025		2030		2035	
		N	% change	N	% change	N	% change	N	% change
0-9	11	12	9.1	12	9.1	12	9.1	12	9.1
10-17	65	68	4.6	73	12.3	72	10.8	73	12.3
18-24	110	108	-1.8	102	-7.3	109	-0.9	111	0.9
25-34	189	208	10.1	203	7.4	188	-0.5	191	1.1
35-44	181	185	2.2	199	9.9	209	15.5	206	13.8
45-49	95	82	-13.7	75	-21.1	81	-14.7	87	-8.4
50-54	100	100	0.0	86	-14.0	78	-22.0	84	-16.0
55-59	70	78	11.4	77	10.0	67	-4.3	61	-12.9
60-64	47	50	6.4	57	21.3	57	21.3	49	4.3
65-69	50	46	-8.0	49	-2.0	56	12.0	56	12.0
70-74	30	36	20.0	33	10.0	36	20.0	41	36.7

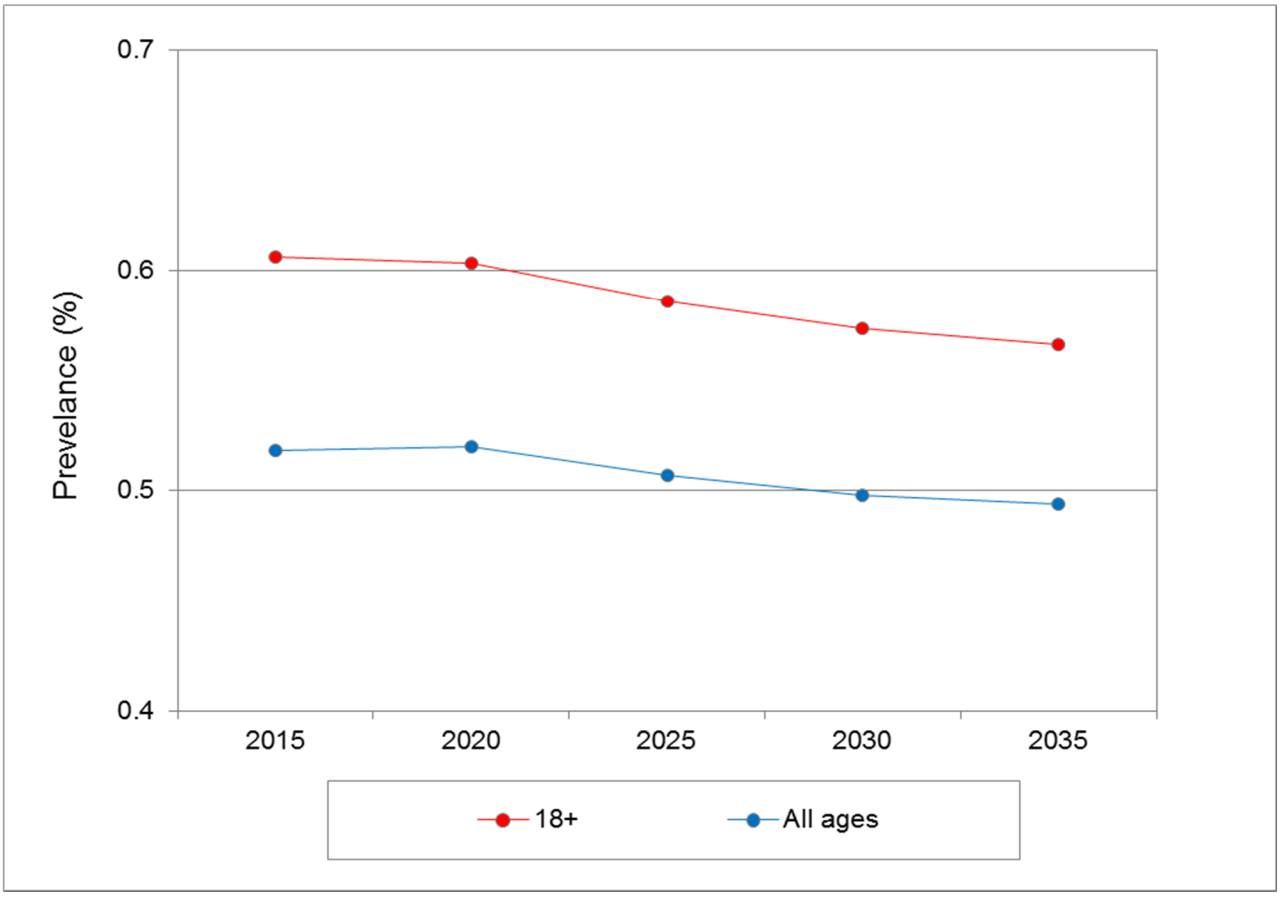
75+	28	32	14.3	39	39.3	44	57.1	48	71.4
Total	976	1005	2.97	1005	2.97	1009	3.38	1019	4.41
18+ Total	900	925	2.78	920	2.22	925	2.78	934	3.78

Source: Intelligence Unit, Herefordshire Council

Whole Population Predictions

Predictions on future numbers of LD cases as provided by POPPI and PANSI indicate that the total number in Herefordshire will rise steadily from the current estimate of 3,573 to 3,892 in 2035 (Table 5). However, in relation to age, the increase in numbers is primarily related to 65+ cohort which show a predicted rise of 393 cases, while for cohorts aged 18 – 64 numbers are predicted to fall by 74. Despite the predicted increase in numbers of LD cases the overall prevalence is not predicted to change appreciably between 2017 and 2035.

Figure 14: Estimated all age and adult registered learning disability prevalence, 2015 – 2035.



Source: Intelligence Unit, Herefordshire Council

Table 5: Estimated future numbers of all population adult learning disability cases by age group in Herefordshire.

Age group	2017	2020		2025		2030		2035	
		N	% change	N	% change	N	% change	N	% change
18-24	343	319	-7.0	301	-12.2	332	-3.2	337	-1.7
25-34	540	558	3.3	545	0.9	505	-6.5	513	-5.0
35-44	504	515	2.2	553	9.7	585	16.1	577	14.5
45-54	639	597	-6.6	532	-16.7	527	-17.5	567	-11.3
55-64	595	629	5.7	665	11.8	620	4.2	553	-7.1
65-74	540	551	2.0	542	0.4	599	10.9	643	19.1
75-84	293	329	12.3	408	39.2	432	47.4	440	50.2
85+	119	131	10.1	158	32.8	201	68.9	262	120.2
Total	3573	3629	1.6	3704	3.7	3801	6.4	3892	8.9
Prevalence %	2.32	2.32	0.01	2.31	-0.40	2.30	-0.64	2.31	-0.49

Source: POPPI & PANSI / Intelligence Unit, Herefordshire Council

Between 2017 and 2035 the number of moderate and severe LD cases are predicted to rise locally from 723 to 758, while the predicted prevalence is not expected to change appreciably over this period (Table 6).

Table 6: Estimated future numbers of all population adult moderate of severe learning disability cases by age group in Herefordshire.

Age group	2017	2020		2025		2030		2035	
		N	% change	N	% change	N	% change	N	% change
18-24	80	74	-7.5	71	-11.3	79	-1.3	81	1.3
25-34	116	120	3.4	117	0.9	109	-6.0	110	-5.2
35-44	127	129	1.6	139	9.4	147	15.7	146	15.0
45-54	143	133	-7.0	120	-16.1	120	-16.1	130	-9.1
55-64	129	137	6.2	143	10.9	132	2.3	118	-8.5
65-74	87	89	2.3	88	1.1	97	11.5	104	19.5
75-84	30	34	13.3	42	40.0	44	46.7	45	50.0
85+	11	12	9.1	15	36.4	18	63.6	24	118.2
Total	723	728	0.7	735	1.7	746	3.2	758	4.8
Prevalence %	0.47	0.46	-0.85	0.46	-2.33	0.45	-3.63	0.45	-4.23

Source: POPPI & PANSI / Intelligence Unit, Herefordshire Council

Between 2017 and 2035 neither the number nor the prevalence of severe LD cases are predicted to change appreciably in Herefordshire (Table 7).

Table 7: Estimated future numbers of all population adult moderate of severe learning disability cases by age group in Herefordshire.

Age group	2017	2020		2025		2030		2035	
		N	% change	N	% change	N	% change	N	% change
18-24	26	25	-3.8	23	-11.5	26	0.0	27	3.8
25-34	33	34	3.0	33	0.0	30	-9.1	31	-6.1
35-44	34	35	2.9	38	11.8	40	17.6	39	14.7
45-54	32	29	-9.4	26	-18.8	27	-15.6	29	-9.4
55-64	30	32	6.7	34	13.3	32	6.7	28	-6.7
Total	155	155	0.0	154	-0.6	155	0.0	154	-0.6
Prevalence %	0.14	0.14	0.18	0.14	0.37	0.15	2.46	0.15	3.06

Source: POPPI & PANSI / Intelligence Unit, Herefordshire Council

Observation
While the number of adult LD cases in Herefordshire is predicted to rise relatively slowly, the proportion of these individuals represented by those aged 65+ is going to increase more rapidly. As the care of these older individuals is likely represent greater complexity of need it is evident that a concomitant increase in the capacity across all relevant services will be required to ensure that future provision of support is at an adequate level to meet the needs of the county's adult LD community and its changing age profile.

Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) are developmental disorders involving difficulties with social interaction, communication and imagination and are commonly associated with learning disabilities. It is estimated that that between 20 and 33 per cent of adults known to CASSR (Council with Adult Social Services Responsibility) as people with learning disabilities also have autism[54], while more than half of people with severe learning disabilities also have some kind of ASD [55].

[54] Emerson, E. and Baines, S. The Estimated Prevalence of Autism among Adults with Learning Disabilities in England. IHAL 2010. Available at: http://www.wenurses.eu/MyNurChat/archive/LDdownloads/vid_8731_IHAL2010-05Autism.pdf

[55] Wing, L. and Gould, J. (1979). Severe Impairments of Social Interaction and Associated Abnormalities in Children: Epidemiology and Classification. *Journal of Autism and Childhood Schizophrenia,* **9:** 11–29.

Data from Herefordshire GP practices indicates that in March 2017 there were 718 patients across Herefordshire recorded on their list has having ASD which represents a prevalence of 0.39 per cent.

The prevalence of registered ASD cases across Herefordshire GP practices range from 0.18 per cent at Kingstone to 0.65 per cent at Quay House (Figure 15). When looking at ASD prevalence across Herefordshire it is evident that the highest levels occur at practices in and around Hereford and the market towns with lower levels recorded in rural and semi-rural practices and no significant differences observed between the average prevalence in the four CCG localities. When plotting the ASD prevalence at each practice geographically the pattern described above is evident with high levels occurring in Hereford with lower level generally recorded in rural and semirural areas (Figure 16). However, it is interesting to note that there was a correlation between the prevalence of ASD and LD recorded in each practice ($r = 0.55$, $P < 0.01$).

Predictions on future numbers of autistic spectrum cases as provided by POPPI and PANSI indicate that the total number in Herefordshire will rise steadily from the current estimate of 1,513 to 1,673 in 2035 (Table 8). However, in relation to age, the increase in numbers is primarily related to 75+ cohort which show a predicted rise of almost 150, representing a proportional increase of 73 per cent over this period; in contrast, for the cohorts aged 18 – 74 combined numbers are predicted to increase by 23, a proportional increase of less than 2 per cent. Despite the predicted increase in numbers of autistic spectrum cases the overall prevalence is not predicted to change appreciably between 2017 and 2035.

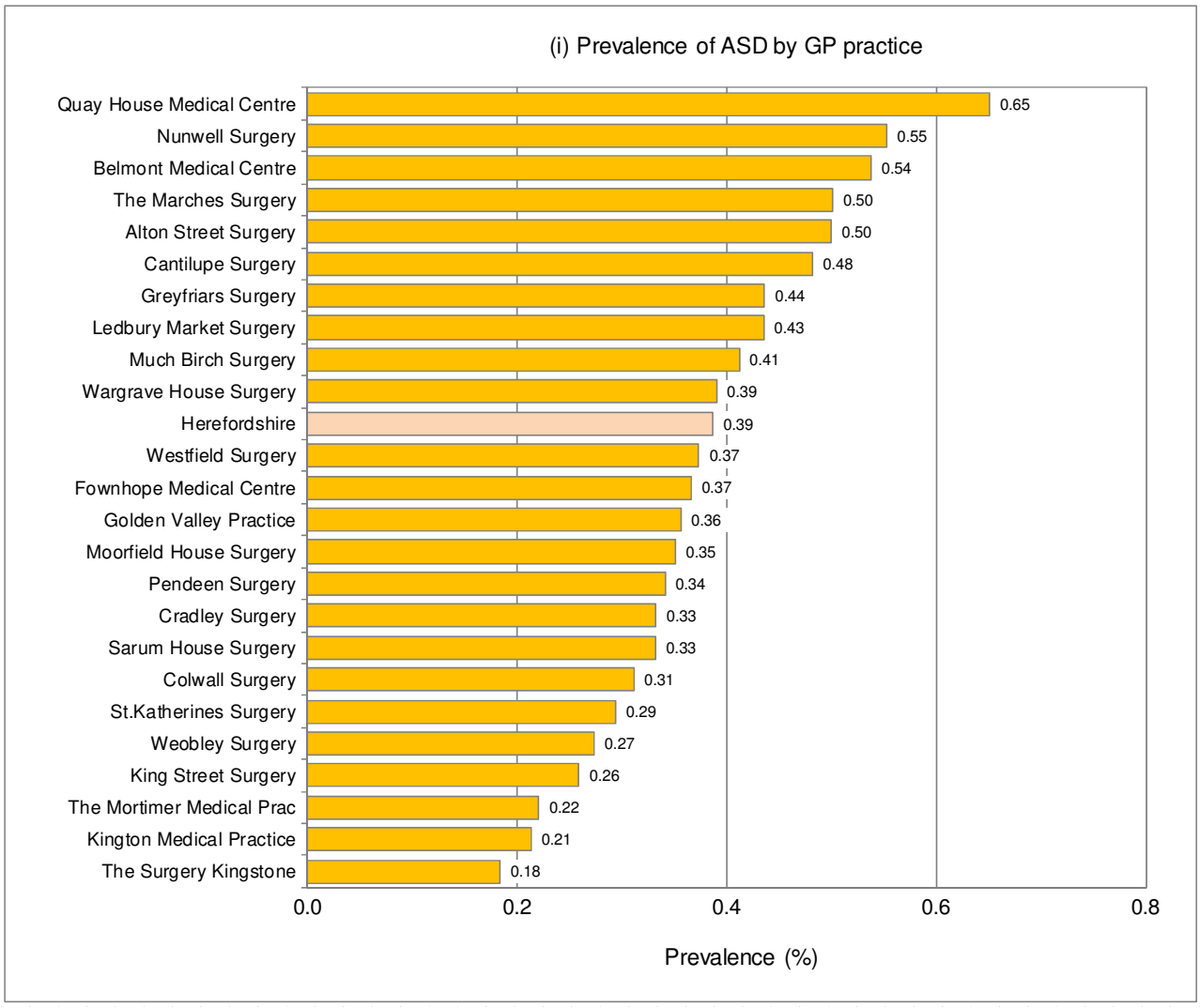
It should be noted that all discussions in relation to LD in this report only include ASD cases if there is a learning disability present and are not included by virtue of an autistic spectrum disorder alone.

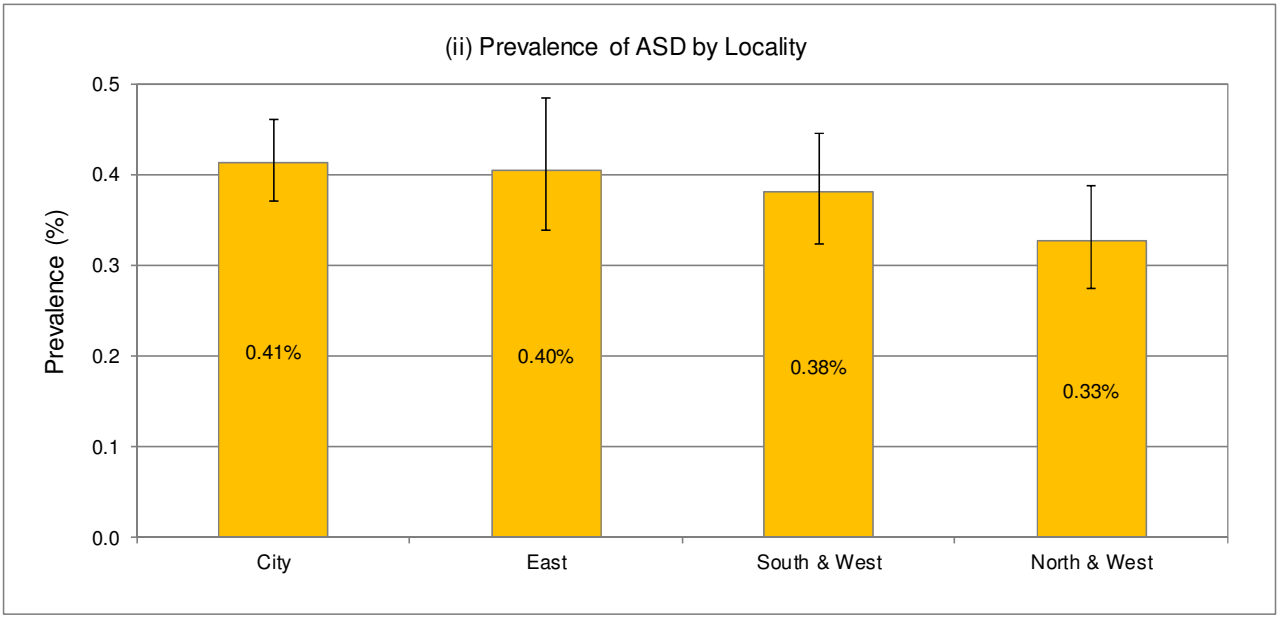
Table 8: Estimated future numbers of all population adult autistic spectrum disorder cases by age group in Herefordshire.

Age group	2017	2020		2025		2030		2035	
		N	% change	N	% change	N	% change	N	% change
18-24	132	124	-6.06	118	-10.61	130	-1.52	132	0
25-34	226	234	3.54	231	2.21	215	-4.87	217	-3.98
35-44	202	208	2.97	226	11.88	241	19.31	238	17.82
45-54	267	249	-6.74	219	-17.98	217	-18.73	235	-11.99
55-64	256	273	6.64	287	12.11	266	3.91	236	-7.81
65-74	243	247	1.65	245	0.82	273	12.4	291	19.8
75+	187	211	12.8	263	40.6	293	56.7	324	73.3
Total	1,513	1,546	2.18	1,589	5.02	1,635	8.06	1,673	10.6
Prevalence %	0.98	0.99	0.62	0.99	0.90	0.99	0.93	0.99	1.01

Source: POPPI & PANSI / Intelligence Unit, Herefordshire Council

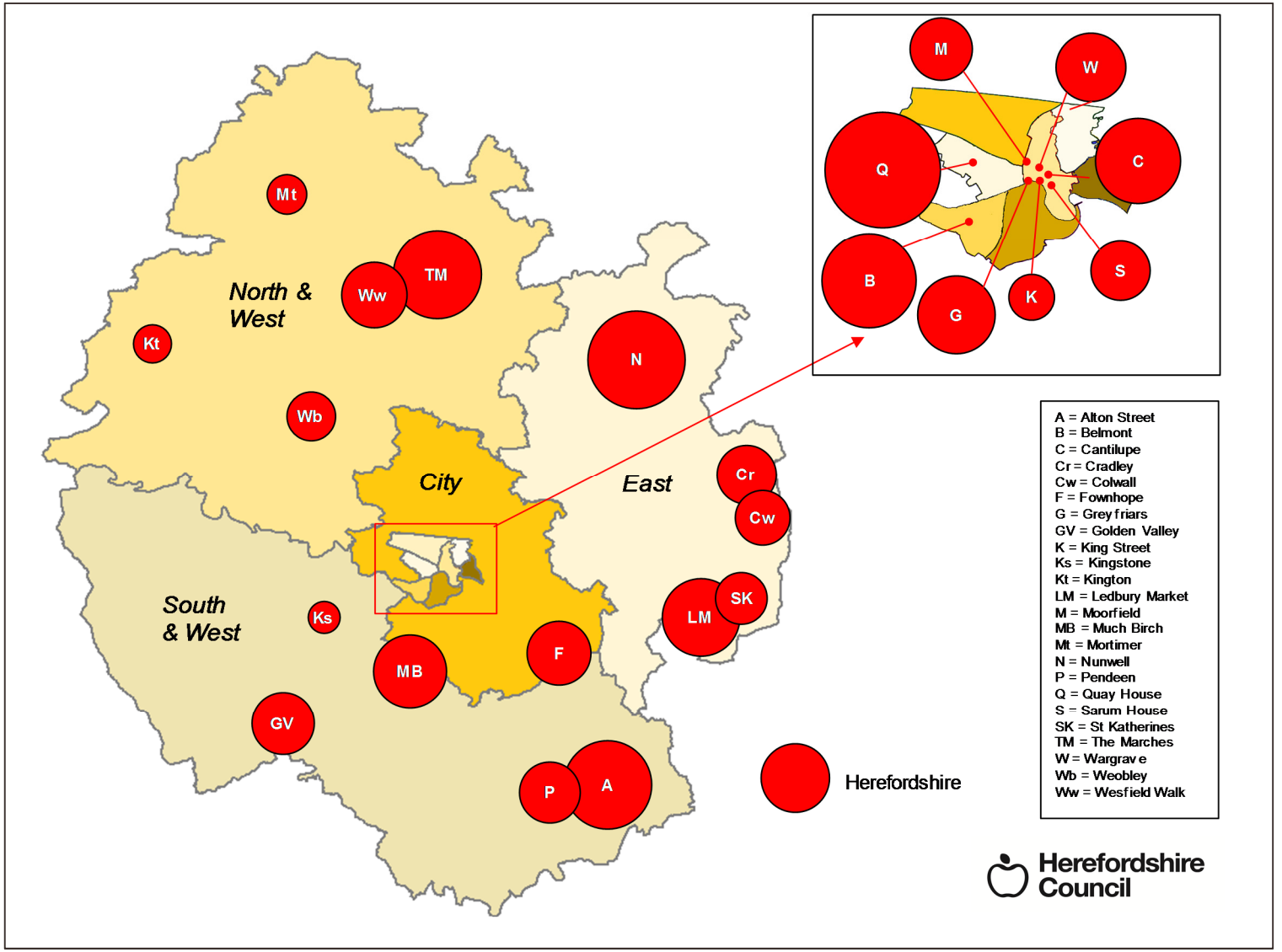
Figure 15: Prevalence of autism disorder spectrum cases in Herefordshire GP practices, March 2017. (shaded bars = significantly different from England prevalence)





Source: Herefordshire CCG/GP practices

Figure 16: Spatial distribution of prevalence of Autistic spectrum disorder cases in Herefordshire GP practices, March 2017 (circle size proportional to prevalence).



Source: Herefordshire CCG/GP practices

HEALTH NEEDS

Lifestyle Health Risks

Diet, Physical Activity and Obesity

Research has shown that adults with a LD often have a poor diet with Robertson et al. (2000) reporting that less than 10 per cent of individuals with LD in residential accommodation eat a balanced diet (including insufficient fruit and vegetable consumption), and poor diet was identified as a particularly issue in adults with greater ability in less restrictive settings[56]. Other workers have indicated that the knowledge of carers of public health recommendations on diet is low which was a factor in the likelihood of dietary change for the better in those they cared for[57].

Emerson *et al*. (2012)[58] in an analysis of the Millennium cohort study, which tracks children born between 2000 and 2002, and found that more than half of seven year olds with learning disabilities (56%) never do sport/exercise, compared to a quarter (25%) of those with no learning disability. The authors also showed that over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health's minimum recommended level, a much lower level of physical activity than the general population (53%-64%). People with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity. In a recent study about carer intentions, only 56% of care staff planned to encourage physical activity in those they support.

Generally, obesity is more common in people with LD compared to the general population[59], although there is evidence to suggest those living in supported accommodation are at risk of being significantly underweight[60]. Demographic factors, genetic syndromes, low levels of physical activity, poor diet, and use of medication which may cause weight gain have all been cited as contributory factors in prevalence of obesity in the LD community[63, 67].

Sexual Health

Generally, people with LD and those in the general population have similar sexual health needs, although there are also differences between young people with LD and their non-disabled peers which arise from the nature of particular disabilities in combination with societal barriers and stigma

[56] Roberston, J., Emerson, E., Gregory, N., Hatton, C., Turnet, S., Kessissoglou, S. and Hallam, A. (2000). Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities,* **21:** 469–486.

[57] Melville, C.A.; Hamilton, C.R.; Miller, S. and Boyle, S., Robinson, N., Pert, C. and Hankey, C.R. (2009). Carer Knowledge and Perceptions of Healthy Lifestyles for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities,* **22(3):** 298-306.

[58] Emerson, E., Baines, S., Allerton, L., and Welch, V. (2012) Health Inequalities & People with Learning Disabilities in the UK. IHaL 2012:11.

[59] Melville, C.A.; Hamilton, S.; Hankey, C.R.; Miller, S. and Boyle, S. (2007).The prevalence and determinants of obesity in adults with intellectual disabilities. *Obesity Review,* **8(3):**223-230.

[60] Emerson, E. (2005). Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Intellectual Disability Research*. **49:** 134–43.

faced by people with LD[61]. Some studies indicate that men with LD are more likely to have sexually transmitted diseases than the general male population[62]

Smoking

Although different studies have reported considerable variability in the prevalence of smoking in adults with LD[63] information from national datasets indicate that in 2008 in England 19 per cent of people with learning disabilities reported that they smoked cigarettes, a figure lower that that reported across England as a whole [64]. Prevalence among people with mild to moderate LD was 30 per cent, a figure considerably higher than those in people with severe LD (11 per cent) and with profound and multiple learning disabilities (4 per cent); smoking was also more prevalent among people living in private households.

Substance and alcohol misuse

Generally, fewer adults with a learning disability drink alcohol compared to the general population[63]. Similarly, although available information is scarce, the use of illicit drugs and overuse of prescription medicines by those with LD is lower than in the general population[65].

Oral Health

People with learning disabilities are more likely to have tooth decay, loose teeth, gum disease, higher levels of untreated disease, and a larger number of extractions and adults with LD tend to have fewer teeth present than individuals in the general population with the difference increased in older age groups[66]. This may be explained by a poor diet, poor dental hygiene and because oral health promotion may not be accessible to people with learning disabilities. Despite this they are less likely to visit their dentist. Dental work for people with learning disabilities might be awkward and require a general anaesthetic which can only be carried out in certain settings. This means that dental problems can take longer to treat. People with Down's syndrome have a high rate of oral complications, including mouth deformities and gum problems.

---

[61] Fraser, F. and Sim, J. The Sexual Health Needs of Young People with Learning Disabilities. Health Scotland, 2008. Available at: http://www.healthscotland.com/uploads/documents/6140-RegainingTheFocusLD.pdf

[62] van Schrojenstein Lantman-De Valk, H.M., Metsemakers, J.F., Haveman, M.J. and Crebolder, H.F. (2000). Health problems in people with intellectual disability in general practice: a comparative study. Family Practice, **17:** 405–7.

[63] Whitaker,S. and Hughes, M. (2003). Prevalence and influences on smoking in people with learning disabilities. *The British Journal of Developmental Disabilities,* **49(2)**:, 91-97.

[64] Emerson, E., and Hatton, C. People with Learning Disabilities in England. Centre for Disability Research (CeDR), 2008.

[65] Taggart, L., McLaughlin, D., Quinn, B. and Milligan, V. (2006). An exploration of substance misuse in people with intellectual disabilities. *Journal of Intellectual Disability Research*, **50(8):** 588-597.

[66] Dental health among adults with learning disabilities in England. PHE, 2017. Publications gateway number 2016563. Available at: http://www.nwph.net/dentalhealth/adult/Adultswithlearningdisabilitiesdentalsummary.pdf

Barriers to Accessing Healthcare Services for People with Intellectual Disabilities

Historically the health needs of people with LD have not been met and risks to the health and wellbeing of individuals in the care system were evident[29]. As a result people with LD were likely to receive less effective care than they were entitled to receive, especially as they moved from child to adult services. Previously, a comprehensive review on access to healthcare for people with LD identified potential barriers to accessing healthcare[67]. These included:

- People with learning disabilities have problems identifying and communicating health needs which affects approaches to health services.
- Carers have problems recognising signs and symptoms of illness in the people with learning disabilities they care for, particularly where deterioration is gradual and over the longer term. It is often carers, rather than patients themselves, who make decisions about when it is appropriate to seek health advice.
- Physical access difficulties, lack of communication aids (including competent, consistent translation services), and notices and signs in NHS premises affect access to mainstream healthcare for people with learning disabilities.
- People with learning disabilities under-use GP and dental health services, given their levels of health need.
- Communication and examination difficulties, as well as time constraints, affect provision of primary care; this can have the consequence of also barring access to appropriate specialist or continuing health care services.
- Some GPs lack knowledge about learning disability generally and about conditions associated with specific syndromes. They also sometimes lack information on specialist services available to these patients.
- Difficulties are apparent in accessing mental health care because carers and entry-level professionals sometimes interpret symptoms and signs of mental ill health as an aspect of the person's learning disability (overshadowing).
- Access difficulties are exacerbated by confusion over the relative roles and responsibilities of mental health services as opposed to learning disability health services.
- Mainstream health care workers and professionals are perceived by some people with learning disabilities and their carers to have negative attitudes towards these patients.
- Health checks are successful in overcoming barriers to accessing health care raised by problems in identifying health needs and deciding whether to seek health advice.

Consequently, people with learning disabilities can struggle with a range of limitations which prevent them being able to access services available to them. The following summarise limitations that people with learning disabilities are currently likely to struggle with:

[67] Alborz, A., McNally, R., Swallow, A. and Glendinning, C. (2004). From the cradle to the grave: A literature review of access to health care for people with learning disabilities across the lifespan. National Co-ordinating Centre for NHS Service Delivery and Organisation, London.

- Limitations in ability to identify and communicate healthcare needs;
- Fear of accessing services;
- Fear of encountering negative attitudes amongst healthcare providers Carer;
- Failure to recognise a gradual deterioration in health loss;
- Fear of upsetting the individual with intellectual disabilities Organisational;
- Physical inaccessibility (e.g. wheelchair access, ramps, lifts, disabled toilets);
- Communication difficulties (unable to communicate pain & distress, lack of assistive technology);
- Time constraints (e.g. 10min GP appointments);
- Lack of knowledge (medical staff training);
- 'Unhelpful attitudes' (assumptions about capabilities of those with learning disabilities, judgements on their quality of life[9]).

Morbidity

Although people with learning disabilities have the same needs as those without, it is recognised that they have specific health needs[68].

Cancer

Cancers predominantly found in people with learning disabilities differ from those in people without learning disabilities. People with learning disabilities have higher levels (roughly double) of gastrointestinal cancers such as oesophageal, stomach and gall-bladder, and lower rates of lung, prostate, breast and cervical cancers. Down's syndrome is a risk factor for lymphoblastic leukaemia.

In 2015/16 the overall prevalence in people in Herefordshire with LD who have a diagnosis of cancer was 0.82 per cent which, while being lower than that for the country as a whole, the difference was not statistically significant; the local figure was similar to that for the West Midlands (Table 9). The local prevalence of cancer in individuals with LD was approximately one third of that in the population as a whole (2.57 per cent).

Coronary Heart Disease (CHD)

Coronary heart disease is the second highest cause of death for people with learning disabilities. People with learning disabilities are more likely to develop hypertension and obesity and also a lack exercise, all of which are risk factors for ischaemic heart disease. People with Down's syndrome are at higher risk of congenital heart problems.

In 2015/16 the **CHD** prevalence in people in Herefordshire with LD was 1.13 per cent which was similar to both the national and regional figures (Table 9). The local prevalence of CHD in individuals with LD was approximately one third of that in the population as a whole (3.49 per cent).

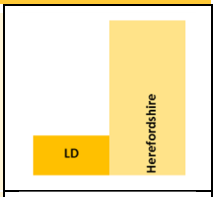
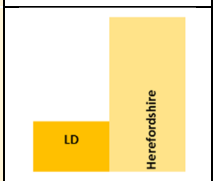
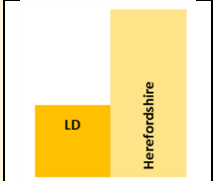
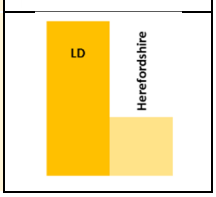
[68] Meeting the health needs of people with learning disabilities, Royal College of Nursing (2013)

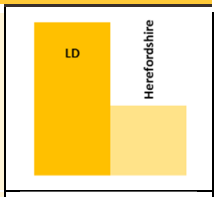
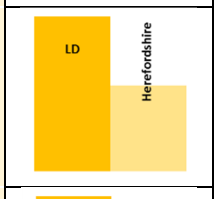
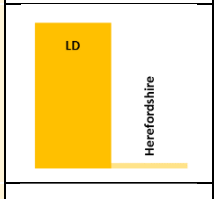
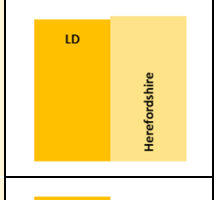
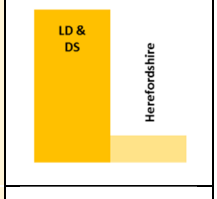
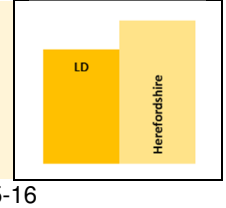
The local prevalence of **heart failure** in individuals with LD was 0.82 per cent which, while being less than both the national and regional figures the differences were not statistically significant (Table 9). The local prevalence of heart failure in individuals with LD was 69 per cent of that in the population as a whole (1.18 per cent).

In 2015/16 the prevalence of **hypertension** in people with LD in Herefordshire was 11.8 per cent, a figure broadly similar to both the national and regional figures (Table 9). The local prevalence of hypertension in individuals with LD was 73 per cent of that in the population as a whole (16.1 per cent).

Table 9: Prevalence (%) of major conditions in learning disability communities in Herefordshire, England and the West Midlands, 2015/16.

(Compared with England lower similar higher)

Condition	England	West Midlands	Herefordshire LD prevalence	Herefordshire whole population prevalence	
Cancer	0.97	0.80	0.82	3.19	
Coronary Heart Disease (CHD)	1.14	0.95	1.13	3.49	
Heart Failure	0.89	0.84	0.82	1.18	
Hypertension (High Blood Pressure)	9.79	9.55	11.8	16.1	
Chronic Obstructive Pulmonary Disease (COPD)	1.03	0.92	0.92	2.15	
Obese	22.0	21.4	23.9	9.09	

Condition	England	West Midlands	Herefordshire LD prevalence	Herefordshire whole population prevalence	
Underweight	3.55	3.59	2.77	1.27	
Type 1 Diabetes	0.66	0.75	0.71	0.39	
Non-type 1 Diabetes	6.81	7.28	8.20	5.02	
Gastro Oesophageal Reflux Disease (GORD)	7.34	7.04	8.40	-	-
Epilepsy	17.9	17.5	23.4	0.90	
Dementia	1.41	-	0.92	0.94	
Dementia (individuals with LD and Down's Syndrome)	7.24	-	5.32	0.94	
Depression	12.8	12.2	9.63	7.40	

Source: NHS Digital - Health and care of people with Learning Disabilities, Experimental Statistics, 2015-16

Respiratory Disease

Respiratory disease is the main cause of death in people with learning disabilities. They are at risk of respiratory tract infections caused by aspiration or reflux if they have swallowing difficulties, and they are less likely to be immunised against infections. People with Down's syndrome are

particularly at risk because they have a predisposition to lung abnormalities, a poor immune system and a tendency to breathe through their mouth. Pulmonary complications are also seen in people with tuberous sclerosis.

In 2015/16 the prevalence of **chronic obstructive pulmonary disease (COPD)** in people in Herefordshire with LD was 0.92 per cent, a figure broadly similar to both the national and regional figures (Table 9). The local prevalence of COPD in individuals with LD was 47 per cent of that in the population as a whole (2.15 per cent).

Body Mass Index

Severe obesity, obesity, and being underweight are more common in people with learning disabilities. Having a healthy weight and being overweight are less common.

In 2015/16 the prevalence of **obesity** in people with LD in Herefordshire was 23.9 per cent. The local prevalence was similar to the national figure and broadly similar to the regional prevalence (Table 9). The local prevalence of obesity in individuals with LD was over two and a half times that in the population as a whole (9.09 per cent).

In 2015/16 the local prevalence of **underweight** individuals with LD was 2.77 per cent. Although the local prevalence was less than both the national and regional figures the differences were not statistically significant (Table 9). The local prevalence of underweight in individuals with LD was over twice that in the population as a whole (1.27per cent).

In terms of prevention of obesity, people with learning disabilities are less likely to eat healthily and exercise because they may not always have the knowledge or understanding to make healthy choices for themselves, instead being reliant on others for communication and support.

Diabetes

People with learning disabilities are more prone to developing diabetes than those without learning disabilities. This may be attributed to increased levels of obesity, poor diet and inactive lifestyles.

In 2015/16 the prevalence in **Type 1** diabetes people in Herefordshire with LD was 0.71 per cent which was similar to both the national and regional figures (Table 9). The local prevalence of Type 1 diabetes in individuals with LD was almost twice that in the population as a whole (0.39 per cent).

For **non-type 1** diabetes the local LD community prevalence was 8.20 per cent. While being higher than the national and regional figures the local prevalence was broadly similar to these figures (Table 9). The local prevalence of Type 1 diabetes in individuals with LD was more than one and a half times that in the population as a whole (5.02 per cent).

Gastro-Intestinal Problems

Gastro Oesophageal Reflux Disease (GORD) can affect as many as half of people with learning disabilities, and has a higher prevalence in those with more severe and profound learning disabilities. It has also been associated with fragile-X syndrome. GORD is easily treated yet often goes unnoticed, possibly because of communication difficulties and/or the lengthy diagnostic process. GORD might account for the higher levels of oesophageal cancer seen in people with learning disabilities.

In 2015/16 the prevalence of GORD in those with LD in Herefordshire was 8.4 per cent. Although the local prevalence was higher than both the national and regional figures the differences were not statistically significant (Table 9).

Other Gastro-Intestinal Problems:

Constipation **-** Constipation is more prevalent in people with learning disabilities than in those without. It is more likely to occur in people with profound learning disabilities, those who are less mobile, where there is inadequate hydration or limited food choice, and in people on long-term medication with constipation as a side effect. In certain situations or environments there can be an over reliance on laxatives rather than adequate nutrition and fluids.

Helicobacter pylori **-** Many people with learning disabilities have high levels of *H. pylori*, particularly those who have lived in shared accommodation, or attended day centres with other people with learning disabilities. *H. pylori* is associated with peptic ulcers, which can perforate if left untreated. Gastric carcinoma is seen in greater levels in people with learning disabilities, and *H. pylori* has been cited as a possible predisposing factor.

People with learning disabilities are prone to reinfection with *H. pylori* and might require testing and treatment throughout their lives.

Coeliac disease **-** People with Down's syndrome are prone to coeliac disease. People with coeliac disease must have a gluten free diet.

Neurological Problems

Epilepsy **-** Epilepsy affects about one per cent of the population. It is more prevalent in people with learning disabilities and one third of this population have the condition. The prevalence rises with an increase in severity of learning disabilities, with nearly half of people with severe learning disabilities having epilepsy.

In 2015/16 the prevalence of epilepsy in people in Herefordshire with LD was 22.7 per cent which was approximately over thirty times that for the county as a whole (0.68 per cent). The local prevalence was significantly higher than both the national and regional figures (Table 9). The local prevalence of epilepsy in individuals with LD was over 33 times that in the population as a whole (0.68 per cent).

People with learning disabilities who have epilepsy often have more than one type of seizure and more complex seizure patterns. They are at risk of further cognitive impairment due to prolonged seizures, secondary injuries that might go unnoticed, hospitalisation, placement breakdown, and a more restricted lifestyle.

Sensory Impairments **-** Sight and hearing problems are common in people with learning disabilities; it is estimated that up to 40 per cent of people with learning disabilities have sight problems and a similar number of people with severe learning disabilities have hearing problems. Additionally, people with learning disabilities are prone to ear and eye infections.

Sight Problems **-** People with learning disabilities have a higher prevalence of sight problems, and over recent years ophthalmologists have been adapting assessments to meet their needs. Individuals may need reminding about the importance of eye tests and support in accessing them. Sight problems may be acquired as people get older, or as a result of brain damage or cerebral

visual impairment. Some causes of learning disabilities, such as Down's syndrome, cerebral palsy, Fragile X syndrome and congenital rubella syndrome, are associated with vision problems.

Hearing Problems **-** People with learning disabilities are more likely to need a hearing aid, but many have never had a hearing test. Hearing problems might further compound already poor communication skills. Although some hearing problems are caused by structural abnormalities such as abnormal-shaped ear canals, or by neural damage, other reasons like impacted earwax, which has a higher prevalence in people with learning disabilities, should not be overlooked. Some diagnoses, including Down's syndrome, congenital rubella syndrome, cerebral palsy and Fragile X syndrome, are particularly associated with hearing loss.

Mental Health Problems

People with learning disabilities are vulnerable to all mental health problems through a range of biological, psychological and social factors that they are more likely to encounter. Common mental health problems include:

Dementia - Dementia affects individuals with LD in much the same way as those without LD. However, those with LD are at a greater risk of developing dementia at a younger age, particularly those with Down's Syndrome a third of whom are likely to develop dementia in their 50s[69].

In 2015/16 the overall local prevalence of dementia in individuals with LD of 0.92 per cent was significantly lower than the figure for England of 1.41 per cent, although was similar to that for the Herefordshire population as a whole (0.94 per cent) – see Table 9. In Herefordshire dementia prevalence in those with a diagnosis of Down's Syndrome was 5.32 per cent compared to 4.24 per cent nationally.

Depression - Depression can be diagnosed in people with mild LD in the same way as people who do not have LD. But in people with more severe LD or with communication difficulties, it might be physical signs such as weight loss, a change in sleep pattern, or social withdrawal that suggest depression. There might also be atypical indicators such as self-injury or aggression, uncharacteristic incontinence or screaming.

In 2015/16 the prevalence of depression in people in Herefordshire with LD was 9.63 per cent which was approximately eight tenths of that for the county as a whole (12.1 per cent). The local prevalence was significantly lower than both the national and regional figures (Table 9). The local prevalence of depression in individuals with LD was 80 per cent of that in the population as a whole (12.0 per cent).

Anxiety Disorders **-** These include general anxiety, phobias and panic disorders. The physical signs of anxiety, such as rapid breathing, muscle tension, and motor agitation, can be observed in people with learning disabilities, but other psychological symptoms might be harder to detect. Anxiety is often seen in people with autistic spectrum disorders, especially when their routine and structure is disrupted.

[69] Learning disabilities and dementia. Alzeimer's Society Factsheet 430LP (March 2015). Available at: https://www.alzheimers.org.uk/download/downloads/id/1763/factsheet_learning_disabilities_and_dementia.pdf

Schizophrenia **-** Schizophrenia is three times more prevalent in people with learning disabilities than in those without learning disabilities. People with learning disabilities can experience the full range of psychotic symptoms associated with schizophrenia, but these tend to be less marked and less complex. Schizophrenia is very difficult to diagnose in people with severe learning disabilities since the diagnostic criteria rely on the person being able to communicate their internal experiences.

Other Health Problems

Dental Issues/Oral Hygiene - People with learning disabilities are more likely to have tooth decay, loose teeth, gum disease, higher levels of untreated disease, and a larger number of extractions. This may be explained by a poor diet, poor dental hygiene and because oral health promotion may not be accessible to people with learning disabilities. Despite this they are less likely to visit their dentist. Dental work for people with learning disabilities might be awkward and require a general anaesthetic which can only be carried out in certain settings. This means that dental problems can take longer to treat. People with Down's syndrome have a high rate of oral complications, including mouth deformities and gum problems.

Swallowing/Feeding Problems **-** Problems with swallowing are more prevalent in people with learning disabilities than in those without, with the highest prevalence in those with profound disabilities. These can be caused by neurological problems or structural abnormalities of the mouth and throat. Problems can also arise from rumination, regurgitation or self-induced vomiting. Swallowing problems can lead to choking, secondary infections and weight loss. Some people with severe problems may need a percutaneous endoscopic gastrostomy (PEG) to ensure they receive adequate nutrition. This can be used in conjunction with oral feeding so that they can develop appropriate swallowing and eventually have the PEG withdrawn. Speech and language therapists can carry out assessments where there are concerns about swallowing and, along with occupational therapists, might be able to provide advice and adaptations.

Thyroid Disease (Hypothyroidism) **-** Common symptoms of hypothyroidism include weight gain, constipation, aches, feeling cold, fluid retention, tiredness, lethargy, mental slowing and depression. If hypothyroidism is not treated it can lead to further problems, including heart disease, pregnancy complications and, rarely, coma. Hypothyroidism affects 1-in-50 women and 1-in-1000 men and becomes more prevalent with age. It is more common in people with learning disabilities and is associated with Down's syndrome. Annual blood tests for people with Down's syndrome are recommended. Hypothyroidism might also occur as a side effect of medications such as lithium and amiodarone.

Health Check

It has been recognised that people with a learning disability are at danger of not getting equal access to healthcare partly in relation to individuals with learning disabilities communicating their health problems to carers and health care workers (as discussed above). In 2008, the Learning Disability Directed Enhanced Scheme (LD-DES) was introduced by NHS England to incentivise Primary care teams to carry out annual health checks for people with LD. These annual checks reduce health inequalities for people with LD by identifying and monitoring needs with the regularity being important to ensure that any issues are not missed. The health check involves the person

with learning disabilities and a family member, carer, care worker, GP or social care practitioner (as appropriate) who knows them. NICE outlines what the health check should include[70]:

- a review of any known or suspected mental health problems and how they may be linked to any physical health problems;
- a physical health review, including assessment for the conditions and impairments that are common in people with learning disabilities;
- a review of all current interventions, including medication and related side effects, adverse events, interactions and adherence for both mental health and physical health conditions;
- an agreed and shared care plan for managing any physical health and mental health problems (including pain).

Early reviews of health checks suggested that they were effective in identifying previously unidentified conditions and led to targeted actions to address health needs in the LD community (Robertson et al., 2011). However, a more recent study indicated that despite LD health checks being associated with increases in health related activities, identification of important co-morbidities and referrals to secondary care, up to 40 per cent of LD patients were not offered a health check[71].

Data from NHS Digital[72] indicates that since 2013/14 the proportion of LD patients in Herefordshire receiving an annual health check has shown considerable variability, ranging between 51.5 per cent in 2015/16 and 80.8 per cent in 2014/15; the latest proportion is not significantly different from that recorded I 2013/14 (Figure 17). Over this period the national proportion has shown a general increase with the 2016/17 figure of 67.3 per cent being significantly higher than that recorded locally (63.0 per cent).

Across Herefordshire the proportion of registered LD cases receiving an annual health check in 2016/17 ranged from 20 per cent at Kington to 88 per cent at Quay House in Hereford (Figure 18). Compared to the England figure of 67 per cent eight of the 11 practices in Herefordshire reported a proportion higher than the national figure, with four being statistically significantly higher than the national level. When looking at proportions across the localities it is evident that the highest levels occur in the East Locality and the lowest in and around the City Locality. The City proportion of 62 per cent was significantly lower than the national figure with the figures for other three localities were broadly similar to that for England overall.

When comparing the local proportion of LD cases receiving an annual health check with nearest neighbour CCGs it is evident that, with the exception of Shropshire, the Herefordshire figure is higher than all those in the CCGs considered, although the difference is only significant in five cases (Figure 19). It should be noted that all nearest neighbour figures were significantly lower than the national figure.

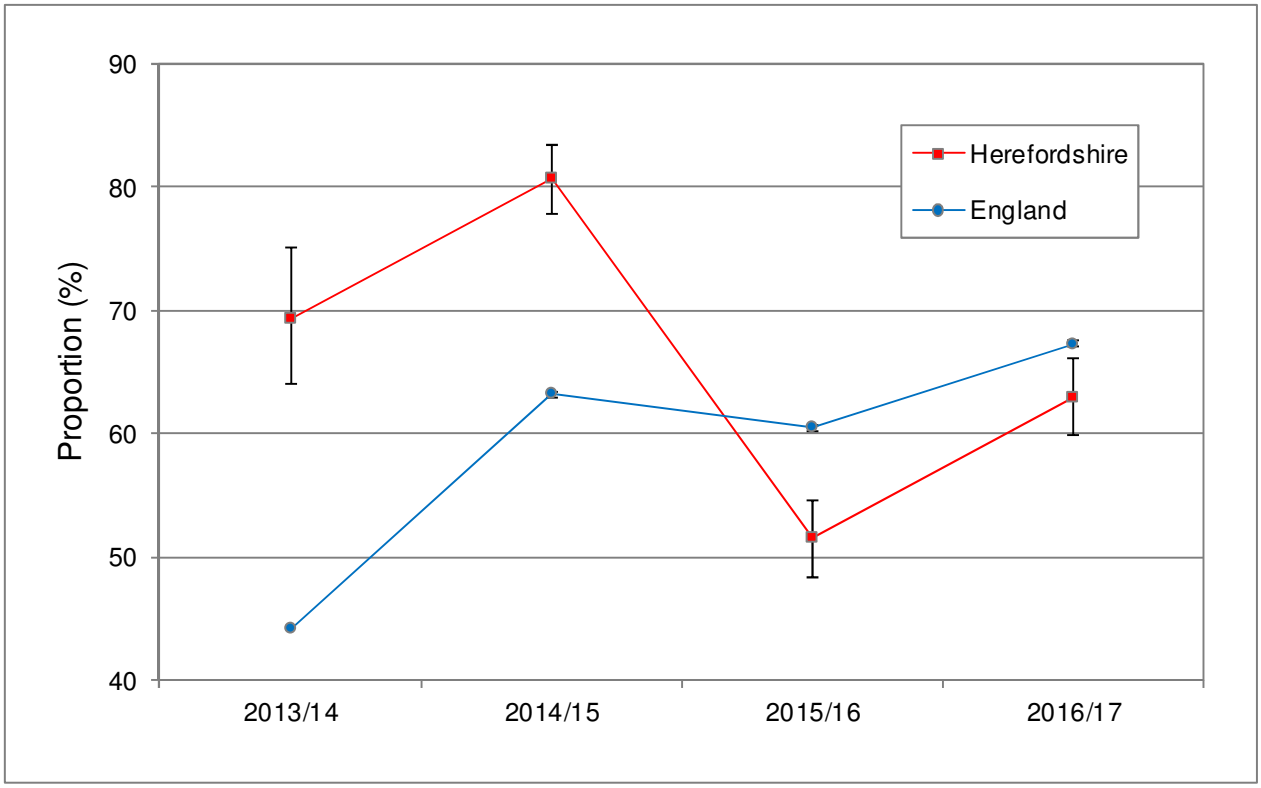
---

[70] Learning disabilities: identifying and managing mental health problems. National Institute for Health and Care Excellence (NICE). Avaialble at: https://www.nice.org.uk/guidance/qs142/chapter/Quality-statement-1-Annual-health-check

[71]The Learning Disabilities Elf. Avaialble at: https://www.nationalelfservice.net/populations-and-settings/quality-of-life/six-out-of-ten-gp-surgeries-are-signed-up-to-the-directed-enhanced-scheme-in-england-but-40-of-patients-with-learning-disabilities-did-not-get-a-health-check/

[72] Learning disabilities health check scheme: http://content.digital.nhs.uk/ld-healthchecks

Figure 17: Proportion of individuals with a learning disability having a GP health check in Herefordshire and England, 2013/14 to 2016/17.



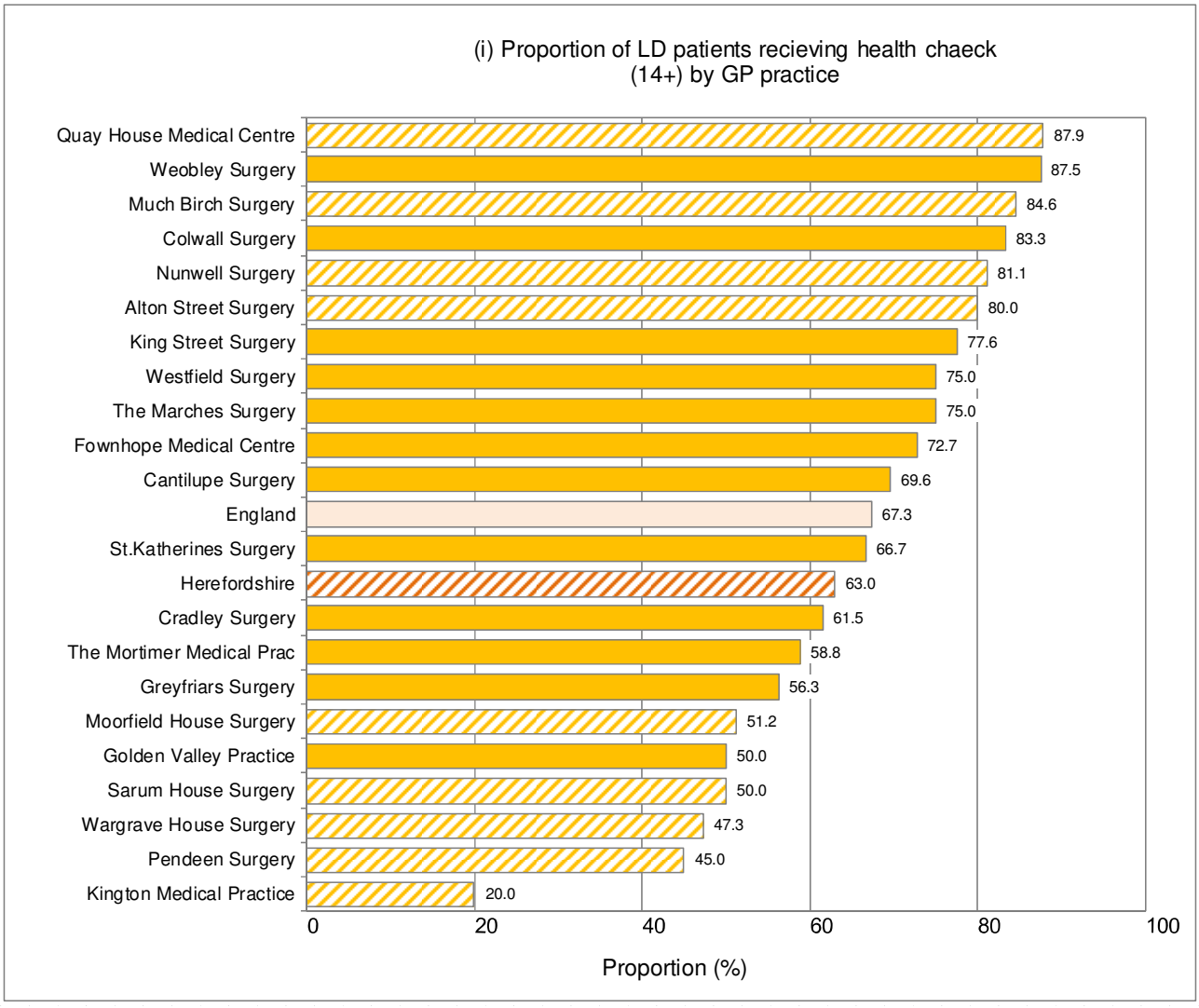
Source: NHS Digital - Learning disabilities health check scheme / Intelligence Unit, Herefordshire Council

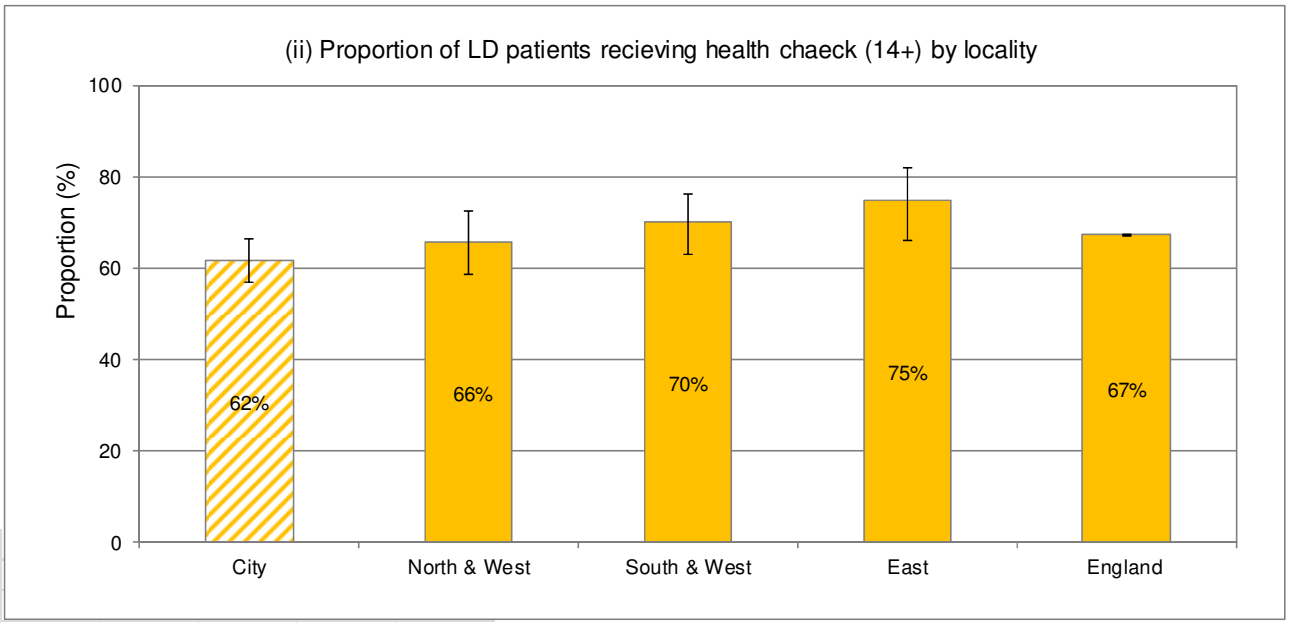
Observations

While the local proportion of LD cases receiving an annual health check is comparatively high compared to comparators since 2015/16 it has fallen below that reported nationally. It may be interesting to note that the West Midlands Quality Review Service (MWQRS) were told that the number of annual health checks had reduced since funding for the Directed Enhanced Services (DES) had ceased.

While the checks are being undertaken there are no readily available documented results outlining any subsequent treatment plans are being adopted. NICE states that a care plan for managing any physical health and mental health problems should be developed as appropriate. However, information recording of any such plans is not readily available. Consequently, it is recommended that results of health checks are made readily available to support services so that requirements are made known to and clearly understood by support providers.

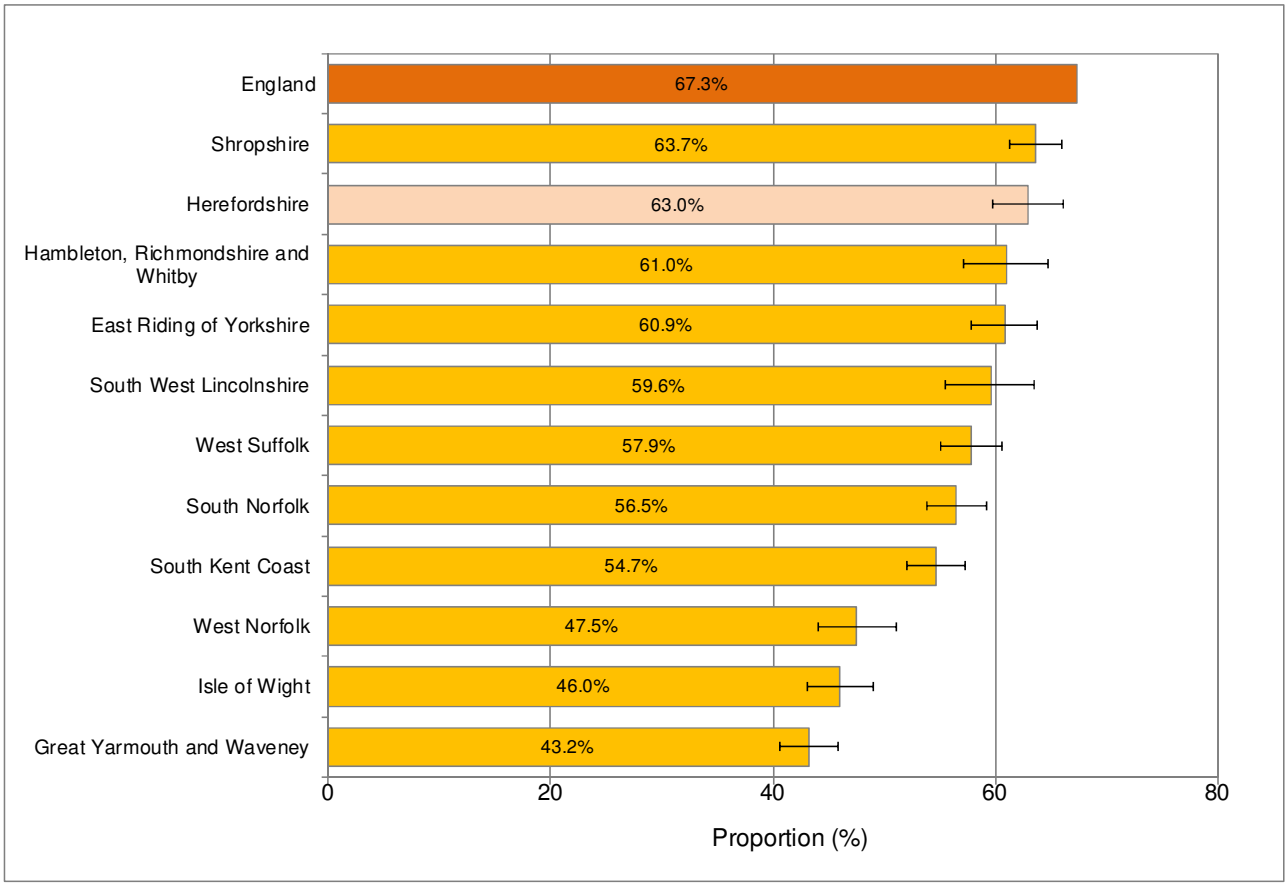
Figure 18: Proportion of individuals with a learning disability having a GP health check in Herefordshire GP practices, 2016/17. (shaded bars = significantly different from England figure)





Source: NHS Digital - Learning disabilities health check scheme / Intelligence Unit, Herefordshire Council

Figure 19: Proportion of individuals with a learning disability having a GP health check in Herefordshire and nearest neighbour CCGs, 2016/17.



Source: NHS Digital - Learning disabilities health check scheme / Intelligence Unit, Herefordshire Council

Barriers to Screening, Vaccination and Immunisation

Improving access to screening programmes for people with learning disabilities has been recognised as an issue. For Public Health England commissioned programmes (flu vaccination, cancer screening) work is currently underway with providers to ensure they firstly collect information about and secondly improve access for people with protected characteristics includes learning disability.

People with learning disabilities often have difficulty in recognising illness, communicating their needs and using health services. Carer recognition of needs is paramount to maintenance of health of people with learning disabilities as recognition can lead to taking action. The Annual Health Check is a chance for the person to overcome barriers to healthcare access and get used to going to their GP practice. This in turn reduces their fear of going at other times. Currently only adults with learning disabilities are entitled to a free annual NHS health check.

Public Health England have commissioned programmes (flu vaccination, cancer screening) work is currently underway with providers to ensure they firstly collect information about and secondly improve access for people with protected characteristics includes learning disability.

Cancer Screening

Adults with learning disabilities are still significantly less likely to receive cancer screening tests than those without learning disabilities[73], a pattern supported by the information outlined below.

In 2015/16 the local uptake for **cervical cancer screening** in females with LD who were eligible was 26.4 per cent, a figure just over one third of that for the county population as a whole (71.3 per cent). The local proportion was similar to those recorded both nationally the regionally (Table 10).

In Herefordshire the uptake of **breast cancer screening** in eligible female LD patients aged 50 to 69 was 50.9 per cent which was approximately three quarters of that for the county as a whole (69.6 per cent). While the local proportion was higher than both the national and regional figures the differences were not statistically significant (Table 10).

In 2015/16 the local proportion of LD patients aged 60 to 69 who were eligible for **colorectal cancer** screening was 83.5 per cent which was lower than the figure for the county as a whole (86.0 per cent). Although higher than the national proportion the local figure was not statistically higher than that for the West Midlands (Table 10).

Table 10: Proportion (%) of eligible learning disability population undergoing cancer screening in Herefordshire, England and the West Midlands, 2015/16. (Figures in parentheses = 95% confidence intervals)

	Herefordshire	England	West Midlands
Cervical Cancer	26.4 (21.5 – 31.8)	29.2 (28.7 – 29.6)	28.7 (27.4 – 30.2)
Breast Cancer	50.9 (41.7 – 60.1)	45.9 (45.1 – 46.6)	43.4 (41.0 – 45.8)
Colorectal Cancer	83.5 (74.9 – 89.6)	75.1 (74.4 – 75.8)	65.4 (62.9 – 67.9)

Source: NHS Digital - Health and care of people with Learning Disabilities, Experimental Statistics, 2015-16

[73] Robertson, J., Roberts, H and Emerson, E. (2010). *Health Checks for People with Learning Disabilities: A Systematic Review of Evidence*. Learning Disability Observatory. Available at: http://webarchive.nationalarchives.gov.uk/20160704155636/http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemticReview.pdf

Observation

It is clear that in Herefordshire the cancer screening rates for eligible individuals with LD is are appreciably lower than for the population as a whole. This is an important factor which can lead to late and missed diagnosis as indicated by the local prevalence of cancer in individuals with LD is approximately one third of that in the population as a whole. As a result outcomes are likely to be poorer and premature mortality from cancer more likely.

Currently, the availability of health data relating to adults with LD in Herefordshire is poor. Improved sharing of data concerning all aspects of health care (health check, screening, diagnosis, stage of presentation, outcomes, etc.) would facilitate the assessment of the health of the individual and of the LD community as a whole across the county. All such information should be made readily available to all relevant services and should apply equally to all aspects of health care of adults with LD to encompass all co-morbidities and risk factors.

Sensory Impairment – people with LD are more likely than the general population to have sensory impairment, especially regarding eye sight. A London study of sensory impairment in a cohort of people with learning disabilities found 58 per cent of participants were either prescribed glasses for the first time or required a new prescription. Half of participants were not previously receiving regular eye care[74].

Immunisation

Free Flu vaccination - people with learning disabilities are eligible for a free flu jab. As described above, providers are now being requested to monitor uptake by people with learning disabilities in order to improve access in the future.

Tuberculosis (TB) vaccination - People with learning disabilities are not routinely eligible for TB vaccination unless they are in a high risk category of coming from a high incidence country or having relatives with TB – same as general population.

Hep B Vaccination - eligibility for Hep B vaccination is on a case by case basis e.g. dependent on exposure to risk e.g. staff and residents of institutes for people with learning disabilities[75].

Life Expectancy

Research has indicated that persons with a learning disability have a shorter life expectancy and elevated risk of premature mortality compared to the general population[76]. Furthermore, there is a

[74] Sheffield Learning Disability Health Needs Assessment 2016

[75] Hawker. J, Begg N, Blair I, Reintjes R, Weinberg J, Ekdahl K Communicable Disease Control and Health Protection Handbook (third edition) Oxford: Wiley Blackwell

negative association between severity of learning disability and life expectancy, where those with a mild learning disability have a life expectancy approaching that of the general population. Recent work has indicated that in the UK men with learning disabilities die, on average, 13 years sooner than men in the general population, and women with LD died 20 years sooner than women in the general population and overall, 22 per cent of people with LD were under the age of 50 when they died compared to 8 per cent in the general population[77]. Similar finding were subsequently reported by Glover et al. (2017)[78] with the only difference being that the short fall in life expectancy of 20 years in both males and females with LD. However, it has been reported that life expectancy for people with LD is increasing, particularly for people with Down's syndrome, and there is evidence to indicate that for people with mild learning disabilities life expectancy may be approaching that of the general population (Puri *et al*., 1995[79] - cited in IHAL, 2015[80]).

Mortality

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)[81] indicated that the most common certified underlying causes of death in people with LD were heart and circulatory disorders and cancer, which represented 22 and 20 per cent of deaths respectively. While these conditions are also the two most common underlying causes of death in the general population, the proportion of related deaths are 29 per cent for circulatory disease and 30 per cent for cancer. The report states that almost half of LD deaths (49 per cent) occurred at ages and from causes considered as potentially avoidable, which is more than twice that recorded for the population of England as a whole (23 per cent).

In 2015/16 a collaborative team comprising the Learning Disabilities Observatory team, LeDeR[82] and the Medicines and Healthcare Products Regulatory Authority (MHRA) studied the mortality in people with LD using national data covering the four year period between April 2010 and March

---

[76] Patja, K, Iivanainen, M., Vesala, H., Oksanen, H. and Ruoppila, I. (2000). *Life expectancy of people with intellectual disability: a 35-year follow-up study*. Journal of Intellectual Disability Research, **44:** 591–9.

[77] Pauline Heslop et al, "Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report",(University of Bristol, 2013), p.2, http://www.bris.ac.uk/cipold/fullfinalreport.pdf

[78] Glover, G., Williams, R., Heslop, P., Oyinlola, J. and Grey, J. (2017). Mortality in people with intellectual disabilities in England. Journal of Intellectual Disability Research, 61: 62 – 74.

[79] Puri, B.K., Lekh, S.K., Langa, A., Zaman, R. and Singh, I. (1995). *Mortality in a hospitalized mentally handicapped population: a 10-year survey*. Journal of Intellectual Disability Research, **39:** 442-46

[80] Emerson E., & Baines S. Health Inequalities & People with Learning Disabilities in the UK. IHAL 2010. Available at: www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf

[81] CIPOLD Final Report.. Available at: http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

[82] http://www.bristol.ac.uk/sps/leder/

2014. The group reported that people with LD had a standardised mortality rate (SMR)[83] of 3.2, indicating that the number of deaths in those with LD was more than three times the number expected for a cohort of similar size and age/sex composition from the overall population; when looking at gender specific rates the figure for women was 3.4 and that for men 3.0[46]. The findings also indicated that the most common causes of death were circulatory diseases (22.9 per cent of LD deaths), respiratory diseases (17.1 per cent) and cancer (13.1 per cent). When comparing the SMRs for people with LD with the general population LD death rates were 2.8 times the expected number of deaths from circulatory diseases and 4.9 times the number of deaths from respiratory diseases, while the cancer death rate was similar to the figure for the general population. Mortality related to epilepsy and aspiration pneumonitis, both of which are potentially preventable causes of death, represented 3.9 and 3.6 per cent of LD deaths respectively. The study highlighted important areas for health promotion initiatives such as the control of cardiovascular risk factors, epilepsy and dysphagia and the management of thrombotic risks and colorectal screening.

It is difficult to generate reliable local information on mortality and life expectancy as LD is not routinely recorded on death certificates[45]. However, in 2015/16 there were 11 registered deaths in Herefordshire which had a recording of a learning disability diagnosis which represents 0.54 per cent of all adult deaths in the county that year as recorded within PCMD[84], a proportion of deaths lower than the prevalence of registered adult LD cases in the county (0.60 per cent). Nationally, death certification data indicates that of around 450,000 deaths annually around 1,000 record that the deceased had a learning disability[85], a figure which represents 0.22 per cent of registered deaths.

Observation

Recording of LD in relation to mortality is poor in Herefordshire. This would be improved by the recording of LD status on appropriate certification so that the true mortality rate within the LD community can be better monitored which in turn can be employed as a further indicator of where health care programmes should be targeted and as a measure of the success in the health care of the LD community

[83] The SMR is a ratio of the numbers of deaths observed in a group of people compared to the numbers expected if they had the same age and sex-specific death rates as the general population.

[84] PCMD – Primary Care Mortality Database.

[85] Learning Disabilities Observatory. People with learning disabilities in England 2015: Main report. PHE – IhaL, 2016. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

LIVING

Throughout 2015/16 a total of 590 Herefordshire adults received long term LD support, of which 525 were aged between 18 and 64 and 65 were 65 and over[86]. The total figure for 2015/16 represents a 9.4 per cent increase on the number of adults receiving support from Herefordshire Social Services in 2009/10 (480)[87].

At the end of 2015/16 there was a total of 555 adults receiving long term support, which represents 61.7 per cent of the 900 adults included on the LD register. Of these 500 had been in care for more than 12 months (445 aged 18-64; 55 aged 65+) representing 90 per cent of individuals receiving long term LD support.

Supported Residents in Residential and Nursing Accommodation

Across Herefordshire a total of 140 adults with LD were in residential accommodation at some point in 2015/16. At the end of March 2016 there were 130 in residential accommodation, 110 of which were aged between 18 and 64 and 20 aged 65 and over; of these 125 had been in care for more than 12 months (105 aged 18-64; 25 aged 65+) representing 96 per cent of adults in residential accommodation.

Five adults with LD were in nursing accommodation at some point in 2015/16, all of which were aged between 18 and 64 and were resident at years end. There were no LD adults aged over 65 in nursing accommodation during 2015/16.

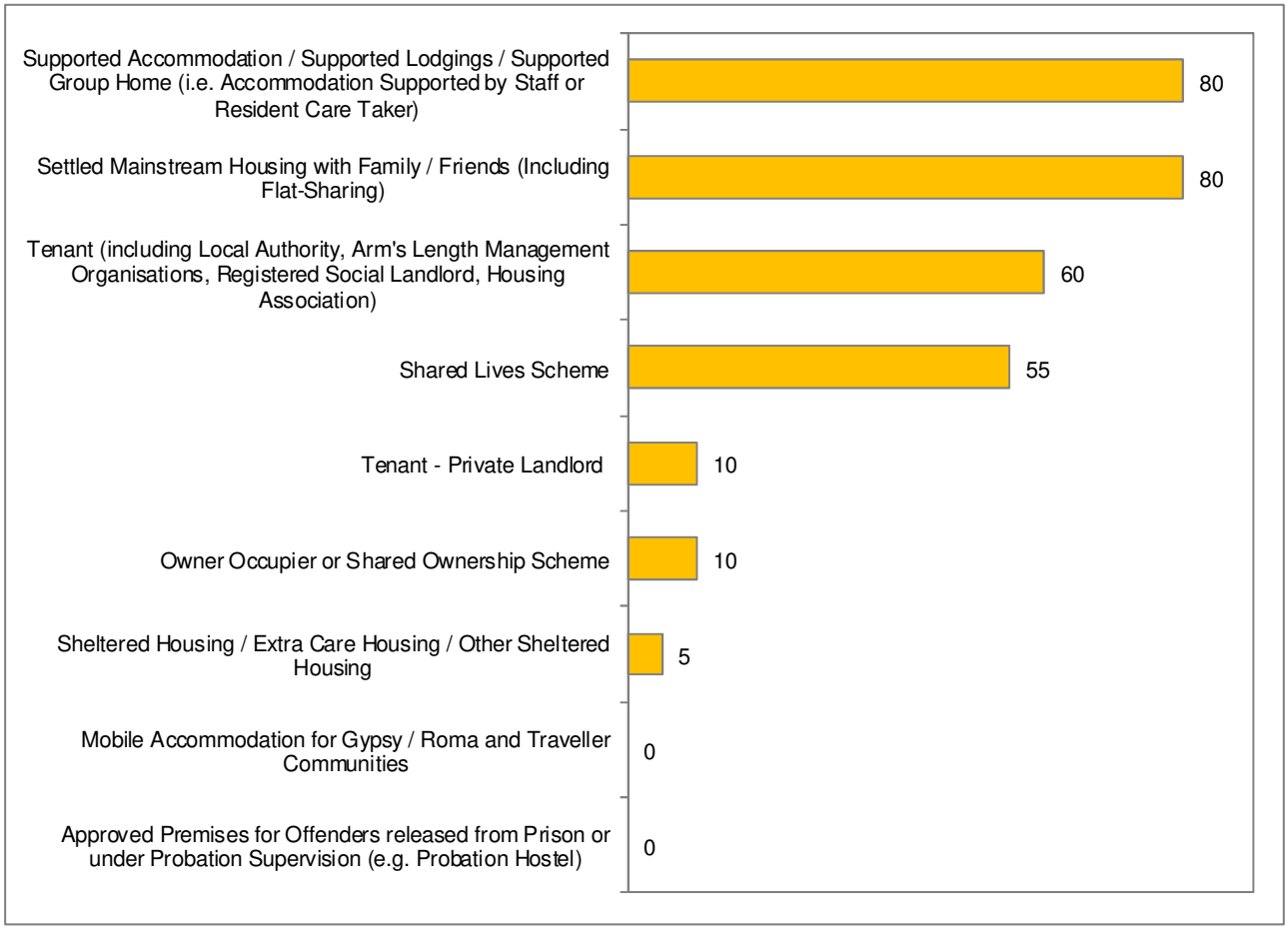
Settled Accommodation

'Settled' accommodation refers to accommodation arrangements where the occupier has medium to long term security of residence, or is part of a household whose head holds such security. Of the 525 people aged 18-64 with LD who received long term care in Herefordshire in 2015/16 305 were recorded as living in settled accommodation, which represents 58 per cent of this cohort. A breakdown of numbers in each type of settled accommodation indicates that the most common types of accommodation Supported Accommodation and Living with Family/Friends both of which represented 26 per cent of those in settled accommodation (Figure 20). Other important accommodation types are Shared Living Schemes and Tenant (private landlord) which between them represent 38 per cent of those in settled accommodation.

[86] NHS Digital - Community Care Statistics, Social Services Activity, England 2015-16.

[87] Facts and Figures about Herefordshire - Adults with learning disabilities. Available at: https://factsandfigures.herefordshire.gov.uk/about-a-topic/vulnerable-people/adults-with-learning-disabilities.aspx

Figure 20: Numbers of individuals with LD living in settled accommodation in Herefordshire, 2015/16.



Source: NHS Digital - Community Care Statistics, Social Services Activity, England 2015-16

Unsettled Accommodation

'Unsettled' accommodation refers accommodation arrangements which is either unsatisfactory or, where, like in residential care homes, residents do not have security of tenure. Categories of 'unsettled accommodation' include:

- Rough sleeper/Squatting;
- Night shelter/emergency hostel/direct access hostel (temporary accommodation accepting self-referrals);
- Refuge;
- Placed in temporary accommodation by the council (including Homelessness resettlement) - e.g., Bed and Breakfast;
- Staying with family/friends as a short term guest;
- Acute/long stay healthcare residential facility or hospital (e.g. NHS or Independent general hospitals/clinics, long stay hospitals, specialist rehabilitation/recovery hospitals);
- Registered Care Home;

- Registered Nursing Home;
- Prison/Young Offenders Institution/Detention Centre;
- Other temporary accommodation;
- Unknown.

In 2015/16 across Herefordshire there were 220 supported adults aged 18 to 64 with learning disability living in unsettled accommodation, which represents 41 per cent of those receiving long term LD support. Of these 115 were in Registered Care Homes and the residence of 100 were unknown; this latter figure represents 19 per cent of those receiving long term care in Herefordshire.

Supporting Carers

The families of people with learning disabilities are usually their main source of care and support, especially for those with greater or more complex needs. It is vital that family carers are recognised and valued in accordance with the Government strategy 'Carers at the heart of 21st century families and communities'[88] and it is acknowledged that that there is an absolute need to increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively[3]. Carers supporting people with learning disabilities are more likely to have been a carer for longer periods than those caring for people with other needs and are likely to live in the same household as the person they care for, and to provide a greater number of hours of care each week.

In Herefordshire, approximately 2,500 people (2015/16) are in receipt of long-term support from adult social care at any one time, the majority of whom (1,700 people) are supported to live in their own homes. The remaining 800 people live in care homes. The most common types of support provided can be differentiated by age groups; 91 per cent of clients aged over 50 years receive 'physical support', whilst half of clients aged below 50 years received support in relation to a learning disability[89].

In 2015/16 there were 75 adults with LD in Herefordshire whose carer received direct support throughout the year while a further 30 carers received no direct support. Of those receiving support 15 received direct payment, 5 received part direct payment, 10 CASSR (Council with Adult Social Services Responsibility) commissioned support, while 15 received Information, advice and other universal services / signposting; a further 30 received respite or other forms of carer support delivered to the cared for person[45].

[88] Carers at the heart of 21st-century families and communities. "A caring system on your side. A life of your own." HM Government, 2008. Available at: http://webarchive.nationalarchives.gov.uk/20130105000047/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_085338.pdf

[89] Herefordshire Integration and Better Care Fund. Narrative Plan 2017/19 (Draft). Herefordshire Council/Herefordshire CCG.

Transport

In 2012 The Brandon Trust held an event where over 150 people with LD and autism spoke about the problems they face when using public transport, the findings of which were included in Transport Select Committee's 'Disabled Access to Transport' report[90]. In relation to access to transport for disabled people the House of Commons Transport Committee stated “Enabling and encouraging access to transport for disabled people delivers widespread benefits across government, through widening employment opportunities; through access to healthcare and education; and by enabling disabled people to participate more in society”.

The Brandon Trust event produced the 100 Voices on Transport report[91] which contained the views expressed by those people with LD and autism who attended the event. This included the following reasons why people with LD felt that transport was very important to them:

- Most people with learning disabilities don’t drive and therefore have to rely on others or on public transport to get to places.
- Transport enables them to go to work, college, visit family and friends, access their local community, have a social life, go shopping, use leisure facilities. Some of them would even like to travel further, go on holiday or explore other places.
- Without transport, people with learning disabilities are stuck at home and become isolated.
- Transport gives people with learning disabilities freedom and independence.
- Transport makes them feel that they are like everybody else.

The report also listed the reasons why people with LD and autism found using public transport difficult:

- It is too expensive.
- Lack of availability, in terms of both routes and times.
- Lack of accessibility. This refers to every aspect of transport: from the vehicles themselves, to train and bus stations, to timetables and signage.
- Fear of being abused or of being mistreated and disrespected by bus drivers, train and station staff, and other passengers. Some of the people we support reported frightening experiences, especially on buses (bullying and teasing).
- Lack of understanding, on behalf of the general public, of the barriers a person with a learning disability faces when travelling alone on public transport. Some people can be impatient and rude.

[90] Access to transport for disabled people. Fifth Report of Session 2013–14. House of Commons Transport Committee, September 2013. Available at: https://publications.parliament.uk/pa/cm201314/cmselect/cmtran/116/116.pdf

[91] Brandon Trust. 100 Voices On Transport - A report on transport-related issues, by people with learning disabilities and autism. Available at: https://www.brandontrust.org/media/59175/100voices_transport_report.pdf

- Inability to use concessionary bus passes before 9.30am and therefore having to pay for a taxi to go to college or work.
- Lack of appropriate training and support on how to use public transport for people with a moderate learning disability.

The report then listed suggestions on how the above problems could be solved:

- Better transport solutions for people with learning disabilities, organized by councils, charities and communities in partnership.
- Wider time coverage of concessionary travel passes so that they are not restricted to certain hours.
- Training for bus and taxi drivers, and other transport staff, on the needs of people with learning disabilities.
- More public awareness of learning disabilities and increased acceptance of disabled people on public transport. This can be achieved through media coverage and campaigns.
- Better accessibility on buses and trains, fewer environmental barriers.
- Easy read complaints procedures.
- Easy read timetables.
- A telephone number displayed at bus stops or in train stations that people can call if the bus/train is late or if they require assistance.
- Cameras on buses to capture abusive behaviour.
- More travel and transport training for people with learning disabilities, like the 'Travel Buddy' scheme.
- More engagement with local MPs and people who can influence social policy so that the views of people with learning disabilities are heard.

In Herefordshire transport solutions are offered to people with LD of all ages with transport options ranging from home to school travel, travel to work/college, access to day care, GP/hospital appointments, socialising etc. Travel Links[92] co-ordinate community transport services to adult residents in Herefordshire who do not have access to suitable transport services, or are unable to use the public services available. However there are limitations in terms of availability, accessibility and cost with charges made to help towards the cost of operating the service. Every parish in Herefordshire is served by a community transport scheme, based in the voluntary sector and supported by Herefordshire Council.

Herefordshire Council follows the English National Travel Scheme and provides bus passes which allow free travel to the holder. Currently around 32,000 passes have been issued across the county of which approximately 400 have been issued to people with disabilities Applications for

[92] https://www.herefordshire.gov.uk/info/200187/transport/164/community_transport

passes from disabled people go through an Independent Medical Advisory Board which then makes the decision as to whether a pass is issued or not. Herefordshire Council is currently examining options to improve the application/renewal process.

Employment

Employment is an important way that people are included in society, but it remains extremely low among people with learning disabilities. People with a learning disability have the same right to work as everyone else, but they find it much harder to get a job. Research shows that 65 per cent of people with a learning disability would like to work and that with the right support they make highly valued employees[3].

The Government report Valuing *Employment Now*[93] details a strategy aimed at strategy supporting people with moderate and severe LD to work for at least 16 hours per week, a point at which most would personally be financially better off and achieve greater inclusion. The report outlines a number of issues which would need to be tackled to enable individuals with LD obtain gainful employment.

Locally in 2015/16 there were 60 individuals with LD of working age (18-64) in paid employment[86], which is twice that recorded in 2014/15. The 2015/16 figure represents 11.4 per cent (compared to 5.8 per cent in 2014/15) of the working age LD population in Herefordshire receiving support, a proportion considerably higher than the figures reported for both England (5.8 per cent) and the West Midlands (4.5 per cent); while the local proportion doubled between 2014/15 and 2015/16 both the national and regional figures showed no change over this period. Of those individuals in paid employment in Herefordshire in 2015/16 ten were employed for 16 hours or more per week and 50 for less than 16 hours a week; males represented two thirds of those individuals in paid employment.

Safeguarding

Safeguarding is the term used to cover all work undertaken to support individuals with care and support in order to maintain their safety and wellbeing. It describes the preventative and responsive actions undertaken to support those who are experiencing, or at risk of experiencing abuse or neglect.

Safeguarding Adults is now a statutory duty under Section 42 of the Care Act 2014[94], and applies to incidences where a local authority has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there)

- has needs for care and support (whether or not the authority is meeting any of those needs),
- is experiencing, or is at risk of, abuse or neglect,

[93] Valuing Employment Now: real jobs for people with learning disabilities. Department of Health, 2009.
Available at: http://www.mcch.org.uk/publicmedia/Documents/Strategy%20Document.pdf

[94] http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

- as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

In these situations the local authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult's case and, if so, what and by whom.

The Herefordshire Safeguarding Adults Board (HSAB)[95] was established by Herefordshire Council, health commissioners and West Mercia Police in 2009 with the aim of co-ordinating the effectiveness of safeguarding services provided to Adults at Risk in the county and became a statutory function under the Care Act 2014 on 1st April 2015. The main statutory objective of a Safeguarding Adults Board is to assure that local safeguarding arrangements and partners act to help and protect Adults at Risk.

HSAB comprises representatives from various agencies and organisations including:

- Herefordshire Council - Adults and Wellbeing
  - Childrens Wellbeing
  - Public Health
  - Economics, Communities and Corporate
- Care Quality Commission;
- Herefordshire Clinical Commissioning Group;
- 2gether NHS Foundation;
- Wye Valley NHS Trust;
- NHS England West Midlands;
- West Mercia Police;
- National Probation Service;
- Warwickshire and West Mercia Community Rehabilitation Company;
- West Mercia Women's Aid;
- Healthwatch Herefordshire;
- Royal National College;
- Association of Care Trainers.

The board meets throughout the year working in partnership and sharing best practice and expertise to ensure that adults have access to the right support and services they need.

[95] https://herefordshiresafeguardingboards.org.uk/

A safeguarding concern is a sign of suspected abuse or neglect that is reported to the council or identified by the council. A safeguarding enquiry is the action taken or instigated by the local authority in response to a concern that abuse or neglect may be taking place. An enquiry could range from a conversation with the adult to a more formal multi-agency response. In 2015/16 there were 170 section 42 LD safeguarding concerns in Herefordshire which resulted in 75 section 42 safeguarding enquiries; this latter figure represents 44.1 per cent of all LD safeguarding concerns across the county and 19.2 per cent of the total number section 42 enquiries reported in the county. For England the number of 42 safeguarding enquiries represented 63.7 per cent of all LD safeguarding concerns across reported nationally and 13.9 per cent of the total number section 42 enquiries reported in the county.

Advocacy

The Government report *Valuing People*[71] states that as an overall policy objective "people with learning disabilities will be treated as equal citizens in society and supported to enact their rights and fulfil their responsibilities". Consequently, Government policy is clear that people should be able to be active citizens and have a say about how things work where they live and also recognises that some people need support to make this happen. There are specific rights in law for advocacy in some circumstances:

- The Mental Capacity act 2005: this provides a statutory framework for acting and making decisions on behalf of individuals who lack the mental capacity to do so for themselves. The independent Mental Capacity advocate (IMCA) service supports people who lack capacity and who have no family or friends to support them when serious decisions are taken in their lives; and

- The Mental health act 2007: arrangements will be made to provide independent Mental health advocates (IMHA) for 'qualifying' patients in England from April 2009.

The Mental Capacity Act is underpinned by five principles:

- A person must be assumed to have capacity unless it is established that they lack capacity.

- A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success.

- A person is not to be treated as unable to make a decision merely because they make an unwise decision.

- An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests.

- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

For this to be achieved individuals with LD need to be able to speak up and be heard about what they want from their lives and, if required, receive support to do this in the form of advocacy. There are different forms of advocacy:

- Self-advocacy – people coming together to speak up for themselves;

- Citizen advocacy – volunteers developing long-term relationships with people and speaking up for them;
- Professional or representational advocacy – people being paid to advocate with, and for, individuals on a short- or long-term basis; and
- Peer advocacy – people who have the same or similar experience of discrimination as the person they are acting as an advocate for.

Herefordshire Council has recently commissioned Onside Independent Advocacy[96] to provide advocacy services for adults to meet statutory obligations and ensure the availability of confidential and independent advocacy for vulnerable adults in Herefordshire. The contract is for a period of three years from 1st August 2017 to 31st July 2020, with the option of one year's extension and will encompass the whole of Herefordshire from its base in Hereford. The service covers, but is not restricted to, adults with LD (including people with autism or Asperger's syndrome) and will provide a range of advocacy services to adults to include:

- IMHA
- IMCA (including Deprivation of Liberty Safeguards - DoLS)
- Care Act 2014 Advocacy
- Generic advocacy
- NHS Complaints Advocacy

Payments

There are a number of pathways by which services can be procured to support individuals with LD:

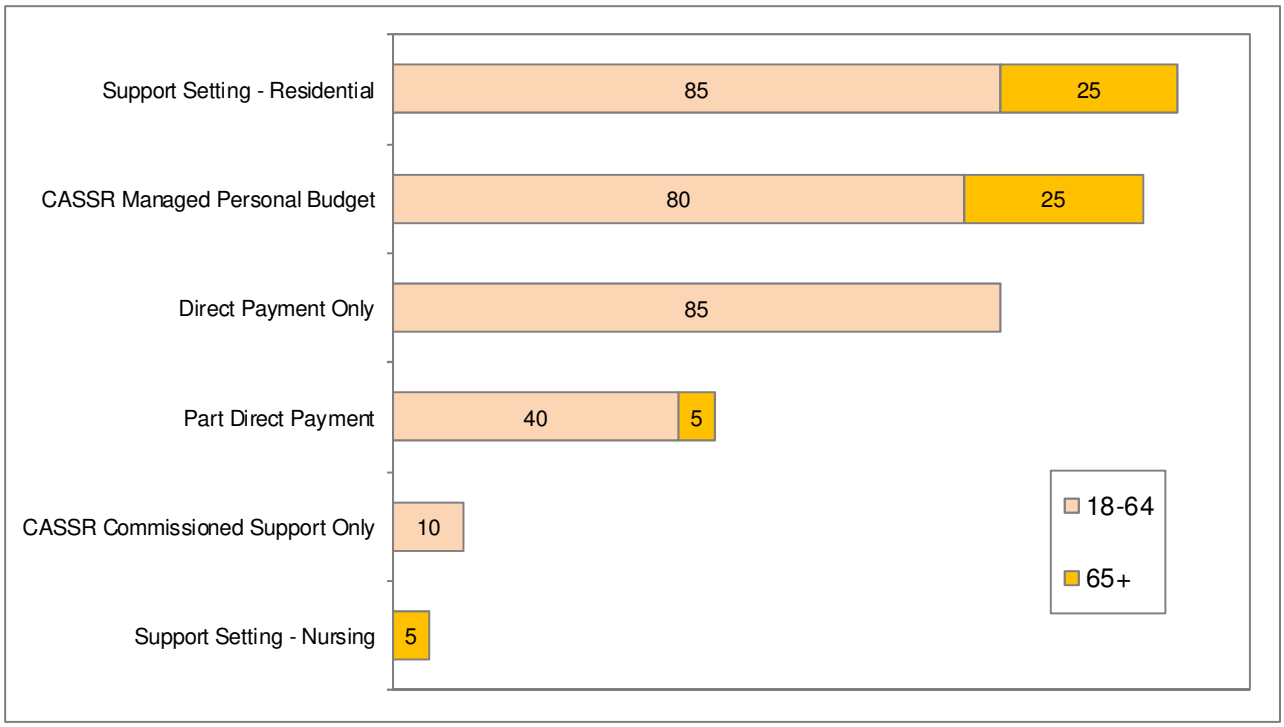
- Direct Payment – this is a cash payment made by a CASSR to individuals who have been assessed as needing services, The aim of a direct payment is to give more flexibility in how services are provided individuals have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered.
- Part Direct Payment - a payment where a proportion of support required by an individual is provided by a cash payment by a CASSR e.g. where payment is given to help a carer purchase some equipment and in addition, respite services are arranged by the CASSR on an ongoing basis.
- CASSR Managed Personal Budget – where an individual (or their representative) has been informed about upfront allocation of funding which enabling them to plan their support arrangements. While there is an agreed support plan which outlines what outcomes are to be achieved with the money the individual (or their representative) can use the money in ways and at times of their choosing.
- CASSR Commissioned Support Only - a package of services provided by the CASSR but not within a personal budget and with no cash payments.

[96] http://www.onside-advocacy.org.uk/

- Residential/Nursing - payments made directly to residential and nursing homes that provide health and social care services and are registered with the Care Quality Commission (CQC) under the Health and Social Care Act 2008[97].

In 2015/16 of a total of 365 adults with LD receiving long term support payments in Herefordshire 305 were of working age (18 – 64) and 60 were aged 65 and over[65]. Overall, the most prevalent payment type was to individuals in residential accommodation with a total of 110 individuals receiving support (Figure 21). Of those in the community the most common all age support setting was CASSR managed personal budget while direct payments only were also important. For those of working age the most common payment pathway for those in the community were direct payment only and CASSR managed personal budget; for those aged 64 and over CASSR managed personal budget was the most common.

Figure 21: Numbers of individuals with LD receiving different payments in Herefordshire, 2015/16.



Source: NHS Digital - Community Care Statistics, Social Services Activity, England 2015-16

[97] https://www.legislation.gov.uk/ukpga/2008/14/contents

CURRENT PROVISION OF SERVICES

Governance

The Government White Paper 'Valuing People' stipulated the requirement for the creation of a Learning Disability Partnership Board (LDPB) to be established in each local authority. This was further emphasised by in 'Valuing People Now' and the Department of Health published guidance on how these should operate[98]. The Boards are part of the delivery mechanism for achieving the priorities as originally set out in 'Valuing People' and aim to bring together all the relevant local agencies and stakeholders and to give a voice to people with learning disabilities and their family carers. They are established locally within the overall governance accountability arrangements for Local Authorities and CCGs with the overall accountability resting with the Director of Adult Social Services and the CCG Chief Executive.

In the terms of reference the Herefordshire Learning Disability Partnership Board (HLDPB) states that it exists on behalf of adults with LD with the aims of:

- Giving people with LD a voice.
- Working with the Council and NHS to make sure people with learning disabilities have the best possible services.
- Challenging and questioning the council and providers of services on decisions they make.
- Communicating important information and decisions to adults with learning disabilities using the best ways to meet their needs.
- Influencing the future of learning disability services.

HLDPB comprises representatives from various agencies and organisations including:

- Voluntary sector;
- Advocacy services;
- Providers of day activities;
- Providers of residential care;
- Home support/supported living;
- Family carers;
- Commissioners (council – adults and children's);
- Commissioners (clinical commissioning group);
- Moving into adulthood (transitions);

[98] Department of Health. Good learning disability partnership boards: "Making it happen for everyone." London: Department of Health; 2009. Available at: http://www.centralbedfordshire.gov.uk/Images/good-learning-disability_tcm3-10939.pdf

- Assessment and review (operations);
- Safeguarding;
- Mental health.

Herefordshire Council's adults and wellbeing leadership team are responsible for HLDPB. The board meets four times a year and reports to Herefordshire's Health and Wellbeing Board.

The Joint Commissioning Board (JCB) provides the overall strategic oversight and direction to the joint commissioning arrangements in Herefordshire and as such is responsible for integrated health and social care for adults. However, where learning disabilities are concerned Herefordshire Council is currently the lead commissioner for this service through a Section 75 Partnership Agreement[99]; the CCG's commissioning activity around learning disability issues focuses on narrower issues such as the post-Winterbourne View Transforming Care Programme.

Providers – Community Services

[2]Gether NHS Foundation Trust

Currently, community services are commissioned from [2]Gether NHS Foundation Trust through the Community Learning Disability Team (CLDT) with an annual budget of £970,000, which is funded primarily from the council base budget with funds originally transferred from the Primary Care Trust in 2008, plus supplementary funds from the Better Care Fund. The service provided is essentially two teams in one and comprises:

- A multi-disciplinary team with a typical mix of Community LD nurses and allied health professionals, undertaking assessment long term case management, co-ordination and liaising with other services.
- A specialist mental health team, incorporating psychiatry, clinical psychology and counselling and working with learning disabled people in diverse ways including diagnostics, group and individual programmes, medication review and specialist programmes.

Currently the community mental health services for people with learning disabilities or autism delivered by [2]Gether have a Care Quality Commission (CQC) rating of 'Good'[100].

Echo

Echo is an independent Herefordshire-based charity which runs a range of activities primarily for people with moderate or severe learning disabilities. They include day opportunities, which provide a full day of supported activity where people work together to learn new skills such as horticulture,

[99] Section 75 of the National Health Service Act 2006 permits agreements to be made between local authorities and NHS bodies which can include arrangements for pooling resources and delegating certain NHS and local authority health-related functions to the other partner/s. Details available at: http://www.legislation.gov.uk/ukpga/2006/41/section/75

[100] Full details of the rating are available here: https://www.cqc.org.uk/sites/default/files/new_reports/AAAE5942.pdf

cooking, theatre skills, and working with textiles, while leisure and social activities include music, sports, arts and in a variety of community venues.

Aspire

Aspire is a registered charity based in Hereford which provides support to individuals with LD. Services provided include residential care, support at home helping people to live independently and also helping individuals to undertake tasks such as shopping, volunteer and leisure activities. Aspire have a CQC rating of 'Good'.

Ategi

Ategi which operates a Shared Lives Scheme in Herefordshire is registered to provide personal care for people who live in their homes - approved Shared Lives Carers offer accommodation and support within their own homes and families to vulnerable and disabled adults who prefer to live in an ordinary household. Ategi provide personal care to around 70 people. Ategi have a CQC rating of 'Good'.

Affinity Trust

Affinity Trust (known as Score Community Opportunities in Herefordshire) is a registered charity providing support for people with learning disabilities. Day opportunities are provided on weekdays including activities such as swimming, bowls, walking, golf, skittles, arts and crafts, keep fit, drama, and Ad Mag delivery.

Salters Hill

Salters Hill work alongside people with learning disabilities providing accommodation and associated support, support people with LD to live in their own homes and encourage creative learning and encourage involvement in the community. Salters Hill have a CQC rating of 'Good'.

Providers – Residential Services

There are 36 establishments across Herefordshire which provide residential accommodation for adults with LD as listed by WISH[101]. Of these all but one have a CQC rating of 'Good', with a single establishment rated as 'Requires Improvement'. Over a third of these establishments are located in and around Hereford with others near Ross and in Leominster; there is only one located in the west of the county at Kington (Figure 22). Further details are given in Appendix A.

Day Opportunities

As an alternative to attending a traditional day centre people with LD may wish to access a range of activities which ensure their days are busy, enjoyable and productive and which help promote independent living and supports people with LD to stay active and independent. These are known as 'day opportunities' and can include education, training, volunteering or paid work in and with their local communities.

Currently, around 150 people with LD are provided with day opportunities at seven locations across the county. These clients are a mixture of people funded by Herefordshire Council under a

[101]Wellbeing Information and Signposting for Herefordshire (WISH) - http://www.wisherefordshire.org/

spot basis, some self-funders and some people using their direct payments. In addition, NHS continuing health care (CHC) funding supports some placements and one young person is funded by the council's children's wellbeing directorate. Various locations are utilised across Herefordshire to provide day opportunities with the St Owen's Centre in Hereford providing the most complex service and supporting the largest group of learning disabled people in the county. Other locations are found in Hereford, Ross-on-Wye, Ledbury and Leominster.

Aspire run the St. Owens Centre and also provide other services in the city at the Aspire Community Hub and also at Widemarsh. Opportunities are offered five days a week and include health and wellbeing activities, learning and employment projects and other leisure activities.

ECHO delivers the day opportunities at a number of locations including Priory Centre in Leominster, Eaton Barn and Bridge Street Workshop with activities including theatre workshop, arts and crafts, gardening projects and volunteering.

Salter's Hill provide day opportunities in south and east Herefordshire with activities including gardening, land and livestock, woodwork, art and crafts, drama, home skills and cooking.

A range of other opportunities and support are offered across the different locations across the county by various appropriate social care providers operating in these areas.

In the 12 months up to the end of August 2017 a total of 141 adult clients were provided with day opportunities at a weekly cost of £21,800, which equates to an annual cost of £1.05 million. The locations of users residences are illustrated in Figure 23 which indicates a concentration of individuals in Hereford and Leominster and Ross-on-Wye with very few living in rural and semi-rural areas.

Observation
It should be noted that according to CQC reports that Herefordshire is providing some of the best care for adults in the West Midlands. The latest CQC inspection report shows that Herefordshire has the highest proportion of 'Good' or 'Outstanding' care homes and the second highest proportion of home care providers in the region. Furthermore, across the West Midlands Herefordshire has the highest proportion of nursing homes providing specialist care for medical conditions rated as 'Good' and the second highest proportion of providers delivering home care services helping people live independently in their own home rated as 'Good' or 'Outstanding'.

Figure 22: Location of establishments offering residential care for learning disabilities in Herefordshire.

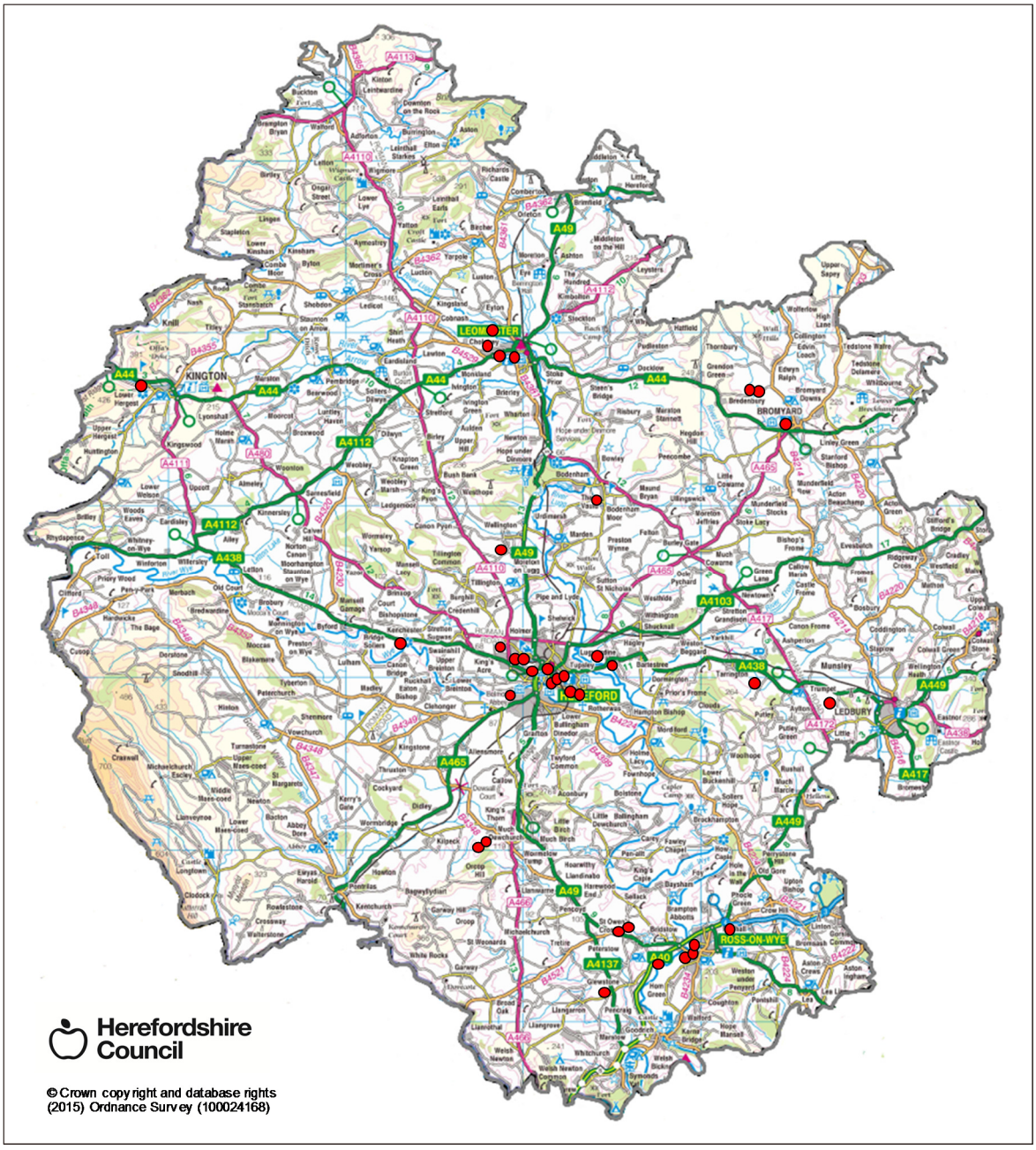


Figure 23: Location of residence of day opportunity clients across Herefordshire, 2017.

Expenditure

According to Adult Social care finance data provided for 2015/16 by NHS Digital[102] the weekly unit cost of **long term** care for those with LD aged 18 – 64 in Herefordshire was £1,162 per week; the unit cost for England was £1,359 per week while for the West Midlands the figure was £1,375. When compared to the unit costs for comparator authorities it is evident that the figure for Herefordshire is relatively low with only that for one authority being lower than that spent locally (Figure 24). Between 2014/15 and 2015/16 the local unit cost fell proportionally by 2.73 per cent compared to an average increase of 4.37 per cent in the comparator group and a 2.33 per cent increase nationally.

For individuals aged 65 and over the long term weekly unit cost for Herefordshire was £622 per week while the weekly figures for England and the West Midlands were £868 and £898 respectively. When compared to the unit costs for comparator authorities it is evident that the figure for Herefordshire is relatively low with the figures fir two authorities being lower than that for Herefordshire, while Rutland reported no spend on those aged 65+ (Figure 25).

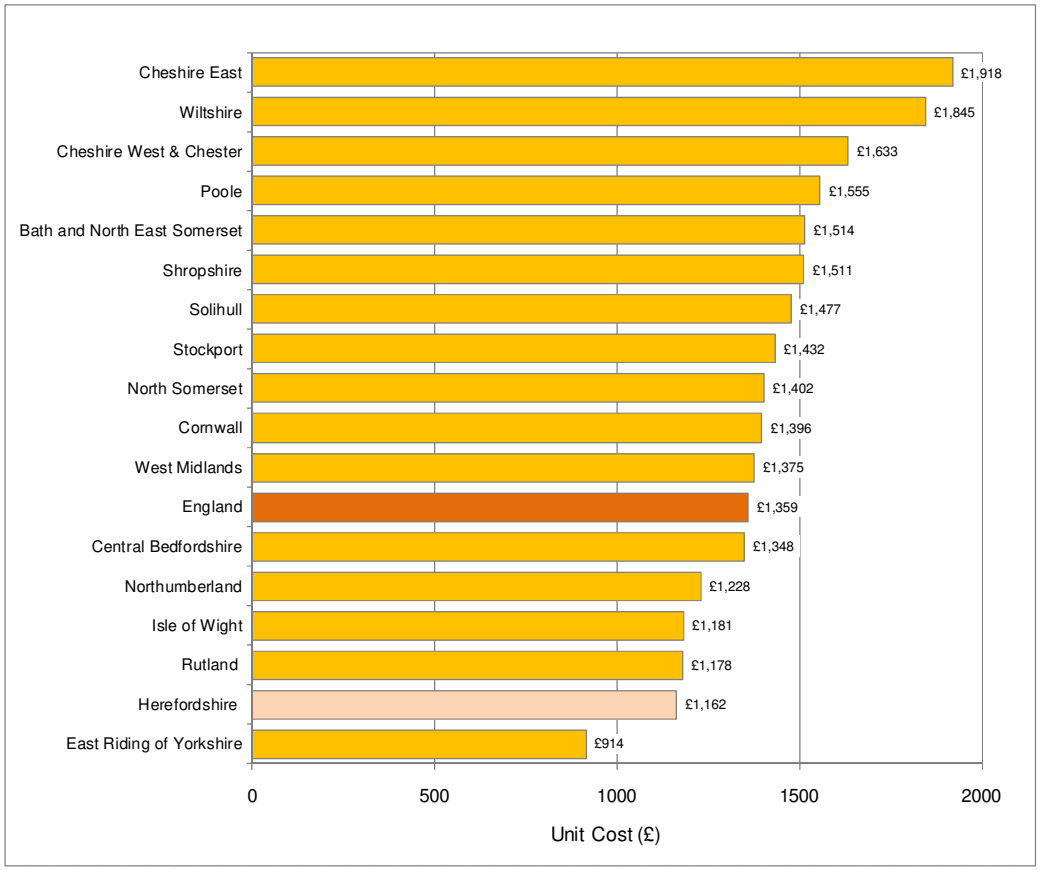
The weekly unit cost of **short term** care for those with LD aged 18 – 64 in Herefordshire was £214 per week which represents a proportional fall of 14.4 per cent compared to the 2014/15 figure. The national figure was £494 per week and the regional figure £531 which represented proportional falls of 35.5 and 33.0 per cent respectively compared to the previous year's unit costs. Of the comparators where a short tern cost was recorded the Herefordshire figure was relatively low (Figure 26).

For individuals aged 65 and over the weekly unit cost for Herefordshire was £77 per week while the weekly figures for England and the West Midlands were £381 and £584 respectively. The Herefordshire figure was lower than those reported by comparators which reported a unit cost (Figure 27).

In 2015/16 the total expenditure in Herefordshire for long and short term care combined was £18.48 million, which was made up of £16.45 million for those aged 18-64 and £2.04 million for those aged 65+. Of the overall expenditure £18.22 million was for long term care and £0.26 million for short term care. Locally, the 2015/16 overall expenditure represented a 20.7 per cent fall on the figure for 2014/15 of £23.32 million, although within this there was almost an 80 per cent increase in expenditure on those aged 65+ (Figure 28). In national and regional contexts between 2014/15 and 2015/16 the overall expenditure on LD care increased by 3.7 and 7.6 per cent respectively, which included increases in both age cohorts in both cases.

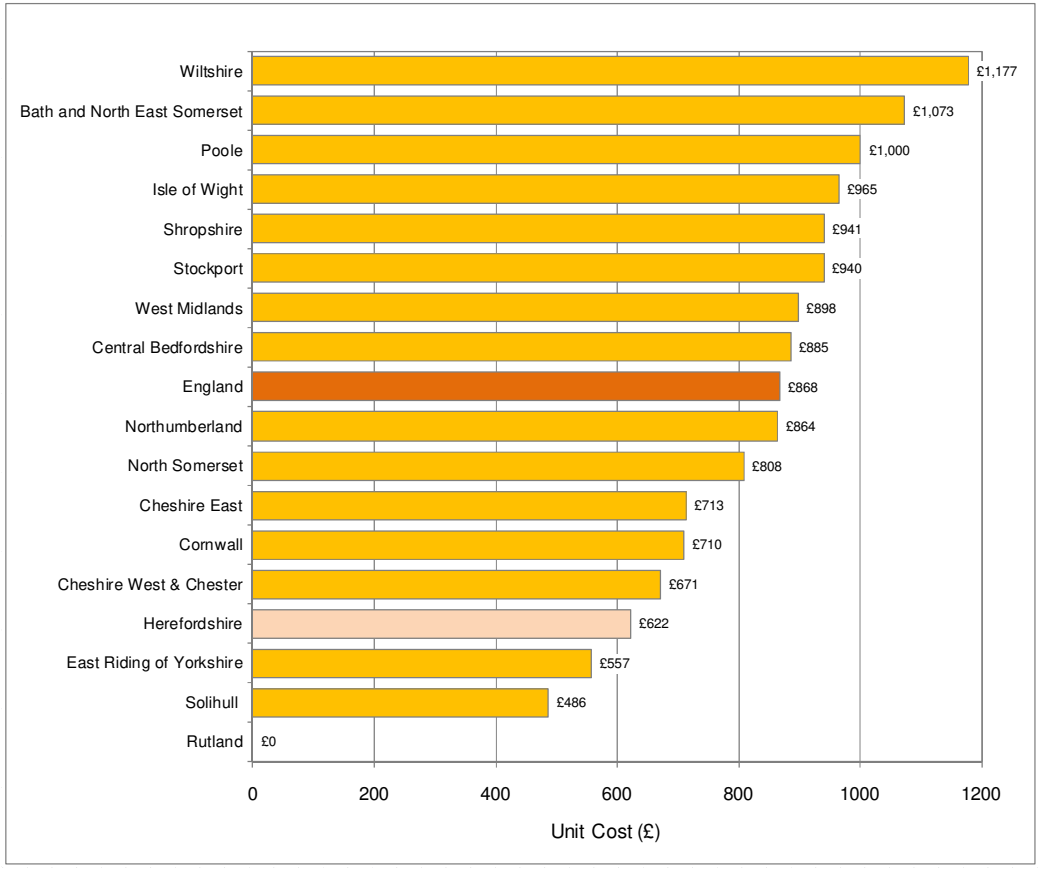
[102] Personal Social Services: Expenditure and Unit Costs, England - 2015-16 [NS]. Available at: http://www.content.digital.nhs.uk/catalogue/PUB22240

Figure 24: Weekly unit cost for LONG term LD care for adults aged 18 – 64 in Herefordshire, 2015/16.



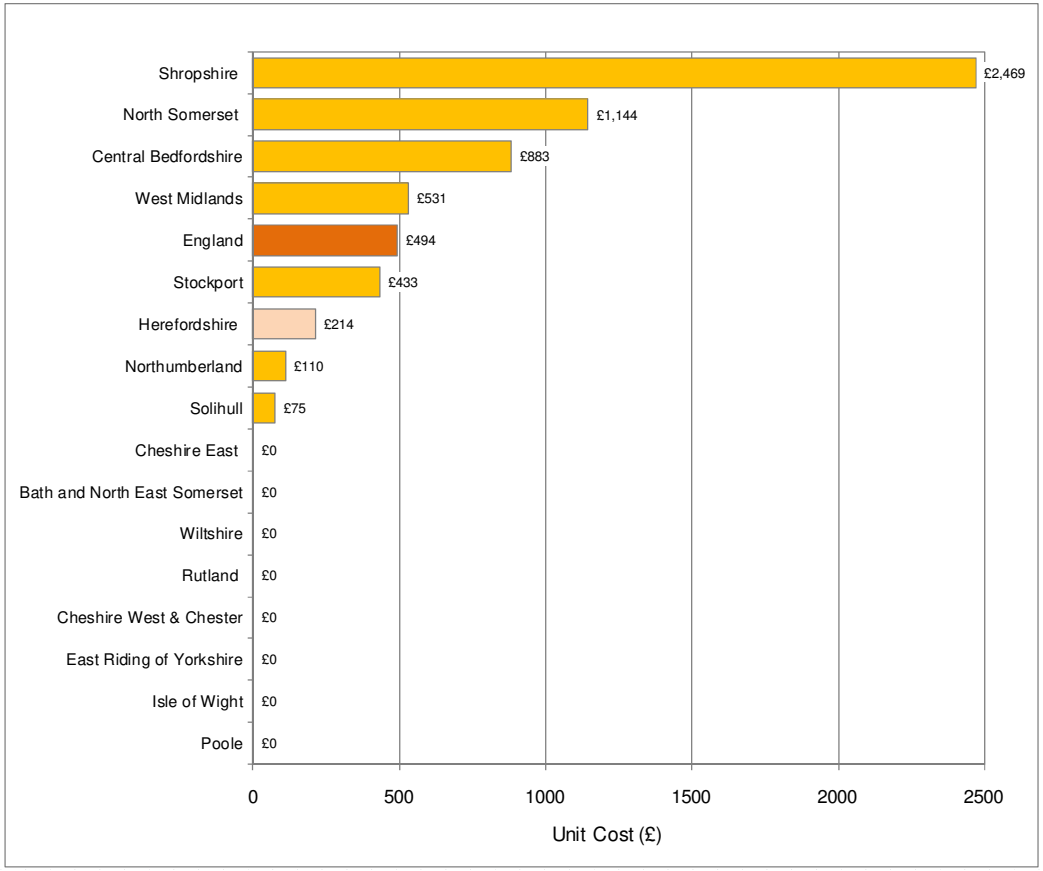
Source: NHS Digital – Adult Social Care – Finance

Figure 25: Weekly unit cost for LONG term LD care for adults aged 65+ in Herefordshire, 2015/16.



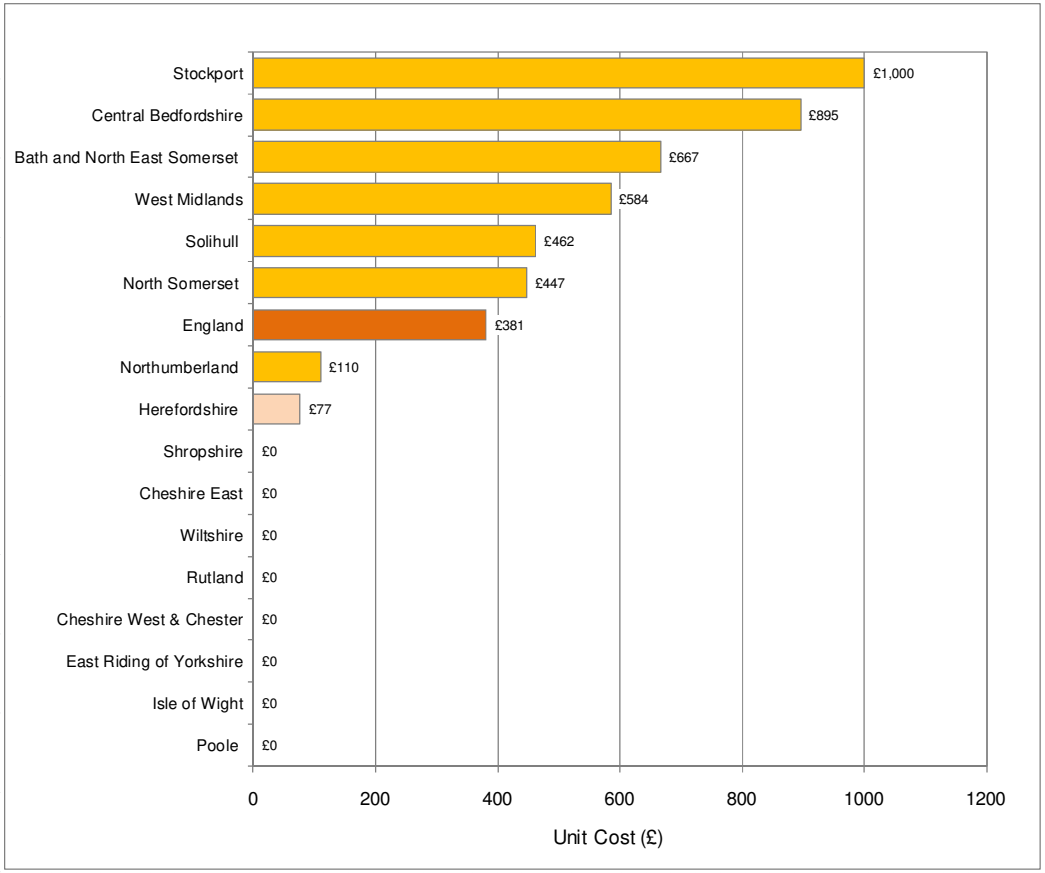
Source: NHS Digital – Adult Social Care – Finance

Figure 26: Weekly unit cost for SHORT term LD care for adults aged 18 – 64 in Herefordshire, 2015/16.



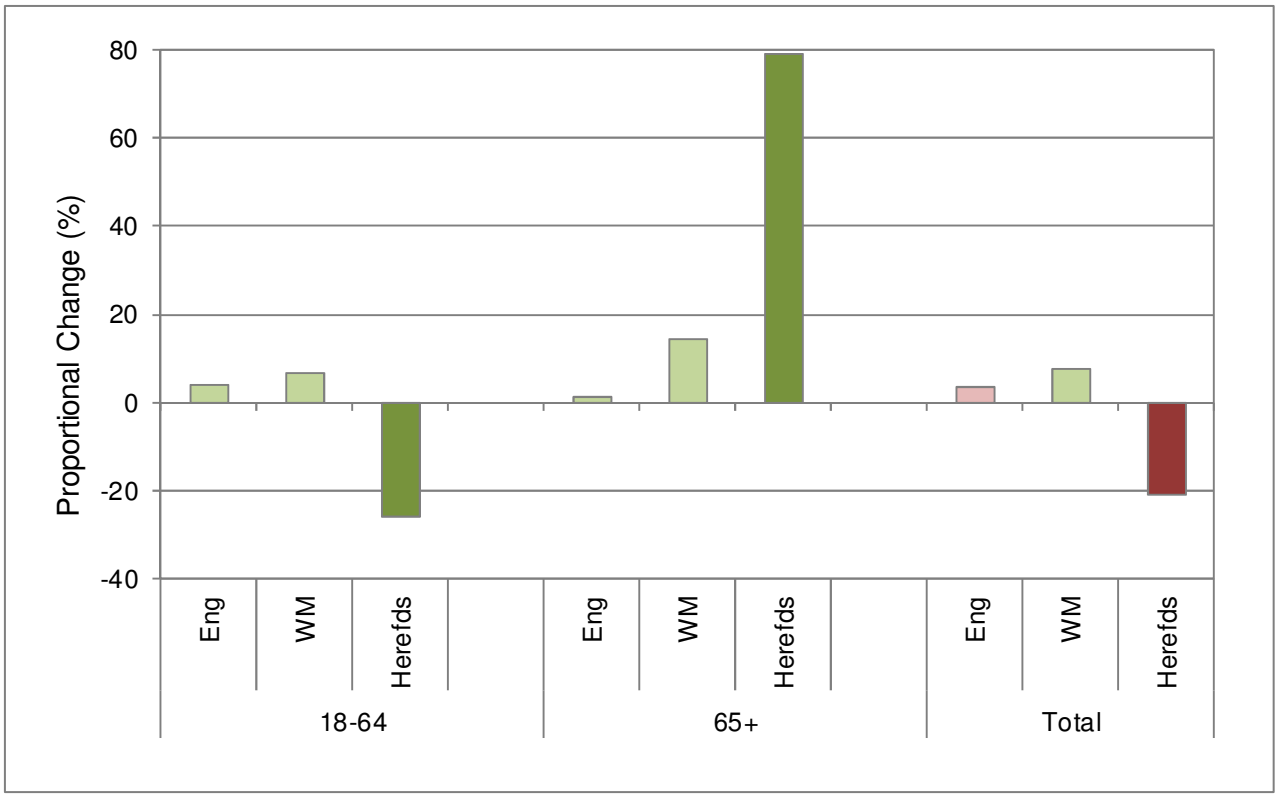
Source: NHS Digital – Adult Social Care – Finance

Figure 27: Weekly unit cost for SHORT term LD care for adults aged 65+ in Herefordshire, 2015/16.



Source: NHS Digital – Adult Social Care – Finance

Figure 28: Proportional change in overall expenditure on LD care between 2014/15 and 2015/16 in Herefordshire, England and the West Midlands.



Source: NHS Digital – Adult Social Care – Finance / Intelligence Unit - Herefordshire Council

Observation

It is evident that the expenditure in Herefordshire on the care of adults with LD is lower than across the rest of the West Midlands and England. This, allied with the god quality of services provided, as indicated by CQC reports, highlights the good value for money currently obtained for services supporting adults with LD in the county.

Transition into adult services

Children with a learning disability who are eligible for social care support can receive it until they become an adult, whereupon they transition to social care services designed for adults. The transition from children's services to adults' services is often very challenging for young people with a learning disability and their families as it combines a change of services and professionals at the very time when they are also negotiating wider changes to their life such as their educational circumstances. Consequently, it is essential that these changes are planned well in advance.

In England, if a child, young person, or their carer is likely to have needs when they turn 18, the local authority must assess them if it considers there is "significant benefit" to the individual in doing so regardless of whether the child or individual currently receives any services. The assessment is the starting point for the transition process. There is no particular age at which assessment should be made, although it may be appropriate to undertake an assessment when the young person is aged 14 or 15, particularly where an individual has complex needs and is

going to continue to need high levels of support from adult services. The complexity of their needs will mean that meticulous planning and a gradual transition to new services will be required.

When the transition between children's and adults' services takes place the local authority must continue to provide the individual with any children's services they were receiving throughout the assessment process so that there are no gaps in service and support provided to the individual. This will continue until adult care and support is in place to take over, or at that point after the assessment at which it is deemed appropriate that adult care and support does not need to be provided. This managed process should ensure that no individual receiving support at the age of 18 will suddenly find themselves without the care and support they need at the point of becoming an adult. This continuation of children's services into adulthood can also happen in order to avoid the transition to adult services coinciding with other stressful events such as exam periods.

The Herefordshire 'Multi-Agency Transition Protocol for Children and Young People with Disabilities and Complex Needs'[103] aims to ensure every young person and their parents/carers have a positive transition experience. The purpose of the protocol is to make clear the transition planning and review processes that support the move from adolescence to adulthood for young people with disabilities and complex needs from 13 up to their 25th birthday.

In order to achieve successful outcomes the protocol seeks to ensure that:

- Young people and their families are well supported and placed at the centre of all planning.
- Young people are encouraged to develop the skills and understanding they need to make informed choices.
- The transition process is coordinated, systematic and consistent.
- Post-16 services and opportunities are commissioned effectively, based on early identification of likely need for support.

The young person is at the centre of the transition planning process thus allowing them to have appropriate control and choice over their future in line with their hopes and aspirations. Families of young people are actively involved in planning their future in partnership with relevant agencies who provide a clear understanding of the specific roles and responsibilities of the key agencies involved in transition. Clear information is provided to help raise aspirations of young people by illustrating what has already worked for others with information being developed with young people and their families ensuring that it is relevant, accessible and understandable for all concerned.

Transition planning is focused on life outcomes, promoting independence and support for young people to lead meaningful and enjoyable adult lives. The process starts at key stage 4 and 5 where desirable outcomes are identified and baselines against which progress is measured with the young person being monitored through the transition register. Outcomes are further measured by obtaining feedback from young people, their families and other stakeholders. All young people are monitored to ensure none "fall through the net".

Safeguarding is essential and it is a fundamental principle that disabled children have the same right as non-disabled children to be protected from harm and abuse. For all practitioners and

[103] Available at: https://www.herefordshire.gov.uk/info/200228/local_offer/606/transitions_for_children_with_special_educational_needs/3

agencies, ensuring young people are safeguarded should therefore always be integral to everything they do. Within Herefordshire it is stressed that practitioners should ensure that any young person subject to a protection plan is supported to remain safe as they move into adulthood.

The management of Herefordshire's multi-agency approach for young people with disabilities includes:

- Transition Lead - provides the local strategic lead for development work around transition, liaises with the Department of Education and practitioners across Herefordshire and reviews and amends the protocol appropriately in light of national developments.
- Transition Support Coordinator - works with all relevant agencies involved in the Herefordshire multi-agency practitioners group and manages the Transition Register which holds information on all Statemented young people from Year 9 onwards and, when notified, other young people requiring transition support and identifies future needs of adult services and other specialist provision.
- Herefordshire multi-agency practitioners group – represents organisations at both operational and commissioning level and promotes the smooth implementation of the protocol, discusses and ensures resolution of difficult cases and identifies procedural issues arising from individual cases which may enhance the service. The multi-agency practitioners group will usually include representatives from:

    - Children's Wellbeing;
    - Adult Wellbeing;
    - Adult Wellbeing Commissioning;
    - Childrens Wellbeing Commissioning;
    - Localities;
    - EN PAs;
    - CAMHS;
    - Health;
    - Post 16 Education & Training.

There is no specific measure of individuals transitioning from child to adult services. However, examining the prevalence of special educational needs (SEN)[104] among children and young people (CYP) will give an indication of the numbers of people likely to be transitioning into adult services.

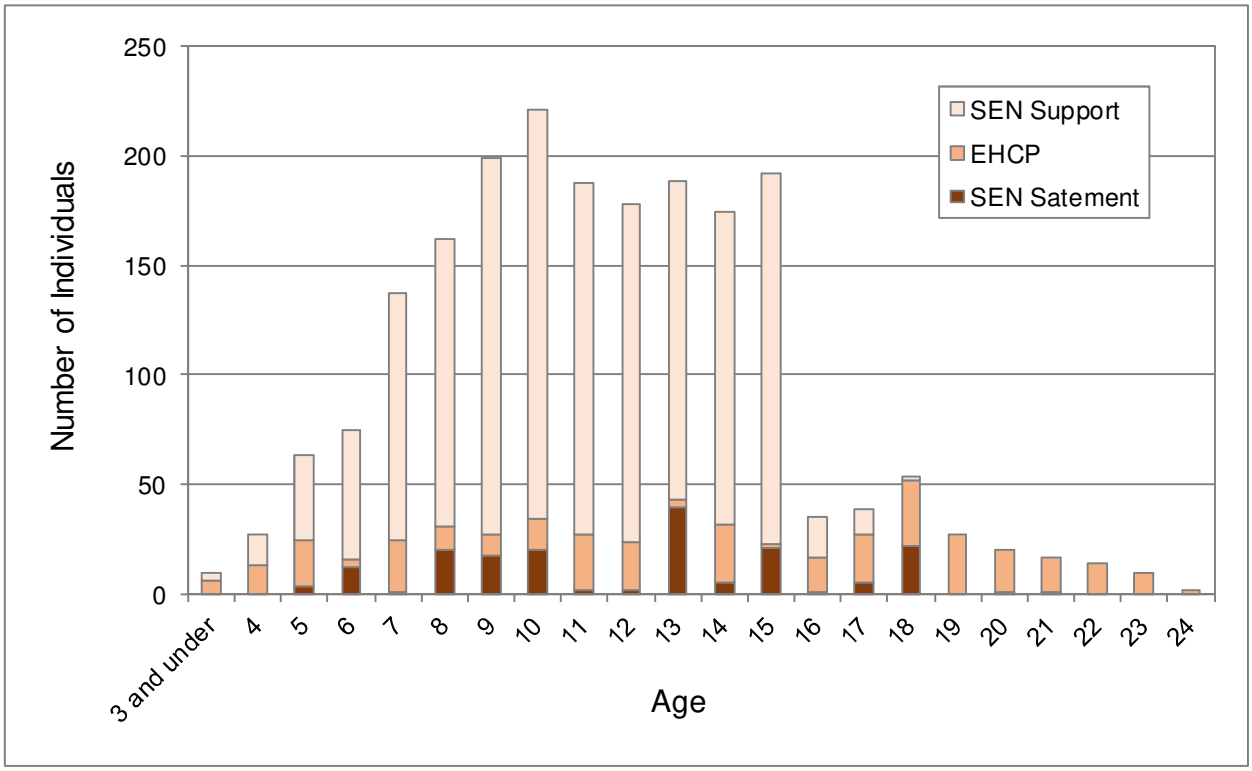
The number of CYP with LD registered in Herefordshire as having SEN in 2016/17 where the primary need was either a specific, moderate, severe or multiple and profound learning disability or autistic spectrum disorder are shown by age in Figure 29. The figures have been broken down by age and indicate the level provision: Education, Health and Care Plans (EHCP), Statements of SEN and SEN Support. Overall, the proportion of children with SEN increases with age up until the

[104] A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her.

age of 10 and then plateaus before declining at the age of 16 where children are likely to be leaving full time education. Although numbers with SEN aged 16+ are small this still suggests that a proportion of people leaving education will need to transition from child to adult services. It should be noted that up to age 15 the majority of individuals receive SEN Support and that in older individuals this support is no longer provided due to the individuals leaving compulsory schooling resulting in the observed fall in the total number of CYP with LD receiving SEN provision. Of those aged 19 and above all have an ECHP, although the numbers are relatively low. It is anticipated that this pattern will be repeated in subsequent years.

The evident difference in the number teenagers with SEN aged up to 15 years and those older (as indicated in the graph) does not correspond with the number of registered LD cases at that age which show an increase between the 10-17 and 18-24 cohorts. This would indicate that the educational needs of these young people with LD are currently under catered for and that greater attention should be concentrated on this cohort as they move from an education setting to possible employment.

Figure 29: Number of children and young people with SEN by age in Herefordshire with level of SEN provision indicated, August 2017.



Source: Childrens Wellbeing – Herefordshire Council

Observations

Currently there is no available data monitoring what is happening to young people with LD when they leave full-time education. Collection of such information could be used to monitor the progress of such individuals which would facilitate the identification of any support requirements and could also be used to monitor the success of current support initiatives.

It is evident that in Herefordshire (along with the rest of the country) that LD cases are being under diagnosed, a fact that can lead to individuals not being able to access support and services from which they would benefit. It is possible that this is related to the number of adult cases not being documented which may be due to a missed childhood diagnosis, or an individual "dropping off the radar". Such a pattern may be ameliorated if that throughout an individual's lifetime contact with health professionals any indicators of LD are recorded and acted upon appropriately collaboratively by all relevant practitioners and carers.

QUALITY AND OUTCOMES

West Midlands Quality Review Service

In September 2015 a review of the care of people with learning disabilities in Herefordshire was undertaken by the West Midlands Quality Review Service (WMQRS) which is a collaborative venture between NHS organisations in the West Midlands which aims to improve the quality of health services by developing evidence-based Quality Standards. The purpose of the review was to assess compliance with WMQRS Quality Standards 'Health Services for People with Learning Disabilities, Version 1.1, December 2010 (with minor amendments to reflect later guidance)'. The aim of the review was to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. For commissioners, the review provides assurance of the quality of services commissioned and identifies areas where developments may be needed. The review looked in detail at the work of the health Learning Disabilities Team, for which compliance with the relevant Quality Standards was reviewed. Reviewers also met staff of the social care Learning Disabilities Team and considered the overall pathway for people with learning disabilities

Of the 73 applicable quality standards which related to primary care, specialist LD services and commissioning 32 were met, which represents a proportion of 44 per cent[105]. Of these primary care met three out of eight standards (38 per cent), specialist LD services 23 out of 48 (48 per cent) and commissioning 6 out of 17 (35 per cent).

Generally, the review found staff to be highly committed to providing good care for people with LD and were working hard to provide the best care possible. In addition it was recorded that day opportunities service provided a good range of services that were responsive to the needs of service users and that links with social workers were working well, including social care assessments being undertaken on the premises. However, reviewers were seriously concerned about the services available for people with learning disabilities in Herefordshire for a combination of reasons with the issues contributing to this level of concern being:

- **Partnership Board** - A Partnership Board was in place, co-chaired by a person with learning disabilities, but was not yet working effectively. Three meetings had been held, but the next planned meeting had been cancelled. The Board had no clear work plan and no sub-groups or other mechanisms for implementing a work plan. Membership of the Board may not be appropriate; in particular, the heads of the health and social care Learning Disabilities Teams were not members of the Board. Reviewers saw no evidence that the Partnership Board was effectively planning and driving improvements in services for people with learning disabilities.

- **Commissioning of services** - The number of people with learning disabilities for whom services were needed was not clear. Reviewers were given a range of numbers between 400 and 900, without a clear explanation of their origin. A Joint Strategic Needs Assessment covering people with learning disabilities had not yet been completed, and the needs of people on the autistic spectrum and early onset dementia did not appear to have been appropriately considered. Reviewers were told that a draft strategy had been prepared, but neither the health nor the social care Learning Disabilities Team had been involved in its development. The staff's expertise and understanding of service users' needs appeared not to be valued by the commissioner of their services.

[105]Report available at: http://www.wmqrs.nhs.uk/download/680/2015-Hereford-LD-report-V1-20151217_1464447363.pdf

Access criteria for the services were not clearly defined, and reviewers were told that the criteria for access to the specialist health and social care teams were different. Crisis and acute hospital liaison services were not commissioned. Reviewers also saw no evidence of commissioner support and encouragement for integrated working between the teams, while separate funding, management and IT systems contributed to difficulties in the integration of care.

Reviewers were also surprised that both health and social care services were commissioned by the Local Authority without effective mechanisms for the involvement of health commissioners. Activity data were reviewed by commissioners, but key performance indicators, including those relating to service quality, had not been specified.

Health funding for the services was set at an historic level, and arrangements for the review of funding levels, as the need for services changed, were not evident.

- **Leadership and governance of the health specialist team** - Several aspects of the governance of the team were of concern to reviewers. At the time of the review some members of the team, including the consultant, the speech and language therapist (although an appointment had been made to a second post), the physiotherapy assistant and the occupational therapist, were working alone without effective cover for absences. The physiotherapy assistant was working without clear arrangements for professional supervision. Reviewers saw limited evidence of a competence framework or training plan. Several of the policies and procedures, including the Local Authority Safeguarding Policy and Lone Working Policy, were out of date. On several occasions the governance arrangements described by Trust senior managers were different from those described by the staff of the team.

Overall, reviewers considered that the teams were working in difficult circumstances that were not conducive to providing a holistic, integrated response to service users' and carers' needs. Staff were working hard to mitigate the impact of these circumstances on their clients, but this was having a detrimental effect on staff morale. When combined with some long-term sickness, retirements and recruitment difficulties, this left the teams – and therefore the care of their clients – in a very vulnerable position.

The issues described above are clearly inter-related and require system-wide action. Reviewers were also concerned by the apparent lack of urgency about tackling these issues, with a common view that action would take place sometime in 2016/17.

In relation to **primary care** reviewers were told that the number of annual health checks and Health Action Plans had reduced since funding for the Directed Enhanced Services (DES) had ceased. Reviewers did not see monitoring of numbers of annual health checks or examples of Health Action Plans. It was concluded that further work in this area may be helpful.

In relation to **Specialist LD Services** the reviewers noted that:

- A considerable amount of information was available for service users, although some was not in 'easy-read' formats with some formats being confusing, with lots of text, different fonts and unclear use and placing of symbols. Reviewers suggested that the information available may benefit from review involving service users and taking into account latest guidance on presentation of information.

- The Strategic Health Facilitator had a role that appeared to encompass primary care facilitation and training, aspects of acute hospital liaison and possibly other activities and, although significant

work had been achieved, it suggested that it may be helpful to review whether these roles can be effectively performed by one person.

- Some of the policies seen by reviewers referred to 'mental health'. Reviewers wondered if these were generic Trust policies that may benefit from being made specific for the care of people with learning disabilities.

In relation to commissioning, in addition to the issues detailed above, the reviewers noted concerns in relation to:

- Crisis support - Crisis support for people with learning disabilities was not commissioned. The specialist health and social care teams were only available 9am to 5pm, Mondays to Fridays. Reviewers were given examples of situations in which services were needed in an emergency but appropriate care could not be accessed. All of the crisis-related documentation seen by reviewers related to people with mental health problems, and it was not clear that these services would provide support for people with learning disabilities.

- Acute hospital liaison - Acute hospital liaison for people with learning disabilities was not commissioned from either Wye Valley NHS Trust or 2gether NHS Foundation Trust. Some support was provided by the Strategic Health Facilitator, including training for staff working in acute hospital services.

Adult Social Care Outcomes Framework

Adult Social Care Outcomes Framework (ASCOF)[106] draws on data from a number of data collections which give a measure of how well care and support services achieve the outcomes that matter most to clients. Although the information is related to adult social care in general, it also represents a measure of how LD services are perceived and how these perceptions have changed over time. Council level data is available for the period 2011/12 to 2015/16[107] and temporal patterns are shown in Figure 30.

The overall social care-related quality of life (SCRQoL) score is derived from the responses to eight question with a maximum possible score of 24. In 2015/16 the SCRQoL reported for Herefordshire in was 19.1, a figure higher than both those recorded for England (19.1) and the West Midlands (19.0). The local figure has risen steadily since 2012/13, while nationally and regionally the increase has been more gradual.

In 2015-16, 80.5 per cent of service users in Herefordshire reported they have control over their daily lives, compared to 76.6 per cent across England and 75.0 per cent in the West Midlands.

In Herefordshire, 69.7 per cent of service users reported they were extremely or very satisfied with their care and support in 2015-16, a figure higher than both the national (64.4) and regional (64.2) proportions. The local figure has increased proportionally by approximately 9 per cent since 2013/14 while no appreciable change has been evident across England or the West Midlands.

[106] http://content.digital.nhs.uk/article/3695/Adult-Social-Care-Outcomes-Framework-ASCOF

[107] 2015/16 - https://digital.nhs.uk/catalogue/P
2014/15 - http://content.digital.nhs.uk/pubs/aduscoccareof1415fin
2013/14 - http://content.digital.nhs.uk/pubs/adusoccareof1314fin
2012/13 - http://content.digital.nhs.uk/pubs/adusoccareof1213fin
2011/12 - http://content.digital.nhs.uk/pubs/adultsocialcareoutcom

The proportion of service users and carers who find it easy to find information about services in 2015/16 locally, nationally and regionally were similar, ranging between 72.2 and 73.5 per cent. While the latest Herefordshire figure is proportionally 10 per cent lower than that recorded in 2011/12 the proportions for England and the West Midlands in 2015/16 were broadly similar to those reported for 2011/12.

While 71.5 per cent of service users in Herefordshire reported feeling safe in 2015-16, the national and regional figures were both below 69 per cent. However, while the local figure has increased proportionally by 9 per cent since 2011/12, across England and the West Midlands the proportional increases were 11 and 12 per cent respectively.

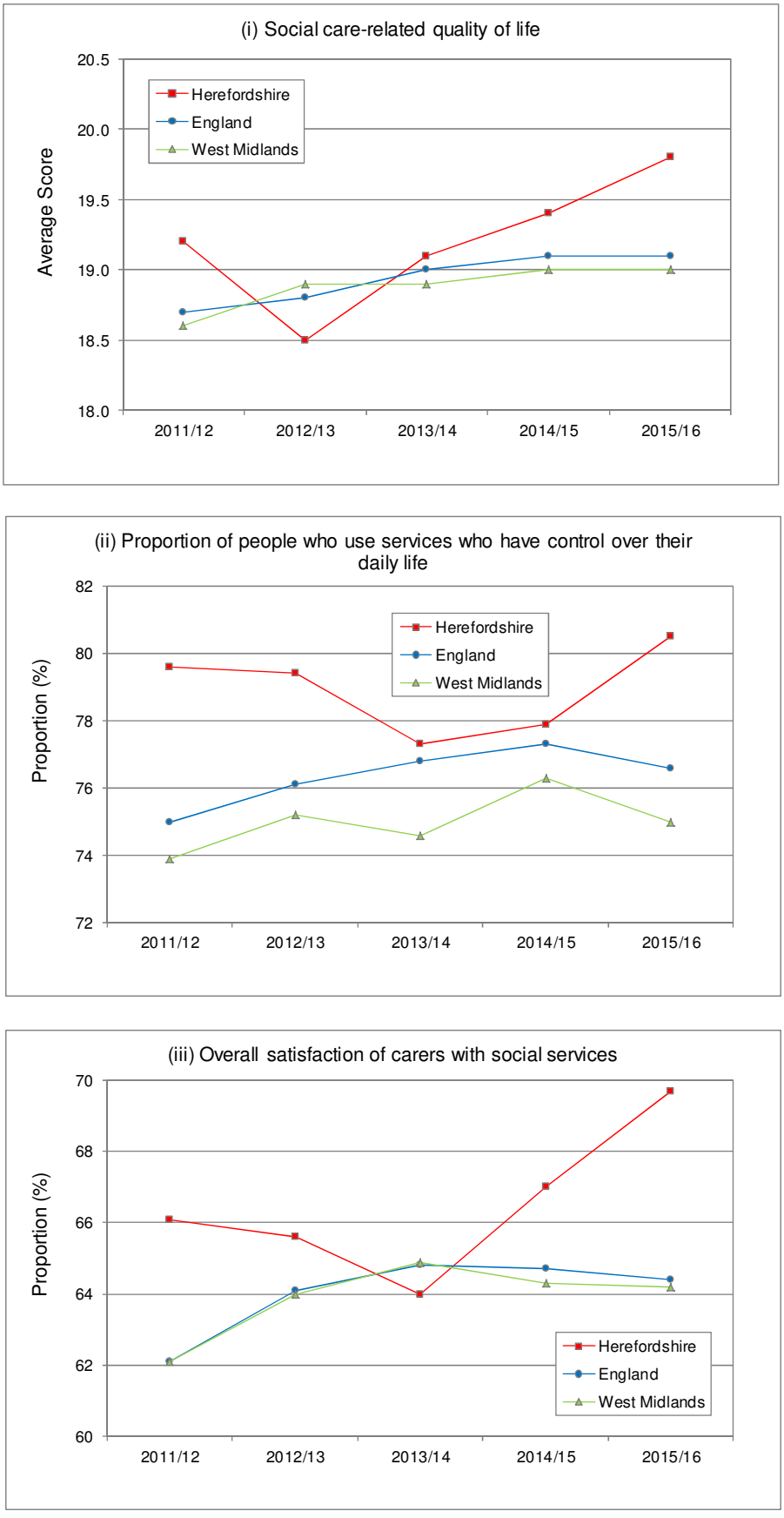
Since 2011/12 the proportions of service users in Herefordshire and across England and the West Midlands have increased steadily with proportional increases of 18 per cent observed locally compared to 12 per cent nationally and 17 percent regionally. In 2015/16 the figure for Herefordshire of 88.0 per cent was marginally higher than those recorded both nationally (84.5) and regionally (86.7).

Recommendation

Although services provided for adults with LD are generally performing well as evidences by MWQRS and ASCOF improvements can still be made. It is recommended that all appropriate services work closely with adults with LD and their carers/support workers to understand their particular needs and experiences within the Health and Social Care system. This should include:

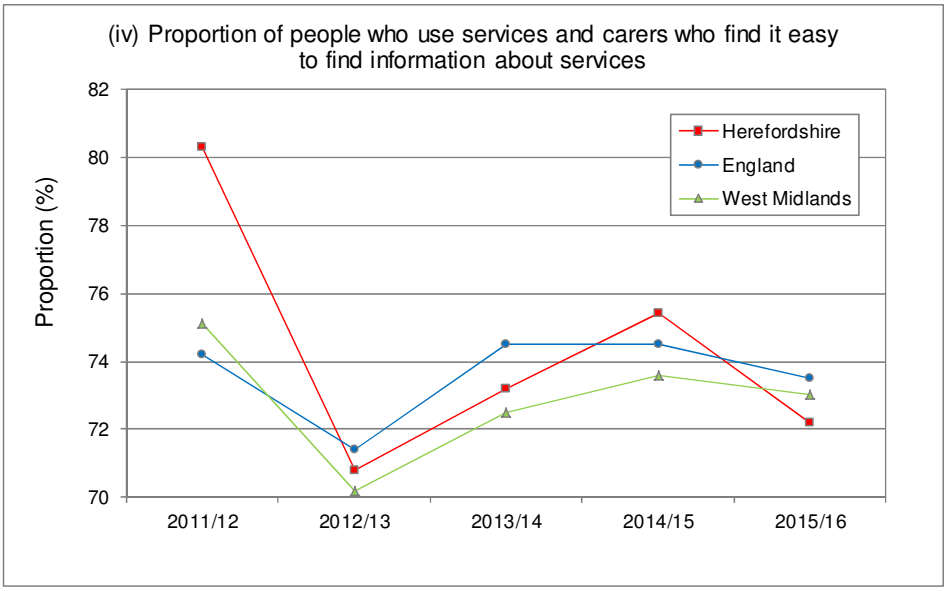
- *consultation with individuals who currently access services to identify areas that require improvement;*
- *as life expectancy increases there should be special emphasis on working with older adults with LD in order to determine requirements of this group and inform the design of service to that will best meet these needs.*

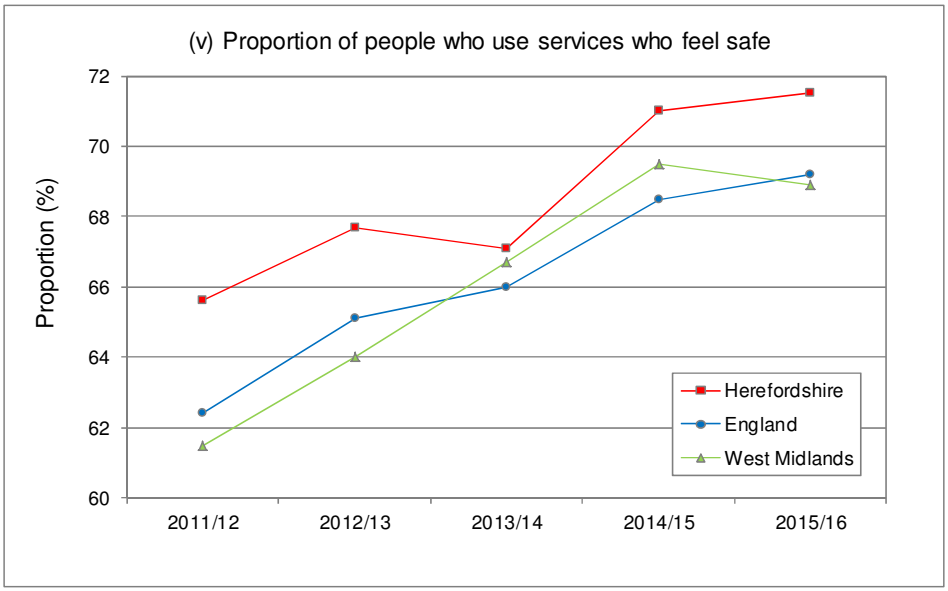
Figure 30: Adult Social Care Outcomes Framework scores for Herefordshire, England and the West Midlands, 2011/12 to 2015/16.

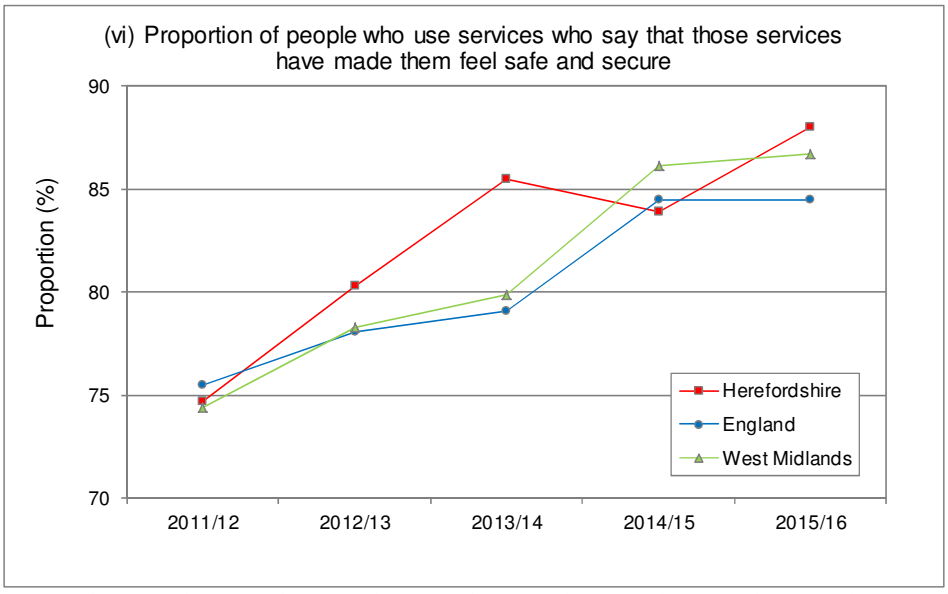


Source: NHS Digital – ASCOF

Figure 30: (continued)







Source: NHS Digital – ASCOF

CONCLUSIONS

- The prevalence of LD in adults is higher in Herefordshire than nationally and regionally. Numbers have been increasing year on year locally, although the rate of increase is slower than observed in England and the West Midlands.
- The greatest proportion of adults with LD are aged between 18 and 44 years.
- Males represent 60 per cent of adults with LD and females 40 per cent.
- The highest prevalence of adult LD is observed in Hereford with lower levels generally recorded in rural and semirural areas.
- Local adult LD prevalence is significantly higher than in other comparator areas.
- Whole population prevalence of LD is greatly underestimated with registered numbers representing a prevalence of 0.52 per cent compared to the estimated whole population figure of 5.2 per cent.
- Although the number of registered LD cases are predicted to rise over the next 20 year the overall prevalence is predicted to fall.
- Overall, morbidity levels in Herefordshire adults with LD were broadly similar to those observed nationally and regionally.
- The proportion of LD patients in Herefordshire receiving an annual health check has shown considerable annual variability with a figure of 63.0 per cent recorded in 2016/17 which was significantly lower than the national figure. With the exception of Shropshire, the Herefordshire figure is higher than those recorded for nearest neighbours.
- Cancer screening in Herefordshire is broadly similar to national and regional levels.
- In 2015/16 a total of 590 Herefordshire adults received long term LD support which represents a 9.4 per cent increase on the number of adults receiving support 2009/10 (480).
- At the end of 2015/16 there was a total of 555 adults receiving long term support, of which 500 had been in care for more than 12 months.
- Across Herefordshire a total of 140 adults with LD were in residential accommodation at some point in 2015/16.
- Five adults with LD were in nursing accommodation at some point in 2015/16.
- In 2015/16 there were 305 adults with LD who received long term care in Herefordshire living in settled accommodation.
- In 2015/16 across Herefordshire there were 220 supported adults aged 18 to 64 with learning disability living in unsettled accommodation.
- In 2015/16 there were 75 adults with LD in Herefordshire whose carer received direct support throughout the year while a further 30 carers received no direct support.

- Locally in 2015/16 there were 60 individuals with LD of working age (18-64) in paid employment , which is twice that recorded in 2014/15; of those individuals in paid employment in Herefordshire in 2015/16 ten were employed for 16 hours or more per week and 50 for less than 16 hours a week.
- In 2015/16 there were 170 section 42 LD safeguarding concerns in Herefordshire which resulted in 75 section 42 safeguarding enquiries.
- In 2015/16 of a total of 365 adults with LD receiving long term support payments in Herefordshire 305 were working of working age (18 – 64) and 60 were aged 65 and over.
- In the 12 months up to the end of August 2017 a total of 141 adult clients were provided with day opportunities at a weekly cost of £21,775, which equates to an annual cost of £1,045,192.
- In 2015/16 the weekly unit cost of long term care for those with LD aged 18 – 64 in Herefordshire was £1,162 per week compared to £1,359 per week in England and £1,375 in the West Midlands. Between 2014/15 and 2015/16 the local unit cost fell proportionally by 2.73 per cent compared to an average increase of 4.37 in comparator areas and a 2.33 per cent increase nationally.
- For individuals aged 65 and over the long term weekly unit cost for Herefordshire was £622 per week while the weekly figures for England and the West Midlands were £868 and £898 respectively.
- The weekly unit cost of short term care for those with LD aged 18 – 64 in Herefordshire was £214 per week compared to the national figure of £494 per week and the regional figure of £531.
- For individuals aged 65 and over the short term weekly unit cost for Herefordshire was £77 per week while the weekly figures for England and the West Midlands were £381 and £584 respectively.
- In 2015/16 the total expenditure in Herefordshire for long and short term care combined was £18.48 million, which was made up of £16.45 million for those aged 18-64 and £2.04 million for those aged 65+. Of the overall expenditure £18.22 million was for long term care and £0.26 million for short term care.
- Locally, the 2015/16 overall expenditure represented a 20.7 per cent fall on the figure for 2014/15 compared to the national and regional contexts where the overall expenditure on LD care increased by 3.7 and 7.6 per cent respectively.

Appendix A. Establishments in Herefordshire offering residential care for adults with LD.

Establishment	Provider	CQC Rating
Chepstow House	Chepstow House (Ross) Ltd.	Good
Chesfield House	Inspiration Care Ltd.	Good
Newman's Care Home	Newman's Care Home	Good
Buckfield House	Inspiration Care Ltd.	Good
Mill House	A.E. Gray	Good
Old Court Barn	S.R. Dodds	Good
Keeper's Cottage	Salters Hill Charity	Good
Pound Farm	Salters Hill Charity	Good
Martha House	Martha Trust Hereford Ltd.	Good
Merrivale house	Alphagrange	Good
Lyndale	Lyndale (Hereford) Ltd.	Good
The Weir	The Weir Nursing Home Ltd.	Good
Moor Court	Innovation Care Ltd.	Good
Eastbank	R.V. James	Good
Blackwells	Blackwells (Hereford) Ltd.	Good
Wall Street	Livability	Good
Montfort Fields	MacIntyre Care	Good
Winslow Court	Winslow Court Ltd.	Good
Orchard End	Winslow Court Ltd.	Good
Park House	Winslow Court Ltd.	Good
94 Chatsworth Road	Aspireliving	Good
1 – 2 Markyes Close	Aspireliving	Good
48 Hafod Road	Voyage Care Ltd.	Good
Ridgemoor	Fitzroy Support	Good
Ivy Close	Midland Heart	Good
Wykenhurst Care	July VII Ltd.	Good
Hunters Lodge	Voyage care Ltd.	Good
Stable Cottage	Parkcare Homes (No.2) Ltd.	Good
Tithe Barn	Parkcare Homes (No.2) Ltd.	Good
Falcons Rest	Voyage Care Ltd.	Requires Improvement
Cedar Lodge	Winslow Court Ltd.	Good
The Trio House	M.C. Stevenson	Good
Sophie House	Martha Trust	Good
Woodpecker Lodge	Parkcare Homes (No.2) Ltd.	Good
Lammas Lodge	Parkcare Homes (No.2) Ltd.	Good
Weir End House	Parkcare Homes (No.2) Ltd.	Good