

LEARNING DISABILITIES NEEDS ASSESSMENT

Warwickshire Joint Strategic Needs Assessment 2014



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| Author: | Emma Adams, Rita Ansell, Jenny Bevan, Rob Mantell, Simon Tidd | | | | |
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EXECUTIVE SUMMARY

Individuals with a learning disability are described in the 2001 Government White Paper '*Valuing People*' as having a significantly reduced ability to understand new or complex information and learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood and had a lasting effect on their development.

The World Health Organisation International Classification of Diseases (ICD) divides learning disability into four main categories: mild, moderate, severe and profound, depending on the level of cognitive impairment. People with profound learning disability have an IQ of less than 20, compared to an IQ of 50 to 69 for people with a mild learning disability.

Rights, independence, choice and inclusion are the overarching messages within national policies such as the Government White Paper, '*Valuing People Now*' (2009), relating to people with learning disabilities in the United Kingdom. However, people with learning disabilities often suffer many disadvantages and poor outcomes, and are one of the most vulnerable groups in society.

The true picture of the number and identity of people with learning disabilities in Warwickshire is poorly understood. Figures based on social care returns and/or school census data alone would significantly under-estimate the true prevalence of learning disabilities due to a failure to report at school level and the likelihood of a 'lost' population with a learning disability who are unknown to social services. Warwickshire has an older resident population than the England average, and this combined with reduced mortality among older adults with learning disabilities is likely to lead to higher demand for services over the next decade.

This needs assessment will inform the production of a new All Age Learning Disabilities Strategy which is to cover the period from 2015 to 2020, focusing on adults and young people in transition. Commissioners will benefit by having access to robust evidence to support or question the applicability of suggested models of care for people with learning disabilities now and in the future and it will ensure that the needs of children and young people with learning disabilities are included.

Recommendations

- In the absence of a national register, GPs should be cooperating with the LA to develop a local register of those people with a diagnosed learning disability as stated in the LD Directed Enhanced Service (DES).
- Data on parents and neonates with a learning disability from the Maternity Services Data Set (submitted from 01 May 2015) must be added/matched to the proposed local register

and brought to the attention of Warwickshire's Special Educational Needs and Disability Assessment and Review (SENDAR) team.

- Preventive healthcare and public health activities should be reviewed to ensure provision across Warwickshire, with focus towards pregnant women at higher risk of having a child with a condition associated with learning disabilities.
- Commissioners need to consider how to ensure that learning disability health checks are made available to people whose GPs are currently not signed up to the Directed Enhanced Service.
- IT support is required to ensure that Health Action Plans and Annual Health Checks are integrated within GP operating systems in order to prevent this being a barrier to their completion.
- Commissioners in Warwickshire need to work closely with the Community Learning Disability Nursing team to develop programmes specifically targeting adults with learning disabilities and their carers to raise awareness of the dangers of coronary heart disease.
- Health and social care professionals in Warwickshire must continue to work in partnership to ensure appropriate support mechanisms are established which enable parents with a learning disability to receive the support they need.
- All services should promote the opportunity for adults and children with learning disabilities to access healthy lifestyle initiatives and services through schools and in the community.
- Customers' needs who are placed out of area will continue to be regularly reviewed. The appropriateness of the placement will be assessed and whenever possible the person will be supported to move back to Warwickshire.
- Every person aged between 0 and 25 years who has been diagnosed with a learning disability should be referred for a statutory assessment of Special Education Needs and Disability (SEND) and an Education, Health and Care (EHC) Plan issued where appropriate.
- Mechanisms must be in place to strategically embed national policy documents including specific recommendations and requirements for local implementation
- Commissioners must seek to come up with innovative and engaging ways to develop people's understanding and awareness of the benefits of self-directed support and assistive technology in Warwickshire.
- There should be strong representation from learning disability service users and carers to improve transparency in decision making, accountability, and engagement of the local community

- Specialised services for adults and children with learning disabilities must be responsible for maintaining their own, accurate databases to help ensure resources are appropriately allocated and their use justified.
- An audit should be undertaken to assess the success of the community hubs including their usage, footfall, peak accessibility and customer views.
- Carer assessments must be carried out for young carers under the age of 18 in accordance with the Children and Families Act 2014. This information must be recorded appropriately so that accurate numbers of children who care for someone with a learning disability are available and these young people are given the help and support they need.
- Housing initiatives which give people with learning disabilities independence such as Extracare housing schemes should continue to be prioritised and potential new sites across the county found. Supply and demand for such housing by people with learning disabilities must be recorded and monitored.

INTRODUCTION

People with learning disabilities are people first with the right to lead their lives like any others. They have the same needs as everyone else and should have access to all the same things everybody else does. All people with a learning disability should be respected as citizens and supported to make choices with regards to their own lives. They should not experience abuse, discrimination, harassment or exclusion from the community. This human rights approach based on rights, independence, choice and inclusion is the overarching message within national policies such as the Government White Paper, '*Valuing People Now*' (2009)¹, relating to people with learning disabilities in the United Kingdom.

However, people with learning disabilities often suffer many disadvantages and poor outcomes, and are one of the most vulnerable groups in society. They experience health inequalities, social exclusion and stigmatisation. The disability which they have can be magnified by the environment within which they live. The social model of disability views it as the disadvantage, or restriction of activity and participation, caused by aspects of society which take little or no account of the needs of people with impairment².

Learning disabilities can place a considerable lifelong challenge on the individual as well as family, friends and carers with markedly worse health than the population as a whole, overall shorter lifespan and a host of health conditions unequally suffered.

¹ Department of Health (2009) *Valuing People Now*. A new three year strategy for people with learning disabilities – Making it happen for everyone

² Department of Health (2010) *Creating a Fairer and more Equal Society*. The Social model of disability. Available at: <https://www.gov.uk/government/policies/creating-a-fairer-and-more-equal-society/supporting-pages/the-social-model-of-disability>

A host of new changes are currently being implemented, most notably due to the Children and Families Act 2014³, the Care Act 2014⁴ and the Better Care Fund⁵. These will all have a significant effect on the way that services for people with learning disabilities are developed and evolve over the coming years.

SCOPE AND AIM OF THIS NEEDS ASSESSMENT

This needs assessment focusses on people of all ages with a learning disability in Warwickshire, capturing children from early years, through school, the transition from children's into adult's services and into old age. It will address the demographic picture of Warwickshire's population and those who have a learning disability, the prevalence of learning disabilities locally and nationally, and both the supply and utilisation of relevant services in the county.

The aim of this needs assessment is to systematically address the needs of people with learning disabilities in Warwickshire, assess whether the services provided in Warwickshire are fully meeting those people's needs and to make recommendations where appropriate as to how any gaps could be filled. This needs assessment will review the current evidence and provide intelligence which will enable commissioners to identify where services meet needs and where there are gaps. It will focus on the outcomes for people with learning disabilities and their carers as well as the systems and services which provide for their needs. It will also help to evaluate the outcomes of Warwickshire's Learning Disability Strategy 2011-2014 and help inform future commissioning intentions.

³ HM Government (2014) Children and Families Act 14 Part 5. Available at: <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

⁴ HM Government (2014) Care Act Part 1. Available at: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm>

⁵ http://www.local.gov.uk/health-wellbeing-and-adult-social-care/-/journal_content/56/10180/4096799/ARTICLE

SECTION 1: NATIONAL PERSPECTIVE

The following chapter contains detailed information relating to:-

- The definition of learning disabilities.
- Estimates of the prevalence of learning disabilities in England.
- The needs of people with learning disabilities.
- The policy context, supporting reports and legislation.

1.1 DEFINITION OF LEARNING DISABILITY

Individuals with a learning disability are described in the 2001 Government White Paper '*Valuing People*' as having a significantly reduced ability to understand new or complex information and learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood and had a lasting effect on their development.⁶

While all professionals across agencies agree that IQ should not be used in isolation to assess the degree of learning disability, existing systems largely rely on this to define subcategories. Unfortunately they do not always use the same categories, which can cause confusion.⁷

| IQ | Diagnostic & Statistical Manual of Mental Disorders (DSM 1V) / International Classification of Diseases (ICD 10) Assessment of disability ⁸ | Educational Assessment of learning difficulty |
|----------|--|---|
| 50-70 | Mild Disability | Mild/Moderate Difficulty |
| 35-49 | Moderate Disability | Severe Difficulty |
| 20-34 | Severe Disability | |
| Below 20 | Profound Disability | |

1.1.1 LEARNING DISABILITY DEFINITIONS IN EDUCATION

In the UK, education services use the term '*learning difficulty*' to also include people who have specific learning difficulties (e.g., dyslexia), but who do not have a significant general

⁶ Department of Health, 2001. *Valuing People: A New Strategy for Learning Disability for the 21st Century*. (Chapter 1, Page 14). London: Department of Health.

⁷ <http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/childrens-medical-guides/learning-disability/what-is-learning-disability/>

⁸ <http://www.who.int/classifications/icd/en/bluebook.pdf>

impairment in intelligence⁹. The two terms have historically been used interchangeably when used in the context of health and social care for adults. Professionals across agencies use different categories and IQ scores to assess the degree of learning *disability*, whereas IQ is not necessarily relevant when talking about a learning *difficulty*. Therefore there is sometimes confusion between the terms *learning difficulty* and *learning disability*.

Children in schools and nurseries who have needs or disabilities that affect their ability to learn are said to have special educational needs (SEN). SEN cover a wide range of disabilities including physical impairments, behavioural difficulties, dyslexia and problems with concentrating and understanding. Children with a learning disability are allocated to one of three SEN need categories which are used to categorise them as having learning disabilities (rather than learning difficulties, despite the terminology); moderate learning difficulty (MLD), severe learning difficulty (SLD) and profound and multiple learning difficulties (PMLD). Further detail on School Census definitions is provided in Appendix 1.

1.1.2 CAUSES AND RISK FACTORS

The cause of learning disabilities can be subdivided into those conditions that arise at conception and those that arise during pregnancy, labour and after birth. Causal agents fall into three main categories; genetic, infective and environmental. However no cause is found in approximately 30-80% of all cases of learning disabilities¹⁰.

In the UK, genetic factors result in the majority of cases of learning disabilities where cause is known, with Down syndrome accounting for around 30% of cases at birth. The second most common known genetic cause is X-linked disorder (commonly known as fragile X syndrome) which accounts for approximately 12% of cases.

Infection, non-accidental injury and accidents are all non-genetic factors which can occur during pregnancy, labour and after birth and are responsible for approximately 25% of severe learning disabilities. Birth injury and obstetric complications are responsible for approximately 10%.

A study carried out in 2012 that looked at the association between household disadvantage, local area deprivation, ethnicity and the identification of learning disability found that lower

⁹ Ken Holland, 2011. *Factsheet: Learning Disabilities* (Page 3). Worcestershire: British Institute of Learning Disabilities <http://www.who.int/classifications/icd/en/bluebook.pdf>

¹⁰ Rees S, Cullen C, Kavanagh S, Lelliott P. Chapter 17 Learning Disabilities. In: Stevens A, Raftery J, Mant J, Simpson S. (eds.) *Health Care Needs Assessment. First Series. Second.* Oxford: Radcliffe Publishing Ltd; 2004. pp451–540.

household socio-economic position is associated with increased rates of identification of learning disabilities, especially less severe forms. Black and Minority Ethnic communities have lower rates of identification of learning disabilities compared with the England average, however rates of identification are higher (especially of severe forms) among people with Bangladeshi or Pakistani heritage.

1.2 ESTIMATES OF LEARNING DISABILITY IN ENGLAND

There is currently no definitive national record or statistical collection of the number of people with a learning disability in England, therefore any figures published on the true prevalence of learning disabilities are based on estimations rather than actual figures.

There are a number of ways to estimate how many people in England have a learning disability, including basing figures on social care returns and/or school census data. However, using these data alone would significantly under-estimate the true prevalence due to a failure to report at school level and the likelihood of a 'lost' population with a learning disability who are unknown to social services. In 2004, the Centre for Disability Research led by Emerson and Hatton was commissioned by the Department of Health to derive robust estimates of current and future numbers of people with learning disabilities in England¹¹. The figures that they produced were derived from combining information from a wide range of sources and have subsequently been adopted by a number of national institutions, including the programme 'Projecting Adult Needs and Service Information' (known as PANSI)¹². Therefore this was the method of prevalence estimation adopted within this needs assessment.

In 2012, there were approximately 1.14 million people in England with a learning disability (2% of the general population). This includes 236,000 children (identified at School Action Plus or above in Department for Education (DfE) statistics as having either a primary or secondary SEN associated with learning disabilities) and 908,000 adults aged over 18. On average, only 22% (199,000) of adults with a learning disability are known to their GP, however 44% (404,000) were receiving Disability Living Allowance.¹³

¹¹ Emerson E, Hatton C. Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England. Lancaster: Institute for Health Research, Lancaster University, 2004.

¹² <http://www.pansi.org.uk/>

¹³ <http://nomis.org.uk>

1.2.1 PARENTS WITH LEARNING DISABILITIES

Research has shown that the number of people with a learning disability who are having children is increasing¹⁴.

People with learning disabilities have an increasing life expectancy and growing numbers of children and young people with more complex disabilities are now surviving into adulthood¹⁵. Adults with learning disabilities are being encouraged and supported to live in their local community with some level of independence, in accordance with their legal human right to an ordinary life. This has meant that it is increasingly likely for adults with a learning disability to develop relationships and start a family¹⁵.

The precise number of parents with a learning disability is unknown, but the most referenced and seemingly robust estimate comes from the National Survey of adults with learning disabilities in England in 2003/04, who found that approximately 7% (202/2898) of those interviewed had a child¹⁶.

Many parents with learning disabilities (reports suggest 30-40%) lose their parenting rights despite IQ not being a predictor of parenting performance¹⁷. However research suggests that mothers with learning disabilities are far more able to develop parenting skills when their circumstances and individual needs are taken into consideration when tailoring support and antenatal/postnatal care packages¹⁸.

The Government white paper 'Valuing People Now: A new three year strategy for people with learning disabilities' which was published in 2009, states that:

"Parents with a learning disability do not get sufficient access to support, putting families at risk of enforced separation."

Many health professionals receive insufficient training on learning disabilities, but when they receive good training it has been shown to equip them with the values, knowledge, skills and expertise which are needed to adequately support parents with learning disabilities⁵.

¹⁴ Booth et al (2005) *Care proceedings and parents with learning difficulties*, Child and Family Social Work, 10, 4, 353-360

¹⁵ Department of Health (2009) *Valuing People Now: a new three-year strategy for people with learning disabilities*. London: DH

¹⁶ Emerson E, Malam S, Davies I and Spencer K (2005). *Adults with learning difficulties in England 2003/4*

¹⁷ Mencap (2003) *Inclusive support for parents living with a learning disability*

¹⁸ Department of Health (2007) *Good practice guidance on working with parents with a learning disability*. London: DH

1.2.2 FUTURE PREVALENCE AND DEMAND FOR SERVICES

Emerson and Hatton predict that the number of people with learning disabilities in the UK will increase by 20% over the next two decades due especially to three factors:

- An increase in proportion of younger 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

Increased prevalence is likely to lead to higher demand for services, which is of particular significance in the older age groups since older adults with learning disabilities are more likely than younger adults to rely on public funding for long term supported accommodation¹⁹.

1.3 WHAT DO PEOPLE WITH LEARNING DISABILITIES NEED?

People with learning disabilities have the same needs as everyone else and should have access to all the same things that everyone else does, with reasonable adjustments to ensure that they are not disadvantaged. The current government vision remains as set out in Valuing People²⁰ in 2001: that all people with a learning disability are people first, with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens.

National social policy emphasises that services should be individual: Making it Real²¹ (2012) sets out what people who use services and carers expect to see and experience if support services are truly personalised and is built around “I” statements. These express what people want to see and experience; and what they would expect to find if personalisation is really working well. As part of Coventry and Warwickshire’s local response²² to the Winterbourne View report, the development of local “I” statements is a focus of engagement activities, describing what service users and carers want from care and support services. The following are examples of “I” statements:

- I am safe.

¹⁹ Emerson E, Hatton C. Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England. Lancaster: Institute for Health Research, Lancaster University, 2004.

²⁰ Department of Health (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century

²¹ Think Local Act Personal (2012) Making it Real. Marking progress towards personalised, community based support

²² Coventry and Warwickshire’s local response to Winterbourne View Hospital. A work programme for 2014-2016 DRAFT v0.5 April 2014

- I am treated with compassion, dignity and respect.
- I am involved in decisions about my care
- I am protected from avoidable harm, but also have my own freedom to take risks
- I am helped to keep in touch with my family and friends.
- I have a care team around me that are well supported.
- I am supported to make choices in my daily life.
- I get the right treatment and medication for my condition.
- I get good quality general healthcare.
- I am supported to live safely in the community.
- I get the support I need in the most appropriate setting to meet my additional care needs.
- I have my care regularly reviewed to see if I should be moving on

Valuing People Now²³ (2009) addressed the following areas that were identified through consultation as being what people with learning disabilities and their families need:

| | |
|---------------------|--|
| Including everyone. | People with more complex needs, people from black and minority ethnic groups and newly arrived communities, people with autistic spectrum disorders and offenders are least often heard and most often excluded, so strategies and services need to ensure they are included. |
| Personalisation. | Reinforcing the need to give people more independence, choice and control; empowering people with learning disabilities to shape their own lives and the support they receive by allowing them to use resources more flexibly to suit their needs and lifestyle |
| Health. | Better health and wellbeing for people with learning disabilities is a key priority. People with learning disabilities have the same right of access to NHS and other services as the rest of the population and although there may be a need for additional and/or specialist support, generic services should be fully |

²³ Department of Health (2009) Valuing People Now. A new three year strategy for people with learning disabilities – Making it happen for everyone

| | |
|--|--|
| | accessible. |
| Housing. | Increasing the housing options available to people with learning disabilities so that more people with learning disabilities can choose where they live and with whom. |
| Work, education and getting a life. | Helping people with learning disabilities to have ordinary lives and do the things most people take for granted, such as study at college and get a job. Key transition moments may require planning and support: general planning for young peoples' futures; post-compulsory education and/or training; employment; independent life (including housing, finances, social life). |
| Relationships and having a family. | Emphasising the importance of enabling people with learning disabilities to form all kinds of relationships, including their right to become parents and the need for adequate support to sustain the family unit. |
| Advocacy. | Ensuring the right level of support, information and advice and advocacy is available to people, including those with learning disabilities |
| Transport. | People with learning disabilities are less likely to make journeys than non-disabled people because of transport difficulties, so transport needs to be made more inclusive. |
| Leisure services and social activities. | People with learning disabilities are often not connected to their communities or given meaningful vocational, social, leisure or learning activities so local services need to be made more accessible. |
| Being safe in the community and at home. | Recognising that the lives of people with learning disabilities are constrained by experience of abuse and neglect. Many people do not feel safe in their local communities and have been victims of hate crime. |
| Access to justice and | There are concerns that people with learning disabilities are less |

| | |
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| redress. | likely to report a crime or take part in the criminal process as a witness, because they may lack the confidence or support to speak out and find processes complex. People with learning disabilities and their families may need help to understand their rights and how to complain. |
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1.4 HEALTH NEEDS AND INEQUALITIES

1.4.1 PHYSICAL HEALTH AND MORTALITY

Research has shown that people with a learning disability have significantly poorer health and a shorter life expectancy compared to that of the general population²⁴. This risk is positively correlated with severity of learning disability, i.e. an individual with a severe learning disability is more likely to die prematurely compared to an individual with a mild learning disability whose life expectancy is approaching that of the general population. A large cohort study undertaken in Finland which contained mortality follow-up over 35 years showed that people with profound learning disabilities had an all-age reduction in expected life loss of more than 20%²⁵.

Some of the causes of death for those with a learning disability are potentially preventable. After the publication of the White paper '*Healthcare for all*' in 2008, the Government commissioned the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) in England. The Inquiries' main aim was to provide evidence about contributory factors to avoidable and premature deaths of people with learning disabilities who died between 1st June 2010 and 31st May 2011.

The Confidential Inquiry reviewed the deaths of 247 people with learning disabilities, of which nearly a quarter (22%) were under the age of 50 when they died (compared with 9% in the general population) and the median age at death was 64 years (14 years younger than the general male population and 19 years younger than the general female population). Of the

²⁴ Bittles AH, Petterson BA, Sullivan SG, Hussain R, Glasson EJ, Montgomery PD. The influence of intellectual disability on life expectancy. *J Gerontol A Biol Sci Med Sci* 2002; **57**: M470–2.

²⁵ Patja K, Iivanainen M, Vesala H, Oksanen H, Ruoppila I. Life expectancy of people with intellectual disability: a 35-year follow-up study. *J Intellect Disabil Res* 2000; **44**: 591–9.

244 people with learning disabilities for whom final ICD-10 coding²⁶ of cause of death was available, avoidable deaths accounted for 49% (119) of deaths. Contributory factors included problems in advanced care planning, adherence to the Mental Capacity Act, living in inappropriate accommodation, adjustment of care as needs changed, and carers not feeling listened to.

The main causes of death for people with a learning disability differ from that of the general population. Tyrer et al (2007)²⁷ reported that the five conditions or diseases which people with a learning disability were at greatest risk of dying from were congenital malformations, diseases of the nervous system/sensory organs, mental disorders excluding dementia, respiratory infections, and genito-urinary system diseases. The results of the Confidential Inquiry stated that the most frequent cause of death amongst their study cohort was respiratory infection. Other studies have suggested that people with a learning disability are at an increased risk of developing cardiovascular disease, with the risk of death in those aged under 50 with a learning disability significantly higher than that of the general population²⁸.

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable. As such, these differences represent health inequalities. The health inequalities faced by people with learning disabilities in the UK start early in life and can result from barriers they face in accessing timely, appropriate and effective health care.

In terms of prevention, 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.

Autism Spectrum Disorder

The 2010 Government White Paper '*Fulfilling and Rewarding Lives: The strategy for adults with autism in England*' defines autism as a lifelong condition that affects how a person communicates with, and relates to, other people²⁹.

In 2010 the Learning Disability Observatory undertook a systematic literature review and in depth analysis to estimate the prevalence of autism spectrum disorder (ASD) among people

²⁶ International Classification of Diseases 10th version

²⁷ Tyrer F, McGrother C. Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *J Intellect Disabil Res* 2009; **53**: 898–904.

²⁸ Wallace RA, Schluter P. Audit of cardiovascular disease risk factors among supported adults with intellectual disability attending an ageing clinic. *J Intell Dev Disabil* 2008; **33**: 48–58.

²⁹ Department of Health. *Fulfilling and Rewarding Lives: The strategy for adults with autism in England*. London: Department of Health, 2010.

with a learning disability. They predicted that 20-30% of all people with a learning disability known to local authorities in England have ASD. Unlike many other conditions, there is no link between severity of learning disability and the likelihood of having autism. However, studies have shown statistically significant differences in the symptoms, care and treatment of males and females who have autism and a learning disability, suggesting that the needs of this population may differ, dependent on sex. More information on ASD can be found in Warwickshire's Autism Spectrum Disorder Needs Assessment, published in 2013³⁰.

1.4.2 MENTAL HEALTH

People of all ages with learning disabilities are at greater risk of developing mental health problems than the general population³¹. Children and adults with severe or profound learning disabilities experience greater mental illness compared to those with mild or no disabilities. Anxiety and depression are particularly common amongst people with Down syndrome, and there is evidence to suggest that the prevalence rates for schizophrenia in people with learning disabilities may be three times greater than for the general population.²⁴

There are numerous factors which are thought to contribute towards this risk, which were categorised by Holt et al (2005) into four domains; biological, physiological, social and familial. The causes of mental health problems for people with learning difficulties are similar, albeit exacerbated, to those of the general population.

Dementia

According to *Emerson et al (2011)*³², the prevalence of dementia is higher among adults over the age of 65 with learning disabilities compared to the general population (22% vs 6%). Adults with a learning disability are also more likely to develop dementia at an earlier age compared to the general population. There is considerable evidence that adults who have Down syndrome are at high risk for developing Alzheimer's disease in later life. It is agreed that prevalence increases steadily in adults with Down's syndrome who are over the age of 30. It is estimated that between 10 and 25% of people with Down's syndrome in their 40s

³⁰ Warwickshire Joint Strategic Needs Assessment. (2013) Warwickshire's Autism Spectrum Disorder Needs Assessment. [Online]. Available from: <http://hwb.warwickshire.gov.uk/2013/12/02/warwickshires-autism-spectrum-disorder-needs-assessment/>

³¹ Holt G, Hardy S, Bouras N. *Mental health in Learning Disabilities: A training resource*. Brighton: Pavilion Publishing; 2005.

³² Emerson E, Baines S, Allerton L, Welch V. (2011) Health Inequalities and People with Learning Disabilities in the UK. Improving Health and Lives Learning Disabilities Observatory. [Online]. p. 1-36. Available from: [http://www.surreycare.org.uk/cms/uploads/Ldis%20Network/IHaL2011-09HealthInequality2011\[2\].pdf](http://www.surreycare.org.uk/cms/uploads/Ldis%20Network/IHaL2011-09HealthInequality2011[2].pdf)

have dementia, between 20% and 50% of those in their 50s, and between 30 and 75% of those over 60³³. Peak incidence is in the early fifties.

1.5 CONTEXT - NATIONAL POLICY AND SIGNIFICANT REPORTS

The 2001 Government White Paper '*Valuing People*' recognised that people with a learning disability are amongst the most vulnerable and socially excluded in our society³⁴. The paper set out the Government's commitment to improving life chances for people with learning disabilities, enabling them to live full, active lives within their local communities. However, at this time, around 3,000 people with learning disabilities were living as inpatients in NHS Campus accommodation; long stay institutions with little or no social inclusion or personalisation.

In 2006 the Government published their White Paper '*Our health, our care, our say*' which outlined plans to close all NHS-run Campus accommodation by 2010; the fundamental reasoning behind the decision being that a person-centred planning approach cannot occur whilst people with learning disabilities are living in institutional environments.

In 2007, Mencap released a report, '*Death by Indifference*' which highlighted institutional discrimination against six people with learning disabilities who all died whilst under the care of the NHS³⁵. This report triggered an independent inquiry and an investigation of the six cases by the Parliamentary and Health Service Ombudsman ('*Six Lives*' report³⁶). The inquiry findings, published in the Department of Health report '*Healthcare for All*' (2008) found that people with learning disabilities receive sub-standard care and treatment for health-related problems which may or may not be associated with their disability³⁷. The report also identified evidence of significant levels of avoidable suffering and higher rates of avoidable deaths amongst people with learning disabilities.

The 2001 White Paper was revised in 2009, '*Valuing People Now*' which incorporated the recommendations in '*Healthcare For All*' and placed greater emphasis on inter-agency

³³ Holland A, Hon J, Huppert FA, Stevens F and Watson P. (1998). Population-based study of the prevalence and presentation of dementia in adults with Down's syndrome. *The British Journal of Psychiatry*. 172. p. 493-498

³⁴ Department of Health. *Valuing people: a new strategy for learning disability for the 21st century*. London: Department of Health; 2001.

³⁵ MENCAP. *Death by indifference: following up the Treat me right! Report*. London: MENCAP; 2007.

³⁶ Local Government Ombudsman, Parliamentary and Health Service Ombudsman. *Six lives: The provision of public services to people with learning disabilities*. London: The Stationery Office; 2009

³⁷ Michael J, The Independent Inquiry into Access to Healthcare for People with Learning Disabilities. *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*. London: Department of Health; 2008.

working to achieve the best possible outcomes for people with learning disabilities³⁸. The Paper stated that the commissioning and funding of learning disability social care services would transfer from the NHS to local government as of April 2009. This was the end for historical funding agreements when people with learning disabilities lived in old, long stay hospitals and was a step towards social-led, community-based care services.

In 2010, the Learning Disabilities Observatory was established as a three year programme following one of the recommendations of the report of the Independent Inquiry, to provide better, easier to understand information on the health and wellbeing of people with learning disabilities. Gathering information from across England, its aim is to help hospitals and health and social care commissioners to have a better understanding of the needs of people with learning disabilities, their families and carers. Another recommendation of the report of the Independent Inquiry was to establish a time-limited Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) whose aims were to detect potentially avoidable and modifiable contributory factors in the care of a person with a learning disability who has subsequently died, leading to improvement in the standard and quality of care for people with learning disabilities in the future.

In May 2011, the BBC's Panorama programme broadcast undercover footage of systemic abuse of patients by staff at Winterbourne View Hospital near Bristol, a privately run assessment and treatment Hospital for adults with learning disabilities, autism, complex needs and challenging behaviour, many of whom were detained under the Mental Health Act 1983. The Department of Health responded and published their final report, '*Transforming care: A national response to Winterbourne View Hospital*' in December 2012 which contained a number of actions for commissioners, including the need to focus on commissioning prevention and early intervention services, and the need to develop person centred approaches across commissioning and care. A Concordat was published alongside this guidance which set out a programme to transform services for people with learning disabilities and mental health conditions or behaviours described as challenging. It set out specific actions to which each relevant organisation (local/national government, NHS, third sector etc.) must be committed to take forward within clearly defined timeframes.

In direct response to failings at Winterbourne View, the Care Quality Commission (CQC) developed an unannounced inspection programme that would review the care provided by 150 hospitals in England for people with learning disabilities. Services were inspected against

³⁸ Department of Health. *Valuing People Now: a new three-year strategy for people with learning disabilities*. London: Department of Health; 2009.

two outcomes; care and welfare of people who use services and safeguarding people who use services from abuse. The results showed that overall compliance with both outcomes were low, with 48% of all locations inspected non-compliant. Assessment and treatment services were found to admit people for disproportionately long periods of time and discharge arrangements took too long to organise.

The Government-led focus for commissioning services for people with learning disabilities who also have mental health conditions or behaviours described as challenging, is on providing that individual with the support and care that they need in a community-based setting, close to family and friends. These individuals may sometimes need a period of short term treatment and/or assessment in a hospital, however hospitals are not where anyone should be made to live

Most recently, '*Three Lives*' was published by the CQC and the Challenging Behaviour Foundation (CBF) in 2014. This report is based on the discussion and feedback of an event hosted by the CQC, where delegates listened to real-life experiences of three people with learning disabilities and then had the chance to identify actions they would take, within the context of established initiatives and opportunities, to address the issues illustrated.

Further detail is provided on policy and the legal framework in Appendix 2.

1.5.1.1 PERSONALISATION

Personalisation is a fundamental concept in Government policy and requires thinking about care and support services in a different way, starting with the person as an individual with strengths, preferences and aspirations. It puts people who use services at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives.

Putting People First (2007)³⁹ promoted personalised support through the ability to exercise choice and control against a backdrop of strong and supportive local communities. To broaden the focus of Adult Social Care departments beyond those with the highest needs, councils were tasked to ensure that the application of eligibility criteria is firmly situated within the wider context of personalisation, including a strong emphasis on prevention, early intervention and support for carers.

³⁹ Department of Health, 2007. Putting People First: A shared vision and commitment to the transformation of Adult Social Care. London: Department of Health

The Fair Access to Care Services (FACS) framework (2003)⁴⁰ was updated in 2010⁴¹ and made it clear that ***personalisation can only flourish when investment is made in all aspects of support for individuals and their carers.*** This concept is further supported by the Care Act 2014, which states that councils have a duty to promote the wellbeing of both service users and their carers.

The implementation of personal budgets or self-directed support is part of the personalisation agenda⁴². The Care and Support White paper (2012)⁴³ confirmed the target of 100% of people who access on-going, community based support to be on personal budgets, preferably as direct payments⁴⁴, by April 2013. It has also included plans to make personal budgets a mandatory part of all care plans, including those in residential care, by the time the Care and Support bill is implemented, pencilled in as April 2015.

The Children and Families Act 2014 is transforming the system for children and young people with special educational needs as of September 2014. Changes include replacing old statements of SEN with a new education, health and care plan (EHC) for people aged from birth to 25. Local authorities and health commissioning groups will be required to commission services jointly for children and young people with SEN, and families will be offered personal budgets to pay for provisions which are specified on their child's EHC plan.

SECTION 2: WHAT IS HAPPENING IN WARWICKSHIRE?

The following chapter contains detailed information relating to:-

- Estimates of the future prevalence and demand of learning disabilities in Warwickshire.
- What we know about the needs of people with learning disabilities in Warwickshire.
- The types of services available for children, young people and adults with learning disabilities and an analysis of the numbers of people utilising those services .

⁴⁰ Department of Health, 2003 – Updated 2010. Fair Access to Care Services – guidance on eligibility criteria for adult social care. London: Department of Health

⁴¹ Department of Health, 2010. Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. London: Department of Health

⁴² Self directed support allows an individual to have more flexibility and choice in arranging the services they need. It involves identifying and allocating a personal budget. A personal budget is an upfront sum of money to meet a person's social care needs.

⁴³ HM Government, 2012. Caring for our future: reforming care and support. London: Department of Health

⁴⁴ A direct payment is a sum of money paid directly to a customer in order for them to arrange their own care and support services.

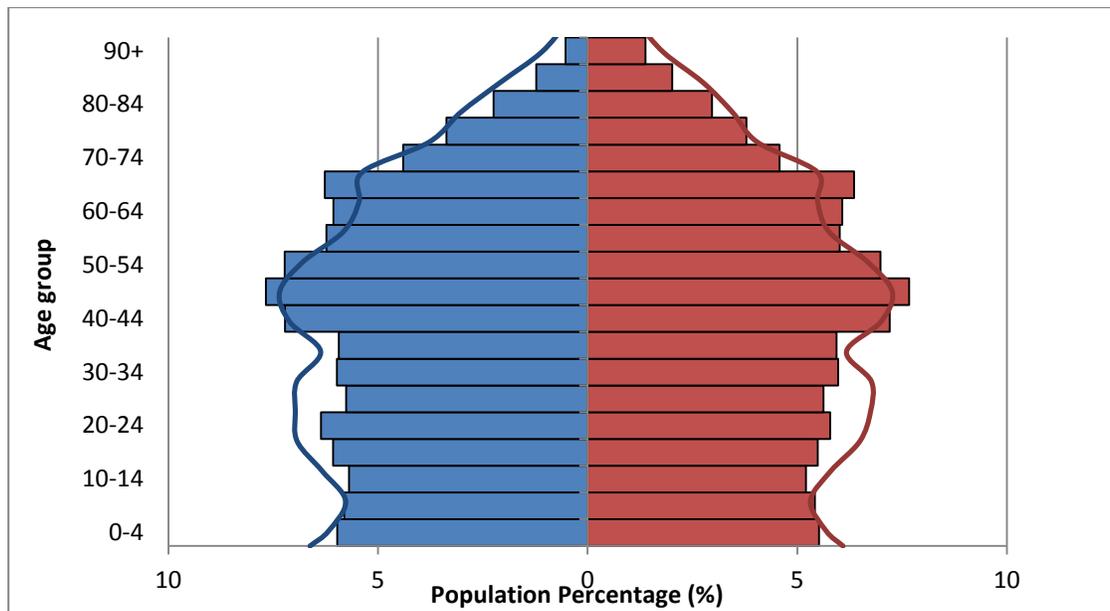
2.1 PREVALENCE AND PROJECTIONS

2.1.1 WARWICKSHIRE'S RESIDENT POPULATION

The total population of Warwickshire residents using the ONS 2013 mid-year population estimate is 548,729. This represents an increase of 6.5% in 10 years, up from 513,062 in 2003. Figure 1 shows Warwickshire's population pyramid using data from the ONS. If the proportion of each age group in Warwickshire is compared with England, Warwickshire has a lower proportion of age groups under 40 for both males and females, and a higher proportion in age groups over 40.

The 2011 census data showed that Warwickshire has a population which is 88.5% White British and a BME population of only 7.3%. The South Asian population (specifically Pakistani and Bangladeshi ethnicities) in Warwickshire is 0.37% compared with 2.93% across England.

Figure 1. Warwickshire's Population Pyramid



2.1.2 PREVALENCE OF LEARNING DISABILITIES IN WARWICKSHIRE

The prevalence of learning disabilities in Warwickshire is difficult to determine as there is currently no definitive record held either regionally or nationally. The main source of prevalence data is from rates predicted by Emerson and Hatton.

The total estimated 'true'⁴⁵ prevalence of all people with a learning disability in Warwickshire in 2013 is 11,030 of whom 9,469 are adults aged 18+ and 1,561 are children and young people aged 0-17. 69.7% of people are estimated to be between 18 and 64 years of age, with the proportion of people aged 0-17 and over 65 relatively similar (14.1% and 16.2% respectively). The largest proportion of people with a learning disability in Warwickshire live in Warwick (2,818 persons) followed by Nuneaton and Bedworth (2,517 persons). Approximately 60% of people with a learning disability in Warwickshire are expected to be male.

Figure 2. Estimated population of people with a learning disability in Warwickshire in 2013 by District and Age group

| Age Group | 0-17 | 18-64 | 65+ | Total |
|-----------------------|--------------|--------------|--------------|---------------|
| District | | | | |
| North Warwickshire | 179 | 861 | 207 | 1,246 |
| Nuneaton and Bedworth | 367 | 1,772 | 376 | 2,517 |
| Rugby | 314 | 1,410 | 312 | 2,035 |
| Stratford upon Avon | 337 | 1,594 | 483 | 2,414 |
| Warwick | 363 | 2,048 | 407 | 2,818 |
| Total | 1,560 | 7,685 | 1,785 | 11,030 |

Emerson and Hatton also calculated the estimated administrative prevalence of learning disabilities (those people known to social services). This figure is much lower than the 'true' prevalence estimate at 2,446 people in Warwickshire of which 1,989 are expected to be adults over the age of 18.

However, it should be noted that when Emerson and Hatton's calculated prevalence rate is applied to local areas this will produce an over-estimate of learning disabilities in communities with a relatively small South Asian community and an under-estimate in communities with a larger South Asian community. As previously mentioned, Warwickshire has a relatively small South Asian community of 0.37% compared with 2.93% across England.

2.1.3 CHILDREN WITH A LEARNING DISABILITY IN WARWICKSHIRE

In many cases, the first time a child is recognised as having a learning disability is when they first attend school. The school census is a statutory return which collects information on

⁴⁵ Emerson E, Hatton C. Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England. Lancaster: Institute for Health Research, Lancaster University, 2004.

individual pupils (including all those with a statement of SEN) from all maintained schools, academies and non-maintained special schools in England.

The Warwickshire Assessment, Statementing and Review Service (ASRS) is responsible for co-ordinating the statutory assessment of pupils with special educational needs, issuing statements of SEN and monitoring and reviewing the provision made in school for pupils with statements of SEN.

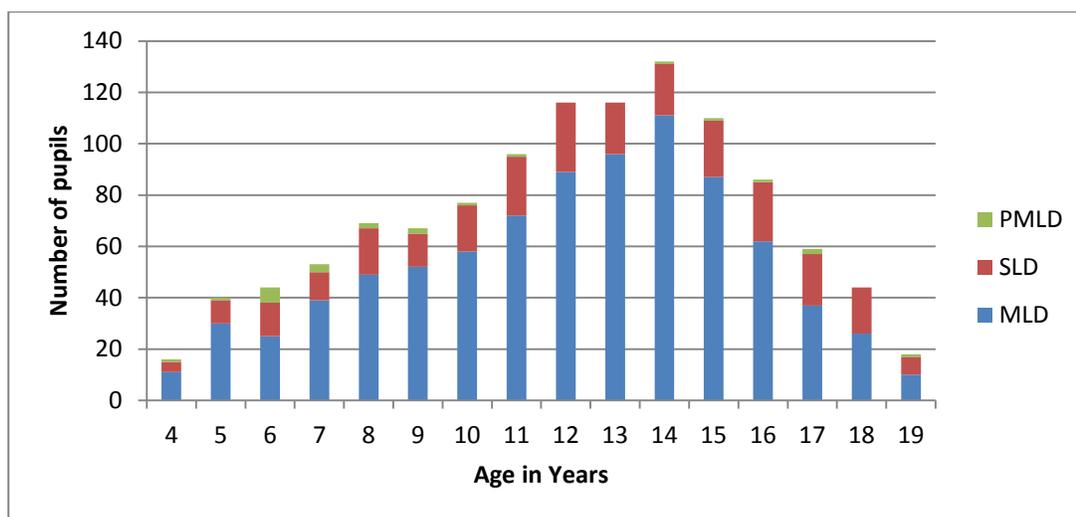
Combining the data recorded from the school census and ASRS is the most effective way of establishing the prevalence of learning disabilities among children in Warwickshire.

In Warwickshire, there are currently 1,143 pupils aged between 4 and 19 with a SEN statement of a learning disability of which 854 (74.7%) have a moderate learning difficulty, 266 (23.3%) have a severe learning difficulty and 23 (2.0%) have a profound and/or multiple difficulty. The number of pupils in Warwickshire with MLD and SLD have decreased since 2013 (2013: MLD n=867 % change = -1.5, SLD n=287 % change = -7.3) whereas the number of pupils in Warwickshire with PMLD has risen by 15%.

95.7% of pupils with PMLD and 85.0% of pupils with SLD attend a special school whereas 44.0% of pupils with MLD attend a mainstream school, suggesting that a child with MLD is more likely to have their special educational needs met at a mainstream school with extra support than a child with SLD or PMLD where their needs are more likely to be greater and more complex.

The number of children with an SEN statement of LD increases with age until the peak incidence aged 14 (n=132, 11.5%). After this, the number of children declines back to almost the same level as where it began (age 4 n=16, age 19 n=18).

Figure 1. Pupils with a statement of SEN for LD by Age and Need

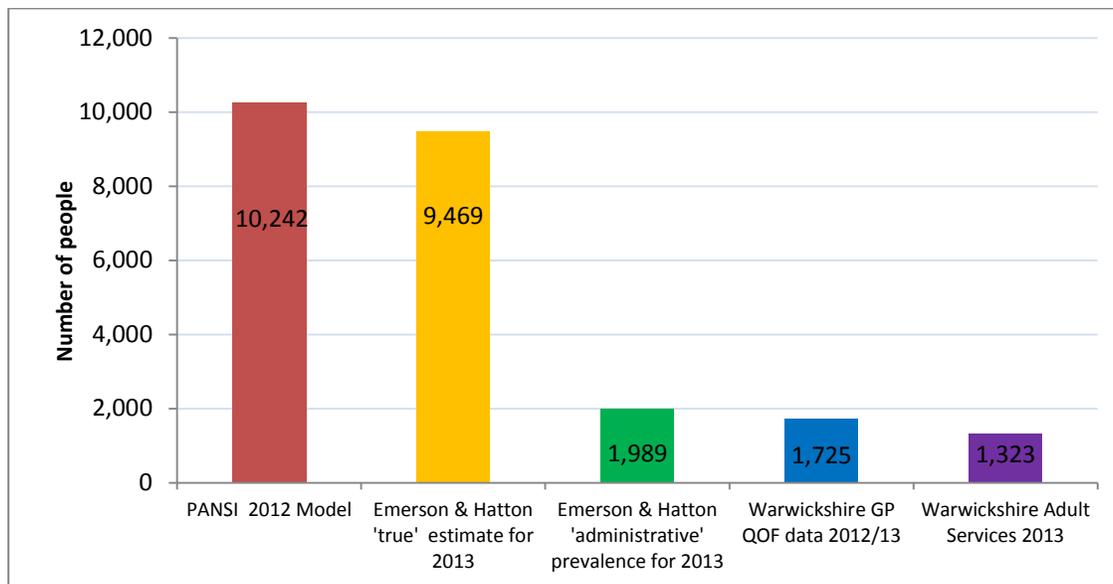


Ethnicity of pupils with a statement of SEN is poorly recorded with 42.2% of children in 2014 recorded as 'Information not yet obtained'. Out of the 661 pupils with an ethnicity recorded, 89.3% are White British.

2.1.4 ADULTS WITH A LEARNING DISABILITY IN WARWICKSHIRE

Importantly, the difference between Emerson and Hatton's administrative prevalence of adults aged 18+ with a learning disability for Warwickshire (1,989) and the number of adults over 18 actually receiving social care services in Warwickshire (1,323) is 666 (33.5%). This means that approximately two thirds of the adults with learning disabilities expected to be in contact with social services are actually receiving a service from social care in Warwickshire.

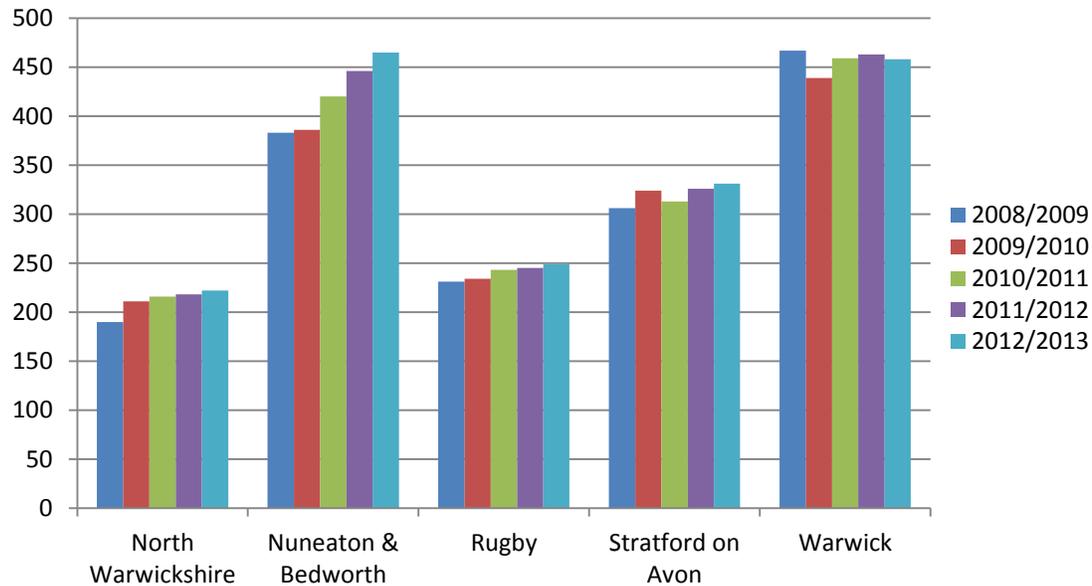
Figure 2. Adults in Warwickshire with a Learning Disability aged 18+



The prevalence rate of Warwickshire GP patients who are recorded as having a learning disability has increased slightly from 3.82 per 1000 persons in 2011/12 to 3.84 per 1000 persons in 2012/13. This is lower than the England figure (4.53 per 1000 persons in 2011/12 and 4.66 per 1000 persons in 2012/13) and lower than Warwickshire's statistical neighbour average of 4.63 per 1000 persons in 2011/12. The prevalence rate in Warwickshire is markedly different between districts and boroughs, with an increase in Nuneaton and Bedworth of 18.9% from 2008/09 to 2012/13 compared with a decrease of 4.1% in Warwickshire as a whole over the same time period. Figure 3 shows the number of Warwickshire GP patients with a learning disability has increased year on year in all districts/boroughs except for Warwick. However, caution must be taken when interpreting

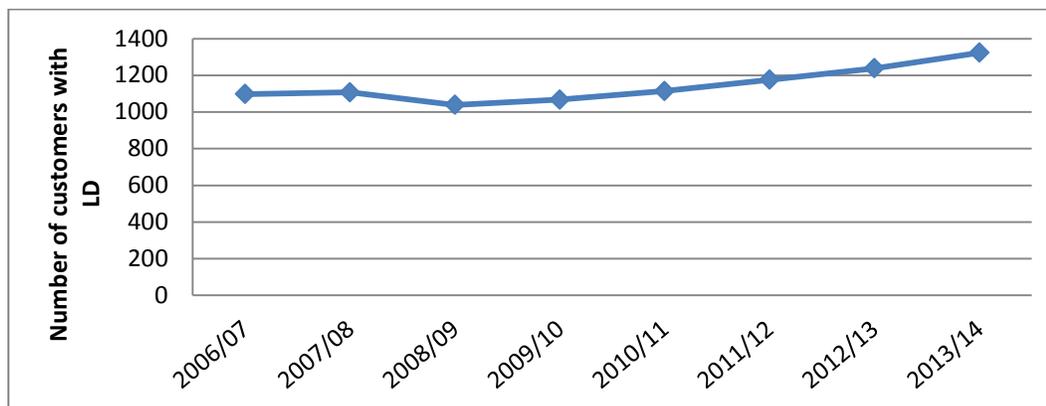
these figures. It is likely that GPs in Warwick were better at recording the number of their patients with a learning disability earlier, whereas in Nuneaton and Bedworth there may have been a more gradual improvement. It is important to note that the Quality and Outcomes Framework (QOF) where these figures are obtained from is a *voluntary* programme for GP surgeries in England to opt into rather than a legislative requirement.

Figure 3. Number of Warwickshire GP Patients with a Learning Disability



The number of people with a learning disability known to Warwickshire Adult Social Care services has been steadily increasing since 2008/09, with an increase of 24.0% in the past 5 years. The total number of people with a learning disability in 2013/14 over the age of 18 was 1,323. Of which 740 (56%) are male and 1,153 (87%) are aged between 18 and 64.

Figure 4. Number of customers known to Warwickshire Adult Social Care services by year



2.1.5 PARENTS WITH LEARNING DISABILITIES IN WARWICKSHIRE

The National Survey of adults with learning disabilities in England in 2003/04 found that one in fifteen people over the age of 16 who were interviewed for the survey had a child (approximately 7%)⁴⁶. The number of people over the age of 16 who were interviewed for the survey were converted to percentages to show the proportion of men and women in each age group in the study cohort (see figure 1).

Figure 1. Number of men and women by age with LD interviewed for National Survey

| Age group | Males | % Males | Females | % Females | Total |
|-----------|-------|---------|---------|-----------|-------|
| 16-24 | 576 | 21.78 | 352 | 13.31 | 928 |
| 25-34 | 331 | 12.52 | 241 | 9.11 | 572 |
| 35-44 | 317 | 11.99 | 179 | 6.77 | 496 |
| 45-54 | 170 | 6.43 | 147 | 5.56 | 317 |
| 55-64 | 114 | 4.31 | 108 | 4.08 | 222 |
| 65+ | 63 | 2.38 | 46 | 1.74 | 109 |
| Total | 1571 | 59.42 | 1073 | 40.58 | 2644 |

Figure 2. Estimated number of men and women by age with LD in Warwickshire National Survey

| Age group | Males | % Males | Females | % Females | Total |
|-----------|-------|---------|---------|-----------|-------|
| 16-24 | 930 | 9.46 | 586 | 5.96 | 1516 |
| 25-34 | 949 | 9.65 | 669 | 6.81 | 1618 |
| 35-44 | 1040 | 10.58 | 712 | 7.24 | 1752 |
| 45-54 | 1054 | 10.72 | 732 | 7.45 | 1786 |
| 55-64 | 804 | 8.18 | 568 | 5.78 | 1372 |
| 65+ | 995 | 10.12 | 791 | 8.05 | 1786 |
| Total | 5772 | 58.72 | 4058 | 41.28 | 9830 |

Learning Disability prevalence estimates for Warwickshire were then calculated using the same age groupings (see figure 2). The percentage of males compared with females in the study cohort were similar to the Warwickshire prevalence estimates (Males: 59.4% vs 58.7%, Females: 40.6% vs 41.3%). However the study cohort contained a far greater proportion of young adults than older people with approximately 57% of those interviewed under the age of 35 compared with 32% calculated from Warwickshire prevalence estimates.

If the prevalence estimate calculated in the National Survey of adults (over 16 years) with learning disabilities who had a child was applied to Warwickshire prevalence estimates looking at the same age range, this would equate to approximately 688 out of 9830 people with a learning disability over the age of 16 in Warwickshire who have a child. However, this estimate is most likely very conservative, especially when taking into consideration that the

⁴⁶ Emerson E, Malam S, Davies I and Spencer K (2005). *Adults with learning difficulties in England 2003/4*

study is now over 10 years old and the average age of the cohort was much lower than the estimated population of people living in Warwickshire with LD.

2.1.6 FUTURE PREVALENCE & SERVICE DEMAND IN WARWICKSHIRE

The table in figure 5 shows the estimated predicted prevalence of learning disabilities in Warwick from 2013 to 2021 by age group. The most pronounced rise is predicted to be in those who are over the age of 65, with a 9.9% rise in the 4 years from 2013 to 2017 and an 18.0% rise from 2013 to 2021. Warwickshire has an older resident population than the England average, and this combined with reduced mortality among older adults with learning disabilities is likely to lead to higher demand for services over the next decade.

Figure 5. Predicted Future Prevalence of Learning Disabilities in Warwickshire

| Year | 2013 | 2017 | % change from 2013 | 2021 | % change from 2013 |
|-----------------|---------------|---------------|--------------------|---------------|--------------------|
| Age Band | | | | | |
| 0-17 | 1,561 | 1,581 | 1.30% | 1,688 | 8.10% |
| 18-64 | 7,684 | 7,752 | 0.90% | 7,824 | 1.80% |
| 65+ | 1,785 | 1,961 | 9.90% | 2,106 | 18.00% |
| All Ages | 11,030 | 11,295 | 2.40% | 11,618 | 5.30% |

2.1.5 COMORBIDITIES ASSOCIATED WITH LEARNING DISABILITIES

Research shows that people with learning disabilities often suffer from comorbid conditions or disorders relating to their disability. Few studies have been conducted which aim to establish the prevalence of comorbidities associated with learning disabilities using formal diagnostic criteria, but the results of some such studies are presented here. These results have then been applied to Warwickshire learning disability prevalence data relating to the age groups studied and in accordance with any methodological limitations that may exist, to determine an estimated prevalence of comorbid conditions in the county.

Psychiatric Disorders

*Emerson et al (2007)*⁴⁷ looked into the prevalence of diagnosable psychiatric disorders (against ICD-10⁴⁸ criteria) in children with and without intellectual disabilities and found that

⁴⁷ Emerson, E and Hatton, C. (2007). Mental Health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*. 191, p.493-499.

children with learning disabilities were significantly ($P < 0.0001$) more likely to suffer from a psychiatric disorder than children without (36% vs 8%).

The estimated number of children in Warwickshire aged between 5 and 16 with a learning disability suffering from psychiatric disorders is 479 out of 1331.

Cooper et al (2007)⁴⁹ studied the prevalence of mental ill health in adults with learning disabilities against a range of diagnostic criteria including ICD-10, DC-LD⁵⁰ and clinical diagnoses. Point prevalence⁵¹ of mental ill-health in adults with LD ranged from 15.7% to 40.9% depending on the diagnostic criteria.

The estimated number of adults in Warwickshire aged 18 - 83 with a learning disability suffering mental ill-health is between 1505 and 3921 with an average of 2509 out of 9586.

Autism Spectrum Disorders

Emerson & Bains (2010)⁵² carried out a systematic literature review to estimate the prevalence of autism among adults (excluding those in residential care) with learning disabilities in England. The authors proposed to employ two prevalence rates based on their review; a lower estimate of 20% (close to the median rate across studies), and an upper estimate of 33% (reported by community-based samples of adults accessing specialist services).

Emerson & Bains (2010) also reviewed the available literature on the prevalence of autism among children with learning disabilities. Reported prevalence of autism has increased over time due, at least in part, to improved methods of detection and a broadening concept of autism. The authors combined the estimated prevalence of learning disabilities and the

⁴⁸ International Classification of Diseases 10th version

⁴⁹ Cooper et al (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*. [Online]. 190. p.27-35. Available from: <http://bjp.rcpsych.org/content/190/1/27.full>

⁵⁰ Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities

⁵¹ A measure of the proportion of people in a population who have a disease or condition at a particular time, such as a particular date.

⁵² Emerson, E. and Baines, S. (2010). The estimated prevalence of autism among adults with learning difficulties in England. *Improving Health and Lives Learning Disabilities Observatory*. [Online]. p7. Available from: http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf

estimated prevalence of autism to give a range from 12%-72% with an average of 34% among children aged 7-15.

The estimated number of children in Warwickshire aged 7-15 with a learning disability and autism is between 123 and 740 with an average of 350 out of 1028.

Epilepsy

McGrother et al (2006)⁵³ conducted a population-based prevalence study to identify the proportion of adults with LD in Leicestershire with concurrent epilepsy. Individuals with the lowest level of understanding were significantly more likely to have reported epilepsy than those with a higher level of understanding ($P < 0.0001$). Results showed that 25.9% of adults with LD in the study group also had epilepsy.

The estimated number of adults in Warwickshire over the age of 20 with a learning disability and epilepsy is 2372 out of 9142.

Dementia

According to Emerson et al (2011)⁵⁴, the prevalence of dementia is higher amongst older adults with learning disabilities compared to the general population (22% vs 6% aged 65+).

This gives an estimated prevalence of adults in Warwickshire over the age of 65 with a learning disability and dementia of 393 out of 1785.

There is considerable evidence that adults who have Down's syndrome are at high risk for developing Alzheimer's disease in later life. It is agreed that prevalence increases systematically in adults with Down's syndrome who are over the age of 30. It is estimated that between 10 and 25% of people with Down's syndrome in their 40s have dementia, between

⁵³ McGrother CW, Bhaumik S, Thorp CF, Hauck A, Branford, D, Watson JM. (2006). Epilepsy in adults with intellectual disabilities: prevalence, associations and service implications. *Seizure*. 15(6). p. 376-386

⁵⁴ Emerson E, Baines S, Allerton L, Welch V. (2011) Health Inequalities and People with Learning Disabilities in the UK. Improving Health and Lives Learning Disabilities Observatory. [Online]. p. 1-36. Available from: [http://www.surreycare.org.uk/cms/uploads/Ldis%20Network/IHaL2011-09HealthInequality2011\[2\].pdf](http://www.surreycare.org.uk/cms/uploads/Ldis%20Network/IHaL2011-09HealthInequality2011[2].pdf)

20% and 50% of those in their 50s, and between 30 and 75% of those over 60⁵⁵. Peak incidence is in the early fifties.

Figure 6. Estimated number of people in Warwickshire with Down's syndrome

| Age | Total number of people with Down's syndrome | % who may develop Alzheimer's | Number who may develop Alzheimer's |
|-------|---|-------------------------------|------------------------------------|
| 35-44 | 45 | 7-15% | 3 - 6 |
| 45-54 | 52 | 10-25% | 5 - 13 |
| 55-64 | 42 | 50% | 21 |
| 65+ | 4 | 30-75% | 1-3 |

2.2 PREVENTATIVE HEALTH AND HEALTH INTERVENTION

A healthy and active lifestyle is as important for people with learning disabilities as it is for the general population. However, people with learning disabilities have significantly poorer health than their non-disabled peers. Good health begins with promoting well-being and preventing ill-health, but evidence suggests that access to the NHS for people with learning disabilities is poor, leading to undiagnosed illness and in some cases, avoidable death.

There is a need for all General Practices to know who has a learning disability and how many people with a learning disability there are on the caseload. As there are risks to physical and mental health associated with learning disabilities it is important that those people with learning disabilities have adequate access to services. There is a need therefore to ensure that primary care offer NICE compliant services for health issues such as cancer, epilepsy, heart disease and dementia, in such a way that is accessible to people with learning disabilities. By law, all public sector services have a legal duty to provide 'reasonable adjustments' for people with learning disabilities. Reasonable adjustments include removing physical barriers to accessing services, but also changing the ways in which services are delivered, ensuring that policies, procedures and staff training all enable services to work equally well for people with learning disabilities.

⁵⁵ Holland A, Hon J, Huppert FA, Stevens F and Watson P. (1998). Population-based study of the prevalence and presentation of dementia in adults with Down's syndrome. *The British Journal of Psychiatry*. 172. p. 493-498

2.2.1 PREVENTATIVE HEALTHCARE

Annual Health Checks

NHS GPs can sign up and be paid to undertake annual health checks for people with learning disabilities who are over the age of 18 and are known to have a learning disability by both their local social services department and their GP. The service is a Directed Enhanced Service which is part of the Quality Outcomes Framework.

The health check consists of a general physical examination, an epilepsy review, where appropriate, a syndrome specific assessment, and other chronic illnesses such as asthma or diabetes, a behaviour and mental health assessment and a review of any arrangements with other health professionals such as physiotherapists or speech therapists.

People with learning disabilities often have difficulty in recognising illness and communicating their needs. Research shows that regular health checks for people with learning disabilities often uncover easily preventable and/or treatable health conditions⁵⁶. Most of these are simple to treat, while sometimes serious illnesses such as cancer are found, but the health check means that it is found at an early stage when it is more likely to be successfully treated.

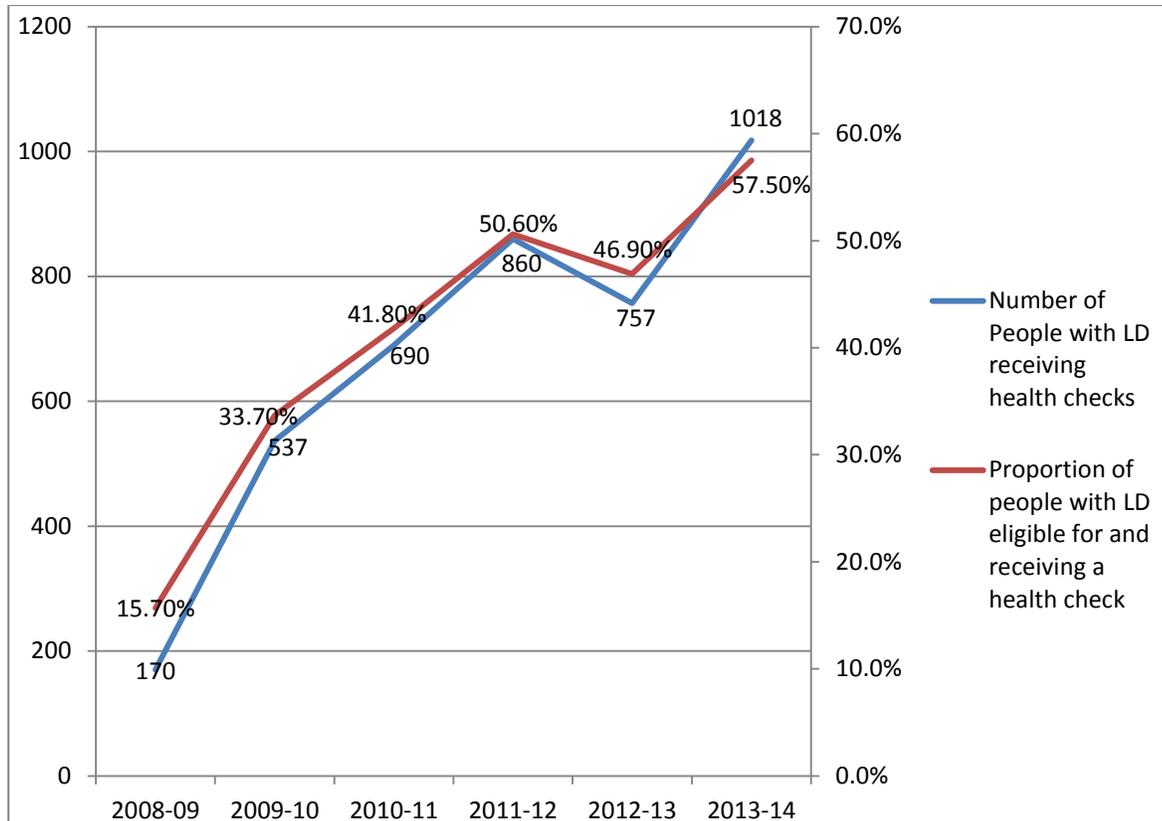
The Annual Health Check is also a chance for people with learning disabilities to get used to going to their GP practice, which reduces their fear of going at other times.

In Warwickshire, 1,770 adults over the age of 18 were identified as eligible for an annual health check in 2013-14 of which 1,018 people (57.5%) went on to have one. This is higher than the previous year in terms eligibility and the proportion of checks undertaken, as seen in Figure 1. The number and proportion of annual health checks carried out by Warwickshire GPs has increased considerably since 2008-09. The reduction seen in 2012-13 has not continued into 2013-14. The proportion of eligible adults with a learning disability who had a GP health check in 2013/14 is significantly higher than the England and West Midlands average at 44.2% and 46.0% respectively. There are 76 GP practices within Warwickshire of which 68 (89%) were signed up to offer learning disability Annual Health Checks in 2012/13.

⁵⁶ Robertson J, Roberts H, Emerson E, Turner S, Grieg R. The impact of health checks for people with intellectual disabilities: a systematic review of evidence. *J Intellect Disabil Res* 2011;55:1009–19.

The learning disability health checks programme is a central element in national plans to make primary care more accessible and effective for people with learning disabilities. However, the provision of health checks by GPs is on a voluntary rather than compulsory basis. It is important that consideration is given to how to ensure that learning disability health checks are made available to people whose GPs do not sign up to the Directed Enhanced Service to do them.

Figure 1. Annual Health Checks in Warwickshire by year, 2008-09 to 2013-14



Coventry and Warwickshire Partnership NHS Trust has developed a resource pack for all Warwickshire GP practices. The pack is given to GPs at events and is designed to raise awareness of health issues for people with learning disabilities. The nominated learning disability lead in the practice also receives electronic copies of the documents and the folder can be updated as necessary.

The folder contains information on what a learning disability is and a screening tool to help determine if someone has a learning disability. There is advice about read codes (all GP practices in the area now use standardised read codes to identify and record that an

individual has a learning disability) and a practice protocol for delivering health checks, including an easy read invitation letter. There is information on the Mental Capacity Act and consent, tips on communication and signs and symbols, information on the associated health needs of people with learning disabilities, epilepsy management plans and other useful information. The folder includes information on referring to the Community Adult Learning Disability Service. All referrals to the team go through a central booking service, making it easier for GPs and others to refer.

The Community Learning Disability Nursing Team and Allied Health Professionals within Specialist Services provide regular Learning Disability Awareness Training to GP's and practice staff. The Community Nursing Team support practices to identify people who have a learning disability and update the Learning Disability Registers. The Consultant Psychiatry Team also provide regular training on the GP's Protected Learning programme.

Health Action Plans

A Health Action Plan details the actions that are needed in order to maintain or improve the health of a person with a learning disability. They were recommended in the 2001 Government White Paper '*Valuing People*' as a mechanism to link an individual to the range of support and services which they need if they are to have better health. Health Action Plans are often implemented or reviewed at the same time as receiving an Annual Health Check, however, an individual does not have to be eligible for an Annual Health Check in order to have a Health Action Plan.

The Community Learning Disability Nursing Team have provided GP Practices with guidance about completing Health Action Plans, however, the Health Action Plan and Annual Health Checks are not currently integrated within the GP operating systems which may be a barrier to their completion.

In 2012/13, 1,725 aged over 18 with a learning disability in Warwickshire were eligible for a Health Action Plan of which 779 were completed.

Secondary Healthcare

There are Acute Liaison Nurses who support all of the hospitals across Warwickshire. The Acute Liaison Nurses support people with a learning disability to access mainstream health services and ensure the Mental Capacity Act is adhered to and that reasonable adjustments are made. Information is put into accessible formats. Acute Liaison Nurses provide regular Learning Disability Awareness Training to hospital staff. People with a learning disability support in delivering these training sessions.

Cancer Screening

People with learning disabilities have significantly higher rates of mortality and morbidity than their non-disabled peers. Whilst the incidence of deaths from most cancers in the UK among people with learning disabilities is currently lower than the general population, this is likely to change in the coming years as a result of their increased longevity. People with learning disabilities have proportionally higher rates of gastrointestinal cancer, and children with Down's syndrome are at particularly high risk of leukaemia⁵⁷.

People with learning disabilities with cancer are less likely to⁵⁸:

- be informed of their diagnosis and prognosis;
- be given pain relief;
- be involved in decisions about their care
- receive palliative care

Data on the number of people with learning disabilities who have been offered or received cancer screening is collected by the Joint Health and Social Care Self-Assessment Framework, informally known as the LD SAF. All 154 Learning Disability Partnership Boards registered to report their local conclusions in 2013, with all but one providing at least some details of local services.

In Warwickshire, data is collated from each GP practice in the county to inform the LD SAF. For the 2014 submission, 37% of GP practices (28 out of 76) responded to the data request (due to time restrictions and governance issues). This represents approximately 42% of Warwickshire's known population of adults over the age of 18 with a learning disability.

The uptake of cancer screening by people with a learning disability in Warwickshire is lower than the uptake of cancer screening by Warwickshire's general population for cervical, breast and bowel cancer. The difference in uptake was most pronounced for breast cancer screening where uptake among eligible women with learning disabilities in Warwickshire was 62.4% lower than that of the general population.

⁵⁷ Cooke LB. Cancer and learning disability. *Journal of Intellectual Disability Research* 1997;41:312-16.

⁵⁸ Bemal J. Telling the truth-or not: Disclosure and information for people with intellectual disabilities who have cancer. *International Journal on Disability and Human Development* 2008;7:365-70.

Cervical cancer screening:

Out of **242** women with learning disabilities in Warwickshire who were eligible* for screening only **62** had received a cervical smear test in the past 5 years.

25.6% compared with **75.8%** of Warwickshire's general population

* aged 25-64 and have not had a hysterectomy

Breast cancer screening:

Out of **126** women with learning disabilities in Warwickshire who were eligible* for screening only **19** had mammographic screening in the past 3 years.

15.1% compared with **77.5%** of Warwickshire's general population

* aged 50-69 years

Bowel cancer screening:

Out of **97** people with learning disabilities in Warwickshire who were eligible* for screening only **23** had satisfactorily completed bowel cancer screening within six months of invite.

23.7% compared with **62.0%** of Warwickshire's general population

* aged 60-69 years

Diet, physical activity and obesity

Many studies have shown that adults with a learning disability are more likely to be obese compared to the general population. Reasons for this higher prevalence include a mix of biological, behavioural and environmental factors such as low levels of physical activity, poor diet, living independently, use of psychotropic medications and genetic syndromes. Levels of obesity are particularly high among women with mild learning disabilities. Obesity increases the likelihood of heart disease, stroke and Type 2 diabetes along with a host of secondary effects on a person's general health.

People with learning disabilities are at risk of obesity at an earlier age than the general population and as a consequence are likely to experience obesity-related health problems at a younger age.

According to the 2014 LD SAF submission, 561 people with learning disabilities over the age of 18 registered with Warwickshire GPs had their body mass index (BMI) recorded, of whom 225 (40%) had a BMI in the obese range of 30 or higher.

Body Mass Index:

40% of adults over the age of 18 with learning disabilities in Warwickshire have a BMI in the obese range compared with **22%** of Warwickshire's general population.

Coronary heart disease is the second highest cause of death for people with learning disabilities⁵⁹. People with learning disabilities are more likely to develop hypertension and obesity, and 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. Rates of coronary heart disease are increasing among people with learning disabilities as a result of increasing life expectancy and an increase in exposure to risk factors as a result of lifestyle changes associated with living in community settings.

Data from Warwickshire's 2014 LD SAF submission shows that 9 out of 743 (1.2%) adults with a learning disability in Warwickshire are known to their doctor to have coronary heart disease. Warwickshire's latest observed prevalence of coronary heart disease in the general population is 3.2%. If rates of coronary heart disease are higher among people with learning disabilities than that of the general population, this would suggest that there is a cohort of people with learning disabilities in Warwickshire who have undiagnosed coronary heart disease. Commissioners in Warwickshire need to work closely with the Community Learning Disability Nursing team to develop programmes specifically targeting adults with learning disabilities and their carers to raise awareness of the dangers of coronary heart disease.

Coronary heart disease:

1.2% of adults over the age of 18 with learning disabilities in Warwickshire are known to their doctor to have coronary heart disease compared with **3.2%** of Warwickshire's general population.

⁵⁹ Hollins S, Attard M, van Fraunhofer N, McGuigan SM, Sedgwick P. Mortality in people with learning disability: risks causes, and death certification findings in London. *Developmental Medicine and Child Neurology* 1998;40:50-56.

Diabetes

Rates of Type 1 and Type 2 diabetes are considered to be higher among people with learning disabilities than they are in the general population⁶⁰. The higher rate of Type 2 diabetes among people with learning disabilities is likely to be related to their increased risk of obesity, poor diet and sedentary lifestyle.

Data from Warwickshire's 2014 LD SAF submission shows that 76 out of 822 (9.2%) people with a learning disability in Warwickshire are known to their doctor to have diabetes compared with 5.97% of Warwickshire's general population.

Diabetes:

9.2% of people with learning disabilities in Warwickshire are known to their doctor to have diabetes compared with **6.0%** of Warwickshire's general population.

Asthma

Respiratory disease is possibly the leading cause of death for people with learning disabilities, with rates much higher than for the general population (46%-52% vs 15%-17%)⁶¹. People with asthma and learning disabilities were found to be twice more likely to be smokers than patients with learning disabilities who do not have asthma. More than half of women with learning disabilities and asthma are also obese⁶².

According to Warwickshire's 2014 LD SAF submission, 116 out of 822 (14.1%) people with a learning disability in Warwickshire are known to their doctor to have asthma compared with 9.1% of Warwickshire's general population.

Asthma:

14.1% of people with learning disabilities in Warwickshire are known to their doctor to have asthma compared with **9.1%** of Warwickshire's general population.

⁶⁰ Reichard A & Stolze H Diabetes Among Adults With Cognitive Limitations Compared to Individuals With No Cognitive Disabilities. *Intellectual and Developmental Disabilities*, 49, 3, 141-154.

⁶¹ Hollins S, Attard M, van Fraunhofer N, McGuigan SM, Sedgwick P. Mortality in people with learning disability: risks causes, and death certification findings in London. *Developmental Medicine and Child Neurology* 1998;40:50-56.

⁶² Gale L, Naqvi H, Russ L. Asthma, Smoking and BMI in adults with intellectual disabilities: a community-based survey. *Journal of Intellectual Disability Research* 2009;53(9):787-96.

Epilepsy

People with learning disabilities have a higher risk of having epilepsy than the general population. This risk increases with the severity of the impairment. The risk of epilepsy in the general population is 0.5%. For those with a mild intellectual impairment, an IQ of between 50 and 70, the risk is approximately 4%. For those with moderate to severe impairment, an IQ range of 20 to 50, the risk is 30%. 50% of those with an IQ of less than 20 have had at least 1 epileptic seizure⁶³.

Epilepsy is more common in those who have suffered brain injury in the perinatal or post-natal period. Seizures are a cause of excess mortality in people with learning disabilities and there is evidence that they may be linked with mental ill health problems too.

Data from Warwickshire's 2014 LD SAF submission shows that over a quarter (214 out of 822) of people with a learning disability in Warwickshire are known to their doctor to have epilepsy compared with 0.6% of Warwickshire's general population.

Epilepsy:

26.0% of people with learning disabilities in Warwickshire are known to their doctor to have epilepsy compared with **0.6%** of Warwickshire's general population.

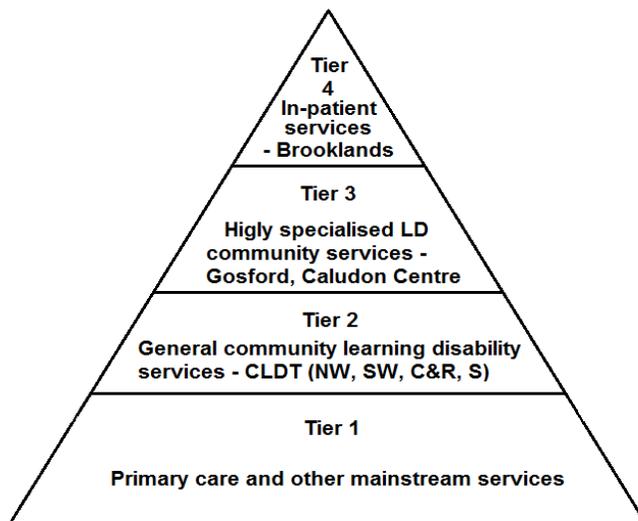
2.2.2 COVENTRY & WARWICKSHIRE PARTNERSHIP TRUST SERVICES

Coventry and Warwickshire Partnership Trust (CWPT) provides specialist learning disability services across all 4 tiers of care as described by the Faculty of the Psychiatry of Learning Disability Royal College of Psychiatrists in their Faculty report from 2011⁶⁴ (see Figure 1).

⁶³ Bird, J. 1993. Epilepsy and Learning Disabilities. In Seminars in the Psychiatry of Learning Disabilities, Gaskell, London (IV).

⁶⁴ Faculty of the Psychiatry of Learning Disability (2011) *Future role of psychiatrists working with people with learning disability*. London. Royal College of Psychiatrists.

Figure 1 – CWPT Tiered care model for services for people with a learning disability



Inpatient services

CWPT hosts a Specialist Assessment and Treatment Service (SATS) which is an inpatient service for people who have a learning disability along with severe mental health and behavioural problems which put themselves and others at risk. The service is run from Brooklands Hospital (tier 3 & 4) and the Caludon Centre (tier 3) where there are separate wards/units for males and females, adults, young people and adolescents and those with higher dependency or greater needs.

The Brooklands site hosts CWPT's secure services for men and women with a mild to moderate learning disability who are detained under Part 3 of the Mental Health Act. There are four units; the Janet Shaw clinic, a male, medium secure unit, and three single-sex low secure units. The Brooklands Sex Offender Treatment Programme and Fire Setter Treatment Programmes are specialist cognitive behavioural programmes offered by CWPT who accept patients regionally and nationally. The Women's Service is one of only a few specialist dedicated women's services for women with learning disabilities and complex needs in the UK.

Respite and day services

CWPT provides respite care for people with a learning disability and their families. Respite is available from three sites; Ashby House near Nuneaton, a 7-bed residential short break service for people with a severe learning disability, associated conditions and mental health needs; Gilliver Road in Shirley and Ivy Lodge in Marston Green, both 5-bed facilities which

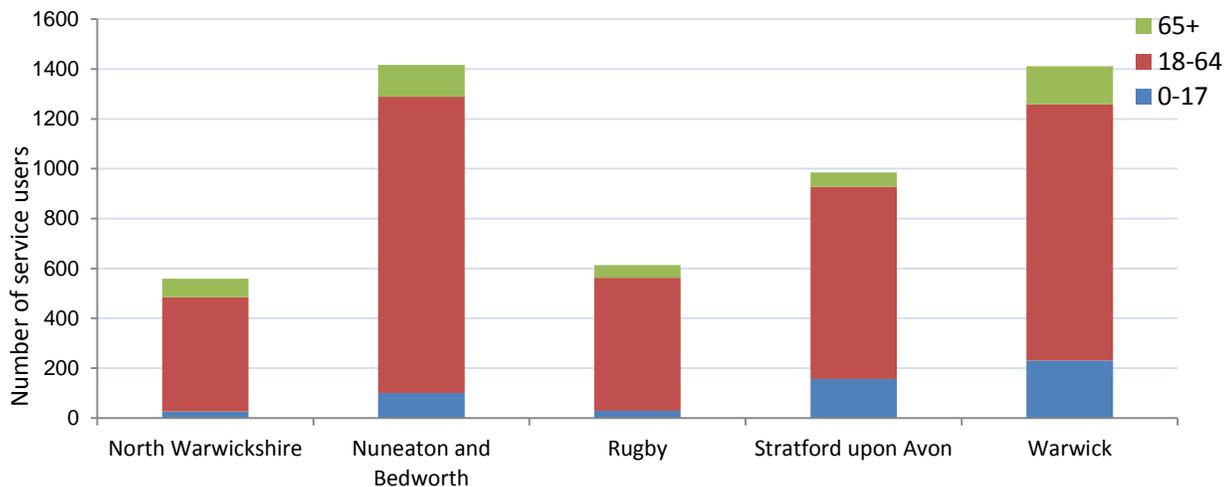
offer care on a rota basis, with each family offered either a weekend or mid-week break every four or five weeks.

Community Learning Disability Teams

Community Learning Disability Teams (CLDT) provide community services to people with a learning disability. Teams comprise of speech and language therapists, music therapists, occupational therapists, community nurses, psychologists, psychiatrists and physiotherapists. There are five CLDT; South Warwickshire, North Warwickshire, Rugby, Coventry and Solihull which offer services Monday to Friday from 9am to 5pm.

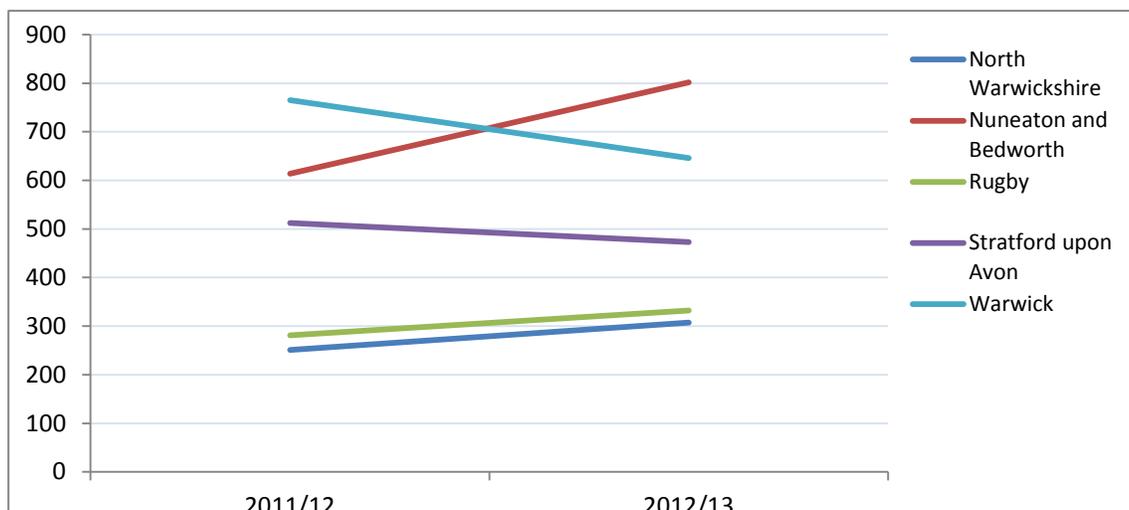
Within CLDT are the health facilitation and acute liaison team whose role is to ensure that adults with a learning disability are treated equally in society and receive the care that they need in order to live healthy and fulfilling lives.

Figure 2. Total number of CLDT service users in 2011/12 and 2012/13 by district and age group



Nuneaton and Bedworth have the most customers using CLDT services in Warwickshire with a total of 1416 in 2011/12 and 2012/13. North Warwickshire has the highest proportion of customers over the age of 65 and Warwick has the highest proportion of customers aged 0-17 (13.1% and 16.4% respectively). The majority of customers in all districts are adults aged 18-64.

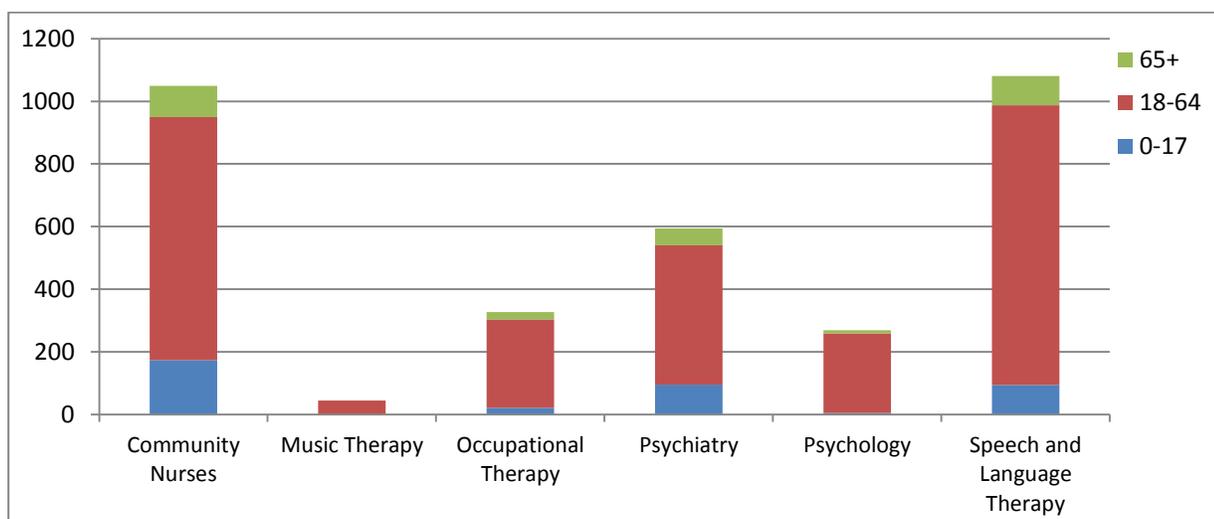
Figure 3. Service users by date and district



The number of customers using CLDT services decreased from 2011/12 to 2012/13 in South Warwickshire (Stratford upon Avon and Warwick) but increased in Nuneaton and Bedworth, North Warwickshire and Rugby.

The services received by the highest number of customers in 2012/13 were those offered by the speech and language therapists (see Figure 4). Customers aged 0-17 and aged 65+ used the services offered by the community nurses most frequently. The number of customers has increased from 2011/12 to 2012/13 across all service types apart from Psychiatry where numbers have fallen.

Figure 4. Customers by type of service received and age group in 2012/13



2.3 EARLY INTERVENTION

The 2011 Green paper '*Support and aspiration: A new approach to special educational needs and disability*' published by the Department of Education, identified that families often struggle to get the early and targeted help that they need from the education, health and social services sectors for their children with learning disabilities⁶⁵.

A review by Allen in 2011 highlighted the value of early intervention, which can help to improve educational outcomes for children and young people, improve employability, increase earnings, and reduce negative behaviours such as anti-social behaviour and crime⁶⁶. The review stated that the sooner a family or child receives support, the less harm is done to development (including brain development) and the impact on health and well-being throughout later life is improved.

Research undertaken by The Office for Standards in Education, Children's Services and Skills (Ofsted) in 2013 stated that missing out on education and support in school often results in offending behaviours for some of the more vulnerable young people with learning disabilities, which will then ultimately lead to support being provided much later by the Youth Justice Team⁶⁷.

Ofsted reported that most children with profound and/or complex learning disabilities are effectively identified, often at or soon after birth. Hearing tests are undertaken for all newborns and a health and development review is routinely undertaken by health visitors for children aged 2-2½. In Warwickshire, if a child is found to be showing signs of significant delay in areas of their development they will be referred to the Integrated Disability Service.

2.4.1 INTEGRATED DISABILITY SERVICE

The Integrated Disability Service (IDS) is a partnership between Warwickshire County Council and the NHS to provide support services to disabled children, young people and their families. The IDS is made up of teams who are responsible for providing different aspects of care depending on the needs of the individual. These teams include:

⁶⁵ Department of Education, 2011. *Support and aspiration: A new approach to special educational needs and disability*. HMSO London.

⁶⁶ Allen MP, G. (2011) *Early intervention: the next steps. an independent report to her majesty's government*. Cabinet Office [Online] <http://media.education.gov.uk/assets/files/pdf/g/graham%20allens%20review%20of%20early%20intervention.pdf>

⁶⁷ Ofsted. November 2013, No. 130048. *Pupils missing out on education: low aspirations, little access, limited achievement*. Ofsted: Manchester

- The Birth to Three Portage Service providing a home-based teaching service for babies and very young children up to the age of 3.
- The Child Development Service; providing a co-ordinated, multi-agency assessment and follow up services to pre-school children with complex needs.
- The Pre-School Service, who support children in mainstream Early Years' Settings across Warwickshire.

IDS Social Care Team

The IDS social care team provide dedicated social workers to support disabled children, young people and their families from birth to 18 years within their own home. A range of services are on offer, which include emotional support, social work advice, specialist day care, play schemes and leisure activities. Any child living permanently in Warwickshire who has a severe or significant level of disability that has a negative impact on their family can be referred to the service where an assessment will then be undertaken.

Table 1 shows the number of IDS social care clients by their type of disability as a snapshot on a particular day from 2009 to 2013. There were substantially more clients with a learning disability from 2009 until 2013 when the number of clients with autism rose higher. The number of clients with behavioural, mobility, communication and learning disabilities peaked in 2009 and then followed a similar downward trend reaching their lowest levels in 2013. The number of clients with autism followed the same trend until 2011, then numbers began to rise until they reached their peak in 2013. This is indicative of a change in recording rather than a change in prevalence.

Table 1. IDS Social Care Clients by Disability

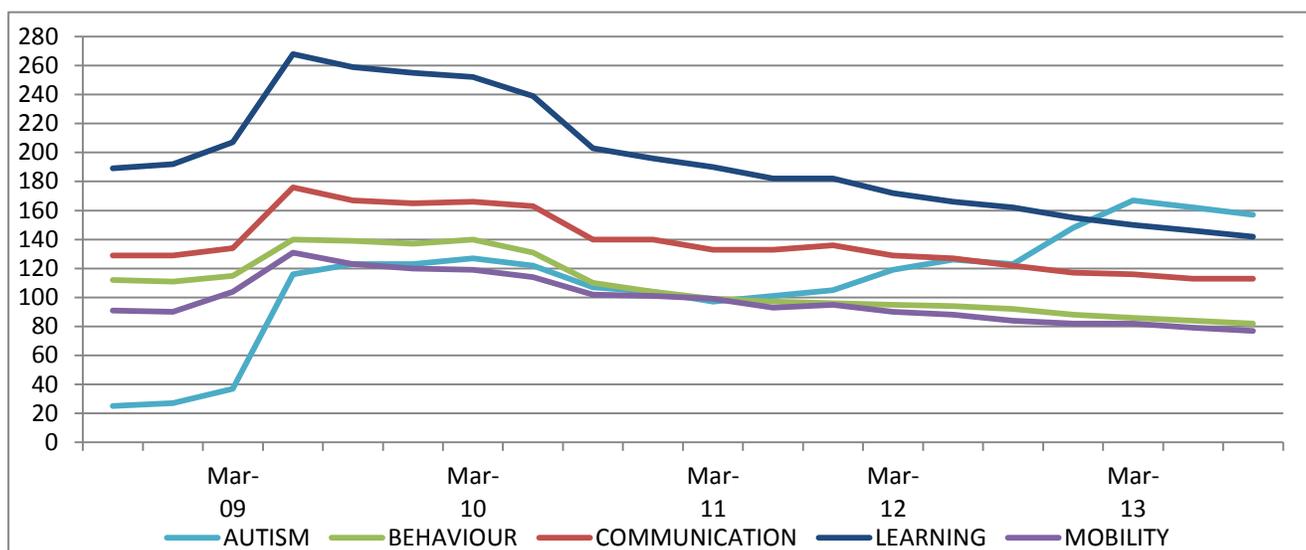
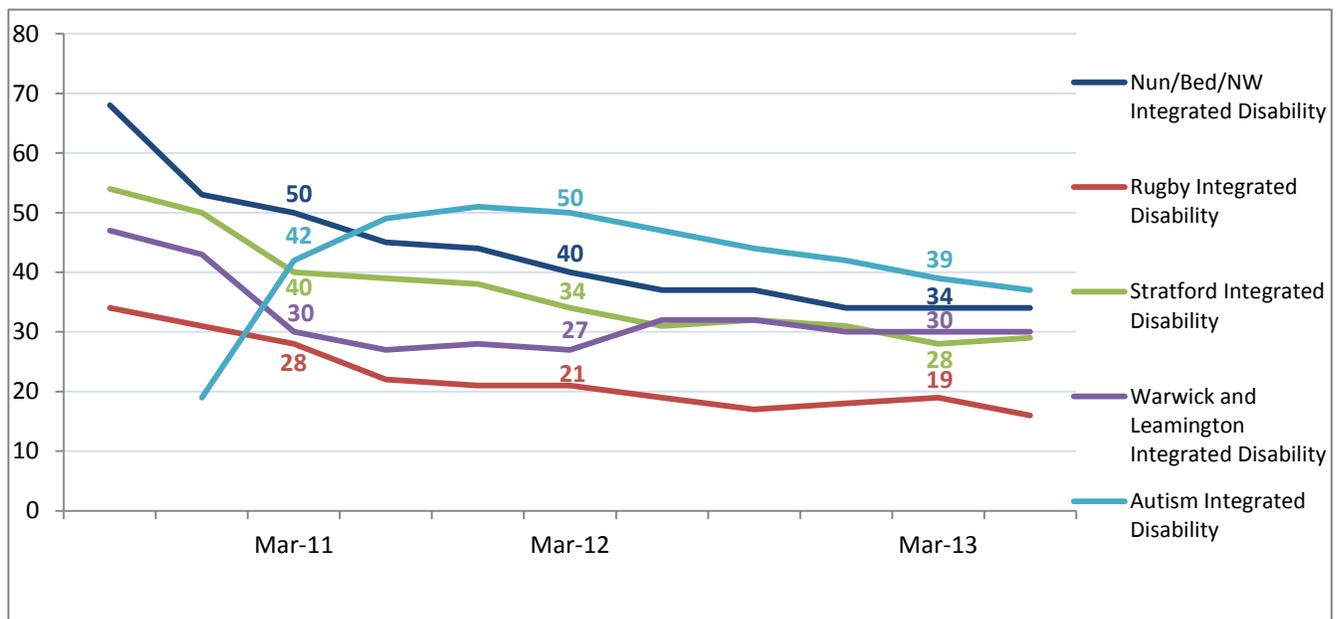


Table 2 shows the number of IDS social care clients with a learning disability by social care team. There are four teams which cover different areas of Warwickshire, and a separate team whose clients all have autism specifically. The number of clients in the Autism ID team grew from 2011 and peaked in 2012 when numbers fell again. The trend from 2011 to 2012 is indicative of a change in recording rather than a change in prevalence. However, from 2012 to 2013 there is a downward trend across all teams. Nuneaton, Bedworth and North Warwickshire ID team have the most clients of all the area teams, with Rugby ID having the fewest. The number of clients decreased from 2011 to 2013 in all area teams apart from Warwick.

Table 2. Number of IDS Social Care Clients with LD by IDS Social Care Team



IDS Complex Needs Team

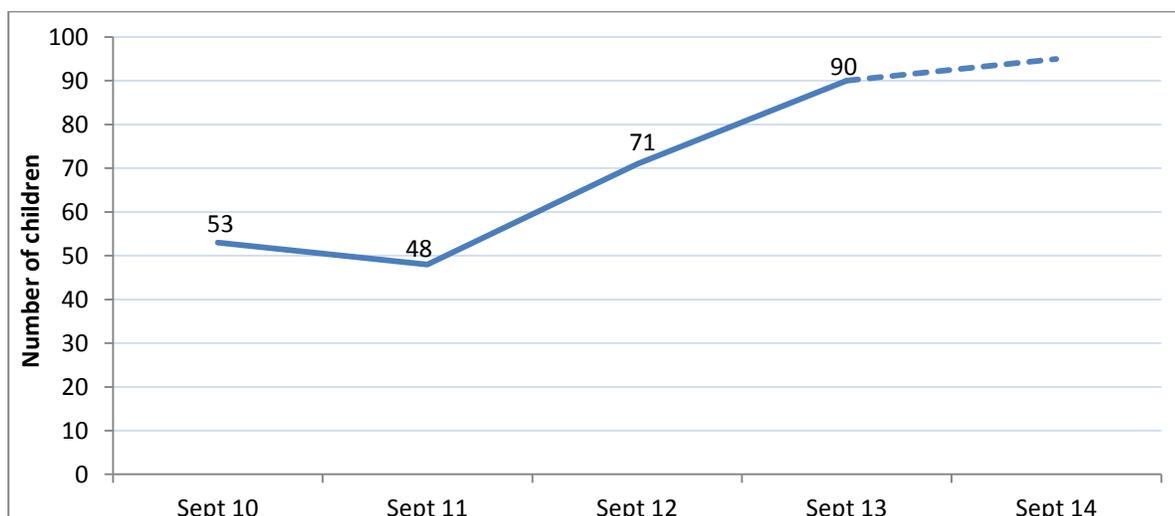
The complex needs team is a team of specialist teachers who provide support to primary aged children (5 to 11 years) in Mainstream schools across Warwickshire with severe and complex learning needs. All children are visited at least fortnightly in school, with advice provided on appropriate curriculum modification, teaching programmes, behaviour support, assessment & moderation and inclusion.

The team's caseload is currently 86 children (as of March 2014), which is expected to rise to 95 children by September 2014. However, the number of children can be quite fluid as new

referrals are received through the year and children leave Mainstream education to attend a special school or move out of county.

Table 1 shows a snapshot of the number of children being supported by the complex needs team by year. The dashed line in 2014 represents the predicted number of children for September 2014.

Table 1. Snapshot of the caseload of the complex needs team by year



The number of children supported by the complex needs team has increased since 2011 due to the number of older children being referred over the course of the school year and also because of the net gain of Reception children joining and Year 6 children leaving. It is predicated that it will be at least another three years until the numbers in the older age groups are similar to the younger age groups.

The team supports more boys than girls (65% vs 35%), with 75% of children in school Year 3 and under (including reception). 86% of children are in the correct school year for their age. Academic progress is tracked by a statistical programme which enables the team to monitor whether children are on track to make and sustain expected progress. In 2012/13, 80% of children fell within the expected threshold for progress, 3% exceeded expectation and 17% fell below the expected threshold. However this does not take into account progress in behaviour, self-esteem, participation, social interaction or independence.

The majority of children under the care of the complex needs team leave the service being able to handwrite at a basic level and being functionally literate (reading age of approximately 8 years). Some children require specialist seating in class but the majority don't, and some still require hygiene changing facilities but most are toilet trained. Some children still require

Augmentative and Alternative Communication (AAC) although the majority are verbal and understandable.

IDS 0-5 Teaching and Learning Service

The IDS 0-5 Teaching and Learning Service has statutory responsibilities to carry out continual, coordinated assessment of children from birth (adopting the Team Around the Child process as described in the Common Assessment Framework), contribute to Integrated Health and Educational Reviews for children aged 24-36 months and liaise with Health and Continuing Care colleagues in order to ensure the safe and effective placement of children with severe and complex needs. Whilst the service is not specifically designed to solely meet the needs of children with learning disabilities, many of these children and their families will benefit from the Service.

The Service undertakes assessments for all children under 5 in maintained and non-maintained settings, referring to Educational Psychology and liaising closely in relation to Statutory Assessment Advice prior to school entry.

As stated in the SEN Code of Practice (2001) and the Early Support framework, the Specialist 0-5 Team often support parents of children with learning disabilities and other professionals; to ensure that assessments, records and programmes of intervention are effective, relevant and coordinated (especially in preparation for multi-disciplinary and statutory assessment processes).

2.4 EDUCATION

Children who have learning difficulties or disabilities are identified at school as either having a statement of special educational need (SEN) or are identified under School Action Plus.

Needs are categorised under a number of primary and secondary headings, only some of which are relevant to learning disabilities. Each year the entire school population across England (excluding public schools) is captured in a school census and this identifies a number of characteristics of pupils including their special educational needs.

Since summer 2013, the age at which young people can leave full time education has increased, requiring pupils to continue in education or training until the end of the academic year in which they turn 17 years of age, increasing to 18 years of age in 2015⁶⁸.

Children with a recognised learning disability are categorised by their level of need ranging from a moderate learning disability (MLD), severe learning disability (SLD) then finally profound and multiple learning disability (PMLD). The higher the level of need, the more likely it is that a child will need to be educated in an establishment which has been specifically designed, staffed and resourced to provide appropriate special education for children with additional needs, i.e. a special school.

In 2014, there were 2,878 children recorded as having special education needs relating to a learning disability. Of these, 76.4% are recorded as having MLD, 20.2% are recorded as having SLD and 3.3% are recorded as having PMLD. 84% of children with PMLD attended a special school, whereas 86% of children with MLD attend a mainstream school.

Figure 1. Pupils with a SEN category of learning disability by year, type of school & level of need

| | 2011 | 2012 | 2013 | 2014 |
|--------------------|--------------|--------------|--------------|--------------|
| Mainstream | 2,120 | 2,092 | 2,133 | 2,013 |
| MLD | 1996 | 1956 | 2003 | 1889 |
| SLD | 108 | 120 | 120 | 109 |
| PMLD | 16 | 16 | 10 | 15 |
| Special | 807 | 783 | 786 | 865 |
| MLD | 378 | 341 | 308 | 311 |
| SLD | 361 | 369 | 400 | 473 |
| PMLD | 68 | 73 | 78 | 81 |
| Grand Total | 2,927 | 2,875 | 2,919 | 2,878 |

⁶⁸ The Education and Skills Act 2008 (Part 1)

The number of children attending a special school has risen over the past three years, due in part to the increase of children with a SEN need of SLD or PMLD. The number of children with SLD has risen by 24% since 2011, from 469 pupils in 2011 to 582 pupils in 2014, whilst the number of pupils with PMLD has risen by 14% since 2011, from 84 children in 2011 to 96 children in 2014. The number of children with MLD has fluctuated year on year but the number of pupils with MLD is lower in 2014 than it was in 2011.

Figure 2. Pupils with a SEN category of learning disability attending a mainstream school by year & level of need

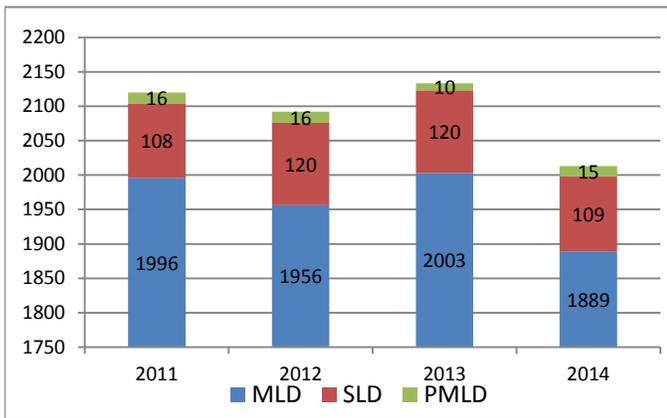
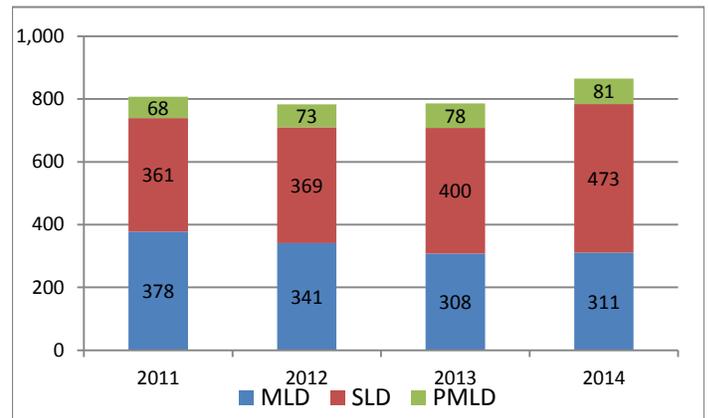
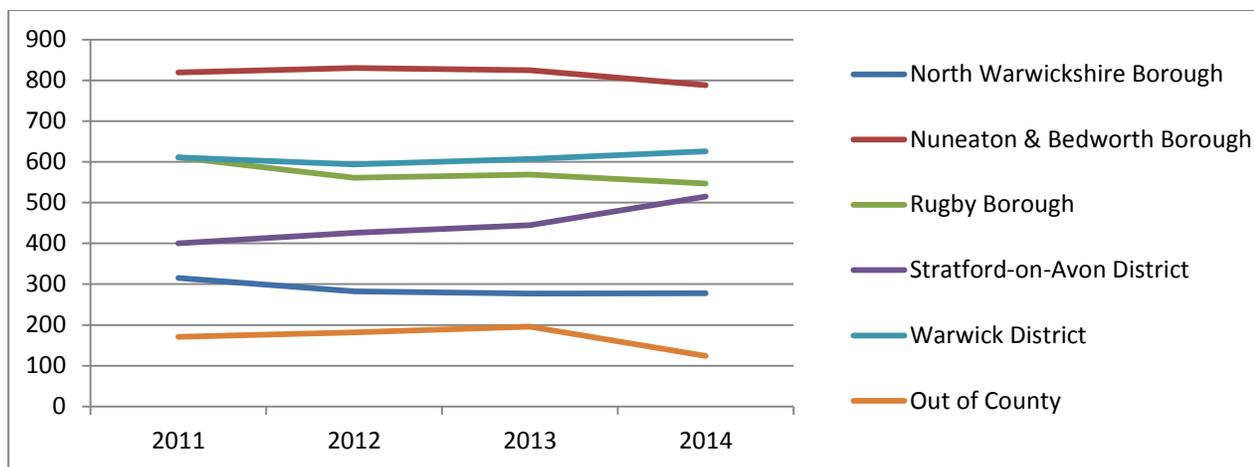


Figure 3. Pupils with a SEN category of learning disability attending a special school by year & level of need



Nuneaton and Bedworth historically has the highest number of children in the county with a category of SEN relating to a learning disability, although the number has decreased over the past two years. The number of children with a learning disability in the south of the county has increased since 2012, with the number of children attending schools in Warwickshire but who live out of county decreasing.

Figure 4. Pupils with a SEN category of learning disability by year & district/borough of residence



The table below shows the total number of pupils with either a primary or secondary special educational need relating to learning disabilities who attend either a state funded primary/secondary school or a special school by year and age group. This figure does not include children who attend independent schools. The total number of pupils has remained constant over the past few years but the number of pupils in older year groups are increasing as awareness regarding SEN is raised.

Figure 2. Pupils with a SEN category of learning disability by year and age

| | 2011 | 2012 | 2013 | 2014 |
|---------------------|--------------|--------------|--------------|--------------|
| Males | 1916 | 1884 | 1897 | 1946 |
| 2-4 years | 53 | 59 | 74 | 68 |
| 5-10 years | 1003 | 968 | 964 | 974 |
| 11-17 years | 857 | 819 | 814 | 862 |
| 18+ years | 35 | 38 | 45 | 42 |
| Females | 913 | 925 | 975 | 927 |
| 2-4 years | 23 | 24 | 28 | 23 |
| 5-10 years | 470 | 477 | 504 | 459 |
| 11-17 years | 401 | 404 | 427 | 420 |
| 18+ years | 19 | 20 | 16 | 25 |
| Total Pupils | 2,861 | 2,809 | 2,872 | 2,873 |

In 2014, 86.5% of pupils with a SEN category relating to a learning disability were White British. Just over 2% did not have their ethnicity recorded. Only 7.7% of pupils were from black or minority ethnic groups (excluding white, non-British ethnicities).

Figure 3. Pupils with a SEN category of learning disability by ethnicity and year

| | 2011 | 2012 | 2013 | 2014 |
|-----------------------------|--------------|--------------|--------------|--------------|
| White | 2,579 | 2,525 | 2,592 | 2,590 |
| White - British | 2,469 | 2,413 | 2,481 | 2,484 |
| White - Irish | 9 | 10 | 9 | 10 |
| Traveller of Irish Heritage | 7 | 10 | 15 | 8 |
| Gypsy / Roma | 29 | 28 | 19 | 19 |
| Any Other White Background | 65 | 64 | 68 | 69 |
| Mixed | 95 | 104 | 98 | 100 |
| White and Black Caribbean | 29 | 34 | 35 | 39 |
| White and Black African | 6 | 8 | 9 | 8 |
| White and Asian | 21 | 23 | 16 | 15 |
| Any Other Mixed Background | 39 | 39 | 38 | 38 |
| Asian | 93 | 97 | 106 | 83 |
| Bangladeshi | 4 | 2 | 0 | 0 |
| Indian | 63 | 58 | 65 | 55 |
| Pakistani | 11 | 13 | 11 | 7 |
| Any Other Asian Background | 15 | 24 | 30 | 21 |
| Black | 24 | 27 | 22 | 25 |
| Black Caribbean | 7 | 8 | 11 | 12 |
| Black - African | 8 | 10 | 5 | 6 |
| Any Other Black Background | 9 | 9 | 6 | 7 |
| Chinese | 1 | 1 | 2 | 2 |

| | | | | |
|-------------------------------------|--------------|--------------|--------------|--------------|
| Information Not Yet Obtained | 27 | 22 | 22 | 39 |
| Refused | 29 | 23 | 19 | 22 |
| Any Other Ethnic Group | 13 | 10 | 11 | 12 |
| All pupils | 2,861 | 2,809 | 2,872 | 2,873 |

2.4.1 FURTHER EDUCATION

According to a recent longitudinal study by Ofsted into progression post-16 for young adults with a learning disability, too few young learners with LD were found to progress from school to complete programmes of learning in post-16 settings. The Government Green Paper, 'Support and aspiration: A new approach to special education needs and disability' published in 2011 estimated that 30% of young people who had a statement of special educational need (SEN) when they were in Year 11, and 22% of young people with a declared disability, were not in any form of education, employment or training when they reached age 18 in 2009 compared with 13% of their peers.

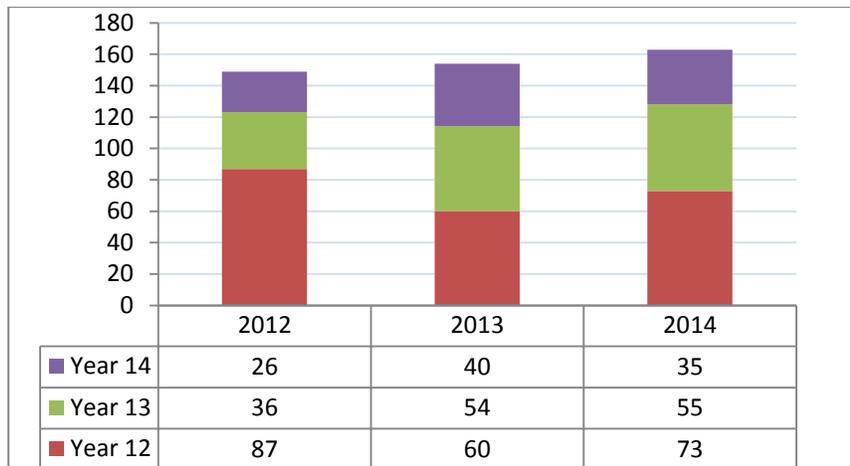
The options for young adults with learning disabilities when they leave compulsory education post 16 should be the same for all school leavers. These options are staying at school, continue with education or training at a college, with a training provider or in the workplace. Every child with a SEN enrolled in a grant-maintained school should have a Transition Plan drawn up for them in Year 9 which helps to plan for their future after leaving school.

Tables published by the Department for Education in March 2014 show that 82.4% of pupils aged 16-17 in Warwickshire with a learning disability or difficulty are recorded as participating in education or training compared to 91.2% of pupils aged 16-17 in Warwickshire without a learning disability or difficulty. The percentage of pupils in education or training with a learning disability or difficulty in Warwickshire is lower than the England average of 86.0%.

Post-16 Sixth-form School

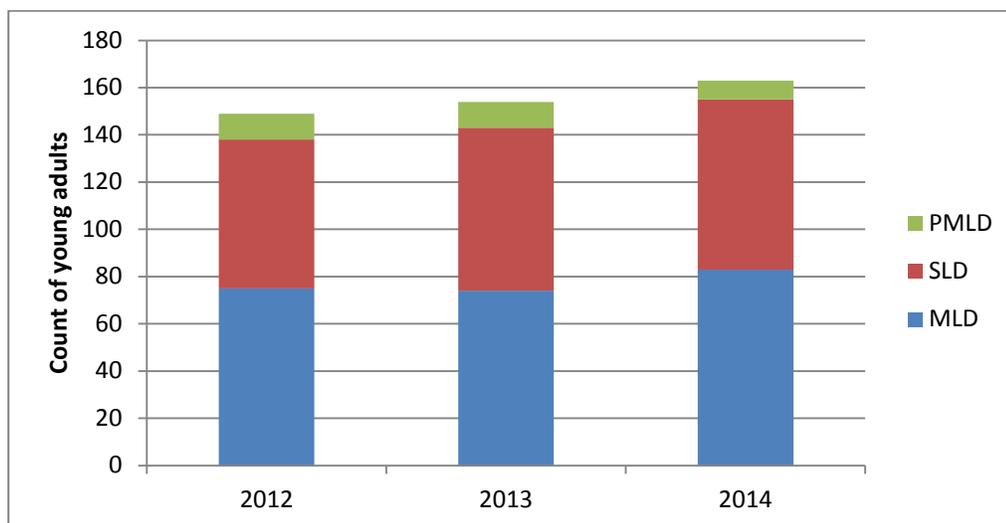
The number of young adults with a learning disability who were enrolled in post-16 education in a Warwickshire grant-maintained school or academy according to the Spring School Census is shown in Table 1. Each year is broken down into the numbers learners in each school year group. Numbers have risen each year with a 9.4% increase in the number of learners from 2012 (n=149) to 2014 (n=163).

Figure 1. Young adults in post-16 education by year and year group



The number of young-adults with a learning disability in post-16 education decreases as their level of need increases. The proportion of learners within each level of need has remained relatively unchanged for the past three years (2012-2014). On average, 50% of learners are recorded as having a moderate learning disability (MLD), 44% of learners are recorded as having a severe learning disability (SLD) and 6% of learners are recorded as having a profound or multiple learning disability (PMLD).

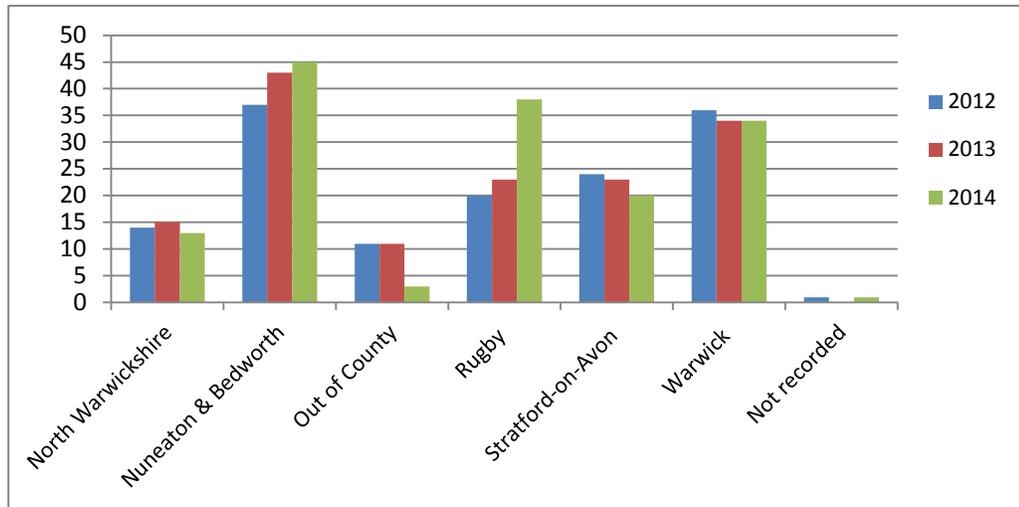
Figure 2. Young adults in post-16 education by year and level of need



The ratio of males and females is on average 2:1, although the rise in numbers of learners over the three years can be attributed to females rather than males (25% vs 2% increase).

In 2014, 95% of all young adults in post-16 education with LD were in a special school with the remaining 5% in mainstream education. Figure 3 shows young adults in post-16 education with LD registered in a special school by the district in which they reside. 38% of those who attend a special school live in the north of the county (Nuneaton and Bedworth and North Warwickshire districts), with only 2% living out of county.

Figure 3. Young adults in post-16 education in a Warwickshire grant-maintained special school by district pupil resides in and year



From 2012 to 2014, numbers of young adults who reside in three districts (North Warwickshire, Stratford upon Avon and Warwick) have fallen along with those living out of county, and risen in two districts (Nuneaton and Bedworth and Rugby). The recording of pupil's home address is good, with only 1 pupil not recorded in 2014, 0 in 2013 and 1 in 2012.

83% of pupils were recorded as being of White ethnicity, with 80% recorded as White British. Pupils from other ethnic background constituted only 12%, with the remaining 5% not yet recorded or they refused.

Further Education Colleges and Training Providers

Further education colleges offer a greater range of opportunities for young adults with learning disabilities. For example Warwickshire College runs five, full time courses specifically

for young adults aged 16-24 years with a learning disability who want to continue to gain skills and develop confidence so that they can become more independent in the future⁶⁹. Courses include subjects such as Countryside skills and Catering and are full time programmes run over two years.

The table below shows the number of learners with a learning disability who reside in Warwickshire and studied at a further education college or attended training at a registered training provider by year. Unfortunately this data is no longer available from the Education Funding Agency due to pressure on content for their releases and therefore is no longer included in their institution reports from 2012/13 onwards.

Figure 4. Learners aged 16-19 in Warwickshire with a registered learning disability by training provider/FE college by year

| | 2009/10 | 2010/11 | 2011/12 |
|---------------------------------------|------------|------------|------------|
| Further Education Colleges | 429 | 375 | 377 |
| King Edward VI College | 1 | 0 | 0 |
| North Warwickshire & Hinckley College | 311 | 270 | 280 |
| Stratford Upon Avon College | 15 | 18 | 11 |
| Warwickshire College | 102 | 87 | 86 |
| Training Providers | 69 | 79 | 65 |
| Arthur Rank Training | 47 | 60 | 32 |
| Heart of England Training | 22 | 17 | 31 |
| Nuneaton Training Centre Ltd | 0 | 2 | 2 |
| Total | 498 | 454 | 442 |

The number of learners aged 16-19 with a registered learning disability in further education or training has decreased from 2009/10 to 2011/12 by over 10%. It is unknown whether this decrease continued in 2012/13 and 2013/14 due to the inaccessibility of the data.

⁶⁹ http://www.warwickshire.ac.uk/courses/subject_areas/supported_learning.aspx?theme=cell

2.5 TRANSITIONS

Transition is the process in which a young person moves through adolescence to adulthood and decisions are made regarding their future. The transition period takes place over a number of years, beginning formerly for children with a statement of special educational need (SEN) at their Year 9 Transition Annual Review aged 14. Transition plans should clearly set out the young person's hopes for the future and should cover all aspects of life and not just which college or service they are moving on to.

For many young people with a learning disability and their families/carers, the transition period from school to adulthood can be a complex and challenging time. The process of transition requires a multi-agency approach and should be flexible and personalised to accommodate the needs and aspirations of each young person.

Warwickshire Transitions

In Warwickshire, there is a strategic group, the Multi-Agency Transition Group, which is represented by services involved with young people in Transition. The group meets bi-monthly to review and develop good practice and procedures around Transition in Warwickshire.

The Integrated Disability Service (IDS) are responsible for passing on information regarding young people approaching adulthood who are likely to require an ongoing service within Adult Services and to plan arrangements for their transfer. For young people who require support from social services, responsibility for this will transfer from children's to adult social services on their 18th birthday and will involve a community care assessment being undertaken before they reach the age of 18 to determine eligibility for services under the Fairer Access to Care Services guidance.

Raising the participation age in education took effect in summer 2013⁷⁰ and increased the minimum age at which young people can leave learning, requiring them to continue in education or training until the end of the academic year in which they turn 17 from 2013 and until their 18th birthday from 2015.

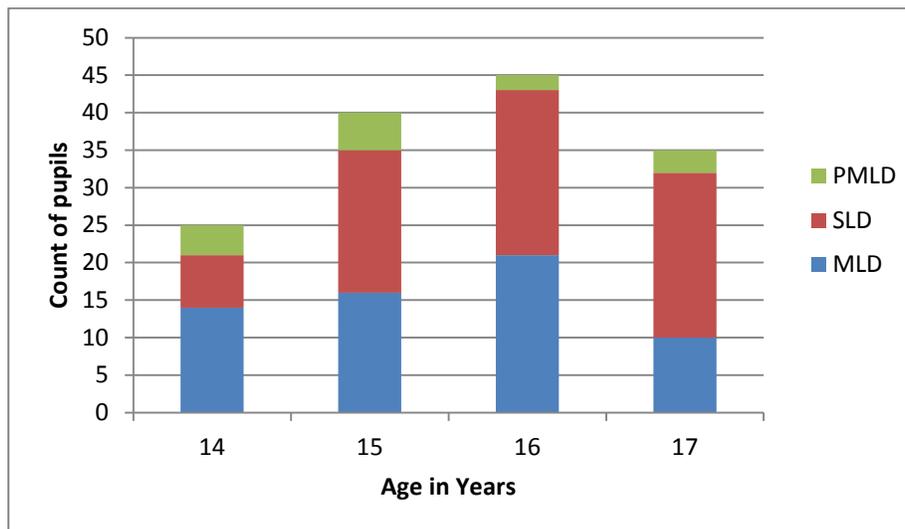
⁷⁰ The Education and Skills Act 2008

For young people between 16 and 25 who are likely to require additional support as part of their future education, the local authority can undertake a Learning Difficulty Assessment to identify the educational and training needs and the learning provision required to meet those needs.

As of March 2014 there were 364 pupils in Warwickshire schools aged between 14 and 17 with an open IDS referral. 35 of these pupils do not attend a Warwickshire school or academy and therefore no data are held on their SEN need. Of the remaining 329 pupils, 145 (44%) have a primary or secondary SEN need of Moderate Learning Difficulty (MLD), Severe Learning Difficulty (SLD) or Profound & Multiple Learning Difficulty (PMLD).

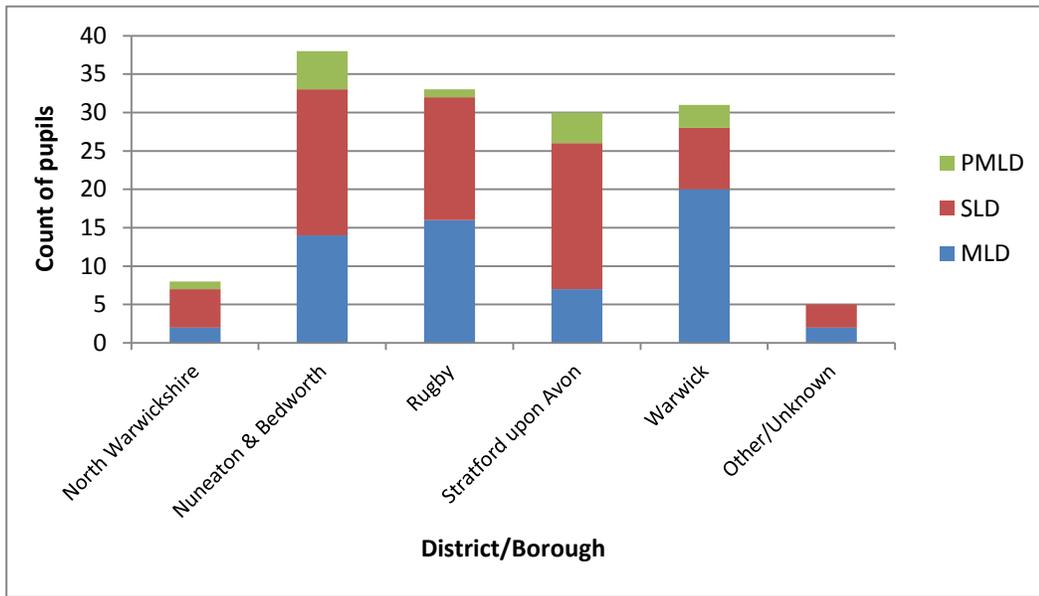
The total number of pupils with an open IDS referral and SEN need of LD increases with age from 25 pupils aged 14 to 45 pupils aged 16 (a percentage increase of 80%). However, this increase is driven by pupils with MLD and SLD as the number of pupils with PMLD drops from 5 pupils aged 15 to 2 aged 16 (although care must be taken when interpreting trends of small numbers). The total number of pupils then decreases again from age 16 to age 17 (35 pupils).

Figure 1. Pupils with an open IDS referral by LD SEN need and Age



The highest total number of pupils with an open IDS referral and SEN need of LD attend a school or academy within Nuneaton and Bedworth whereas the fewest attend a school or academy within North Warwickshire. The second highest total number of pupils attend a school or academy in Rugby but this is where the lowest (ignoring the other/unknown category) number of pupils attend who have a need of PMLD. The highest number of pupils with MLD (65%) attend a school within Warwick.

Figure 2. Pupils with an open IDS referral by LD SEN need and District



2.6 EMPLOYMENT

Employment is an important way that people are included in society, but it remains extremely low among people with learning disabilities. In 2013/14 only 6.8% of adults with learning disabilities in England were reported to be in some form of paid employment. This figure remains static, with a rise of only 0.2% since 2010/11. Those who do have paid employment are likely to work part-time and for low-pay.

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% of people with a learning disability would like to work and that with the right support they make highly valued employees¹.

Valuing Employment Now (2009)¹ set out a strategy focused on enabling people with moderate and severe learning disabilities to have the possibility of working at least 16 hours per week (the point at which most would be better off financially). The paper details the range of issues which need to be tackled for people with learning disabilities to be able to access employment.

Warwickshire Employment Support Team (WEST) is a countywide support service for people with a learning disability who want to find paid work. The specialist team help find people full and part-time employment by providing:

- expertise on disability employment and benefit issues;
- personal profiling and job matching;
- developing the skills people need for employment; and
- ongoing support to employees and employers.

The team have won the 2013 Equal Opportunities Specialist Project Award for utilising E4E European funding to find new ways of engaging with local employers in conjunction with Coventry City Council's equivalent Employment Support Team (TESS). The funding was used to work with a specialist trainer from the British Association of Supported Employment (BASE) who helped the team market the service to local employers and research their employment needs in order to build long-term relationships that lead to sustainable employment for their customers. The project has helped to raise the aspirations of disabled people, challenge discrimination and demonstrate that with the right support they can make a valuable contribution to the community and economy.

Data from WEST shows that the service supported 130 people with learning disabilities in Warwickshire in 2012/13, with a total of 87 people either gaining (32 people) or retaining (55 people) a job.

Data regarding employment for people with learning disabilities is now held on CareFirst. This will allow for much more detailed analysis on employment data in the future. Data from CareFirst shows that in 2013/14, there were 115 people with learning disabilities in some form of paid employment with another 128 carrying out voluntary work.

Figure 1. Employment data from CareFirst, 2013/14

| Employment Type | Number of people |
|--|------------------|
| Paid Employee / Self Employed 0-4 hours pw | 39 |
| Paid Employee / Self Employed 4-16 hours pw | 37 |
| Paid Employee / Self Employed 16-30 hours pw | 34 |
| Paid Employee / Self Employed 30+ hours pw | 5 |
| Unpaid Voluntary Work only | 128 |
| Unemployed | 1177 |
| Total | 1457 |

The table below shows which district/borough in Warwickshire the 115 people in paid employment in 2013/14 live. This is also likely to be where they work. The highest proportion of people with a learning disability in paid employment live in Warwick (36%), followed by Nuneaton and Bedworth (30%). Rugby has the lowest number of people with learning disabilities in paid employment in Warwickshire with just 6/115 (5%).

Figure 2. The district/borough in which people in paid employment with a learning disability reside

| District/Borough | Number of people |
|-----------------------|------------------|
| North Warwickshire | 10 |
| Nuneaton and Bedworth | 34 |
| Rugby | 6 |
| Stratford | 19 |
| Warwick | 41 |
| Out of County | 5 |
| Total | 115 |

Outcome measures from the Adult Social Care Outcomes Framework (ASCOF) relating to employment for people with learning disabilities shows that the proportion of adults with learning disabilities in paid employment in Warwickshire has increased since 2012/13 from 5.8% to 7.3% in 2013/14. Warwickshire currently benchmarks above all its comparators (similar Local Authorities, West Midlands and England).

2.7 DIRECT PAYMENTS

A direct payment is an upfront sum of money that is paid directly to people who have been assessed as needing help from social services and who would like to arrange and pay for their own care and support services instead of receiving them directly from the local trust. Direct payments allow people to have more flexibility and choice in arranging the services they need, who provides them and when they are provided. If a person has capacity they can ask someone to help them with managing their direct payment. This is often a family member or a friend

If a person is deemed to lack capacity to receive their direct payment, a 'suitable person', can take on the full responsibility on their behalf. We cannot make assumptions who can act as a suitable person is and the council must work through a series of steps to help identify who the suitable person can be. The suitable person is accountable for the direct payment and they must be willing to take on this responsibility.

Direct Payments have been offered and available since 1997 and the implementation of them and other forms of self-directed support are part of the delivery of the personalisation agenda. The Care and Support White paper (2012)⁷¹ confirmed the target of 100% of people who access on-going, community based support to be on personal budgets, preferably as direct payments, by April 2013. Self-directed support is also part of the new Adult Social Care Outcomes Framework⁷² and as such provides opportunity for Councils to compare their services with other Councils on outcomes which have been agreed to be of value.

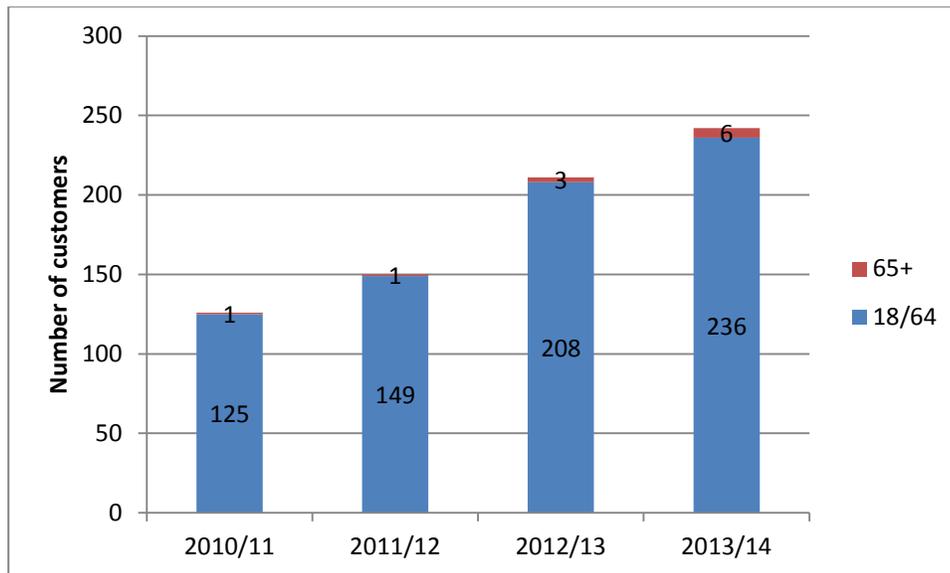
Direct Payments in Warwickshire

In 2013-14, there were 242 people aged 18+ with a learning disability in Warwickshire who received a direct payment (excluding those in residential care), approximately 22% of those known to social services. This is up from 211 people in 2012-13 and 150 people in 2011-12; a 61% increase over 2 years. 97.5% who received a direct payment in 2013-14 were aged between 18 and 64.

⁷¹ HM Government, 2012. Caring for our future: reforming care and support. London: Department of Health

⁷² Department of Health 2012 Transparency in outcomes: a framework for quality in adult social care

Figure 1. People in Warwickshire Aged 18+ with a learning disability receiving a Direct Payment By Age-group and Year



Customers in Warwickshire are supported in the take-up and understanding of Direct Payments, so that they can choose the best care packages for themselves from their own personal budget, according to their own needs. The aim is to ensure customers are supported to learn how to use their payments in more imaginative and cost effective ways, for example: pooling money or resources and using non-traditional type support.

Warwickshire County Council offers a whole host of information relating to direct payments on their website and has produced an easy-read guide to direct payments for customers with a learning disability⁷³.

The Councils Independent Living Team

(Previously the Personal Budget Support / Direct Payment Team)

Warwickshire County Council actively encourage everyone who chooses to receive a Direct Payment to seek advice and support. The Councils internal Independent Living Team act as the first port of call for direct payments advice .The team specialise in the development and improvement of the direct payments scheme on behalf of the Council .

⁷³ <http://www.warwickshire.gov.uk/DPGuidance>

They are the central point of contact for direct payment related queries. They provide advice, information and support to all customers who are considering or are receiving a direct payment. They support with understanding the different ways of using the direct payment, support with understanding the agreement and what it means. assist people with brokering non- employment related support and support with pooling the money. They act as the set up team for processing payments, agreements and other useful documents on behalf of Social Care and Support Operational teams.

The team support customers to link with other direct payment users to learn from their experience by facilitating peer network meetings.

The Council contract with two voluntary sector organisations to provide free advice, guidance and support when people decide direct payments are for them and they to employ a personal assistant.

The Rowan Organisation

The Personal Assistants and Recruitment Support Service in Warwickshire is provided by The Rowan Organisation.

Once people decide that direct payments are right for them. A referral will be made with agreement to The Rowan Organisation

Support for people who will become employers is particularly important when people recruit their own staff. The Rowan Organisation is a user-controlled organisation that offers support and advice to customers in Warwickshire on the recruitment and retention of Personal Assistants and in all aspects of becoming a good employer. They aim to support customers to become independent of the need for ongoing employment related support wherever possible⁷⁴. They also host a Personal Assistant register which can support people to find personal assistants. Once the customer has a personal assistant and they are ready to start working for them. The Rowan Organisation will make a referral to Compass Disability for payroll support .

Payroll and Managed Account are provided by Compass Disability. Compass Disability act as the payroll and managed account service in Warwickshire.

⁷⁴ <http://www.therowan.org/>
<http://www.compassdisability.org.uk/>

Compass are a user led organisation who provide support, advice and guidance about payroll services to direct payment employer's. They take away the complexity and fear of managing payroll and provide guidance on how much to pay personal assistant's etc. If people don't want to receive the money into a bank account or have difficulty with managing the money Compass provide a third party managed account service. The Council will decide with people if a managed account is the best way of supporting them to manage the money and pay for support.

Customer & Professional Perceptions of Direct Payments in Warwickshire

62 references were made to self-directed support as part of qualitative research undertaken in Warwickshire, comprising 10 interviews/focus groups and responses from the service user and professional/carer survey. 18% of the references to direct payments were made by agencies or organisations supporting and advocating for people with learning disabilities.

The service user survey showed that 21% of service users had a direct payment, of whom 29% felt that the direct payment helped them to get the support they needed to live their lives the way they want to.

Comments made by respondents were mixed about the impact of direct payments on the lives of the direct payment holder, carers and other family members, and were largely negative about all aspects of the self-directed support process and the stress and worry associated with direct payments including:-

- Lengthy and delayed process
- Complicated paperwork
- Confusion or uncertainty concerning rules, regulations and policies, information about services and other choices
- Flexibility and service availability
- The experience or fear of reduced services or budget cuts

"We have done a lot of work over the past two years trying to explain direct payments and it is really a hard concept to grasp. I don't think carers have got it yet either - and one of the things that we are encountering, people who do have a direct payment, it's in their bank account, but they don't want to spend it. They think it is theirs - but it should be used to buy services, but it used to be paid for them, but now they have to control it and it's a very difficult concept to move to." (Advocate, North Warwickshire)

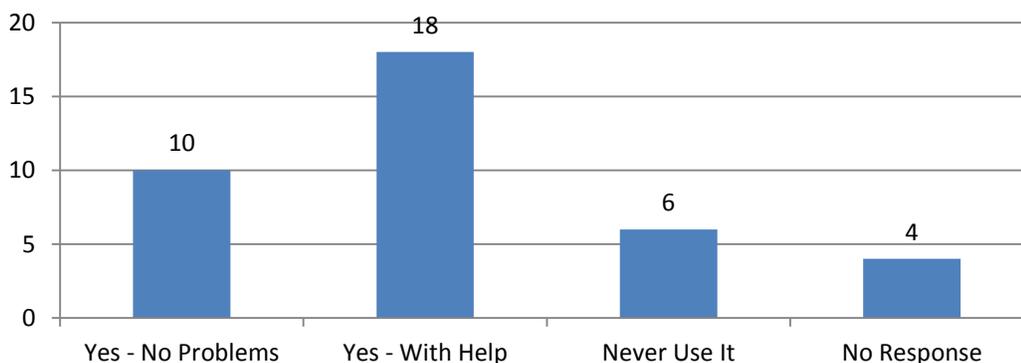
2.8 TRANSPORT

The House of Commons Transport Committee (2013) states that “enabling and encouraging access to transport for disabled people delivers widespread benefits through widening employment opportunities; through access to healthcare and education; and by enabling disabled people to participate more in society”.

Warwickshire County Council offers transport options to people with learning disabilities of all ages, ranging from home to school travel, travel to work/college, access to day care, GP/hospital appointments, socialising etc. However there are limitations in terms of availability, accessibility and cost.

Qualitative research indicated that of those Warwickshire residents who responded to the service user survey question about access to public transport, 82% were able to do so without any problems, or with some support.

Figure 1: Response from service user survey, question 17 - Are you able to access public transport safely?



Source: Service User Survey

However issues relating to transport were also highlighted through qualitative research from interviews, focus groups and surveys. Barriers which prevent people with learning disabilities accessing public transport in Warwickshire include:

- Fear of bullying, or verbal or physical abuse
- Lack of understanding or skills
- Problems navigating the geography
- Lack of support
- Lack of community understanding
- Lack of mobility training, particularly for younger people

- Anxiety/lack of confidence.

2.4.1 TRANSPORT TO SCHOOL FOR PUPILS WITH SEND

Travel assistance is available for pupils with a statement of special educational need aged 19 and under who live in Warwickshire and attend either the nearest qualifying special or maintained school/sixth form as named in their statement*. For those who meet these criteria, travel assistance may be offered in two forms, travel allowance payments or Warwickshire county council transport.

Travel Allowance Payments

Travel assistance is primarily offered in the form of travel allowance payments. Travel allowance payments enable a parent or carer (or the student themselves if over the age of 16) to make their own arrangements to transport the pupil to and from school. They are paid at a rate of 25 pence per mile with the amount paid calculated on the basis of two return journeys per day.

Warwickshire County Council Transport

Transport may be provided to pupils whose parents/carers are unable to make their own school transport arrangements. Transport may be given in the form of a bus pass, train pass or private hire vehicle. This is currently provided free of charge for eligible pupils under the age of 16, however there is a contributory charge of £660 per year for students over the age of 16. Students aged between 19 and 25 who attend a full time course at a college or further education setting may also be eligible for assistance if they agree to pay £660 per year as a flat-rate contribution towards the cost of their transport. Families/individuals in receipt of certain benefits may qualify for a 50% reduced charge.

“Post 16 they have to pay for transport. If they need a bus pass or supported transport there is a cost of £660 which parents have to contribute - but that has been quite hard for some parents - even finding the lower amount if they are on benefits or lower income. Transport to college is possible but parents still need to pay for it.” (Careers Advisor, Warwickshire).

2.4.1 ENGLAND NATIONAL CONCESSIONARY TRAVEL SCHEME

The England National Concessionary Travel Scheme (ENCTS) is a national scheme that enables qualifying individuals to travel free on off-peak local buses throughout England. Eligibility is determined either by age or a qualifying disability, including people with learning disabilities.

Currently the national scheme allows travel from 9.30am Monday to Friday and all day at weekends and on bank holidays. In Warwickshire the scheme also currently allows free travel from 9am on Monday to Friday for Warwickshire residents. Companion passes, which allow a disabled person to travel with a family member/carer are no longer issued in Warwickshire.

“We had one client who completely cancelled his support - his parents could not afford the bus fare - we had supported him for at least 20 years and we were the only real social contact he had - his parents were elderly - he could not go out on his own. So they just cancelled all his support – that’s the most extreme but it has filtered down to different people at different levels.” (Support Worker, South Warwickshire)

2.4.1 PERSONAL INDEPENDENCE PAYMENT – MOBILITY COMPONENT

Personal Independence Payment (PIP) is the new benefit that is replacing Disability Living Allowance (DLA) for people with a disability aged 16 to 64. As with DLA, PIP is the main benefit for people who are disabled and is designed to help with some of the extra costs associated with being disabled. PIP is paid as two separate components, a daily living component and a mobility component.

Motability is a government-funded system that enables disabled people to lease a new car, scooter or electric wheelchair in exchange for their mobility allowance. Currently over 620,000 people use and benefit from the Motability scheme, with 10,040 customers in March 2012 and 11,452 customers in March 2013. Although unfortunately there is no way of knowing how many of these customers are Warwickshire residents.

2.9 DAY OPPORTUNITIES

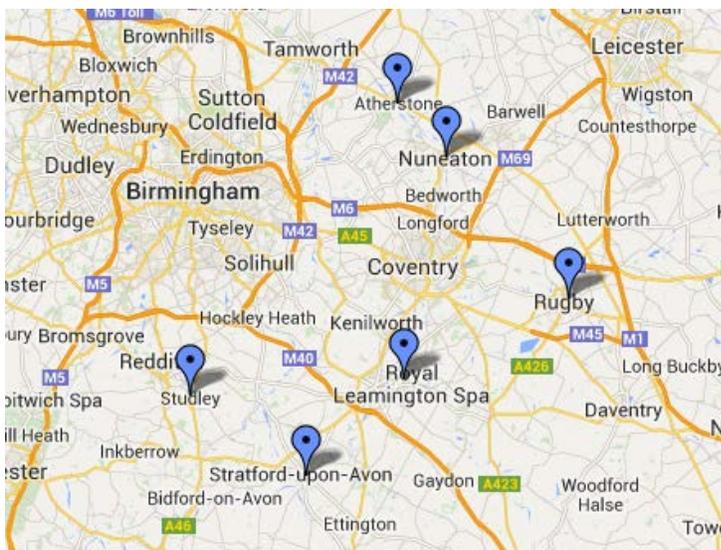
Day opportunities give people with learning disabilities the opportunity to engage in one to one or groups activities of their choice which meet personalised outcomes. Day opportunities promote independent living and supports people with learning disabilities to stay active and independent.

Warwickshire County Council undertook a transformation programme for learning disability day service provision during 2011-12. In June 2012, 6 Community Hubs were commissioned across Warwickshire to provide:

- A local central base for people with learning disabilities and their carers/families to access a range of information and advice, including supporting and signposting people to a range of day opportunities.
- Promoting healthy living and well-being.
- Creating job opportunities within the service for people with a learning disability.
- Facilitating access for the use of mainstream community resources, leisure facilities, colleges, public transport.
- Providing support to enable people to report hate crime and ensure they feel safe in their communities.

The hubs are located across Warwickshire, with at least one hub in each district/borough. The map below shows the location of each hub.

Figure 1. Community Hubs for people with Learning Disabilities, located in Atherstone, Nuneaton, Rugby, Studley, Stratford upon Avon and Leamington Spa



The Community Hub contracts have recently been extended to 2015 to align with the Mental Health Well-being Hubs commissioned with Public Health. These will be jointly reviewed in 2014-15 to inform future commissioning intentions and associated action.

Complex Needs Service

Warwickshire County Council runs four, building-based day support services for people with learning disabilities who have high support needs. These are the Ramsden Day Centre in Nuneaton, the Sesame Centre in Rugby, the Fordsfield Centre in Leamington Spa and Brook Bank in Stratford upon Avon.

As of the 19th February 2014 there were 46 social care customers accessing learning disability day provision through one of the complex needs services. The average age of these customers was 35 and 48% were male (22 customers vs 24 female customers). All customers accessed their day support at the centre which is located within the district or borough in which they live (apart from customers who live in North Warwickshire who attend the Ramsden Centre as there is no service in North Warwickshire). Figure 2 shows the number of customers with an open service package for complex needs support as a snapshot on 19th February 2014.

Figure 2. The number of customers with an open service package at an internal complex needs service unit as of 19th February 2014

| Provider | Number of Customers |
|-----------------------------------|----------------------------|
| RAMSDEN DAY CENTRE, NUNEATON | 20 |
| SESAME CENTRE, RUGBY | 12 |
| BROOKBANK, STRATFORD UPON AVON | 2 |
| FORDSFIELD CENTRE, LEAMINGTON SPA | 12 |

External Day Service Provision

Many learning disability charities and independent organisations offer building based day support for people with learning disabilities. Warwickshire County Council issued 40 such organisations with spot contracts to provide day opportunities for people who wished to spend some of their managed budget to purchase their day care.

Daycare and Direct Payments

With increasing emphasis placed on the personalisation agenda and targets in place for the number of people accessing support through direct payments, more customers are being encouraged to opt for direct payments to commission their own day support in the community. However, due to reporting mechanisms within the council, it is currently not possible to

provide information on what customers are spending their direct payments on. Most community-based direct payments are recorded under the umbrella term of 'Independent Living'. If the majority of customers end up receiving an independent living direct payment via their personal budget it will make market facilitation and outcome focused future commissioning for day care services virtually impossible.

An overview of current day provision

As of 19th February 2014 there were 470 customers recorded as accessing learning disability day provision with 569 open packages on CareFirst. Customers accessing learning disability day provision range from 18 to 85 years of age with an average age of 41.

Figure 3. Age-range of customers

| Age-group | Number of customers |
|--------------|---------------------|
| 18-24 | 77 |
| 25-30 | 49 |
| 30-35 | 44 |
| 35-40 | 52 |
| 40-45 | 56 |
| 45-50 | 59 |
| 50-55 | 52 |
| 55-60 | 58 |
| 65+ | 22 |
| Total | 470 |

Figure 4. Customers by home residence

| District | Customers |
|------------------------------|-----------|
| NORTH WARWICKSHIRE DISTRICT | 69 |
| NUNEATON & BEDWORTH DISTRICT | 171 |
| RUGBY DISTRICT | 90 |
| STRATFORD DISTRICT | 66 |
| WARWICK DISTRICT | 74 |
| Total | 470 |

51% of customers live in the north of the county in the districts of North Warwickshire and Nuneaton and Bedworth, whilst 30% of customers live in the districts of Stratford upon Avon and Warwick, with the remainder (19%) in Rugby.

397 customers (83%) have at least one learning disability day care service package provided by an external provider (470 current service packages). There are 43 external providers delivering one or more day service packages to adults with a learning disability. The average weekly cost of an externally provided service package is £151.90 with a minimum of £5.38/week, a maximum of £881.50 and a median cost of £93.24. The average cost per session per external service package is £49.24.

As of 19th February 2014 there were 93 customers with a learning disability who were not recorded as receiving day care services but who were recorded as receiving a direct payment for independent living and therefore could be spending their money on day provision.

Figure 6. Customers receiving a direct payment for independent living by home residence

| District | Total |
|------------------------------|-------|
| NORTH WARWICKSHIRE DISTRICT | 12 |
| NUNEATON & BEDWORTH DISTRICT | 18 |
| RUGBY DISTRICT | 2 |
| STRATFORD DISTRICT | 34 |
| WARWICK DISTRICT | 27 |

If a proportion of the customers receiving a direct payment for independent living were spending it on day care provision, the total figures for LD day provision would be as shown in figure 6.

Figure 7. Potential total number of customers receiving learning disability day provision including a proportion of customers receiving a direct payment for independent living

| District | Total if 25% | Total if 50% | Total if 75% | Total if 100% |
|------------------------------|--------------|--------------|--------------|---------------|
| NORTH WARWICKSHIRE DISTRICT | 72 | 75 | 78 | 81 |
| NUNEATON & BEDWORTH DISTRICT | 176 | 180 | 185 | 189 |
| RUGBY DISTRICT | 91 | 91 | 92 | 92 |
| STRATFORD DISTRICT | 75 | 83 | 92 | 100 |
| WARWICK DISTRICT | 81 | 88 | 94 | 101 |
| Total | 495 | 517 | 541 | 563 |

2.10 HOUSING

All people with a learning disability should have the opportunity to live in an ordinary street in an ordinary house, just like everybody else. In recent years there has been a movement away from the use of residential care and institutional accommodation for people with learning disabilities towards supported housing services that allow individuals to live more independent

lives. Much of the impetus for this change comes from the increasing emphasis placed on personalisation of services for people with learning disabilities, and more specifically from the 2006 Government white paper, ‘*Our health, our care, our say*’ which outlined plans to close all NHS-run campus accommodation by 2010. The right to independent living is covered in international human rights law. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), ‘*Living independently and being included in the community*’⁷⁵, clearly states that people with a disability have the right to independent living.

Warwickshire offers a range of housing options to people with learning disabilities dependent on their level of need and personal preferences. These options include living in a family home, supported living, Extra care, renting from the Local Authority/private landlord or living with another family (Shared Lives scheme). The table below shows people with a social care package associated with a learning disability in Warwickshire by year and the type of accommodation in which they live. Tenure type recording was introduced in 2012/13 therefore it is not possible to compare data prior to this.

Figure 1. Warwickshire leaning disability customers by tenure type, 2012/13 & 2013/14

| Tenure Type | 2012/13 | 2013/14 | % change |
|---|----------------|----------------|-----------------|
| With family / friends | 353 | 355 | 0.6% |
| Registered Care Home | 250 | 237 | -5.2% |
| Tenant (Local Auth / Housing Assoc) | 206 | 209 | 1.5% |
| Supported accommodation / Lodgings | 118 | 121 | 2.5% |
| Owner occupier / shared ownership | 49 | 45 | -8.2% |
| Tenant (private landlord) | 79 | 85 | 7.6% |
| Registered Nursing Home | 45 | 44 | -2.2% |
| Other temporary accommodation | 4 | 4 | 0.0% |
| Sheltered housing / Extra care | 6 | 10 | 66.7% |
| Residential College | 4 | 5 | 25.0% |
| Acute/Long stay healthcare resident or hospital | 4 | 4 | 0.0% |
| Adult placement scheme | 3 | 3 | 0.0% |
| Placed in temporary accommodation by LA | 2 | 2 | 0.0% |

2013/14 ASCOF measures show that Warwickshire is currently in the bottom 25% of all councils in England for the number of working age learning disability customers who live on their own or with their families (67.4% vs National Average 74.8%). The nature of

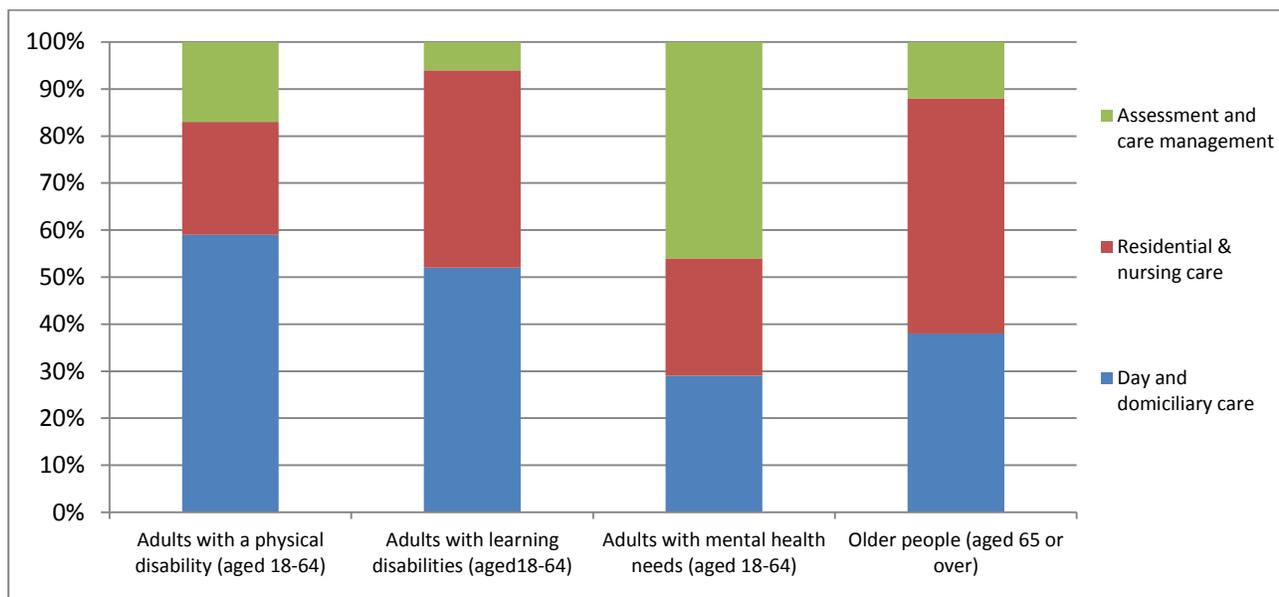
⁷⁵ Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

accommodation for people with a learning disability has a strong impact on their safety, overall quality of life and the risk of social exclusion⁷⁶.

Figure 1 shows that the number of people with learning disabilities living in residential settings has decreased from 2012/13 to 2013/14, whereas the number of people living independently is increasing.

Figure 2 shows the percentage of total gross expenditure in Warwickshire in 2012/13 by client group. 42% of total gross expenditure on adults with learning disabilities is spent on residential and nursing care. Spending on residential and nursing care for adults with learning disabilities is far greater than those with a physical disability or mental health need. This will be due to both the number and the nature of the placements, with high costs associated with residential care packages for people with a learning disability. Spending on residential care has reduced from £19.5 million per annum in 2011/12 to £17.8 million per annum in 2013/14, partly due to the de-registration of some care homes to become supported living settings and also because of Warwickshire County Council’s commitment to cost reduction using a competitive tender process.

Figure 2. Percentage of total gross expenditure in Warwickshire by client group in 2012/13



⁷⁶ Department of Health (2013). The Adult Social Care Outcomes Framework 2013/14. London.

2.4.1 SUPPORTED LIVING

Supported living is where a person with a learning disability is supported to live independently in the community. The principles behind supported living are of choice, control and inclusion.

Supported housing is typically accommodation where an individual has a tenancy agreement with the landlord of their property. Care and support is provided to the individual in their home either by the landlord or by another organisation (s) or through a completely personalised 'bespoke' arrangement.

Supported housing models outlined below require a joined up approach between housing, Social Services and Supporting People functions:

- Shared supported housing
- Extra care schemes – commonly people have their own flat within a wider development of flats for people who need support, sometimes with additional communal space.
- Shared Lives – commonly the person with support needs lives in another person's home and gets support and accommodation from them.
- Community Living networks such as the Keyring model. This works by supporting and networking people in their own homes within a particular area⁷⁷.

Additionally, in each local authority area, people with learning disabilities should have access to low cost home ownership schemes, home ownership on the open market, public sector rented properties and private sector rented properties although often options are non-existent or difficult to access⁷⁸.

Shared supported housing

Shared supported housing is the most common model of supported living in England. It is a good option for those who are 'stepping down' from residential care and who are making the transition to living independently in the community. In line with the personalisation agenda, many care homes are being de-registered and converted into supported housing. In 2013, Warwickshire County Council developed a de-registration team comprising of social care occupational therapists and community support workers who worked with seven providers in

⁷⁷ National Development Team for Inclusion (NDTi) 2010 Supported Living – Making the Move: Developing supported living options for people with learning disabilities.

⁷⁸ National Development Team for Inclusion (NDTi) 2010 Supported Living – Making the Move: Developing supported living options for people with learning disabilities.

the county to help them de-register their residential care homes into supported housing. As part of this project, 20 people with learning disabilities have successfully moved into shared supported housing.

Extracare housing

Extra care housing (also known as sheltered housing, assisted living, or housing with care) offers a new way of supporting people with learning disabilities to live independently in their own self-contained homes, with their own front doors and a legal right to occupy their property⁷⁹. Extra care housing offers a team of carers who are on site and on call 24 hours a day. Residents have more choice and control than traditional residential care can offer, in a safe and secure environment, free from loneliness or isolation.

Richmond Bede in Bedworth provides 10 extra care units specifically to people with a learning disability, within a village environment housing people with other disabilities and a care home for the frail/elderly. Rosedale in Stratford district is a new development of 10 x 1-bedroom affordable extra care flats for people with learning disabilities which opened in June 2014

In June 2014, Warwickshire opened the first of two extra care schemes suitable for adults with a learning disability which have been developed on Warwickshire County Council land by Creative Support, a non-profit organisation. Murray House in Stratford upon Avon district has 9 x 1-bedroom flats available to rent. The second scheme, due to be opened later in 2014 in Warwick district, is a former LD residential care home which has been re-developed into 15 x 1-bedroom flats available for rent.

Several other extra care facilities are going through planning or currently out to tender. This will potentially provide another 66 extra care units across 6 sites in the county, although it is unclear at this stage how many of these units will be utilised by people with a learning disability.

2.4.1 HOUSING RELATED SUPPORT

Housing Related Support (HRS) services are delivered across the county and funded primarily through Warwickshire County Council funding. Services are either specialist, i.e.

⁷⁹ www.warwickshire.gov.uk/extracare

they are designed to support the needs of a specific primary client group, or they are non-specialist services (generic).

Services generally are offered:

- To persons over the age of 16 years
- As either accommodation based (where the person moves into specific accommodation to receive support) or floating support (where the person can receive support in their own home)
- For up to 2 years (for short term services) or long term (on a permanent basis, e.g. some LD or Older People services).
- Irrespective of property tenure (can be available to home owners as well as those in rented accommodation)
- To offer support to gain or maintain appropriate accommodation; improve independent living skills (including opportunities for employment); prevent homelessness.
- Support to move on from supported accommodation to independent tenancy

WCC currently (as at July 2013) funds 25 services run by 14 different organisations specifically for people with a learning disability.

Service users can access these services through a number of routes, including self-referral. You do not need to be FACS eligible to use housing related support services and you do not need to be referred by a social worker. However, for the majority of the services listed below, customers will have been referred by adult social care (although they may not necessarily be FACS eligible); or by their families in conjunction with ASC.

The maximum number of units that can be supported by these services is 207. All of these services are offered on a block gross basis, which means that the service provider manages the in-out flow of customers within eligibility criteria. WCC does not currently record information at a customer level.

In January 2013, to support a learning disability review exercise, customer information was provided by service providers. This was matched to information in Care First to determine the number of customers who were receiving HRS alongside social care services. This information (alongside current PI workbooks) confirms that all services are operating at capacity and that currently, 207 service users are being supported.

This information indicated that:

- 58 of the 207 customers did not receive any adult social care support. This means that 72% of service users currently using HRS services for LD are also in receipt of ASC services.
- Average level of HRS per unit is 11.63 hours per week.
- There is an assumption that HRS hours are being used to 'back-fill' ASC assessed need. However, this cannot be confirmed without individual customer reviews/assessments that include HRS. This is currently being discussed with operational teams.

2.11 ASSISTIVE TECHNOLOGY

Assistive technology is any piece of equipment, software or system that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities, giving them independence and a sense of control.

Telecare is an assistive technology service whereby a series of equipment and detectors are used to monitor a customer's home, care needs and lifestyle changes and to raise an alarm, via a control centre or family member's phone, if something is wrong⁸⁰. The service facilitates and enables customers to maintain their independence and quality of life whilst giving peace of mind to family and loved ones concerned for their welfare.

Types of assistive technology include personal alarms, bogus caller buttons (which a person can press if there is a stranger trying to gain access to their property), light sensors (a cheap, unobtrusive solution to prevent night falls), smoke and carbon monoxide alarms, movement detectors and flood detectors.

A study by Aspinall⁸¹ in 2008 followed a group of people with learning disabilities living in supported housing with a variety of forms of telecare implemented, which found that residents were more able to achieve more for themselves with reduced input from staff, such as independently travel with the use of a mobile phone and GPS trackers.

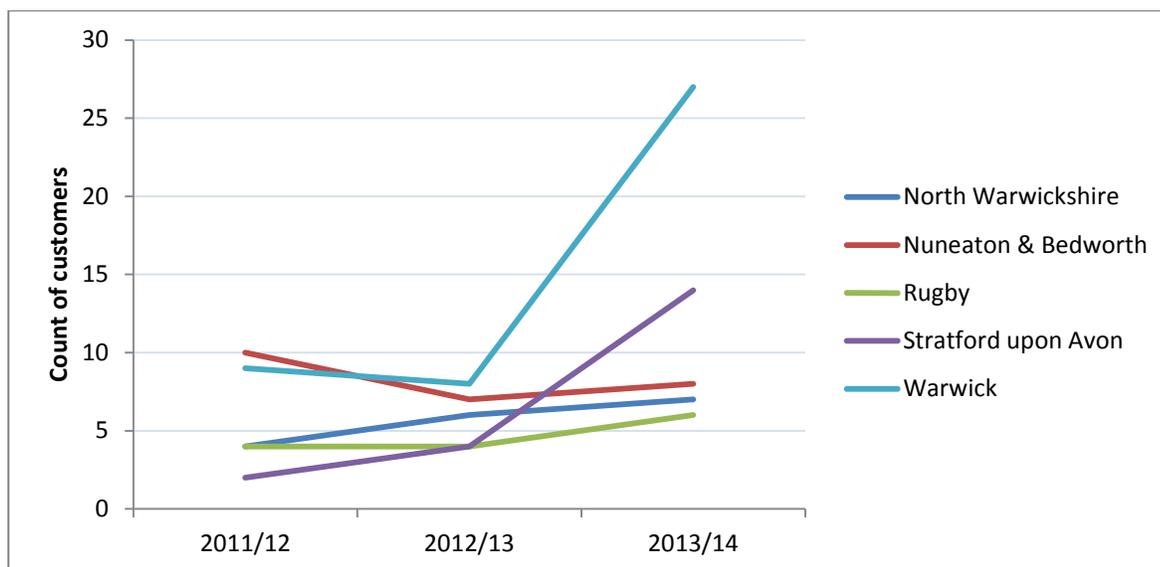
⁸⁰ Warwickshire Direct (2013). *Telecare*. Available: <http://www.warwickshire.gov.uk/telecare>. Accessed 3rd April 2014.

⁸¹ Aspinall A (2008) Resources to support adults with learning disabilities who use assistive technology: outputs of the TATE Project. *Journal of Assistive Technologies*, 2(2), pp52–55

Assistive technology in Warwickshire

The uptake of assistive technology among people with LD in Warwickshire is low, with only 80 customers recorded on Care First from April 2011 until March 2014. However, there is limited awareness of the benefits of assistive technology amongst the population of potential users in the county. Attempts to raise awareness have successfully increased the uptake of assistive technology, with nearly half (49%) of the total number of users beginning their assistive technology package in 2013/14 and higher figures projected for 2014/15. Assistive technology is more popular in the south of the county, with 61% of assistive technology users living in Warwick and Stratford upon Avon. Table 1 shows the number of assistive technology users in Warwickshire by district and year.

Figure 1. Assistive technology users in Warwickshire by district and year



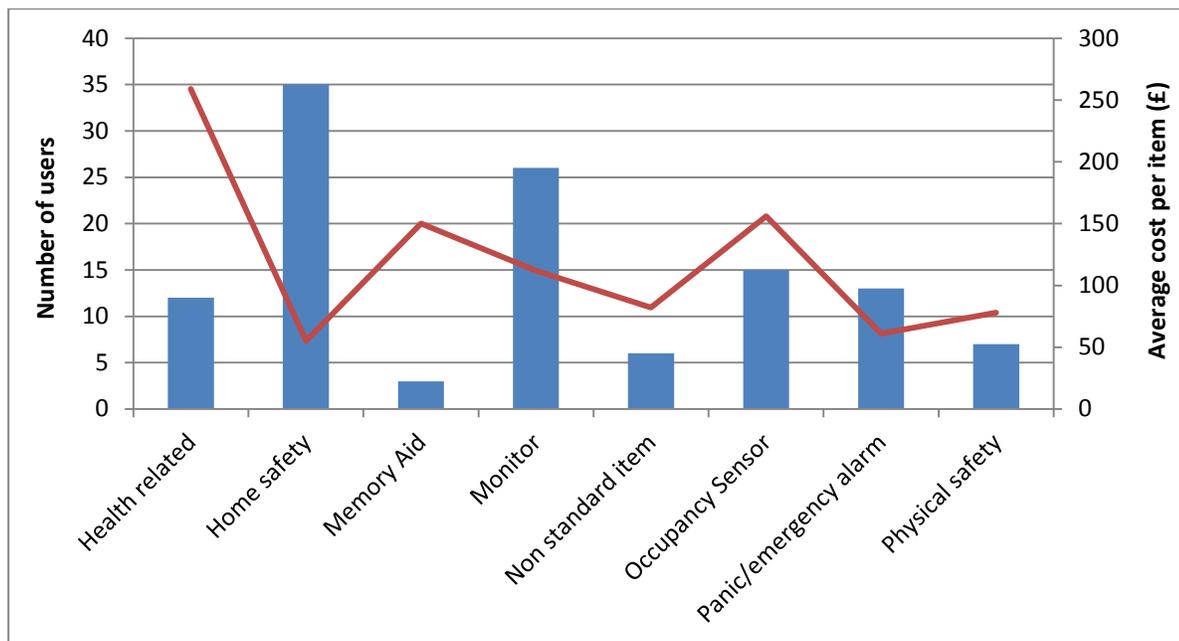
The maximum charge to the customer for a telecare service (excluding equipment) is £4.87 per week. The charge to Warwickshire County Council depends on the district in Warwickshire in which a customer resides, ranging from £3.57 for customers in Warwick District to £14.70 in Stratford District.

Assistive technology costs range from £2.20 for bath/basin plugs to prevent overflowing, to £280 for epilepsy sensors which can detect epileptic seizures whilst a person is in bed. 11/80 (14%) of assistive technology customers with LD in Warwickshire have epilepsy sensors. It is known that the frequency of epilepsy occurring in people with a learning disability is higher

than that of the general population and the frequency increases with the level of severity of the disability. Approximately 30% of people with a learning disability also have some form of epilepsy, rising to 50% of those with a severe learning disability.

Table 2 shows the number of users of assistive technology categorised by the type of need. The categories are as follows: Health related: equipment for monitoring health conditions such as epilepsy sensors and enuresis; Home safety: including smoke alarms, CO detectors, bath plugs and temperature sensors to keep a customer safe in their home environment; Memory aids: such as memo minders and pill dispensers for customers who need reminders to carry out important regular tasks; Monitors: which record activity from sensors and detectors; Occupancy sensors: including sensors to check if a customer is in or out of their bed or a chair and pressure mats to record whether a customer leaves their house; Panic/emergency alarms: which a customer can use if they feel threatened or have injured themselves; Physical safety: such as fall detectors and Non-standard items: which have been allocated to a customer based on individual need and are not on the standard assistive technology list.

Figure 2. Number of users of assistive technology by type of need



35/80 (44%) of assistive technology customers have one or more pieces of home safety equipment. Memory aids and physical safety equipment are used least frequently with only 3

(4%) and 7 (9%) users respectively. However on average these types of equipment are more expensive than home safety items and therefore may not offer as good value.

2.12 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*', published in 2008.

According to a report by the Department of Health⁸² the provision of unpaid care and support to family members or friends is a major contributing activity to the health and welfare of our society. The report stated that the contribution that carers make is often forgotten and taken for granted and that many are left feeling isolated in their caring role.

"Most of my friends have drifted away as my family life has been so challenging. My family live away. We are isolated in our community." (Respondent, Professional/Carer Survey)

According to the 2011 National Census there are over half a million (545,474) unpaid carers in Warwickshire, of which a proportion of these will be looking after someone with a learning disability, many of whom will not be receiving any type of support.

The Care Act 2014⁸³ reinforces adult carers' right to an assessment; this includes the same rights for young adult carers aged 18 – 24 years old. It also clarifies the local authority's responsibility for carers who are under 18 years old during transition to adulthood. The Care Act 2014 stipulates that support should be provided by Adult Social Care to ensure no young carer is relied upon to provide an inappropriate level of care to an adult.

The number of carers to adults over the age of 18 with learning disabilities in Warwickshire who were assessed and their assessment recorded on CareFirst in 2013/14 was 415. Of which, 183 (44%) are aged between 18 and 64, 106 (26%) are aged between 65 and 74, and 126 (30%) are aged over 75. This has decreased from 439 in 2012/13, a 5% decrease.

⁸² Department of Health (2010) *Carers and Personalisation: Improving Outcomes*. Department of Health, London

⁸³ HM Government (2014) Care Act Part 1. Available at: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm>

The number of carers that received a service as an outcome of a review or carer assessment in 2013/14 was 155. Carers for adults aged between 18 and 64 with a learning disability were most likely to receive services themselves, with virtually all of these services relating to respite breaks.

No carers under the age of 18 were recorded as being assessed for their own needs on CareFirst in 2013/14. However, this does not mean that there are no young carers for people with learning disabilities in Warwickshire, just that this information is not currently recorded.

From April 2015 the Children and Families Act 2014⁸⁴ will give young carers the right to an assessment of their needs for support. The new legislation will affect all services working with an adult or a child who is cared for by a young carer.

The table below shows the total number of unpaid carers under the age of 24 in Warwickshire as at census day, 27 March 2011. A proportion of these people will be caring for someone with a learning disability.

Figure 1. Provision of unpaid care in Warwickshire by persons aged 0 – 24

| Carers | North Warwickshire | Nuneaton & Bedworth | Rugby | Stratford upon Avon | Warwick |
|--|--------------------|---------------------|------------|---------------------|------------|
| Provides 1 to 19 hours unpaid care a week | 332 | 756 | 507 | 514 | 652 |
| Provides 20 to 49 hours unpaid care a week | 45 | 147 | 102 | 62 | 79 |
| Provides 50 or more hours unpaid care a week | 58 | 135 | 68 | 63 | 69 |
| Provides unpaid care: Total | 435 | 1,038 | 677 | 639 | 800 |

6.1.1 LEARNING DISABILITY RESPITE SERVICES IN WARWICKSHIRE

Respite is a service which provides a range of short term, planned breaks for adults with a learning disability. Respite can be residential, domiciliary or activity based.

Warwickshire County Council has recently tendered for a framework of support providers to offer short breaks to children, young people and adults with a learning and or physical disability across the county. Contracts are being awarded to a number of providers promoting greater variety, choice and flexibility for disabled people in Warwickshire. Customers, parents and carers will have the ability to mix and match their short breaks in line with their individual needs, circumstances and preferences, maximising their personal budget allocation.

⁸⁴ HM Government (2014) Children and Families Act 14 Part 5. Available at: <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

Residential Short Breaks Services for Adults with a Disability

8 support providers are being offered a contract to deliver residential short breaks to disabled adults with provision in each district in the county. Some providers are offering the opportunity for young people in transition age 16 – 17 years old to access support. The provision located in Warwick district includes a retained bed to deliver short breaks in an emergency.

While they have been awarded a contract we will be working with 2 of the 8 providers during 2014 to support them to become active providers of residential short breaks locally.

Overnight Community Short Break Services for Children, Young People and Adults with a Disability

14 support providers are being offered a contract to deliver overnight community short break services for disabled children, young people and adults in the county. As a new service offer this will allow children, young people and adults the opportunity to consider alternative ways of meeting their needs as opposed to residential short breaks. The short break services providers are offering can be experienced on an individual or group, planned or emergency basis: activity holidays with people with similar needs and interests, activity and new learning experiences and a wide range of supported sports, social, horticultural and leisure opportunities. Some customer may choose to have their short break at home whilst the family are away.

While they have been awarded a contract we will be working with 5 of the 14 providers during 2014 to support them to become active providers of overnight community short breaks for disabled people in Warwickshire.

Community Short Breaks for Children, Young People and Adults with a Disability

19 support providers are being offered a contract to deliver community short break services for disabled children, young people and adults across the county during the daytime. The new framework will provide increased choice and control to parent carers. As with lot 2 the short break services providers are offering can be experienced on an individual or group, planned or emergency basis and include activities and opportunities to learn new things as well as a wide range of supported sports, social, horticultural and leisure opportunities. These can be whole day opportunities or for specific days and times that suit individual needs and meet personal outcomes whilst providing a break for carers.

While they have been awarded a contract we will be working with 7 of the 19 providers during 2014 to support them to become active providers of community short breaks for disabled people in Warwickshire.

Residential Short Breaks Services for Children with a Disability

1 support provider is being awarded a contract to deliver residential short breaks for children and young people with a disability in Warwickshire. The provision located in Warwick district will offer support to children and young people on a planned and emergency basis where possible.

6.1.2 CARER SUPPORT SERVICES IN WARWICKSHIRE

Carer support services in Warwickshire are available through Guideposts Trust, a charity whose main aim is to help all people lead independent, fulfilling lives. Guideposts Trust offers a range of different services to those who care for somebody with a learning disability in Warwickshire. The Guideposts carer support service operates from offices based in Nuneaton and Leamington Spa which are open 52 weeks of the year during normal office hours but with home visits and training offered out of hours to accommodate working carers.

Specialist information and advice

Guideposts provides up to date knowledge and information so as to meet the needs of carers on an individual basis and aid their caring role. This includes advice for working carers, legal and financial entitlements, health and social care arrangements etc. Carer support workers are working in partnership with Warwickshire Mobile Library service so that advice can be sought by carers in remote areas of the county and those from hard to reach communities.

Carer Support Groups

There are a number of peer-led carer support groups specifically for those who care for someone with a learning disability in Warwickshire. The groups give carers an opportunity to meet and support each other in an informal setting to reduce isolation and share their experiences with one another.

Learning Disabilities Specialist Support Worker

Guideposts employs a learning disability specialist support worker who provides one to one support to carers who look after an adult with learning disabilities, autism and/or Asperger's

syndrome. Their role helps to prevent situations involving an adult with a learning disability reaching a critical stage.

Training

Guideposts offer a variety of training opportunities for carers including online, e-learning toolkits which can be accessed from home at a time which suits and skills workshops on a range of topics relating to caring for someone with a learning disability, held at accessible venues across Warwickshire.

Carer Emergency Cards

Warwickshire County Council, NHS Warwickshire and Guideposts introduced a Carer Emergency Card for carers to carry in their purse or wallet to identify them as a carer should they be caught up in an emergency situation such as a medical emergency. The card has room on the back for the details of up to three people that could be contacted to quickly arrange support for the person the carer looks after, giving peace of mind to the carer & the person cared for. The scheme has proved popular, with 1082 applications received from July 2012 to June 2013.

Health Information Events

Guideposts care support service has carried out a number of health information events to provide carers with advice about the health and wellbeing of the person they care for and to remind carers of the importance of looking after their own health as well. Free health checks are offered to carers in partnership with GP surgeries across Warwickshire.

2.13 KEEPING SAFE

People with learning disabilities may find it difficult to fit in with mainstream society and are therefore considerably more likely to suffer prejudice and discrimination in their everyday lives. This can lead to social exclusion and leave a person at risk of harm and exploitation. People with learning disabilities may be classed as vulnerable.

In 2000, the Government published 'No Secrets'; guidance on developing and implementing procedures to protect vulnerable adults from abuse. It provides a definition of 'Vulnerable Adult' and of adult abuse. The guidance explains how agencies that have contact with vulnerable adults should act jointly to produce and implement local procedures to protect vulnerable adults from abuse.

Warwickshire County Council, through its adult social care services, is required to play a co-ordinating role in developing local policies and procedures to safeguard Vulnerable Adults in conjunction with other key statutory agencies such as the Police and Probation Services, NHS organisations, and other providers of health and social care. The Warwickshire Safeguarding Adults board comprises of individuals from each key agency.

177 references were made with regard to safeguarding issues for people with learning disabilities by respondents taking part in this qualitative research, some with first-hand experience of hate or mate crime and/or exploitation.

"I was involved in a case where the client was being abused by people in the community – so much so that when he picked his benefits up people were waiting to take his benefits off him. He wouldn't put his lights on because he didn't want anyone to know he was home. And if he didn't hand his benefits over he would get beaten up very badly." (Social Care Professional, South Warwickshire)

In 2010, Warwickshire Safeguarding Adults Board commissioned a panel to undertake a serious case review following the murder of Gemma Hayter, a young woman with learning disabilities who was the victim of a hate crime murder. The outcome of the review concluded that there was no evidence that Gemma's death could have been prevented but that timely and effective social care intervention may have prevented her from associating herself with people who presented her with serious risks.

In response to the Gemma Hayter Serious Case Review, a range of work has been undertaken in Warwickshire to respond to the recommendations, resulting in some significant service changes. Examples include; improved guidance and training for staff across health and care agencies; better integration between social care and housing services staff; the implementation of the Safe Places scheme (see below) and the formation of the Safeguarding Adults Short Term Team, which acts as the first point of contact for all safeguarding alerts received within the county.

Warwickshire Safeguarding Adults Alerts and Referrals

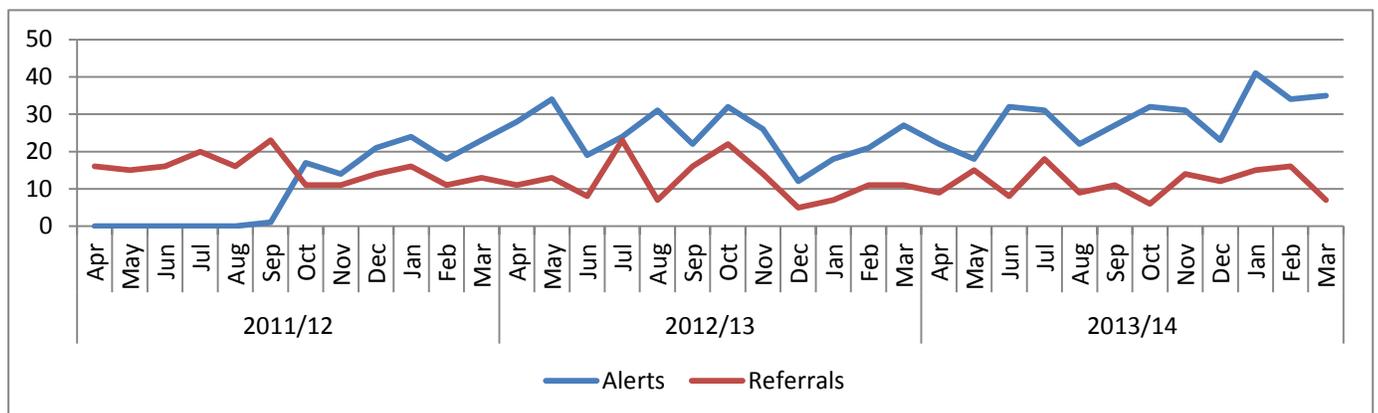
If someone is concerned that a vulnerable adult may be the victim of abuse, they can contact Warwickshire County Council who will record the details of the alleged abuse on CareFirst. This is known as a safeguarding alert. Multiple alerts may be received about the same person or the same allegation. A safeguarding referral is an adult protection investigation or assessment into concerns reported, and may or may not directly follow the receipt of an alert. The table below shows the number of alerts and referrals regarding people with learning disabilities received by Warwickshire by financial year. The recording of alerts only began around October 2011 therefore the figures for 2011/12 cannot be compared with 2012/13 and 2013/14.

Figure 1. Number of Safeguarding alerts and referrals regarding people with a learning disability by financial year

| | 2011/12 | 2012/13 | 2013/14 |
|---------------------------|---------|---------|---------|
| Alerts Received | 118* | 294 | 348 |
| Referrals Received | 182 | 148 | 140 |

* Recording of alerts began in October 2011

Figure 2. Safeguarding alerts and referrals regarding people with a learning disability by month and year



There were 81 adults with learning disabilities who were subject to one or more safeguarding referrals in 2013/14. The average age at time of referral was 37 years and 52% were male (42 males vs 39 females). Only 4 people (5%) were over the age of 65 which is in stark comparison to the general population where 61% of people who were subject to a safeguarding referral were over the age of 65.

Figure 3. Adults with learning disabilities in Warwickshire subject to a safeguarding referral, 2013/14

| Age group | Females | Males | Persons |
|--------------------|-----------|-----------|-----------|
| 18-19 | 3 | 2 | 5 |
| 20-29 | 10 | 15 | 25 |
| 30-39 | 5 | 10 | 15 |
| 40-49 | 7 | 7 | 14 |
| 50-59 | 11 | 6 | 17 |
| 60-69 | 3 | 1 | 4 |
| 70-79 | 0 | 1 | 1 |
| Grand Total | 39 | 42 | 81 |

52% of adults with learning disabilities who were subject to a safeguarding referral live in the north of the county in the districts of Nuneaton and Bedworth and North Warwickshire, whilst 35% live in the districts of Stratford upon Avon and Warwick, with the remainder (13%) in Rugby.

The highest proportion of referrals were associated with alleged abuse within the victim's own home (29%), followed by a nursing or residential care setting (17%). 6% of people were the victim of alleged abuse within multiple settings.

Figure 4. Referrals received by location of alleged abuse, 2013/14

| Location of Alleged Abuse | Number of referrals |
|--------------------------------------|---------------------|
| Residential or Nursing Care Home | 24 |
| Hospital | 12 |
| Own Home | 41 |
| Other Persons Home | 4 |
| Public Place | 13 |
| Service Setting within the Community | 16 |
| Multiple Locations | 9 |
| Unknown | 21 |

Abuse can be categorised into seven 'types'. People may be subject to more than one type of abuse within one referral. The below table shows the number of referrals in which each of the seven types of abuse was alleged. Physical abuse was the most likely type of abuse alleged

(31% of referrals involved allegations of physical abuse), followed by psychological/emotional abuse (21% of referrals) then financial or material abuse (18% of referrals).

Figure 5. Referrals received by type of alleged abuse, 2013/14

| Type of alleged abuse | Number of referrals |
|---------------------------------|---------------------|
| Discriminatory Abuse | 3 |
| Financial or Material Abuse | 31 |
| Institutional Abuse | 3 |
| Neglect | 13 |
| Physical Abuse | 53 |
| Psychological / Emotional Abuse | 36 |
| Sexual Abuse | 16 |
| Unknown | 17 |
| Total | 172 |

Children with Learning Disabilities Subject to Section 47 Enquires in Warwickshire

A Section 47 investigation is carried out by a Local Authority when a child is considered to be at risk of significant harm and where inquiries are needed to decide what action, if any, may be needed to safeguard the child's welfare.

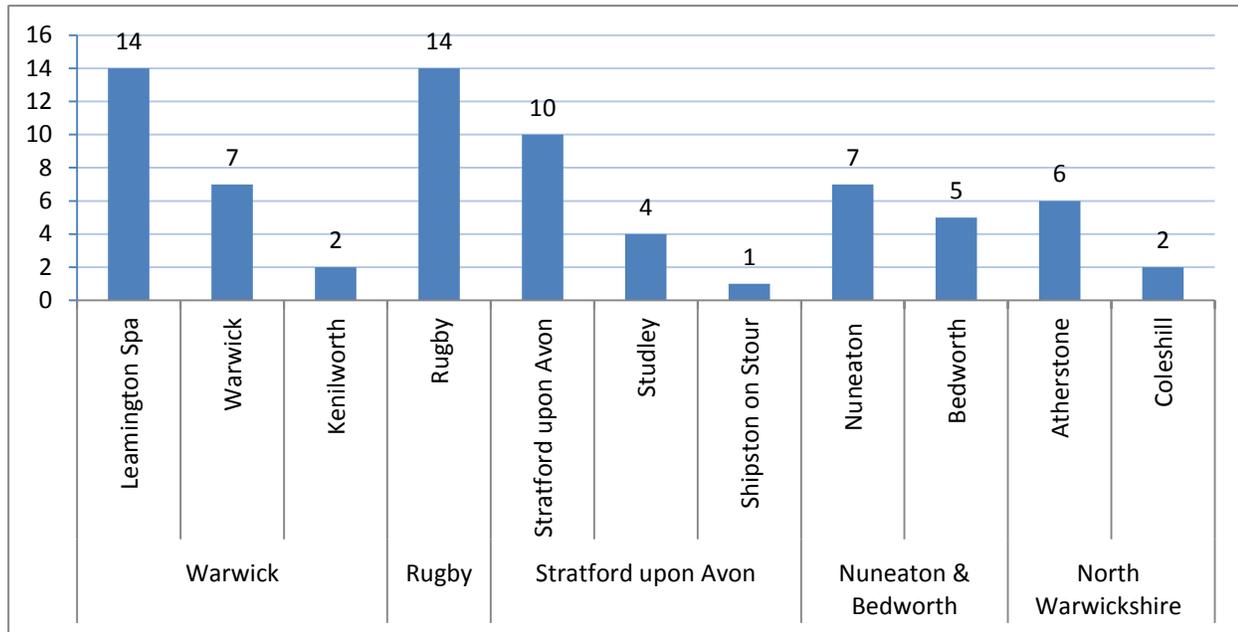
Only 1.5% of all S47 investigations from 1st April 2011 to 31st March 2014 have a primary disability recorded (including the category 'none'). Of those where a primary disability was recorded, 16 were under the category of learning disability; 7 in 2011/12, 5 in 2012/13 and 4 in 2013/14.

2.14.1 SAFE PLACES SCHEME

Warwickshire's Safe Place Scheme was initiated following consultation with people with learning disabilities in the county, of whom 50% said they had been the victim of hate crime and sometimes felt unsafe or scared whilst out in the community.

Safe Places are community places such as shops and cafes where people with learning disabilities can go if they are feeling scared or at risk whilst they are out and about. A member of staff at the Safe Place will then contact the person's support worker, family member, carer or the police. Safe Places are advertised by a sticker in the window. The figure below shows the current (as of August 2014) number of Safe Places in Warwickshire towns by district/borough.

Figure 6. Safe Places in Warwickshire Towns, August 2014



NEXT STEPS

Lead commissioner:

Date brought to JSNA Commissioning Group:

Information and research requirements:

2.13.1 APPENDIX 1 – DEFINITIONS OF LEARNING DIFFICULTIES

The School Census⁸⁵ uses the following definitions of learning difficulties. They include recognition of the need for further help with self-help skills and personal care.

Severe Learning Difficulty (SLD)

Pupils with severe learning difficulties have significant intellectual or cognitive impairments. This has a major effect on their ability to participate in the school curriculum without support. They may also have associated difficulties in mobility and coordination, communication and perception and the acquisition of self-help skills. Pupils with SLD will need support in all areas of the curriculum. They may also require teaching of self-help, independence and social skills. Some pupils may use sign and symbols but most will be able to hold simple conversations and gain some literacy skills. Their attainments may be within the upper P scale range (P4-P8) for much of their school careers (that is below level 1 of the National Curriculum).⁸⁶

Profound and Multiple Learning Difficulty (PMLD)

Pupils with profound and multiple learning difficulties have severe and complex learning needs, in addition they have other significant difficulties, such as physical disabilities or a sensory impairment. Pupils require a high level of adult support, both for their learning needs and also for personal care. They are likely to need sensory stimulation and a curriculum broken down into very small steps. Some pupils communicate by gesture, eye pointing or symbols, others by very simple language. Their attainments are likely to remain in the early P scale range (P1-P4) throughout their school careers (that is below level 1 of the National Curriculum).⁸⁷

Autism Spectrum Disorder (ASD)

Pupils with ASD cover the full range of ability and the severity of their impairment varies widely. Some pupils may also have learning disabilities or other difficulties, making identification difficult. ASD recognises there are a number of sub-groups within the spectrum of autism.

⁸⁵ <https://www.gov.uk/school-census>

⁸⁶ Source: Department for Education (2010) 'Glossary of special educational needs (SEN) terminology'. [Online at: <http://www.education.gov.uk/schools/pupilsupport/sen/schools/a0013104/glossary-of-special-educational-needs-sen-terminology>; accessed: 1.1.12]

⁸⁷ Ibid;

Pupils with ASD may find it difficult to:

- understand and use non-verbal and verbal communication
- understand social behaviour, which affects their ability to interact with children and adults
- think and behave flexibly, which may be shown in restricted, obsessional or repetitive activities.⁸⁸

Complex Learning Difficulties and Disabilities

Children and young people with Complex Learning Difficulties and Disabilities (CLDD) have conditions that co-exist. These conditions overlap and interlock creating a complex profile. The co-occurring and compounding nature of complex learning difficulties requires a personalised learning pathway that recognises children and young people's unique and changing learning patterns. Children and young people with CLDD present with a range of issues and combination of layered needs – e.g. mental health, relationships, behavioural, physical, medical, sensory, communication and cognitive. They need informed specific support and strategies which may include multi-disciplinary input to engage effectively in the learning process and to participate actively in classroom activities and the wider community. Their attainments may be inconsistent, presenting an atypical or uneven profile. In the school setting, learners may be working at any educational level, including the National Curriculum and P scales. This definition could also be applicable to learners in Early Years and post-school settings.⁸⁹

Children

Children will be considered to have a learning disability if any of the following conditions are met:

- They have been identified within education services as having a Special Educational Need (SEN) associated with 'moderate learning difficulty', 'severe learning difficulty' or 'profound multiple learning difficulty'. Children aged 7 or older should be at the School

⁸⁸ Abridged from: Department for Education (2010) 'Glossary of special educational needs (SEN) terminology'. [Online at: <http://www.education.gov.uk/schools/pupilsupport/sen/schools/a0013104/glossary-of-special-educational-needs-senterminology>; accessed: 1.1.12]

⁸⁹ From: Carpenter, B. et al. (2011) The Complex Learning Difficulties and Disabilities Research Project: *Developing pathways to personalised learning*. London: The Schools Network (formerly Specialist Schools and Academies Trust). [Online at: [http://complexld.ssatrust.org.uk/uploads/CLDD%20research%20project%20\(Final\)%20Exec%20sum.pdf](http://complexld.ssatrust.org.uk/uploads/CLDD%20research%20project%20(Final)%20Exec%20sum.pdf); accessed: 1.1.12]

Action Plus stage of assessment or have a Statement of SEN.⁹⁰ Younger children should also be included if they are at the School Action stage of assessment of SEN.

- They score lower than two standard deviations below the mean on a validated test of general cognitive functioning (equivalent to an IQ score of less than 70) or general development. Care should, however, be taken when considering the results of tests carried out in English on children below the age of 7 living in bi-lingual households or households where English is not spoken.
- They have been identified as having learning disabilities on locally held disability registers (including registers held by GP practices).

Adults

Adults will be considered to have a learning disability if any of the following conditions are met:

- When a child they were identified within education services as having a Special Educational Need (SEN) associated with 'moderate learning difficulty', 'severe learning difficulty' or 'profound multiple learning difficulty'.
- They attended a special school or unit for children with 'moderate learning difficulty (or mental handicap)', 'severe learning difficulty (or mental handicap)' or 'profound multiple learning difficulty (or mental handicap)'.
- When a child they scored lower than two standard deviations below the mean on a validated test of general cognitive functioning (equivalent to an IQ score of less than 70).
- As an adult they scored lower than two standard deviations below the mean on a validated test of general cognitive functioning and there is good evidence to suggest that they have had difficulties in learning since childhood. Care should, however, be taken when considering the results of tests carried out in English on adults for whom English is not their first language, or where the person is experiencing disrupted mental health at the time of the test.
- They have been identified as having learning disabilities on locally held disability registers (including registers held by GP practices or Primary Care Trusts) or by relevant Read Codes in health information systems.

⁹⁰ Department for Education and Skills. *Special Educational Needs Code of Practice*. London: Department for Education and Skills; 2001 and Department for Education and Skills. *SEN Toolkit*. London: Department for Education and Skills; 2001.

- They report having significant difficulties in literacy and numeracy and there is good evidence to suggest that they have had these difficulties since childhood.
- They screen positive for learning disabilities using a validated screening test.⁹¹
- In response to survey questions, they identify themselves as having a long-term illness, health condition or disability associated with 'learning disabilities' (or equivalent term) and have low educational attainment (equivalent to no GCSEs at grade C or above).

2.13.2 APPENDIX 2 – POLICY AND LEGAL FRAMEWORK

Learning Disability Policy

Department of Health. 2001 'Valuing People: A New Strategy for Learning Disability for the 21st Century'. White Paper

Valuing People Now: a new three year strategy for people with learning disabilities. 2009. HM Government

Aiming High for Disabled Children. May 2007. Department for Education and Skills.

Adult Social Care Policy

Putting People First. 2007.

Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care. England 2010.

Department of Health.

A Vision for Adult Social Care. Capable Communities and Active Citizens. 2010. Department of Health

'Caring for our Future' White paper. July 2012

Care and Support - draft bill 2012

Autism

'Fulfilling and Rewarding Lives. The strategy for adults with autism in England (2010). HM Government

⁹¹ Hayes S. Hayes Ability Screening Index. Sydney: Faculty of Medicine. University of Sydney; 2000 and Søndena E, Rasmussen K, Palmstierna T, Nøttestad J. The prevalence and nature of intellectual disability in Norwegian prisons. Journal of Intellectual Disability Research 2008;52: 1129–37.

Carers

‘Carers at the Heart of 21st-century families and communities’ HM Government 2008

‘Recognised, valued and supported: Next steps for the Carers Strategy’ HM Government 2010

‘Carers and Personalisation: improving outcomes’ Department of Health. 2010

Learning Disability - Influential Reports

‘Services for People with Learning Disabilities and Challenging behaviour or Mental Health Needs’ (Revised edition) - Mansell Report Department of Health. 2007

‘Learning Disability Services Inspection Programme National Overview’ Care Quality Commission June 2012 103

Mencap and Challenging Behaviour Foundation. ‘Out of sight. Stopping the neglect and abuse of people with a learning disability’. August 2012

‘Winterbourne View Hospital: A Serious Case Review’ South Gloucestershire Safeguarding Adults Board. Author Margaret Flynn. August 2012

‘Report of the NHS Review of commissioning of care and treatment at Winterbourne View’. NHS South of England. August 2012

‘Healthcare for all. Independent Inquiry into access to healthcare for people with learning disabilities’. Sir Jonathan Michael. 2008

Legislation

Three pieces of legislation on **Carers** should be seen as cumulative and all powers and duties in these currently apply to any one carer situation.

The Carers (Recognition and Services) Act 1995

This was the first piece of legislation for carers and was seen as a major step forward for carers, giving them important new rights and a clear legal status. Under the Act, individuals who provide or intend to provide a substantial amount of care on a regular basis are entitled to request (at the time the person they care for is being assessed for community care services) an assessment of their ability to care and to continue caring. Local authorities are required to take into account the results of that assessment in making decisions about the type and level of community care services to be provided to the cared for person. The assessment under the 1995 Act is of the carer’s ability to provide care and of his or her ability

to sustain the care that he or she has been providing. The 1995 Act applies to carers of all ages.

The Carers and Disabled Children Act 2000

This made four principal changes to the law, with the objective of empowering local authorities to offer new support to carers to help them to maintain their own health and well-being as follows:

To supply certain services (those services which help the carer to care) direct to carers following assessment. It gives carers the right to an assessment independent of the community care assessment for the cared for person.

To make direct payments to carers (including 16 and 17 year old carers) for the services that meet their own assessed needs. Since the Carers and Disabled Children Act 2000, the legislative framework relating to direct payments for carers has been updated through Section 57 of the Health and Social Care Act 2001.

To run short term break voucher schemes. Voucher schemes are designed to offer flexibility in the timing of carers' breaks and choice in the way services are delivered to cared for people while their usual carer is taking a break.

To charge carers for the services they receive.

The Carers (Equal Opportunities) Act 2004

Carers to have more choice and better opportunities to lead a more fulfilling life by ensuring that carers receive information about their rights to an assessment under the 2000 Act.

Ensures that those assessments now consider the carer's wishes in relation to leisure, education, training and work activities.

Co-operation between local authorities and other public authorities, including housing, education and health, in relation to the planning and provision of services that may help support the carer in their caring role.

Mental Capacity Act 2005

The Mental Capacity Act (2005) provides a statutory framework to empower and protect people who may lack capacity to make some decisions for themselves. The MCA applies to

anyone who works with or cares for an adult who lacks capacity and is supported by a Code of Practice.⁹²

The Mental Capacity Act makes clear who can take decisions in which situations, and how they should go about this. Anyone who works with or cares for an adult who lacks capacity must comply with the MCA when making decisions or acting for that person. The underlying philosophy is to ensure that those who lack capacity are empowered to make as many decisions for themselves as possible and that any decision made, or action taken, on their behalf is made in their best interests. The Code of Practice supports the MCA.⁹³

Autism Act 2009

This Act put a duty on the Government to produce a strategy for adults with autism, which was published on 2 March 2010.

It also placed a duty on the Government to produce statutory guidance for local councils and local health bodies on implementing the adult autism strategy by the end of 2010 (published 17 December 2010).

Disability Discrimination Act 1995 and the Equality Act 2010

Since the Disability Discrimination Act, people with learning disabilities (along with other groups of disabled people) have had a legal entitlement to have equal access to public services, including those provided by the NHS. Over time, principally through the Disability Discrimination Act and reinforced in the recent Equality Act, this fundamental entitlement has been increasingly well-defined as the Disability Equality Duty.

In law, all public sector services have a legal duty to make 'reasonable adjustments' to the way they make their services available to people with learning disabilities, to make them as accessible and effective as they would be for people without disabilities.

'Reasonable adjustments' include removing physical barriers to accessing health services, but importantly also include making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities.

This legal duty for health services is 'anticipatory'. This means that health service organisations are required to consider in advance what adjustments people with learning

⁹² *Mental Capacity Act 2005 Code of Practice*. London: TSO Access at www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

⁹³ *Mental Capacity Act 2005 Code of Practice*. Access at www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

disabilities will require, rather than waiting until people with learning disabilities attempt to use health services to put ‘reasonable adjustments’ into place.

The Children and Families Act

This Act incorporates a new single assessment process and an ‘Education, Health and Care Plan’ from birth to 25 and includes support into employment. Local Authorities retain their duties to provide young people with learning difficulties or disabilities (up to the age of 25) with targeted support to enable them to participate in education or training.

It includes measures to improve provision for children with special educational needs and disabilities, based on the Green Paper, Support and Aspiration, published in May 2011.⁹⁴

A new approach to identifying Special Educational needs (SEN) in early years and schools with the aim of setting higher expectations and providing the support for children to succeed and fulfil their potential. This incorporates a new single assessment process and an ‘Education, Health and Care Plan’ from birth to 25 and will include support into employment. Local Authorities will retain their duties to provide young people with learning difficulties or disabilities up to the age of 25, with targeted support to enable them to participate in education or training.

Part of the bill is ‘Preparing for Adulthood’ and recognises the additional challenges many young people with disabilities face during their teenage years and in their transition to successful adult life. Parents have talked about having to cope with disjointed and confusing processes from their local authority, school or college and health providers. Often professionals working with the young people are not encouraged to focus on young people’s ambitions for adulthood and how to help them prepare. This poor planning is exacerbated by a lack of choice and opportunities for young people with disabilities in choice of courses, in further education, poor quality work experience and a lack of employment opportunities. The goal is for young people with disabilities to have the best opportunities and support so that, as far as possible, they can succeed in education and in their careers, live as independently and as healthily as they are able to and be active members of their communities.

Revision dates:

| Data | Update due |
|------|------------|
| | |

⁹⁴ Department of Education, 2011. Support and Aspiration: A new approach to special educational needs and disability – A consultation. London: Department for Education

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