# INTEGRATED STRATEGIC NEEDS ASSESSMENT:

# ADULTS WITH LEARNING DISABILITIES

# SUMMARY

## KEY ISSUES AND GAPS

- Adults with learning disabilities are, in general, more likely to experience poorer levels of health, shorter life expectancies and greater inequalities than the general population.
- Many people who have learning disabilities may have a number of have unmet needs, either as a consequence of a failure in diagnosis or difficulties in accessing services, lost during transition phases or being excluded from services due to different criteria. It is difficult to determine how many individuals this concerns or where they are located and therefore this issue concerns a wide cross-section of services and not solely those designed to meet specific needs of people with learning disabilities.
- Using national estimates it is suggested that just over 1,250 adults should be known to services locally, this is slightly more than recognised locally (about 1,000 adults) but still represents a higher proportion of our total population compared nationally. These national estimates also suggest that, similarly to elsewhere, there are possibly 4,600 people who are living within the community independently without receiving special help. These people will largely be those with mild learning disabilities.
- Whilst local population projections identify a relatively static or slightly declining population of people with moderate to severe learning disabilities in the next 5-20 years, the predicted populations of people with learning disabilities in the older (65+) age groups is anticipated to increase significantly. This highlights a shift in the type of service provision that may be required to support a changing client demographic.

## SUMMARY OF RECOMMENDATIONS FOR DECISION MAKERS AND COMMISSIONERS

- Ensure the recommendation of the Supporting People Housing Needs Assessment, to increase provision of floating services over accommodation based services to enable greater independent living.
- Provide greater access to floating services for clients not eligible for Fair Access to Care Services including those with mild or moderate need.
- Ensure that all providers and commissioners deliver the specific recommendations and requirements of Six Lives and Healthcare for All.
- Increase numbers of people with learning disabilities who are in settled accommodation.
- Increase capacity for people with learning disabilities to enter supported employment and increase the proportion of those in paid employment. This requires a boraod multi-organisational approach.
- Learning disability awareness training should be rolled out within all primary and secondary care health settings to facilitate a greater depth of understanding and facilitate appropriate care pathway development.
- Continue to commission Learning Disabilities Directed Enhanced Services and ensure completion of health checks on all eligible persons and enhance mechanisms to ensure active case finding of people with learning disabilities to help facilitate appropriate access to services for those who need them.
- Wider workforce development plan should address current issues such as developing understanding of personal budgets, availability of assistive technology and such like.
- Ensure services remain fit for purpose in light of likely future population changes, including additional services to cater for the needs of older persons with learning disabilities.

# INTEGRATED STRATEGIC NEEDS ASSESSMENT
# ADULTS WITH LEARNING DISABILITIES

# MAIN REPORT

## INTRODUCTION

Adults with learning disabilities represent a section of society with a range of complex care needs which reflects the spectrum of severity of learning disabilities and differing conditions which may co-exist. In addition to health needs, people with learning disabilities may also have a number of needs generated as a result of social exclusion, such as unemployment, lack of housing and poverty. Many people with complex or more severe learning disabilities are likely to require lifelong support for a variety of health and social care needs from childhood. Children and adults with mild to moderate learning disabilities may require specialist support in education but may subsequently require more general support and benefits similar to any socially excluded groups rather than specialist support.

There is no universal definition of learning disability. Although 'learning disability' commonly refers to a group of individuals with history of developmental delay, delay or failure to develop social functioning or behaviour appropriate to chronological age, with evidence of intellectual impairment.

The definition that has been widely adopted within the social context is that of Valuing People (2001) and one which the General Medical Services (GMS) contract uses:

"A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood (18 years), with a lasting effect on development."

The Learning Disability Observatory estimate that in England in 2011 1,191,000 people have learning disabilities. This includes

- 286,000 children aged 0-17;
- 905,000 adults aged 18+, of whom 189,000 (21%) are known to learning disabilities services.

This needs analysis considers adults with moderate to more severe learning disabilities, and will not include those adults who may be identified with as having milder, intellectual or social levels of disability, whose disability may be more broadly defined in educational legislation. This needs assessment does not include children with learning disabilities.

## CAUSES OF LEARNING DISABILITIES

Learning disabilities can be broadly categorised into conditions which occur at conception and those which occur during pregnancy, labour and post-natally.

### Genetic factors

In the UK, genetic factors result in the majority of cases of learning disability; with non-inherited Down's syndrome accounting for approximately 30% of cases at birth. The second most common cause is X-linked disorder, single-gene disorders account for 12% of cases. Other recognised genetic disorders cause only 5-10% of cases of mild learning disabilities.

### Non-genetic factors

Infection, non-accidental injury and accidents are responsible for approximately 25% of severe learning disabilities which arise either ante- or post-natal. Birth injury and obstetric complications are responsible for approximately 10%.

Infective causes are of learning disability are now uncommon. Rubella infection in early pregnancy can lead to foetal death, but in pregnancies that continue can severely affect the on-going development of the growing foetus. Infection resulting from toxoplasma and cytomegalovirus may also cause some level of developmental impairment. Antenatal HIV infection may cause delay in cognitive development that requires educational support in mainstream schools.

Maternal alcohol consumption is considered to be the leading cause of learning disabilities in the United States. European research gives lower figures but it remains an important consideration.

Neural-tube defects (NTDs) and other central nervous system malformations, such as microcephaly, are associated with learning disabilities. Dietary folate deficiency is associated with an increased risk of NTDs.

## WHO'S AT RISK AND WHY?

Men are slightly more likely than women to have either a mild learning disability (1.2 males: 1 female) or severe learning disability (1.6 males: 1 female), due to the sex-linked genetic causal factor of some conditions which

result in learning disability (Emerson et al 2001). The ratio decreases with age as women typically live longer.

Mild learning disabilities are strongly associated with parental social class and family instability, but no relationship is reported between these factors and severe learning disabilities, suggesting that deprivation may be a contributory factor for mild but not severe learning disabilities (Emerson et al 2001).

## HEALTH INEQUALITIES

Compared to the rest of the population, people with learning disabilities can have (Cooper et al 2004):

- Lower life expectancy – people with learning disabilities have an higher risk of premature death compared to the general population. People with more severe learning disability experience the lowest life expectancy (median life expectancies of 74.0 with mild disability, 67.6 with moderate disability and 58.6 with severe disabilities) (Bittles et al 2002).
- Different causes of death – Approximately half of people with a learning disability die as a result of respiratory disease which represents the main cause of death for people with learning disabilities. The second largest cause of death is cardiovascular disease (predominantly congenital heart disease rather than ischemia) (Hollins et al 1998). The leading causes of death within the general population are cancer, heart disease and cerebrovascular disease.
- Higher levels of unrecognised and unmet physical and mental health needs – although people with learning disabilities visit their GP with similar frequency to the general population, they are less likely to receive regular health checks. A study undertaken in 2006 (Baxter 2006) carried out health screening for 181 adults with learning disabilities. In over half those tested, new health issues were identified in the health checks, 9% of the newly identified health issues were deemed to be serious, and included breast cancer, suspected dementia, asthma, post-menstrual bleeding, diabetes, hypothyroidism, high blood pressure and haematuria.
- Barriers to accessing health services – people with learning disabilities often experience barriers in accessing health services. Barriers can include problems with communication, inadequate facilities, rigid procedures, a lack of appropriate interpersonal skills among mainstream health professionals and a lack of accessible information (Alborz et al 2005). Uptake of screening amongst people with learning disabilities is lower than the general population, and people with learning disabilities are less likely to be fully immunised than the general population.

- Different lifestyle issues – accessible health promotion services and materials may mean that adults with learning disabilities have a reduced ability to gain information and limited understanding about health risks and consequently limited opportunity to determine own healthy lifestyle choices (NHS Scotland 2004). People with learning disabilities:

    - have higher levels of obesity than the general population
    - are less likely to participate in the recommended levels of physical activity than the general population
    - are less likely to eat a healthy diet with an insufficient intake of fruit and vegetables than the general population
    - have lower rates of smoking and harmful drinking than the general population.

## THE LEVEL OF NEED IN THE POPULATION

There are no definitive statistics which report the exact numbers of adults in the UK who have a learning disability. Identifying exact numbers is difficult as many people may not be known to local services and the spectrum of conditions which can be defined as learning disability is very wide.

The Learning Disability Observatory provides estimates about how many people with learning disabilities are expected to live in a particular population (based on estimates by Emerson and Hatton). It estimates that around 2% of all people have a learning disability. This proportion includes an estimate of the 'hidden' numbers of people with (predominantly) mild learning disabilities. It also estimates that 0.5% of people has a learning disability and are known to health and social services. These are likely to be those with moderate to more severe learning disabilities. This means that three quarters of people likely to have a learning disability are living independently, or receiving no special help.

In Cheshire West and Chester, there is broadly estimated to be around 5,880 adults with learning disabilities, of which 1,255 are likely to be known to services (table 1). This suggests that possibly 4,600 people with learning disabilities are living in the community independently without receiving special help. These are likely to be those with mild learning disabilities.

**Table 1: Age distribution of population estimates of individuals with learning disabilities and those known to services in Cheshire West and Chester.**

| Age Band | Prevalence | | Population (2011) | Number of People | |
|---|---|---|---|---|---|
| | Known to services | Estimated Total | | Known to services | Estimated Total |
| 0-4 | 0.15% | 0.15% | 18,300 | 27 | 27 |
| 5-9 | 0.47% | 0.97% | 17,600 | 83 | 171 |
| 10-14 | 0.50% | 2.26% | 18,800 | 94 | 425 |
| 15-19 | 0.67% | 2.67% | 20,400 | 137 | 545 |
| 20-24 | 0.60% | 2.60% | 20,000 | 120 | 520 |
| 25-29 | 0.51% | 2.40% | 18,100 | 92 | 434 |
| 30-34 | 0.52% | 2.41% | 16,500 | 86 | 398 |
| 35-39 | 0.59% | 2.38% | 19,600 | 116 | 466 |
| 40-44 | 0.60% | 2.40% | 24,200 | 145 | 581 |
| 45-49 | 0.55% | 2.25% | 25,800 | 142 | 581 |
| 50-54 | 0.43% | 2.12% | 22,600 | 97 | 479 |
| 55-59 | 0.49% | 2.09% | 20,500 | 100 | 428 |
| 60-64 | 0.38% | 1.97% | 22,300 | 85 | 439 |
| 65-69 | 0.31% | 1.80% | 18,200 | 56 | 328 |
| 70-74 | 0.25% | 1.72% | 14,900 | 37 | 256 |
| 75-79 | 0.16% | 1.52% | 11,900 | 19 | 181 |
| 80 and over | 0.13% | 1.43% | 16,900 | 22 | 242 |
| All ages | | | 326,500 | 1,459 | 6,501 |
| Children | | | | 204 | 623 |
| Adults | | | | 1,121 | 4,871 |
| Older People | | | | 134 | 1,007 |

Source: Learning Disabilities Observatory, based on methodology from “Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England” (Emerson and Hatton 2004). Cheshire West and Chester Research & Intelligence – Population Projections, 2010

The Learning Disabilities 2012 Profile produced by the Learning Disabilities Observatory suggest that the number of people with a learning disability per head of population known to the local authority is higher than the national average (table 2).

**Table 2 : Number and rate per 1000 adults (18-64) with learning disability known to local authorities**

| Year | Rate per 1000 population | | | Number of adults |
|---|---|---|---|---|
| | England Average | North West | CWAC | |
| 2009-10 | 4.21 | 4.66 | 4.84 | 965 |
| 2010-11 | 4.27 | 4.71 | 5.09 | 1,015 |

Source: Learning Disabilities Observatory – Learning Disabilities Profile 2012

## Accommodation

National Indicators (NI 145) measures the proportion of adults known to social services who live in settled accommodation at the time of their assessment or latest review. In this indicator stable accommodation includes categories such as owner occupied, tenants, settled with family/friends, supported accommodation and such like but not care homes and temporary accommodation. Cheshire West and Chester Adult Social Care Combined Activity Return (ASC-CAR) for 2010/11 show that 60.3% adults (aged 18-64) with a learning disability are recorded as living in stable accommodation. This is slightly higher than the England average of 59%.

## Employment

National Indicator (NI146) measures the proportion of adults with learning disabilities known to social services who are in employment at the time of their assessment or latest review. In 2010/11 Cheshire West and Chester had 7.4% of adults with learning disabilities in paid employment which was higher than the England figure of 6.6%. The caseload for supported employment varies with new clients and the withdrawal of support for established clients. As of March 2012 Cheshire West and Chester provides support for the following clients:

- 55 in Full time Employment
- 39 in Part time employment
- 33 in Voluntary works

## CURRENT SERVICES IN RELATION TO NEED

Adults with learning disability have a wide range of needs and cover a wide spectrum of severity. Whilst adult social care within the local authority assess and provide a support plan for a section of the community with learning disabilities (see below) we need to recognise the role of a wide cross section of services and the community in delaying or avoiding the need for care through, for example, adapted housing smart technology and equipment, appropriate access to healthcare, increasing uptake of benefits and such like.

### Social Care

Cheshire West and Chester Social Services provide support for clients with learning disabilities as part of the Fair Access to Care Services, which assess clients under a national framework for those individuals who's needs are assessed as being critical or substantial, the Local Authority need to provide a support plan and encourage the use of Personal Budgets to deliver choice in care provision.

Cheshire West and Cheshire also operate the Supporting People Programme which commissions (through partnership) housing related support services for vulnerable people, including those with learning disabilities, to live more independently. This may take the form of:

- Housing based support - where support is linked to accommodation
- Floating support - where support is linked to the individual
- Home improvement

Tables 3a and 3b highlight the numbers of clients with learning disabilities in receipt of services through Fair Access to Care Services (FACS) in Cheshire West and Cheshire.

**Table 3a**

| Client Category | Total Clients | Community | Residential | Nursing |
|---|---|---|---|---|
| "Substantial needs" Aged 18-64 | 289 | 263 | 35 | - |
| "Substantial needs" Aged 65+ | 15 | 15 | - | - |
| "Critical needs" Aged 18-64 | 77 | 63 | 15 | 2 |
| "Critical needs" Aged 65+ | 4 | 3 | 2 | 1 |
| *No FACs criteria recorded Aged 18-64* | *528* | - | - | - |
| *No FACs criteria recorded Aged 65+* | 37 | | | |

**Table 3b**

| Client Category | Total Clients | Homecare | Day care | Meals | Short Stay |
|---|---|---|---|---|---|
| “Substantial needs” Aged 18-64 | 263 | 148 | 135 | 3 | 46 |
| “Substantial needs” Aged 65+ | 15 | 13 | 11 | 1 | 2 |
| “Critical needs” Aged 18-64 | 63 | 38 | 37 | - | 13 |
| “Critical needs” Aged 65+ | 3 | 3 | 3 | - | 1 |
| **Client Category** | **Direct Payments** | **Professional Support** | **Equipment** | **Other** | |
| “Substantial needs” Aged 18-64 | 57 | 36 | 42 | 56 | |
| “Substantial needs” Aged 65+ | 1 | 1 | 3 | - | |
| “Critical needs” Aged 18-64 | 19 | 10 | 14 | 4 | |
| “Critical needs” Aged 65+ | - | - | 1 | - | |

NB. Data in Table 3b illustrates the number of clients receiving a service; clients may be in receipt of more than one service (Data: Cheshire West and Chester 2010-2011).

**Table 4** illustrates the number of service units currently provided by Cheshire West and Chester for clients with learning disabilities. Clients are frequently in receipt of multiple units of service as part of their care package.

**Table 4**

| Service Category | Number of units of service |
|---|---|
| **Adaptations** | **8** |
| Major | 7 |
| Minor | 1 |
| **Community Meals** | **80** |
| Hot Meals | 80 |
| **Day Care** | **4318** |
| Full day session | 3955 |
| Specialist day care session | 363 |
| **Direct Payments** | **2024** |
| Agency care | 47 |
| Carers payment | 107 |
| Community activity | 1850 |
| Contingency payment | 2 |
| Domicillary – 60 minutes | 2 |
| Short break or respite | 9 |
| Start up grant | 7 |
| **Equipment** | **12** |
| Choicequip Community Equipment | 12 |
| **Extra Care Housing** | **34** |
| Band 1 | 11 |
| Band 2 | 8 |
| Band 3 | 15 |
| **Family Based Care** | **378** |
| 3hr session – carers home | 43 |
| 3hr session – clients home | 128 |
| 6hr session – carers home | 23 |
| 6hr session – clients home | 135 |
| 9hr session – carers home | 25 |
| 9hr session – clients home | 24 |
| **Family Based Care – Long Stay** | **63** |
| Long stay | 63 |
| **Family Based Care – Meals** | **22** |
| Meals lunch | 22 |
| **Family Based Care – Respite** | **16** |
| Respite | 16 |
| **Family Based Care - Respite Migrated** | **39** |
| Respite Migrated | 39 |
| **Home Care** | **2233** |
| 15 minutes | 42 |
| 15 minutes – hard to serve* | 10 |
| 30 minutes | 196 |
| 30 minutes – hard to serve* | 11 |
| 45 minutes | 52 |
| 60 minutes | 1487 |
| 60 minutes – hard to serve* | 11 |
| Other Domiciliary | 424 |

| Service Category | Number of units of service |
|---|---|
| | |
| **Intermediate Care – Home Care** | **33** |
| 30 minutes | 22 |
| 60 minutes – hard to serve* | 11 |
| **Network Care** | **882** |
| Network Care | 882 |
| **NHS Support** | **22** |
| Social Work Support | 11 |
| Professional Support | 11 |
| **Nursing** | **522** |
| Nursing | 201 |
| Nursing – elderly mentally ill | 321 |
| **Personal Support** | **3322** |
| Personal Support Contract – week | 3108 |
| Substantial Care Package – week | 214 |
| **Personal Support – Sleeping Nights** | **11** |
| Sleeping Night | 11 |
| **Personal Support – Waking Nights** | **50** |
| Waking Night | 50 |
| **Reablement Care – Home Care** | **50** |
| 30 minutes | 4 |
| 60 minutes | 46 |
| **Residential** | **1782** |
| Residential | 1648 |
| Residential – elderly mentally ill | 134 |
| **Respite Nursing** | **3** |
| Nursing Respite | 3 |
| **Respite Residential** | **537** |
| Residential Respite | 537 |
| **Social Work Support** | **1016** |
| Social Work Support | 1016 |
| **Telecare** | **109** |
| Telecare | 109 |
| **Transport** | **2160** |
| Transport to/from Day Care | 2160 |

* denotes clients in remote location, not complexity of need

NB. Data in Table 4 illustrates the number units of service; clients may be in receipt of more than one service (Data: Cheshire West and Chester for financial year 2011/12, data as of March 2012).

Accommodation for clients with learning disabilities is currently under review through a sub-group of the Cheshire West and Chester Learning Disabilities Partnership Board. An action plan has been implemented to collate information on the range and scope of learning disability accommodation. The Supporting People Housing Needs Assessment (2011) recommended a shift in balance of support from accommodation based to floating support based options to reflect the aspirations and needs of clients and to increase the number of individuals provided with support to gain independence.

As of March 2012 there is a wide variety of provision for housing and accommodation services and support for people with learning disabilities. The Learning Disabilities Partnership Board has developed an action plan and are working to ensure a clear picture of the provision and need across Cheshire West and Chester is available.

**Table 5** illustrates the variation in current service provision through Supporting People and is a mixture of accommodation based services and floating support. This data is not complete and the landscape will change considerably with a shift towards more floating support based options in line with the Supporting People Housing Needs Assessment.

**Table 5: variation in current service provision**

| Provider | District | Clients* | Service Description |
|---|---|---|---|
| Allied Healthcare | Chester<br>Ellesmere Port | 6 | Care and Support service (all age groups) with Learning Disabilities within a shared housing environment. On site staffing with sleep in. |
| Alternative Futures Group | Chester<br>Chester<br>Winsford and Rural East | 13 | Detached 5 bedroom house (adults 18-65)<br>Detached 4 bedroom bungalow with disabled access (adults 18-65)<br>Detached 4 bedroom bungalow (adults 18-65) |
| Always There Homecare Ltd | Winsford and Rural East | 4 | 24/7 Nursing and Support Services (ages 18-95+) |
| Barrowmore | Chester | 35 | 35 room residential support (adults 18-84) |
| Carr Gomm | Chester<br><br>Floating Support Services:<br>Chester<br>Winsford and Rural East | 21 | National charity (all age groups) places individuals at the center of planning and decision making, enabling them to have control over their lives working with people with a variety of needs who need support because of illness or disability or because they are experiencing a crisis in their lives. |

| Provider | District | Clients* | Service Description |
|---|---|---|---|
| Cheshire and Wirral Partnership | Chester | | |
| Cheshire West & Chester Council | Chester and Ellesmere Port Chester, Ellesmere Port, Vale Royal – | 143 | Floating Support<br><br>Family Based Care |
| Home Farm Trust | Ellesmere Port | 34 | Provides inclusive services (ages 18-95+), which are individually tailored to each person's needs and wishes. |
| MacIntyre | Ellesmere Port | 12 | Accommodation based service (all age groups). Service users have own bedrooms and communal facilities. |
| Muir Group | Chester, Winsford and Rural East | 16 | Young People Leaving Care, (Ages: 16-21) provides self-contained independent living with on-site support |
| Stonham Housing Association | Ellesmere Port<br><br>Ellesmere Port Floating Support Services | | Self-contained flats with on-site housing related support workers |
| The Chester Link | Chester | | Supported housing/care/empowerment (with opportunity for further independence) for people with learning disabilities (age 26-49) within their own individual tenancies and within their own area of choice. |

* Estimated client base (as of March 2012). Data represents a mixture of accommodation based support and Floating Services.

## Primary Care Services

All GP practices in the West Cheshire Clinical Commissioning Group have signed up the Directly Enhanced Service for Learning Disabilities, although some practices do not yet have sufficient information and are due to commence or will have implemented Annual Health Checks during 2012. All GP practices in the Vale Royal CCG have signed up to the Directly Enhanced Service for Learning Disabilities and have implemented Annual Health Checks. The learning Disability DES has been extended until March 2013. This is illustrated in **Table 6.**

**Table 6**

| Data as of March 2012 | Number of GP Practices | |
|---|---|---|
| | West Cheshire CCG | Vale Royal CCG |
| LD Health Checks in place/lists confirmed | 21 | 12 |
| Lists not fully confirmed | 10 | - |
| Lists not yet established | 4 | - |
| Not commenced/no contact | 4 | - |
| **Total number of practices** | **39** | **12** |

**Table 7.** Shows the number of adult with learning disabilities who received a health check from a general medical practitioner as part of a Directed Enhanced Service scheme for NHS Western Cheshire, compared to NHS Central and East Cheshire, regional and national data.

**Table 7**

| | 2009-10 | | | 2010-11 | | | 2009-10 to 2010-11 % change | | |
|---|---|---|---|---|---|---|---|---|---|
| | Number of People with LD receiving health checks | Number of eligible - adults known to both GP and Social Services with LD | Number of people with LD receiving health checks as a proportion of people with LD (%) | Number of People with LD receiving health checks | Number of eligible - adults known to both GP and Social Services with LD | Number of people with LD receiving health checks as a proportion of people with LD (%) | Number of People with LD receiving health checks | Number of eligible - adults known to both GP and Social Services with LD | Number of people with LD receiving health checks as a proportion of people with LD (%) |
| NHS Western Cheshire | 288 | 589 | 49% | 279 | 799 | 35% | -3% | +36% | -14% |
| NHS C&E Cheshire | 823 | 1,237 | 67% | 965 | 1,400 | 69% | +17% | +13% | +2% |
| North West SHA | 8,193 | 18,868 | 43% | 9,837 | 20,885 | 47% | +20% | +11% | +4% |
| England | *58,919* | *145,130* | *41%* | *72,782* | *149,480* | *49%* | +24% | +3% | +8% |

Uptake of health checks has been lower in Western Cheshire PCT compared with Central & Eastern Cheshire PCT and nationally.

Cheshire and Wirral Partnership NHS Foundation Trust provide a Learning Disabilities Health Facilitation Service. The health facilitation service's main function is to focus on improving health access and reducing health inequalities for people with learning disabilities delivering assessment, care planning and interventions for mental health needs for individuals over the age of 18 with a learning disability. The service is led by a consultant nurse and there is currently one (1) whole time equivalent strategic health facilitator linked to the GP practices.

**Specialist Learning Disability services**

Cheshire and Wirral Partnership also provide inpatient assessment and treatment units for clients whose mental health needs assessment and/or treatment needs cannot be met in a non-hospital or mainstream hospital setting, The number of beds available vary dependent upon complexity of needs. The service is located at Eastway (Chester) which has 9 beds and at Greenways (Macclesfield) for clients in Vale Royal which has 8 beds (with 4 additional via spot purchase arrangement). There is also a multidisciplinary Community Learning Disability Team which includes a range of professionals

covering Community Nursing, Psychology, Psychiatry, Occupational Therapy, Physiotherapy and Speech and Language Therapy. There is also a 0.5 Whole Time Equivalent nurse for patients with Autistic Spectrum Conditions.

A care pathway for Primary Care dental services exists in Western Cheshire for adults with special needs (commissioned from Bridgewater Community Foundation Trust). This pathway is delivered in Primary Care and can be delivered through Secondary Care facilities (Countess of Chester Foundation Trust) if some clients require this.

**Secondary care services**

The Countess of Chester NHS Foundation Trust has a policy for the 'Management of patients admitted with a learning difficulty'. Healthcare services within the Trust continuously promote safeguarding patients, carers and the public and promote the individual rights of the person to access the service, supporting their independence and ensuring a fair and open process for decision making.

**Useful links**

Cheshire and Wirral Partnership learning disabilities web pages click here
Cheshire West and Chester Council learning disabilities web pages click here
Cheshire West and Chester Council Supporting People web pages click here
West Cheshire Health and Care web pages click here

## PROJECTED SERVICE USE AND OUTCOMES IN 3-5 YEARS AND 5-10 YEARS

Nationally, the numbers of adults with learning disabilities is set to increase in the next 10-15 years. Local projections of the number of people with learning disabilities have been estimated using population projections produced by Cheshire West and Chester's Research & Intelligence team.

**Table 8 a and b** provide baseline estimates for individuals in Cheshire West and Chester with learning disabilities through to 2029 by age group. Based on methodology in Emerson and Hatton (2004); figures based on estimate of prevalence across national population which have been applied to Cheshire West and Chester Population Projections, 2010

**Table 8a**

| Age Group | Year | | | | |
|---|---|---|---|---|---|
| | 2011 | 2015 | 2020 | 2025 | 2029 |
| 19 – 24 | 1,065 | 1,022 | 985 | 994 | 1,022 |
| 25 – 34 | 832 | 875 | 960 | 983 | 962 |
| 35 – 44 | 1,047 | 897 | 831 | 925 | 1,016 |
| 45 – 54 | 1,060 | 1,090 | 1,003 | 846 | 785 |
| 55 – 64 | 867 | 843 | 943 | 1,005 | 957 |
| Total population 19 – 64 predicted to have a learning disability | 4,871 | 4,727 | 4,722 | 4,753 | 4,742 |

**Table 8b**

| Age Group | Year | | | | |
|---|---|---|---|---|---|
| | 2011 | 2015 | 2020 | 2025 | 2029 |
| 65 – 74 | 584 | 661 | 693 | 687 | 752 |
| 75 – 79 | 181 | 201 | 225 | 280 | 260 |
| 80 and over | 242 | 266 | 319 | 382 | 462 |
| Total population aged 65 and over predicted to have a learning disability | 1,007 | 1,128 | 1,237 | 1,349 | 1,574 |

Whilst it is projected that the number of the people with learning disability in younger age groups will fall steadily by 3% up to 2029, the number of those with learning disabilities aged 65 and over is predicted to rise by 56% up to 2029. The total change across all ages equates to an increase of 7% of the total population of people with learning disabilities by 2029.

Table 9 a and b provide baseline estimates for individuals in Cheshire West and Chester with moderate or severe learning disabilities likely to be in receipt of services through to 2029 by age group. Based on methodology in Emerson and Hatton (2004); figures based on estimate of prevalence across national population which have been applied to Cheshire West and Chester Population Projections, 2010.

**Table 9a**

| Age Group | Year | | | | |
|---|---|---|---|---|---|
| | 2011 | 2015 | 2020 | 2025 | 2029 |
| 19 – 24 | 257 | 246 | 237 | 240 | 246 |
| 25 – 34 | 178 | 187 | 205 | 211 | 207 |
| 35 – 44 | 261 | 223 | 207 | 230 | 252 |
| 45 – 54 | 239 | 244 | 224 | 188 | 176 |
| 55 – 64 | 185 | 182 | 204 | 215 | 204 |
| Total population 19 – 64 predicted to have a moderate or severe learning disability | **1,120** | **1,082** | **1,077** | **1,084** | **1,085** |

**Table 9b**

| Age Group | Year | | | | |
|---|---|---|---|---|---|
| | 2011 | 2015 | 2020 | 2025 | 2029 |
| 65 – 74 | 93 | 107 | 110 | 110 | 121 |
| 75 – 84 | 19 | 21 | 24 | 29 | 27 |
| 85 and over | 22 | 24 | 29 | 35 | 42 |
| Total population aged 65 and over predicted to have a moderate or severe learning disability | **134** | **152** | **163** | **174** | **190** |

The number of people in the younger age groups, diagnosed with moderate or severe learning disabilities is likely to decrease steadily by 3% by 2029, although the number of people in the older, 65 years and older age group with a moderate or severe diagnosis is projected to increase by 42% by 2029. Overall the total population with a diagnosis of moderate to severe learning disability will increase by around 2%. People with moderate to severe learning disabilities, are more likely to require the need for services than those with milder conditions, and therefore the development of future services needs to take account of the increase in populations likely to require services, and specifically, the particular requirements of an older client group.

The National Autistic Society state estimates may vary considerably. Many with Autistic Spectrum Disorders will not be known to services and will have adapted to overcome difficulties. Others may be able intellectually, but will still be in need of support owing to difficulties in social interaction and living independently. The total number of people aged 18-64 is projected to decrease by around 5% from 2011 to 2030, although there is estimated to be

an increase of 3-5% in 25-44 age groups with an Autistic Spectrum Disorder. The change is likely to reflect changing diagnostic patterns and those more recently diagnosed move into older age bands.

## EVIDENCE OF WHAT WORKS

### National Guidance

The Government's commitment to improving life chances and enabling people with learning disabilities to live full active lives was set out in the 2001 White Paper Valuing People.

A 2007 report Death by Indifference, released by Mencap provides a details summary of 6 cases believed to demonstrate institutional discrimination within the NHS, resulting in poorer health care and outcomes for people with learning disabilities. An independent inquiry into the report resulted in the publication of the Department of Health Report Healthcare for all (2008). Healthcare for All upheld concerns that people with learning disabilities had inequitable access to health care and received a poorer quality of care than they are entitled to. The report also identified evidence of significant levels of avoidable suffering and higher rates of avoidable deaths amongst people with learning disabilities. Healthcare for All made 10 clear recommendations for improving services and outcomes.

In 2007, the Department of Health issued a revised edition of the Mansell Report, first published in 1993. The 2007 report: Services for people with learning disability and challenging behaviour or mental health needs, provides good practice guidance and identifies actions that should be taken in order to effectively meet the needs of people with challenging behaviour.

The Government revised the 2001 white paper in a 2009 (Valuing People Now with Resource Pack), maintaining the principles of the 2001 white paper, incorporating the recommendations of the Healthcare for All report and placing a greater emphasis on inter-agency working to achieve the best possible outcomes for people with learning disabilities. Further to the Valuing People Now publication, a report of the Health Ombudsmen into the cases highlighted within Death by Indifference, Six Lives (2009), placed a requirement on the NHS and all social care organisations to review:

- the effectiveness of local systems to enable understanding and planning to meet the needs of people with learning disabilities
- the capacity and capability of services to meet the complex needs of people with learning disabilities.

The government's strategy to improve employment opportunities for people with learning disabilities was set out in the 2009 Valuing Employment Now paper.

Equal access? A practical guide for the NHS: creating a Single Equality Scheme that includes improving access for people with learning disabilities published in 2009 is a guide to support the NHS to include people with learning disabilities in their equality schemes, with practical examples of reasonable adjustments to achieve equality of access.

Improving the health and wellbeing of people with learning disabilities (2009) is a World Class Commissioning document that supports commissioners to meet the needs of people with learning disabilities, and ensure they are fulfilling their duty to promote equality.

Raising our sights: services for adults with profound intellectual and multiple disabilities (2010) report, commissioned as part of the Valuing People Now delivery plan, highlights the most important parts of planning and delivering support for people with the most complex needs.

In 2010, the first Autism Strategy for England was published, Fulfilling and rewarding lives: The strategy for adults with Autism in England to help kick-start fundamental change in public services helping adults with autism to live independent lives and find work and sets out a clear framework for all mainstream services across the public sector to work together for adults with autism.

The Learning Disability Observatory was established in 2010 to provide better, easier to understand information on the health and wellbeing of people with learning disabilities. By collecting information from across England, it will act as a resource to inform health and social care commissioners and providers and provide better understanding of the needs of people with learning disabilities, their families and carers.

There is currently no NICE guidance available relating to learning disability, however, NICE published Clinical Guideline for Autism (CG128: Autism in children and young people) in September 2011. This guidance identifies key recommendations for implementation:

- Local pathway for recognition, referral and diagnostic assessment of possible autism
- Autism diagnostic assessment for children and young people.
- Communicating the results from the autism diagnostic assessment.

The Guidance does not cover in depth social care needs or service requirements and refers only to children and young person up to 19 years of age.

## Local Guidance

The joint Cheshire West and Chester, NHS Western Cheshire Learning Disability Strategy 2010-13 identifies 10 key overarching objectives based on national and local priorities and consultation. The Cheshire West and Chester Learning Disabilities Partnership Board are continuing to work towards developing their action plan coordinating delivery of the strategy.

## SERVICE USER VIEWS

As part of the development of the Cheshire West and Chester Learning Disabilities strategy 2010-13 a consultation process was undertaken with people with learning disabilities, carers and family members who are currently engaged in services. A series of facilitated semi-structured focus groups were conducted. Overall 53 people took part. In addition to the focus groups, an easy read questionnaire was designed and distributed. The consultation process focussed on key themes around relationships, information, transport, health, housing, training and employment. Based on the consultation, appropriate recommendations were made and included in the strategy.

The primary consultation took place with people with learning disabilities and their families and carers who are currently engaged with services. As such these were likely to have moderate to severe disabilities. The initial consultation did not identify the unmet needs of those currently not known to services or who may have less severe forms of learning disability.

Through engagement with key stakeholders within the Local Authority, NHS Western Cheshire, the Learning Disabilities Partnership Board and carers groups; a scoping exercise in the form of a facilitated discussion has been undertaken to assess some aspects of unmet needs. This qualitative scoping exercise was informed by work by the Centre for Public Scrutiny (2008) designed to scrutinise health and social care topics.

The exercise took place in December 2011. The facilitated discussion involved parent carers and a representative from a third sector care facility.

Key issues highlighted in discussion:

- There was recognition there have been improvements in the uptake of annual health checks and health action plans, but more progress needed.
- There are a number of cross-border issues with neighbouring boroughs in terms of access to appropriate services and communication between services.
- Poor attitude/awareness/communication from some health staff. This varies between facilities but reduced standards of awareness were highlighted.
- Lack of understanding/awareness results in staff appearing frightened or not knowing how to cope with challenging behaviour
- Appointments are often difficult when there is a lack of general awareness or lack of awareness of an individual's need – such as the maintenance of routine.
- When there are unplanned admissions, the Patient Passport is useful but can be large – a brief or concise cover with bullet points may provide sufficient pertinent information
- to facilitate a better patient experience. This concept may also be useful in other scenarios outside of healthcare.
- The facilities for parents/carers to stay overnight in the case of an admission should be reviewed.
- There are communication problems between healthcare providers where assumptions are made surrounding ownership of care. Carers would welcome a 360 degree approach to health care and other needs as part of a global assessment
- Service users' treatment and access to services are dependent upon a diagnosis. This leaves gaps in services for those with less severe diagnosis or where there is an overlap in care with other conditions such as dementia.

- There was recognition of the work surrounding transition planning. Again, this requires more progress. A concern was there appears to be no recognition of other phases of transition where those with a learning disability may fall between services.

    - There is a gap between the level of services provided for children and adults. This introduces risks for those who lose access to a level services normally provided to children, but with no similar or replacement service for adults
    - As carers become older, the ability to care diminishes and greater support is needed
    - The needs of service users changes over time and can be compounded with more complex health needs
    - Those with ASC who do not meet the criteria for the definition of learning disability may enter “crisis” and have unmet and unrecognised need.
    - Carers are unaware of who to contact during “crisis”
    - There is a separation between the differing groups of carers i.e. younger parents who do not have access to sharing the experiences of the older carers

- There was a level of uncertainty surrounding the future of service provision in light of cost efficiency savings

**UNMET NEEDS AND SERVICE GAPS**

- Many people who have learning disabilities may have a number of have unmet needs, either as a consequence of a failure in diagnosis or difficulties in accessing services, lost during transition phases or being excluded from services due to different criteria. It is difficult to determine how many individuals this concerns or where they are located and therefore this issue concerns a wide cross-section of services and not solely those designed to meet specific needs of people with learning disabilities.
- Using national estimates it is suggested that just over 1,250 adults should be known to services locally, this is slightly more than recognised locally (about 1,000 adults) but still represents a higher proportion of our total population compared nationally. These national estimates also suggest that, similarly to elsewhere, there are possibly 4,600 people who are living within the community independently without receiving special help. These people will largely be those with mild learning disabilities.

- There is a need to consolidate Supporting People Housing Floating Services to ensure that this service maintains a role as a “safety net” for clients who may be in crisis and ensure they meet their role in enabling greater independent living.
- Despite progress in improving the number of adults who have received an annual health check and the uptake of practices for the Learning Disabilities Directed Enhanced Service, there is still room for improvement and a need to improve the identification and recording of patients with mild to moderate learning disability on primary care registers. This must be seen as a route to identifying unrecognised health needs and enhance the primary care offer to adults with learning disability
- Whilst local population projections identify a relatively static or slightly declining population of people with moderate to severe learning disabilities in the next 5-20 years, the predicted populations of people with learning disabilities in the older (65+) age groups is anticipated to increase significantly. This highlights a shift in the type of service provision that may be required to support a changing client demographic. Future service needs should consider these changing needs.

## RECOMMENDATIONS FOR DECISION MAKERS & COMMISSIONERS

- Ensure the recommendation of the Supporting People Housing Needs Assessment, to increase provision of floating services over accommodation based services to enable greater independent living.
- Provide greater access to floating services for clients not eligible for Fair Access to Care Services including those with mild or moderate need.
- Ensure that all providers and commissioners deliver the specific recommendations and requirements of Six Lives and Healthcare for All.
- Increase numbers of people with learning disabilities who are in settled accommodation.
- Increase capacity for people with learning disabilities to enter supported employment and increase the proportion of those in paid employment.
- Learning disability awareness training should be rolled out within primary and secondary care health settings to facilitate a greater depth of understanding and facilitate appropriate care pathway development.

- Continue to commission Learning Disabilities Directed Enhanced Services and ensure completion of health checks on all eligible persons and enhance mechanisms to ensure active case finding of people with learning disabilities to help facilitate appropriate access to services for those who need them.
- Wider workforce development plan should address current issues such as developing understanding of personal budgets, availability of assistive technology and such like.
- Ensure services remain fit for purpose in light of likely future population changes, including additional services to cater for the needs of older persons with learning disabilities.

## RECOMMENDATIONS FOR NEEDS ASSESSMENT WORK

- A more in-depth understanding of the needs of those with Autistic Spectrum Conditions or challenging behaviour
- A more in-depth understanding of health needs identified as part of annual health checks and use of healthcare services

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