

Chapter 7: People with a Learning Disability

Key Issues:

- The projected number of people aged 18+ with learning disability in Wirral is expected to remain approximately the same from 5,600 in 2011, to 5,561 in 2030.
- People with learning disability have lower life expectancy than the general population and are more likely to have undiagnosed long term conditions.
- 'Valuing People Now' expects planners to take account of the issues for people with complex needs; from black and racial minority communities; with autistic spectrum conditions, and those who have committed criminal offences. However, it was recognised that comprehensive and robust information systems need to be developed by the NHS and Councils to make this happen.
- 'Valuing People Now' says that residential care should continue to be available for those who actively choose it, but more emphasis is needed on alternative ways of providing the housing that people want and the support they need to live in it.
- Nationally and in Wirral, people with learning disabilities experience some of the lowest levels of employment of any working age group. To address this, there has been significant development of national policy and local approaches in the profile of employment as a mainstream life option for people with learning disabilities.
- Local people with learning disability have stated the importance of using plain language so that they can understand issues about their care.
- Sir Jonathan Michael's Independent Inquiry (Healthcare for All, Independent Inquiry into Access to Healthcare for People with Learning Disabilities, 2008) highlighted "basic and serious shortcomings in the way that services are provided for people with learning disabilities, contributing to poorer health outcomes, avoidable suffering and at worst, premature deaths."
- More people with a learning disability now have their disability recorded on GP registers. There is still a need for more local data on the health status of people with a learning disability. Health checks provided in GP practices are valuable for patients with a learning disability and work needs to continue to identify 'reasonable adjustments' which could be made to health services to reflect the specific needs of people with learning disability
- The 'green light toolkit' has been used to help people say what they liked or didn't like about our services for people with learning disabilities in 2009 compared to 2005. People said that planning and access to care was better, but care processes, equality, engagement and service design and delivery could improve.
- The Coalition Government has endorsed Valuing People Now and has stated that employment remains a significant priority for future action. In addition, the Government's vision for Adult Social Care, as set out in *A Vision for Adult Social Care: Capable Communities and Active Citizens* (DH, 2010), actively encourages the use of personal budgets for employment.

- To increase the number of people with a learning disability who are self employed and/or in employment, a specific target (NI 146) was set nationally. Although this target has now expired, Wirral will continue to monitor it, as delivering this target will make an important contribution to achieving Wirral's wider economic priorities to reduce worklessness; improve skills for sustaining employment; improve the health and well-being of the most vulnerable communities and reduce the persistent inequalities experienced by some groups of people.
- A national survey identified that people with learning disabilities may be at increased risk of hate crime; there is little understanding of this in the general population and within community safety initiatives.
- In order to improve housing outcomes for people with learning disabilities, a key priority is to develop a comprehensive understanding of the current and future supply of housing and accommodation options available locally. The data collection to inform this needs analysis will be an ongoing process in order to respond to the changing needs of the client group.

'Valuing People Now', published in January 2009 is the Government's three-year strategy for people with learning disabilities. The implementation of 'Valuing People Now' is supported by a Valuing People Now Delivery Plan (February 2009) and "World class commissioning for the health and wellbeing of people with learning disabilities" published in November 2009. Both documents emphasise a need for PCTs and Social Services to develop a comprehensive needs assessment which seeks evidence on the numbers, health needs and experiences of people with learning disabilities. Wirral has addressed this in our Strategic Commissioning Framework for people with Learning Disabilities approved by Council's Cabinet in January 2010.

The coalition government has reinforced its support for Valuing People Now and has funded the Learning disability public health observatory (LDPHO) for the next 2 years (2011) until March 2013.

The Learning Disability Public Health Observatory operates under the title of improving health and lives (IHAL) <http://www.improvinghealthandlives.org.uk/>. Its resources have been used to support the development of JSNA.

Definition of learning disability

The definition of 'learning disabilities' is as follows:

“a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood with a lasting effect on development.”

Source: Valuing People: A new strategy for learning disability for the 21st Century, Department of Health, 2001

The presence of a low intelligence quotient, for example an IQ below 70, is not a sufficient reason for deciding whether an individual receives additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments.

Learning disabilities does not include all those who have a 'learning difficulty' which is more broadly defined in education legislation.

The definition covers adults with autism who also have learning disabilities, but not those with autism who may be of average or even above average intelligence, such as some people with Asperger's Syndrome. However people on the autistic spectrum may have communication difficulties and problems accessing universal health services effectively and should also be treated on the basis of their needs, with similar allowances made as for those with learning disabilities.

7.0: Local Indicators

There are four national indicators which stopped on 31st March 2011 that relate to learning disabilities. Wirral has continued to collect the data, so from 1st April 2011, these can now be described as local indicators:

The indicators used are outlined below;

- NI 130 – Social care clients receiving Self Directed Support
- NI 145 – Adults with learning disabilities in settled accommodation
- NI 146 – Adults with learning disabilities in employment.
- NI135 – Carers receiving specialist carers services

In addition, Sir Jonathan Michael's Independent Inquiry (Healthcare for All, Independent Inquiry into Access to Healthcare for People with Learning Disabilities, 2008) highlighted “basic and serious shortcomings in the way that services are provided for people with learning disabilities, contributing to poorer health outcomes, avoidable suffering and, at worst, premature deaths.”

The following information (7.0.1 to 7.0.4) illustrate Wirral's performance in respect of these 4 key indicators.

7.0.1: NI 130 - Social care clients receiving self-directed support per 100,000 population, Wirral 2009/10 and 2010/11

NI130 illustrates the Number of clients and carers receiving social care through self directed support as a percentage of the total number of clients receiving community based services and carers receiving carers' specific services in the year to 31st March aged 18 and over.

Year	Indicator
2009/10	5.55%
2010/11	31.57%

Source: Wirral PIMS July 2011

In 2010/11 Wirral has increased the percentage to 31.57% from 5.5% in 2009/10.

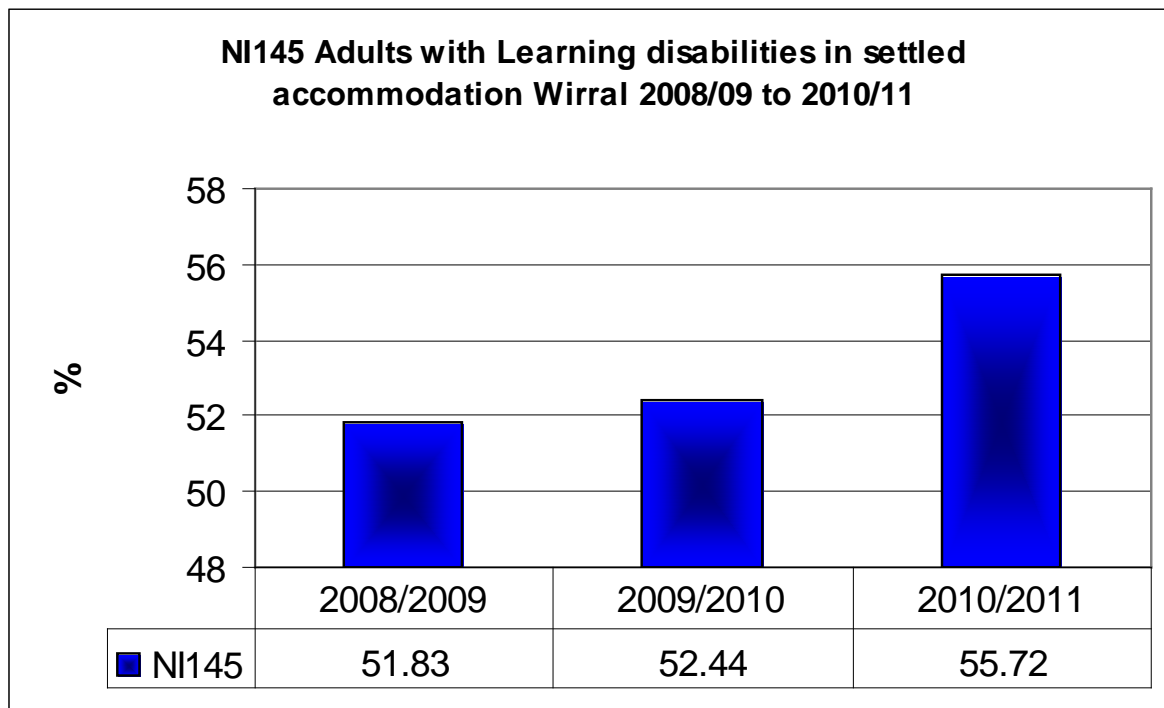
Information was collected for carers receiving Direct Payments for the first time in 2008-09, this was collected for a full year by age group and young carers aged 16-17 are included in the 18-64 group. Therefore, the 2008-09 indicator is not comparable with previous years. In 2009-10 the definition of this indicator expanded to include those clients and carers receiving self directed support via a direct payment and/or a personal budget. Therefore, the indicator value for 2009-10 is not directly comparable with 2008-09

To be counted, the person (adult, older person or carer) must:

- be getting a direct payment; or
- have in place another form of personal budget which meets all the following criteria:
 - The person (or their representative) has been informed about a clear, upfront allocation of funding, enabling them to plan their support arrangements; and
 - There is an agreed support plan making clear what outcomes are to be achieved with the funding; and
 - The person (or their representative) can use the funding in ways and at times of their choosing.

7.0.2: NI 145 - Adults with learning disabilities in settled accommodation, Wirral 2008/09 to 2010/11

NI145 illustrates the percentage of adults with learning disabilities known to Councils with Adult Social Services Responsibilities (CASSRs) aged 18-64 in settled accommodation at the time of their assessment or review in the financial year who had received a service, as well as those assessed and/or reviewed but who have not received a service.



Source: Wirral PIMS July 2011

The indicator is intended to improve settled accommodation outcomes for adults with learning disabilities – a key group at risk of social exclusion.

Settled accommodation: Refers to accommodation arrangements where the occupier has security of tenure/residence in their usual accommodation in the medium- to long-term, or is part of a household whose head holds such security of tenure/residence. The accommodation types that represent settled accommodation for the purpose of this indicator are:

- Owner Occupier/Shared ownership scheme (where tenant purchases percentage of home value from landlord)
- Tenant – Local Authority/Arms Length Management Organisation/Registered Social Landlord/Housing Association
- Tenant – Private Landlord
- Settled mainstream housing with family/friends (including flat-sharing)
- Supported accommodation/Supported lodgings/Supported group home (accommodation supported by staff or resident caretaker)
- Approved premises for offenders released from prison or under probation supervision (e.g. Probation Hostel)
- Sheltered Housing/Extra care sheltered housing/Other sheltered housing
- Mobile accommodation for Gypsy/Roma and Traveller community

Non-settled accommodation: Refers to accommodation arrangements that are precarious, or where the person has no or low security of tenure/residence in their usual accommodation and so may be required to leave at very short notice. The accommodation types that represent non-settled accommodation for the purpose of this indicator are:

- Rough sleeper/Squatting
- Night shelter/emergency hostel/direct access hostel (temporary accommodation accepting self referrals)

- Refuge
- Placed in temporary accommodation by Local Authority (including Homelessness resettlement) – e.g. Bed and Breakfast
- Staying with family/friends as a short term guest
- Acute/long stay healthcare residential facility or hospital (e.g. NHS or Independent general hospitals/clinics, Long stay hospitals, specialist rehabilitation/recovery hospitals)
- Registered Care Home
- Registered Nursing Home
- Adult placement scheme
- Prison/Young Offenders Institution/Detention Centre
- Other temporary accommodation

This information was collected for the first time in 2008-09 and so is not shown for previous years. The first year of collection should be treated with caution as it may not be as robust as information that has been collected for a number of years.

Information for the numerator in 2008-09 was only collected for the second half of the year and then doubled to represent the full year, although this does not take into account any seasonal trends and differing local practices. Councils whose numerator then exceeded the denominator have had the indicator value capped at 100 per cent.

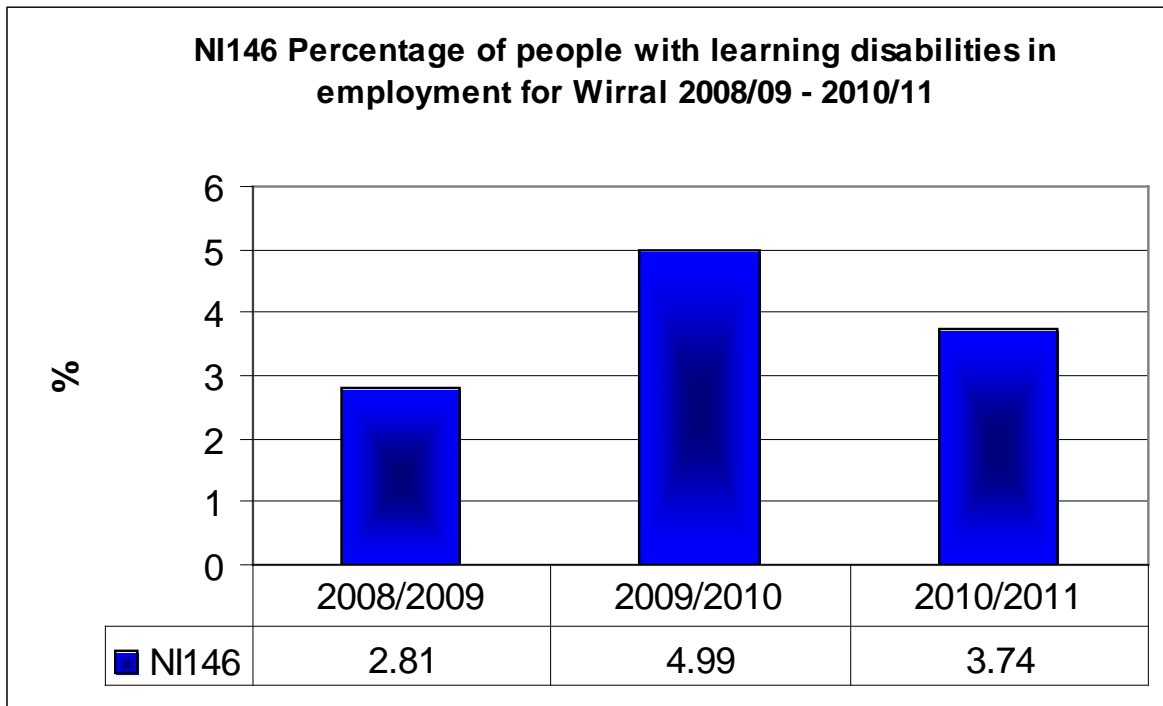
The information for the numerator was collected for the full year in 2009-10 and therefore, data for 2009-10 will be more robust.

7.0.3: NI 146 – Percentage of people with learning disabilities in employment

The indicator is intended to improve the employment outcomes for adults with learning disabilities – a key group at risk of social exclusion.

NI146 illustrates the percentage of adults with learning disabilities known to Councils with Adult Social Services Responsibilities (CASSRs) in paid employment at the time of their assessment or latest review aged 18 – 64 who are assessed or reviewed in the financial year and who have received a service as well as those who are assessed and/or reviewed but who have not received a service.

This information was collected for the first time in 2008-09 and so is not shown for previous years. The first year of collection should be treated with caution as it may not be as robust as information that has been collected for a number of years. Information for the numerator in 2008-09 was only collected for the second half of the year and then doubled to represent the full year, although this does not take into account any seasonal trends and differing local practices. Councils whose numerator then exceeded the denominator have had the indicator value capped at 100 per cent.



Source: Wirral PIMS July 2011

The information for the numerator was collected for the full year in 2009-10 and therefore, data for 2009-10 will be more robust

Paid employment is measured using the following categories:

Working as a paid employee or self-employed for; 30 or more hours per week, 16 to less than 30 hours per week, more than 4 to less than 16 hours per week, more than 0 to 4 hours per week or working regularly as a paid employee or self-employed but less than weekly (e.g., fortnightly, monthly or on some other regular basis)

Categories above are to be combined to report on the per cent of learning disabled clients known to CASSRs in paid employment.

The indicator will also collect data on those in voluntary unpaid work using the following categories:

- Working as a paid employee or self-employed and in unpaid voluntary work
- In unpaid voluntary work only
- Unpaid voluntary work: Work of a voluntary nature that is unpaid, including unpaid work experience.
- The unpaid voluntary work categories are not to be included in the count of those who are in paid employment.

Data for this indicator is to be reported by gender and type of service that the client is receiving, that is, community based service, residential care service or no services.

- Community based services are services provided to support clients living in the community.
- Residential care services include the following:
 - LA residential care (excludes short-term residential). Residential care provided by the CASSR.

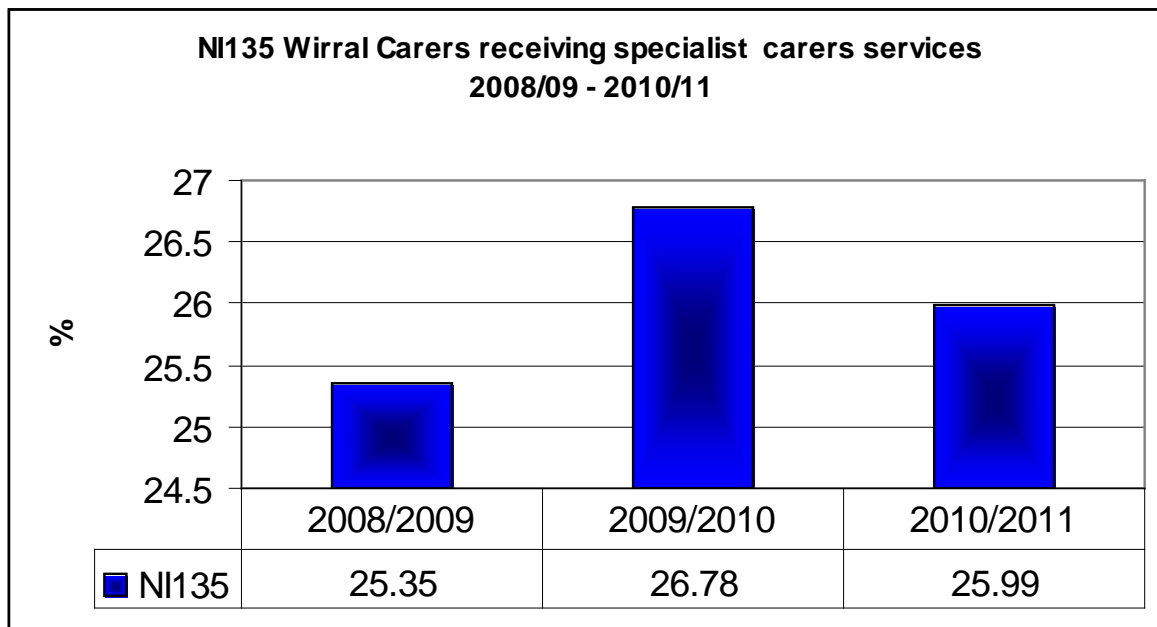
- Independent sector residential care (excludes short-term residential). Includes residential care provided by another CASSR. Also includes adult fostering.
- Nursing care (excludes short-term residential).

7.0.4: NI135 – Carers receiving specialist carers services

Support for carers is a key part of support for vulnerable people. Support for carers also enables carers to continue with their lives, families, work and contribution to their community. This measure provides a measurement of engagement with, and support to, carers.

The number of carers whose needs were assessed or reviewed by the council in a year who received a specific carer’s service, or advice and information in the same year as a percentage of people receiving a community based service in the year.

The guidance regarding Carers' Services was revised in 2008-09 and so caution should be taken when comparing this indicator over time.



Source: Wirral PIMS July 2011

7.1 Socio-demographics

7.1.1 Population

Current population

- It is difficult to obtain precise information on the number of people with learning disabilities living within a population. However, Valuing People Now (2009) and Improving the health and wellbeing of people with learning disabilities (2009) provide some estimates, as does the work of Emerson and Hatton (2004). The work of Emerson and Hatton and websites Projecting Older People Population

Information (POPPI) / Projecting Adult Needs and Service Information (PANSI) and IHAL (The Improving Health and Lives Learning Disabilities Observatory) are used as a data source. These sites were developed by the Institute of Public Care (IPC) for use by local authority planners and commissioners of social care provision in England, together with providers and supporting organisations. It is a programme designed to help explore the possible impact that demography and certain conditions may have on populations aged 18-64 (PANSI) 65 and over (POPPI).

- There is an expectation in national guidance about the information that NHS commissioners and Councils need to know about their local populations to commission local services. This comes with a recognition that authorities will need to set out a plan to improve the collection of required information.

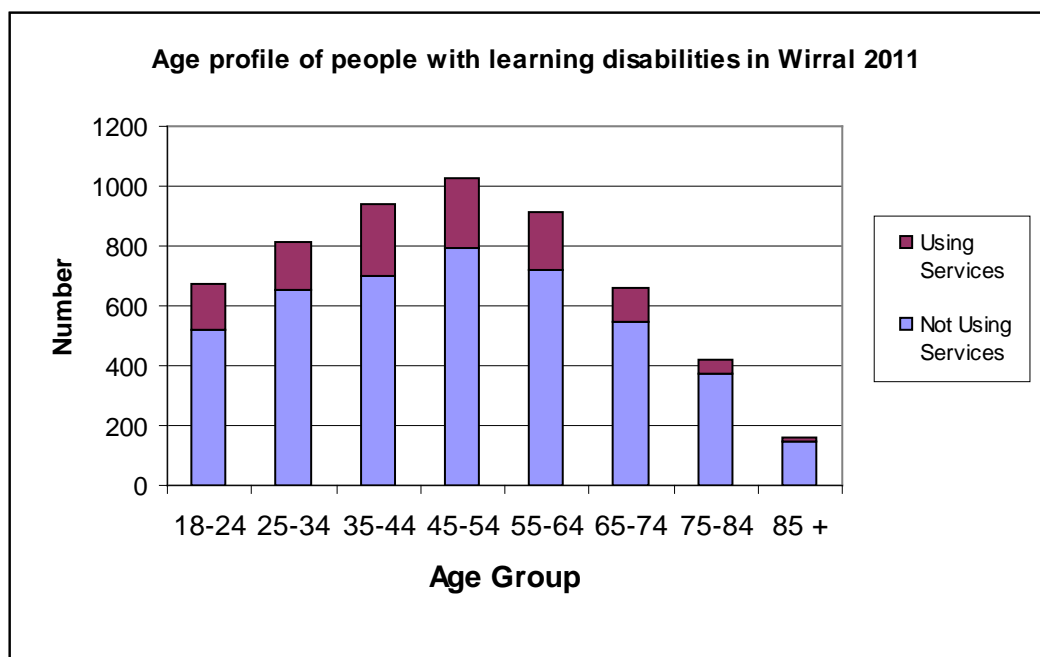
Emerson and Hatton's work on the prevalence of learning disability (Emerson and Hatton, 2004) offers estimates that were used by the Department of Health's Learning Disability Task Force. They have estimated that the current 'true' prevalence of learning disabilities in England (i.e. the total number of people with learning disabilities) is 2% of the population but the proportion of people using specialist learning disability services is 0.46%. Based on this national research, prevalence of learning disability in Wirral amongst Wirral adults for 2011 (18 years and above) can be estimated:

- 1144 with moderate and severe learning disabilities expected to be using services of which 166 at age 65 and above;
- 5,600 true prevalence (total) including people with mild to moderate learning disabilities.

(Source: PANSI / POPPI 2011)

The chart below indicates the estimated number of people with learning disabilities by age profile in Wirral for 2011 showing the proportion of each age group using services and those not using services. Figure 7.1.1

Figure 7.1.1: Age profile of the estimated number of adults with learning disability in Wirral, 2011



Source: POPPI & PANSI website 2011

Future numbers of people in Wirral with learning disabilities

The number of people (both children and adults) with a learning disability has increased considerably (Association of Directors of Social Services, 2005). The three main factors are:

- Children are surviving into adulthood with major/ complex disabilities.
- Adults are living longer and surviving into older age.
- There is a higher prevalence of learning disabilities reported among younger people from South Asian, black and minority ethnic communities.

Over the period 2009- 2030 it is predicted that nationally there will be a:

- 13% increase in adults with severe learning disabilities;
- 17% increase in people with mild to moderate learning disabilities.

This increase in numbers is significant in older people:

- 43% increase in people aged 65-84 with a moderate or severe learning disability.
- 100% increase in people aged 85+ with a moderate or severe learning disability.

Ethnicity

The Centre for Research in Primary Care at the University of Leeds was commissioned by the Department of Health to conduct a scoping study of services for people with learning difficulties from minority ethnic communities [Mir G, Nocon A, Ahmad W, Jones L. Learning Difficulties and Ethnicity. London: Department of Health, 2004.] The study consisted of a review of the literature and interviews with key respondents.

While people with learning difficulties from minority ethnic communities and their carers face considerable problems in accessing relevant services, there were also examples of approaches and projects which seek to meet their needs more appropriately. The main points highlighted in this report were as follows.

- Minority ethnic communities face substantial inequalities and discrimination in employment, education, health and social services.
- The higher prevalence of learning difficulties in South Asian communities has been linked to high levels of material and social deprivation. These may combine with other factors such as poor access to maternal health care, misclassification and higher rates of environmental or genetic risk factors.
- People with learning difficulties from minority ethnic communities experience simultaneous disadvantage in relation to race, impairment and, for women, gender. Negative stereotypes and attitudes held by service professionals contribute to the disadvantage they face.

The ethnicity of people in receipt of LD services from Wirral Department of Adult Social Services is very similar to the general population of Wirral. Figure 7.1.1a shows a comparison between England, the Wirral population and adults known to Wirral Council during period April 2010 to March 2011 compared to the estimates from the office for national statistics 2007 mid year estimate of ethnicity for Wirral.

Figure 7.1.1a Ethnicity of population compared to Learning Disability Population

	England	Wirral	People with LD aged 18+ known to Wirral Council
Black or Black British (includes Black Caribbean, black African and other Black)	2.70%	0.42%	0.22%
Chinese or other ethnic group	1.63%	0.71%	0.65%
Mixed Ethnicity (includes White & Black Caribbean, White & Black African, White & Asian and other mixed)	1.09%	0.88%	0.22%
No ethnicity recorded	..	0.06%	0.22%
Not stated/refused	1.19%
White (includes British, Irish, Traveller of Irish heritage, Gypsy, Roma and other)	89.26%	97%.0	97.50%
Asian or Asian British (includes Indian, Pakistani, Bangladeshi)	5.31%	0.93%	..

Source: Office for National Statistics and Wirral Department of Adult Social Services ASC-CAR

* England data from ONS Mid 2007

As shown 3% of adults and older people with disabilities who are receiving services from Wirral Council are non white ethnic origin, similar to the Wirral estimates of 2.5%. However there were no people known to Wirral Council from the Asian or Asian British grouping whilst National studies indicate a higher prevalence of learning disability in South Asian communities.

A breakdown of ethnicity of people on GP practice registers, with a learning disability, will enable further analysis. These figures will be collated in order to provide additional baseline data.

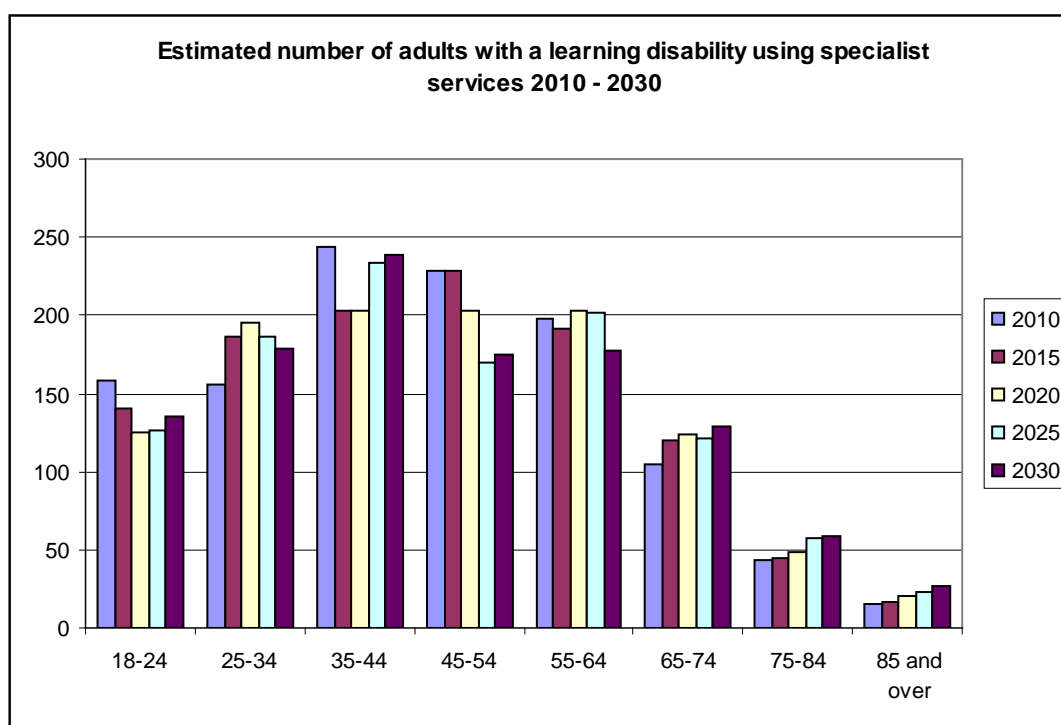
In addition the Wirral Learning Disability Partnership Board Citizenship Sub Committee is starting work with the North West Training & Development Team to develop ways to secure better engagement of people with learning disabilities from minority ethnic communities, which may bring forward groups of people currently not in contact with services.

Estimates of Use of Services by People with Learning Disabilities in Wirral

Figure 7.1.1b shows numbers of adults estimated to be using specialist services, defined as having moderate to severe learning disabilities in Wirral. The PANSI and POPPI websites where this data comes from do not differentiate between health and social care services.

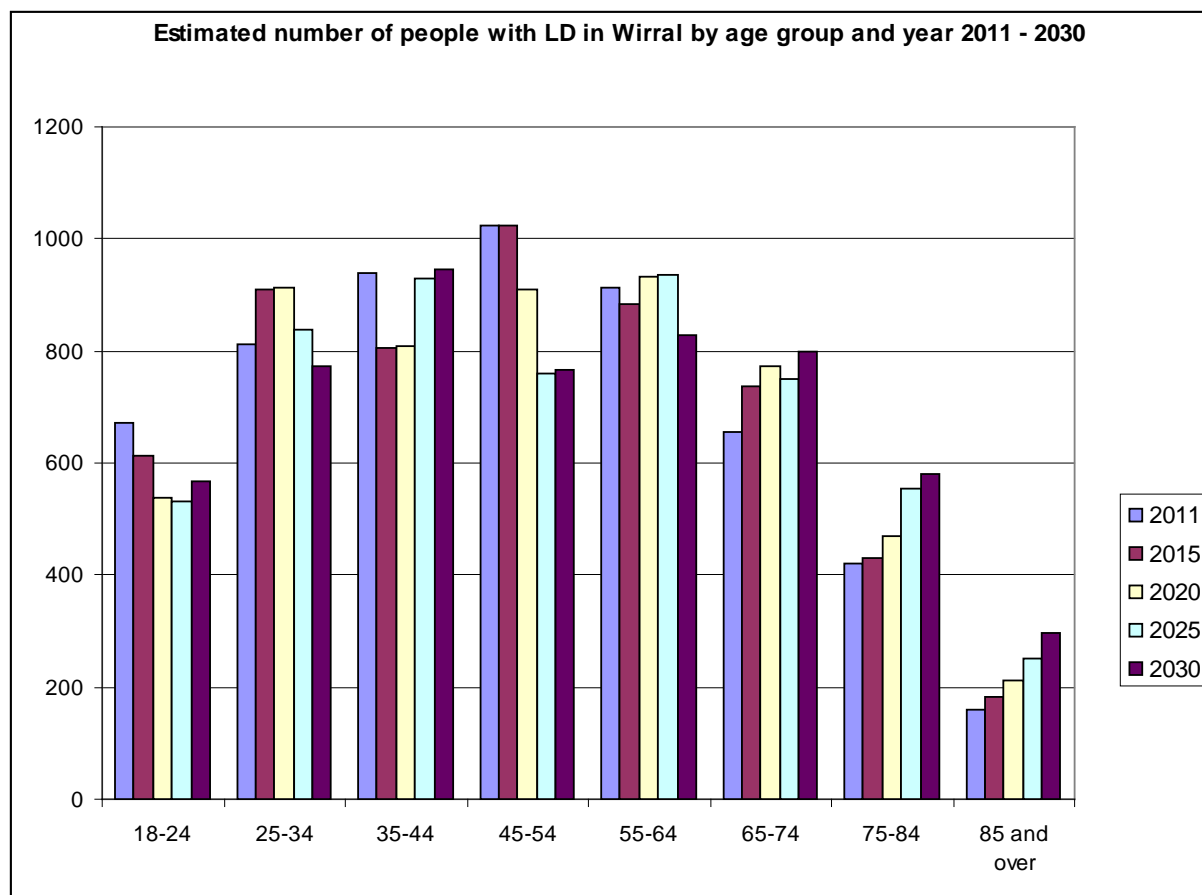
Figure 7.1.1c shows the estimated total number of adults with learning disabilities, this includes people with mild learning disabilities and people who would not be known to services.

Figure 7.1.1b: Projected number of adults with a learning disability using specialist services in Wirral (2010-30)



Source: POPPI/PANSI websites, 2011

Figure 7.1.1c: Projected number of adults living with a learning disability in Wirral (2011-30)



Source: POPPI/PANSI websites, 2011

GP practice recorded prevalence of learning disabilities

The number of people with a learning disability recorded on Wirral GP practice registers at April 2011 (as part of the Quality Outcomes Framework/QOF), are shown in table 7.1.1d.

The total has increased considerably since the last update of the JSNA in February 2010 because all but two GP practices in Wirral have now signed up for the Designated Enhanced Scheme (DES) to provide annual health checks to people with a learning disability.

Table 7.1.1d: QOF learning disability registers, April 2010 to March 2011

Area	No. adults with a learning disability	Rate per 1000 population*
Wirral GP Commissioning Consortium (GPCC)	689	5.4
Wirral Health Commissioning Consortium (HCC)	626	3.9
Wirral NHS Alliance	185	4.2
Wirral	1500*	4.5

Source: QMAS, 2011

* 18 years and over

- The rate of individuals having learning disabilities is much higher in Wirral GP Commissioning Consortium, perhaps indicating there is a link between poverty and learning disabilities as identified in the Michael report “Whilst the incidence of severe learning disability is relatively evenly spread across the population, mild to moderate learning disability is linked to poverty and nationally incidence rates are higher in deprived and urban areas (Sir Jonathon Michael).”
- Another local factor would be the location of a variety of larger residential and supported living facilities for people with learning disabilities in the vicinity of Birkenhead Park. More than half of the adults on the GP registers of learning disabilities live in the most deprived areas.
- National estimates of learning disability prevalence would predict a considerably higher number of people for Wirral (5600) compared to the total number of people recorded on GP registers in Wirral. Therefore a proportion of people with a learning disability are not being recognised or recorded on GP registers.

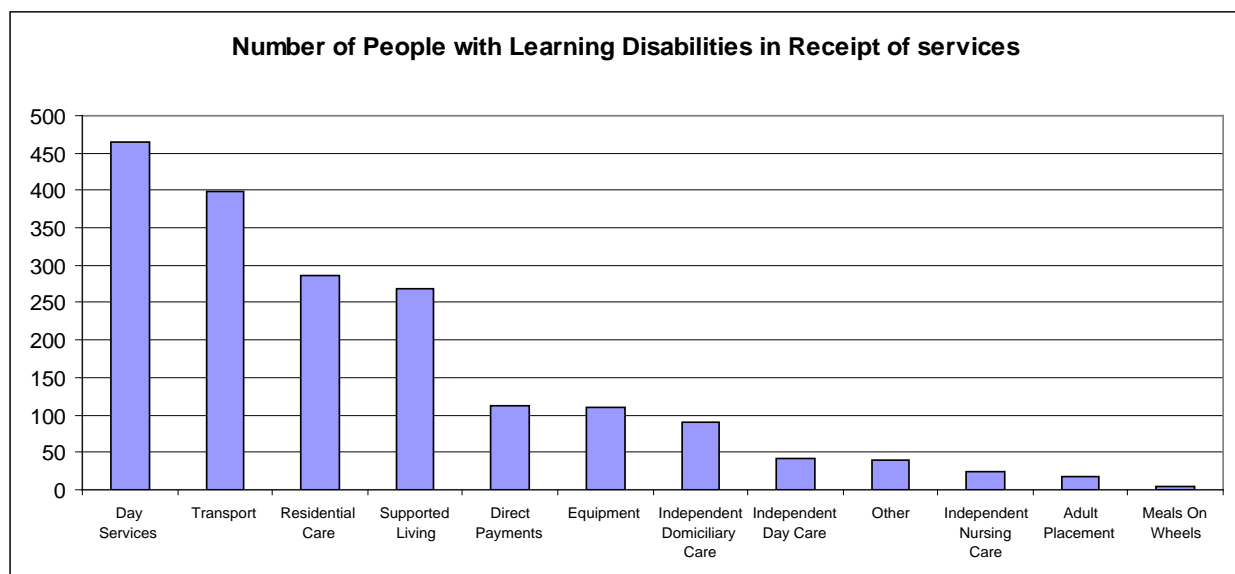
During the year 2010/11 893 with learning disability received a health check from their GP with 1799* recorded on GP clinical systems. The total has increased considerably since the last update of the JSNA in February 2010 because all but two GP practices in Wirral have now signed up for the Designated Enhanced Scheme to provide annual health checks to people with a learning disability.

*all ages

People with Learning Disabilities Using Adult Social Care Services

The number of people recorded to be in receipt of Adult Social Care Services with a Learning Disability is outlined in figure 7.1.1e below

Figure 7.1.1e. Number of people in receipt of services known to Local Authority



Source: Wirral Department of Adult Social Services - SWIFT

The total number of people receiving services (as shown in Figure 7.1.1e.) is 984 with 46% receiving 1 service, 26% receiving 2 services, 21% receiving 3 services, 6%

receiving 4 services and 1% receiving 5 services. With a total of 1862 services provided to 984 people. (source Swift 2011)

Autistic Spectrum Disorders

Definition of Autism

Within the National Autism Strategy, autism is defined as a lifelong condition that affects how a person communicates with, and relates to, other people. There are three main areas of difficulty: social communication, social interaction and social imagination

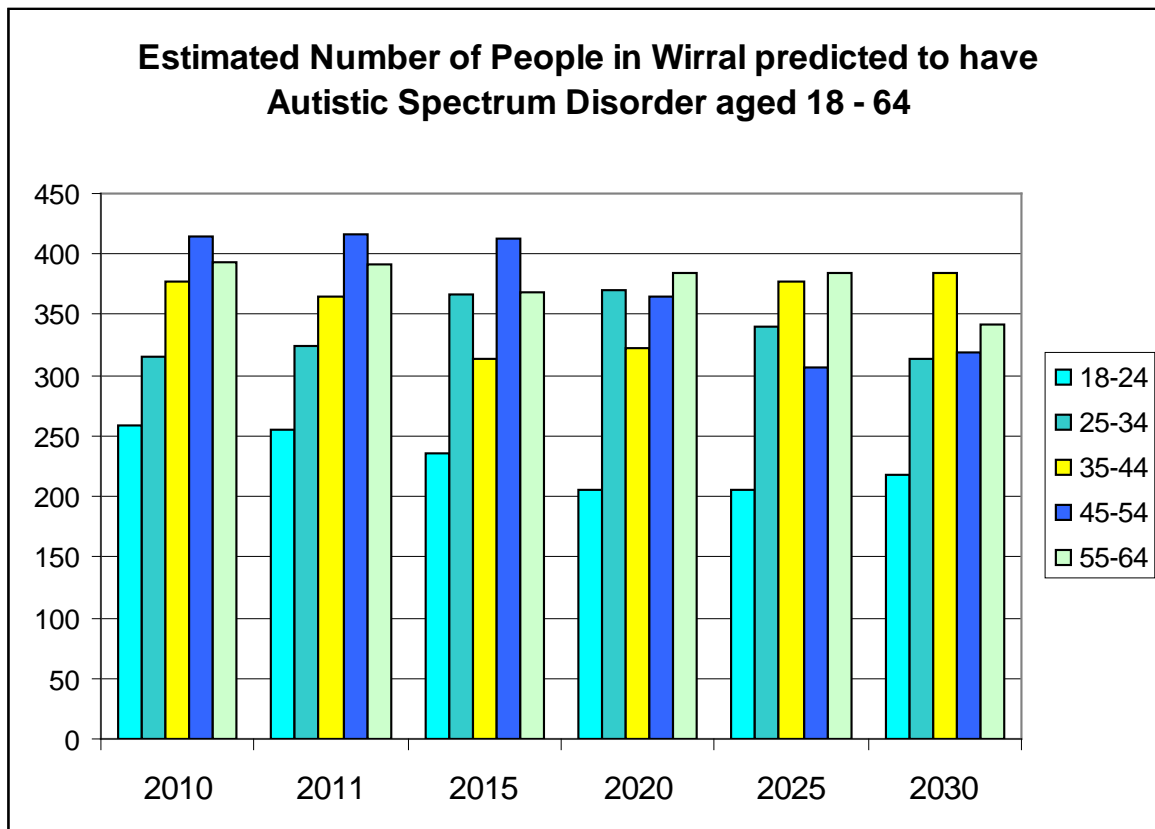
National Position

Information about ASD is based on Autism Spectrum Disorders in adults living in households throughout England: Report from the [Adult Psychiatric Morbidity Survey 2007](#) was published by the Health and Social Care Information Centre in September 2009.

The prevalence of ASD was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case. The rate among men (1.8%) was higher than that among women (0.2%), which fits with the profile found in childhood population studies.

Autism Spectrum Disorders (ASDs) are developmental disorders characterised by impaired social interaction and communication, severely restricted interests and highly repetitive behaviour.

7.1.1f: Number of people in Wirral estimated to have Autistic Spectrum Disorder



Source: PANSI 2011

Autism in Wirral

Wirral does not have detailed information about the numbers of people who may be expected to have autism. Prevalence data is based on studies of children and there is some suggestion that the extent of autism may vary in different parts of the UK. However based on figures from the National Autistic Society there are likely to be approx 2830 people in Wirral who would be on the autism spectrum, this figure is made up as follows

- 704 people aged 19 and below
- 467 are adults with learning disability
- 1659 adults who do not have learning disability are likely to be on the spectrum (some of whom may have been diagnosed with Asperger's Syndrome in childhood). It is from this latter group of 1659 that we would expect a percentage of people to have a diagnosis of Asperger's Syndrome.

National evidence and other sources indicate that whilst the diagnosis of autism in children is improving, diagnosis into middle age and beyond in adults is still common.

The Autism Act 2009 requires NHS bodies to ensure robust diagnostic pathways and that post diagnostic support is made available via NHS bodies and Local Authorities. The National Institute for Health and Clinical Excellence (NICE) is developing a new clinical guideline for adults with autism that will set out a model care pathway (or pathways), which will form the foundation for local commissioners to develop referral and care pathways in their areas. As part of this, NICE will consider how to make the diagnostic process more accessible and consistent. This work is not scheduled to be published before July 2012.

Some of the issues that people with autism face are:

- social and economical exclusion
- Services that are not available consistently; different adults with autism in the same area will have very different experiences
- Risk of severe health and mental health problems, homelessness, and descent into crime or addiction for those without support.
- Although many adults with autism make successful and important contributions to their communities, the economy and their families, too many are dependent on benefits.

Examples of good practice include:

- Making adjustments for people with autism, for example not having to use waiting rooms.
- Taking account of hypersensitivities and providing quiet or lower-light areas, scheduling appointments at less busy times and allocating extra time.
- Preliminary visits to allow adults with autism to familiarise themselves with settings.
- Avoiding ambiguous questions, not pressurising adults with autism in conversation and being aware of sensitivity to touch, ensuring essential documents and forms are available in accessible formats – in particular, easy read and formats that take account of sensory issues in their choice of colours.

The Autism Act 2009 requires:

- the provision of relevant services for the purpose of diagnosing autistic spectrum conditions in adults;
- the identification of adults with such conditions
- the assessment of the needs of adults with such conditions for relevant services;
- planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults;
- other planning in relation to the provision of relevant services to adults with autistic spectrum conditions;
- the training of staff who provide relevant services to adults with such conditions;
- local arrangements for leadership in relation to the provision of relevant services to adults with such conditions.

Actions that local health and social care organisations will need to take will include:

- Increasing awareness and understanding of autism among frontline professionals.
- Contribute to developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment.
- Improving access for adults with autism to the services and support they need to live independently within the community
- Helping adults with autism into work.
- Working with local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

7.1.2 Income

There is little available data about the income levels of people with learning disabilities, there are a number of reasons for this, including:

- Poverty may be masked if a person lives with their parents or other family members;
- People in residential care do not have access to the full range of benefit entitlement and there are examples of people with learning disabilities not being seen as capable of managing their own finances;
- Separate information about the number of people with a learning disability who claim incapacity benefit or disabled living allowance is not available.

It is however known that people with a learning disability are less likely to be in paid employment (see employment Section).

7.1.3 Employment

There are varying national estimates available that demonstrate that people with learning disabilities are severely under-represented in the workplace:

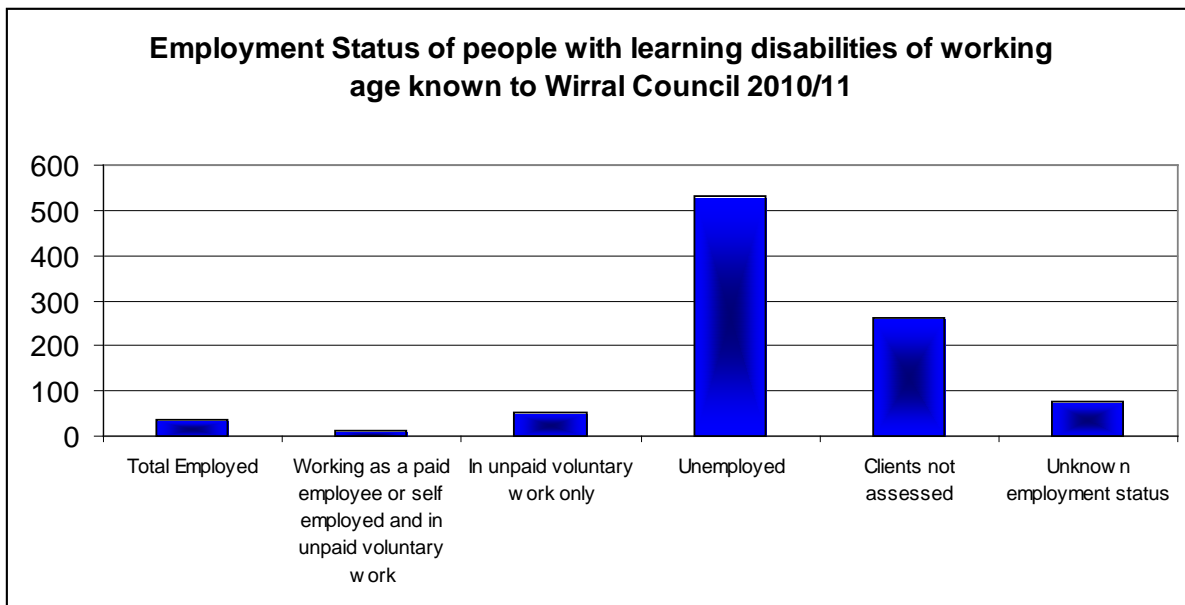
- An estimate of 17% of people with learning disabilities in work was made in an English National Survey ¹
- The latest data from NI 146 shows an overall employment rate for people “known to social services” of 6.4% ². This is likely to be closer to 12% for those known to social services but not assessed or reviewed in the financial year.
- The Labour Force Survey puts the overall employment rate for disabled people at 46%, but the average employment rate for people with severe or specific learning difficulties (a broader category than those receiving social services) over the past two years at 15% ³

These figures compare with 78% employment for the general population and 46% for the disabled population⁴. Overall, the employment rate for disabled people has been rising, but this has not been the case for the population of people with learning disabilities. As highlighted in the State of the Nation report: Poverty, Worklessness and Welfare Dependency in the UK (Cabinet Office, June 2010), people with learning disabilities have a significantly lower employment rate. There is, therefore, a considerable disadvantage to be overcome if people with learning disabilities are to be more equitably included in the workforce.

Employment Status of people with learning disabilities of working age known to Wirral Council 2010/11

The chart below illustrates the number of people known to Wirral council between the age of 18-64 and their employment status;

Figure 7.1.3a Employment status of people with learning disability known to Wirral council.



Source: Wirral Council, Department of Adult Social Services

Note: Total Employed includes working as paid employee or self-employed 30+ hours, between 16-30 hours, between 4-16 hours, between 0-4 hours and working regularly as paid employee but less than weekly.

¹ Commission for Social Care Inspection 2007/08

² “Employed” includes people working as an employee or self-employed. “Known to social services” includes people aged 18-64 who were assessed and/or reviewed in the financial year

³ This average is taken over the last eight quarters of data available from the quarterly Labour Force Survey

⁴ Labour Force Survey

Figure 7.1.3a shows 4% (n=36 people) are in the total employed category, whilst 55% (n=531) are in the unemployed category.

If this data is representative of Wirral overall, within the estimated population of people with learning disability (n=5600), then this could mean the total number of people with a learning disability who are unemployed would be 3080 (55%).

Valuing Employment Now says that 65% of people with learning disabilities would like a paid job and sets a target that by 2025: '*any disabled person who wants a job, and needs support to get a job, should be able to do so*'. A number of actions are outlined to achieve this goal:

- i. *Growing the presumption of employability*
- ii. *Joint working to create employment paths for individuals*
- iii. *Better work preparation at school, college and adult learning*
- iv. *The role of personal budgets and social care to support adults with learning disabilities into work*
- v. *Increasing high quality job coaching*
- vi. *Clearing up confusion about the benefits system*
- vii. *Promoting self-employment*
- viii. *Encouraging employers to see the business case*
- ix. *Better support for the most excluded adults with learning disabilities*
- x. *People with learning disabilities and their families leading the way*
- xi. *Better data and performance management*

Reflecting this, a commitment to support more people with a learning disability to access and stay in paid work is an agreed priority for Wirral partners. Achieving this requires a co-ordinated approach across a range of public, private and voluntary organisations, and local employers.

An Employment action plan is being developed by the Learning Disability and Employment sub-group of the LDPB, through engagement with representatives of all key stakeholders including people with a learning disability and their families.

A conference was held on learning disabilities and employment in Wirral in October 2009 "Valuing People Now Making It Happen In Wirral". The majority of people who came to the conference had a learning disability and the top issues and suggestions were;

- Wirral Council and NHS Wirral could do a lot more to employ people with learning disabilities.
- Not everyone needs training to get into employment.
- Need to help employers identify where to go when employing people with a learning disability.
- Need to raise expectations/aspirations of people with learning disabilities living in poorer areas.
- All jobs are valuable – whether cleaning or packing - people can progress – a job is a job.
- Being in employment increases a person's circle of friends and increases self-esteem.

- Give young people with disabilities aspirations of working.
- Person Centred Planning should include aspirations for employment.
- Payment/ benefit difficulties
- Too much red tape in getting people into employment.
- Employers need more support.
- Universal employment agencies need to address the needs of people with learning disabilities
- Emphasis should be on the 'ability' to do a job rather than a 'disability'.

The Learning Disability Partnership Board includes a clear commitment to progress local implementation of *Valuing Employment Now*. It is also essential to make sure that the employment of people with learning disabilities is prominent in wider economic strategies. Wirral Council has, together with partners, long recognised the need to prioritise the economic well being of the Borough through increasing investment and enterprise, and reducing economic inactivity. Our Investment Strategy is a cornerstone of Wirral's plans for economic growth and plays a vital role in our Economic Recovery Plan: 'Planning for Recovery' our response to the recession, to address structural issues and to maximise the competitiveness and the long term growth of Wirral businesses.

Labour market indicators show a mixed picture, with some fundamental economic strengths and challenges for Wirral's economy. These include:

Strengths

- Gross Value Added (GVA) per capita (a key measure of economic performance) has increased over the past decade
- Wirral has a young, well skilled and educated population
- Excellent communication links for access to domestic and global markets and supply sources - Wirral sits at the centre of a unique SuperPort region
- Wirral is committed to developing a world class digital infrastructure to boost economic competitiveness
- A consistent and significant increase in new business start ups in the last 4 years
- Over the last 12 months, reductions in Wirral's Job Seekers Allowance (JSA) rates have been faster than the Liverpool City Region, North West and England
- Some world class businesses based in Wirral including Unilever, Bristol Myers Squibb, significant developments in Wirral's maritime sector

Challenges

- The lowest GVA per capita in England, although Investment Strategy initiatives have seen an increase - which is expected to continue with imminent significant opportunities
- Very low job density of 0.58 which means that there are 58 jobs per 100 working age residents
- Significant concentrations of Economic Inactivity in disadvantaged communities in England
- Above average levels of Economic Inactivity across the Borough - almost 34,000 people.
- JSA rate which is above North West and England rates

- Wirral's economy is predominantly made up of small or medium sized businesses.
- More than 40,000 residents currently travel outside Wirral to access higher paid employment in the wider region
- Wirral is the 8th most deprived area for employment as measured by English Indices of Deprivation
- Low levels of VAT registered businesses
- A number of poorly performing employment sites and a limited office market

In response to this, Wirral is committed to radically grow our economy to increase the overall number of jobs, and ensure that all Wirral residents have the skills and opportunities to move into and maintain employment. This includes increasing the role of the private sector, given that Wirral's economy has a high proportion of public sector jobs which may be adversely affected by central government budget reductions. However the commitment to increase the numbers of people with Learning Disability in public sector employment locally is still a key priority.

While the employment rate of disabled people in Britain overall has risen steadily, that of people with learning disabilities is much lower – just 10% for people receiving adult social services. We have a big challenge ahead as only 15 of all of the people with a learning disability of working age, known to social services are in paid jobs.

Wirral's emerging Learning Disability Employment Strategy sets out a number of specific actions to address these issues, and ultimately ensure that people with a Learning Disability have the most effective support to get (and maintain) a job.

7.1.4 Education, skills and training

The focus of education for adults with learning disabilities in Wirral is around developing knowledge and skills for employment. A strategic approach including an employment sub group that reports to the various partnership boards is in place. This group ensures a partnership approach and an efficiency of resources.

Wirral's emerging LD and Employment action plan will map employment needs and opportunities across the spectrum of learning disability.

People with learning disabilities need approaches to support them into and in work that reflect their individual needs. Where people have mild levels of learning disabilities, pre-vocational training offered through some mainstream welfare to work programmes may be appropriate and effective.

However, as levels of learning disability increase, pre-vocational and qualifications-based training may be less effective, and more intensive supported employment approaches strategies may be needed. Analysis of the skills and employment aspirations of social services registered clients is essential in order to identify whether a supported employment approach is appropriate.

Local authorities spend considerable resources on day services, further education and adult education for people with learning disabilities. Partners are reviewing this. For more people with learning disabilities to move into employment, local authorities will need to ensure that the employment support they commission, and the approaches

taken to employment within day services, suit the needs of the individual. A shift and reallocation of resources towards supported employment may be required.

7.1.5 Accommodation

‘Valuing People Now’, the national strategy for People with Learning Disabilities gave high profile to housing. Amongst the Key Policy Objectives was the requirement that “all people with learning disabilities and their families...will have an informed choice about where and with whom they live”. This was expanded upon in the associated delivery plan in which it was stated that it was imperative “to increase the range of housing options for people with learning disabilities and their families”

Following on from this, Valuing People Now also says that whilst residential care should continue to be available for those who actively choose it, more emphasis needs to be placed on alternative ways of providing the housing that people want, and the support they need to live in it. Possibilities include people with learning disabilities being supported to live in their own home as owners or tenants or being supported to share with a group of friends. Independent supported living can be enjoyed by people with very high or complex needs as well as those with fewer needs, because the support is tailored to their particular requirements. This was identified in the evaluation of Department of Health’s extra care housing pilot programme for people with learning disabilities, *A Measure of Success* (CSip, 2008).

The Strategy recognised that most people with learning disabilities live with their families. Often they leave the family home only as the result of a crisis such as the illness or death of the carer. The Government wishes to see better forward planning by local councils so that carers do not face continuing uncertainty in old age and their sons and daughters gain greater independence in a planned way.

Current accommodation type used by people with a learning disability

A snapshot of people with learning disabilities current accommodation type in March 2011 showed that there were:

- 122 people in residential/ nursing care homes
- 170 people in supported living schemes
- 16 people in adult placements
- 14 people in independent / NHS long stay hospitals

This makes a total of 322 people.

It is likely that those people whose accommodation is not recorded are living with their family or otherwise independently outside formal schemes.

In July 2011 in Wirral there were:

43 residential and nursing care homes registered with the Care Quality Commission⁵, offering 366 beds for people who have a learning disability.

The Care Quality Commission data gives detail of ‘supply’ rather than ‘need’. However, homes report that there are only a few vacancies at any time.

⁵ Taken from the CQC Directory of Care Services

Out of borough placements

There were 48 people placed out of Wirral by the NHS or the Department of Adult Social Services in 2011. This has reduced from 50 people in 2010. The breakdown is shown in table 7.1.5a.

Table 7.1.5a: Type of accommodation of out of borough placements in 2011

Type of Accommodation	Number of People
Secure Hospital or Independent Hospital	6
Nursing Home	2
Residential Home	28
Supported Living	12
Total	48

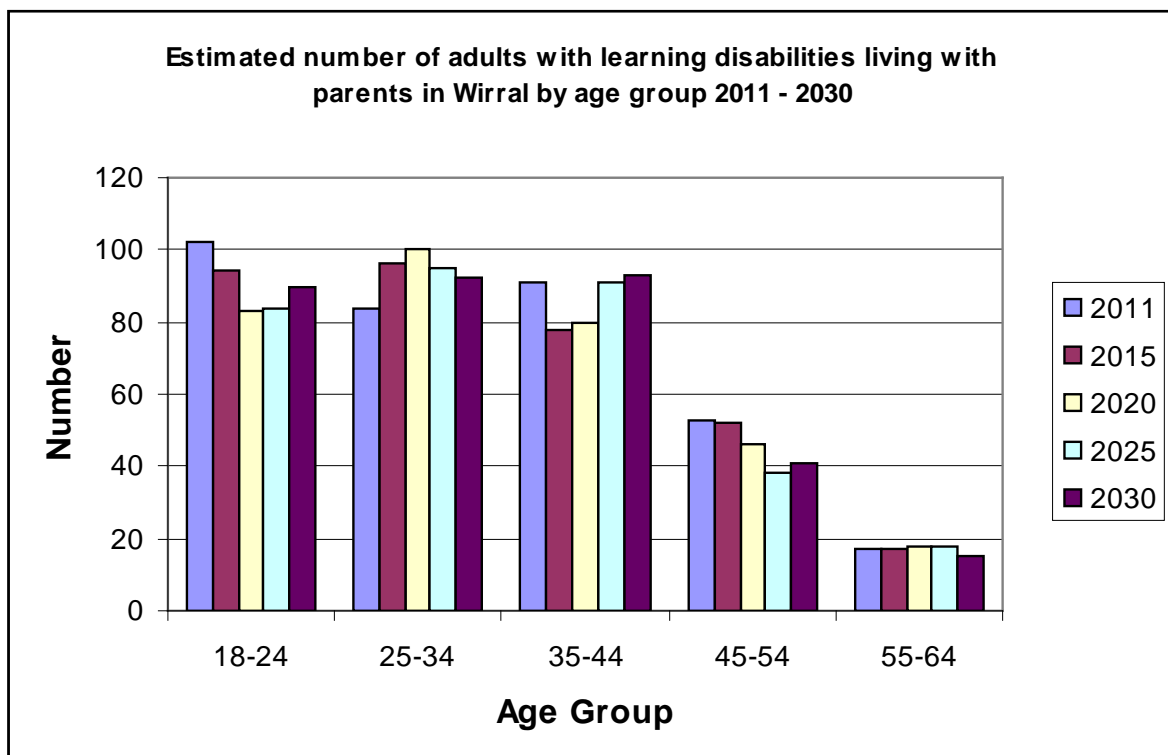
Source: Wirral Council Adult Social Services Department (Finance section)

People who are placed out of area must be reviewed regularly by health or social services professionals to ensure the continued appropriateness of their placement and where possible, to start planning their return to Wirral. Nine Wirral people are placed in neighbouring local authorities (Ellesmere Port & Neston or Liverpool) to maintain links with relatives, but it is expected that approximately half of these 48 people could return to Wirral over time.

People with learning disabilities living with family carers

According to the PANSI Website, it is estimated that the number of adults with learning disabilities living with parents is 347 see 7.1.5a.

Figure 7.1.5.a: Estimated number of adults with learning disabilities living with parents



Source: PANSI website, 2011

Wirral has an ageing population; this is also true of the learning disabilities community. Many carers are reaching retirement age or are already retired. As they grow older carers have increasing health problems. Confronting health issues and death is difficult. Some carers and the person with learning disabilities are mutually dependent on each other for day to day life. All these issues need sensitive handling and time to resolve.

As the carers register is voluntary therefore not every carer in Wirral will be included on the register. The lack of a comprehensive carers register means that obtaining accurate figures for people needing services is difficult. There are one or two referrals a month for people with learning disabilities aged 40 yrs+ who were not previously known to services.

The recording of a patient's status as a carer is also a consideration for the future. Patients should ideally inform their practice and GP that they are a carer and Practices need to be sensitive to knowing when patients are carers but are not necessarily reporting themselves as such. These variations in reporting lead to inconsistencies in the accuracy of the data and so the subsequent analysis can be questioned.

The PANSI Figures above indicate that there could be 161 older carers known to learning disability services:

- Parents / carers in their sixties - 91 families
- Parents / carers in their seventies – 53 families
- Parents / carers over 80 years – 17 families

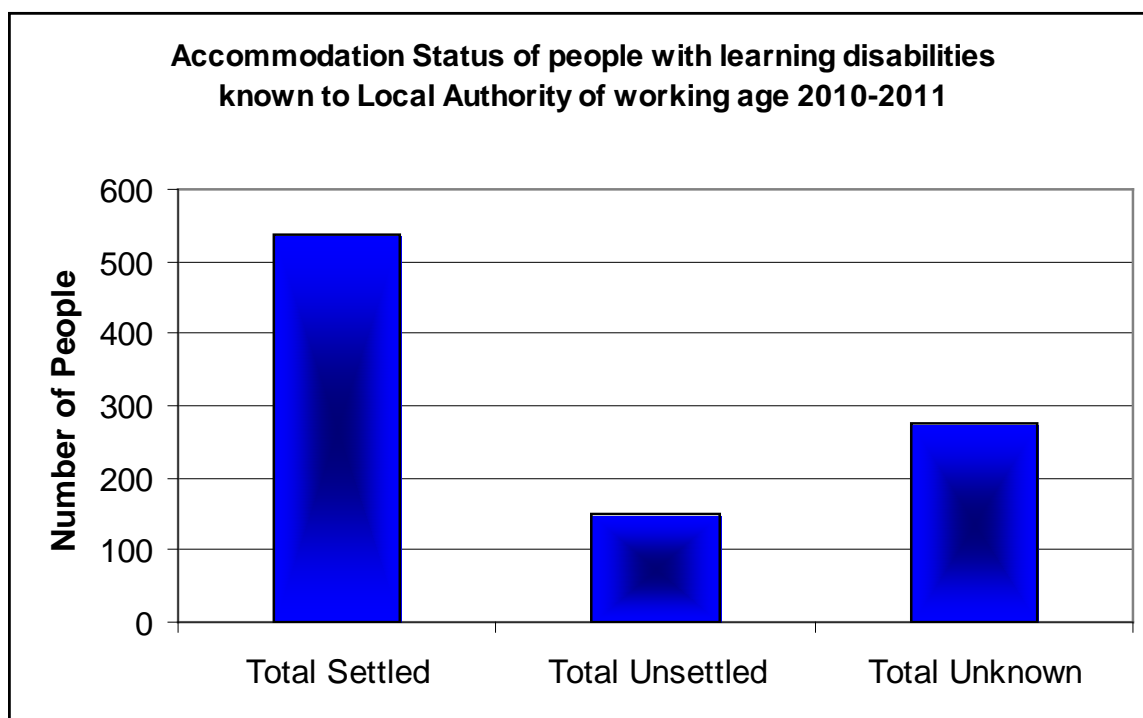
For more information on Carers, see Chapter 8

Accommodation status of people with learning disabilities known to Local Authority

The chart below illustrates the number of people with learning disabilities known to Wirral Council the categories include;

1. Settled Accommodation – includes owner occupier/shared ownership, tenant (local authority or private landlord), living with parents, accommodation supported by staff or resident caretaker, adult placement scheme, probation hostel, sheltered housing mobile accommodation for Gypsy/Roma or Traveller
2. Unsettled Accommodation – includes Rough sleeper/squatting, temporary accommodation accepting self referrals, refuge, temporary accommodation by Local authority (e.g. bed and breakfast), Acute long stay hospital/residential facility, registered care/nursing home, prison and any other temporary accommodation.
3. Unknown – includes unknown accommodation status and those clients who were not assessed in the year April 2010 to March 2011

Figure 7.1.5b Accommodation status of people with learning disability known to the local authority



Source: Wirral Council: Department of Adult Social Services 2011

- 537 people were recorded as being in settled accommodation
- 149 in unsettled accommodation
- 275 people with learning disability are recorded as unknown accommodation status or were not assessed during the financial year April 2010 to March 2011

The Wirral Strategic Commissioning Framework for people with learning disabilities (2010) reflects a will to facilitate people’s access to housing of their choice, including:

- more people receiving personal budgets and direct payments to increase their choice and control over where they live and with whom;
- local authority care managers to have an increased understanding of housing options and housing tenures for People with Learning Disabilities and
- Through person centred planning, work with people still living with families to establish if that is the person’s preferred option and to instigate plans accordingly.

The Housing Strategy 2011- 2026 sets out key actions to better understand and evidence the current level of learning disability housing needs in the Borough. This will form the basis of a Housing Plan for people with learning disabilities to be in place by December 2011.

A Housing sub group of the LDPB has been established in recognition that further work around accommodation options needs to be undertaken. This group includes members of Housing Strategy, Supported Housing, Re-housing Services, Health, Social Care and Registered Providers. The primary objective of this group is to plan for, and respond to, the current and future housing needs of people with Learning

Disabilities through the development of the LD Housing Plan in order to improve housing outcomes for people with learning disabilities.

In order to achieve this, it is a key priority of the group to develop a comprehensive understanding of the current supply of housing and accommodation options that are available locally, and to have information about the future viability and sustainability of the current supply of housing. The data collection to inform this needs analysis will be an ongoing process in order to respond to the changing needs of this client group and will also contribute to subsequent iterations of the JSNA.

The purpose of this 'Stock-take' is to develop a comprehensive picture of the current format and volume of housing options available to People with Learning Disabilities. This will provide the 'baseline' by which future changes to the supply of housing options can be made in response to the needs and the expectations of people with learning disabilities, their carers and other partners.

In order to develop a sufficiently robust needs analysis on which to base commissioning decisions, it will be necessary to use a combination of traditional sources of information, such as prevalence data and more sophisticated mapping techniques such as the assessment of the 'fitness for future purpose' of current supported housing and residential care services and the use of GIS (Geographical Information Systems) to show geographically the variation between the provision of residential care and supported housing services and the actual locations where adults with learning disabilities live now and wish to live in future

Therefore the groups main area of work is to give people with learning disabilities and their families information about housing options including the range of opportunities for supported living in the private and social sector and to enable a more strategic, focussed approach to commissioning housing which offers both choice and the appropriate level of support.

The group will:

- Ensure that the housing needs of people with a learning disability are recognised and addressed in Wirral Council's Housing Strategy 2011 – 2026
- Develop action plans to ensure increased number of people living in settled accommodation to support the requirements of NI145.
- Identify the housing needs of people with learning disabilities including the identification of the number of people with learning disabilities living with family carers over 70 and those with complex needs
- Evaluate current information available regarding housing options, existing research and examples of good practice, to inform the development of a housing plan.
- Develop protocols to address pathways into housing between Housing department/DASS & NHS Wirral and local housing providers
- Confirm arrangement and responsibilities for reviewing the housing needs of new clients both FACS and Non FACS.
- Develop information which is currently not available linked to access to housing protocols.

The housing plan will address;

- The potential savings through a reduction in the use of residential care which place major funding pressures on councils.
- The “Ordinary Residence rules” that have been an obstacle preventing some people moving from residential care to supported living.
- The Turnbull Judgment has reduced flexibility in providing supported living for some people with the most complex needs and the issues of funding sufficient living space for people with complex needs
- How the council will work collaboratively with providers, many of whom are keen to develop alternative models
- Acknowledge and maximise the potential of Assistive Technology

There have also been some innovative developments in the use of assistive technology to support people with learning disability and a CSED review of Cheshire’s Learning Disability Service found that “People with learning disability have been enabled to remain in their own home for longer rather than moving on to more restricted settings and have been able to move out of residential back to the community. Additionally people who would have needed to be supported in residential settings have been supported in the community with the use of Assistive Technology.” As such, the *Strategic Commissioning Framework for People with Learning Disabilities in Wirral* confirms that the range and use of Assistive Technology solutions to promote independence, choice and control for people with Learning Disabilities will increase.

Young people in transition to adulthood

Transition from child to adulthood is a time of celebration, change and challenges for all young people. This can be especially challenging if a young person has complex health needs, learning or physical disabilities.

Additional support at transition to adulthood is vital to enable disabled young people to gain independence, choice and control over the assistance they need, and achieve their aspirations.

Transition planning starts at Year 9 at school (aged 14) and transition support can continue until a young person is either supported in adult services or reaches the age of 25 years old.

Wirral have a Transition Services team. This consists of transitional social workers, representatives from connexions, local education and health services to ensure that young people have their holistic needs met.

The link below is to the transition directory and transition pathway that can support young people and their parents / carers to the correct resources.

<https://www.i-choosewirral.org.uk/CAP/Index.aspx?SiteMapId=371>

Wherever possible, transition plans and year 9 reviews (at 14 years old) should address future accommodation choices and contain a section on health needs and start the development of a health action plan (Valuing people Now).

Within Wirral there are 79 y aged young people 14-16 with a learning disability and 11 young people aged 16+ with a learning disability.

7.1.6 Keeping People Safe

The Government has seen keeping people safe as a priority. This is reflected in a whole section of the annual Health Self Assessment and Performance Framework relating to Safeguarding. In addition, on 2nd June 2011, in response to the BBC's recent Panorama programme about the abuse of patients with learning disabilities at a hospital near Bristol (Winterbourne View), the health secretary announced an independent review and said that "People with a learning disability should be able to lead their lives free from fear and discrimination and receive the care and support they need."

The review is to find out what happened at Winterbourne View from all the people and organisations that had something to do with the patients at the hospital. It will find out the facts, find out what needs to be changed in the system and learn lessons for the future. It will help the Government decide what needs to be done to keep people safe.

Wirral Adult Safeguarding Partnership Board

The Adult Safeguarding Partnership Board (ASPB) has recently revised its Terms of Reference, sub-committee and Board membership to reflect the seniority of office it requires. In addition, Governance arrangements were further established to reflect national learning and good practice.

The chair has now been replaced with the chair of Children's Safeguarding Board, who will now chair the business of both Boards. A key business priority for the Board was to establish a business plan with plans based on local need.

The Board revised and drafted safeguarding procedures which included the management of serious incidents and Serious Case Reviews. From December 2010 to March 2011, three cases were referred and one multi-agency review is being conducted using the National Social Care Institute of Excellence (SCIE) model recommended in the Munro Review for child protection.

The Board is developing a local budget against the business priorities and beginning an audit of agencies with safeguarding responsibilities. The development of a dataset for the Board was agreed which included the national indicator set, but also included some local indicators. The data set used in 2010 was included within the ASPB business plan and annual report and referred to the number of contacts/alerts that concerned adults at risk who had a) mental health issues b) learning disabilities c) physical disability and those who were using substances.

Contacts to the Local Authority Central Advice and Duty Service for learning disability cohort is the highest category and mainly concerns peers.

There has been an ASPB training plan published for agencies who work across the partnership to access from contains level 1 –level 3 training. This includes general

awareness raising to advanced level for those who have responsibility to investigate safeguarding concerns about adults at risk.

Hate Crime

Valuing People Now committed the Home Office and the Department of Health to work together to tackle hate crime against people with learning disabilities.

Definition

Hate Crime is any incident whereby the perpetrator's prejudice against any identifiable group of people is a factor in determining who is victimised.

The effects of Hate Crimes can be widespread and long lasting. Physical or verbal assaults, for example, may lead people to feel isolated and vulnerable, rendering many to curtail their movements, remain in their home, give up jobs or even move house.

The National picture

Higgins (2006) found that perpetrators of Hate Crimes against people with learning difficulties are generally adults leading everyday lives aged 16-44 years.

The Hate Crime National Survey (Lamb and Redmond, 2007) identified hate crime as a significant problem for many people with learning difficulties. This survey found that these problems are not always being dealt with or reported. The findings support the following actions:

- We need to know which crimes happen and who they are happening to;
- We need to know who is committing these crimes;
- Learning Disability and Community Safety Partnerships need to work together;
- Advocacy Groups and Learning Disability Partnership Boards should be represented on Community Safety Partnerships;
- We need to find ways to make sure that staff in the different organisations talk to each other and share information about Hate Crimes against people with learning difficulties.

Nationally 80% of advocacy groups and 75% of partnership boards have identified that Hate Crime was an issue. By comparison most Crime Reduction Partnerships had not (only 43.1%).

Mencap's Living in Fear Survey (1999) found that 88% of people with learning disabilities reported being bullied in the last year.

Hate Crime – The Cross-Government Action Plan published in 2009, set out what steps agencies should take to tackle hate crime, increase reporting, and support victims. Action points included:

- Identify current resources that could support people with learning disabilities in reporting hate incidents and hate crimes. Explore further development and dissemination of these resources.
- The publication of a new national policy on prosecuting cases involving victims and witnesses with learning disabilities and/or mental health needs.

- National Director of Learning Disabilities and Home Office to work together to identify and disseminate good practice on tackling all hate incidents and hate crimes against people with learning disabilities. This will engage with existing forums and groups of people with learning disabilities.
- Develop guidance for Learning Disability Partnership Board on hate incidents and hate crime against people with learning disabilities. This will include guidance on:
 - monitoring the number of hate crimes / incidents reported against people with learning disabilities,
 - preventing hate incidents and hate crimes;
 - empowering and supporting people with learning disabilities who are victims of hate crime; and
 - Strengthening the link between the Board and the local Crime and Disorder Reduction Partnership to ensure that multi-agency responses meet the needs of people with learning disabilities.

7.2 Health and Wellbeing

Drawing upon previous studies, the Sir Jonathon Michael Independent Inquiry (2007) and the recently published World Class Commissioning guidance on the health and well-being of people with learning disabilities (DH November 2009) provided some data relating to the health and wellbeing of people with learning disability. The World Class Commissioning Guidance suggested that patterns of ill health amongst this population are manifested differently to patterns of ill health in the general population.

7.2.1 Health Issues

- People with learning disability are 58 times more likely to die before the age of 50 than the general population.
- Around one person in three with learning disabilities is obese, compared with one in five of the general population.
- Coronary heart disease is the second most common cause of death in people with learning disability.
- The incidence of respiratory disease is three times higher in people with learning disability than in the general population.
- 40% of people with learning disability have a hearing impairment and many have common visual impairments.
- The rate of dementia is four times higher and that of schizophrenia three times higher than in the general population.
- People with learning disabilities tend to have substantially less bone density and experience higher levels of osteoporosis.
- Epilepsy is 20 times more common in people with learning disabilities than in the general population. Sudden unexplained death in epilepsy is five times more common in people with learning disabilities than in others with epilepsy.
- Early death was significantly associated with cerebral palsy, incontinence, problems with mobility and residence in hospital.

The National Patient Safety Agency (2004) suggested that 26% of people with learning disability are admitted to hospital each year, whilst only 14% of the general population are admitted.

Both Michael and WCC cite Hollins et al (1998) regarding, mortality rates amongst the learning disability population:

Michael also indicates that people with learning disability present a range of common health risks, but also suggest that some health risks that are common in the general population are less common amongst people with learning disabilities:

- A restricted range of opportunities to exercise or eat healthily.
- Smoking and substance misuse are less common than in the general population.
- People with learning disability can find it more difficult to identify and describe symptoms of illness and also find it much harder to navigate the health system; this does pose challenges for NHS professionals to deliver health care effectively.

Michael also cites additional studies indicating that:

- Behavioural disturbance and disability were better predictors of a low volume and poor quality primary care than the person's location (Halstead et al 2000)
- Ethnicity appears to be important; morbidity and mortality are higher amongst those with learning disability from minority ethnic groups (Mir et al 2004).
- Unmet health needs are high; indicated by a study showing that health reviews resulted in a new health need being identified for 50% of those reviewed. This included diabetes, hypertension, high cholesterol, thyroid disorders, dental problems, cardiac difficulties, asthma and mental health difficulties (PEARL study, 2002)

The Michael Independent Inquiry made the following statement:

The inquiry believes that the findings on health needs, unmet needs and variation in health outcomes for people with learning disability strongly imply that in addition to avoidable morbidity, there are deaths occurring which could be avoided..'

7.2.2 Treatment

The Michael Independent Inquiry also provides a summary of the key issues relating to treatment and care

- People with learning disability have a higher uptake of medical and dental services but a lower uptake of surgical specialities; they have similar rates of admissions but shorter stays (Morgan et al 2006).
- People with learning disabilities have fewer measurements of their BMI than the general population; those who have had a stroke have fewer blood pressure checks.
- Cervical screening (Davies et al 2001) and mammography (NHS Scotland 2004) are less likely to be undertaken.
- People with learning disability are less likely to be given pain relief and to receive palliative care (Tuffrey Wine 2007) this is especially true if they are from an ethnic minority group (Ahmed et al 2004).

- Treatment is sometimes not offered because a judgement is made about its value.

The Disability Rights Commission (2006) suggested that people with learning disability are often subject to diagnostic overshadowing. This is the tendency to attribute symptoms and behaviour to the learning disability, which can mean that illnesses and symptoms of illness are overlooked. This is reported to be particularly problematic in palliative care or when someone is experiencing pain and can only communicate distress through behaviour.

Sir Jonathon Michael in summarising his introductory chapter makes the following statement:

'The evidence from the literature.....suggests very clearly that high levels of health need are not currently being met and that there are risks inherent in the system. People with learning disabilities appear to receive less effective care than they re entitled to receive.....and discrimination is evident in access to and outcomes from services. Many of these problems concern basic shortcomings in the way that treatment is delivered that would be simple to remedy. However there is also evidence of a significant level of avoidable suffering due to untreated ill health and a high likelihood that avoidable deaths are occurring.'

The Disability Rights Commission (2006) also recommends that regular, evidence-based health checks should be provided for all people with a learning disability; regular health checks can reduce inequities in access to health care provision by identifying unmet needs and preventing unnecessary ill health, deaths and save costs (Disability Rights Commission). The health check provides the opportunity for health concerns to be discussed by people with learning disabilities (and their families/carers) with health professionals (Alborz et al, 2006). This is particularly important for people with learning disabilities as they have higher levels of both health needs and unmet health needs.

Regular health checks could also support people who have a pre-existing medical condition. Evidence suggests that there is a need to increase rates of interventions and support for people with learning disabilities who have been diagnosed with a disease.

This recommendation is further enhanced by one of the accompanying policy and guidance documents to *Valuing People Now - Health Action Planning Guidance* (DH 2009), and the roll over of the Direct Enhanced Service for Health checks into 2010/11.

7.2.3 Local situation

Audit of screening opportunities for clients with learning disability

In 2008, the Government introduced a Directed Enhanced Service which introduced annual health checks for people with learning disabilities.

Annual health screening is now offered by Wirral GP practices and between April 2010 and March 2011:

- 998 people with a learning disability were invited to attend a health screening appointment in 2010-11;
- 893 (89%) attended this appointment

Source: Miquet LHD Analysts 2010-11

Locally the Learning Disability Health Facilitators employed across Cheshire and Wirral devised an annual health check template to assist General Practitioners to deliver a high quality, comprehensive health check to this vulnerable patient group. The Health Facilitators also undertook an audit, which provided evidence of a significant improvement in the number of clients with learning disabilities who access health screening opportunities as a result of the training provided to carers by the Health Facilitators.

The audit aimed to:

- Identify whether people with learning disabilities living in Cheshire and Wirral were accessing routine screening and health surveillance programmes, in line with national averages.
- Identify whether people living in out of area placements were accessing routine national screening programmes in line with national averages.
- Identify whether variances such as where people lived, what living arrangements they had, their age or sex made a difference to the uptake of screening opportunities.

The screening programmes which were subject to scrutiny were:

- Mammography
- Cytology
- Chlamydia

In addition questions were asked about exercise, dental checks, eye testing and weight monitoring.

The most recent audit from September 2010 gave the following results;

Sample size 100 of which 62 were Male and 36 Female.

In some areas, the results of the audit were both encouraging and positive and demonstrated that people were having health checks done:

- 94% of the Wirral sample had routine dental checks
- 87% of the Wirral sample had regular eye tests
- 91% had annual health checks
- 38% had cervical screening with 12% being successful
- 71% had breast screening with 58% being successful
- 77% completed the bowel cancer screening programme

7.2.4 Specialist learning disability health services

Wirral's specialist learning disability service is provided by Cheshire & Wirral Partnership NHS Foundation and based mainly in Ashton House in Oxton. It is comprised of:

- Inpatient Assessment & Treatment Unit (Kent House,)
- Community Learning Disability Team: Specialist LD Health Services
- Specialist Health Respite Service (Thorn Heys, six beds)
- Intensive Community Enablement
- LD Health Facilitators
- LD Forensic Support Services

This service provides specialist clinical support to both people with learning disability and challenging behaviour and to community based providers who support people in the community.

7.2.4. People with challenging behaviour

A working definition of challenging behaviour was proposed by Emerson et al (1987) and confirmed by Mansell in *Services for people with learning disabilities and challenging behaviour or mental health needs* (2007).

“Severely challenging behaviour refers to behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities.”

When the term was introduced, it was intended to emphasise that problems were *often caused as much by the way in which a person was supported* as by their own characteristics. In the ensuing years, there has been a drift towards using it as a label for people. This is not appropriate. Behaviours that seem challenging should not be assumed to be simply part of a person's disability; we know that these behaviours serve a function for the individual and it is essential to identify what that function is. Often these behaviours are the only way that individuals have of communicating that their needs are not being met and it is essential to address this – ignoring them may put lives at risk (Valuing People Now).

NHS Wirral and the Department of Adult Social Services reviewed local services against the recommendations in the Mansell Report: *Services for people with learning disabilities and challenging behaviour or mental health needs* (2007).

The review built on an analysis of the 94 admissions to Kent House between April 2005 and March 2009 which indicated that:

- 36% of patients were admitted with challenging behaviour, 54% with mental health problems.

- 70% (66) are admitted from Community Placement funded either by DASS or the PCT.
- The behaviour of individuals whether a result of challenging behaviour or mental health issue means that in 39% of cases the originating service do not have the capability to meet the needs of the patient.
- 67% of individuals with challenging behaviour do not return to their originating placement,
- 47% of individuals with mental health do not return to their originating placement.
- Assessment and Treatment services may not have the full range of skills to effectively intervene with many of this client group and therefore for some, their condition does not improve whilst in Kent house.
- The nature of challenging behaviour mitigates against short term interventions and it is reasonable to expect that assessment of the underlying causes of challenging behaviour as well as its treatment may have to take place over a substantial period of time.

The findings from the work indicate three very clear messages:

- Wirral has more in-patient beds for the learning disability population than other comparable areas in the North West
- Specialist Learning Disability health services could re-align so that more emphasis is placed on provision of appropriate specialist LD community support than on inpatient assessment and treatment
- More effective models of support require better and more robust relationships with the wide range of service providers than currently exist

Source: Valuing People Now: Review of Services for People with Learning Disability Presenting With Mental Health Problems and/or Challenging Behaviour, NHS Wirral Professional Executive Committee Report, September 2010

There are also 11 (29%) of the 38 people currently supported in placements outside of Wirral who fall within the definition of people with challenging behaviour.

7.3. Residents' views

In recent years there has been widespread consultation with people that have learning disabilities to find out their views on key topics. These include:

Health

A 'Big Health Day' was held in July 2010. 90+ people attended of whom 40 people had learning disabilities

People agreed what health services in Wirral do well for people with a learning disability – listed below:

- Dentistry
- NHS staff Listen more
- Health Passports
- Some people said their GPs were very good

- Good support staff in houses

People also agreed what health services need to do better / differently – listed below

- Diagnosis for autism
- Provide better information about NHS services
- Annual health checks
- Communicate
- Better understanding of our communities
- Avoid jargon
- Improve waiting times and facilities when waiting
- Passports not always used/looked at
- Who cares for the carers / listens to carers

People also voted for their Priorities which were:

- More training for NHS Staff
- Better Communication between People
- Healthchecks
- Access info re leisure and sport
- Easy read information
- Waiting is a worry
- Health Passport not working for all
- Nobody is listening - shout
- Make money go further
- Health Service too Rigid
- Who will Help Me in an emergency
- Cut the jargon

Source: Big Health Day Feedback to Health Action Group, August 5th 2010 (Gerry Flanagan)

- The 'green light toolkit' was used to help people say what they liked or didn't like about our mental health services for people with learning disabilities in 2009 compared to 2005. People said that planning and access to care was better, but care processes, equality and engagement, and service design and delivery could all improve.

Employment

- Wirral Council and NHS Wirral could do a lot more to employ people with learning disabilities.
- Not everyone needs training to get into employment.
- Need to help employers identify where to go when employing people with a learning disability.
- Need to raise expectations/aspirations of people with learning disabilities living in poorer areas.
- All jobs are valuable – whether cleaning or packing - people can progress – a job is a job.
- Being in employment increases a person's circle of friends and increases self-esteem.

- Give young people with disabilities aspirations of working.
- Person Centred Planning should include aspirations for employment.
- Payment/ benefit difficulties
- Too much red tape in getting people into employment.
- Employers need more support.
- Universal employment agencies need to address the needs of people with learning disabilities
- Emphasis should be on the 'ability' to do a job rather than a 'disability'.

Housing

- Independent living is considered to be a good thing, as long as vulnerability is taken into account and reasonable choice available.

<p>Next steps</p> <p>The Joint Strategic Needs Assessment process is an iterative journey that will look to reflect and then include new and latest data and information as and when it becomes available.</p> <p>This version of the Learning Disability Chapter of 'our' JSNA was published as Version 2 on Friday 9th September 2011.</p>
<p>Key contacts</p> <p>If you require any information, support, guidance on using the data and information or the content in the JSNA then please call us on 0151 651 0011.</p> <p>If you would like to receive Wirral JSNA Newsletter then please email to SubscribeJSNA@wirral.nhs.uk</p>

References

Alborz, A., Kalambouka, A., McNally, R. and Parkinson, G. (2006). *A Literature Review on the Effectiveness of Interventions to Improve the Physical Health of People with Learning Disabilities*. Disability Rights Commission.

Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J (2009). Autism Spectrum Disorders in adults living in households throughout England. Report from the Adult Psychiatric Morbidity Survey 2007. NHS Information Centre.

Commission for Healthcare Audit and Inspection (2005) *Draft three-year strategic plan for assessing and encouraging improvement in the health and healthcare of adults with learning disabilities 2006-2009*. Commission for Healthcare and Audit Inspection.

Department of Health (2007) *Valuing People's Oral Health*. Department of Health.

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: The Stationary Office.

Department of Health Valuing People Now: The Delivery Plan 2010/11

Department of Health: Valuing Employment Now (2009): Real Jobs for people with Learning Disabilities

Audit of National Health Screening Opportunities for Clients with Learning Disabilities: NHS Wirral 2010

Sir Jonathan Michael: Healthcare for All: report of the independent inquiry into access to healthcare for people with learning disabilities 2008

Department of Health (2009) *World class commissioning for the health and wellbeing of people with learning disabilities*. London: The Stationary Office.

Disability Rights Commission. (2006). *Equal Treatment: Closing the Gap (Part 1). A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*. Disability Rights Commission.

Emerson E, Barrett S, Bell C, Cummings R, McCool C, Toogood A, et al. *Developing services for people with severe learning difficulties and challenging behaviours*. Canterbury: Institute of Social and Applied Psychology, 1987.

Emerson, E. et al (2005) *Adults with learning difficulties in England 2003/4*. Institute of health research Lancaster University.

Emerson, E. and Hatton, D. (2004) *Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England*. Institute for Health Research, Lancaster University

Hatton, C. et al (2003) *'Key Highlights' of Research Evidence on the Health of People with Learning Disabilities*. Institute of Health Research, University of Lancaster.

Healthcare commission (2005) *Draft three year strategic plan for assessing and encouraging improvement in the health and healthcare of adults with learning disabilities 2006 -2009*

Higgins, K. (2006) *Some Victims Less Equal Than Others*. SCOLAG Journal, August 2006,

HM Government (2009) *Cross-Government Action Plan on Hate Crime*.

Lamb and Redmond (2007). *Hate Crime National Survey Valuing People Support Team*. August 2007.

Mencap (2004) *Treat me right! Better Healthcare for people with a learning disability*. Mencap.

Mencap (1999) *Living in Fear*.

NAO (National Audit Office) (2009). *Supporting people with autism through adulthood*.

NHS Health Scotland (2004) *Health Needs Assessment Report: People with learning disabilities in Scotland*. NHS Health Scotland.

NICE (2004) *The epilepsies. The diagnosis and management of the epilepsies in adults and children in primary and secondary care*. Clinical Guideline 20. NICE.

PANSI (Projecting Adult Needs and Service Information System) (2011).

POPPI (Projecting Older People Population Information System) (2011)

Labour Force Survey

Department of Adult Social Services 2011

Mir G, Nocon A, Ahmad W, Jones L. *Learning Difficulties and Ethnicity*. London: Department of Health, 2004.