



Jobs and  
Learning



Your Health



Your Rights



Your Life

# The Big Plan

joint strategic  
needs assessment

2009 to 2012



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# Contents Page

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Executive Summary ..... 1

Main Big Plan Themes..... 12

    Including everyone ..... 12

    Having real choice and control..... 14

    Having a home I can call my own ..... 18

    What people do during the day ..... 21

    Better health ..... 24

    Making transition a positive experience ..... 38

    Being part of my community..... 40

    In partnership with families..... 43

References ..... 45



# Executive Summary

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This Joint Strategic Needs Assessment (JSNA) considers the needs of adults with learning disabilities. People with learning disabilities face enormous challenges to have the same life opportunities as people without a learning disability. This includes having a job, having good health or living independently. It is estimated that there are over 4,000 people with a learning disability in Westminster, of whom 700 have a moderate or severe level of disability. Within the Borough nearly 600 people access Westminster Learning Disability Partnership Services (WLDP). This needs assessment assessed the needs of this population within the main themes set out in Westminster's learning disability strategy, the Big Plan. Across and within these themes were a number of key findings, these were:

- The majority of people with learning disabilities are not in contact with specialist services. Although not requiring specialist input, this group are likely to face similar inequalities to those who do. Therefore any initiatives to reduce these inequalities should focus on the whole learning disability population.
- There is a lack of consistent information about people with learning disabilities. WLDP collect information on their service users, however outside their remit, such as with the police, there is no recorded learning disability status making quantifying and monitoring issues a challenge. No information is collected about people with learning disabilities who do not access services. Therefore, where there are opportunities to increase information collection this should be undertaken, for example general practice registers should be comprised of all people with learning disabilities.
- There is a lack of consistent monitoring of outcomes for people with learning disabilities. This is crucial to being able to identify areas of concern or evaluate new service areas. This should be improved over the course of the implementation of The Big Plan.
- There are groups of people which are thought to face particular challenges in achieving equitable access to services or outcomes; these include those with complex needs, from BME communities, with autistic spectrum disorder and those not accessing specialist services. Monitoring and action should be taken to improve the situation.
- Increasing "choice and control" is a major government policy agenda for all care groups. Further work is required to implement the agenda, and to focus on those groups who are currently least likely to be utilising the opportunity, in Westminster this is people without carers. The outcomes related to personalisation should also be carefully monitored to ensure that they are conferring benefits.

These key findings are largely being explored in the Big Plan, the greater detail in this needs assessment should inform the accompanying action plans.

## Which population is this needs assessment about?

Adults with learning disabilities

## What is the issue and why is it important for Westminster?

People with learning disabilities are a group of people who face unequal opportunities across all aspects of their lives, these results in distinct inequalities. Health and social care service providers in Westminster have a responsibility to ensure that both specialist and mainstream quality services are provided in an equitable way to reduce these inequalities as far as possible.

## Expected numbers, distribution and pattern by person, place and time.

### *Person*

Prevalence - How many people are there with learning disabilities in Westminster?

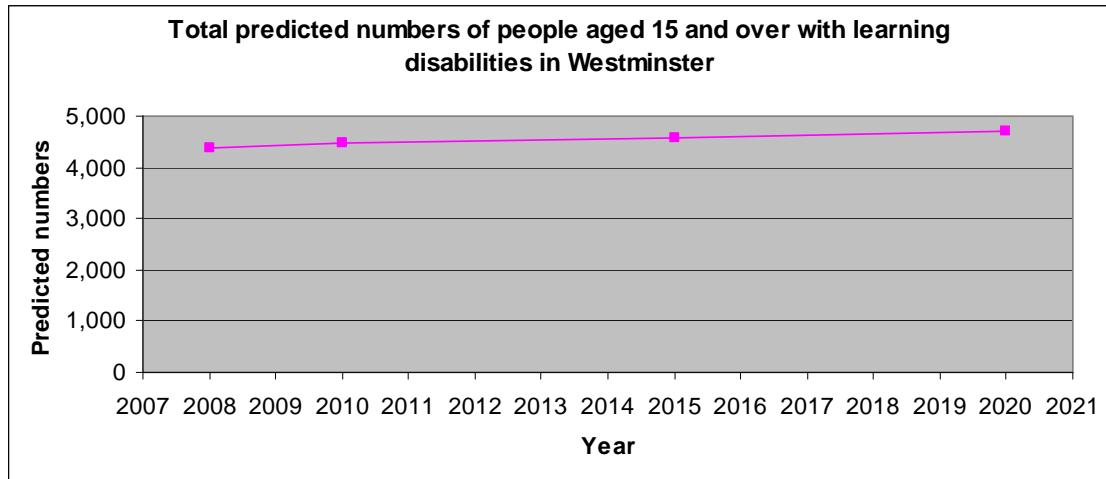
These estimates were calculated using prevalence figures from Emerson and Hatton's paper, *Estimating Future Need* (2004), figures used by POPPI and PANSI<sup>1</sup> and GLA population figures. This method estimated that there are 4,377 people aged over 15 with a learning disability in Westminster. There is expected to be a steady increase in the total number of people over the age of 15 with learning disabilities in Westminster over the next 12 years, rising from 4,377 in 2008 to 4,700 in 2020 (a 7.4% increase.) This reflects the predicted population increase in Westminster, but also an expected increase in prevalence of learning disabilities across the country. The expected increase is inferred from a number of factors (Emerson and Hatton, 2004, Michael, 2008), these are the:

- predicted increase in the number of young adults belonging to South Asian minority ethnic groups, in whom there is a higher prevalence of learning disabilities.
- increased awareness and detection of learning disabilities.
- reduced mortality among people with learning disabilities.
- improvements in maternal and neonatal care.

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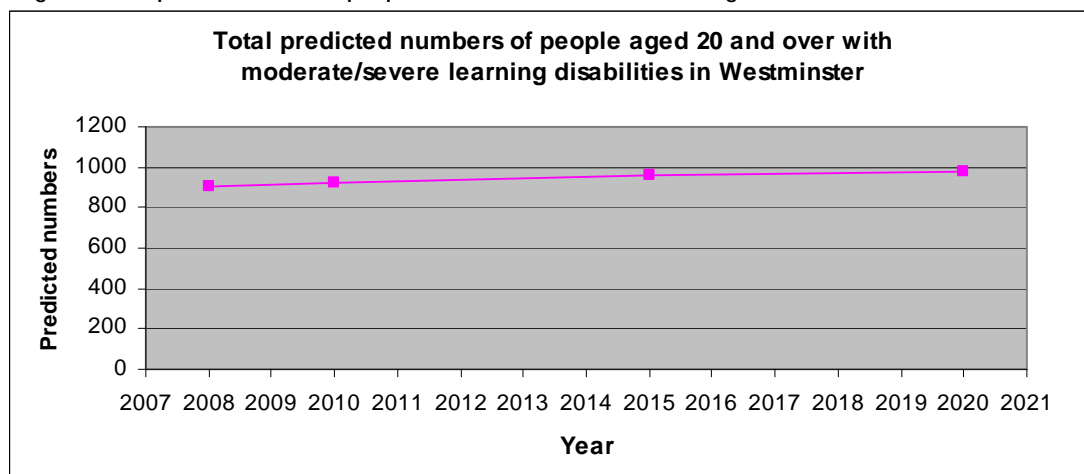
<sup>1</sup> [www.pansi.org.uk](http://www.pansi.org.uk) Projecting Adult Needs and Service Information System and [www.poppi.org.uk](http://www.poppi.org.uk) Projecting Older People Population Information System; Emerson, E. and Hatton, C. Estimating Future Need/ Demand for Supports for Adults with Learning Disabilities in England. Institute for Health Research, Lancaster University, UK. 02/06/2004; note that the prevalence figures used have been adjusted to take account of the increase in proportion of younger English adults who belong to South Asian minority ethnic communities, amongst whom there is a higher risk of learning disabilities. The prevalence for the years 2008 and 2010 were calculated using the 2001 baseline and the estimate for 2011. The prevalence for 2020 was calculated using the estimates for 2011 and 2021.

Diagram 1 – Expected number of people with learning disabilities 2008-2020



Of the 4,377 people with learning disabilities, 708 people are expected to have them at a moderate or severe level (16% of the total). It is predicted that the number of people with moderate/severe learning disabilities in Westminster will increase from 908 in 2008 to 978 in 2020, a 7.7% increase over the 12 years. The reasons for this are the same as those explained above.

Diagram 2 – Expected number of people with moderate/severe learning disabilities 2008-2020



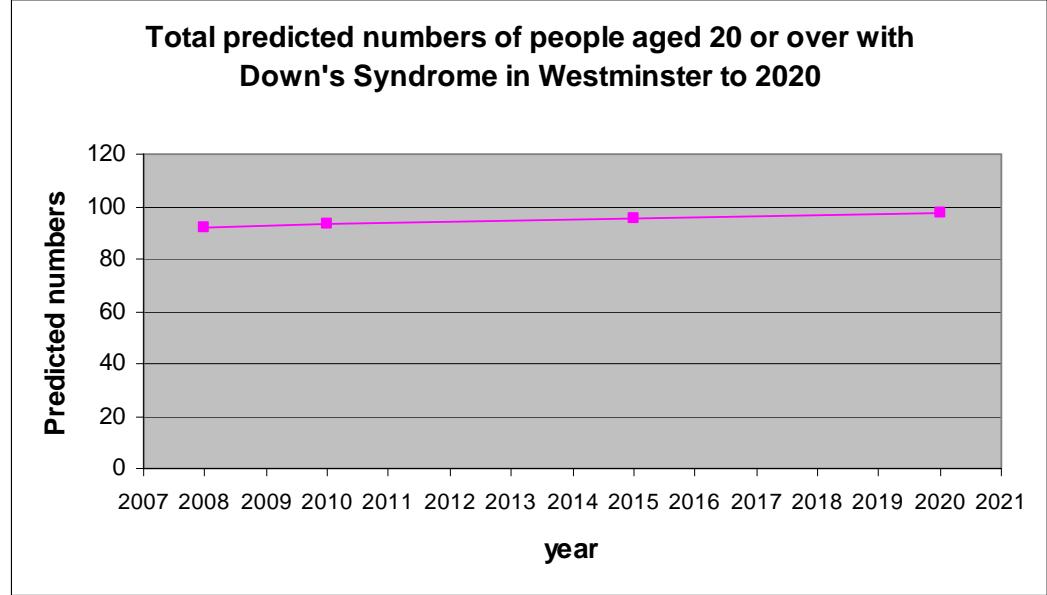
### *Down's Syndrome*

Prevalence figures for Down's Syndrome were taken from POPPI and PANSI.<sup>2 3</sup> It is estimated that there are 92 people in Westminster with Down's Syndrome. The number of people with Down's Syndrome aged 20 or over is predicted to increase between 2008 and 2020, but only by 5 people (from 92 to 97). This is unlikely to have a large impact on services.

<sup>2</sup> [www.pansi.org.uk](http://www.pansi.org.uk) Projecting Adult Needs and Service Information System and [www.poppi.org.uk](http://www.poppi.org.uk) Projecting Older People Population Information System

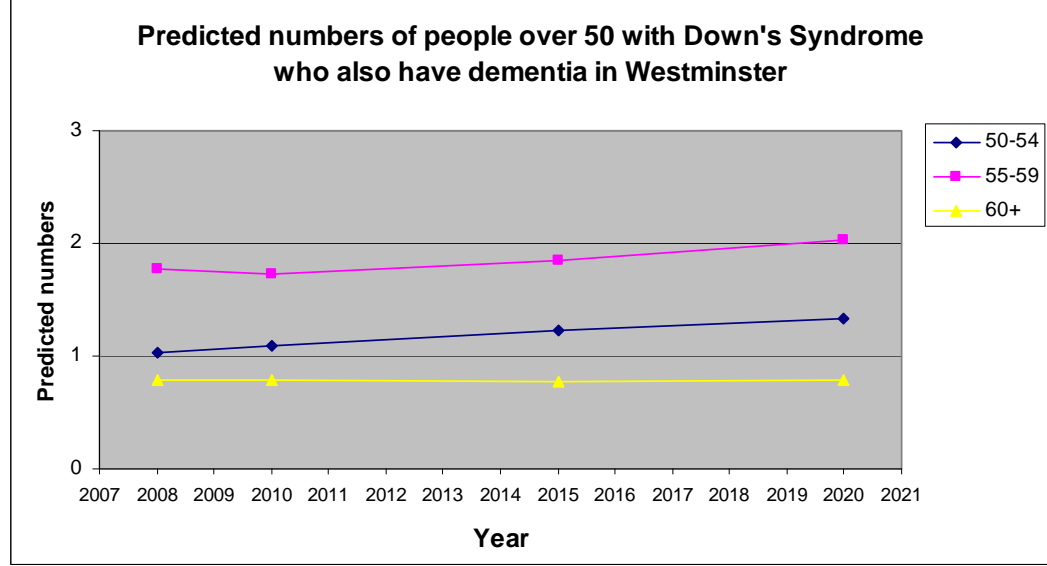
<sup>3</sup> These were estimated as 0.625 per 1,000 15-50 year olds, 0.534 per 1,000 50-59 year olds, 0.177 per 1,000 60-69 year olds, 0.027 70-79 year olds and 0 per 1,000 people aged 80 and over.

Diagram 3 – Expected number of people with Down’s syndrome 2008-2020



The numbers of over 50 year olds with Down’s syndrome and dementia in Westminster is very small, the increase over the next 12 years is also expected to be small.

Diagram 4 – Expected number of people over 50 with Down’s syndrome and Dementia 2008-2020

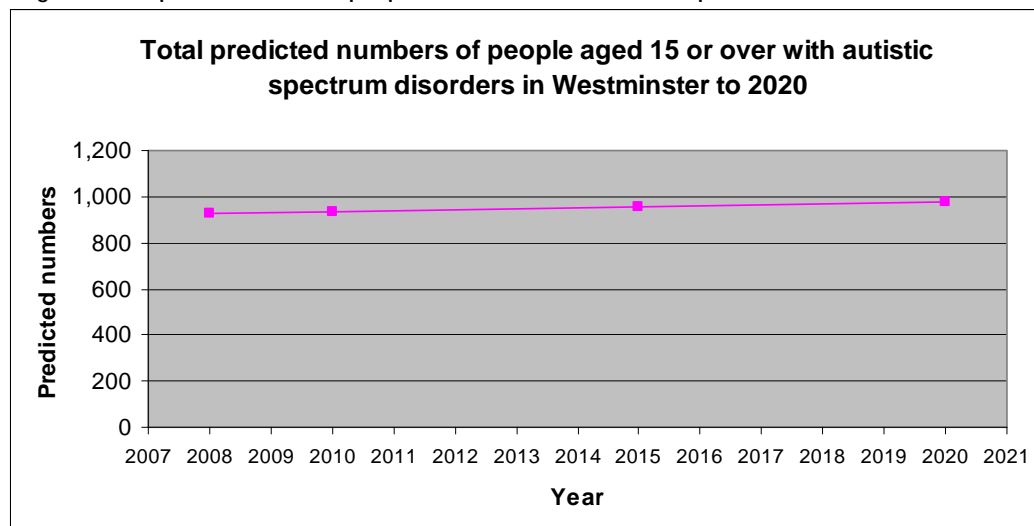




### *Autistic spectrum disorders*

The prevalence figure for autistic spectrum disorders was estimated as 5 per 1,000 people, taken from the report *All About Autistic Spectrum Disorders* (2001) by The Mental Health Foundation, as used in PANSI.<sup>4</sup> In Westminster the number of people with Autistic spectrum disorder is thought to be 925. It is predicted to increase from 925 to 974 over the next 12 years, a 5.4% increase.

Diagram 5 – Expected number of people 15 and over with autistic spectrum disorder 2008-2020



What are the features of the population affected? Are some groups over or under represented?

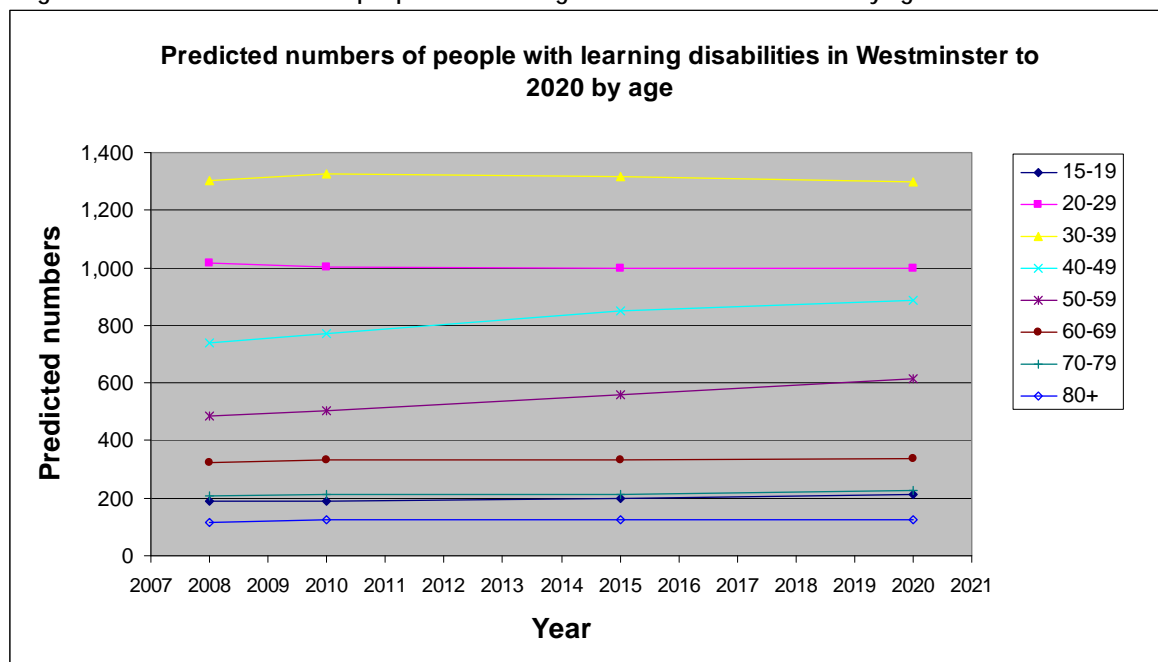
### *Age*

People with learning disabilities are younger than the general population, about half the estimated learning disabilities population are under the age of 30-39. The age group with the largest number of people with learning disabilities is the 30-39 years age group, representing over a quarter of the total number of people with learning disabilities. This age distribution is likely to be as a result of the shorter life expectancy of people with severe learning disabilities than the general population. This may also reflect recent developments in knowledge about learning disabilities, technological advancements and increased survival, and the fact that these may be easier to detect amongst a younger age group.

The numbers of people with learning disabilities in Westminster is predicted to increase across all age groups over the next 12 years except among 20-29 year olds where it is predicted to decrease slightly (less than 20 people). The greatest increase between 2008 and 2020 is expected in 40-49 and 50-59 year olds, with an increase of 149 people and 128 people respectively. The number of older people with learning disabilities is predicted to stay relatively constant over the next 12 years. These age-specific patterns reflect the predicted population growth across Westminster for this age-group within the GLA estimates. They may also reflect reductions in mortality rates among older adults with learning disabilities (Emerson and Hatton, 2004). This suggests that different patterns of service provision may have to be developed for the increased numbers of people in older middle age who may no longer have family carers.

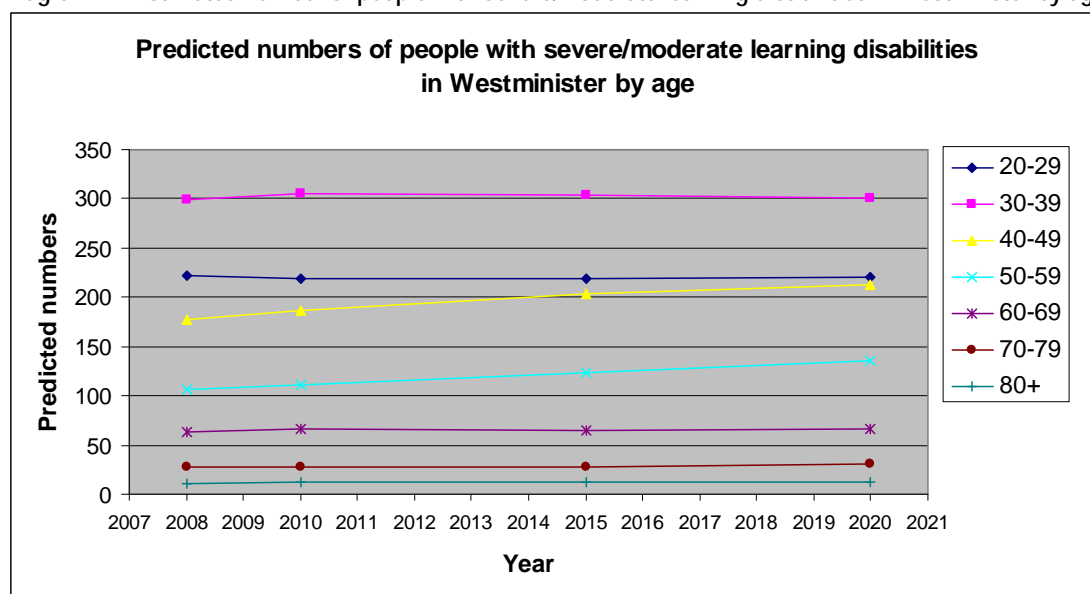
<sup>4</sup> [www.pansi.org.uk](http://www.pansi.org.uk) Projecting Adult Needs and Service Information System

Diagram 6 – Estimated number of people with learning disabilities in Westminster by age 2008-2020



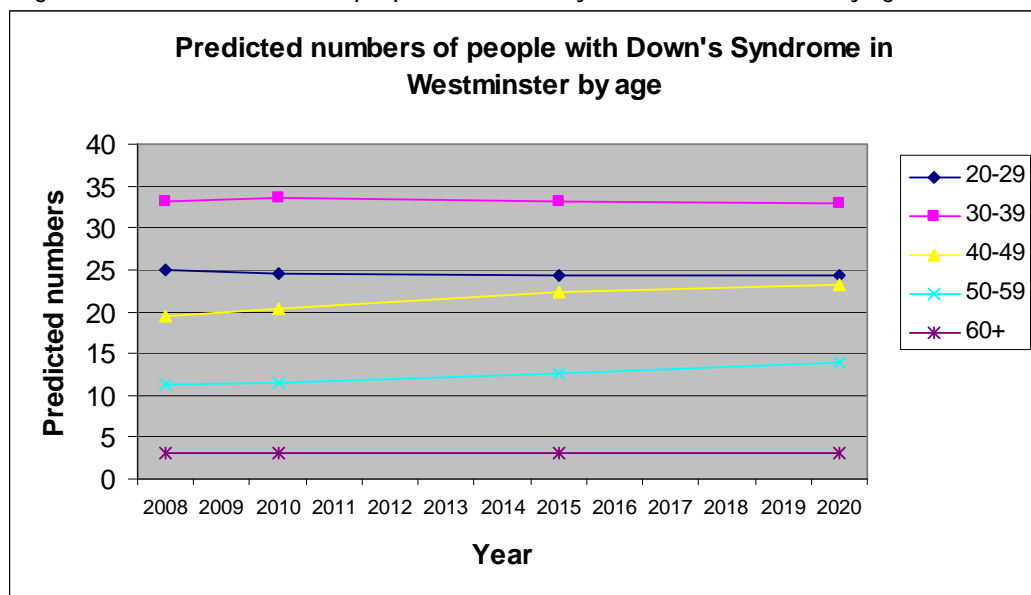
A similar pattern is found for the numbers of people with moderate and severe learning disabilities.

Diagram 7 – Estimated number of people with severe/moderate learning disabilities in Westminster by age 2008-2020



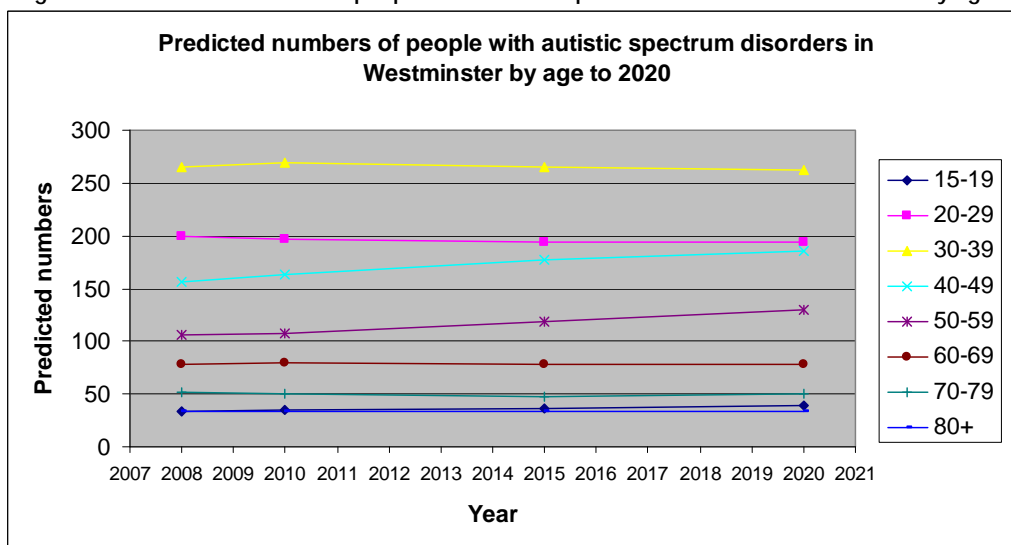
Over half of the over 20 year olds with Down's Syndrome in Westminster are under 40. The numbers of over 60 year olds with Down's Syndrome in Westminster are very small due to the lower expected life expectancy. The numbers of people with Down's syndrome are not expected to change substantially in the future. However they could be affected by current national screening policy and termination rates following prenatal diagnosis. Overall prevalence may not, however, decline due to increasing life expectancy of people with Down's Syndrome.

Diagram 8 – Estimated number of people with Down's syndrome in Westminster by age 2008-2020



The greatest number of people with autistic spectrum disorder are aged between 30-39. The majority of the increase in predicted numbers of people with autistic spectrum disorders in Westminster over the next 12 years is predicted to come among those aged between 40 and 59 years old (increase of 29 people aged 40-49 and 24 people aged 50-59.) The other age groups are not expected to change significantly,

Diagram 9 – Estimated number of people with autistic spectrum disorder in Westminster by age 2008-2020



### Ethnicity

There is a higher prevalence of learning disabilities, notably at the more severe end of the spectrum, among younger people belonging to South Asian minority ethnic groups, particularly Pakistani and Bangladeshi communities than the national average (Emerson and Hatton, 2004). Westminster has a greater representation of people from Bangladeshi communities which could mean that this has an impact on our numbers of people with learning disabilities, especially in areas where this community is represented, for example south Westminster.

## **Is there anything that could change the need for services in the future e.g. population change, legislation?**

The expected increase in the numbers of older people with learning disabilities is likely to pose a major challenge to services as it is recognised that they are more likely to require support than younger adults (Emerson and Hatton, 2004).

The current policy direction is aimed at ensuring personalisation in services. Health and social care providers will need to be able to respond to the differing demands of service users and to provide support to people when they are choosing how to spend their funding.

Another key piece of strategic policy direction is that care for people with learning disabilities is emphasised as part of mainstream service delivery. This would benefit those people with learning disabilities who access specialist services and also those who don't. This will mean a new emphasis on training and raising awareness in mainstream services.

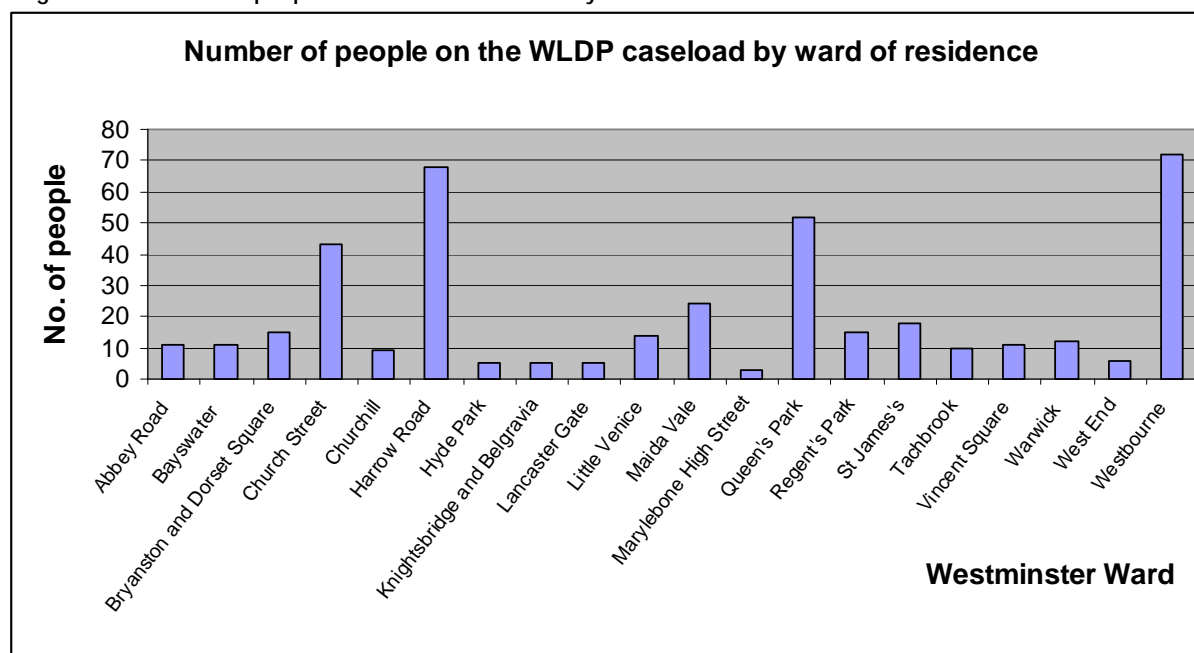
## ***Place***

Where are the people with the issue locally?

The number of people in Westminster with learning disabilities will vary by ward, depending the numbers of people and their demographic profile. National studies have found that people with learning disabilities are more likely to live in areas of greater deprivation (Emerson and Hatton, 2008). In Westminster we would therefore expect greater prevalence in the north east and far north of the borough. It is therefore of little use to apply standard prevalence estimated to ward populations.

The ward of residence of people who are accessing services from the Westminster Learning Disabilities Partnership (WLDP) service gives an indication of where people with learning disabilities live. However, this only includes those people who have severe enough learning disabilities to require their service and it is also likely that the ward figures are skewed those areas where there is suitable housing. The graph below presents this information (data from October 2008). The four wards with the largest number of people with learning disabilities on the (WLDP) caseload in Westminster are Westbourne, Harrow Road, Queen's Park and Church Street. These areas are amongst the most deprived in the borough.

Diagram 10– Number of people on the WLDP caseload by ward of residence



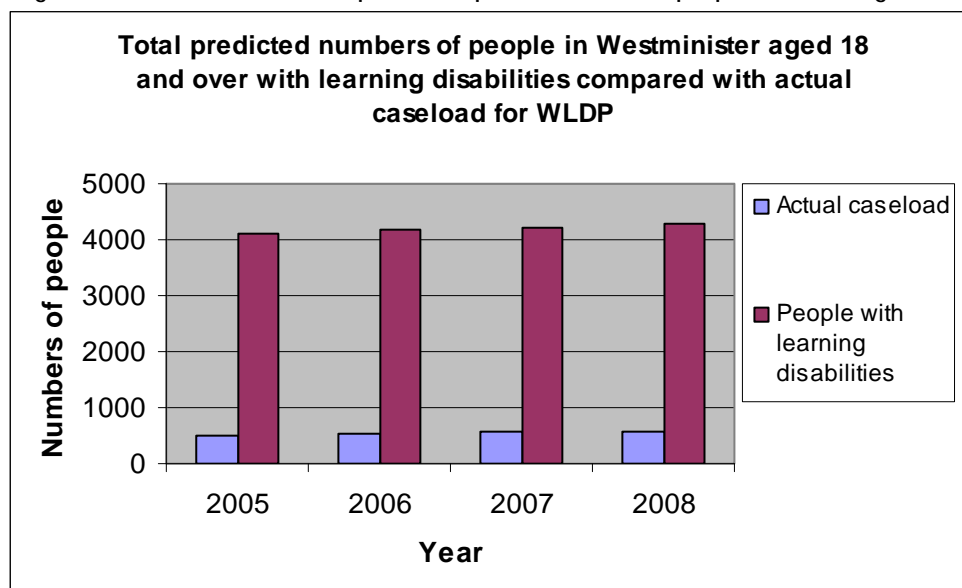
### Existing services and outcomes

Services for people with learning disabilities are provided by mainstream and specialist services. Mainstream providers include social care agencies, hospitals and primary care providers such as General Practices. Specialist services are provided by voluntary sector organisations and the Westminster Learning Disability Partnership, a joint NHS and local authority organisation. This section begins with a brief profile of the people with learning disabilities who access specialist services. The remainder of this section focuses on needs in relation to key outcome areas as described in The Big Plan strategy document rather than individual services.

### *Westminster Learning Disabilities Partnership*

At 31 March 2008 the WLDP caseload was 572 people. The graph below shows that since 2005 there has been a small increase in numbers of people accessing services. Comparing the actual caseload figure to the expected number of people with learning disabilities, 13.4% of the numbers of people estimated to have a learning disability in Westminster was in contact with WLDP. This reflects that not everyone with a learning disability will need to be in regular contact with the services provided by the WLDP or has a disability serious enough to meet their eligibility criteria. The Department of Health *Specialised Services National Definition Set* on learning disabilities explained that only a minority of adults with a learning disability have severe complex needs that will require specialised service provision (Department of Health, 2007). It is also the feeling of the WLDP that the predictions for learning disability prevalence in Westminster are too high. That being so, the World Health Organisation publication on the classification of mental and behavioural disorders (WHO, 1992; Corbett, 2007) mentioned that someone with a moderate learning disability, although achieving a degree of independence, will probably require support in a number of areas to do so. The predicted number of people in Westminster with moderate/severe learning disabilities in 2008 is 908, which suggests that 63% of people with at least moderate learning disabilities are in contact with services. This could suggest unmet need for services, as people do not have their needs identified or the criteria is set higher than an overall diagnosis of "moderate" learning disabilities. This could also suggest that the estimates are too high.

Diagram 11 – WLDP caseload compared to expected numbers of people with learning disabilities 2005-2008



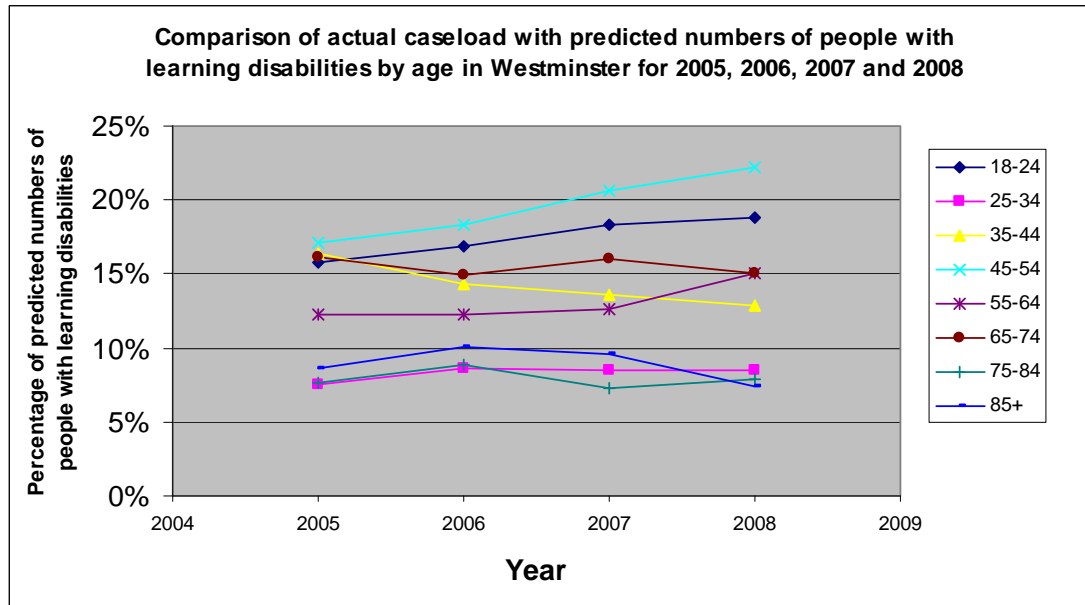
Note: this refers to actual caseload as at March 31 of each year.

### Age

In March 2008 23% of the WLDP caseload was aged between 35-44, with around 22% being made up of 45-54 year olds and a similar percentage of 25-34 year olds.

The graph below presents for each age group the proportions of people estimated to have learning disabilities accessing WLDP services. There are some differences by age group. The 45-54 year old age group has the greatest proportion of people expected to have learning disabilities accessing services, it is lowest in the 25-34 and 75+ age groups. The reasons why there are differences in the age bands accessing services is unclear. It may be an issue of inequity, with some groups more able to access services than others. For example the 18-24 year olds may receive better signposting and support having recently left education. It may also be related to the needs of those age groups. For example, acknowledging the lower life expectancy of some groups of people with learning disabilities and that their needs may increase towards the end of their lives. It may also be as a result from inaccuracies in the underlying estimates. There have been some changes over the last few years, this has included a steady increase in the proportions of people with learning disabilities in the 45-54 and 18-24 age groups who are accessing services.

Diagram 12 – Percentage of people estimated to have learning disabilities on WLDP caseload by age 2005-2008



### ***Ethnicity***

62% of people accessing WLDP services are white, compared to 14.2% Black, 6.5% Mixed ethnicity, 6% Asian and 11.4% "other" ethnicity. Compared to the ethnic mix in Westminster, this suggests that the Black population is overrepresented and the White and Asian population is potentially underrepresented, especially considering the greater prevalence in some south Asian communities. It is challenging to assess whether is a real indication of over met or under met need, or whether it is normal variation in the population.

# Main Big Plan Themes

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## Including everyone

This theme is focussed on ensuring that people with learning disabilities have access to the same life opportunities as everyone else, regardless of the level of their support needs. There have been identified a number of key groups within the learning disabled population who need special consideration when considering inclusion these are people:

- with complex needs. Their needs may be too challenging and can result in residential placements away from their home borough.
- from BME communities. There is a sense they may not be accessing services and that services are not adequately culturally appropriate.
- with autistic spectrum disorder. It has been recognised that this group do not routinely meet the eligibility criteria for learning disability or mental health services and therefore have unmet need. Where they do not access services it is recognised that their health and wellbeing may suffer, as they face significant issues notably accessing housing and employment.
- who do not meet the criteria of specialist learning disability services. As explained before not everyone will need specialist services, yet the inequalities resonate through the whole spectrum of learning disabilities.

## Situation in Westminster

In Westminster 28% of those people in contact with WLDP are living outside of Westminster mainly in residential placements. These are largely people with complex needs. A number of steps have been taken to ensure that those people who live in Westminster with complex needs have adequate services and that in the future fewer people need to be placed outside of the borough. This has included developing a housing strategy with a key aim of reducing the number of people who are placed outside of the borough, the development of a flexible response service to work with people with challenging needs and a review of the short break services.

In Westminster approximately 38% of people accessing WLDP services are from BME communities. There is some suggestion as discussed previously that there is an under representation of people from south Asian groups accessing services. This could be explored to ensure that services are culturally and age sensitive to ensure that people get the maximum benefit from the services they use. There is also a lack of information about important BME groups in Westminster, such as those people from the middle east and other parts of Europe to assess equity of access to services.

There has been a general recognition that there is a lack of information about people with autistic spectrum disorder in Westminster, and whether their needs are being met. The estimates earlier in this document suggested that there were 925 people in Westminster with the disorder. Work has been commissioned to carry out a needs assessment of this group of people.

The demographic profile suggested that there were over 3,000 people with learning disabilities who were not receiving specialist services, of whom around 300 had a moderate or severe level of disorder. Regardless of the accuracy of these estimations it suggests that there is likely to be large numbers of people with learning disabilities who are not accessing specialist services. They are likely to be in receipt of the same inequalities as those who meet WLDP criteria. Work to further increase the skills and knowledge of mainstream services regarding people with learning disabilities should help improve the care of people with lower level learning disabilities. This work needs to emphasise the spectrum of disability so that the focus does not remain on those already receiving services.



### **What are professionals' opinions on services in terms of met and unmet need?**

Staff felt that mainstream and specialist services were not responsive to people with learning disabilities who are challenging or have autism. This has resulted in a number of out of borough placements. There may also be some unmet need as a result of a lack of flexibility to different cultural needs. Suggestions for improvement included ensuring that people with learning disabilities are included in equality and diversity policies, and that staff are aware of the differing local needs. With regards to complex cases it was felt that local services should be adapted to ensure that they meet the needs of people who require complex care.

### **Information gaps**

There are a number of gaps of information regarding this theme. The main gap is the lack of information about people who have a learning disability but who are not accessing specialist services. This proves challenging in terms of monitoring the service use and health and wellbeing status. This is important to measure any change following interventions. Capturing people with all learning disabilities in mainstream services such as general practice could allow monitoring of outcomes to take place, for example the Pomona indicators.

The lack of information about people with autistic spectrum disorder has been discussed previously and this remains a major gap. Information about different BME groups is also an omission.

### **Conclusions and Recommendations**

- People with complex support needs and challenging behaviour may not have the same opportunities for independence and choice, and are often placed outside of the borough. Work should be undertaken to ensure that:
  - People with complex needs have the same opportunities to make a person centred plan and direct their own care
  - There is the capacity locally to work with people who have complex needs
- Both specialist and mainstream services have to work with people with learning disabilities from a number of different countries and across all age groups. Services should be responsive to the different needs of these groups, further investigation may need to be made to assess equity of access and outcomes.
- There are large numbers of people with learning disabilities who do not need specialist services. These people should be identified and receive appropriate help and support from mainstream services. Mechanisms to monitor their health and wellbeing status should be developed.
- There is thought to be unmet need for people with Autistic Spectrum Disorder. A needs assessment, strategy and support pathways should be developed for people who do not qualify for specialist services.

## Having real choice and control

Personalisation of services is about people having real choice and control over their lives and services through individual budgets, direct payments and person-centred planning, underpinned by strong self advocacy and family carer support (DH, 2009). People express what they need and want through their person centred plan. Personalisation is major policy initiative across all health and social care groups.

Across the country the uptake of direct payments has increased significantly however it still only represents a small part of the total budget, approximately 1.1%, although 2.1% of people with learning disabilities are receiving them (Davey, 2007). People with learning disabilities are less likely to be in receipt of a direct payment than other groups of disabled people (Williams, 2006). Increasing the numbers of people with direct payments and person centred plans is a major challenge for any service.

Williams (2006) divides the issues surrounding providing Direct Payments to people with learning disabilities into five main areas; the lack of accessible information, perception of people's abilities to manage the process, lack of availability of quality personal assistants, inflexibility of services to meet people's demands and the need in some cases for ongoing and intensive support to manage their packages of care. Other factors hindering implementation that have been identified include lack of demand, inadequate staff training, weak voluntary sector service provision and lack of support at all levels in an organisation.

Two factors have been identified that are thought to aid in the success of the implementation of direct payments (Williams, 2006). The first is the training and support for front line staff, which includes having a champion for direct payments, nominated "direct payments" finance staff, reduced bureaucracy and flexible pay for assistants. The second factor is providing effective ongoing support to people with learning disabilities who have chosen to access direct payments. This support can be in the form of Centres for Independent Living, general accessible information and trained personal assistants (Williams, 2006).

### The situation in Westminster

In December 2008, 52 people were receiving direct payments; 9% of the total caseload (570 people) at that time. The number of people receiving direct payments has been increasing each year, 38 people were receiving them in March 2007. When the last comparison was available Westminster had the second highest number of people on direct payments of all the inner London boroughs.

A brief analysis of those people who are receiving direct payments was carried out, to assess whether those people receiving payments had particular characteristics, such as being young, living with families or being from a white ethnic group. This analysis found that if you live in certain wards, or in a less deprived super output area, or with a carer or in a settled home with family you were more likely to receive a direct payment. A further logistic regression analysis was carried out, this takes all the factors together taking into account they may be connected one another (for example having a carer and the type of accommodation you live in). This found that one factor alone was significantly related to being in receipt of a direct payment, this was having a carer. Therefore to ensure that the opportunity of having a direct payment is equitable, ways of supporting people who don't have a carer to use direct payments and individual budgets need to be explored.

## **Evidence of Effectiveness**

The national evaluation of individual budgets (IB) pilot programme found a slightly confusing picture for people with learning disabilities (Glendinning, 2008). The study found that people who received IB were more likely to feel they had control over their daily lives (although this was not statistically significant). If this comparison excluded those people who were in the IB group but chose not to take up the offer of IB, the difference became significant. However, those people who did take up IB were more likely to report that they were less likely to be fully occupied in activities than those who didn't. This analysis recorded responses from people with learning disabilities, and where they were unable to respond a proxy respondent replied on their behalf. In this case if the proxy's responses were excluded then the analysis found that those who took up IB were more likely to be fully occupied by activities. The study also found that in those who received IB, self perceived health was significantly lower compared to the comparison group, again if proxy respondents were excluded the result changed and it became non-significant. These differing results with the proxy respondents may reflect the different perspectives of the proxy and person with learning disabilities or that those less disabled people who were able to respond for themselves were better able to take advantage of the IB. Overall it was thought that overall people with learning disabilities and their carers found the IB process stressful, which was thought to be enhanced by the length of time it took to implement an IB.

The evaluation found that IBs were cost effective in relation to social care when there was a support plan in place. However, the study also found that the provision of standard care was slightly more cost-effective than IBs when assessing the psychological wellbeing of the person with a learning disability.

This suggests that the further implementation of personalisation and individual budgets need careful local monitoring to ensure that they are improving outcomes for people with learning disabilities.

Other studies have found more general positive results, such as allowing people to gain confidence and skills, having high levels of satisfaction (Cole, 2007).

### **What are service users' experiences of services?**

Service users noted that information on person-centred planning and self-directed support should be available in a range of accessible formats. Service users also emphasised the importance of the right people being involved in planning, and of the need for all support workers to be person-centred planning facilitators.

Carers commented that personalisation initiatives would allow them more control over the type and quality of people who are employed.

### **What are professionals' opinions on services in terms of met and unmet need?**

Staff expressed they had concerns about the new system especially given the fast pace of change; the main concerns were to do with safeguarding, financial risks, changing job roles, the ability to make real choices and raising people's expectations unrealistically.

Staff emphasised the need for a change in attitudes and culture within organisations. This would need to include support and training for staff, the stimulation of the local market to respond to demands and increased access to responsive mainstream services.

Some staff wondered whether the changes would actually result in having more choice and more control over their lives.

### **Information gaps**

There are gaps regarding wider contextual reasons why people do and do not take up direct payments. There is also a lack of overwhelming evidence that personalisation will be beneficial to people with learning disabilities.

### **Conclusions and Recommendations**

- In light of studies into the successful implementation on the personalisation agenda, personalisation needs to be fully embedded organisationally and culturally within health and social care services. This would need to be supported by continued training and support for frontline workers and to ensure that assistants and carers are also trained to support the individual budget process.
- National findings have suggested that local markets are not fully developed to respond to the breadth of demands that could be made by people with learning disabilities. Therefore in Westminster a priority will need to be developing the capacity in local voluntary and mainstream services to be able to respond to the potential demand.
- Research suggests that plan to ensure full effectiveness and cost effectiveness of the implementation of IB every person with learning disabilities should have a person centred plan. This should be aim for people with learning disabilities who meet the criteria for IB.
- Ongoing support has been found to be important in ensuring the full implementation of personalisation initiatives. In Westminster this could be implemented through accessible materials and appropriate support agencies.
- Local findings suggested that people without a carer were less likely to be in receipt of direct payments. This suggests that work needs to be carried out to facilitate the use of direct payments and individual budgets for people without carers.

- As the national evidence has not been overwhelming in support of individual budgets, there should be local monitoring of outcomes for people with and without direct payments and other personalisation initiatives. This will allow some measurement of the perceived positive outcomes associated with individual budgets and to compare to the slightly less encouraging findings of the national work.

## Having a home I can call my own

People with learning disabilities are less likely to live on their own with friends or partners or own their own home than the general population. Nationally only about 15% of people with learning disabilities own their own home or live in accommodation with a secure long-term tenancy, compared to 70% in the general population. Over half of adults continue to live with their families into middle and older age, with the remainder living in residential care, or other kind of placements or shared housing that they may not have chosen themselves. Issues may present themselves as people age, where family carers may not be able to continue to care. This can result in premature admittance to older peoples residential homes (Housing, Learning and Improvement Network, 2006). Also issues have been identified for older people who have lived on their own and may have undiagnosed learning disabilities who are only just managing to maintain their independence (Easterbrook, 2007).

### Situation in Westminster

In Westminster the pattern is slightly different for those who are in contact with services, with a quarter of people living outside the borough due to the lack of suitable housing in Westminster, especially for people with high support needs. A total of 29% of people in Westminster live with their families which is less than the national figure. A large proportion of people (38%) with learning disabilities from Westminster live in residential care, many of these people will be placed outside of the borough. Just under a quarter (24%) of people live with public sector tenancy, over a half of these are linked to support. This is greater than elsewhere.

A specific strategy has been written with the aim of enabling more people to live in Westminster in supported and independent housing and to reduce the number of people who are placed outside of the borough in residential care. A key part of this is enabling all people to have a person centred plan, for them to state and work towards their desired housing.

### Evidence of Effectiveness

A number of barriers have been identified for people with learning disabilities to take up independent housing. These have been identified as:

- Knowledge and Communication
  - Lack of awareness by professionals and families that social housing is an option (Hall, 2008)
  - Housing staff lack awareness of the needs of people with learning disabilities
- Lack of empowerment for people with learning disabilities
- Systems
  - Complications of organising funding and support alongside tenancies
  - Little choice of properties to meet needs
  - Complications of viewing and bidding system for council or housing association properties makes it challenging for people with learning disabilities to discuss the property, gain a second opinion and explore options for corresponding support packages

These issues may not be so explicit if the person has milder or undiagnosed learning disabilities.

The choice based lettings programme is a recent development designed to improve the choice for people applying for council and housing association properties. Instead of using the register and waiting list process it advertises properties and invites bids. A study was undertaken to see how this process could benefit people with learning disabilities (Hall, 2008). The recommendations were:

- To ensure that information is accessible and easy to understand.
- Priority and allocation policies should take into account the personalisation and independence agendas which are encouraging people to access mainstream housing.
- Availability of help for people with learning disabilities to apply and bid for housing.
- Housing staff need training to understand the needs of people with learning disabilities and to be confident to support them.
- Viewings should not be shared for properties.
- Joint protocols between housing and support services to ensure that they are coordinated.

### **What are service users' experiences of services?**

People with learning disabilities mentioned a range of housing preferences, some said they wanted to live on their own, others with friends or a partner; some said they wanted to stay in their local areas close to friends and family but with appropriate support workers who they had chosen, and some wanted to live in a different area.

### **What are professionals' opinions on services in terms of met and unmet need?**

There was a recognition that people with learning disabilities did not have the same opportunity as non-disabled people to develop independence skills, due to a number of factors - a shortage of affordable, accessible housing, the cost of some care packages, and in some cases families' own expectations.

There were a number of suggestions for increasing independent housing opportunities: more strategic planning, promoting a culture of independent living among families and organisations, including individual housing solutions in transition plans, increasing the capacity of outreach teams, and having a 'try out' period for new accommodation.

Staff and family carers highlighted the need to ensure that any increase in independence was matched by appropriate levels of support so that people were supported to manage the running of their homes and be involved in their communities.

### **Information gaps**

There is a lack of information about those people with learning disabilities who do not access specialist services. It could be inferred that people with more moderate and mild learning disabilities face challenges in achieving independence and accessing appropriate housing. This information could help tailor support and raise awareness of this group.

## Conclusions and Recommendations

- A quarter of people with learning disabilities from Westminster are not able to live in the borough. Therefore a future aim would be to reduce the numbers of people who are placed outside the borough in residential homes.
- As it has been expressed that more people with learning disabilities would like to live independently, support and advice can be given to people who live with families to explore the ideas of independence.
- The processes of accessing social housing have been identified in national studies as being challenging. Therefore in the borough new ways of accessing social housing could be explored.
- As housing options and preferences change over time, there is a need to evaluate and monitor the quality of life and satisfaction of these people to ensure that the changes are to their benefit.
- It can be assumed that people with a whole spectrum of learning disabilities access housing through local agencies. Therefore housing agencies should be aware of the needs of people with learning disabilities, including for those people who may not be in contact with formal services but still require support.
- Studies suggest that housing for older people is a challenge, the issues range from people having to prematurely access residential care to those who have lived independently but where sustaining independence is harder as they age. This could benefit from further exploration.



## What people do during the day

The current focus for people with learning disabilities is ensuring that people with learning disabilities have the opportunity of paid work, meaningful educational courses and activities which reflect what they want to do.

Employment levels for people with learning disabilities have increased but the proportion is still very low, and less than all other groups of disabled people. Surveys report that between 5% and 17% of people with learning disabilities are in work, this is significantly lower than the general population (DH, 2001). Also it has been found that when they work, it is often part time and for low pay (Emerson et al, 2005). National studies have also found that 2 out of 3 people with learning disabilities who are unemployed would like to be employed (Emerson et al, 2005).

Employment is seen as a beneficial activity for people with learning disabilities as it provides income and therefore increases independence, it establishes a role in the community, gives access to wider social networks and increases self respect (Mencap, 2002).

There have been identified a number of barriers to employment for people with learning disabilities, Beyer (2004) identified two types of barriers to employment for people with learning disabilities:

- Structural
  - The inflexibility of the benefit system
  - The lack of funding to support employment
  - Lack of preparation for work
  - Inadequate transition planning
  - Job centres and connexions not having the expertise to work with people with learning disabilities.
  - Attitude of employers
  - Reluctance of carers
  - Availability of information
- Individual factors for people with learning disabilities
  - Poor communication
  - Lack of concentration
  - Lack of social skills
  - Lack of independence skills
  - Confidence
  - Lack of expectation

Day centres have been a key feature of the provision of services for people with learning disabilities. They have two main roles, as a forum for people to learn and develop new skills and abilities and to provide opportunities for carers to have a break (Mencap, 2002). In 2005, a national survey found that 39% of people with learning disability were attending a day centre (Emerson et al, 2005). The national policy direction has focused on modernising day services to ensure that they meet their clients needs enabling them to move on to other activities including work (DH, 2001), however large numbers of people have remained in day centres and have not been able to move on to other thing. The most

recent policy guidance has been not to focus on day centres and their provision but to concentrate on person centred planning to facilitate access to work (DH,2009).

### **The situation in Westminster**

In 2007/08 11% of people in contact with WLDP were in paid work at some time. It is difficult to assess whether this is higher, lower or comparable with other parts of the country since the Westminster measurement only includes those people in contact with services. There has also been no assessment of the employment and activity status of those people who have less severe learning disabilities who could benefit from some assistance to gain and stay in employment.

In Westminster work has been undertaken to modernise day and employment services. Other initiatives have included paid consultancy, accessible recruitment process and 'job carving'.

### **Evidence of effectiveness**

There is a lack of evidence regarding what works with regards to supporting people into work (Riddell, 2005). There are examples of schemes and programmes which have been used across the country to enable people to work, these include subsidising employers, businesses built around workers who have special needs, sheltered employment and pathways for employers and people with learning disabilities.

A review of the research evidence carried out by Cole (2007) regarding day centres found that there was little explicit evidence. The review did identify that those attending day centres tended to be positive about them however surveys also found that people who had moved on to other activities were more negative about day centres and there would be a preference for activities out of the day centre environment.

A number of barriers have been identified for people who attend day centres, including the lack of integration with non-disabled people, a lack of emphasis on moving on to things such as employment and a lack of adequate trained staffing (Cole, 2007, Whitaker, 2000). It is also recognised that some day services have moved on and provide modern and stimulating community based services. The positive characteristics of these services have been identified as having a strong partnership with people and their families, having strong leadership, willing to undergo a cultural change in their services and carrying out person-centred planning (Cole, 2007). The place of day centres therefore has to be seen within the context of the services they are providing and to whom.

### **What are service users' experiences of services?**

The service users reported that they wanted to gain qualifications and attend college courses on a variety of subjects to help them gain the skills to live and work. They also reported that they wished to work and be paid, to increase independence and the ability to be able to afford to do more activities. It was recognised that not everyone wants to work.

There were a wide range of leisure activities which people wanted to undertake in their own time.

### **What are professionals' opinions on services in terms of met and unmet need?**

Professionals identified that there are significant barriers to people with learning disabilities attaining paid work. These included low expectations, attitudes from employers, lack of jobs and benefits. The shortage of appropriate college courses, and fees were particular barriers to continuing education. Ways to improve the situation were thought to be higher expectations in schools and transition, on the job training and raised awareness in business of the abilities of people with learning disabilities.

### **Information gap**

There is a lack of information regarding the number of people with person centred plans and their detailed preferences for things to do in the day. The latter would help future planning of services

### **Conclusions and Recommendations**

National and local information suggests that a number of courses of options could be taken, these include to:

- Work with local colleges to ensure there are courses available to prepare people with learning disabilities for work.
- Work with local colleges to ensure there are educational opportunities for different stages of people's lives.
- Work with local employers (including the council and PCT) to support the employment of people with learning disabilities.
- Ensure that the day centres are responsive to people's needs and work in partnership with local employers.
- Leisure services are responsive and accessible to people with learning disabilities.
- Assess the employment status of those people with lower level learning disabilities.

## Better health

Compared to the rest of the population people with learning disabilities tend to have poorer health. They are more likely to have a range of conditions including high blood pressure and mental health problems. They also have a significantly shorter life expectancy. Although people with learning disabilities have a greater need for services they have been found to have poorer access to services. This can be a result of general lack of accessibility, and a lack of awareness and understanding by health professionals. In many cases professionals only see their learning disability not the actual problem that they are presenting with. This has resulted in occurrences of misdiagnosis and consequently avoidable death (Michael, 2008, Mencap, 2007).

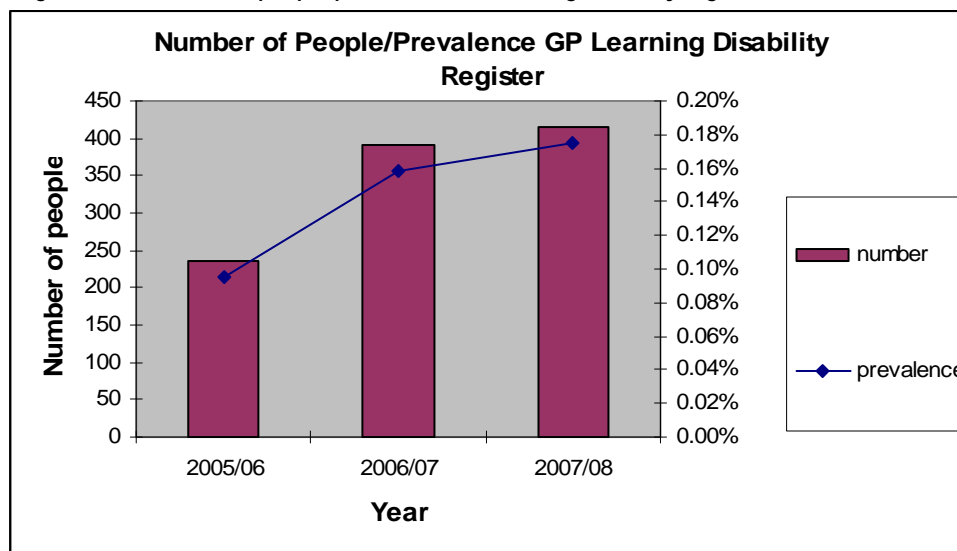
Mainstream health services are provided by primary care for example general practice and secondary care largely in hospitals. This section will consider the work undertaken in primary care and general health issues. There is little information from secondary care.

### Primary Care

The learning disabilities Local Enhanced Scheme has been running with Westminster GPs since 2005/06. This LES established a contractual payment for GPs in managing the physical health needs and providing health promotion advice to people with learning disabilities. Payment structure is based on the number of patients with learning disabilities registered at the practice. Eligibility for the register is defined by being in contact with WLDP. The key tasks in the LES are completing an annual health check (this includes recording their blood pressure and BMI), identifying a health facilitator for the individual and the development of health action plans.

The graph below presents the number of people on learning disability registers in Westminster GPs. The 2005/06 figure is from the first year of the LES, the figures for 2006/07 and 2007/08 are from the Quality and Outcomes Framework (QOF, a part of the GP contract where practices are rewarded for having registers for groups of patients and providing evidence based care) returns. This may explain the rise in those on the registers as all practices, not just those taking part in the LES would be developing registers. There has been a continued increase from 2006/07 which suggests that more people are being identified in practices, accurately coded and being provided with services.

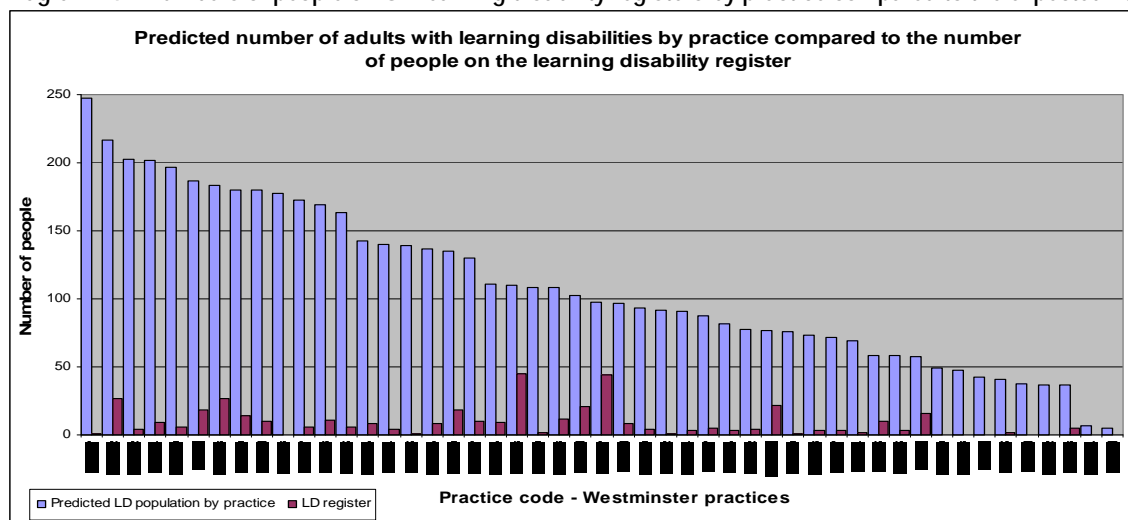
Diagram 13 – Number of people/prevalence GP learning disability register



A total of 27 GP practices are signed up to the LES. Training was provided to the practices that signed up to enable them to recognise and increase their awareness of the needs of people with learning disabilities. WLDP provide services to the patients registered to practices which are not signed up to the LES to ensure full coverage.

The total number of people on practice learning disability registers in Westminster is 416, as taken from QOF figures for March 2008. The numbers of people on the register is lower than the number known to services (572) because of the number of people placed outside Westminster to live. This is 10% of those expected to have learning disabilities in the borough. The graph below presents the numbers of people expected to have learning disabilities in a practice population and the number of people who were on the register in March 2008. There is a large variety in the numbers of adults with learning disabilities estimated to be within each practice population because of the differing size of practice population. However, this does not seem to explain all the variation. We would expect the register numbers to be significantly smaller than the numbers expected as we know the register is restricted to people who are seen by the WLDP.

Diagram 14 – Numbers of people on GP learning disability registers by practice compared to the expected number

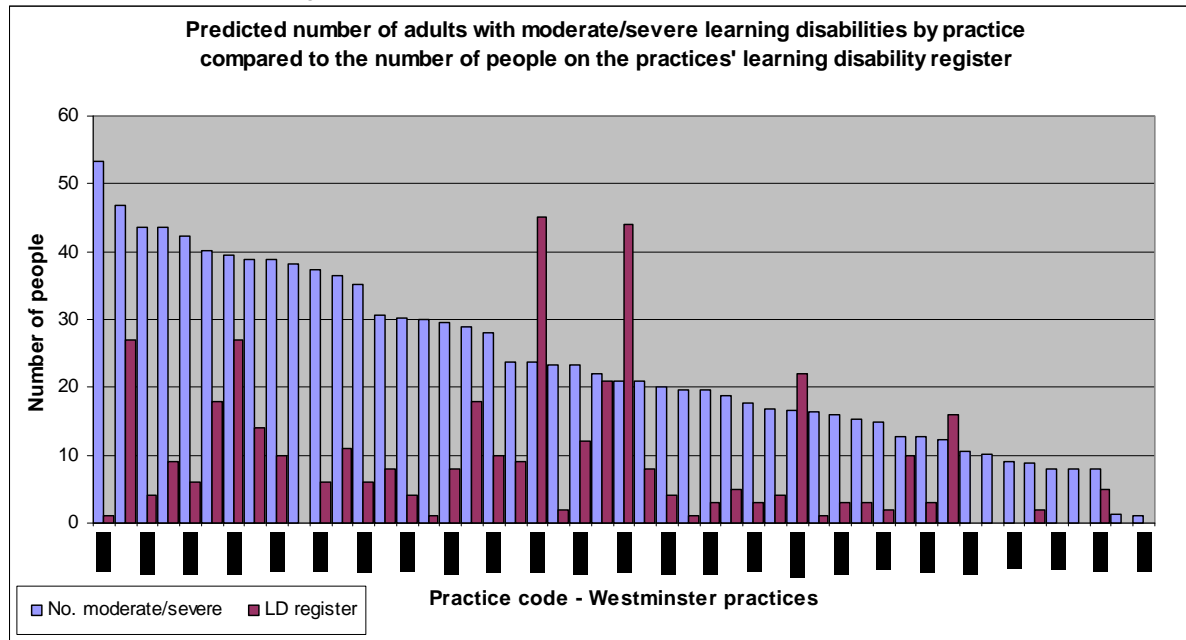


Two practices have a comparatively greater proportion of people with learning disabilities on their learning disability register, when compared to the expected number of people with learning disabilities that might be expected within their practice population: 45% in Fluxman Harrow Road Health Centre (E87637) and 41% in New Elgin Practice (E87723.) Some practices have none, or very few people, on their lists recorded as having a learning disability. This may be due to variety in the definition of what constitutes a learning disability (Corbett, 2007; Michael, 2008). It could be that the predicted learning disability figures vary in their accuracy by practice, depending on the population profile (for example age and ethnicity.) The two university based practices are likely to have a different profile (E87768 and E87677).

When restricting to comparison of register sizes to the numbers of people estimated to have severe and moderate learning disabilities, some practices remain having low proportions of the estimated numbers on their register. In four practices the number of people on the register exceeds the predicted number of people with moderate/severe learning disabilities in those practices (E87723, E87637, Y00902, E87751). These are the Fluxman Harrow Road Health Centre, the New Elgin Practice, the Westbourne Green Surgery and Srikrishnamurthy Harrow Road Surgery. This is likely to be because there are more people living in those areas with learning disabilities, something also suggested by the graph over the page, where the WLDP caseloads for Harrow Road, Queen's Park and Westbourne wards (where these practices are located) are comparatively high. These are areas of greater deprivation.

Sir Jonathan Michael comments in his *Healthcare for All* report (2008) that the overall number of people with learning disabilities recorded as part of QOF registers corresponds to the number of people with profound and multiple disabilities in the population as a whole. This suggests people with moderate and mild learning disabilities are not being included.<sup>5</sup> Sir Michael goes on to comment that this may be because GPs are still new to the task of identifying people with learning disabilities. He also suggests that some people at the milder end of the learning disability spectrum may be uncomfortable being branded as having a disability.<sup>6</sup> This document suggests that all people with learning disability should be included in the register and this is something that should be aimed for in Westminster.

Diagram 15 – Numbers of people on GP learning disability registers by practice compared to the expected number of people with moderate/severe learning disabilities

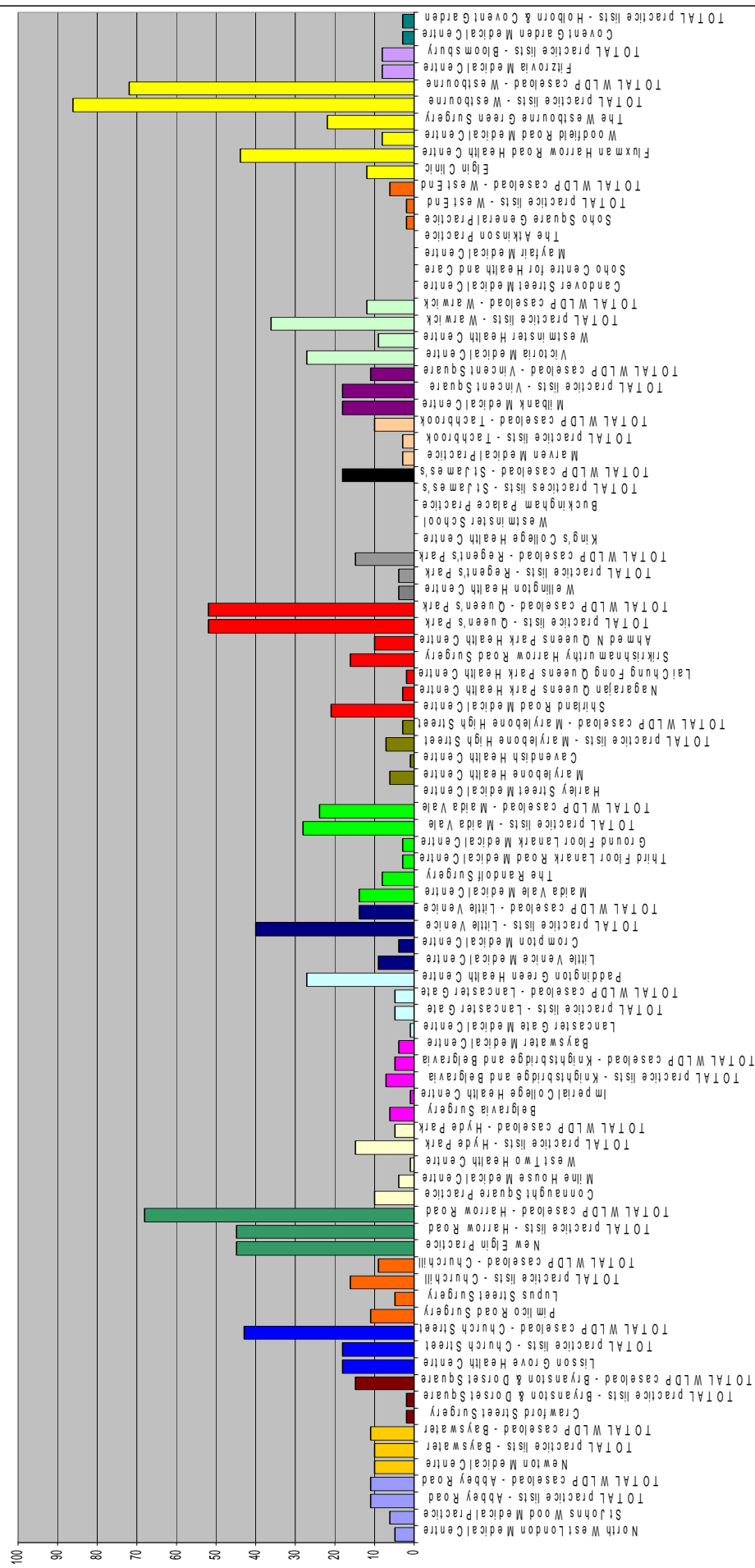


To explore further whether the difference in prevalence between the different practices is attributable to the wards of residence, the register sizes for learning disability in a ward and the ward based caseload were compared. The gaps between numbers on both lists are particularly large in Church Street, Harrow Road, Little Venice and Warwick wards. These differences may be explained by the fact that people with learning disabilities may chose to be registered with a particular GP, or may be registered with a GP practice outside their ward of residence which, with small numbers, could have a significant impact on the figures. For example, in St James's ward there were 18 people on the WLDP caseload and no people with learning disabilities registered on the practice lists.

<sup>5</sup> Michael, J. Healthcare for all. Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. July 2008. p.28

<sup>6</sup> Michael, J. Healthcare for all. Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. July 2008. p.36

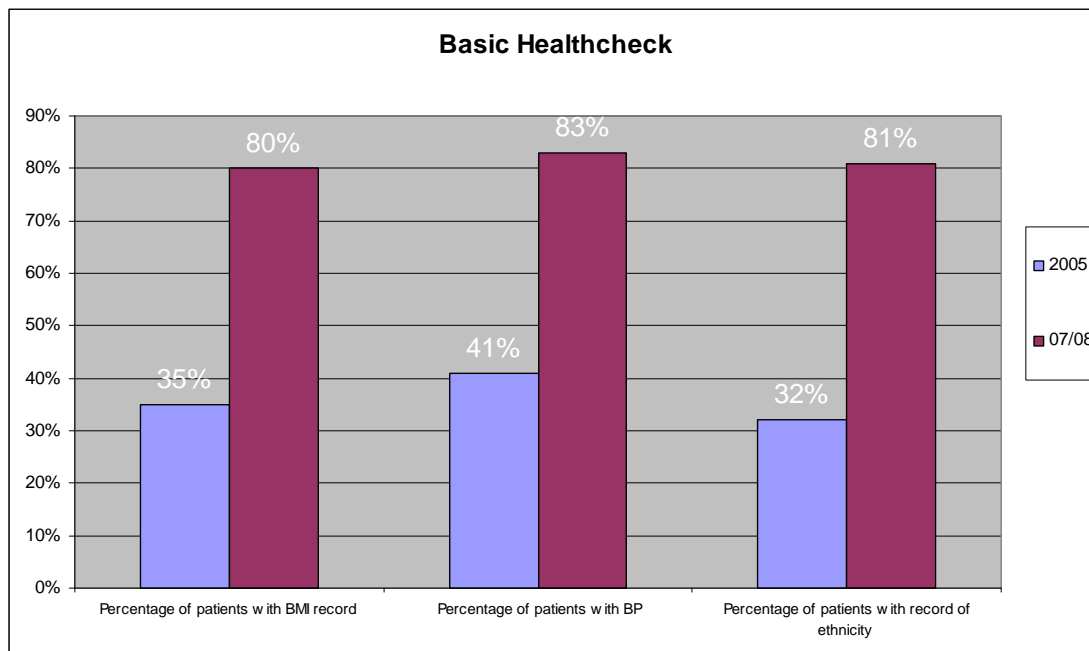
Comparison between the number of people with learning disabilities recorded on practice lists and the number of people on the WLDP caseload by ward in Westminster



## Health Check

The annual health check was a policy pledge from the Government and forms a key part of the learning disability LES. The health check is monitored through 3 key elements, the measurement of Body Mass Index (BMI), Blood pressure (BP) and recording of ethnicity. The graph below shows since there has been a LES there has been a great increase in the recording of key elements of care for people with learning disabilities, with all three elements having around 80% compliance. Although an achievement, it remains that 20% of those registered are not having basic health interventions.

Diagram 16 – Comparison of percentage of people of learning disability register in Westminster receiving a basic health check between 2005 and 2007/08



The health check in its current form provides the starting point for systematic health assessments. The health checks could now be expanded to look at the actual health outcomes for people on the register with learning disabilities, such as blood pressure measurements, interventions for obesity, and outcomes for other chronic diseases. This would provide a better measure of decreasing inequalities in health for people with learning disabilities. One way to measure wider outcomes would be to use the health indicators for people with learning disabilities derived from the Pomona project (<http://www.pomonaproject.org/> [accessed 04/11/08]). This is a Europe wide project which has developed 18 indicators across 4 domains (Demographics, Health Status, Determinants, and health systems) to measure the health and wellbeing of people with learning disabilities. This would give a comprehensive picture of the health and wellbeing of people with learning disabilities in Westminster, and allow for some measurement of inequalities.

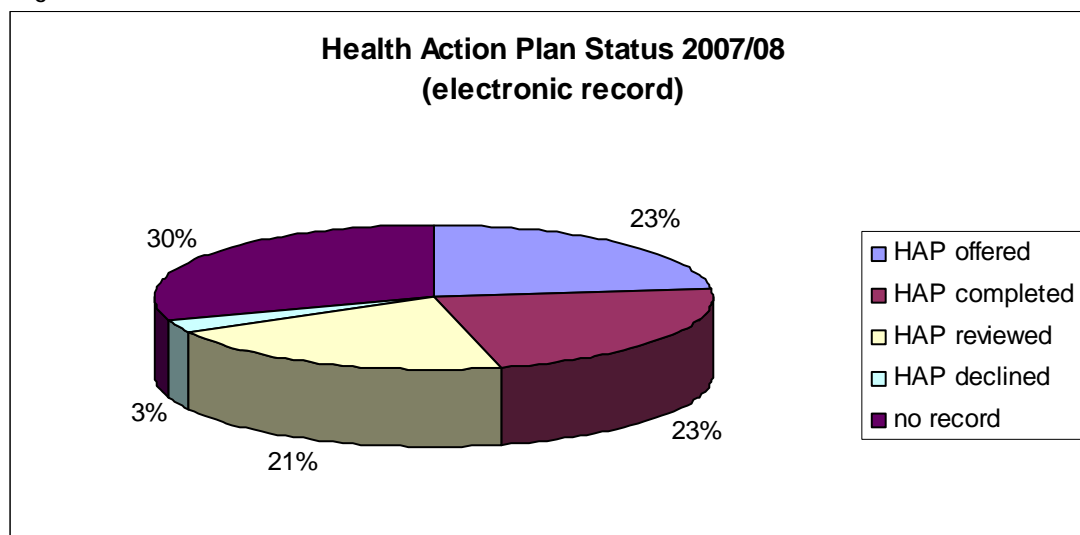
## Health Action Plan

The health action plan facilitates a discussion between the person with learning disabilities and the health professional. This agreement should focus on actions to be taken in the following year to facilitate an improvement in health.

In 2007/08 23% of those on the registers had an action plan completed and 21% had been reviewed. This means that over half of the population have not got a plan. Also there is little detail concerning the quality of the plans and the outcomes for those patients.



Diagram 17 – Health Action Plan Status 2007/08



The pledge by the government referred to all people with learning disabilities having a health action plan. As the LES only applies to those who are receiving interventions from the WLDP, it is likely that only a small proportion of those with learning disabilities are in receipt of a health action plan. There is likely to be unmet needs for those who do not access care from WLDP but have a learning disability and face the same health inequalities.

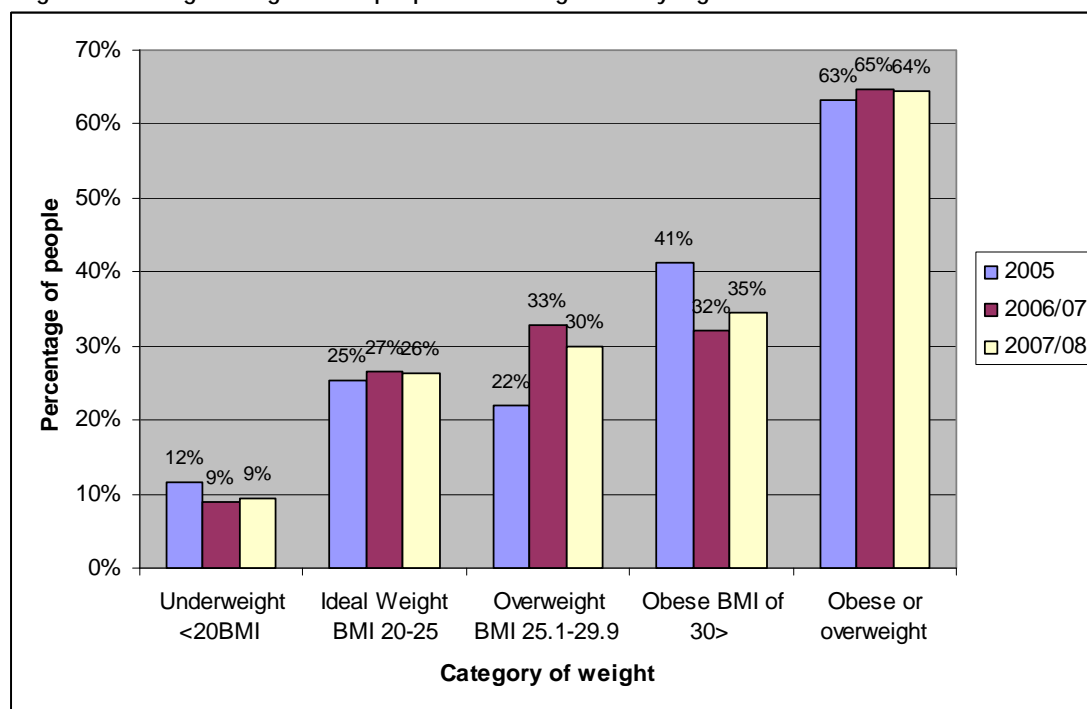
### Obesity

Levels of obesity are higher in people with learning disabilities and are more notable in those with milder learning disabilities especially women. Obesity is a risk factor for diabetes, cardiovascular disease and respiratory problems and is reflected in higher levels of mortality and morbidity for these areas.

Part of the general practice local enhanced service is the recording of BMI. The 2005 baseline audit found that only 30% of those registered as having learning disabilities had their BMI taken, in 2007/08 this had risen to 80% which is a significant improvement.

Diagram 18 presents the categorisation of the results of the BMI checks, this suggests that from 2005 to 2008, there has been little change in the proportion of people who are classified as underweight or ideal weight. In the overweight or obese category, the overall proportions have not changed. However, from 2005 there is a suggestion that there has been a reduction in the proportions of people who are obese which is reflected in an increase in the overweight category. However, as a relatively small proportion of people had their BMI measured in 2005, this may reflect small numbers of people that were measured and that only visually obese people were measured.

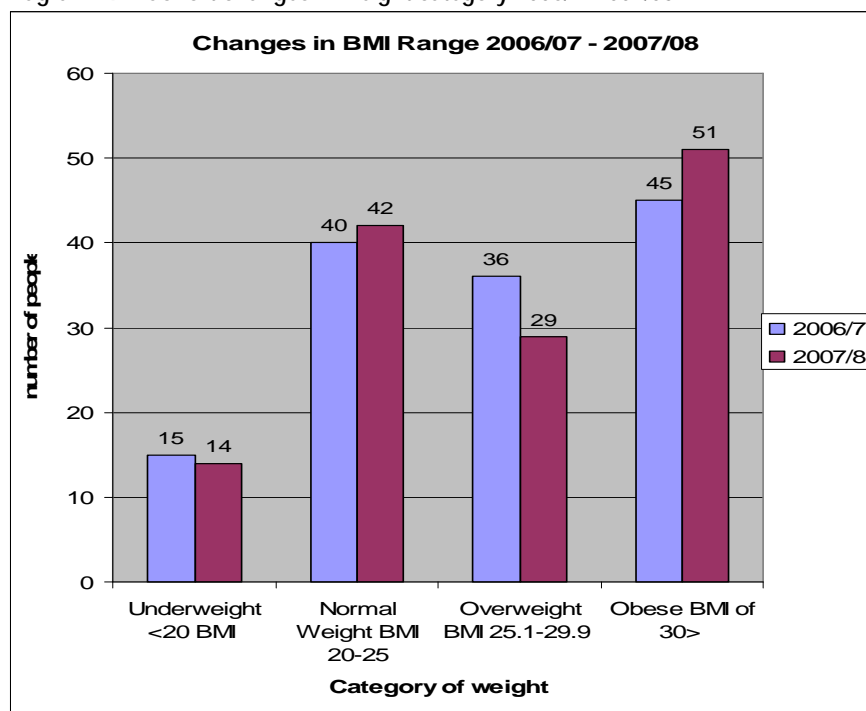
Diagram 18 – Weight categories for people on learning disability register 2005-2007/9



As expected the proportion of people overweight and obese in the learning disability population is higher than has been found in the general population, the health survey for England found that 45% of men and 55% of women were either obese or overweight (Health Survey for England, 2006). There is also a greater proportion of people from this group who are underweight than is found nationally. One population study in the UK found that 49% of people with learning disabilities were overweight or obese (Bhaumik et al, 2008). This could suggest that there are greater levels of obesity in Westminster compared to other areas, or this may reflect that the Westminster results are based on those registered with a GP and in contact with specialist services and therefore only one part of the total learning disability population.

The monitoring of the LES has allowed a cohort 138 individuals' weight to be monitored over time. The graph below presents the changes in weight in this cohort over 1 year. There has been a decrease in the numbers of people who are overweight; however this has been compensated by an almost equivalent increase in the numbers of people who are obese. This could be demonstrating an upward trend in obesity in people with learning disabilities, however the numbers are relatively small and the people who are now obese may have been close to the boundary and had only a small weight increase that would change the classification. However, this should not detract from the detrimental affect of obesity to health and the numbers of people who are either obese or overweight.

Diagram 19 – Cohort changes in weight category 2006/7- 2007/08



### Situation in Westminster

In 2007, the reducing obesity in people with learning disabilities project was launched with the aim of reducing the level of obesity in people with learning disabilities by 2% in 2007/08 using the QOF learning disabilities register. The project included a detailed action plan. This included diverse interventions including health promotion, weight management programmes and strategic planning.

The timescales to achieve the target were quite short, and the figures above illustrate that this was not met. Further monitoring and evaluation of the measures will need to take place.

Also, the outcomes of the strategy are measured through those people who are part of a QOF learning disabilities register. This could be a risk in causing inequalities between this group and the wider population of people with learning disabilities. This group will be in receipt of mainstream messages regarding obesity.

### Sexual Health

Studies have found that people with learning disabilities can face a number of barriers to experiencing good sexual health. It has been identified that the sexuality of people with learning disabilities is not routinely acknowledged, so subsequently their needs are ignored. People with learning disabilities may feel overprotected by professionals and family carers which can result in them being unable to express their sexuality.

People with a learning disability complain about a lack of information and this may have resulted in a poorer knowledge of their bodies and sexuality.

## **Situation in Westminster**

In response to this a project was launched in August 2007 to embed good sexual health for people with learning disabilities in Westminster. This has seven key objectives:

1. Provide Sex and Relationship Education through individual and group work
2. Provide Sexual Health training for staff working with people with learning disabilities
3. Undertake support work with parents and carers
4. Develop and implement a Sexuality Policy
5. Develop guidance on consent and setting appropriate boundaries
6. Increase access to screening and GUM clinics
7. Increase access to Cervical Smears and Breast Screening

The first three were to be commissioned from third sector organisations, the remaining objectives would be delivered through PCT led service development. The aims of these would be to increase knowledge in people with learning disabilities and professionals working with them through education and information. Screening for women and self examination of testicles would also be an expected outcome.

No measurable outcomes have been reported on this as yet.

## **Mental Health**

People with learning disabilities are vulnerable to all mental health problems. It is estimated that 25–40 per cent of people with learning disabilities also have additional mental health needs (Foundation for Learning Disabilities [accessed 30/10/08]).

### **Anxiety disorders**

These include general anxiety, phobias and panic disorders. The physical signs of anxiety, such as rapid breathing, muscle tension and motor agitation, can be observed in people with learning disabilities, but other psychological symptoms might be harder to detect.

### **Depression**

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

### **Schizophrenia**

Schizophrenia is three times more prevalent in people with learning disabilities than in those without learning disabilities. People with learning disabilities can experience the full range of psychotic symptoms associated with schizophrenia.

The combination of learning disabilities and mental health problems can result in very complex needs. These needs may not be well defined, so that individuals are passed between different agencies. Challenging behaviour may also make it difficult to find a service, and can put undue pressure on the individual and their carer. Services need to work together to ensure that the needs of people with learning disabilities can be met (MIND, [www.mind.org.uk/Information/Factsheets/Learning%2Bdisabilities/#\\_ftn1](http://www.mind.org.uk/Information/Factsheets/Learning%2Bdisabilities/#_ftn1) [accessed 24 November 2008]). Diagnosing mental health conditions in people with learning disabilities can also be challenging, and it is often undiagnosed.

The baseline assessment (2005) of people with learning disabilities who were registered with a GP in Westminster found that 16% of the 318 who were on the register had a mental health problem noted. This is lower than the national prevalence figures noted above where 22% reported depression and 18% schizophrenia. In a survey of service users accompanying the baseline review, 31% reported having a mental health problem (this is self reported and would not represent a formal diagnosis), suggesting that there are perceived needs that are either not recognised or reported by general practitioners.

An updated audit could be carried out to review the numbers of people who are in touch with services. Mental health is included in the Pomona indicators.

### **Situation in Westminster**

One of the priorities for the service is to produce a mental health pathway. It would be useful to repeat this audit to specifically look at whether the pathway is functioning effectively and to assess whether there is unmet need.

Psychiatry services are available from Westminster Learning Disability Partnership.

As before this evaluation only covers those who are accessing care for WLDP and therefore any training or pathway would need to be extended to the whole learning disabilities population. This could be linked in with the current emphasis on expanding the capacity of primary care mental health.

### **Oral Health**

Studies have found that people with learning disabilities have poorer oral health than the general population. People with learning disabilities may not be able to articulate problems they are having, and in some cases may present pain and discomfort through challenging behaviour. Treatment may also need to be provided in different ways if the individual cannot cooperate or has a complex condition, for example in secondary care.

The barriers to accessing care have been identified as poor information (dental services and oral health), access (physical and transport), negative attitudes from Professionals to provide care, negative attitudes to the need to care from carers and support staff, anxiety and fear and general lack of training (BSDOH, 2006).

A local baseline audit (Stephan Brusch, 2004) of GP registers of patients with learning disabilities highlighted that of 233 people only about 10% had a record of their oral health and only 4% had seen the dentist in the last year. Combining this survey with the LES identified at least 25% people with learning disabilities were not seen within the last year. Of those seen by a dentist 35% were seen within the Community Dental Service and 35% by a local general dental practice. This suggests that

the situation in Westminster is similar to that in the rest of the country, and there is unmet need in the population for dental services.

### **Situation in Westminster**

This unmet need has been recognised within Westminster and plans have been put in place to enable people with learning disabilities to access services. This includes the development of a care pathway, which would ensure that people are appropriately referred and signposted and that dental services receive training to increase their knowledge of the potential needs of this population. This also includes the appointment of an oral health promoter.

As these services are implemented careful monitoring will need to be completed to ensure that needs are met.

### **Screening**

Studies have shown that women with learning disabilities are less likely to undergo screening for cervical and breast cancer.

([www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=259853](http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=259853)) There are a number of reasons suggested for this including not being offered (for example with cervical screening where an assumption is made about sexual activity), perceived difficulties of performing test or getting adequate consent (Cancer Screening Programme, 2006).

In a recent survey of Westminster residents with a learning disability only 40% of women had had a cervical smear test and only 29% had had a breast screening test.

There is guidance for providing screening for people with learning disabilities, and examples of good practice to do this (Cancer Screening Programme, 2006).

### **Situation in Westminster**

The PCT is currently refreshing its approach to cancer screening across all groups in the PCT. The needs of people with learning disabilities across the spectrum of severity will be included in this review.

## **Chronic Diseases**

### ***Coronary heart disease***

Coronary heart disease is the second highest cause of death for people with learning disabilities (Hardy et al, 2006). The incidence of coronary heart disease amongst people with learning disabilities are increasing due to increased life expectancy and increased exposure to risk factors as a result of living within the general community.

People with learning disabilities are more likely have risk factors for coronary heart disease, such as obesity, hypertension and a sedate lifestyle. People with Down's Syndrome are at higher risk of congenital heart problems (Hardy et al, 2006). People with Prader-Willi Syndrome are at risk of coronary heart disease and sudden cardiac death (Patel, 2007).

In 2005 the baseline review of primary care and learning disabilities, found that only 0.4% (1 person) was registered as having learning disabilities and CHD. This would be expected to be much higher, which could suggest a lack of coding or under-diagnosis. Following the introduction of the LES and the embedding of chronic disease registers using the QOF, this would be expected to have increased significantly. There would be benefit from repeating this exercise and looking at the outcomes for those

with learning disabilities when compared to the rest of the population. This exercise would not assess the inequalities for those who are not on registers but have a learning disability.

### ***Respiratory Disease***

Respiratory disease is the leading cause of death for people with learning disabilities (46%-52%), and is much higher than for the general population (15%-17%).

The baseline review of primary care and learning disabilities in 2005, found that only 0.7% were also noted as having COPD, and 6.8% had asthma. The latter figure is higher than the general population. The outcomes for these populations and the increase in register numbers should also be investigated.

### ***Diabetes***

People with learning disabilities have a higher risk of diabetes than those without learning disabilities. This may be attributed to increased levels of obesity, poor diet and inactive lifestyles.

The prevalence of diabetes in people with Prader-Willi syndrome is high, with one small study finding a rate of 25% (Butler et al, 2003).

The baseline assessment found a prevalence of 9% of diabetes in the learning disability population. This is higher than the general population, as before the current prevalence and outcomes for this group should be investigated.

### **What are service users' experiences of services?**

A recent consultation event for service users found that although people felt that health professionals were helpful, there was more that could be done especially in terms of awareness of the difference in practical needs of people with learning disabilities. This included a lack of professionals' listening skills. It was also suggested that GPs give longer times for consultation and that people with learning disabilities are fast-tracked to primary care and other health appointments. This was supported by feedback from carers.

There was an inconsistent picture surrounding health action plans; some people reported having one, whilst others had reported not having had them offered to them.

Both carers and service users expressed an interest in receiving more information about having a healthy lifestyle.

### **What are professionals' opinions on services in terms of met and unmet need?**

The WLDP services felt that although secondary and mental health services are engaged in the process, that primary care does still not fully recognise the needs of people with learning disability. This was supported by other service providers.

As noted by service users and their carers it was also felt by professionals that people with learning disabilities need more time for their appointments and also support.

They also identified that there was not enough capacity for psychiatric assessment and treatment beds.

They felt that for services to improve work need to be done to increase awareness and skills to work with people with learning disabilities for people in mainstream services. It was also felt that improving strategic level links would significantly help improve actual care for people with learning disabilities.

## Information gaps

Currently GPs appear to only be recording people on their registers with severe learning disabilities. This means that it is difficult to assess whether there are others with more moderate or mild learning disabilities who might not be receiving services they need.

## Conclusions and recommendations

This quick review of health has found that in Westminster, many initiatives have already been taken to meet the needs of people with learning disabilities, notably increasing the quality of care at primary care level. Westminster also has a specialist service which meets a spectrum of needs for the population. Some of those initiatives that have taken place may now need revisiting to ensure that outcomes are measured effectively to confirm that needs are being met and inequalities minimised.

The profile of the population identified that as expected not all of the people with learning disabilities will require specialist support. Many of the subsequent developments have focussed on the population who access specialist services. It is likely that those people with learning disabilities who do not access specialist services will suffer to some extent similar inequalities to those who do. Therefore, the mainstreaming of the approach that has been taken in generic services for those people in contact with specialist services should be facilitated.

## Key Messages:

- The number of people on the QOF registers for learning disabilities has grown year on year since the development of the registers in 2005. There are now 416 people on the registers reflecting the number of people with learning disabilities receiving services from WLDP and thus eligible to be entered on the register. This is a notable achievement; every person registered with WLDP is registered with a GP.
- The total number of people with learning disabilities in Westminster in 2008 is predicted to be 4,377 (9% of which are on the WLDP caseload.) The local learning disability population is predicted to increase over time (4,700 by 2020). Of these there are predicted to be 908 with moderate/severe learning disabilities (45% of which are on the WLDP caseload.) This indicates that there may be some people in Westminster with more moderate learning disabilities who may have some need for the services provided, but are not currently accessing them.
- A total of 80% of people on the learning disabilities register have received a health check. This is an increase of 50% from the baseline measure in 2008, however it remains that 20% of people are at increased risk of a number of health issues are not receiving their check.
- The recording of an annual health check is completed through the recording of BMI, BP record and ethnicity. This could be linked more effectively to actual outcome measures in the learning disability population, for example BP measurements, interventions and outcomes for other chronic diseases.
- Around 50% of those who are registered with a GP have received a health action plan, which demonstrates a great step forward to implementing the plans; however there remain issues of coverage. This process could be improved by some assessment of the quality of the plans and improved outcomes for the individuals. The lack of coverage was clear from the consultation with service users, who had not consistently received an action plan. This was attributed by service providers to a continuing lack of engagement in recognising and working with the needs of people with learning disabilities. Work to improve this is a suggested area for improvement.



- In 2007/09 80% of people with learning disabilities on the register had had their BMI checked, this was an increase from 30% in 2005. There has been little change over time in the classifications of people's weights with 64% of individuals being classified as overweight or obese. As expected this is greater than the general population, it is also greater than other studies that have measured BMI in populations of only people with learning disabilities. Clear outcomes should be measured to assess the effectiveness of interventions in relation to the overall burden of overweight and obese people with learning disabilities.
- Baseline work was undertaken to look at the mental health needs of people with learning disabilities. This suggested that people with learning disabilities had self perceived mental health needs that were not recognised by General Practice. A follow up of these aspects could be investigated.
- Key pieces of work are being undertaken in sexual health, and dentistry. Key outcome measures should be linked to these pieces of work to ensure that an improvement in the health and wellbeing of individuals could be observed.
- Work could be undertaken to cross reference those people on the learning disabilities register with the other chronic disease registers in general practice. This would give an insight into the level of chronic disease in Westminster's population of people with learning disabilities, and also provide some clinical outcome based information.
- Develop a suite of indicators to allow the monitoring of the health and wellbeing of people with learning disabilities. The Pomona indicators could be used.
- The GP registers and individual initiatives are aimed at those people with learning disabilities who are accessing specialist services through the WLDP. This group are likely to be those with the most complex needs, and have a need for dedicated services. However, there are likely to be many people with learning disabilities at the milder end of the spectrum who are in receipt of health inequalities and could benefit from some dedicated attention. The messages that have been distributed for providing healthcare for people with more complex needs should be mainstreamed for all people with learning disabilities. The inclusion of these people on the register (with those in contact with WLDP identifiable) should be facilitated. The national prevalence figures suggest that this is the case nationally, the healthcare for all review (Michael, 2008) noted this and made suggestions for wider inclusion.
- It was felt by all those consulted that people with learning disabilities may require longer times in consultation. This is something that can be explored with primary and secondary care.

## **Making transition a positive experience**

Transition from children's and adults services is recognised as a difficult time in the lives of young people with learning disabilities and their families. They can feel excluded from decisions made about them and find that when they have transferred to adults services they receive segregated services which do not meet their holistic needs as a young person. Transition provides a unique opportunity to develop a person centred plan which can facilitate paid employment, ordinary housing and greater independence.

There have been two recent changes which is creating a renewed focus on transition arrangements. The first is the growing number of children and young people with severe and complex needs who are surviving into adulthood, and the numbers of school age children with autistic spectrum disorder, some of whom have learning disabilities.

### **Situation in Westminster**

In Westminster there are currently 306 young people in years 11 to 16 (aged 12-21) who are in the process of transition. Of these, 150 people are on a universal transition pathways, 100 are on intensive pathways and 56 did not have their pathway defined in the information available. Those people who are identified on the intensive pathway will meet the eligibility criteria for WLDP services. This is a considerable number of people who will require adult specialist service support over the next 5 years, especially considering that the current total caseload is 572. The majority (72%) of the young people are in years 11-14. This could signify that people go through transition at variable times, the increased numbers at a younger age may also reflect the national trend of increased numbers of people being transferred to adults services. This information requires further exploration to assess trends and future impact of the numbers of people within the service.

Work has been undertaken in Westminster to improve the transition arrangements. This includes a transition strategy group and designated pathways for those young people who will meet the eligibility criteria for adult services.

### **What are service users' experiences of services?**

Family carers in particular identified a number of things that they felt would help to make transition to adult services a more positive experience for young people and their families. This included having their case seen as individual and unique. The experience was also thought to be able to be improved by starting discussions around transition earlier and on a regular basis.

### **What are professionals' opinions on services in terms of met and unmet need?**

It is thought that the transition process could be improved.

### **Information gaps**

There is a lack of good quality information regarding children and young people who are approaching transition. For example severity is not routinely recorded, this makes forward planning challenging. Better information sharing from children's and adult's services could improve the situation and handover.

## **Conclusions and recommendations**

- There was found to be some issues with the level of information transferred from children's to adult services. Improved recording of information should enable better planning.
- Carers' feedback suggested that there is a need for improved information at specific points in transition about the process and what options are available. This would improve the experience and provide greater options for the future.
- The assessment suggested that not all the information available about the people in transition is collated to inform the transition process, for example information from schools and colleges. A wider collation of information could provide improved the quality of decision making regarding the person's future.
- To ensure the equity of opportunity for people for people with learning disabilities, every young person is offered the largest possible range of services.

## Being part of my community

This aspect considers the issue of people with learning disabilities being able to live as full and as active a life in their community as those people without one. There can be barriers to achieving this for people with learning disabilities as those things that define citizenship in society prevent their full participation. Therefore action has to be taken to ensure that they have the opportunities that are open to most people.

### Situation in Westminster

Advocacy is seen as an important tool to increase participation for people with learning disabilities. Westminster has increased what it spends on advocacy for people with learning disabilities year on year in absolute terms and amount spent per head. The spend in pounds per 1,000 population in Westminster is slightly lower (0.67) than the inner London average (0.9). This may suggest that Westminster spends less, however this figure does not take into account the actual numbers of people with Learning Disabilities in the borough. The advocates have been used for a wide range of activities including facilitating participation in the partnership boards and providing training about learning disabilities to the police.

Transport is identified as a barrier for people with learning disabilities participating fully in their community. Information and signage for transport may not be accessible, they may not have anyone to travel with and people may feel more vulnerable to abuse on transport. In Westminster guidance has been provided to managers of the taxi card scheme to raise their awareness of how to provide a service to people with learning disabilities.

It has been that identified people with learning disabilities have fewer friends than those without, and that staff may not encourage those relationships. In Westminster friendship groups have been set up for those people with high support needs. The sexual health work stream has also identified actions to ensure the sexuality of people with learning disabilities is recognised.

Hate crime has been identified as a major problem for people with learning disabilities in the distress and harm caused by actual events and feelings of anxiety which prevent them from participating fully in the community. The situation is complicated as it may be more difficult for people with a learning disability to report crime as the processes may be inaccessible, if a person with learning disabilities does access services staff may not be able to support or respond adequately. It is difficult to quantify the situation as data is not recorded about learning disability status.

### What are service users' experiences of services?

Service users felt that they could be supported to speak up for themselves by receiving training to be assertive and also by using an advocate. They felt that they could ensure their voice was heard by accessing mechanisms already available to them such as have a say day groups and the partnership board.

## What are professionals' opinions on services in terms of met and unmet need?

The professionals gave more detailed responses by key areas:

***Rights and Advocacy*** – This was felt to be an area in which Westminster was strong, but that the quality of advocates available could be improved. It was agreed that there were still barriers to people with learning disabilities having an equal voice in mainstream or regional forums.

***Transport*** - Professionals felt that transport was not accessible or well signposted for people with learning disabilities. Awareness and training for those who work in the transport system was felt to be a first step to improving access for people.

***Friends and relationships*** – It was felt that there were issues regarding the recognition that people with learning disabilities have sexual relationships. There was also thought too be a lack of support for people with learning disabilities who have children.

***Hate crime*** – Professionals were concerned about community safety in Westminster, especially for people with learning disabilities who are in general were thought to lack assertiveness and to be less streetwise. A greater level of partnership working with those agencies involved in community safety such as the police and city guardians could increase awareness of the needs of people with learning disabilities. Some local providers of services felt that the police were not taking complaints from people with learning disabilities seriously.

### Information gaps

There is a lack of detailed information about people's use of transport and what could be done to improve the situation.

There is little information about what could help to facilitate friendships for people with learning disabilities.

Information is not collected about the numbers of people with learning disabilities who have crimes committed against them. Therefore the issue cannot be accurately quantified and any outcomes from crimes reported cannot be analysed.

### Conclusions and recommendations

- Local comparisons suggest that there is less spend on advocacy services than in other parts of London. A needs assessment should be carried out to assess whether the current level is meeting needs.
- Research suggests that people with learning disabilities have greater difficulty making friends. Action could be taken to support and facilitate friendships between people with learning disabilities, such as online forums and events.
- Facilitating relationships should be part of the role of staff.
- Research and information from professionals in Westminster suggested that accessibility to transport could be improved to increase independence. Work could be undertaken with TFL to ensure that transport is accessible and safe for people with learning disabilities. It could also be beneficial to support people with learning disabilities to access public transport to build their confidence and knowledge of the systems.

- Safety and feelings of safety has been recognised as a key area of concern for people with learning disabilities. Initial work with stakeholders should be carried out to improve the safety and feeling of safety for people with learning disabilities.
- It has been suggested that people with learning disabilities do not report crime in the same way or receive the same treatment as people without learning disabilities. Key pieces of work would include collaboration with community safety stakeholders to ensure that people with learning disabilities are able to report crimes, that they are understood and are taken seriously.
- Currently learning disability status is not collected by the police, which makes it impossible to quantify the issue or monitor any changes following interventions. This should be improved.

## **In partnership with families**

It is recognised that family carers need support to be able to carry out their caring role and to have a life of their own. It is also recognised that their voice is an important one when deciding on future programmes of care for the person they care for and for service provision as a whole. To enable this, family carers need quality information about help and support, to have their needs assessed and to have access to services necessary to meet their needs.

### **Situation in Westminster**

Over two-thirds of the family carers of people with learning disabilities who are in contact with WLDP services are over the age of 55, reflecting the ages of adults with disabilities. A number of initiatives have been undertaken to meet the needs of carers, a total of 143 carers have received a review or an assessment during 2008. This is 82% of the total numbers of people who are carers.

WLDP have also worked to improve the information kept about carers on their data systems. The partnership has also run with Carers Network Westminster a training programme to help open dialogue about difficult topics. Short break services are also available to carers however a significant minority of the people eligible do not use them effectively.

### **What are service users' experiences of services?**

Family carers highlighted a number of factors that they felt would support both partnership working and their lives as family carers. These included having clear lines of communication, increasing involvement with the partnerships and providing more inclusive and flexible short break services.

### **Information gaps**

There is a lack of information about those people with learning disabilities who are themselves carers.

There is no information about those people who care for people with learning disabilities who are not in contact with specialist services, and if they access mainstream carers support.

## **Conclusions and recommendations**

- To ensure that carers have the opportunity to access all the services available to them, there should be consistent recording within the WLDP system.
- The carer assessment is key to ensuring issues can be identified and actions taken. All eligible family carers should be offered an assessment; the current uptake suggests that this is the case. Currently there is no information about the support for carers that is being accessed by those people who care for someone with learning disabilities but are not in contact with specialist services. Any initiatives to highlight the needs of people with mild and moderate learning disabilities should include some focus on their carers so they are able to access mainstream caring services.
- The carer's voice has an important role in service planning for the person they care for and service design. This voice is being increasingly taken into account and should continue to do so in new ways.
- Assessments for carers are available and there have been one off events to find new ways of supporting them. Consistent sources of support should be identified along with a consistent programme of events.

- It has been suggested that a significant minority of carers are not accessing the short break service. Work should be undertaken to identify who the people accessing the service are, and whether there are any barriers.

## Conclusion

Over 4000 people in Westminster are thought to have learning disabilities, of these nearly 600 access Westminster's specialist learning disability provider, Westminster Learning Disability Partnership. Westminster learning disability partnership provides a wide range of services and initiatives to ensure that their service users are able to reach their full potential with maximum independence. Where there are gaps in the provision of specialist services and wider services, these have been picked up in the Big Plan 2009-2012, which this needs assessment accompanies. Key actions include those around increasing the uptake of individual budgets, maintaining the momentum of the work in GP practices, and supporting people with learning disabilities to maximise their independence through employment and living in safe and accessible environments. All proposed actions should have clear systems to allow their comprehensive monitoring and evaluation.

This needs assessment also considers the needs of those people with learning disabilities who do not need specialist services; the majority of the people with learning disabilities in the borough. There is no information available about this group of people. What can be inferred is that this group is likely to be subject to the same wide inequalities as those people with learning disabilities that are in contact with services, such as accessing employment and maintaining independence throughout their lives. The actions in the big plan focus on WLDP service users. The benefits of these should be felt by all people with learning disabilities as long as the wider aim is made explicit and informs the initiative's content. This is especially the case where training and education is a key part of the action. Specific actions can also be taken for this group, this is especially applicable in universal services such as general practice. By widening the learning disabilities register in general practice to those people not in contact with WLDP services, will ensure that actions are taken to reduce their inequalities but will also provide information about the numbers of people in this group. There is now a clear opportunity to improve the lives of all people with learning disabilities by emphasising the full spectrum of disabilities.



# References

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- Bhaumik, S., Watson, J.M., Thorp, F., Tyrer, C.W., McGrother, C.W (2008) Body mass index in adults with intellectual disability: distribution, associations and service implications: a population-based prevalence study. *Journal of Intellectual Disability Research*. 52 (4) , pp. 287–298.
- British Society of Disability and Oral Health (2006) *A Commissioning Tool for Special Care Dentistry*. BSDOH, London.
- Brusch, S (2007) Good sexual health for people with learning disabilities In Westminster-Project Initiation Document. Westminster PCT.
- Brusch, S., Marsham, M. (2007) Choosing the Chance to Change- Reducing Obesity in people with learning disabilities: Project Initiation Document. Westminster PCT.
- Butler, J. V., Whittington J. E., Holland, A. J. et al (2002) Prevalence of, and risk factors for, physical ill-health in people with Prader-Willi syndrome: a population-based study.
- Cole et al (2007) Having a good day? A study of community-based day activities for people with learning disabilities Adults' Services Knowledge Review 14.
- Cole, A et al (2007b) Adults' Services: Practice Guide 10. Community-based day activities and supports for people with learning disabilities: How we can help people to 'have a good day' Social Care Institute for Excellence Developmental Medicine and Child Neurology. Vol. 44:pp. 248-255.
- Corbett, J. (2007) *Health Care Provision and People with Learning Disabilities – A Guide for Health Professionals*. John Wiley & Sons, London.
- Davey, V et al (2007) Direct Payments: A National Survey of Direct Payments Policy and Practice Personal Social Services Research Unit, London School of Economics and Political Science.
- Department of Health (2009). *Valuing people now: A New Three year Strategy for People with Learning Disabilities*. London, Department of Health.
- Department of Health (2007). Specialised Services National Definitions Set (2<sup>nd</sup> Edition): Specialised Learning Disability Services - Definition No. 21. (updated February 2007)  
[www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Commissioningspecialisedservices/Specialisedservicesdefinition/DH\\_4001695](http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Commissioningspecialisedservices/Specialisedservicesdefinition/DH_4001695) [Accessed 15.12.08].
- Department of Health (2001) *Valuing People - A New Strategy for Learning Disability for the 21st Century*. London, Department of Health.
- Easterbrook, L (2007) *Living on the edge: enabling older owner occupiers with moderate learning disabilities to live independently*. Care and Repair [www.careandrepair-england.org.uk/reports.htm](http://www.careandrepair-england.org.uk/reports.htm).
- Emerson, E., et al. (2005) *Adults with learning difficulties in England 2003/04*, London: Health and Social Care Information Centre.  
[www.dh.gov.uk/en/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/DH\\_4081207](http://www.dh.gov.uk/en/PublicationsAndStatistics/PublishedSurvey/ListOfSurveySince1990/GeneralSurveys/DH_4081207).
- Emerson Eric (2004b); Cluster housing for adults with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, 29(3), September 2004, pp.187-197.
- Emerson, E. and Hatton, C. (2008) *People with Learning Disabilities in England*. CeDR Research Report 2008:1 Centre for Disability Research, Lancaster.
- Emerson, E. and Hatton, C. (2004) *Estimating Future Need/ Demand for Supports for Adults with Learning Disabilities in England*. Institute for Health Research, Lancaster University, UK.
- The Foundation for Learning Disabilities [www.learningdisabilities.org.uk/information/learning-disabilities-statistics](http://www.learningdisabilities.org.uk/information/learning-disabilities-statistics) [accessed 30/11/08].
- Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*, Social Policy Research Unit, University of York, York.

- Hall, C et al (2008) Choice Based Lettings and People with Learning Disabilities. Report for the Valuing People Support Team, Care Services Improvement Partnership.
- Emerson E, Hatton C (2004). Estimating future needs/demands for support for people with learning disabilities in England. Lancaster: University of Lancaster.
- Hardy et al (2006) Meeting the health needs of people with learning disabilities Royal College of Nursing, London.
- Housing Learning and Improvement Network. (2006) Enhancing Housing Choices for People with a Learning Disability.
- Housing Learning and Improvement Network. (2004) New Provision for Older People with Learning Disabilities.
- Mencap (2007) *Death by indifference - Following up the Treat me right!* Mencap, London.
- Mencap (2002) A life in the day: The modernisation of day services for People with a Learning Disability. [www.mencap.org.uk/displaypagedoc.asp?id=1646](http://www.mencap.org.uk/displaypagedoc.asp?id=1646) [Accessed 22/9/08].
- Michael, J. (2008) Healthcare for All –Report of the Independent Inquiry into access to healthcare for People with Learning Disabilities.
- MIND, [www.mind.org.uk/Information/Factsheets/Learning%2Bdisabilities/#\\_ftn1](http://www.mind.org.uk/Information/Factsheets/Learning%2Bdisabilities/#_ftn1) [Accessed 24 October 2008].
- National Audit Office (2005) *Gaining and retaining a job: the Department for Work and Pensions' support for disabled people*. London, National Audit Office.
- National Library for Health [www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=259853](http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=259853) [Accessed 24 October 2008].
- NHS Cancer Screening Programmes (2006). Equal Access to Breast and Cervical Screening for Disabled Women. NHS Cancer Screening Programmes, Sheffield.
- Patel, S (2007) Characteristics of cardiac and vascular structure and function in Prader-Willi syndrome. *Clinical Endocrinology*. 66(6)pp.771-7.
- Robertson, C., Brusch S., Erne, F. (2007) Developing a care pathway for people with Learning Disabilities and a network in NWL sector of PCT clinician leads Special Care Dentistry. Westminster PCT, London.
- Watson, D., Williams, V. and Wickham, C. (2005) *A valued part of the workforce? Employment and disabled people*, Guildford: The Sequal Development Partnership, University of Surrey.
- Westminster PCT and Westminster City Council (2005) A framework to address the Health Inequalities of People with Learning Disabilities In Westminster, London.
- World Health Organisation. Classification of Mental and Behavioural Disorders. *The ICD-10*. Geneva. 1992.
- Williams V (2006). How can local authorities increase the take-up of direct payment schemes to adults with learning disabilities OutLine 3, Research in Practice for Adults, Totnes. [www.ripfa.org.uk/publications/outlines/outlinesPDF/3.pdf](http://www.ripfa.org.uk/publications/outlines/outlinesPDF/3.pdf).





## Westminster Learning Disability Partnership Board and Have a Say Group Joint Day - November 2008



Westminster City Partnership  
Joint Strategic Needs Assessment