A Health Needs Assessment (HNA) for Adults with Learning Disabilities in Salford

EXECUTIVE SUMMARY

July 2011

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**Document Control**

**Version:** FINAL#V1  
**Date:** JULY 2011  
**Location:** Public Health Shared Drive  
1. **LEARNING DISABILITIES – AN OVERVIEW**

1.1 **BACKGROUND & INTRODUCTION**
The health and strength of a society can be measured by how well it cares for its most vulnerable members. Adults with learning disabilities (LD), especially those with severe disability and the most complex needs, are some of the most vulnerable and socially excluded people in society and tend to have increased health needs which differ qualitatively from the rest of the population.

Improving the health, and having a better understanding of the health needs of people with learning disabilities, is a high priority. The Health Needs Assessment (HNA) for adults with LD was commissioned in response. This document summarises the findings and recommendations of the HNA which illustrates the need to renew commitment to systemic improvement across the health system for people with LD.

1.2 **METHODOLOGY**
Health need assessment (HNA) is a systematic method for reviewing the health issues facing a population, leading to a set of agreed priorities and resource allocation that will improve health and reduce health inequalities. The LD HNA takes an epidemiological approach, the purpose of which is to inform pragmatic and effective strategy and commissioning decisions.

The focus of the health needs assessment is on adults (those aged over 18) with a learning disability whom are resident in Salford or those who are registered with a Salford GP.

The aim of the health needs assessment is to provide recommendations for key stakeholders based on the needs and priorities of adults with LD across Salford.

1.3 **DEFINING & CLASSIFYING LEARNING DISABILITIES**
*Valuing People*, the 2001 White Paper on the health and social care of people with learning disabilities, included the following definition of learning disabilities. ‘Learning disability includes the presence of:

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

Within the clinical context, sub-classifications of mild, moderate, severe and profound LD are also used. These are defined by measuring impairment of intellectual functioning using psychometric tests to quantify IQ (Intelligence Quotient). The average IQ is 100. Deviations below the population average of 100 are used to define clinical sub classifications as follows:

- Mild LD = IQ Score 50 – 70
- Moderate LD = IQ Score 35 – 50
- Severe LD = IQ Score 20 – 35
- Profound LD = IQ Score Less than 20

World Health Organisation (1992)
These definitions should be viewed alongside the social model of disability which proposes that systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society.

The terms ‘learning disability’ and ‘learning difficulty’ are used in the context of health and social care for adults and as such are used interchangeably throughout this report.
2. LEARNING DIFFICULTIES IN SALFORD

2.1 DEMOGRAPHIC CHARACTERISTICS
Understanding the demography of the LD population is crucially important, not only because of the wide spectrum of LD which dictates diverse health need, but also because the LD population is so dramatically changing. Improving health and advancing technology are increasing life expectancy. As a consequence people with LD are entering adulthood with complex physical needs and are living longer. These factors have had a differing effect on the size of birth cohorts, which vary significantly, and the spectrum of LD.

2.1.1 Prevalence and incidence of LD in Salford
Most population figures for the UK have been determined from service contact, often derived from case registries and more recently from GP records gathered as part of the annual health check. As a consequence, more is known about people with moderate or severe impairment and co-existing conditions (e.g. those in touch with services) than about the much larger group of people with relatively uncomplicated, mild or borderline intellectual impairment.

Current estimates indicate that there are approximately 4295 adults with a learning difficulty living in Salford. Of these 21% (896) are estimated to have moderate or severe LD. For those with moderate or severe LD in Salford, Congenital Cerebral Palsy is the most prevalent condition type (See Figure 1).

Figure 1: LD Conditions by type for Salford residents

![Pie chart showing prevalence of LD conditions in Salford](image)
2.1.2 Salford LD Population Projections
The number of adults with learning disabilities is predicted to increase by 14 per cent between 2001 and 2021. National projections also anticipate sustained population growth during the period 2009 – 2026; with a corresponding annual increase in service demand estimated between 1.04% and 7.94%. All scenarios dictate an increased need for both health and social care services for adults with LD.

Population projections for Salford suggest that the number of people with LD will have increased to 4885 by 2030; with the majority of these (78%) having a mild to moderate learning difficulty (See Graph 1).

**Graph 1: 2010 – 2030 Salford LD Population Projections**

![Graph showing population projections for Salford](image)

2.1.3 Population Segmentation
Adults with learning difficulties are not a homogenous group. The wide spectrum of learning difficulties present differences in both range and severity. Inevitably these differences manifest diverse health need; affecting the kind of support each person requires. It is therefore important to understand the segmentation of the LD population in order to inform accurate needs assessment. Typically learning difficulties are segmented into three groups; those with mild LD, those with moderate LD and those with severe LD.

2.1.3.1 Mild Learning Difficulties
Establishing the precise number of adults with mild LD is problematic as existing estimates of total prevalence underestimate the number in this group. However, based on current population projections and research on prevalence, there are approximately 3399 adults with mild LD living in Salford.
2.1.3.2 Moderate Learning Difficulties
Much more is understood about people with moderate learning difficulties as they are invariably ‘known to’ or ‘engaged with’ health and social care services. Current estimates suggest that there are 584 people aged 18 – 64 years with moderate learning difficulties living in Salford. By 2030 this figure is expected to increase by 16% to 677.

2.1.3.3 Severe Learning Difficulties
People with severe LD represent approximately 6% of the total LD population. These people often experience the poorest health outcomes; shortest life expectancy and are very dependent on both services and carers. For people with complex needs there are particular health challenges such as muscular skeletal impairment, sensory difficulties and epilepsy. There are 219 people aged 18 - 64 years with severe LD currently living in Salford. Reflecting LD population trends this is expected to increase by 16% by 2030. Age profile data shows that there are proportionally more adults aged 18 – 34 years with severe LD compared with those aged 35 and over.

2.1.4 Austistic Spectrum Disorder (ASD)
According to national estimates there are approximately 1,500 people with ASD living in Salford; a figure which is anticipated to increase. Furthermore, there has been a locally acknowledged increase in demand for services by this group. It is therefore important to recognise and consider the particular needs of this sometimes peripheral population of the LD community.

2.1.5 Age
Age is a particularly significant component of needs assessment for the LD population as its structure has been markedly affected by cultural, medical and technological developments during the last 50 years. As a result successive birth cohorts in the UK are of differing size. Currently, national data suggests that individuals in the largest cohort are those aged in their mid thirties.

As an aging population generally the proportion of older people is anticipated to increase. This pattern is reflected in data for the LD population. However, this increase is expected to be more pronounced in the LD population as a consequence of improved health and technology as well as the effect of large and ageing birth cohorts. In Salford, 11% of the adults, known to Salford Social Services as having a learning difficulty, are 65 years or older. However, the number of adults with learning disabilities aged over 60 is predicted to increase by 36% between 2001 and 2021. Older adults generally are at increased risk of long term illness and disease combined with the physical challenges of old age. For older adults with LD these represent additional health and social care needs.

2.1.6 Ethnicity
It has been suggested that people with learning difficulties from all ethnic minorities in the UK experience insufficient and inadequate services despite sometimes desperate levels of need. Furthermore, morbidity and mortality is higher amongst adults with learning difficulties from an ethnic minority. Despite this both national and local data on the ethnicity of adults with LD is largely speculative. Existing available local data, derived from Salford City Council, indicates that 3% of service users are Jewish and 3% are from other ethnicities including people identified as Irish, Chinese, Pakistani, Arabic, Caribbean, Black British, Indian and mixed.
3. POLICY, EVIDENCE & LEADERSHIP

3.1 POLICY CONTEXT
In the last few years it has become increasingly recognised that people with learning disabilities face many types of health and social inequalities as highlighted in this report. National policy, reports and research reflect this increasing recognition and suggest that when compared to the rest of the population, people with learning disabilities have:

- Lower life expectancy
- Different causes of death
- Higher levels of unrecognised and unmet physical and mental health needs
- Barriers to accessing health services
- Communication difficulties
- Different lifestyle choices and environment issues
- Different patterns of health need and more complex health need
- Difficulties accessing end of life care that meets specific needs

These reports, together with government policy, are the key drivers for taking forward work locally to improve the overall health; access to, and the, health services received by people with learning disabilities across Salford.

3.2 NATIONAL POLICY & REPORTS
The 2001 White Paper, Valuing People, set out the then government’s commitment to improving the life chances of people with LD, through close partnership working between different agencies to enable people with LD to live full and active lives. The White Paper includes the following actions specifically related to health:

- Action to reduce health inequalities: explore the feasibility of establishing a confidential inquiry into mortality among people with learning disabilities.
- Action to challenge discrimination against people with learning disabilities from minority ethnic communities.
- Health facilitators identified for people with learning disabilities by spring 2003.
- All people with a learning disability to be registered with a GP by June 2004.
- All people with a learning disability to have a Health Action Plan by June 2005.
- The NHS to ensure that all mainstream hospital services are accessible to people with learning disabilities.
- Development of local specialist services for people with severe challenging behaviour to be a priority for the capital element of the Learning Disability Development Fund.
- The Mental Health National Service Framework (NSF) to bring new benefits to people with learning disabilities.
- New role for specialist learning disability services, making most effective use of their expertise.

The White Paper was followed up in 2009 by Valuing People Now, to further progress services for people with LD in response to a delay and lack of achievement against a number of actions outlined in Valuing People. The two key issues identified for the NHS were:

- achieving full inclusion of people with learning disabilities in its mainstream work on reducing health inequalities
- ensuring high-quality evidence-based specialist health services
The subsequent *Operating Frameworks for the NHS*, published between 2008 – 2011, complimented national policy by including specific requirements for NHS commissioners and providers in relation to adults with LD.

National policy has also been supported by a number of complementary national guidance documents and reports. The most prolific of these was the 2007 Mencap report *Death by Indifference* which used six case studies to illustrate shortcomings in healthcare for people with LD and identified a range of factors that influenced poor outcomes which were predominantly associated with institutional discrimination across the NHS. *Healthcare for All* (2008) was published, following a Independent Inquiry, in response and made 10 recommendations for the NHS which were subsequently incorporated into *Valuing People Now*. A number of additional reports were also published, looking at specific issues (including human rights, mental health, challenging behaviour and prisoners), which highlighted the health inequalities experience by the spectrum of people with LD.

Assessment of local performance and quality delivery of national policy is managed through the Care Quality Commission, the Comprehensive Area Assessment and the Local Area Agreement.

To date there has been no explicit health policy statement regarding LD following the recent change in government.

### 3.3 REGIONAL CONTEXT

Regional delivery of the national *Valuing People Now* Strategy is discharged via the *North West Valuing People Now Programme Board*. The regional board brings together key stakeholders regionally, including representatives from the Strategic Health Authority, the Regional Forum (of people with learning difficulties) and the Regional Family Carer Network.

The Programme Board has identified the following 3 key priorities for 2010/2011; better health, employment, and housing. The Board is also concerned with the personalisation agenda; integration between adult and children’s services to improve transition, strong and effective leadership and local partnership boards, and friends and relationships. Responsibility for delivery of annually agreed priorities is achieved via the Board’s underpinning network forums.

### 3.4 LOCAL POLICY, LEADERSHIP & COMMISSIONING

At a local level, across the partnership, there is long standing commitment to improving the health and wellbeing of people with LD. There is integrated commissioning and delivery of services for people with LD; a strong LD Partnership Board and good working relationships between organisations. Local governance and leadership is provided through the Learning Difficulties Partnership Board.

However, despite this well established relationship and commitment there is limited reference to adults with LD, and how improving the health of this population group will help to reduce inequalities, in a number of key partnership strategies and plans. There is no specific reference to people with LD in the PCT 5 Year Plan; whilst the health needs of adults with learning disabilities are not adequately reflected in the Joint Strategic
Needs Assessment (JSNA). The absence of direct reference in overarching PCT and Council Strategy is also evident in some key health strategies including the Tobacco Control Strategy; the Alcohol Strategy; the Cancer Strategy; the GM & Cheshire Cardiac and Stroke Network Strategy; the Salford Mental Wellbeing Strategy; or the Salford Oral Health Strategy. There is some very limited reference to adults with LD in the Obesity Strategy and a separate sexual health strategy specifically for people with learning difficulties.

Whilst there is no specific local LD health strategy, the LD Partnership Board has an overarching commissioning strategy (*Our Future Actions not Words 2006 – 2011*) and business plan through which the local implementation of *Valuing People Now* is delivered. The business plan is produced by the partnership board and renewed on a 6 month basis. Delivery of the business plan is actioned via the Partnership Board’s 13 Sub Groups. The achievements of the LD Partnership Board have been considerable but have been restrained by the lack of systematic drive and co-ordination which has resulted in part from an over reliance, rather than whole systems approach, on the LD Partnership Board to deliver the health related recommendations included within *Valuing People Now*. Ad hoc service developments for people with LD within mainstream health services have been achieved at an operational level reliant on the commitment of a few dedicated individuals rather than via coordinated and strategic direction.

### 3.5 RESEARCH EVIDENCE

Epidemiological research on the health of people with learning disabilities is limited due to definition of cases, difficulties in diagnosis, and small sample sizes. There are also significant gaps in the research evidence looking at the effectiveness of health services for people with learning disabilities.
4. INEQUALITIES IN HEALTH

4.1 MORTALITY

The life expectancy of people with LD is increasing. In the 1930s average life expectancy was estimated to be less than 20 years of age. Today, mean life expectancy is now estimated to be 74, 67 and 58 for those with mild, moderate and severe learning disabilities respectively. However people with learning difficulties have a shorter life expectancy and increased risk of premature death when compared to the rest of the population (66 versus 80). The risk of dying before the age of 50 has been found to be 58 times greater than in the general population and all cause mortality rates among people with moderate to severe learning difficulties are three times higher than in the general population.

Life expectancy is shortest for those with the greatest support needs and the most complex and/or multiple conditions. Therefore, life expectancy diminishes with the severity of impairment. The specific causes of differences in morbidity and mortality can be difficult to disentangle however access to treatment, failure to fully investigate physical health problems; delay or absent identification of infections or other health problems are also contributory factors. Research has identified that preventable deaths are four times higher for people with LD as opposed to the rest of the population.

For the non LD population, the leading cause of death in the UK is cancer, followed by heart disease, then cerebrovascular disease. For people with learning disabilities, respiratory disease (related to pneumonia and aspiration) followed by cardiovascular disease (related to congenital heart disease rather than ischaemia) are the leading causes of death.

Currently, death certificates do not record if the deceased individual had a learning difficulty therefore there is no routinely available data, neither at a national or local level, regarding the causes of death for people with a LD. However in order to provide some indication of local mortality and to inform this HNA mortality files for deceased LD clients, who were registered with Salford City Council and died between 2006 – 2010, were analysed. This data suggested that, in Salford, the leading causes of death in the LD population are cancer and cardiovascular disease followed by deaths due to diseases of the nervous system and/or respiratory disease. Analysis of the data by age group (see Table 1) however reveals that the causes of death vary with age.

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<th>Age Group</th>
<th>Leading Causes of Death</th>
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| 15 – 34 years | 1. Disease of the nervous system (3 cases)  
               | 2. LD related (1 case)                                      |
| 35 – 64 years | 1. Circulatory disease (7 cases) and LD related (7 cases)   
               | 3. Respiratory disease                                      |
| 65 – 74 years | 1. Cancer (6 cases)                                         
               | 2. Respiratory disease (4 cases)                            
               | 3. GU system disease (3 cases)                              |
| >75 Years    | 1. Cancer (5 cases) and circulatory disease (5 cases)       
               | 3. Disease of the nervous system (2 cases) and respiratory disease (2 cases) |
For example, the causes of death amongst clients under 64 is consistent with the national LD mortality data and are more likely to be related to having a learning disability. It is probable that amongst this group people are likely to have a more profound learning difficulty and consequently poorest health outcomes; hence the high levels of recorded LD related deaths. Conversely the causes of death amongst those aged over 65 years reflect mortality data for the non LD population. The longer life expectancy and causes of death observed in these clients may indicate that they had a more moderate LD. This supports the theory that the severity of the LD impacts on health outcomes and life expectancy and demonstrates the importance of understanding the segmentation of the LD population. This also indicates the need for a targeted approach towards efforts to improve health outcomes, focusing separately on the leading causes of death for those with severe and profound learning difficulties and those for older people with LD.

4.2 MORBIDITY
People with learning disabilities are two and a half times more likely to have health problems than other people. Furthermore, one in seven adults with learning disabilities evaluate their general health as not good. Despite this evidence however people with learning disabilities have higher levels of unmet need and receive less effective treatment.

National evidence suggests that epilepsy, gastro-oesophageal reflux disorder, sensory impairments, osteoporosis, schizophrenia, dementia, dysphagia, dental disease, musculoskeletal problems, accidents and nutritional problems are all commonly experienced with incidence much in excess of that in the non LD population.

In Salford epilepsy is particularly prevalent amongst the LD population. Information from national evidence suggests that respiratory disease, CVD and stroke are especially common; this is not however echoed in the existing available local data. This may be due to misdiagnosis or diagnostic overshadowing. For example national evidence indicates that mental health problems are particularly prevalent in the LD population but local data suggest that just 6% of the Salford LD population are affected.

Information on health need locally is incomplete therefore it is difficult to make definite conclusions from the available data. The relevance of other conditions as well as the impact of disease on a changing population demographic (e.g. cancer incidence increases with age) should not therefore be overlooked. The increased independence of the LD population is also likely to increase the incidence of lifestyle related conditions.

This HNA has identified a number of priority groups who have increased health need either now or in the future. These groups have very differing health needs and any strategy and commissioning plans will therefore need to acknowledge the heterogeneity within the LD population and plan appropriately. These include; adults with severe and profound LD, older adults with LD, adults with LD from ethnic minority groups and adults with mild LD.

4.2.1 Older adults
Older adults with LD represent a key priority group. Adults with Down’s syndrome should also be included owing to the high incidence of early onset dementia, especially Alzheimer’s disease. The ageing process appears prematurely, and from middle age
onwards people with Down’s syndrome can present as a medically very vulnerable group.

Given the described improvements in life expectancy, the number of older people with LD is increasing. As a consequence age-related illnesses that commonly occur in older age, such as cancer, CVD and dementia and which were previously uncommon in the LD population, now need to be considered. The incidence of cancer and CVD, which is currently lower than the non LD population incidence, is expected to increase as the LD population augments, ages and is more independent.

The physical challenges of old age also represent an additional complication for people with LD as already existing sensory impairments are compounded by ageing increasing the risk of falls and accidental injury. Adults aged over 60 with learning disabilities are also more likely to face barriers to services; less likely to receive an accurate diagnosis and treatment and to access a range of health services compared to younger adults with learning disabilities.

Furthermore, the number of older adults with LD has in the past been relatively small therefore the needs and management of older people with LD are largely unknown and services have very limited experience of supporting this group. This makes commissioning and delivering services a new and challenging issue.

4.2.2 People from ethnic minorities with LD

People from minority ethnic groups experience health inequalities, with some groups particularly vulnerable. Therefore having a learning difficulty for people from ethnic minority groups further intensifies the health inequalities experienced. Moreover as there is very little information on the ethnicity of people with LD; they are difficult to identify and consequently to target. This group therefore represent an important priority.

4.2.3 People with mild LD

Although the life expectancy of people with mild LD is greater than that of people with moderate and severe LD it remains shorter than the non LD population. Furthermore, this group represents the largest sub group within the LD population (80%); therefore contributing significantly to the gap in health inequality in Salford. Importantly however their needs are poorly understood. Whilst the quantity and quality of life for people with moderate and severe LD is worse than for those with mild LD; their health needs are well researched by comparison and they are often in contact and or supported by health and social care services. By contrast people with mild LD are effectively invisible; this is in part a result of difficulties in identifying and diagnosing a mild learning disability.

There is very little information, both nationally and locally, on the health of people with mild LD although the causes of death and morbidity experienced are thought to replicate those of the non LD population. Moreover people with mild LD are thought to be extremely vulnerable to social inequalities, much more so than people with moderate or severe LD and as a consequence extremely dependent on social services and or prevalent within the criminal justice system. They are also more likely to smoke, use alcohol and drugs and have poor sexual health.

Adults with mild LD are therefore an important priority group in terms of both the LD population and reducing the gap in health inequalities within Salford.
4.2.4 Adults with Severe and Profound LD

Health outcomes are worst for people with severe and profound learning difficulties with life expectancy considerably shorter than that of the non LD population. These people often have complex physical needs. Advancing medicine and technology has enabled people, who previously would not have, enter adulthood. As a consequence there are more adults with such needs. Much like older adults with LD; services have limited experience understanding and managing the needs of this group.

Although they are a small group in number, their needs are vast and the number of people increasing. They are therefore an important priority group.

It is important to acknowledge that as the pattern of health need and causes of death differ for people with LD, most current policies and healthy lifestyle initiatives will widen rather than close the health inequality gap. The most effective healthy lifestyle initiatives for people with learning disabilities will therefore be those that target their leading causes of ill health and death.
5. INEQUALITIES IN WELLBEING

5.1 DETERMINANTS OF HEALTH INEQUALITIES
Good health is dependent on a number of factors including biological factors; lifestyle choices, access to services and the environment (including education, housing, employment etc). Research studies have investigated five broad classes of determinants of the health inequalities faced by people with learning disabilities that are, in principle, potentially amenable to intervention. These include the following:

- Increased risk of exposure to well established ‘social determinants’ of health;
- Increased risk associated with specific genetic and biological causes of learning disabilities;
- Communication difficulties and reduced health ‘literacy’;
- Personal health risks and behaviours;
- Deficiencies in access to and the quality of healthcare provision.

5.2 THE ‘SOCIAL DETERMINANTS’ OF HEALTH
People with learning difficulties are more likely to be exposed to common ‘social determinants’ of health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination. In particular, people with mild/moderate learning disabilities are more likely to experience material and social hardship than people with severe or profound and multiple learning disabilities. Furthermore, people with learning disabilities report high levels of community exclusion. A recent study reported that one in three people with a learning disability had reported that someone had been rude to them directly about their learning disability and one in ten had been the victim of crime. These all have an adverse effect on health, contributing to the development of health issues and/or exacerbate existing health problems.

5.2.1 Employment
Employment has been shown to have a positive impact on health. For people with LD, employment provides financial resources and social interaction, both of which play a positive, and protective, role in health. Conversely, unemployment is linked to deprivation and health inequalities. In Salford the majority of people with LD, and known to services (e.g. those with either moderate or severe LD), are unemployed (79%). Of those reported as employed the majority work, either as paid employees or are self employed, between 4 and 16 hours a week (69%).

5.2.2 Housing
Housing also plays a crucial role in good health. In Salford the majority of people with LD and ‘known to services’ live in settled accommodation and are tenants (50%) or living with family and friends (39%). People with LD living in private households are much more likely to live in areas characterised by high levels of social deprivation and are also much more likely to experience material and social hardship than people in supported accommodation. Social deprivation and exclusion are both associated with poorer health. In Salford, the majority of people with LD, and known to services, live in areas acknowledged as deprived, furthermore there is at least one homeless person in Salford registered as having a learning disability.

5.2.3 Inclusion, Crime and Offending
People with LD report experiencing loneliness as they are often isolated living with family, or in independent and or supported, accommodation on their own. Adults with LD
are also more vulnerable to being a victim of crime, particularly hate crime. There are also considerable numbers of offenders (30%) who have a learning difficulty. There is however no current processes in place locally to identify those adults that come into contact with the criminal justice system.

5.3 GENETIC & BIOLOGICAL FACTORS
People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities. In addition a number of syndromes associated with learning disabilities are also associated with some specific health risks. For example:

- congenital heart disease is more prevalent among people with Down’s syndrome and Williams syndrome;
- early onset dementia is more common in people with Down’s syndrome;
- hypothalamic disorders are more prevalent among people with Prader-Willi syndrome;
- mental health problems and challenging behaviours are more prevalent among people with autism spectrum disorders, Rett syndrome, Cornelia de Lange syndrome, Riley-Day syndrome, Fragile-X syndrome, Prader-Willi syndrome, Velocardiofacial syndrome, Williams syndrome and Lesch-Nyhan syndrome;
- obesity is more prevalent among people with Prader-Willi syndrome, Cohen syndrome and Bardet-Biedl syndrome.

5.4 COMMUNICATION & HEALTH LITERACY
People with learning disabilities often find it difficult to recognise, report and describe symptoms of illness. Crucially, limited communication skills may reduce capacity to convey identified health needs effectively to others. A number of high profile cases referenced within the policy literature recognise communication difficulties as a critical factor in the unnecessary and premature death of a number of adults with LD. In most cases poor management and the limited awareness of professionals, with regard to the communication difficulties of people with LD, was implicated; delaying diagnosis and or effective management of pain and resulting in diagnostic overshadowing. In Salford 104 people with LD are known to have communication difficulties, the majority of which (96) are severe in nature. Currently, there is no consistency in the use of aids to communicate with adults with learning disabilities across all services in Salford.

5.5 PERSONAL HEALTH RISKS & BEHAVIOURS
Lifestyle factors such as diet, exercise, smoking, sexual health and substance misuse are all important risk factors which promote unnecessary and or premature onset of illness or disease. A healthy lifestyle is particularly important for people with LD as their risk, for a number of conditions, is already increased. However, people with learning difficulties find that health risks are very difficult to manage by themselves.

Although people with LD are less likely to smoke, drink alcohol and use drugs than the non LD population the increased independence of people with LD has the potential to increase the prevalence of unhealthy lifestyles and subsequently lifestyle related disease. Already there is evidence that the number of obese people with LD greatly exceeds that in the non LD population. Conversely there are also greater numbers of underweight adults with LD compared to the rest of the population (See Graph 2).
There is currently an incomplete and unrepresentative picture of health need regarding the lifestyles of people with LD as local information on substance use, alcohol and sexual health is limited.
6. INEQUALITIES IN ACCESS

6.1 ACCESS TO QUALITY HEALTHCARE

Although people with learning disabilities have a greater variety of healthcare needs compared with the non LD population, many of these needs are unrecognised and unmet. This is reflected in the high prevalence of certain conditions which is not mirrored by demand for services.

The Disability Discrimination Act 1995 places a duty on all health and social care organisations not to discriminate against disabled people or provide them with a poorer quality of service. Organisations are therefore obliged to make ‘reasonable adjustments’ to reflect the health needs of disabled people. However professionals working in general healthcare often have limited knowledge of learning disabilities, there is poor partnership working between agencies, and people with LD are not routinely identified in health data. It has been argued that the poorer health of people with LD results, in part, from a number of organisational barriers. These include:

- scarcity of services;
- physical barriers to access;
- failure to make ‘reasonable adjustments’ in light of the literacy and communication difficulties experienced by many people with learning disabilities;
- variability in the availability of interpreters for people from minority ethnic communities;
- ‘diagnostic overshadowing’ (symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities);
- disablist attitudes among healthcare staff.

National evidence and local experience also indicate that people working within health services lack the knowledge about, and awareness of, the health needs of people with LD. People with LD also report experiencing unhelpful and or negative behaviour towards them from clinical and health staff. Attitudes affect the extent to which concerns are treated seriously or dismissed, symptoms are explored and opportunities to carry out screening or medicine reviews are taken up or missed. Diagnostic overshadowing is frequently reported, with physical or psychological symptoms being inappropriately attributed to the learning disability. Historical and cultural provision for people with LD has also led to the incorrect assumption that the health needs of people with learning difficulties are met by specialist LD services. Furthermore, for many community services there is very little information on the number and type of services used by people with LD.

In Salford there have been a number of examples across the health system demonstrating changes which constitute reasonable adjustments; making services easier for people with LD to access. These include the dental service, self care healthy lifestyle programmes, the annual health check, SRFT flagging and passports and breast and cervical screening. However these developments have largely been ad hoc, supported and initiated by a few dedicated people, rather than co-ordinated and systematic.
6.1.1 Health Promotion & Screening

There is currently no specific reference to people with LD, in all but a few public health strategies in Salford and there is no LD specific health strategy. Therefore there is limited mainstream, or directed, targeting of public health strategies towards the LD population even where there is clear evidence and health need (e.g. LD population prevalence exceeds non LD prevalence) to do so.

There are also few specific healthy lifestyle initiatives for this population group and very little information on the numbers of adults with learning disabilities accessing lifestyle interventions. There are however several examples of good practice locally including the Self Care Lifestyle Programme and the Health Walks initiative. These have however been sporadic and locality based rather than strategic and co-ordinated.

There are obviously a number of particular challenges to ensuring effective health promotion for adults with LD. Managing a healthy lifestyle is particularly challenging for people with LD. Adults with LD are often not in control of food choices and preparation; have limited mobility and access to physical activity can be restricted. Furthermore people with learning difficulties find it difficult to understand the importance of a healthy lifestyle, whilst health education materials and messages are often not presented in LD accessible formats.

Information on the uptake of all health screening programmes in Salford by adults with LD is limited. From the available data it is apparent that, like national experience, local uptake of breast and cervical screening is considerably lower than that for the non LD population. In Salford, the proportion of eligible adults with learning disabilities participating in breast cancer screening is 150% lower than the rest of the population and 44% lower for cervical screening. There is no information on the uptake of bowel screening; diabetic retinopathy screening, chlamydia screening or on the use of the newly introduced AAA screening, and the NHS Health Check programme. This is despite evidence which shows that in some instances the risk for people with LD is elevated (DRS and AAA) compared with the non LD population.

Information on the uptake of immunisations is also unknown. In particular, there is no data on the uptake of the annual flu vaccination, nor targeted campaigns to increase attendance, despite respiratory disease being the leading cause of death for people with LD.

6.1.2 Health Checks

Since 2008/2009 primary care has been incentivised, via a LES, to provide an annual general health check for adults with LD as per national guidance. National and international evidence suggest that these checks are effective in identifying health needs and providing opportunities for preventative interventions. Currently all practices in Salford are committed to providing the checks and just over half of all adults, recognised as having a learning disability, have received an annual health check. The information gathered from these checks has provided an enhanced picture of local health need. The potential for the health checks is tantalising.

However the quality of the health checks offered is unclear and the physical / mental health outcomes achieved uncertain. More evidence is required to evaluate whether these checks achieve improved access to mainstream healthcare services. There are issues regarding the completeness of data; the accuracy of coding and the effectiveness
of the intervention. Quality assurance can therefore not be guaranteed. There is also uncertainty about if and how people are referred to services if health issues are identified. For example, evidence from the health checks suggests that levels of morbid obesity in the local LD population is significantly higher than the non LD population however, this is not evident in demand for weight management services. Whilst 90% of morbidly obese people in the non LD population access weight management services, no obese adults with LD access these services. Furthermore, adults with LD that use community based weight management services have all been referred by community workers rather than via general practice.

6.1.3 Primary Care Health Services
Access to primary medical care has a significant impact on how frequently and appropriately people with LD access wider services. Difficulties accessing primary care services can result in conditions going undiagnosed and/or untreated. The failure to obtain timely treatment can result in more difficult to treat symptoms or hospital admissions that could have been prevented.

Virtually all people with LD are now living in the community and depend on GPs for primary health care needs. However, despite having more health need, people with LD visit their GP the same as non LD patients.

Furthermore, whilst there is improved identification and recording of adults with LD in general practice, information on the use of other community primary care services is poor. This limits opportunities to ensure that reasonable adjustments are made to facilitate diagnosis and treatment as well as inhibiting information to inform effective commissioning. Crucially more effective interventions in primary care may reduce the disproportionately high use of secondary care services by those with LD.

6.1.4 Secondary Care Health Services
In the UK an estimated 26% of people with LD are admitted to general hospital every year, compared with 14% of the non LD population. Whilst there are mechanisms in place at SRFT to proactively identify adults with a learning disability it is not clear how this information is used to ensure that pathways of care are reasonably adjusted to meet the health needs of these patients. Furthermore, the appropriateness of acute admissions (including the lengths of stay) and attendances is unclear.

At the time of this report the SRFT CQUIN data was not available. This data will enhance the picture of health need, which will inform commissioning and has the potential to reduce unnecessary acute admissions and to improve community primary care services.

6.1.5 Specialist Services
Specialist services are well regarded locally despite limited information on the impact that specialist services have on the health outcomes for adults with learning disabilities. However, current service provision may not be sufficient to meet the increasing number of adults with learning disabilities in the future, particularly those with severe and complex physical needs.

It is currently unclear if the needs of adults with learning disabilities at the end of life are being met. The Strategic Healthcare Facilitator for LD is however working with end of life/palliative care to improve services for adults with LD.
6.1.6 All Services

Organisations are obliged to make ‘reasonable adjustments’ to reflect the health needs of disabled people. It is currently unknown if local clinical pathways consider the needs of people with learning disabilities.

It is also unclear if there is equitable access to all health services for adults with learning disabilities. Although LD is included within the Equality Impact Assessment (EIA) Framework and Equity Audit there is limited information regarding adults with LD. This is primarily owing to the limitations of existing service use data for adults with LD.
7. RECOMMENDATIONS
The following recommendations have been developed in response to need, the evidence and policy base, gaps in existing policy and or services. In addition, a number of relevant partnership boards and groups have been consulted to contribute to the recommendations included.

The recommendations have been divided into two parts; there are 5 overarching recommendations for all partners and separate, specific recommendations for health promotion and screening; primary and secondary care and specialist services.

7.1 OVERARCHING RECOMMENDATIONS

Recommendation 1: There needs to be stronger recognition of the health needs of people with LD in local strategy and commissioning. Specifically:

- The JSNA should be updated to include the health needs of adults with LD as identified in this HNA.
- Local strategies should also be updated to target the health needs of adults with LD; in particular the following strategies, were there are specific needs amongst the LD population:
  - Cancer
  - CVD
  - Overweight & Obesity
  - Specific cancer and non cancer screening programmes action plans
  - End of Life
- Salford City Council should work with NHS Salford to ensure that local strategy (relating to education, employment and housing) includes actions to address the social inequalities experienced by people with LD.
- Commissioners should use the information included within this HNA to inform future service specifications taking into account the changing demographics of the LD population and the specific needs of older people with LD, those with severe and complex health needs, people from ethnic minority groups and people with mild LD.
- The quality of the Health Check LES, in terms of recording and outcomes, should be assessed (see primary care recommendations).
- Health Impact Assessment and Equity Audits should also be used to monitor access issues, uptake and outcomes amongst the LD population. The requirement for this should be explicitly described in service specifications.
- The use of Health Action Plans for adults with LD should be promoted in service specifications for all relevant services.
• CQUINS, based on those in secondary care, should be established for primary and community services.

Recommendation 2:
The LD Partnership Board, with support from the Public Health Department, should influence GP commissioning, the PCT and SRFT corporate policy and practice to raise the profile of the health needs of adults with LD. This should include:
  • Training for frontline staff, implemented across the health economy, to increase knowledge and understanding of the health and access issues experienced by adults with LD. It should emphasise professional responsibility and make clear the law with regards to consent and capacity and duty of care.

Recommendation 3:
Information systems should be developed or improved to enhance information about, and to monitor outcomes for, people with LD.
  • A system for the collection of local morbidity and mortality data should be established. Data should be analysed annually to inform service planning.
  • LD case finding in primary care should be enhanced to include people with mild LD.
  • The ethnicity of the person and severity of the LD should be routinely recorded.
  • Systems should be put in place to monitor the number of adults who have a health action plan.

Recommendation 4:
The role of adults with LD and their carers in health service planning should be increased. This should include support for patient and carers to better navigate health services.
  • Patient engagement and involvement should be ongoing but not reliant on the LD Partnership Board.
  • Health services, alongside Salford City Council, should work with adults with LD to identify appropriate, standardised communication materials to facilitate better health literacy, access and awareness.
  • Training for support workers and carers should be commissioned to provide basic awareness of health needs, signs and symptoms of prevalent conditions and information about navigating health services, e.g. consent and capacity, screening and vaccinations, advocacy and assertiveness.

Recommendation 5:
A detailed action plan should be developed to provide a framework through which to implement the recommendations outlined in this needs assessment to ensure continuing improvement in health services for adults with learning disabilities.
7.2 SERVICE SPECIFIC RECOMMENDATIONS

7.2.1 Health Promotion & Screening
1. The PCT and Health Improvement Team should ensure that lifestyle interventions/services are accessible for adults with LD and that outcomes are comparable with the non LD population.

2. There should be opportunities for physical activity, and access to healthy food, at residential accommodation and day services. Availability should be audited and SLA’s adjusted as required.

3. Research with providers and service users should be undertaken to identify how uptake of breast and cervical screening can be increased.

4. New and developing cancer (bowel) and non cancer screening programmes should develop tailored plans which target adults with LD and monitor uptake in this group.

5. Seasonal vaccination programmes should target adults with LD and monitor both the offer and uptake in this group.

7.2.2 Primary Care
1. All primary care and community services should identify and record people with LD across the whole LD spectrum, using a standardised and agreed method of identification.

2. The Health Check LES should be reviewed to assure quality; including a regular review of performance, completeness of data, accuracy of coding and analysis of referral to, and the use of, services for prevalent conditions.

7.2.3 Secondary Care
1. Secondary care services should improve recording of LD as a sub diagnosis in coding and on death certificates.

2. SRFT and the PCT should analyse the appropriateness of attendances and admissions, lengths of stay and incomplete recording for patients with LD to assess LD patient outcomes compared with the non LD patient population.

3. SRFT should work with primary care, support workers and carers to develop protocols for routes in and out of hospital for LD patients. For example, notification of incoming patients with LD to enable reasonable adjustments e.g. extended time, equipment or private bay and on discharge effective and appropriate discharge and discharge planning.

4. SRFT should audit the LD flagging system to assess the impact of recording on patient outcomes, e.g. reasonable adjustments and improved patient experience.
7.2.4 **Specialist Services**

1. Health outcome measures should be defined in all specialist LD service specifications, providers should work with commissioners to identify appropriate measures.

2. Specialist services should audit and assess the workforce against anticipated population change, health need and projected increases in demand for services.

3. Specialist services should work with HMP Forest Bank and the Police to improve identification of, and services for, adults with LD in the criminal justice system.