NHS Nottingham City

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A Health Needs Assessment for Adults with a Learning Disability in Nottingham and Nottinghamshire

Anne Pridgeon
Health Improvement Principal
NHS Nottinghamshire County &
NHS Bassetlaw

Iain Little
Public Health Development Manager
NHS Nottingham City

With:
Barbara Brady
Consultant in Public Health
NHS Nottinghamshire County &
NHS Bassetlaw

Dr Jo Copping
Consultant in Public Health Medicine
NHS Nottingham City

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1 INTRODUCTION

> "All people with a learning disability are people first with the right to lead their lives like any other, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens."[1]

> "Better health for people with learning disabilities is a key priority. There is clear evidence that most people with learning disability have poorer health than the rest of the population and are more likely to die at a younger age. Their access to the NHS is often poor and characterised by problems that undermine personalisation, dignity and safety."[2]

People with learning disabilities are one of the most vulnerable groups in society. They are known to experience inequalities in health and as a result suffer poorer health outcomes compared to the general population.

There is now an increasing national and international body of evidence as to the pattern of health needs of people with learning disabilities. However, no detailed assessment of the health needs of people with learning disabilities that live within Nottingham and Nottinghamshire has been undertaken previously. A Health Needs Assessment was therefore undertaken to capture this information.

1.1 Aim

The aim of this Health Needs Assessment is to systematically assess the health needs of adults with learning disabilities across Nottinghamshire (including Nottingham City and Bassetlaw), identify gaps in current service provision and make recommendations for changes to meet their needs and reduce the health inequalities experienced by this population group.

1.2 Objectives

The objectives of this Health Needs Assessment are to:

- Review the current evidence on the health needs of adults with learning disabilities.
- Identify patterns of local healthcare use, to include strengths, gaps and inequities in services.
- Look at demographic projections to inform service planning in future.
- Identify future work required to:
    - Reduce health inequalities experienced by people with learning disabilities
    - Enhance the provision of health services and care for people with learning disabilities across the life course.

This Health Needs Assessment has been jointly undertaken by the Public Health teams at NHS Nottingham City and NHS Nottinghamshire County on behalf of NHS Nottingham City, NHS Nottinghamshire County and NHS Bassetlaw.

2 BACKGROUND

Findings

- Learning disability is diagnosed if there is evidence of significant cognitive impairment and impairment in adaptive functioning, with both present before the age of 18.
- The causes of learning disability can arise at conception, during pregnancy, during labour or after birth.
- Risk factors include being male, socioeconomic deprivation and being of South Asian ethnicity.
- There are a number of primary prevention interventions that can reduce the incidence of learning disabilities.

Key issues

- The terms mild, moderate, severe and profound learning disabilities are rarely used in mainstream services except by specialist services.
- The interchangability of *learning disabilities* and *learning difficulties*, although there are differences between the two.
- The impact of consanguineous marriages on the causes of learning disabilities isn't fully discussed in the literature.

2.1 Definitions

Intellectual disability is defined by ICD 10 (World Health Organisation's International Classification of Diseases, version 10) as

'…a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contributes to the overall level of intelligence, i.e. cognitive, language, motor and social abilities.' (1996)

The term *intellectual disability* is currently used by the academic literature, however in Britain, the term *learning disability* is used and in the USA *mental retardation.* For the purpose of this document, the term learning disability will be used.

A diagnosis of learning disability requires an assessment to establish that an individual meets three main criteria:[3]

- There is evidence of significant cognitive impairment, measured as having an intelligent quotient (IQ) of equal to or less than 70.
- There is also evidence that the individual has a significant impairment in adaptive functioning – assessed using standardised tools that measure everyday living and coping skills.

- Both of these impairments are shown to have been present before the age 18 years.

All three of these criteria must be met for a diagnosis of learning disability to be made. Learning disability encompasses a very wide range of functioning. ICD-10 also provides further categorisation within the diagnosis of cognitive impairment.

Levels of cognitive impairment as described by ICD-10

ICD code	Level of cognitive impairment	Associated IQ
F70	Mild	50-69
F71	Moderate	35-49
F72	Severe	20-34
F73	Profound	<20

This classification defines the degree of disability according to how far an individual is from the normal distribution of IQ for the general population. Using this system an individual who consistently scores more than 2 Standard Deviations (SD) lower than the mean on an IQ test, with a measured IQ of less than 70 is said to have a learning disability. There are problems with using IQ as it does not indicate individual strengths or weaknesses such as verbal and motor skills. Assessment of the degree of learning disability will identify the level of support a person needs.

Locally, a wide range of terms are used in general practice including learning difficulties and learning disabilities (interchangeable) with the very occasional categorisation of severe learning disability. This is similar in the acute hospital trusts. In reality the terms mild, moderate, severe, and profound are only used by the specialist services provided by Nottinghamshire Healthcare NHS Trust. Sometimes categorisations are informed by psychometric testing but it is mostly clinical impression.

A learning disability is lifelong and usually has a significant impact on the person's life and the lives of their family.

2.1.1 Profound and multiple learning disabilities (PMLD)

People with profound and multiple learning disabilities:[4]

- have more than one disability
- have a profound learning disability
- have great difficulty with communication
- need high levels of support with most aspects of daily life
- may have additional sensory or physical disabilities, complex health needs or mental health difficulties
- may have behaviours that challenge

2.1.2 Learning difficulties

There is often confusion over the term learning disabilities and learning difficulties. Learning difficulty can be defined as:

'an unexpected and unexplained condition, occurring in a child of average or above average intelligence, characterised by a significant delay in one or more areas of learning.' [5]

This health needs assessment does not consider those with learning difficulties.

2.1.3 Autistic spectrum disorders

The National Autistic Society defines autistic spectrum disorder (ASD) as:

'a term to describe a lifelong developmental disorder that is characterised by impairments in social interaction, communication and imagination. There is a spectrum or range of disorders with these features, including autism and Asperger syndrome.' [6]

There is a very strong association between ASD and learning disabilities, with approximately half of those with severe learning disabilities having some type of autistic spectrum disorder.

This health needs assessment does not consider those who solely have an autistic spectrum disorder. A health needs assessment for adults with an autistic spectrum disorder is to be completed during 2010/2011.

2.2 Causes of learning disability

The causes of learning disabilities can be subdivided into those conditions that arise at conception (whose prevention lies before conception) and those that arise during pregnancy, labour and after birth.[7]

2.2.1 Conception

Some of the primary causes of learning disabilities are genetic. Genetic abnormalities may be subdivided into *chromosomal, single gene disorders, and multifactorial disorders.*[8]

- *Chromosomal disorders* include Down's syndrome, Edward's syndrome and Patau's syndrome.
- *Single gene disorders* include phenylketonuria (PKU), Prader-Willi syndrome, Fragile X syndrome and Tuberous Sclerosis which cause or are associated with differing degrees of learning disabilities.
- *Multifactorial disorders* include neural tube defects such as spina bifida and occur when both genetic and environmental factors combine.

2.2.2 Pregnancy

Chemicals (such as radiation, cigarette smoke and alcohol), *drugs* (including 'recreational' and prescription) and *diseases* (such as rubella and measles) can interfere with the normal development of the embryo or foetus that leads to conditions associated with learning disability.

Pre natal alcohol exposure can lead to the occurrence of foetal alcohol syndrome. Although not a common condition, it is regarded as the leading known cause of non-genetic learning disabilities. In recent years, the number of women of childbearing age who drink heavily has risen and therefore foetal alcohol syndrome is likely to increase.[9]

2.2.3 Labour and after birth

Oxygen deprivation (during or after birth) can cause learning disability, as can traumatic birth, meningitis or head injury. Low birth weight and prematurity are strongly correlated to the later development of learning disabilities.[10]

Learning disabilities are not inevitable but can occur as a result of the brain damage that has caused cerebral palsy. Cerebral palsy is caused by damage to the brain, which normally occurs before, during, or soon after birth. Other causes of cerebral palsy include infections such as meningitis or encephalitis while the child is young and the brain is still developing.

Congenital hypothyroidism which appears from birth is a cause of learning disabilities. Causes of congenital hypothyroidism are:

- Abnormalities in the development of the thyroid gland while the baby is in the womb.
- Genetic abnormalities that interfere with thyroid hormone production.
- Iodine deficiency (the most common cause worldwide but rare in the UK).
- Problems with the pituitary gland (which regulates the thyroid gland).

2.2.4 Unknown reasons

The cause of learning disabilities cannot be determined in 40%-80% of cases.[8]

2.3 Risk factors

2.3.1 Socio-economic factors

Socio-economic deprivation appears to be a contributory factor for mild and moderate learning disabilities,[11, 12, 13] but not for severe learning disabilities.[11]

2.3.2 Gender

Males are more likely than females to have both a severe learning disability (average ratio reported in studies is 1.2 males: 1 female) and mild learning

disabilities (average ratio reported in studies is 1.6 males: 1 female).[7] This is due to some causes being genetically determined and associated with males. This ratio decreases with age as women typically live longer than men.

2.3.3 Ethnicity

Studies within the UK have suggested that prevalence rates for learning disabilities are higher in South Asian groups, particularly in relation to children and young adults with severe learning disabilities.[14] Between 5 and 34 years of age, the prevalence of severe learning disabilities is approximately 3 times higher among the South Asian community when compared with the non-Asian community.

The reasons for the higher prevalence are not known, but could be due to a combination of factors:[7]

- possible inequalities in access to maternal healthcare
- higher rates of genetic abnormalities due to consanguinity and/or exposure to environmental factors

The Care Quality Commission's '*Count Me In'* 2009 survey of all specialist learning disability in-patient units reported that 13% of patients were from black and minority ethnic groups.[218] Rates were 2 to 3 times higher than average in White/Black Caribbean Mixed, Black Caribbean, Other Black and Other Mixed groups and lower than average in Other White, Indian, Pakistani, Other Asian, Chinese and Other groups.

2.3.4 Consanguinity

Consanguineous marriage increases the risk of having a child with a learning disability. A consanguineous couple is usually defined as being related as second cousins or closer, with first cousin marriages the most common. In the British Pakistani community it is estimated that 50-60% of marriages are consanguineous. British Pakistanis are 13 times more likely to have children with recessive disorders which are associated with having a learning disability (Section 2.2.1) than the general population and have 30% of all British children with recessive disorders.[15]

2.4 Primary prevention

Primary prevention is the implementation of interventions to reduce the incidence of learning disabilities. As with the causes of learning disabilities, primary prevention strategies can also be divided into those implemented prior to conception, during pregnancy, during labour and after birth. However, the stage at which the primary prevention intervention occurs does not always relate to the stage at which the cause of the learning disability arises (for example, phenylketonuria (PKU) is caused by a genetic abnormality arising at conception, however the screening for PKU occurs after birth).

2.4.1 Prevention prior to conception

Genetic counselling allows people to understand the nature of genetic diseases and what options there are for prevention, testing of the disorder and the likelihood of recurrence. It is available to people who are known to be, or are at increased risk of, carrying a genetic disorder.

2.4.2 Prevention during pregnancy

Screening and diagnostic tests

All pregnant women in the UK should be offered screening for Down's Syndrome as part of their routine care.[16] Screening for Down's syndrome takes place during either the first or second trimester by either ultrasound or maternal serum biochemistry, or a combination of both. Results from the screening test(s) provide the basis for calculating the risk of a foetus having Down's Syndrome. More invasive diagnostic tests, such as chorionic villous sampling or amniocentesis, can be undertaken if an elevated level of risk is reported. Not all foetuses having Down's Syndrome will be terminated.

In utero infections

Immunisation programmes for rubella and measles have dramatically reduced the risk of development of learning disabilities due to maternal infections during pregnancy.[17]

Nutritional and toxic causes

Limiting foetal exposure to alcohol reduces the risk of foetal alcohol syndrome. Both the Department of Health and NICE recommend that pregnant women should avoid alcohol, with a limit of no more than 1-2 units of alcohol once or twice a week, should they choose to drink.[16, 18]

Folic acid is needed early on in the development of the foetus. It is estimated that 70% of neural tube defects may be prevented by taking a folic acid supplement.[19] Both the Department of Health and NICE recommend that women planning a pregnancy take 400 micrograms of folic acid a day, continuing until the 12th week of pregnancy.[16, 18] Healthy Start Women's vitamin tablets contain 400 micrograms of folic acid, but they are only available to women who are already pregnant and in receipt of Income Support, Income-based Jobseekers Allowance and/or Child Tax Credit.

Women who have had a previous pregnancy affected by a neural tube defect or who have diabetes are advised to take 5mg of folic acid daily when planning a pregnancy, continuing until the 12th week of pregnancy.[20,21]

It is estimated that only one-third of women take folic acid supplements before conception, partly as many women do not plan a pregnancy. The USA, Canada and Chile fortify wheat flour with folic acid and have seen a reduction in the incidence of neural tube defects. The UK Government is still

considering whether to approve mandatory fortification of either flour or bread with folic acid, alongside voluntary fortification.

2.4.3 Prevention during labour

Improved obstetric care can prevent or reduce brain damage occurring at birth due to obstruction and hypoxia, and relevant NICE guidance should be followed.[22]

2.4.4 Prevention after birth

Endocrine and metabolic causes

Screening at birth for hypothyroidism and phenylketonuria (PKU) allows a replacement therapy or special diet to be commenced initially thereby reducing the level of learning disability.[17] In the UK, all babies should receive a newborn blood spot test (also known as the Guthrie or heel-prick test) between 5-8 days old to test for presence of these conditions.[23]

Other primary prevention measures occurring after birth are directed at the various risk factors that occur during a child's development. These can include early identification and treatment of infectious diseases, optimal management of chronic conditions such as PKU and accident-prevention measures both within and outside the home.[17]

3 POLICY CONTEXT

Findings

- There are many national policies and best practice documents that highlight the health issues of adults with learning disabilities. In recent years, learning disabilities has achieved a high prominence at a national and regional level.
- At a local level, leadership and governance are provided through the Learning Disability Partnership Boards and Commissioning Groups.
- Learning disabilities is a high priority for both the PCTs and the Local Authorities. There is joint working across the NHS organisations of Nottinghamshire County, Nottingham City and Bassetlaw and also the local authority organisations Nottinghamshire County Council and Nottingham City Council.
- There is joint commissioning taking place locally to implement the recommendations made in national documents.
- There is regular performance monitoring by both the Strategic Health Authority and the Commission for Quality care on aspects related to the health of people with learning disability.

Key issues

- There is not always a process to systematically identify and implement national documents relating to learning disability locally.
- PCT corporate strategies and plans make little reference to the health of adults with learning disabilities and how by improving the health of this population group will help to reduce inequalities in health.
- It is unclear how the Quality Panels will inform others of the progress made by acute hospitals in achieving the quality schedule measures for adults with learning disabilities.
- Regular reporting on the health of adults with learning disabilities to Learning Disability Partnership Boards has not taken place. This has been on a more ad hoc basis.
- Performance management is not currently reviewed at Learning Disability Joint Commissioning Groups.

3.1 National context

A number of documents have been published recently that highlight concerns relating to the health and social care needs and services received by people with learning disabilities. These reports, together with the key governmental documents that outline national commitments to improving the life chances for people with learning disabilities, are the key drivers for taking forward work locally to improve the overall health, access to health services and services received for people with learning disabilities across Nottinghamshire.

3.1.1 National policies

Valuing People[1] recognised that people with learning disabilities are amongst the most marginalised and socially-excluded population groups. The White

Paper set out the Government's commitment to improving the life chances of people with learning disabilities, through close partnership working between different agencies to enable people with learning disabilities to live full and active lives. The vision of the document was based on the 4 key principles of Rights, Independence, Choice and Inclusion.

The White Paper set out 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.

A number of these actions were either not achieved or significantly delayed.

The Government published **Valuing People Now**[2] in 2009 to further progress services for people with learning disabilities. The strategy retained the principle that people with learning disabilities are people first and re-emphasised the need for agencies to work together to achieve the best outcomes for people with learning disabilities. The overall policy objective in relation to better health was:

'All people with learning disabilities get the healthcare and support they need to live healthy lives.'

Outlined within Valuing People Now are 2 key issues for the NHS:

- 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 **Disability Discrimination Act**[24] (2005) protects people with disabilities from discrimination and the **Disability Equality Duty**[25] (2006) places a legal

duty on all public services to promote equality of opportunities for people with disabilities.

Our health, Our care, Our say[26] (2006) re-iterated the commitment in Valuing People that people with learning disabilities should have access to regular, comprehensive health checks. It also made commitments to introduce personal health budgets and close and replace NHS campuses with ordinary housing and support by 2010.

The **Operating Framework for the NHS** has in recent years including specific requirements for NHS commissioners and providers in relation to adults with learning disabilities:

- The 2010/11 document[27] requests that PCTs and providers are "mindful of the learning from the independent inquiry by Sir Jonathan Michael into services for people with a learning disability."

- The 2009/10 framework[28] highlights that PCTs should secure general health services that make reasonable adjustments for people with learning disabilities, and should ensure there are effective arrangements for communication and partnership working between primary care and other healthcare providers to improve the overall quality of health care for people with a learning disability. The document also introduces the Vital Signs indicators, split into three tiers in support of national priorities. In Tier 3 of the 'access to personalised and effective care' priority, there are three indicators that relate to learning disabilities (at this tier, primary care trusts choose in consultation with local partners which to prioritise locally):
    - proportion of adults with learning disabilities in settled accommodation
    - proportion of adults with learning disabilities in employment
    - take up of health checks

- The 2008/09 document[29] highlighted the following areas for local action in relation to adults with learning disabilities:
    - develop action plans locally to address shortcomings identified in the Healthcare Commission audit
    - identify local priorities for implementation of Valuing People Now, focussing on making progress on campus closures, developing and implementing plans with individuals on their care and health needs, and preparing for transfer of learning disability funding to local authorities

High Quality Care for All (2008)[30] is the final report of the NHS Next Stage Review. It outlines the visions for the future of health and healthcare to improve health and provide high quality care for all. Although learning disabilities was not one of the eight core "pathways of care" identified nationally, some regions included learning disabilities as an additional pathway.

Supporting guidance

World class commissioning for the health and wellbeing of people with learning disabilities[31] (2009) is a practical guide to support commissioners to meet the needs of this group, and ensure they are fulfilling their duty to promote equality. The report recommends the following key areas of world class commissioning for the health and wellbeing of people with learning disabilities:

- a comprehensive needs assessment which seeks evidence on the numbers, health needs and experiences of people with learning disabilities
- PCT board members exercising their Disability Equality Duty by asking tough questions about how commissioned services are meeting the needs of people with learning disabilities
- Learning Disability Partnership Boards reviewing services and outcomes and helping develop ambitious public commitments to what is to be achieved in the next five years
- building capability so that all those involved in commissioning general health services understand and act on the needs of people with learning disabilities
- working with service users, families and carers to develop and publish preferred service models
- bringing providers into the market as necessary to achieve the desired service models and outcomes
- mainstream services demonstrating 'reasonable adjustments' to ensure that they are meeting known needs, and having staff who understand how to make these adjustments
- adjustments will be at both individual and service and strategic level depending on the nature of the change required
- working with service users to make sure that provider organisations are consistently delivering high-quality services
- Learning Disability Partnership Boards continuously reviewing how to support individuals in improving their own health and wellbeing

Equal access?[32] (2009) is a guide to support the NHS to include people with learning disabilities in their equality schemes, with practical examples of reasonable adjustments to achieve equality of access.

Green Light (2006)[33] is a toolkit to improve mental health services for people with learning disabilities, providing guidance on what a good service looks like and allowing local areas to assess how good their services are.

3.1.2 National reports

A life like no other: A national audit of specialist inpatient healthcare services for people with learning difficulties in England[34] was undertaken by the Healthcare Commission in 2007. The main findings from the audit were:

- procedures for the safeguarding of vulnerable adults were poor
- poor planning of care for people with learning disabilities

- arrangements for the training of staff were often poor
- a lack of internal and external scrutiny, with limited evidence of engagement by commissioners
- poor provision of stimulating activities and opportunities
- services were often old-fashioned and institutional
- evidence of lack of leadership

A subsequent audit in 2008/09[35] demonstrated that progress had been made, but further recommendations were made as detailed in Box 3.1.

Box 3.1: Recommendations for specialist in-patient learning disability services

- Boards and senior management teams in the NHS and independent health care ensure that they have the evidence and reporting mechanisms to show that their learning disability services are meeting essential common standards.
- Each board should consider nominating a non-executive 'champion' for learning disability
- Commissioning needs to have a local focus and develop the competence and capacity to deliver high quality services and support for local people.
- Independent healthcare providers and NHS trusts should be able to justify the care, treatment and assessment they provide, ensuring it meets with national guidance and best practice.
- Learning Disability Partnership Boards should work with people with learning disabilities and family carers to empower and support them to speak up and be directly involved in peer audits with health organisations.

Source: Care Quality Commission

Death by Indifference[36] (2007), provided details that Mencap believed demonstrated institutional discrimination within the NHS towards six people with learning disabilities, leading to shortcomings in care received and ultimately their deaths. The factors identified that they believed contributed towards institutional discrimination:

- people with a learning disability are seen to be a low priority
- many healthcare professionals do not understand much about learning disability
- many healthcare professionals do not properly consult and involve the families and carers of people with a learning disability
- many healthcare professionals do not understand the law around capacity and consent to treatment
- health professionals rely inappropriately on their estimates of a person's quality of life
- the complaints system within NHS services is often ineffectual, time-consuming and inaccessible

Following the publication of Death by Indifference, the Government agreed to hold an independent inquiry into the six cases Mencap had highlighted. **Healthcare for All**[37] (2008), the report of the Independent Inquiry chaired by Sir Jonathon Michael, concluded that people with learning disabilities appear to receive less effective care than they are entitled to receive, with evidence of a significant level of avoidable suffering and a high likelihood that there are

deaths occurring which could be avoided. A total of ten recommendations were made, summarised as follows:

- Undergraduate and postgraduate clinical training must include competence-based, mandatory training in learning disabilities, involving people with learning disabilities and their carers.
- All health care organisations should ensure that they collect the data and information necessary to allow people with learning disability to be identified and their pathways of care tracked.
- Family and other carers should be routinely involved as partners in the provision of treatment and care, and Trust Boards should ensure that reasonable adjustments are made to enable and support carers to do this effectively.
- PCTs should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment, consulting with their Local Strategic Partnership, their Learning Disability Partnership Boards and relevant voluntary user-led learning disability organisations, and using the information to inform the development of Local Area Agreements.
- the Department of Health should establish a learning disabilities Public Health Observatory, which should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.
- The Department of Health should immediately amend Core Standards for Better Health, to include an explicit reference to the requirement to make 'reasonable adjustments' to the provision and delivery of services for vulnerable groups.
- Inspectors and regulators of the health service should develop and extend their monitoring of the standard of general health services provided for people with learning disabilities, in both hospital and community settings.
- The Department of Health should direct PCTs to commission enhanced primary care services which include regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working.
- All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included in the planning and development of services, and in decisions affecting the operation of services.
- All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, 'reasonably adjusted' health services, including arrangements to provide advocacy for all those who need it, and arrangements to secure effective representation on PALS from all client groups including people with learning disabilities.

Valuing People Now included the response of the Department of Health to the recommendations made in Healthcare for All. All 10 recommendations were accepted by the Department of Health, with assurance given that Chief Executives of all NHS trusts are to make sure that reasonable adjustments in the care of people with learning disabilities are being made.

Six Lives[38] (2009) is the report of the Health Ombudsmen into the cases highlighted in Death by Indifference. The report illustrated some significant and distressing failures in services across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care. In some of the cases the Health Ombudsmen concluded that there had been maladministration and service failure for disability-related reasons. The Health Ombudsmen also found in some cases that the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality. The Ombudsman endorsed the recommendations outlined in Healthcare for All, but also recommended that:

> "All NHS and social care organisations in England should urgently review:
>
> - The effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas; and
> - The capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities

> And should report accordingly to those responsible for the governance of those organisations within 12 months of the publication of this report."

As well as those listed above, a number of other reports have highlighted health inequalities experienced by people with learning disabilities in the UK. These reports include:

- **Equal Treatment: Closing the Gap**[39] (2006) was the report of the Disability Rights Commission's formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems.
- **A life like any other: Human Rights of Adults with Learning Disabilities**[40] (2008), was a report published by the Joint Committee on Human Rights that recommended that stronger leadership is urgently needed to create a more positive culture of respect for human rights in the UK, together with the need for practical steps to be taken to promote the rights of adults with learning difficulties in mainstream public services.
- House of Commons Health Select Committee's **Report into Health Inequalities**[41] (2009) reported that people with learning disabilities have worse health than the rest of the population (paragraph 49) and worse access to high quality health services (paragraph 219).

- The **Bradley Report: a review of people with mental health problems or learning disabilities in the criminal justice system**[42] (2009) identified that too many people pass through the criminal justice system without their learning disabilities being recognised, or their specific needs met, leading to a cycle of offending.
- **Raising our sights: services for adults with profound intellectual and multiple disabilities**[219] (2010) was commissioned as part of the Valuing People Now delivery plan and highlights the most important parts of planning and delivering support for people with the most complex needs. The report includes examples of good practice in provision of services, but also highlights that the major obstacles to wider implementing of policy for adults with profound intellectual and multiple disabilities are prejudice, discrimination and low expectations. The report makes 33 recommendations for national government and local health and social care organisations, and a response from the government is awaited.

3.1.3 NHS Constitution

The **NHS Constitution**[43], first published in 2009, captures the purpose, principles and values of the NHS, as well as bringing together a number of rights, pledges and responsibilities for staff and patients alike. The first principle of the Constitution states that

> "The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion or belief. It has a duty to each and every individual that it services and must respect their human rights. At the same time, it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population."

3.2 Regional context

From Evidence to Excellence – our clinical vision for patient care[44] was the response from NHS East Midlands to the Next Stage Review of the NHS undertaken by Lord Darzi. The regional framework included Learning Disabilities as a workstream and identified the following as priorities for change:

- Develop joint strategic commissioning between local authorities and PCTs.
- Undertake disability equality impact assessments in relation to people with learning disabilities.
- Obtain commitment from all GP practices to actively identify and record patients with a learning disability on their registers.
- Give every patient with a learning disability an annual health check and a health action plan.
- Ensure strategic primary healthcare facilitators in all PCTs.
- Design joint children and adolescent mental health and learning disabilities services.

- Develop admission, treatment and discharge pathways in acute hospitals.
- Develop mental health care pathways.
- Further develop specialist local learning disability teams, supported by crisis response and assertive outreach services to bring care closer to home.
- Build access to healthcare into contracts for residential and nursing homes.
- Complete the closure of NHS 'campus' beds by 2010 and move residents into more appropriate community settings.
- Support local authorities in commissioning choice of accommodation as local as possible.
- Design needs-based assessments and treatment services as integral parts of specialist services.
- Commission and develop inter-agency care pathways.
- Ensure adequate community based specialist forensic services.
- Review specialist workforce to ensure fitness for purpose for new pathways and services.

The Health Care of People with Learning Disabilities in the East Midlands (2008) informed the regional Next Stage Review, and outlined the evidence and case for change. The report outlined a vision for a systematic approach to the health care of people with learning disabilities, integrated firmly with wider health and social care services. The report also highlighted that if there was failure to drive forward comprehensive modernisation and improvement across the system the potential outcome is that people with learning disabilities continue to die earlier than they need.

3.3 Local context

3.3.1 Joint Strategic Needs Assessments

Since April 2008, NHS Primary Care Organisations and top-tier Local Authorities have had a statutory duty to produce a **Joint Strategic Needs Assessment** (JSNA). JSNA is a process that identifies the current and future health and wellbeing needs for the local population. The JSNA should inform the priorities and targets set by Local Area Agreements and lead to agreed commissioning priorities that will improve outcomes and reduce health inequalities.[45]

Nottingham City's JSNA[46], updated for April 2010, includes a chapter on Adults with Learning Disabilities. The keys issues and gaps and recommendations for commissioning of services as identified by the chapter are presented in Boxes 3.2 and 3.3.

Box 3.2: Key issues and gaps as identified in the Adults with Learning Disabilities chapter of Nottingham City's JSNA

- There is forecast to be an increase in the prevalence of adults with learning disabilities over the next 10-15 years, with the highest increase being amongst those with the most severe learning disabilities. There is also forecast to be an increase in the number of young people with learning disabilities entering transition who will require adult services.
- There is under-recording of adults with learning disabilities in primary care, especially in relation to adults with mild learning disabilities.
- Adults with learning disabilities in general suffer from poorer physical health than the general population, experiencing a shorter life expectancy and health inequalities.
- There has been a local review of use of general secondary health care services by adults with learning disabilities, providing a better picture of local need and demonstrating a higher use of services. A similar review of primary care data hasn't been undertaken. Monitoring of delivery of the Learning Disabilities Direct Enhanced Service (DES) should ensure regular review of primary care data.
- There is still limited knowledge on the needs of people with learning disabilities from certain groups, such as within the Criminal Justice System, or from Black and Minority Ethnic Communities.
- Supported Living opportunities within the community are limited and not well understood or promoted.
- Further work is required to implement all actions from *Six Lives* and *Healthcare for All*.
- There is no local data on the number of adults with a learning disability in employment.

Box 3.3: Recommendations for Commissioning as identified in the Adults with Learning Disabilities chapter of Nottingham City's JSNA

- To continue to commission the Learning Disabilities Directed Enhanced Service (DES) and to ensure practices are offering high-quality health checks to all eligible patients, including consideration of alternative methods of delivery for those patients registered at a practice not signed-up to the DES.
- To commission services in line with the expected increase in prevalence of adults with a learning disability over the next 10 to 15 years.
- To improve the quality of primary care learning disability registers, including improving the recording of people with mild learning disabilities on practice registers.
- To ensure all requirements of *Six Lives*, *Healthcare for All* and *Improving the Health and Well-being of People with a Learning Disability* are delivered by local providers and commissioners.
- To implement the action plan as required by the East Midlands Performance and Self-assessment Framework to ensure continuing improvement in services for adults with learning disabilities.
- To review the requirement for all adults with learning disabilities requiring low-secure care to be placed out-of-area to determine whether local provision can be provided.
- To stimulate the local market and provide more respite provision within local communities including the capability of meeting the needs of people with challenging behaviour and high-functioning autism and Aspergers.
- To ensure sufficient access to dental services.
- To ensure appropriate weight management and exercise referral schemes are commissioned that are accessible to adults with learning disabilities.
- To reconfigure services so that there is a move towards provision in the community, including day services and supported housing
- To increase the numbers of adults with learning disabilities in settled accommodation and employment.
- To better understand the demand and costs for specialist services to ensure that service provision is delivering value for money.

NHS Bassetlaw and NHS Nottinghamshire County produced a JSNA[47] in conjunction with Nottinghamshire County Council in June 2008. The JSNA identified people with learning disabilities as a vulnerable population, and highlights estimated local prevalence and the health issues associated with people with learning disabilities.

3.3.2 Commissioning strategies

NHS Primary Care Organisations' 5 year commissioning strategies outline how the organisational vision will be achieved through implementation of a number of strategic goals.

NHS Nottingham City's **Five Year Strategy 2009/10 – 2013/14**[48] details the 4 Goals, 15 Outcomes and 15 strategic initiatives that NHS Nottingham City has

identified as key to achieve its mission of ending health inequalities in Nottingham. Adults with learning disabilities do not feature prominently in the strategy, apart from reference to the transfer of funding to local authorities for the provision of services for those with learning disabilities in line with the transfer of commissioning responsibilities guidance, and increasing outreach health promotion work to reduce teenage pregnancy rates amongst the most vulnerable groups, including those with learning disabilities.

NHS Nottinghamshire County's **Strategic Plan 2008 – 2013**[49] sets out the 7 goals, 9 core values, 10 health outcomes and 11 strategic initiatives that will deliver the vision of *improving the health and wellbeing of the people of Nottinghamshire*. The strategy makes reference to learning disability joint commissioning activities with local authority partners.

NHS Bassetlaw's **Strategic Plan 2008 – 2013: Commissioning for Health, a Strategy to Deliver**[50] includes a specific section on Learning Disabilities, recognising the importance of planning for this group, however does not include specific actions relating to the learning disability population.

Nottingham City Council developed the **Better Outcomes for People with a Learning Disability Commissioning Strategy**[51] in January 2009. The focus of the strategy is to improve the health and lives of people with a learning disability and their families in Nottingham, by providing ordinary opportunities that support independence. Whilst not a joint commissioning strategy, NHS Nottingham City and other partners provided input during its development. The commissioning intentions outlined in the strategy were:

- improve health and well-being
- deliver social and health care services through a Person Centred approach
- enable people with a learning disability to contribute positively to their local community
- encourage self-directed care through Direct Payments and individual budgets
- increase the opportunity and access to housing and appropriate support
- promote equality of opportunity and eliminate discrimination
- promote dignity and respect as citizens
- improve access to employment and education
- further improve co-ordinated health and social care commissioning arrangements

There is commitment to work towards a Joint Commissioning Strategy for Nottingham City in the near future.

Nottinghamshire Learning Disability Joint Commissioning Strategy[52] describes how the County Council, NHS Bassetlaw and NHS Nottinghamshire County plan to commission services for people with learning disabilities. Improving health and wellbeing is one of the nine priorities in this joint commissioning strategy. Reducing health inequalities, along with improving

physical health, mental health and specialist health care for those with learning disabilities are key commitments. Additionally, age-related work will be addressed along with work for those who have forensic needs and those who challenge services.

Nottinghamshire Service Review – Learning Disability Workstream Project Initiation Document outlines the priorities for the initial phase of the NSR project:

- To ensure that by May 2010 all people with a learning disability known to specialist services are recorded on primary care Learning Disabilities registers and have been offered the opportunity of a health action plan and the opportunity for at least one health check.
- To ensure that 80% of people with learning disability receiving acute hospital care and their carers report favourably on the experience by May 2010.
- To establish an effective, integrated Assessment and Treatment service, including appropriate beds/locations and countywide coverage of Community Assessment and Treatment Teams by May 2010.
- To establish by May 2010 timetabled plans for the development of specialist learning disabilities forensic services including:
    - medium secure
    - low secure
    - prison in-reach
    - community services
- Completion of the Nottinghamshire learning disability campus re-provision programme by December 2010.

A **Six Lives** and **Healthcare for all** group was established in 2009 and included representatives from NHS Nottingham City, NHS Nottinghamshire County, NHS Bassetlaw, Nottingham City Council, Nottinghamshire County Council, Nottinghamshire Healthcare Trust, Nottingham University Hospitals NHS Trust and Sherwood Forest Hospitals NHS Trust. The group ensured that all local statutory health and social care organisations assessed effectiveness, capacity and capability of their provided and/or commissioned services to meet the needs of people with learning disabilities, and reported to the above organisations Trust boards and NHS East Midlands in March 2010.

3.4 Performance monitoring and quality

The Care Quality Commission (CQC) published its **Strategic plan 2010-2015: position statement and action plan for learning disability**[53] in 2009. In the document, CQC identified three key areas for improvement over the next five years:

- Ensuring that the care of people with learning disabilities becomes more person-centred, including a greater focus on person-centred care plans.
- Ensuring that people with learning disabilities receive care that is safe.

- Improving the commissioning of services for people with learning disabilities.

At the same time, the **Care Quality Commission** published an indicator on '*Access to healthcare for people with learning disability' for acute and specialist trusts*.' This indicator seeks to respond to the recommendations made in 'Healthcare for All' specifically around the collection of data and information necessary to allow people with a learning disability to be identified, and the arrangements trusts have in place to ensure the views and interests of people with learning disabilities and their carers are included in the planning and development of services. This indicator will not be included in the scored assessment for 2009/10. Trusts will however be expected to collect the requisite information and report on it separately. They will be assessed on their responses to six questions given in Box 3.4.

Box 3.4: Trusts will be assessed on responses to the following questions:

- Does the trust have a mechanism in place to identify and flag patients with learning disabilities and protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients?
- In accordance with the Disability Equality Duty of the Disability Discrimination Act (2005) does the trust provide readily available and comprehensive information (jointly designed and agreed with people with learning disabilities, representative local bodies and/or local advocacy organisations) to patients with learning disabilities about the following criteria:
    - Treatment options (including health promotion)?
    - Complaints procedures?
    - Appointments?
- Does the trust have protocols in place to provide suitable support for family carers who support patients with learning disabilities, including the provision of information regarding learning disabilities, relevant legislation and carers' rights?
- Does the trust have protocols in place to routinely include training on learning disability awareness, relevant legislation, human rights, communication techniques for working with people with learning disabilities and person centred approaches in their staff development of health services?
- Does the trust have protocols in place to encourage representation of people with learning disabilities and their family carers within Trust Boards, local groups and other relevant forums, which seek to incorporate their views and interest in the planning and development of health services?
- Does the trust have protocols in place to regularly audit its practices for patients with learning disabilities and to demonstrate the finding in routine public reports?

Source: Care Quality Commission

The **Comprehensive Area Assessment** (CAA) is a new national framework to assess the effectiveness of public services in working together to deliver the outcomes that will improve the quality of life, health and wellbeing for local people. Public services will be assessed by six partner inspectorates for their accountability, responsiveness, quality, impact, use of public money and prospects for delivering sustainable improvement. The CAA will include performance against the National Indicator Set (NIS), and the relevant indicators in the NIS are:

- NI145: adults with learning disabilities in settled accommodation

- NI146: adults with learning disabilities in employment

Local Area Agreements (LAAs) set out the priorities for a local area agreed between central government and a local area. Nottinghamshire Partnership, the local strategic partnership has produced a **LAA for Nottinghamshire 2008 – 2011**[54] (which includes the Bassetlaw locality) and contains an indicator relevant to the learning disabilities population:

- NI 146 Adults with Learning Disabilities in employment. The proposed target is to secure paid employment for 110 people with learning disabilities over the next 2 years across the County. Due to the recession impact on employment, the LAA target for 2009/10 will not be met. Provisional data shows that in Nottinghamshire there is an employment rate of 10.2% for people with learning disability. This is above both the East Midlands and national average of 7.5%.

Nottingham City's Local Area Agreement[55] does not include any indicators specific to the learning disabilities population.

All NHS Commissioners in the East Midlands have to undertake an annual **performance and self-assessment framework** specifically for learning disability providing a rating across a number of top targets. The assessment is undertaken in consultation with a range of stakeholders, including service-users and carers and is validated by NHS East Midlands. Final ratings for 2009/10 are detailed in Section 8.1.

In addition each PCT reports the following information NHS East Midlands on a quarterly basis:

- NHS campus re-provision
- Learning disability population (numbers on QoF registers and those known to social services)
- Number of annual health checks delivered in previous 12 months
- Number of both primary care facilitators and secondary care liaison posts

The **Acute Trust Quality Schedule** (2010/11) for Nottingham University Hospital Trust and Sherwood Forest Hospital Trust include the following quality of healthcare measures.

2010/11 Acute Trust Quality Standards

Standard	Measure:	Evidence
Vulnerable adults / Learning disabilities – improve the quality of healthcare that people receive in acute hospitals	50% of relevant clinical staff to have undertaken vulnerable adult and learning disabilities awareness training (i.e. 50% of all relevant professional groups)	Awareness training programmes available at induction and through continuing professional development. Quarterly review of staff training attendance figures.

	Patients with learning disabilities have a tailored package of care that involves them in care planning in a way that is appropriate to their levels of communication and mental capacity.	Clinical audit demonstrates that 95% of patients with learning disabilities have care plans appropriate to their levels of communication and mental capacity.
	Patients with learning disabilities will have clinical outcomes that are comparable with wider disease group.	Clinical audit demonstrates that people with LD do not have more unexpected adverse outcomes than comparator disease group.
	Concern, compliment and complaint procedures should be in accessible format and hospitals should be able to identify those received from people with learning disabilities and/or their carers.	Complaints procedure is in an accessible format. A report of concerns, compliments and complaints received in which trends are identified and areas of change that are needed.

These measures are monitored at regular quality meetings between the provider and commissioners.

The **Quality Schedule for 2010/11 for Nottinghamshire Healthcare Trust** requires that people with learning disabilities and/or autistic spectrum conditions (ASC) should be able to access mainstream services when necessary. All concerns relating to performance against this requirement would be discussed at the Quality and Performance Group, which includes providers and commissioners, and the Contract Review Meeting.

In addition, the **Commissioning for Quality and Innovation (CQUIN)** payment framework makes a proportion of providers' income conditional on quality and innovation. The 2010/11 CQUIN framework for Nottinghamshire Healthcare Trust includes an indicator requiring Learning Disability service users admitted to in-patient/day-care facilities to receive MUST (Malnutrition Universal Screening Tool) screening.

3.5 Governance and leadership

Local governance and leadership are provided through Learning Disability Partnership Boards and Commissioning Groups. There are a number of other groups that these are either accountable to (but do not have a specific focus on learning disabilities) or that are sub-groups of the above. The relationships between groups can be seen in Figure 3.1.

3.5.1 Learning Disability Partnership Boards

Nottingham City and Nottinghamshire County (including Bassetlaw) both have Learning Disability Partnership Boards, established as a requirement of the Valuing People White Paper[1] to promote stronger local partnerships to improve the services received by people with learning disabilities.

Valuing People Now[2] places even greater emphasis on the role of Partnership Boards in ensuring local delivery of the strategy, stating that they are "central to the strategic planning, commissioning, delivery and performance management of all services as they relate to learning disability in local areas." Within the strategy, Partnership Boards are also formalised as part of a governance structure that allows for the reporting of local data to new Regional Learning Disability Programme Boards.

The Department of Health recently published Good Learning Disability Partnership Boards: Making it happen for everyone[56], which aims to improve the effectiveness of Partnership Boards, through highlighting best practice examples from around the country and being based on the evidence that the most effective Partnership Boards are those with strong links to other local boards and work programmes, delegated or shared financial and commissioning responsibility and meaningful representation of people with learning disabilities and family carers from all local communities.

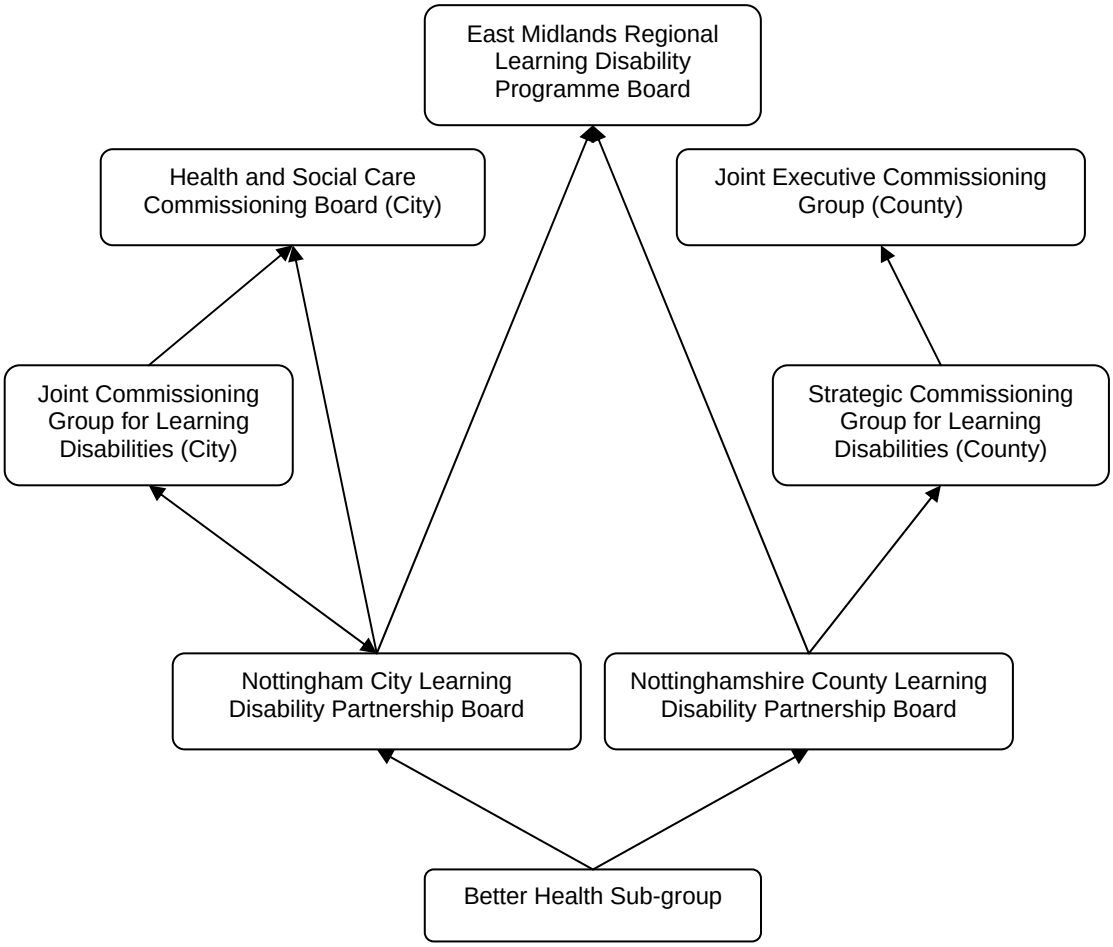
Better Health sub-group

Nottingham City and Nottinghamshire County Learning Disability Partnership Boards have a joint Better Health sub-group. The aim of the group is to work in partnership to improve the health and wellbeing of people with a learning disability who live in Nottinghamshire (including Nottingham City and Bassetlaw). This is achieved by supporting local delivery of the Better Health strand of Valuing People Now.

3.5.2 Commissioning Groups

There are strategic Commissioning Groups in both Nottingham City and Nottinghamshire County (including Bassetlaw) that bring together local authority and NHS commissioners to strategically plan, develop and commission health and social care learning disability services. The County Commissioning Group has a joint commissioning strategy (see Section 3.3.2) that outlines the commissioning intentions of the group. Currently the City group does not have a joint commissioning strategy, though key organisations provided input into Better Outcomes for People with a Learning Disability, Nottingham City Council's Commissioning Strategy for adults with learning disabilities (see Section 3.3.2).

Figure 3.1: Local and regional governance and leadership structure for adults with a learning disability



4 LITERATURE REVIEW OF HEALTH NEEDS

Findings

- Adults with learning disabilities experience inequalities and when compared to the general population 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 disabilities
  - Different lifestyle and environment issues
  - Different patterns of health need and more complex health needs
  - Difficulties accessing end of life care that meets specific needs

Key issues

- The evidence base for health issues for adults with learning disabilities is limited due to definition of cases, difficulties in diagnosis and small sample sizes.
- While some people (with mild learning disabilities) may have few health problems, those with severe learning disabilities may have a variety of interconnecting health needs that impact greatly on all aspects of their lives.

Epidemiological research on the health of people with learning disabilities is limited due to definition of cases, difficulties in diagnosis, and small sample sizes.[57] When compared to the rest of the population, people with learning disabilities experience health inequalities and have:[58]

1. Lower life expectancy
2. Different causes of death
3. Higher levels of unrecognised and unmet physical and mental health needs
4. Barriers to accessing health services
5. Communication disabilities
6. Different lifestyle choices and environment issues
7. Different patterns of health need and more complex health need
8. Difficulties accessing end of life care that meets specific needs

4.1.1 Life expectancy

- People with a more severe level of learning disability are at increased risk of early death compared to general population.
- Life expectancy of those with mild learning disabilities is similar to that in the general population of a similar socioeconomic status.
- Life expectancy is increasing over time.

There have been significant improvements in the mean life-expectancy of people with learning disabilities from as little as an estimated 18.5 years in the 1930's to 59 years in 1970's to 66 years in the 1990's.[59] Evidence from the United Kingdom and the United States indicates that the life expectancy of those with a more severe level of disability, remains reduced compared to the general population, although life expectancy is increasing over time and, for people with mild learning disabilities, approaching that of the general population of a similar socioeconomic status.[60,61] An Australian study showed a strong negative association between severity of learning disability and life expectancy, with median life expectancies of 74.0, 67.6 and 58.6 for people with mild, moderate and severe levels of learning disability.[62] All cause mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population.[222] Significant negative associations were observed with male gender and for individuals diagnosed with a specific genetic disorder. People with Down's syndrome have a shorter life expectancy than people with learning disabilities generally, although the life expectancy of this group is increasing particularly quickly.[61]

4.1.2 Causes of death

- People with learning disabilities are more likely to die of a preventable cause.
- Deaths from respiratory disease are three times higher than the general population.
- The majority of people with learning disabilities do not have learning disabilities or an associated condition mentioned on their death certificate

For the general population, the leading cause of death is cancer, followed by heart disease, then cerebrovascular disease. For people with learning disabilities, respiratory disease (related to pneumonia and aspiration)[60, 61, 63] followed by cardiovascular disease[63] (related to congenital heart disease rather than ischaemia) are the leading causes of death. Cancer is a lower ranked cause of death than for the rest of the population, and the types of cancer most commonly experienced differ from the general population (Section 4.1.9c).[64]

Studies suggest that approximately 60% of people with learning disabilities in the UK do not have learning disabilities or an associated condition mentioned as a contributing cause of death on their death certificate, and those that do, in general, have a severe-profound level of disability.[63, 65]

4.1.3 Unrecognised and unmet physical and mental health need

- Adults with learning disabilities often have health needs that go unrecognised and untreated, due to difficulties in communication, diagnostic overshadowing, discrimination or indifference.
- The learning disability population is less likely to receive expected evidence-based health checks and treatment than the general population.

The unmet health needs of people with learning disabilities can be considered at four levels:

- Strategic and health improvement needs – requiring support to enable healthy lifestyles, appropriate health improvement material and access to health screening programmes.
- Everyday health needs – requiring primary care services.
- Health needs related to having learning disabilities – needing extra support and reasonable adjustments to be in place for services to be accessible.
- Complex health needs related to profound learning and multiple physical disabilities, epilepsy, mental ill health or autistic spectrum disorders.

The Primary care, Evaluation, Audit and Research in Learning Disabilities (PEARL) study[66] conducted in Wales looked at the health care of people with learning disabilities and found that in general practice adults had unmet major health needs. The following unidentified and therefore untreated conditions were found during screening of people with learning disabilities:[67]

- diabetes
- hypertension
- high cholesterol
- thyroid disorders
- dental problems
- cardiac difficulties
- asthma
- mental health difficulties

Diagnostic overshadowing occurs when a presenting symptom of physical illness or mental illness is incorrectly attributed to the person's learning disability and may mean that health needs are not investigated, diagnosed or treated.[36, 68]

4.1.4 Barriers to accessing health services

- Barriers in accessing health services for people with learning disabilities include inadequate facilities, rigid procedures and lack of appropriate interpersonal skills among mainstream health care professionals.
- Eligible adults with learning disabilities have lower uptake of cervical and breast screening than the general population.

People with learning disabilities often experience barriers such as rigid procedures and lack of interpersonal skills among mainstream health care professionals in using health services.[58,69] A lack of accessible information and effective communication can have an impact on medical treatment and management.[70] The Disability Equality Duty provision of the Disability Discrimination Act 2005, requires PCT's to ensure there are 'reasonable adjustments' to enable people with disability to access services. Examples of improving access for people with learning disabilities include making longer appointment times and appointments at the beginning or end of surgery. There is evidence that services are not making the 'reasonable adjustments' required by the Disability Discrimination Act.[39] *'Equal access?'* is a practical guide to support the NHS to include people with learning disabilities in their equality schemes, with practical examples of reasonable adjustments to achieve equality of access.[32]

People with learning disabilities had an average of between 3.6 and 6.9 contacts a year with general practice staff (averages are for different subgroups within the sample). This is higher than consultation rates for the general population. However given the consultation rate in the general population for people with diabetes is 18.5 per year, it would seem that the number of consultations by people with learning disabilities may be lower than expected.[71]

People with learning disabilities should have access to breast, cervical and bowel screening on the same basis as the rest of the population. Good practice guidance is given in the document *Equal access to breast and cervical screening for disabled women*.[72]

Women with learning disabilities are much less likely to undergo cervical smear tests than the general population (19% vs. 77%).[73] Most women with learning disabilities undergoing cervical smear tests do not understand the purpose of the test.[74]

Breast cancer screening has been found to be lower in people with learning disabilities than in the general population, with 23% of women in one study reported as being given no explanation about the procedure, and another, reporting women with learning disabilities being arbitrarily removed from

screening lists by their doctor.[75] Whilst the current evidence base suggests a low incidence of breast cancer and low uptake of breast screening, it should not be interpreted as support to discourage women with learning disabilities from attending breast screening. There is evidence of success in providing knowledge and skills to assist more able women to make an informed decision about the uptake of screening and tolerate invasive procedures.[76]

4.1.5 Communication problems

- People with learning disabilities are highly likely to experience difficulties in communication.

Difficulties in communication are experienced by people with learning disabilities.[77] Between 50-90% of people with a learning disability have communication difficulties due to the nature of the learning disability and/or associated sensory or physical disabilities. Approximately 80% of people with severe learning disabilities do not acquire effective speech and approximately 20% of people with learning disabilities have no verbal communication skills but do demonstrate intentional communication. Another 20% have no intentional skills but it is still possible to recognise positive and negative emotions.[8]

'Inclusive communication' provides a supportive environment where any and every available means of communication is used to understand and to be understood. This may mean simplifying language, slowing down, using easier words and showing people what is meant (using pictures, photos, objects, actions) in order to maximise communication potential and therefore participation in everyday life experiences. There are symbol systems that either substitute for speech or provide help for those with linguistic issues. These include Makaton, Rebus, Picture Communication System and Somerset Total Communication. There are also picture or photo collections such as the Change Picture Bank and Photosymbols.

4.1.6 Lifestyle choices

- Inactivity and obesity are more common for people with learning disabilities.
- Conventional methods of health promotion do not work for this group and current healthy lifestyle initiatives may widen rather than close the inequality gap.

Inactivity, poor nutrition, obesity, excessive alcohol intake and smoking increase the risk of disease. Restricted and lack of opportunities to gain appropriate knowledge, due to a lack of accessible health promotion materials and services, may mean that people with learning disabilities have limited

understanding about health risks and are consequently unable to determine their own lifestyle choices.

Physical activity

People with learning disabilities participate in lower levels of physical activity, well below the recommended daily level to protect and improve health.[78,79] A national survey[80] to consider the life experiences of adults with learning disabilities was conducted in 2003/04. Just one in five (20%) reported that they exercised three or more times a week. This was higher among people with mild/moderate learning disabilities (23%) than in people with severe learning disabilities (18%) and people with profound and multiple learning disabilities (9%). Rates of exercising were higher among people living in private households. Barriers to physical activity include lack of activity choices; poor accessibility of leisure and exercise facilities; an individual's understanding, motivation and mood; whether a person is supported and encouraged to be more physically active; risk assessment issues; and lack of staff training and support.[81, 82,83]

Poor nutrition

Poor diet influences the risk of cancer, heart disease and other conditions and eating a healthy diet could save around one in every ten deaths.[84] Less than 10% of adults with learning disabilities eat a balanced diet, with an insufficient intake of fruit and vegetables, and a lack of knowledge and choice about healthy eating.[79,85]

Obesity

Obesity can increase the likelihood of heart disease, stroke and Type II diabetes.[82,86] In addition there are additional psychological, social and economic consequences of being obese. Levels of obesity are higher in people with learning disabilities and are more notable in those with mild learning disabilities[78] and those living in less restrictive settings.[87] Risk factors to explain the increased prevalence of obesity in those with learning disabilities are:

- Demographic factors such as gender, age, level of learning disability, geographical location and living situation.[78,79,82,88]
- Genetic syndromes such as Prader Willi syndrome or Down's syndrome.[82]
- Taking part in little or no physical activity.[88,89,90]
- Low adherence to a healthy diet.[90]
- Medications (such as antipsychotic or anticonvulsive drugs) that have weight-gain side effects.[91]

In Leicestershire when compared with the general population, women with learning disabilities were more likely to be obese (with a body mass index (BMI) of greater than 30), but not men. In those aged 25 and over, 32% of women with learning disabilities were obese compared with 23% of women in the general population. For men the corresponding prevalence was 5% and

19% respectively. Limitations of the study suggest that these figures may be an underestimate of the true prevalence. Adults with Down's syndrome were 139% and 217% more likely than expected to be obese or underweight. Obesity was twice as prevalent in women as men and associated with living independently/with family, ability to feed/drink unaided, hypertension, Down's syndrome and the absence of cerebral palsy.[78]

The evidence base for successfully managing obesity through diet, exercise, behaviour therapy, drugs and even surgery relates to the general population and needs to be evaluated in the learning disability population. There is a lack of evidence about the effectiveness of weight loss interventions in the long term. Methods for managing weight problems need to be adapted for the learning disability population.

Smoking

Most studies suggest that the prevalence of smoking among adults with learning disability appears to be lower than that found in the general population. A national survey to consider the life experiences of adults with learning disabilities was conducted in 2003/04.[80] Just less than one in five (19%) reported that they smoked cigarettes. This was higher among people with mild/moderate learning disabilities (30%) than people with severe learning disabilities (11%) and people with profound and multiple learning disabilities (4%). Rates of smoking were higher among people living in private households.

4.1.7 Living arrangements

- Living arrangements may make healthy choices more difficult for people with learning disabilities.

There are a variety of settings that people with learning disabilities now reside. These include family homes (many supported by older parents), group residential accommodation, their own homes, sheltered housing, hostels, private shared arrangements supported by home carers or others, or other forms of supported lodgings. Often these living arrangements make healthy choices difficult. Carers play a key role in supporting and encouraging healthier lifestyles and it is essential that they are confident about healthy lifestyle messages.

People with learning disabilities have been shown to more likely to live in areas identified as socially deprived. Social deprivation and exclusion are associated with poorer health.[92]

4.1.8 Immunisation status

- Individuals with a learning disability are less likely to have received regular immunisations when compared to the general population

Individuals with a learning disability are less likely to have received regular immunisations such as tetanus, poliomyelitis and influenza when compared with the general population.[93] Given the high prevalence of respiratory infections and premature death from pneumonia, influenza immunisation is of particular importance for high risk groups. Individuals that live, or access services, in group settings are at higher risk of acquiring hepatitis B infection and immunisation provides long term protection.[64]

4.1.9 Pattern of health need

- Health needs are different to the general population.
- Due to increasing life expectancy people with learning disabilities are experiencing the same age related illnesses as the general population.

People with learning disabilities have a different pattern of health need and are more likely to have physical conditions that need medical attention.[63] Epilepsy, gastro-oesophageal reflux disorder, sensory impairments, osteoporosis, schizophrenia, dementia, dysphagia, dental disease, musculoskeletal problems, accidents and nutritional problems are all much more commonly experienced.[64] Health needs can be related to disabilities e.g. epilepsy, sensory deficits; syndrome related e.g. hypothyroidism in people with Down's syndrome or secondary e.g. obesity and reflux disease. Given the improvements in life expectancy as discussed in Section 4.1.1, age-related illnesses that commonly occur in older age such as dementia now need to be considered.

PHYSICAL HEALTH NEEDS

a. Respiratory disease

- Diseases involving the respiratory system are the commonest cause of death for people with learning disabilities.
- Those with profound and multiple physical disabilities are more at risk of aspiration which can cause respiratory infections.

Respiratory disease is the most common cause of death for people with moderate or severe learning disabilities and is a major factor in premature death.[8]

Respiratory infections are particularly common in those with Down's syndrome, Prader-Willi syndrome and those with profound and multiple learning disabilities due to gastro-oesophageal reflux disease and swallowing problems (Section 4.1.9f) which can lead to aspiration.[64] The clinical features

of aspiration in the presence of severe or profound learning disabilities can be masked and 'silent aspiration' may occur. In this instance lung damage may occur without warning. In some there is very little evidence of bronchial damage even in the presence of known aspiration.

b. Heart disease

- The incidence of heart disease is increasing and is the second most common cause of death among people with learning disabilities (related to congenital heart disease rather than ischaemia).
- Almost half of all those with Down's syndrome are affected with congenital heart problems

Due to increased longevity and lifestyle changes associated with community living, the rate of cardiovascular disease is increasing.[60,94,95] People with learning disabilities are more likely to develop hypertension and obesity and alongside lack of exercise, these are all risk factors for coronary heart disease.

Cardiac disorders experienced may result from an underlying cause of the learning disability. Almost half of all people with Down's syndrome are affected by congenital heart problems, a much higher rate than the general population.[96,97]

c. Cancer

- Higher rates of oesophageal, stomach and gall bladder cancer and leukaemia in those with moderate to severe learning disabilities when compared to the general population.
- People with learning disabilities diagnosed with cancer are less likely to be given their diagnosis than the general population.

Although the incidence of deaths from cancer in the UK is currently lower than the general population (11.7%-17.5% vs. 26%), due to the increased longevity of adults with learning disabilities, the incidence of cancer is rapidly increasing.[98,99,100] Due to methodological problems, it is difficult to draw conclusions about the incidence and prevalence of cancer in people with learning disabilities.[101]

Those with moderate to severe learning disabilities experience a different pattern of cancers compared with the general population, with lower rates of lung, prostate and urinary tract cancers and higher rates of oesophageal, stomach and gall bladder cancer and leukaemia.[64, 102] People with moderate to severe learning disabilities tend to have lower incidence of smoking when compared to the rest of the population[8] which may be a reason for lower rates of lung cancer. Cancers of the stomach and oesophagus may be related to

the high prevalence of gastrointestinal disorders, and in particular gastro-oesophageal reflux disease and *Helicobacter Pylori*. Rates of gastrointestinal cancer are higher than the general population (48%-58.5% vs. 25%).

People with Down's syndrome are at risk of leukaemia, a cancer of the white blood cells, with rates being significantly higher than the general population.[103] Those with Prader-Willi are at increased risk of myeloid leukaemia.[8]

Unlike the general population many people with learning disabilities are less likely to be given a cancer diagnosis, accompanied with a lack of information, preventing them from participating in important treatment decisions. Traditional models for breaking bad news may not be appropriate for people with learning disabilities.[104]

d. Epilepsy

- There is a higher prevalence of epilepsy in people with learning disabilities compared to the general population.

Up to 25% of people with learning disabilities have epilepsy, compared with 0.7% of the general population.[105,106] The more severe the learning disability, the higher the prevalence of epilepsy. People with learning disabilities who have epilepsy often have more than one type of seizure and more complex seizure patterns.[107] They are also at risk of further damage to their cognitive function from prolonged seizures.

e. Oral and Dental Health

- People with learning disabilities are more likely to have poor oral/dental health and less likely to have regular contact with dental services.

People with learning disabilities are more likely to have poor oral health, (including tooth decay, loose teeth, gum disease), higher levels of untreated disease and a larger number of extractions.[108,109] Uptake of screening services is lower than the general population[110] and dental work tends to be reactive rather than preventative. A Sheffield study identified that adults with learning disabilities living in the community have greater unmet oral health needs than their residential counterparts and are less likely to have regular contact with dental services.[111] Dental work for people with learning disabilities might require a general anaesthetic which can only be carried out in certain settings and means that dental problems can take longer to treat.

f. Gastrointestinal disorders

- People with profound learning disabilities tend to suffer more with swallowing problems, gastro-oesophageal reflux disease and constipation.
- In those with profound and multiple disabilities there is a higher prevalence of being underweight than the general population.

Swallowing/feeding problems

Problems with swallowing (dysphagia) are more prevalent in people with learning disabilities than those without, with the highest prevalence in those with profound and multiple disabilities. These can be caused by neurological problems or structural abnormalities of the mouth or throat. Swallowing problems can cause increased risk of mortality, dehydration, malnutrition, respiratory tract infections, and aspiration.

A Leicestershire study identified that in those aged 25 and over, 19% of men with learning disabilities were underweight (Body Mass Index [BMI] <18.5 kg/m^2) compared to 2% in the general population and for women 12% vs. 5% respectively.[78] Being underweight was more common in men than women, and associated with younger age and absence of Down's syndrome.[78] *Those with profound and multiple learning disabilities and those with metabolic disorders such as phenylketonuria are more at risk of being underweight.* Nutritional intake may be inadequate if there are difficulties in eating such as swallowing problems, poor hand to mouth co-ordination or behavioural problems. Being underweight may not be identified because body weight is not always monitored. Annual nutritional screening for all adults in community care homes is recommended by NICE to identify for malnutrition.[112] People with learning disability have a polarised weight distribution with a higher prevalence of both underweight and overweight than the general population. Overweight and obesity is discussed in Section 4.1.6.

Gastro-oesophageal reflux disease

This affects as many as half of people with learning disabilities and has a higher prevalence in those with more profound and multiple learning disabilities. It has been associated with Fragile X syndrome. Gastro-oesophageal reflux disease often remains unnoticed and if untreated there is an increased risk of oesophageal carcinoma.[113]

Constipation

This is more prevalent in people with learning disabilities than those without. It is more likely to occur in those with profound and multiple learning disabilities, in those less mobile, in those with a limited food choice and inadequate hydration and for those on long term medication (in which constipation is a side effect).[114]

g. Sensory impairments

- Adults with learning disabilities have an increased prevalence of visual and hearing impairments compared to the general population.

People with learning disabilities are between 8.5 and 200 times more likely to have a vision impairment compared to the general population. Non-correctable visual impairment is present in 10% of adults with learning disabilities, at least 7 times higher than in the general population.[115] Adults with Down's syndrome aged 30 years and over are at risk for premature age-related cataracts,[116] increasing refractive errors and degenerative corneal changes.[117] For adults with a learning disability, routine screening for age-related visual loss at 45 years and every five years thereafter has been recommended.[118] An extra vision check at 30 has been recommended for adults with Down's syndrome.

Approximately 40% of people with learning disabilities have a hearing loss. Deafness is common, often unrecognised and if recognised poorly managed.[119] People with learning disabilities are more likely to need a hearing aid, but many have never had a hearing test. Hearing problems might further compound already poor communication skills. Some hearing problems are caused by structural abnormalities such as abnormal shaped ear canals or by neural damage. Hearing loss as a result of impacted earwax is a frequent problem in adults with a learning disability. Adults with learning disability aged 30 years and over, especially those with Down's syndrome are at risk for early age related hearing loss. Routine age related hearing loss of all adults age 45 years and every 5 years thereafter has been recommended. Screening of the hearing function of adults with Down's syndrome is recommended every 3 years throughout life.

People with Down's syndrome are at particularly high risk of developing both vision and hearing loss and prevalence increases with age.[120] Sensory disabilities are often associated with challenging behaviour.[107] Additionally people with learning disabilities are prone to ear and eye infections. People with learning disabilities are less likely to be assessed for vision or hearing impairments due to staff attributing lower levels of functioning to the person's learning disability[121,122] and to receive aids to vision[123] or hearing.[122]

h. Metabolic and endocrine disorders

- People with learning disabilities are more at risk of developing osteoporosis and suffering from fractures than the general population.
- Hypothyroidism is more common in those with Down's syndrome.
- The higher prevalence of obesity means that people with learning disabilities are at greater risk of developing Type II diabetes.

Osteoporosis

People with learning disabilities are more at risk of developing osteoporosis due to lower bone density than the general population[124] and suffer from a higher incidence of fractures.[125] Estimates suggest that fractures occur 1.7 – 3.5 times more frequently among people with learning disabilities.[126] Contributory factors include impaired mobility (lack of weight bearing exercise), genetic factors where some learning disability syndromes are associated with a failure of sex-hormones and delayed or lack of puberty, the earlier than average age at menopause for women with learning disabilities and poor nutrition and underweight. Some antiepileptic and antipsychotic drugs can also affect bone structure. Women with learning disabilities should have bone density tests and medication such as Vitamin D supplementation to improve the bone density.

Thyroid disease

Thyroid disease can occur at any age but is more common with increasing age and is particularly common in those with Down's syndrome. Thyroid auto-antibodies are found in 13%-34% of patients with Down's syndrome.[127,128] The reported prevalence of hypothyroidism (where there is under production of thyroid hormone) in adults with Down's syndrome has varied between 3% and 54%[127] compared to 0.8%-1.1% in the general population.[128] People with Down's syndrome should be screened annually for thyroid function.

Diabetes

People with learning disabilities have a greater risk of developing Type II diabetes due to inactivity and high rates of obesity. Within the learning disability population, the existence of diabetes may be overlooked and therefore go untreated. Health checks provided in a Welsh study identified that people with learning disabilities had a higher rate of diabetes (9%) than the general population (4%).[71] The effective prevention and management of obesity is important for people with learning disabilities.

i. Posture and mobility

- There are high rates of mobility problems associated with more severe levels of learning disability.
- Mobility problems can lead to secondary problems such as respiratory diseases, osteoporosis, chronic constipation, gastro-oesophageal reflux or pressure sores.

Mobility problems are associated with more severe levels of learning disabilities and the presence of cerebral palsy. Studies have found that 25-40% of adults with learning disabilities have foot problems and if left untreated can lead to falls. Some antipsychotic and anti-epileptic medication can impair mobility, which may also contribute to falls and injuries.[64] As a consequence of falls and injuries, mobility may be further reduced. Mobility problems can lead to secondary problems such as respiratory diseases, osteoporosis, chronic constipation, gastro-oesophageal reflux disease or pressure sores.

MENTAL HEALTH AND BEHAVIOURAL NEEDS

j. Mental ill health and problem behaviours

- Adults with learning disabilities are more vulnerable to mental health problems than the general population, but are less likely to have them diagnosed.
- Rates of dementia are four times higher in those with learning disabilities compared to the general population, with earlier onset.

Given lifestyle trends and experiences,[129] people with learning disabilities are more vulnerable to mental health problems than the general population.[130,131] This vulnerability is thought to be due to a combination of familial, social, biological and psychological factors (Table 4.1).[132]

Table 4.1: Potential vulnerability factors for developing mental ill health in people with learning disabilities

Potential vulnerability factors for developing mental ill health in people with learning disabilities.	
Biological	**Psychological**
Brain damage	Personality development
Vision/hearing impairments	Deprivation/abuse
Physical illness/disabilities	Separation/losses
Genetic/familial conditions	Other life events
Drugs/alcohol abuse	Positive/negative learning experiences
Medication/physical treatments	Self esteem/insight
Social	**Family**
Attitudes and expectations	Diagnostic/bereavement issues
Supports and relationships	Life-cycle transitions/crises
Inappropriate environments/services	'Letting go'
Under/over stimulation	Social/community networks
Valued/stigmatised role/role models	Stress/adaptation to disabilities
Financial/legal disadvantage	Relationships/resources

A recent UK study found that 41% of adults with a learning disability also experience mental ill health of some type.[58] Drawing firm conclusions about prevalence of mental ill health from the available evidence is problematic[133] due to methodological shortcomings of studies, such as using different methods of assessment and different diagnostic criteria/classification systems. Although people with learning disability have a higher prevalence of mental illness than the general population, medical professionals are less likely to diagnose psychiatric problems in this group.[68] For many of those who do access adult mental health services, there is often a reluctance and lack of confidence expressed by staff, believing that they do not have the right skills or are adequately trained to deal with needs of people with a learning disability.[134] The Green Light Tool Kit[33] has attempted to address this in part. This toolkit is a self assessment tool designed to be used between different partnerships: commissioners, providers, service users and carers across learning disability and mental health services.

Common mental health problems

Reported prevalence rates for anxiety and depression amongst people with learning disabilities vary widely, but are generally reported to be at least as prevalent as the general population[135] and higher amongst people with Down's syndrome.[136] There is evidence that the rate of anxiety and depression in community settings is higher than it was in institutions. This may be a reflection of the stress of coping with day to day living, particularly if there is inadequate or unskilled support and insufficient attention to lifestyle issues.[107] 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 severe learning disabilities or with communication difficulties it might be physical signs such as weight loss, a change of sleep pattern, or social withdrawal that suggest depression. There might also be atypical indicators such as self injury or aggression, uncharacteristic incontinence or screaming.

Severe and enduring mental health problems

The rate of schizophrenia has been shown to be three times higher in people with learning disabilities than the general population (3% vs. 1%).[137] People with learning disabilities can experience the full range of psychotic symptoms associated with schizophrenia, but these tend to be less marked and less complex. Schizophrenia is very difficult to diagnose in people with severe learning disabilities since the diagnostic criteria rely on the person being able to communicate their internal experiences.

Challenging behaviours

Aggression, destruction, self injury and other challenging behaviours are shown in 10%-15% of people with learning disabilities, with age-specific prevalence peaking between 20 and 49.[222] In some instances challenging behaviours result from pain associated with untreated medical disorders. [222]

Eating disorders

Eating disorders, anorexia nervosa, bulimia nervosa and atypical eating disorders have been reported to be more common among people with learning disabilities compared to the rest of the population.[64] The causes of eating disorders are complex and poorly understood, but among people with learning disabilities they have been associated with being younger, having reported abuse, having poorer social networks, having difficulties with eating and drinking and having other behavioural disorders.[138]

Dementia

Dementia is characterised by global cognitive impairment, which represents a decline from previous level of functioning, and is associated with impairment in functional abilities and in many cases, behavioural and psychiatric disturbances.[139] Estimating the prevalence rates of dementia is problematic due to issues with diagnosis of dementia in a population which has pre-existing cognitive and functional impairments and also establishing the true population sample of people with learning disabilities.[140] However there is evidence that people with learning disabilities are at increased risk of early onset dementia and the prevalence is higher amongst older adults with learning disabilities compared to the general population (21% vs. 5.7% aged 65+).[141] Those with Down's syndrome are at particularly high risk of developing dementia of Alzheimer's type, with an age of onset 30-40 years younger than the general population.[142] The prevalence of dementia in people with Down's syndrome is estimated as:[143]

- 8.9% in people aged 45-49
- 17.7% in people aged 50-54
- 32.1% in people aged 55-59
- 25.6% in people aged 60 and over

Coupled to longer life expectancy, it is envisaged that the care of older people with learning disabilities and dementia will become significant in future years.

k. Autistic spectrum disorders

- Half of those with a severe learning disability will have some type of autistic spectrum disorder.

Autistic Spectrum Disorders (ASD) reflects a number of conditions encompassed by the term 'autism'. It refers to a developmental disability affecting social and communication skills. Prevalence rates vary according to the diagnostic criteria used. For the whole spectrum, approximately 900/100,000 of the population may be affected. ASDs are about four times more common in boys than in girls.[144]

There is a very strong association with learning disabilities. Approximately half of those with severe learning disabilities have some type of autistic spectrum disorder. ASDs are also strongly associated with challenging behaviours. Many have repetitive behaviour patterns and strongly resist any change in routine.[145]

4.1.9 End of life and palliative care

- People with learning disabilities may experience difficulties in accessing end of life care that meets their specific needs.

Research into the palliative care needs of people with learning disabilities is limited.[146] People with learning disabilities may experience difficulties in accessing end of life care that meets their specific needs.[147] This may be due to failure to diagnose advanced disease early enough to plan and prepare for end of life care, and to communication difficulties with healthcare professionals.[148] It has been proposed that communication models designed to assist healthcare professionals in breaking news of serious illness and poor prognosis do not meet the needs of people with learning disabilities.[149] This results in the risk of excluding this group of people from engaging in advance care planning and making informed choices for their future care at the end of life. A best practice guide provides guidance for health and social care professionals, service developers and providers to ensure the best quality of end of life care for people with a learning disability.[150]

4.1.10 Offending behaviour

- Prevalence estimates of offenders with learning disability are complicated by diagnostic variations and inconsistencies.
- People with learning disabilities are made vulnerable by the criminal justice system, including prison, and as a safeguard there needs to be early identification.

Although the vast majority of individuals with learning disabilities are law-abiding citizens, there is a small percentage with offending behaviour that is considered antisocial, socially inappropriate, or defined as illegal. Several studies have found that severe social disadvantage is a risk factor for offending behaviour amongst people with learning disabilities.[64] With the increased demands associated with community living, studies have suggested an increased risk of offending for this population group given their individual vulnerabilities of poor coping strategies and limited independence.[151]

Prevalence estimates of offenders with learning disability are complicated by diagnostic variations and inconsistencies in the criminal justice process. Much criminal offending goes undetected or unreported and studies can only investigate those already involved in the criminal justice process.[152] International studies have shown a large range, from 2% to 40%, depending on methodological approaches.[151,152,153,154] Studies using IQ as a continuous variable indicate that significantly below average intellectual ability is an independent predictor of future offending.[152] Numerous studies suggest a higher proportion of individuals with mild to borderline learning disability who are prone to committing sexual and criminal damage offences.[151,155] Very few individuals with moderate to severe learning disability are found in the criminal justice system. There is however a small group of people already known to learning disability services in which the differences between challenging behaviour and offending are unclear.[152]

Nationally there are currently no definitive numbers of people with learning disabilities that have been arrested and taken into police custody due to the inadequacies of identification, difficulties in diagnosis and also the lack of local systematic data collection. One study identified that 7% of those known to the probation service were found to have a learning disability.[156] The accurate number of prisoners with learning disability is not known. Research conducted in three British prisons has identified that 6.7% of prisoners had a learning disability. A recent report[157] however found that the prison reporting system only recorded 0.5% of the prison population as having a learning disability. This under-reporting may mean that a prisoner with learning disabilities may travel through the prison system without their disability or health needs ever being properly assessed and addressed to enable them to participate fully in prison life. As a safeguard against these risks, there needs to be early identification of people with learning disabilities within the criminal justice

system. Even if a prisoner is identified as having a learning disability, evidence suggests that the service fails to assess and then make reasonable adjustments to address their needs.[157,158] Consequently, prisoners with learning disabilities remain a vulnerable and to date, neglected section of the prison population who are at risk of re-offending because of unidentified needs and consequent lack of support and services. [157]

5. EFFECTIVENESS OF HEALTH SERVICES

Findings

- The literature evaluating health services and interventions for adults with learning disabilities at all levels of care is mainly limited to descriptive and uncontrolled research studies.

Key issues

- There are significant gaps in the research evidence for the effectiveness of health services/interventions for people with learning disabilities. More research is needed to determine the effects of different ways to organise services.
- Clinical guidelines may increase the health inequalities of people with learning disabilities as they may not have considered this population groups health needs.

There are significant gaps in the research evidence looking at the effectiveness of health services for people with learning disabilities. Assessing the effectiveness of health services and interventions for people with learning disability is complex because of:[107]

- Definitional problems and the varied case-mix within services.
- The complexity of client problems and multi-agency /multi-intervention approaches to their management.
- The inappropriateness of extrapolating knowledge about effectiveness from non-learning disabled populations to people with learning disabilities.
- Communication difficulties hampering client satisfaction, reliance on the views of third parties and that historically people with learning disabilities have not been encouraged to state their views.
- Difficulties in obtaining informed consent to participate in studies.

Clinical guidelines should aim to promote best practice however there is recognition that these can act to increase the health inequalities experienced by disadvantaged groups such as people with learning disabilities.[159] This is because developers of guidelines may not specifically consider the health needs of people with learning disabilities, and assume that the generic nature will automatically promote health improvement for people with learning disabilities. Secondly there is a shortage of research relevant to the health needs of people with learning disabilities; this means that guidelines specific to persons with learning disabilities are not selected for development.

5.1 Summary of good practice

Valuing People[1] states that the main objective for the NHS is to:

> *'enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a high standard and with additional support where necessary.'*

This relates to both mainstream (primary, acute and preventative care) and specialist learning disability health services.

As the evidence base for service provision is limited, this section considers national guidance and best practice using a tiered approach as a framework identified in the Scottish Health Needs Assessment.[64]

A Tiered Approach to Care for People with Learning Disabilities

Tier 0	Community resources and support, housing and support packages, education and learning, employment, healthy lifestyle initiatives and policy development.
Tier 1	Primary health care services, directly accessed services and their supporting services.
Tier 2	Generic secondary (outpatient, inpatient and tertiary) health services accessed via primary health care services and their supporting services.
Tier 3	Specialist learning disabilities services provided by Local Authorities, NHS and the independent sector.
Tier 4	Supra-specialist (tertiary) learning disabilities services provided by Local Authorities, NHS, and the independent sector.

Source: Health Needs Assessment for Scotland (2004)

The tiers can be considered components of an integrated care pathway and a person may access services at different tiers at different times due to changing needs. It is essential that people with learning disabilities receive the most appropriate care in the right setting. At higher level tiers, services are more specialised and provide for a smaller number of people with increasingly complex needs that are person-centred *only when the needs of individuals cannot be met by ordinary services.*

Tier 0 - Community resources and supports, housing and support packages, education and learning, employment, healthy lifestyle initiatives and policy development.

- To obtain greatest impact on health outcomes the effectiveness of services within tiers 0-1 should be improved to reduce reliance on the more specialised services at higher level tiers.
- Challenges include providing the extra support needed for people with learning disabilities to make informed health choices, and developing appropriate health and lifestyle education.

The wider determinants of health which include accommodation, education and learning and employment are acknowledged to play an important role in improving the health and well-being of people with learning disabilities, however this section will focus on health aspects only.

Healthy lifestyle initiatives

As the pattern of health need and causes of death differ for people with learning difficulties, most current policies and healthy lifestyle initiatives will widen rather than close the health inequality gap.[58] The most effective healthy lifestyle initiatives for people with learning disabilities will be those that target their leading causes of ill health and death. Particular challenges include providing the extra support needed for people with learning disabilities to make informed health choices, and developing appropriate health and lifestyle education.[160]

Tier 1 - Primary health care services, directly accessed services and their supporting services.

- Primary health care services not only provide care and treatment, they also act as a gateway to specialist services.
- More effective interventions may reduce the disproportionately high use of secondary care services by those with learning disability.
- GP practices should play a key role in helping people with learning disabilities make choices about how they manage their health and how they access services.

Primary health care is essential to ensure adequate health surveillance for all people with learning disabilities, who have both ordinary needs for primary care and also special needs relating to the increased rates of certain conditions. Access to primary medical care has a significant impact on how frequently and appropriately people with learning disabilities access wider services. More effective interventions in primary care may reduce the disproportionately high use of secondary care services by those with learning disabilities.

As part of the Quality Outcomes Framework (QOF), general practitioners receive an incentive for generating a register of patients with learning disability. This is however a voluntary scheme and is insufficient on its own to meet the health needs of people with learning disabilities. Under-identification and/or under-recording is common.[37,161]

Other primary care services
Systems need to be in place to make sure that people with learning disabilities access a range of services to maintain good health, such as GP out of hours services, primary dental services, podiatry, community pharmacy and primary ophthalmic services so that they receive the most appropriate care in the right setting.[31]

Tools/Approaches
The use of annual health checks, health action plans and health facilitators to address the health needs of people with learning disabilities are advocated by a number of national documents.[1, 2]

Annual health checks
Providing a structured health check in primary care has identified clinically significant previously unrecognised and untreated illness among adults with learning disabilities in studies conducted both in the UK and elsewhere.[66,67,76,162] Regular health screening of people with learning disabilities improves both health status and access to mainstream health services.[163] When annual health checks for people with learning disability were introduced in New Zealand, 73% of those screened needed follow up interventions which may not have been offered otherwise.[164] The effects of a comprehensive health assessment programme for Australian adults with learning disabilities found:[165]

- a six fold increase in the detection of visual impairments
- a thirty fold increase in hearing testing
- an increase in immunisation updates
- improvements in women's health screening

The level of new need revealed by repeated checks at even the shortest interval since a previous check (mean = 14 months) was as high as that found by the initial check.[166]

The significance of health checks has been reflected in the current Department of Health Directed Enhanced Service (DES). Primary Care Trusts have the duty to offer all GP practices the opportunity to participate in the DES that remunerates them for providing annual health checks for people with learning disabilities who are known to local authorities. Before undertaking the health checks, primary care staff are required to undertake learning disability awareness training provided by health facilitators and/or community learning

disability team members in partnership with self advocates.[167] A recent study suggests that a more targeted approach focusing on incentivising learning disability specific issues along with the current Quality and Outcomes Framework targets might be more appropriate in primary care for improving the health for people with learning disabilities than an extensive learning disability health check.[221]

Health checks are designed to be part of the overall process for health action planning and person centred planning.

Health action plans
Health action planning assists in identifying the health needs of adults with learning disabilities and details the actions needed and the services required to maintain and improve their health.[168] Valuing People[1] had a target that all people with learning disabilities to have a health action plan by June 2005.

Health facilitation
Health facilitation is still in its infancy and there is lack of evidence on the impact. There is evidence to suggest that a primary care facilitator, working with GP's and practice nurses can increase screening and the detection of health problems.[169] Health facilitators are a recognisable contact for both carer and patient, assisting to overcome any potential barriers.[69,170]

Tier 2 - Generic secondary (outpatient, inpatient and tertiary) health services accessed via primary health care services, and their supporting services.

- People with learning disabilities have an increased attendance and admittance to acute general hospitals.
- There is evidence of institutional discrimination.
- Lack of research evaluating interventions and initiatives to improve hospital care for people with learning disabilities.

In the UK an estimated 26% of people with learning disabilities are admitted to general hospital every year, compared with 14% of the general population.[171] This group have an increased attendance and admittance to acute general hospitals due to the higher prevalence of health conditions described in Section 4. There is evidence of institutional discrimination for people with learning disabilities within hospitals due to limited knowledge about the needs of people with learning disabilities.[36] The issues that people with learning disabilities experience in secondary care:[172]

- inflexible hospital care processes (appointment systems, Choose and Book not taking into account the need for reasonable adjustments and waiting times)
- knowledge, attitudes and communicative style of staff
- physical environment not being accessible

There is a lack of published research evaluating interventions and initiatives to improve hospital care for people with learning disabilities. Evidence is limited to case studies, monitoring of data on the type of support provided, observations, the use of pre and post questionnaires with small sample sizes or qualitative feedback from stakeholders after an initiative has been put in place. The Care Quality Commission recently produced an indicator on 'access to healthcare for people with a learning disability' for acute and specialist trusts (see Section 3.4). This seeks to respond to the recommendations made in 'Healthcare for All' specifically around the collection of data and information necessary to allow people with a learning disability to be identified and the arrangements trusts have in place to ensure the views and interests of people with learning disabilities and their carers are included in the planning and development of services.

Tools/approaches

Acute liaison nurse

The role of acute liaison nurses (specialist learning disability nurse working in general hospitals) is still in its infancy and there is lack of information on the impact. The focus of their role is to provide advice and support to enable acute hospitals to recognise and address the particular needs of people with learning disabilities that require hospital services. They liaise with community services including primary care learning disability health facilitators to aid smooth admission and discharge, encourage constructive dialogue with the patient and family members and provide support and training to front line staff. A recent evaluation of a service in Scotland[173] identified three key areas of impact by acute liaison nurses:

- *Clinical care* – the provision of advice and support to general hospital staff in the care of people with learning disabilities, including supporting staff to make adjustments to routine practice and promoting effective communication across complex care systems and co-ordinating the care journey
- *Education* – provision of education and development sessions to enhance the knowledge, skills and attitudes of hospital staff
- *Strategic development* – being a positive influence on developing and improving overall services

In addition, an evaluation of acute liaison nurses in North London[220] found that the posts contributed to:

- a positive effect on individual experiences
- a reduction in hospital stays
- improvements in patient safety

The Specific Needs Access project (SNAP) pilot project in North Staffordshire identified potential cost savings:

- reducing the number of appointments that people failed to attend
- reducing repeat attendees to Accident and Emergency

- appropriate safe discharge.

Tier 3 - Specialist learning disabilities services provided by Local Authorities, NHS and the independent sector.

- Specialist services are those which respond to the health needs directly relating to or arising from a person's learning disability.
- There is limited research within community services for people with learning disabilities, especially in relation to the role, function and outcomes achieved.
- PCTs should promote a collaborative approach to commissioning services, based on close working with local authorities and Learning Disability Partnership Boards.

Specialist services are those which respond to the health needs directly relating to or arising from a person's learning disability. Three major factors are creating change in the demand for specialist learning disability services:[174]

- Increased numbers of people with learning disabilities, partly caused by people living longer and needing additional support around illnesses linked to old age, in particular dementia.
- Changes in the demographic profile with increased numbers of people with profound and multiple learning disabilities requiring input from specialist health professionals. This particularly applies to young people.
- The increasing empowerment of people with learning disabilities and their families, resulting in them expecting and demanding better quality services located nearer to their home.

Commissioning of specialist learning disability health services for people with learning disabilities at both Tier 3 and Tier 4 is the responsibility of Primary Care Trusts (with exceptions regarding secure regional and national provision). PCTs should promote a collaborative approach to commissioning services, based on close working with local authorities and Learning Disability Partnership Boards.[31] Given the importance of these services being strategically commissioned in partnership with the local authority, it is inappropriate to use practice based commissioning for specialist learning disability health services.[174] Outcomes recommended for the commissioning of specialist learning disability services at both Tier 3 and 4 are given in Box 5.1:[174]

Box 5.1: Outcomes recommended for the commissioning of Tiers 3 and 4 specialist learning disability services

- Specialist learning disability health services that both support mainstream practice and directly service those with the most complex needs.
- Specialist learning disability health services that promote safe, person-centred support and evidence based practice.
- Integrated planning and the development of care pathways that promote individualised services that are closer to home.
- Service development that directs people away from institutional responses to crisis and, wherever possible, supports people in their everyday surroundings.
- Support to people and families when needed through swift access to the services of specialist professionals including medical, nursing and allied health professionals.
- Investment in training and development not just for specialist professionals but also for families and for front line support staff to enable them to better support people where they live.
- A robust community infrastructure that takes a broad view on addressing health needs and considers the range of factors associated with poorer health and other risks associated with social exclusion. For example ensuring that response to health problems do not preclude options to achieving paid employment or independent housing.
- New alliances and approaches to secure better and more inclusive services.
- Ensuring the voice of people and families is heard and there is evidence of appropriate representation, including independent advocacy.
- Fulfil all legal requirements, including those arising from the Mental Health Act, Mental Capacity Act and Disability Discrimination Act.

Source: Department of Health

There are no well designed studies that focus on the health services of people with a learning disability and concurrent physical problems. [175]

Specialist learning disability community services.

Community services were developed following the closure of long stay hospitals in the 1970's. They employ a range of specialist learning disability staff who provide a range of clinical services to meet the comprehensive mental and physical health needs of people with learning disabilities.[176] A range of staff skills are required as part of learning disability specialist health services to include (but not necessarily be limited to):[174]

- learning disability nurses
- clinical psychologists
- psychiatrists
- physiotherapists
- speech and language therapists
- occupational therapists

Specialist learning disability community health staff have an essential clinical and therapeutic role to:[174]

- support people and their families when their needs cannot be met by mainstream services
- support in the provision of longer term support for people who have complex and continuing health needs
- provision of emergency support in partnership with mental health colleagues.

In addition they have the following complementary tasks of health promotion, health facilitation, teaching and service development. A key role is to advise and support PCTs and general practice in the development and delivery of the annual health checks, supporting patients and family carers during this process.[177] The effectiveness of specialist community services is relatively under-researched, although this model of care has been criticised for bypassing mainstream primary care services.[178]

The Royal College of Psychiatry has a list of higher specialist training competencies for Learning Disability Psychiatrists[a] and the Department of Health has produced good practice benchmarks for learning disability nursing.[179]

Tier 4 - Supra-specialist (tertiary) learning disabilities services provided by Local Authorities, NHS, and the independent sector.

- Supra-specialist (tertiary) learning disability services are for those adults with learning disabilities with severe challenging behaviour and/or complex mental health needs.
- There have been significant changes in healthcare provision for people with learning disabilities in recent years, including the shift from institutional to personalised community care, leading to greater demand for community health services.
- Absence of or inadequate specialised services locally for people with complex health and behavioural needs tend to be the reason for out of area placements.

Supra-specialist (tertiary) learning disability services are for those adults with learning disabilities with severe challenging behaviour and / or complex mental health needs.

People with learning disabilities and complex needs often experience problems in accessing health services.[180] As with Tier 3, commissioning of specialist learning disability health services for people with learning disabilities at Tier 4 is the responsibility of Primary Care Trusts (with exceptions regarding secure regional and national provision).

The Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) measures outcomes and is useful in determining clinical effectiveness in people with learning disabilities with additional mental health needs.

[a] Available at www.rcpsych.ac.uk/PDF/Learning_Disability_Feb09%20(2).pdf

Inpatient services
There is a need for hospital beds for the assessment and treatment of a small number of people with learning disabilities, such as those with mental illness, sensory impairments or challenging behaviour. Appropriate community provision is needed to prevent delayed discharge. The first national audit of specialist inpatient services for people with learning disabilities carried out in 2007 (Section 3.1.2) identified that significant improvement in the quality of care was needed in the majority of services for people with learning disabilities.[34] A subsequent audit (none of which included Nottinghamshire services) shows that progress has been made and further recommendations are outlined in Box 3.1 in Section 3.1.2.

To improve the quality of care the College Centre for Quality Improvement (CCQI) has developed a standard based accreditation for inpatient services for adults with learning disabilities.[181]

Specialist learning disability community services.
The priority to support people close to home and avoid hospital admission has led to the development of Community Assessment and Treatment Teams (CATT). They support people whose behaviours services find challenging, who have additional mental health needs and with a history or risk of offending.

The effectiveness of Community Assessment and Treatment teams is currently under researched.

Services for offenders
People with learning disabilities are made vulnerable by the criminal justice process, often experiencing personal, systematic and routine discrimination as they progress through the criminal justice system, including prison.[157]

The Bradley report[42] recommends improved screening and identification of people with learning disabilities at the start of the offender pathway to facilitate the earliest possible diversion of offenders from the criminal justice system, signposting to health and social care services as appropriate. The national delivery plan of the Bradley report recommends:[182]

- Provision of easier read materials.
- Developing skills and knowledge of frontline professionals to support them in managing offenders with learning disabilities.
- Ensuring access to primary care services for offenders with learning disabilities, including health checks and health action plans.
- Reducing re-offending by ensuring that offenders with learning disabilities better understand the criminal justice system and the support that is available to them in the community.

Box 5.2 provides information about activity taking place at a national level.[182]

Box 5.2: Activity taking place at a national level to support delivery of the Bradley Report

By May 2010

- Publish World Class Commissioning guidance on commissioning services for offenders.
- Pilot and evaluate a new learning disability screening tool
- Introduce rolling programmes to:
    - Continue the roll-out of training for prison officers in mental health and learning disability awareness;
    - Train all probation staff on mental health and learning disability awareness; and
    - Train all front line staff in NOMS, the NHS and social care agencies working with personality disordered offenders.

By November 2010

- Raise awareness among the judiciary of mental health and learning disability issues.
- Develop a clear cut economic case for the financial and health impact of liaison and diversion services.
- With the Crown Prosecution Service, review the use of conditional cautions for individuals with mental health problems or learning disabilities, and issue guidance to relevant agencies and
- Scope the benefit of, and agree a way forward for, a comprehensive mentoring programme to support individuals with mental health and learning disabilities to resettle into the community on leaving prison.

By May 2011

- Undertake a review of the current reception screen process, strengthening the areas for screening for mental health problems and learning disabilities, and putting a new screen in place.
- Set up a pilot to establish processes for GP registration for all sentenced prisoners.

NHS campuses and similar accommodation

Government policy[1] is that it is inappropriate for people with learning disabilities to live within the NHS. This decision is based on a combination of the evidence base of poor quality of people's lives in NHS campuses and concern about the lack of rights accorded to people in such settings.[174] It became a requirement of 'Our Health, Our Care, Our Say' to close NHS campuses by 2010 and for these to be replaced by appropriate housing and support, (and increased community specialist health care infrastructure) so that no-one with a learning disability has their home in the NHS.

Continuing care

Some people may require health care for a long time and their health needs may be met through primary care, in their own homes or in care homes. People with learning disabilities should not be using NHS commissioned services for continuing care unless their primary need is for healthcare rather than accommodation or other support, identified by use of the National Framework for Continuing Care, which includes a Decision Support Tool.[183]

It is not appropriate for people who challenge services to become the sole responsibility of the NHS nor for intensive NHS continuing care be assumed to be the most appropriate service response. Best outcomes for people who challenge services can be achieved through individually designed services rather than congregate settings based on diagnostic or treatment label.[174]

Out of area placements
Nationally over 11,000 people with learning disabilities are supported in out of area placements. This is over a third of all people with learning disabilities who are supported in residential care and nursing homes. When the old institutions closed, some people, particularly older people, did not move back 'home' and stayed out or area. Others who are more likely to be placed out of area include those with:[184]

- Challenging behaviour
- Autistic spectrum disorders
- Mental health needs
- Complex health needs
- Complex epilepsy
- People who may offend

The Department of Health issued a policy clarification note which emphasised the need to ensure that people with 'forensic' needs or challenging behaviour were not placed miles from home out of a need for specialist help.[185]

Absence of or not enough specialised services locally for people with complex health and behavioural needs tend to be the reason for out of area placements. Such provision is not only expensive in terms of financial resources but also in terms of the human and social cost and has a negative impact on the well-being of clients, families and carers. Money spent on out of area placements cannot be reinvested into the local health and social care economy. Where people are placed away from their own locality it is important that the service is regularly reviewed to ensure that it is still appropriate for that individual.[174]

Work across the five tiers
An integrated approach across the tiers is needed, as work at one level will inevitably impact upon the other tiers in the model. Some functions cut across all five tiers. These functions include communication, clinical governance, education and staff development, research, workforce planning and strategic service planning.

Improved communication and effective liaison between primary care, secondary care and specialist learning disability services is needed to reduce morbidity and mortality and improve quality of life.[68] The Care Quality Commission is currently undertaking a review of physical health care provision for people with learning disabilities. This will look at access, assessment, care

delivery and communication with patients and their carers. It will be based on PCT boundaries and will cover GPs/PCTs, general acute hospitals and specialist learning disability inpatient settings. A national report will be published in autumn 2010.

An Equality Impact Assessment (EIA) is a systematic way of finding out whether a service affects all groups equally including people with learning disabilities. This ensures that all services/initiatives are designed, developed and delivered so that equality is promoted.

6 EPIDEMIOLOGICAL INFORMATION

Findings

- Precise prevalence and incidence figures for learning disabilities are not available, with best estimates used.
- Approximately 2% of the UK population is estimated to have learning disabilities, with 0.46% in contact with specialist services.
- There is projected to be a 20% increase in prevalence of learning disabilities between 2001 and 2021 in the UK, with a 53% increase in those aged 50+.
- There are estimated to be 20,603 adults in Nottinghamshire (including Bassetlaw and Nottingham City) with learning disabilities, of these 4,293 have moderate and severe learning disabilities and 336 have profound multiple learning disabilities.

Key issues

- The prevalence of learning disability on GP Quality and Outcomes Framework learning disability registers is lower than expected.
- National modelling tools need to be used with caution when projecting future local populations.
- There is limited local information on the health needs of adults from black and minority ethnic groups, older people and those with profound and multiple learning disabilities.
- There need to be mechanisms in place to identify children coming through transition to ensure they are recorded on learning disability registers.
- The population of adults with a mild learning disability tend to be hidden.

Determining the frequency of a disease or condition as accurately as possible is necessary to gain a better understanding of the potential level of need in the local population. Two measures frequently used are incidence (the count of new cases of the disease or condition during a specified time period) and prevalence (the number of existing cases of a disease or condition in a defined population at a point in time).[186]

Measuring incidence and prevalence

Establishing precise incidence and prevalence figures for learning disabilities is not easy for a number of reasons:[7]

- the recognition and identification of learning disabilities has varied over time
- there is a wide spectrum of disorder

- definitions are not standardised
- incidence and prevalence have changed over time
- research methodologies that limit the population studied to those in contact with services are common
- difficulties in assessing new-born infants for a learning disability (there is no way of detecting the vast majority of those infants that have learning disabilities at birth)

It is more usual to refer to the prevalence of learning disabilities than incidence as when there is no obvious physical manifestation at birth, diagnosis is delayed to await assessment of significant developmental delay along with other manifestations.

Estimates of prevalence of learning disabilities often use Intelligent Quotient (IQ) scores as an indicator. IQ scores across a population are normally distributed and therefore it is possible to calculate the proportion with an IQ below 70. The shape of a normal distribution means that of all individuals with an IQ score of less than 70, the highest proportion will have mild learning disabilities and may never come into contact with specialist learning disability services. This may reflect a lack of 'need', a wish to avoid stigmatisation associated with such services or that people are deemed 'ineligible' for services. The numbers of people known to services is termed the **administrative** prevalence, as opposed to the **true** prevalence which uses population predictions.[187]

6.1 International incidence and prevalence

The World Health Organisation[188], has estimated that 1-3% of the world's population have a learning disability. Prevalence figures vary considerably because of differing criteria and methods used in surveys, as well as differences in age range of samples. Learning disabilities are more common in developing countries due to more frequent injuries at birth, childhood brain infections and iodine deficiency.[188]

6.2 National incidence and prevalence

6.2.1 Recent historic changes in incidence and prevalence rates

Within the UK, the population of people with learning disabilities increased by 53% between 1960 and 1995.[58] Changes in incidence and prevalence over the last 40 years have been due to a number of factors.[7, 58, 189]

Factors contributing to a decrease in incidence and prevalence rates:

- Antenatal screening for Down's Syndrome, amniocentesis for older women and selective termination.
- Immunisation programmes have decreased encephalitis, encephalopathies and rubella-associated prenatal damage.
- An overall decrease in the numbers of young children since the late 1960s.

Factors contributing to an increase in incidence and prevalence rates:

- Improvements in neonatal care and consequent decrease in early mortality, particularly of low and very low birth weight babies.
- New technologies and general improvements in medical care leading to increased long-term survival and longevity.
- Improved socio-economic conditions.
- A higher average maternal age (for example the risk of a Down's Syndrome pregnancy for a 40-year old mother is 16 times that of a 25-year old mother).

6.2.2 Incidence of specific conditions associated with learning disabilities

Down's syndrome

The risk of having an affected pregnancy is strongly linked to maternal age (risks are 0.5, 10 and 150 per 1000 pregnancies for women aged 20, 40 and 50 respectively).[7] The numbers of diagnoses of Down's syndrome increased by 71% between 1989/90 and 2007/8, yet the numbers of live births with Down's syndrome fell by 1% due to antenatal screening and subsequent termination.[189]

Edward's syndrome

This is a rare condition with a reported incidence of 0.3 per 1000 births, with a typical life expectancy of only a few days.[7] The risk of having an affected pregnancy is linked to maternal age (risks are 0.5, 2.8 and 7.6 per 1000 pregnancies for women aged 35, 40 and 43 respectively).[190]

Patau's Syndrome

The reported incidence of this condition is 0.25 per 1000 births, with survival rarely beyond infancy.[7] The risk of having an affected pregnancy is linked to maternal age (risks are approximately 0.2, 1.1 and 2.1 per 1000 pregnancies for women aged 35, 40 and 42 respectively).[191]

Phenylketonuria (PKU)

The reported incidence of this condition is 0.05-0.07 per 1000 births.[7] PKU is an inborn error of amino acid metabolism and if untreated leads to learning disability usually developing in the first year of life. A national screening programme in the UK should ensure that virtually no new cases with learning disabilities occur.[23]

Prader-Willi syndrome

The reported incidence of this condition is 0.1 per 1000 births.[192] The condition is associated with varying degrees of learning disability, with most individuals having mild or moderate.

Fragile X syndrome

The incidence of this condition is often quoted as 0.8 per 1000 male births and 0.32 per 1000 female births but more recent estimates suggest considerably

lower figures (0.25 per 1000 male births and 0.125 per 1000 female births).[7] The condition causes varying degrees of learning disability. It accounts for approximately 10% of all males with severe learning disabilities and 10% of mild learning disabilities. Only 30% of women with Fragile X have the syndrome, the rest are carriers.

Tuberous sclerosis
Reported incidence is between 0.1 – 0.2 per 1000 births and between 40 and 60% of those with tuberous sclerosis have a learning disability of varying severity.[193]

Neural tube defects
The incidence has declined significantly in the last 30 years and now occurs in approximately 1.5 per 1000 total births.[16] Anencephaly and spina bifida account for up to 95% of all neural tube defects with equal prevalence.[194,195] The majority of births with neural tube defects will not have a learning disability, but a study in Ireland reported that 41% of those born with a neural tube defect survived beyond 5 years old, and of these 17% had a learning disability.[196]

Foetal alcohol syndrome
The reported incidence is 1.95 per 1000 births and it is estimated that 1 in 100 will have alcohol related neurodevelopmental disorders.[9] Foetal alcohol syndrome is the most common non-genetic cause of learning disability.

Cerebral palsy
The reported incidence is 2-3 per 1000 births, and approximately half of all people with cerebral palsy will have a learning disability. The incidence is higher in premature infants and twin births.[197] Other risk factors include maternal age greater than 35, mothers from Black communities and intrauterine growth restriction.[198]

Congenital hypothyroidism
The reported incidence is 0.25-0.3 per 1000 births.[7] This is the most common hormonal disorder linked with learning disabilities. Girls are twice as likely to suffer congenital hypothyroidism as boys. Screening should ensure that virtually no new cases with learning disabilities occur.[23]

Premature births
The estimated incidence of learning disability in babies born before 26 weeks of pregnancy is 4 per 10 births.[199]

6.2.3 National prevalence

There are no reliable official statistics concerning the number of people with a learning disability in the UK[11], and it is therefore necessary to estimate prevalence by making projections from available research. Estimates suggest that the 'true' prevalence of learning disability is approximately 2% of the UK population and the 'administrative' prevalence (those known to services) is 0.46%.[187] Table 6.1 gives the estimated prevalence rates of adults with mild,

moderate and severe learning disabilities using both true and administrative prevalence across different age bands.

Table 6.1: Estimated prevalence rates of adults with mild, moderate and severe learning disabilities using both true and administrative prevalence across different age bands.

Age band	ALL with LD (%) [True prevalence]	Mild LD (%)	Moderate or severe LD (%) [Administrative prevalence]	Moderate LD (%)	Severe LD (%)
15-19	2.77	2.09	0.68	0.46	0.22
20-24	2.69	2.09	0.60	0.40	0.20
25-29	2.49	1.96	0.53	0.38	0.15
30-34	2.49	1.95	0.54	0.40	0.14
35-39	2.45	1.84	0.61	0.45	0.16
40-44	2.45	1.83	0.62	0.45	0.17
45-49	2.28	1.72	0.56	0.43	0.13
50-54	2.37	1.89	0.48	0.38	0.10
55-59	2.33	1.78	0.55	0.43	0.12
60-64	2.20	1.77	0.43	0.31	0.12
65-69	2.01	1.65	0.36	No figures available	No figures available
70-74	2.34	2.00	0.34	No figures available	No figures available
75-79	2.07	1.84	0.23	No figures available	No figures available
80+	1.89	1.71	0.18	No figures available	No figures available

Source: Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI)

Down's syndrome
The prevalence is estimated to be 0.06% for the 18-64 age group and 0.004% for those aged over 65.[200,201]

Prader Willi syndrome
The prevalence is estimated to be 0.006% in adults.[202]

Fragile X syndrome
The prevalence is estimated at 0.025% in males and 0.0125% in females.[203]

Tuberous sclerosis
The estimated total population prevalence is 0.008%.[204]

6.2.4 Future national prevalence trends

Estimates suggest that the prevalence of people with learning disabilities in England will increase over the next few years, driven by 3 main factors:[205]

- an increase in the proportion of younger adults who belong to South Asian communities;
- increased survival rates among young people with severe and complex disabilities;
- reduced mortality among older adults with learning disabilities.

There is estimated to be modest but sustained growth up until 2021 in the numbers of people with learning disabilities. The estimated increase in the 'true' numbers of adults with learning disabilities between 2001 and 2021 is 20%, with a 14% estimated increase in the 'administrative' numbers over the same period.[205] These figures however mask marked changes in the age profiles.

It is projected that for the 15 – 49 age range there will be very little change in either the numbers of people with learning disabilities known to services or the estimated 'true' number of people with learning disabilities in England. However within the 50 plus age group marked increases are predicted in both the numbers of people with learning disabilities known to services and the estimated 'true' number of people with learning disabilities in England (Table 6.2). Increased demand in the older age groups is particularly significant for the future planning of health services for this population group.

Table 6.2: Estimated increase in 'administrative' and 'true' numbers of different age groups of adults with learning disabilities in England, 2001 – 2021

Age range	Estimated increase in the 'true' number of adults with LD (%)	Estimated increase in the 'administrative' number of adults with LD (%)
15-49	2%	0.2%
50+	53%	48%
All adults	20%	14%

Source: Estimating future need/demand for supports for adults with learning disabilities in England. Eric Emerson & Chris Hatton. 2004. Lancaster University

Profound/multiple learning disabilities

A recent report estimates that between 2009 and 2026 there will be an average annual increase of 1.8% in adults with profound and multiple learning disabilities. [206] Rates will be higher in areas that have a younger demographic profile or contain a greater proportion of people from Pakistani and Bangladeshi communities.

6.3 Local incidence and prevalence

6.3.1 Local incidence

Local incidence of births with learning disabilities can be extrapolated using the national incidence rates provided in Section 6.2.2 applied to local birth rates. However, it should be noted that this methodology provides very crude estimates and will under-represent the true number of babies with learning disabilities as there is no way of detecting the vast majority of those infants who have learning disability at birth. In addition, conditions associated with learning disabilities are not mutually exclusive, and therefore an individual with learning disabilities may have more than one of the conditions detailed. Table 6.3 provides crude extrapolated numbers of babies born with learning disabilities in Nottingham City, Nottinghamshire and Bassetlaw, in 2008/09.

Table 6.3: Extrapolated numbers of babies born with learning disabilities in Nottingham City, Nottinghamshire County and Bassetlaw based on national incidence figures and local birth rates (2008/09)

Condition	National incidence per 1000 births[7+]	Expected number of children born with learning disabilities per year*		
		NHS Notts County	NHS Bassetlaw	NHS Nott'm City
Down's syndrome	1	7	1	4
Edward's syndrome	0.3	2	<1	1
Patau's syndrome	0.25	2	<1	1
Phenylketonuria (PKU)	0.1	<1	<1	<1
Prader-Willi syndrome	0.1	<1	<1	<1
Fragile X syndrome	0.25 for males	<1	<1	<1
	0.125 for females	<1	<1	<1
Tuberous sclerosis^	0.15[193]	2	<1	<1
Neural tube defects^	1.5[16]	11	2	6
Foetal alcohol syndrome^	1.95[9]	14	2	8
Cerebral Palsy	1.25	9	2	5
Congenital hypothyroidism	0.3	2	<1	1
	Incidence per 10 babies born less than 26 weeks**			
Prematurity***	0.4[199]	14	2	7

+ Adjusted where necessary for incidence that will have specified condition and learning disabilities
** Source ONS based on all live births to mothers resident in the 3 PCTs at time of birth. Numbers rounded to nearest integer*
^ The actual percentage of these to have a learning disability is unclear. It should be noted that the majority of births with neural tube defects will not develop a learning disability.
*** Data only available for those born before 28 weeks*
**** Sources: ONS and NHS Maternity Statistics, England: 2005-06*

6.3.2 Local prevalence

There were an estimated 20,603 people aged 18 and over with learning disabilities resident in Nottingham City and Nottinghamshire County (including Bassetlaw) in 2009 (Table 6.4). Of these, 4,293 had moderate and severe learning disabilities and 336 had profound multiple learning disabilities.

Table 6.4: Estimated resident numbers of adults with learning disabilities, by severity of condition and district, 2009

	Nottinghamshire (excl Bassetlaw)	Bassetlaw	Nottingham City
All learning disabilities	12,584	2,116	5,903
Moderate and severe learning disabilities	2,603	439	1,251
Profound & multiple learning disabilities	206	33	97

Source: Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI) and Estimating future numbers of adults with profound multiple learning disabilities in England. Eric Emerson 2009

6.3.3 Quality and Outcomes Framework (QOF) learning disability registers

- The prevalence of adults with learning disabilities recorded on GP practice QOF registers is similar across NHS Nottinghamshire County (0.40%), NHS Bassetlaw (0.47%) and NHS Nottingham City (0.42%).
- There is much practice-level and cluster-level variation in the recorded prevalence of adults with a learning disability on GP practice QOF registers.
- QOF learning disability registers currently only record approximately one fifth of the expected *true* prevalence of adults with learning disabilities.

The Quality and Outcomes Framework (QOF) is a voluntary annual reward and incentive programme for GP practices in England. Practices are awarded points for achievement across a number of components, including 4 points for being able to produce a register of patients aged 18 and over with learning disabilities.[207] QOF data is published annually, detailing the number of patients with learning disabilities at each practice, allowing practice and PCT age-specific recorded prevalence rates to be calculated.

The practice learning disability register for QOF should include all adults with learning disabilities as severity of condition is not a pre-requisite for inclusion. In theory therefore, the QOF registers should enable local prevalence of adults with learning disabilities to be calculated. However, QOF does not incentivise practices to have a complete register.

All three local Primary Care Organisations have seen an increase in the numbers of adults with Learning Disabilities on the QOF registers since creation of the registers in 2006/07. In 2008/9 NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City had significantly higher age-specific recorded prevalence rates than England, and NHS Bassetlaw also had a significantly higher recorded prevalence rate than NHS East Midlands (Table 6.5). However, considering the QOF register should include all adults with a learning disability then the recorded age-specific prevalence is still much lower than the estimated true prevalence in the population of 2%. Under-identification and under-recording of adults with learning disabilities on the QOF registers has been identified as an issue in other localities.[37, 161]

There is a wide range in the age-specific recorded prevalence rates between practices and Practice Based Commissioning clusters at each Primary Care Organisation. Some of this difference may be explained by differences in practice demographics (for example the location of care homes within a practice boundary or the age and ethnicity profile of the population), the

variation still suggests some practices have higher rates of identification and/or recording of adults with learning disabilities.

It should be noted that the data reviewed relates to 2008/09 prior to the implementation of the Learning Disability Directed Enhanced Services (Section 5.1, Tier 1 services). Distribution to practices participating in the Directed Enhanced Services of lists of adults with learning disabilities known to Adult Social Care services may have improved the completeness and quality of practice learning disability registers.

NHS Nottinghamshire County
NHS Nottinghamshire County has seen a modest increase in age-specific prevalence, rising from 0.35% in 2006/07 to 0.40% in 2008/09. Over this time period 51 practices increased the number of adults recorded on their learning disabilities QOF register (from a total of 97 practices), with 31 reporting a reduction in numbers. Prevalence rates ranged from 0.03% to 1.79% (Figure 6.1).

The clusters in the north of the county (Middleton Lodge, Newark and Sherwood and High Point) all have significantly higher age-specific recorded prevalence, and the clusters in the south of the county (Nottingham East, Principia and Nottingham West) have significantly lower age-specific recorded prevalence than NHS Nottinghamshire County (Figure 6.4).

NHS Bassetlaw
NHS Bassetlaw saw the largest increase in numbers of people on the QOF register between 2006/07 and 2008/09. Two practices account for over 75% of the 413 people on the register, with an increase in the size of the registers at these 2 practices being the primary reason for the observed increase in prevalence. Prevalence rates ranged from 0.07% to 0.72% (Figure 6.2).

The unclustered practices in NHS Bassetlaw had a significantly higher age-specific recorded prevalence and the Bassetlaw PBC cluster had a significantly lower rate than NHS Bassetlaw (Figure 6.4).

NHS Nottingham City
NHS Nottingham City has seen a modest increase in age-specific prevalence, rising from 0.40% in 2006/07 to 0.42% in 2008/09. Over this time period, 27 practices increased the number of adults recorded on their learning disabilities QOF register (from a total of 62 practices), with 20 reporting a reduction in numbers. The University of Nottingham Health Service had a prevalence rate of 0%, and after excluding this practice prevalence ranged from 0.04% to 1.96% (Figure 6.3).

Robin Hood cluster had a significantly higher age-specific recorded prevalence and the unclustered practices and UniComm cluster had significantly lower age-specific recorded prevalence than NHS Nottingham

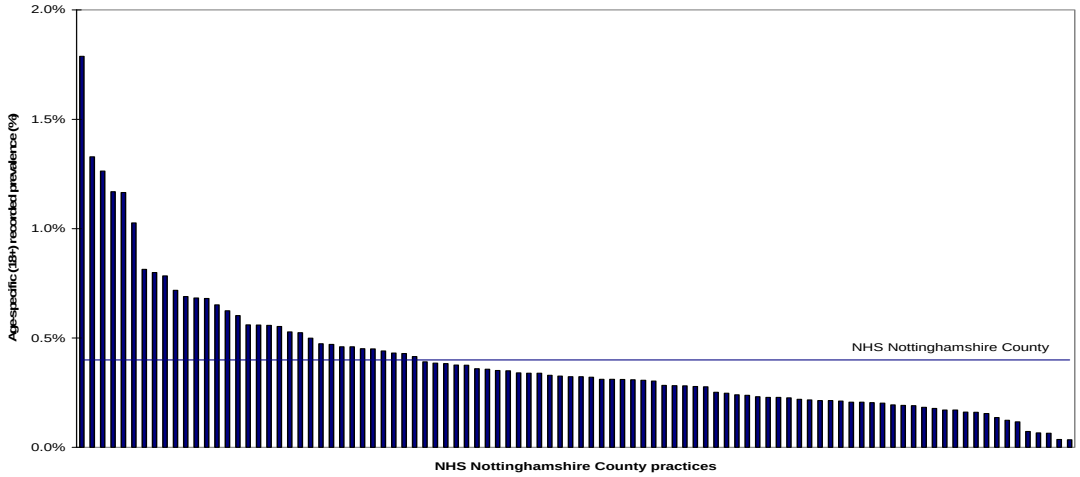
City. As the Unicomm cluster comprises the Nottingham University Health Service, a very low prevalence of adults with learning disabilities would be expected due to the practice population profile (Figure 6.4).

Table 6.5: Numbers of adults with learning disabilities recorded on GP practice QOF registers by Primary Care Organisation, 2006/07 to 2008/09

	2006/07		2007/08		2008/09	
	Number on QOF register	18+ age-specific prevalence	Number on QOF register	18+ age-specific prevalence	Number on QOF register	18+ age-specific prevalence
NHS Notts County	1,835	0.35%	1,844	0.35%	2,097	0.40%
NHS Bassetlaw	240	0.28%	248	0.28%	413	0.47%
NHS Nott'm City	1,019	0.40%	999	0.40%	1,063	0.42%
NHS East Midlands	12,469	0.35%	12,603	0.35%	14,171	0.39%
England	139,321	0.33%	144,909	0.34%	160,165	0.37%

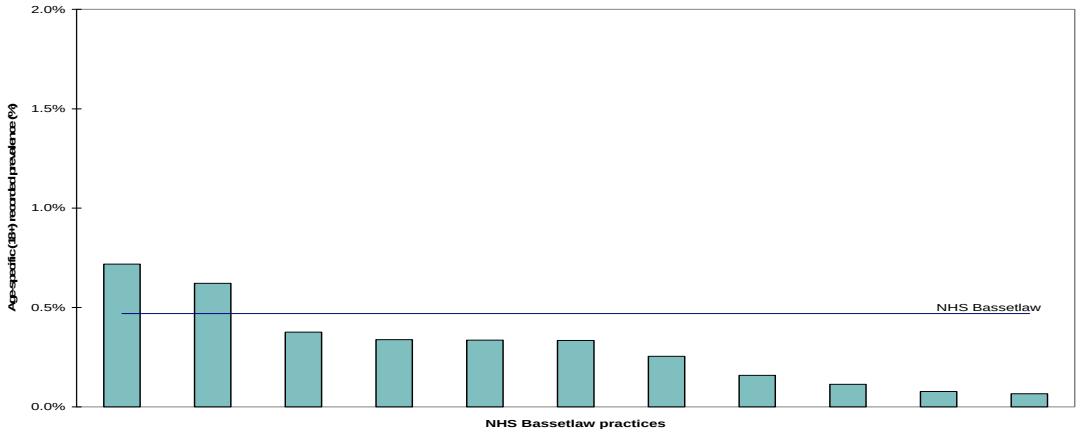
Source: The NHS Information Centre

Figure 6.1: Age-specific (18+) recorded prevalence rates of adults with learning disabilities in NHS Nottinghamshire County, by GP practice, 2008/09



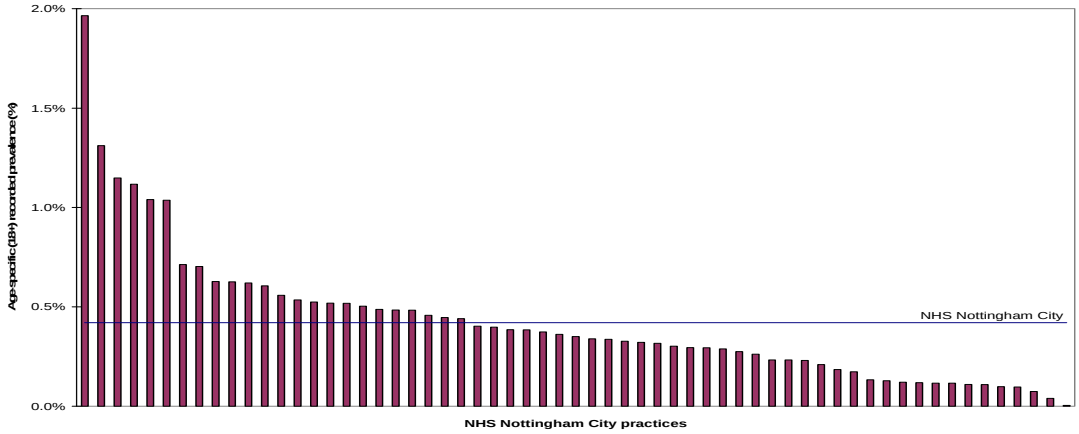
Source: The Information Centre

Figure 6.2: Age-specific (18+) recorded prevalence rates of adults with learning disabilities in NHS Bassetlaw, by GP practice, 2008/09



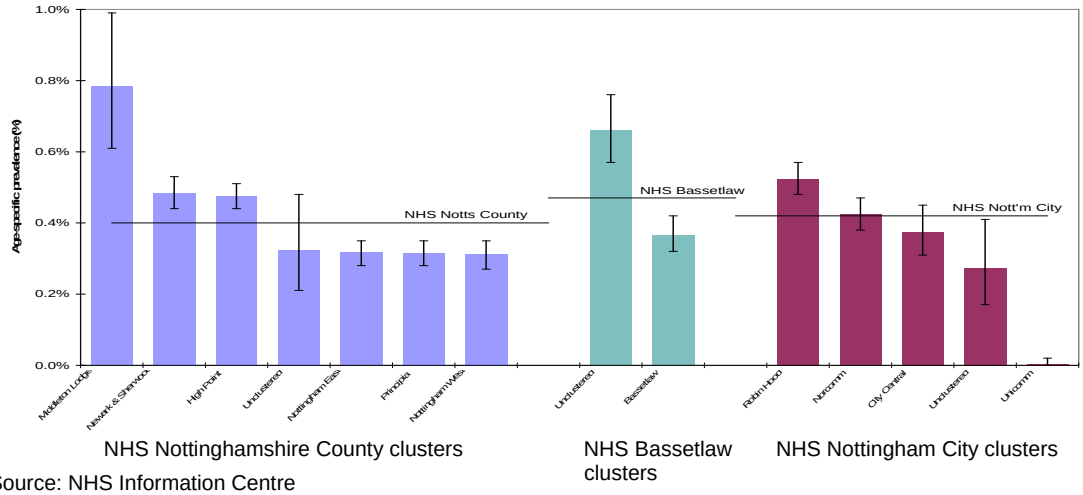
Source: The Information Centre

Figure 6.3: Age-specific (18+) recorded prevalence rates of adults with learning disabilities in NHS Nottingham City, by GP practice, 2008/09



Source: NHS Information Centre

Figure 6.4: Age-specific (18+) recorded prevalence rates of adults with learning disabilities in NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City, by cluster, 2008/09



NHS Nottinghamshire County clusters | NHS Bassetlaw clusters | NHS Nottingham City clusters

Source: NHS Information Centre

6.3.4 Local future trends

There are two nationally available tools, Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI) that model future numbers of people with learning disabilities within local authority areas, based on the national predictions as outlined in Section 6.2.4. The estimates are then applied to ONS population projections of the 18-64 population and 65 and over population for the years 2011 and 2021 and linear trends projected to give estimated numbers predicted to have a learning disability, in future years.

All learning disabilities

For the total population of people with learning disabilities, Nottinghamshire County, Bassetlaw and Nottingham City have similar estimated increases of approximately one fifth between 2009 and 2030 (Table 6.6), with the largest increase expected to be in Nottinghamshire County (19.9%).

Moderate and severe learning disabilities

For people with moderate and severe learning disabilities, the largest increase is predicted to be in Nottingham City (24.8%), with the lowest increase in Bassetlaw (16.2%) (Table 6.6).

Expected increases are based on an estimate of prevalence of moderate and severe learning disabilities across the national population. This will produce an over-estimate in local authority areas with a low South Asian community, and an under-estimate in areas with a high South Asian community.[200, 201] Due to the higher proportion of population from South Asian communities than the national average, Nottingham City may well therefore experience a higher increase than suggested in Table 6.6.

Profound multiple learning disabilities

The largest increase is expected to be seen in adults with profound and multiple learning disabilities, though the increase in numbers are estimated to be small. Nottinghamshire County, Bassetlaw and Nottingham City have similar estimated increases between 2009 and 2030 of approximately 30% (Table 6.6).

A higher increase in rates is expected in local authority areas with a younger demographic profile or with a greater proportion of citizens from Pakistani and Bangladeshi communities.[200,201] This again may lead to a higher than predicted increase in Nottingham City.

Table 6.6: Estimated numbers of adults with learning disabilities and estimated increase in populations between 2009 and 2030, by district

	2009	2015	2020	2025	2030	Change (2009-30)
All learning disabilities						
Notts County*	12,584	13,347	13,926	14,479	15,087	19.9%
Bassetlaw	2,116	2,248	2,332	2,419	2,518	19.0%
Nottingham City	5,903	6,292	6,478	6,717	7,050	19.4%
Moderate and severe learning disabilities						
Notts County*	2,603	2,750	2,866	2,994	3,127	20.1%
Bassetlaw	439	461	476	492	510	16.2%
Nottingham City	1,251	1,344	1,400	1,472	1,561	24.8%
Profound multiple learning disabilities						
Notts County*	206	222	240	271	-	31.6%**
Bassetlaw	34	36	39	44	-	29.4%**
Nottingham City	97	105	113	128	-	32.0%**

*Excluding Bassetlaw

**Estimated numbers only projected up to 2025 therefore figures represent change over period 2009-2025

Source: Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI) and Estimating future numbers of adults with profound multiple learning disabilities in England. Eric Emerson 2009

Changes by age band

The increases in adult learning disability populations detailed above are not consistent across age bands. Nationally, very little change is predicted within

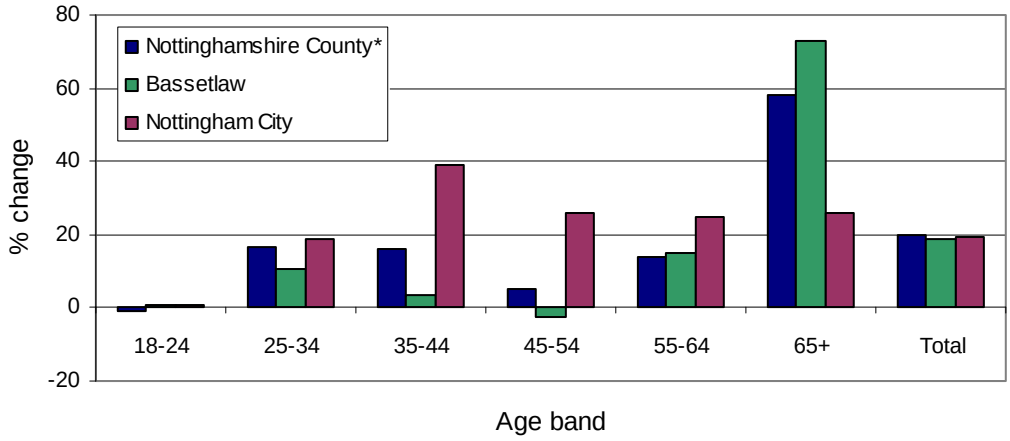
the 15-49 age groups, but with a marked increase in the 50 and over age groups.[205] This will have particular significance for service planning as older adults with learning disabilities will in general have higher health needs than both younger adults with learning disabilities and the general population.

This is reflected in the projections for Bassetlaw and Nottinghamshire County, where the largest predicted change will be among those aged 65 and over for the learning disability population as a whole (Figure 6.5) and those with moderate and severe learning disabilities (Figure 6.6). However, for Nottingham City the largest increases are estimated to be in the 25-44 age groups. Nottingham City has a younger general population than average, primarily for 2 reasons:

- a large student population
- a significant proportion of people migrate out of the city as they get older, for example when starting a family or retiring

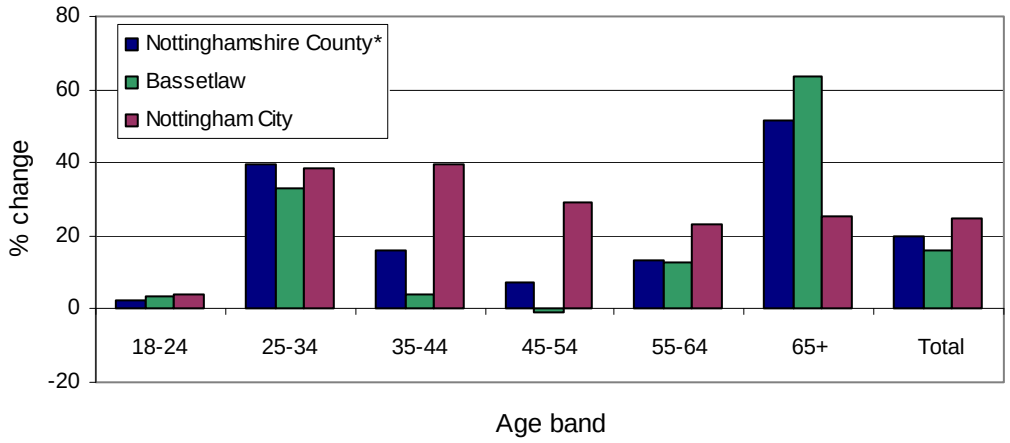
The estimates that the future trend data is calculated on is based on projections for the general population for each Local Authority area.[200,201] However, evidence suggests that people with learning disabilities do not follow a similar migratory pattern out of the city, but in general reside within Nottingham throughout their adult lives. The age profiles of people with learning disabilities known to Adult Social Care and Health show a similar profile across NHS Nottingham City, as NHS Nottinghamshire County and NHS Bassetlaw (Figure 6.8 in Section 6.4.1). Therefore Nottingham City may well experience a larger increase in numbers of adults with learning disabilities by 2030 than projected by the national modelling tools.

Figure 6.5: Percentage change in the estimated numbers of adults with a learning disability between 2009 and 2030 by age band and resident population



Source: Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI)
* excluding Bassetlaw

Figure 6.6: Percentage change in estimated number of adults with moderate or severe learning disabilities between 2009 and 2030 by age band and resident population



Source: Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI)
* excluding Bassetlaw

6.4 Demographic profiling

Two data sources have been used to review demographic information relating to adults with learning disabilities living in Nottinghamshire and Nottingham City:

- individuals known to Local Authority Adult Social Care services primarily due to their learning disability[b]
- individuals known to Nottinghamshire Healthcare Trust Learning Disability services

Both of these providers will, in general, support adults who have moderate and severe learning disabilities, though some people with mild learning disabilities with additional needs may also receive services. Additionally there may be some individuals with moderate or severe learning disabilities who are cared for by relatives and are therefore not in receipt of specialist services. It should be noted therefore that the demographic profiling outlined in this section relates to adults with learning disabilities that are known to specialist services, rather than the total population of adults with learning disabilities.

6.4.1 Adults with learning disabilities known to Local Authority Adult Social Care services

- There are higher rates of adults with learning disabilities in NHS Nottinghamshire County and NHS Bassetlaw than in NHS Nottingham City.
- The age profile is similar in the three primary care organisations, with the majority of adults with learning disabilities aged 18-59.
- There is a ratio of 1.4 males:1 female with a learning disability.
- Rates by ward varied from 0 to 14.5 adults with learning disabilities per 1,000 population, with the population distribution closely mirroring the distribution of registered care homes for adults with learning disabilities.

In September 2008 the Department of Health published guidance for a Directed Enhanced Service (DES) to provide annual health checks in primary care to people with a learning disability. Local Authority lists of people known to social services primarily because of their learning disability were used as the basis for identifying individuals to be offered the checks.[167] Caldicott approval was obtained in October 2008 for Nottingham City Council and Nottinghamshire County Council Adult Social Care services to share information with the 3 local PCOs. A minimum dataset was supplied by both local authorities in December 2008.

[b] The term Adult Social Care services is used throughout this document, to include services provided by Adult Social Care and Health at Nottinghamshire County Council and Adult Support and Health at Nottingham City Council

The lists supplied by Nottingham City Council and Nottinghamshire County Council were cleaned and, where possible, matched to individuals' NHS numbers using date of birth, postcode and surname. This allowed GP practice and registered PCT to be obtained for all matched individuals.

Demographic information

There were a total of 3,970 individuals known to Adult Social Care services, and NHS numbers were identified for 3,244 adults who were registered with NHS Bassetlaw, NHS Nottinghamshire County or NHS Nottingham City (Table 6.8). The majority of adults whose NHS number was identified were registered with a GP in NHS Nottinghamshire County (64.3%), with 25.6% registered with a GP in NHS Nottingham City and 10.1% registered with a GP in NHS Bassetlaw.

Compared to the proportion of the total adult population registered with each Primary Care Organisation (60.1% in NHS Nottinghamshire County, 30.0% in NHS Nottingham City and 9.9% in NHS Bassetlaw), there is a higher proportion of adults registered with NHS Nottinghamshire County in receipt of Adult Social Care services, and a lower proportion registered with NHS Nottingham City.

Table 6.8: Numbers of adults with learning disabilities known to Adult Social Care services, by primary care organisation, 2008

	Count	% of total	% of total whose NHS number was identified
NHS Nottinghamshire County	2,086	52.5	64.3
NHS Bassetlaw	329	8.3	10.1
NHS Nottingham City	829	20.9	25.6
Non-Nottinghamshire PCT/ PCT not known	726	18.3	-
Total	3,970	100	100

Source: Adult Social Care services, Nottinghamshire County Council and Nottingham City Council

Recent research suggests that 0.46% of adults will be known to specialist learning disability services in England.[187] The proportions within the three local primary care organisations are lower than this figure (Table 6.9), however these rates are likely to be an under-estimate due to the following reasons:

- 18% of the original lists received from the local authorities could not be matched, but it is highly probable that a significant proportion of these individuals are registered to either NHS Nottinghamshire County, NHS Bassetlaw, or NHS Nottingham City
- No information was received from neighbouring local authorities who may provide Adult Social Care services to individuals registered with NHS Bassetlaw, NHS Nottinghamshire County or NHS Nottingham City

Both NHS Bassetlaw and NHS Nottinghamshire County have significantly higher proportions of adults with learning disabilities known to Adult Social Care services than NHS Nottingham City. As this proportion relates to access

to services, rather than prevalence of learning disabilities in a population, the difference may be explained by different thresholds for eligibility used by the relevant local authority, or by differences in rates of access to services.

The Department of Health published the Fair Access to Care Services (FACS) guidance[208] to enable all Local Authorities to use a consistent framework for setting their eligibility criteria for adult social care, with implementation leading to fairer and more consistent eligibility decisions across the country. FACS ensures that Local Authorities make decisions based on whether the person with learning disability is able to live independently or would be put at risk if services are not provided or arranged. If there is a risk, a decision is made as to whether the risk is "critical, substantial, moderate or low". If any problems pose a critical, substantial or moderate risk to independence, then the person will be entitled to help. FACS has been replaced (from April 2010) by new guidance on eligibility criteria for adult social care services, *Prioritising need in the context of Putting People First*.[209]

Table 6.9: Proportion of patients registered with NHS Nottingham City, NHS Nottinghamshire County and NHS Bassetlaw and known to Adult Social Care services provided by Nottingham City Council or Nottinghamshire County Council, 2008

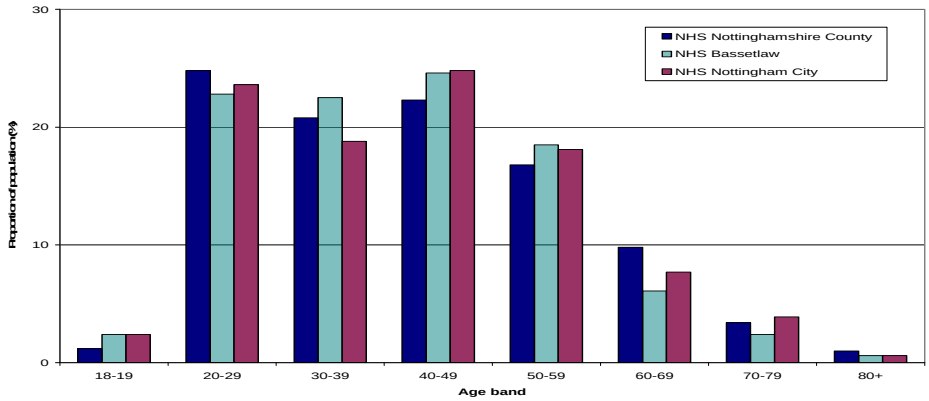
	Proportion per 1000 population (95% confidence intervals)
NHS Nottinghamshire County	3.9 (3.8, 4.1)
NHS Bassetlaw	3.7 (3.4, 4.2)
NHS Nottingham City	3.1 (2.9, 3.3)

Source: Adult Social Care services, Nottinghamshire County Council and Nottingham City Council. Resident 18+ population figures are from July 2009

Age

The age profile of adults with learning disabilities known to Adult Social Care services is similar across NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City (Figure 6.8). The majority of people in receipt of Adult Social Care services are aged between 18 and 59, with a steep drop-off of those in receipt of services aged 60 and above. This is to be expected as studies have shown people with moderate and severe learning disabilities have median life expectancies of 67.6 and 58.6 respectively.[62]

Figure 6.8: Age profile of adults with learning disabilities known to Adult Social Care services, by primary care organisation, 2008



Source: Adult Social Care services, Nottinghamshire County Council and Nottingham City Council

Gender

More males than females are in receipt of Adult Social Care services within NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City (Table 6.10). The overall ratio of 1.41 male:1 female is similar to published data that suggests a higher prevalence of learning disabilities amongst males.[11]

Table 6.10: Gender of adults with learning disabilities known to Adult Social Care services, by primary care organisation, 2008

	Count male (%)	Count female (%)	Total (%)	Ratio (male:female)
NHS Notts County	1,225 (58.7)	861 (41.3)	2,086 (100)	1.42:1
NHS Bassetlaw	182 (55.3)	147 (44.7)	329 (100)	1.24:1
NHS Nottingham City	490 (59.1)	339 (40.9)	829 (100)	1.45:1
Total	1,897 (58.5)	1,347 (41.5)	3,244 (100)	1.41:1

Source: Adult Social Care services, Nottinghamshire County Council and Nottingham City Council

Population distribution

Adults with learning disabilities known to Adult Social Care services were distributed across the majority of wards in Nottinghamshire, but with an unequal distribution (Figures 6.9 and 6.10).

Priory ward in Mansfield had the highest rate of adults with learning disabilities known to Adult Social Care services (14.5 people/1000 population). Of the ten wards with the highest rates, the majority were located in Mansfield district (Table 6.11). There were two wards with no adults with learning disabilities resident within their boundaries (Soar Valley in Rushcliffe and Southwell West in Newark and Sherwood).

Table 6.11: Wards with the highest rates of adults with learning disabilities known to Adult Social Care services, 2008

Ward	District	Rate/1000
Priory	Mansfield	14.5
Ravensdale	Mansfield	13.5
Lambley	Gedling	11.7
Oak Tree	Mansfield	10.6
Eakring	Mansfield	9.5

Ward	District	Rate/1000
Birklands	Mansfield	8.9
Portland	Mansfield	8.7
Magnus	N&S*	8.6
Worksop South	Bassetlaw	8.5
Winthorpe	N&S*	8.1

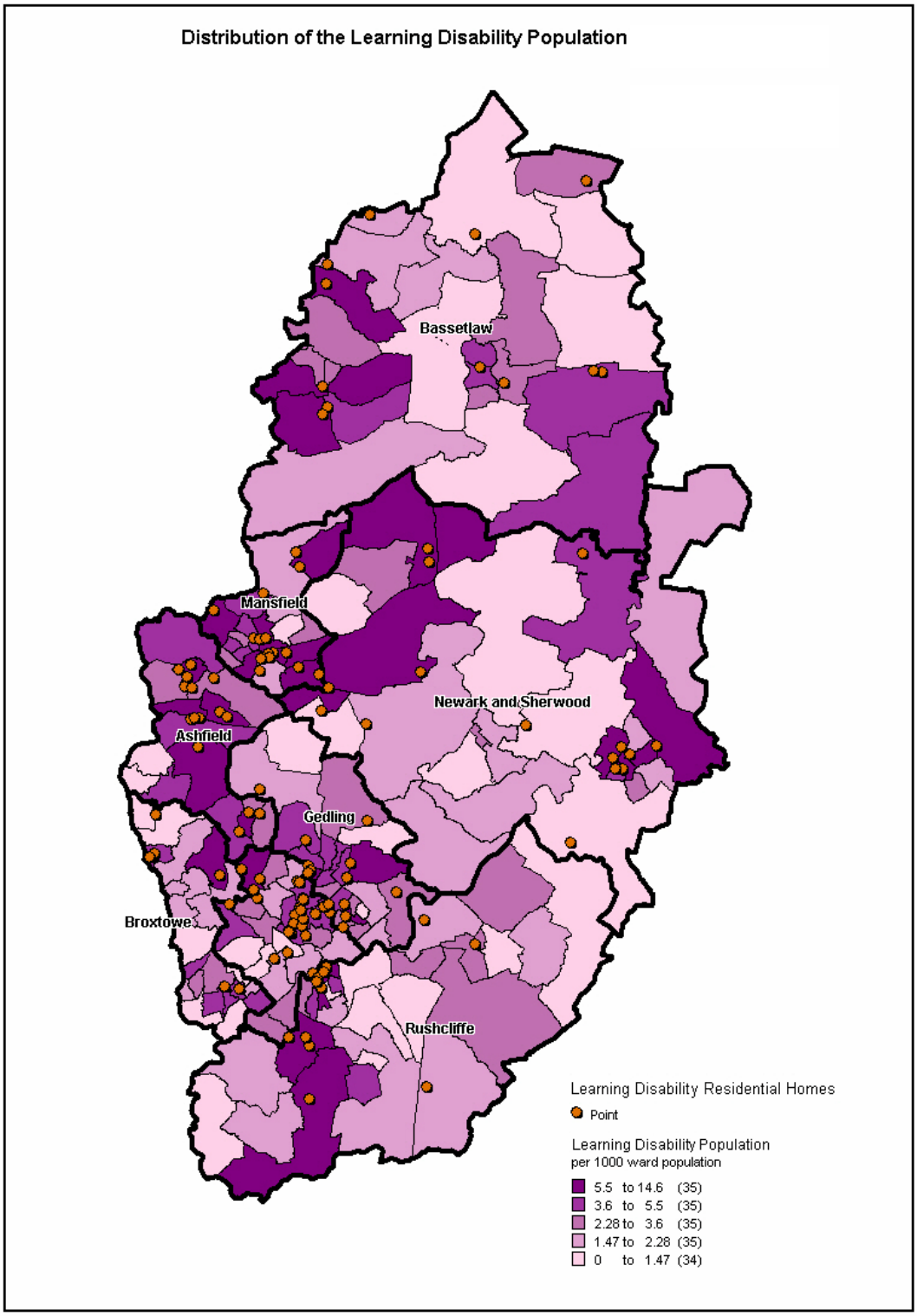
*N&S = Newark and Sherwood

Source: Adult Social Care services, Nottinghamshire County Council and Nottingham City Council

Registered Care Homes

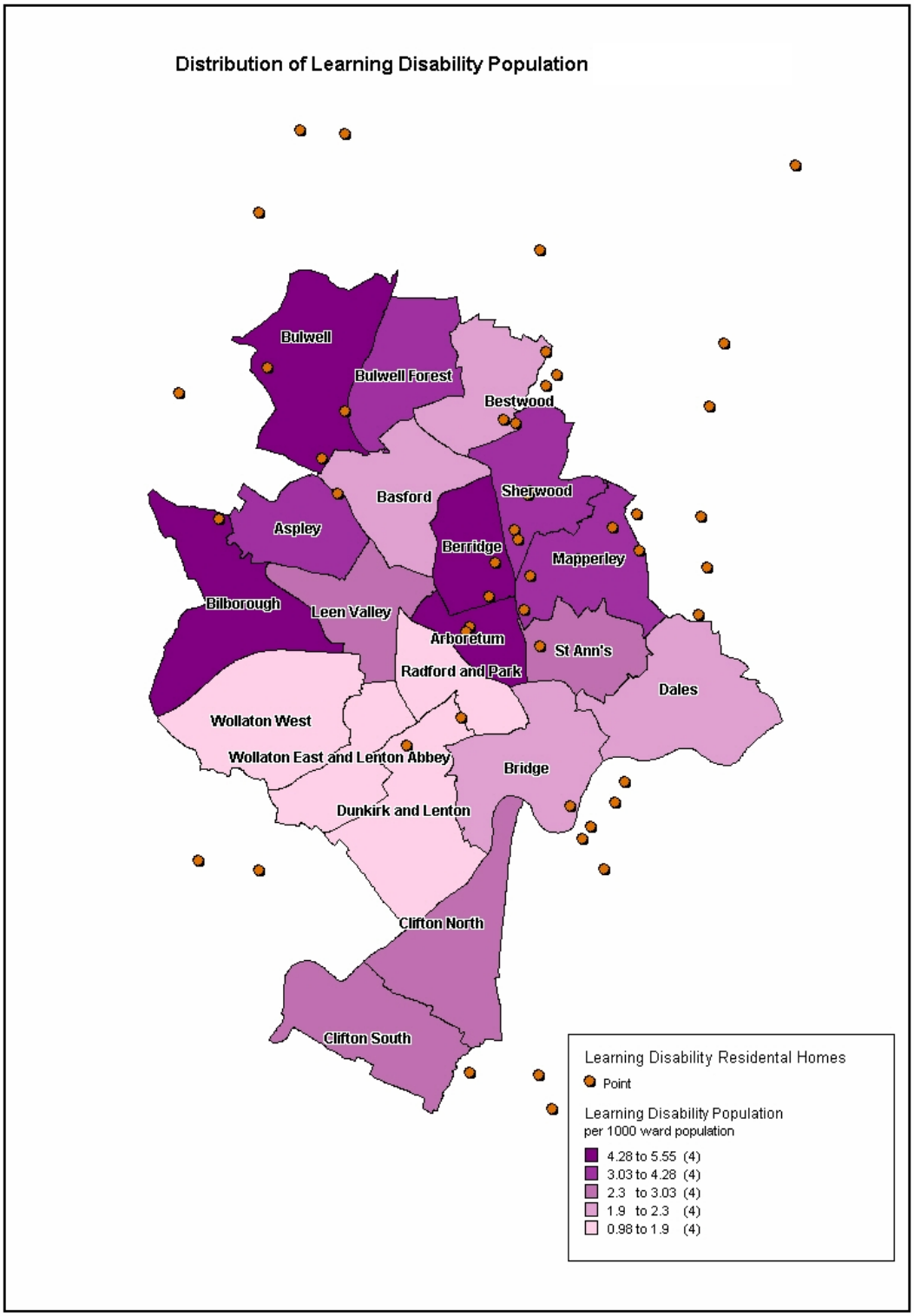
The population distribution closely mirrors the location of care homes registered with the Care Quality Commission for provision of services to adults with learning disabilities (Figures 6.9 and 6.10). Whilst not all adults with learning disabilities that are in receipt of Adult Social Care services will reside in a specialist care home, it would appear that location of registered care homes is a major contributory factor towards the distribution of the adult learning disability population in certain areas across Nottinghamshire.

Figure 6.9: Population distribution in Nottinghamshire of adults with learning disabilities known to Adult Social Care services by ward, and location of Care Homes registered with the Care Quality Commission for provision of services to adults with learning disabilities, 2008



Sources: Adult Social Care services, Nottinghamshire County Council and Nottingham City Council, Care Quality Commission

Figure 6.10: Population distribution in Nottingham City of adults with learning disabilities known to Adult Social Care services by ward, and location of Care Homes registered with the Care Quality Commission for provision of services to adults with learning disabilities, 2008



Sources: Adult Social Care services, Nottinghamshire County Council and Nottingham City Council, Care Quality Commission

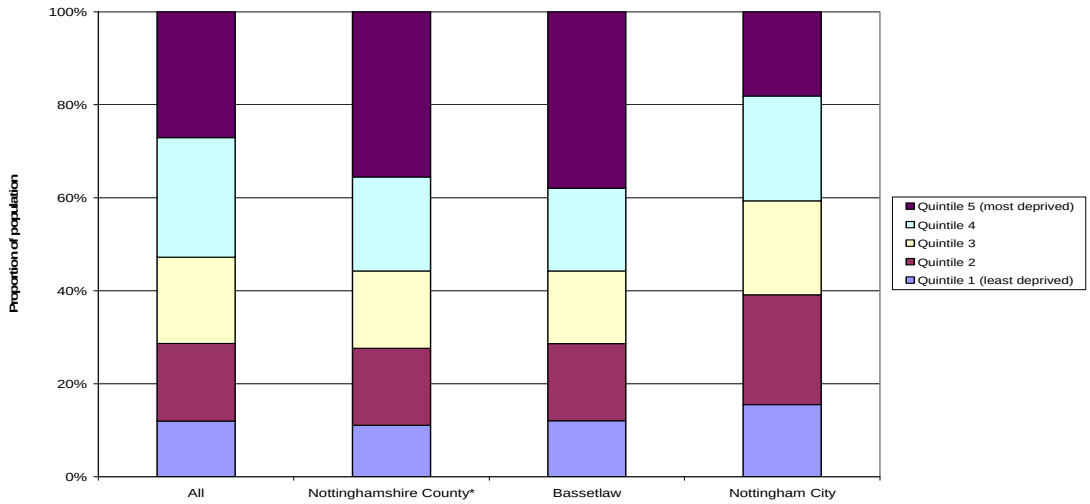
Deprivation

County-wide deprivation quintiles were created by ranking the IMD2007 score for all Lower Super Output Areas (LSOA) across Nottinghamshire, Bassetlaw and Nottingham City. Over one quarter (27.0%) of adults with learning disabilities known to Adult Social Care services resided in the most deprived county-wide quintile, with a reducing proportion across the quintiles, with 12% residing in the least deprived quintile (Figure 6.11).

Separate district-wide deprivation quintiles were also created as Nottingham City is more deprived than Nottinghamshire County and Bassetlaw.[c] Within Nottingham City, the proportion residing in each district-wide deprivation quintile was similar, with no trend observed. However there were higher proportions residing in more deprived district-wide quintiles in both Nottinghamshire County and Bassetlaw, with the lowest proportion residing in the least deprived quintiles (Figure 6.11).

There appears to be an association between deprivation and adults with learning disabilities known to Adult Social Care services across Nottinghamshire, and it has been reported that adults with learning disabilities are more likely to live in areas identified as socially deprived.[92] However as the distribution of the population appears to mirror location of registered care homes (Figures 6.9 and 6.10), the association is probably due to the locations of the care homes. In addition, the care homes are clustered in urban areas of the county which tend to be more deprived.

Figure 6.11: Distribution of adults with learning disabilities by county-wide and district-wide deprivation quintiles



Source: Adult Social Care services, Nottinghamshire County Council and Nottingham City Council.
*excluding Bassetlaw and Nottingham City

[c] For Nottinghamshire County the district-wide deprivation quintiles incorporated LSOAs in Ashfield, Broxtowe, Gedling, Mansfield, Newark and Sherwood and Rushcliffe.

6.4.2 Nottinghamshire Healthcare Trust

- The majority of adults known to Nottinghamshire Healthcare Trust learning disability services are aged 20-59.
- There is a ratio of 1.35 males: 1 female.
- In NHS Nottinghamshire County and NHS Bassetlaw the ethnicity profile of the learning disability population is very similar to the general population, with the vast majority of adults with learning disabilities known to Nottinghamshire Healthcare Trust being White British. In NHS Nottingham City, there was a slight over-representation amongst adults known to Nottinghamshire Healthcare Trust in the White British, Pakistani and Caribbean communities.

Nottinghamshire Healthcare Trust (NHCT) provides NHS services to adults with a learning disability living in Nottinghamshire (including Bassetlaw and Nottingham City). In general, adults in receipt of services from NHCT learning disability teams will have moderate to severe learning disabilities, though adults with mild learning disabilities with additional complex needs may also be supported.

Data on adults with learning disabilities in contact with NHCT learning disability services between April 2009 and January 2010 was reviewed. A total of 2,236 adults were in contact with NHCT learning disability services during this period. The majority of these were registered with NHS Nottinghamshire County (59.3%), with 32.3% registered with NHS Nottingham City and 8.4% registered with NHS Bassetlaw (Table 6.12). This breakdown is very similar to the proportion of the total adult population registered with each Primary Care Organisation (60.1% in NHS Nottinghamshire County, 30.0% in NHS Nottingham City and 9.9% in NHS Bassetlaw).

The proportion of adults in contact with NHCT learning disability services were similar across NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City, although these were lower than the proportions of adults with learning disabilities known to Adult Social Care services (Table 6.9). This suggests that specialist health learning disability services support a smaller cohort of patients than adult social care services, but there will be a large number of adults who receive services from both.

Table 6.12: Number of adults with learning disabilities known to Nottinghamshire Healthcare trust learning disability services, April 2009 to January 2010, by primary care organisation

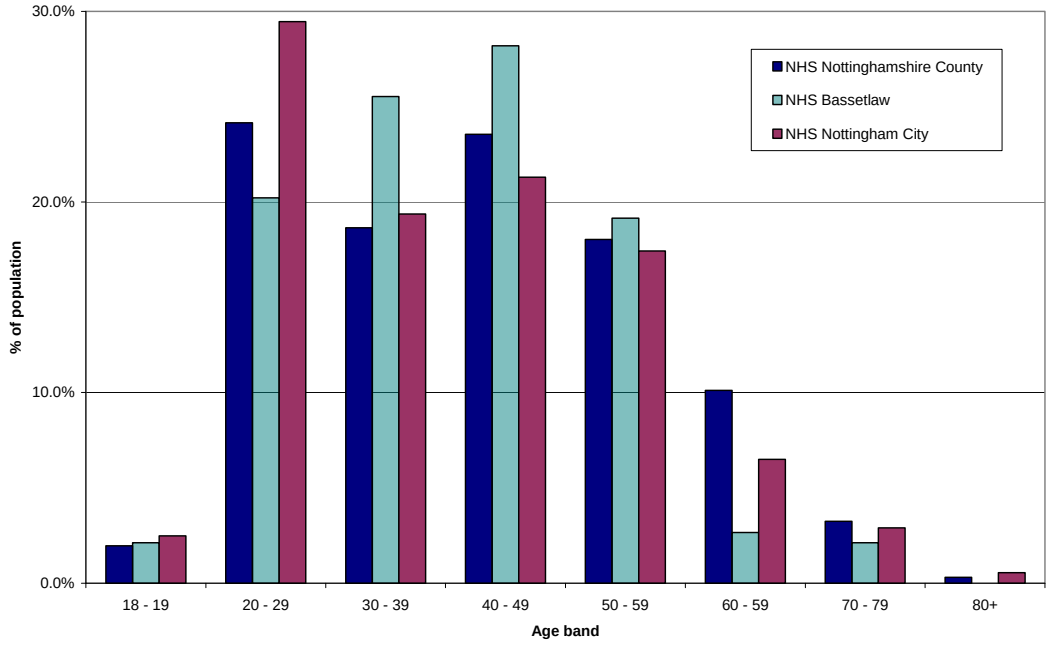
	Count	Proportion of total (%)	Proportion per 1,000 registered population (95% confidence intervals)
NHS Notts County	1,325	59.3	2.5 (2.4, 2.6)
NHS Bassetlaw	188	8.4	2.1 (1.9, 2.5)
NHS Nott'm City	723	32.3	2.7 (2.5, 2.9)

Source: Nottinghamshire Healthcare Trust

Age

As would be expected, due to the need for both health and social care services in the majority of adults with moderate and severe learning disabilities, the age profile of adults with learning disabilities known to NHCT services is similar to those in receipt of Adult Social Care services (Section 6.4.1). The majority of the population is aged 20-59, with a sharp drop-off in the proportion of those in receipt of services aged over 60 (Figure 6.12). NHS Bassetlaw had a higher proportion aged 30-49 and a lower proportion aged 20-29 than NHS Nottinghamshire County and NHS Nottingham City.

Figure 6.12: Age profile of adults with learning disabilities known to NHCT learning disability services, by primary care organisation



Source: Nottinghamshire Healthcare Trust

Gender

The majority of adults known to NHCT services were male (57.4%). This was observed in both NHS Nottinghamshire County and NHS Nottingham City, but NHS Bassetlaw had an equal split between genders (Table 6.12). The overall ratio of 1.35 males: 1 female is very similar to the ratio of those in receipt of Adult Social Care services (Section 6.4.1) and published data.[11]

Table 6.10: Gender of adults with learning disabilities known to NHCT services, by primary care organisation

	Count male (%)	Count female (%)	Total (%)	Ratio (male:female)
NHS Notts County	741 (55.9)	584 (44.1)	1,325 (100)	1.27:1
NHS Bassetlaw	94 (50.0)	94 (50.0)	188 (100)	1:1
NHS Nottingham City	449 (62.1)	274 (37.9)	723 (100)	1.64:1
Total	1,284 (42.6)	952 (42.6)	2,236 (100)	1.35:1

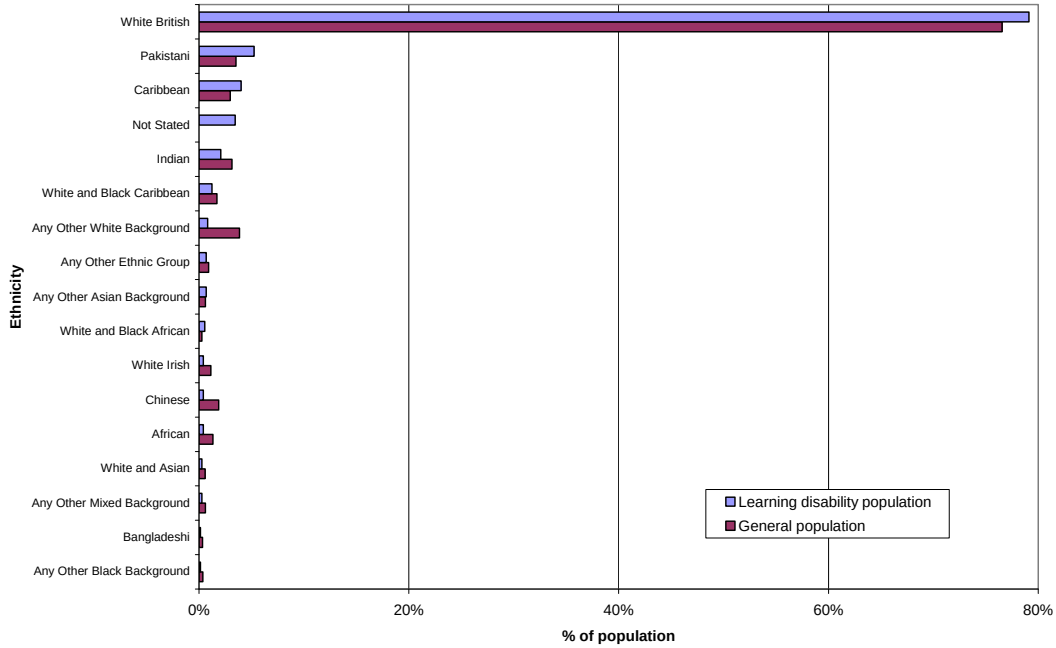
Source: Nottinghamshire Healthcare Trust

Ethnicity

In NHS Nottinghamshire County and NHS Bassetlaw the vast majority of adults with learning disabilities in receipt of NHCT learning disability services were White British (93.2% and 98.4% respectively). Due to small numbers in the remaining ethnic categories, there was very little difference between the ethnicity profiles between the learning disability and general populations.

In NHS Nottingham City, the majority of adults with learning disabilities in receipt of NHCT learning disability services were White British (79.1%). There were a higher proportion of adults with learning disabilities from White British, Pakistani and Caribbean communities compared to the general population, and a lower proportion from Any Other White Background and African communities (Figure 6.13).

Figure 6.13 Ethnicity profile of adults with learning disabilities known to Nottinghamshire Healthcare Trust learning disability services (April 2009 to January 2010) and the general population (2006), NHS Nottingham City



Source: Nottinghamshire Healthcare Trust and Nottingham Insight

Differences between the ethnicity profiles of the learning disability and general populations in NHS Nottingham City and in receipt of specialist services may be due to higher prevalence of learning disabilities in some communities (for example South Asian communities[14]) but may also reflect differing levels of access to services by ethnicity. However, as numbers in ethnic categories other than White British are small, any observed differences should be viewed with caution.

7. PATTERN OF HEALTH NEED AND USE

Findings

- Smoking rates appear to be lower in adults with learning disabilities than the general population.
- A lower proportion of adults known to adult social care and health eligible for screening are not invited or do not attend/participate.
- In comparison to the general population adults with learning disabilities known to adult social care and health have:
    - higher admission rates to secondary healthcare
    - higher attendance rates at out-patient clinics
    - higher attendance rates at Accident and Emergency Departments
- Age profiles of adults known to Adult Social Care and Health suggest a shorter life expectancy than the general population. An analysis of death certificates suggest a median age of death of 56 years.

Key issues

- Limited lifestyle information for people with learning disabilities is available.
- No information is currently available on prevalence and management of chronic conditions in primary care.
- Understanding the reasons why people with learning disabilities are not being invited for screening and why if they are invited they don't attend or participate.
- There is very little information on the pattern on health need and use of adults with mild learning disabilities.
- Locally there are lower rates of admission for respiratory diseases and gastrointestinal disorders than would be expected. It is unclear if this is because they are undiagnosed, managed well in primary care or if there is not a local need for these services.
- It is unclear if work to reduce emergency hospital admissions due to ambulatory care sensitive conditions is being targeted at adults with learning disabilities.

7.1 Lifestyle issues

- Smoking rates appear to be much lower in adults with learning disabilities in Nottinghamshire than the general population.
- Currently there is no information on the levels of obesity, physical activity undertaken or alcohol consumed by adults with learning disabilities in Nottinghamshire

Smoking

A local study found that 6% of people who attended four social care day services in Nottinghamshire were current smokers.[210] Those with mild learning disabilities were more likely to smoke than those with severe learning disabilities, and also reported smoking more heavily. A higher than expected proportion living in hospital and staffed-housing smoked. A third of smokers were concerned about the risks. Controlling for the degree of disability, smokers were more knowledgeable about the risks than non-smokers.

Smoking status is recorded on GP practice records and therefore extraction from practice systems would allow more up-to-date and comprehensive local data to be obtained. Smoking status is also an aspect of the Health Check for People with a Learning Disability of the Learning Disability Direct Enhanced Service (DES). Data extraction from GP practice records has taken place and once analysed information will be added as an appendix to this report.

Obesity

No local data on the prevalence of obesity amongst adults with learning disabilities in Nottinghamshire was available for this Health Needs Assessment. Body Mass Index (BMI) is recorded on GP practice records and therefore extraction from practice systems would allow local data to be obtained. Assessment of BMI is also an aspect of the Health Check for People with a Learning Disability of the Learning Disability Direct Enhanced Service (DES). Data extraction from GP practice records has taken place and once analysed information will be added as an appendix to this report.

Physical activity

No local data on the levels of physical activity undertaken amongst adults with learning disabilities in Nottinghamshire was available for this Health Needs Assessment. Levels of physical activity undertaken are included in the Health Check for People with a Learning Disability as part of the Learning Disability DES. Data extraction from GP practice records has taken place and once analysed information will be added as an appendix to this report.

Alcohol intake

No local data on alcohol intake amongst adults with learning disabilities in Nottinghamshire was available for this Health Needs Assessment. Alcohol intake is included in the Health Check for People with a Learning Disability as part of the Learning Disability DES. Data extraction from GP practice records has taken place and once analysed information will be added as an appendix to this report.

7.2 Primary care information

7.2.1 GP data

- The recording of adults with learning disabilities on the Quality and Outcomes Framework at GP practices should allow information on patients' lifestyle choices, prevalence of chronic conditions and subsequent management to be reviewed.
- Analysis of data extracted from GP practices was not possible in the timescales available for this Health Needs Assessment but is planned to be completed by March 2011.

GP practices are encouraged to identify and record all patients with learning disabilities on the practice Learning Disabilities register as part of the Quality and Outcomes Framework (QOF) (see Section 6.3.3). As demonstrated in Section 6.3.3, currently only one fifth of the expected number of individuals are recorded on practice learning disabilities registers. The QOF also encourages GP practices to maintain practice registers for a number of clinical indicators.[207]

GP practices can also record information relating to patients' lifestyle choices, diagnosis and management of other medical conditions, and uptake of screening tests and annual health checks.

There is therefore a wealth of information relating to the prevalence and management of clinical indicators recorded on primary care data systems. It had been hoped to obtain information in relation to adults with learning disabilities as part of this report to:

- gain a better understanding of the prevalence of chronic conditions amongst adults with learning disabilities in Nottingham and Nottinghamshire
- gain a better understanding of the prevalence of smoking, obesity and harmful drinking amongst other lifestyle factors
- review management of conditions to ensure equity in relation to the general population

Unfortunately analysis of data extracted from GP practices was not possible in the timescales drawn up for this Health Needs Assessment, but is planned to be completed by March 2011 and will be included as an appendix to this report.

7.2.2 Screening rates

- A lower proportion of eligible women with learning disabilities attend breast screening appointments than the general population.
- A much lower proportion of adults with learning disabilities have participated in the bowel cancel screening programme.
- Eligible women with a learning disability have a lower uptake of cervical screening. In addition, there are much higher rates of eligible women with a learning disability that have been *ceased* from the screening programme.

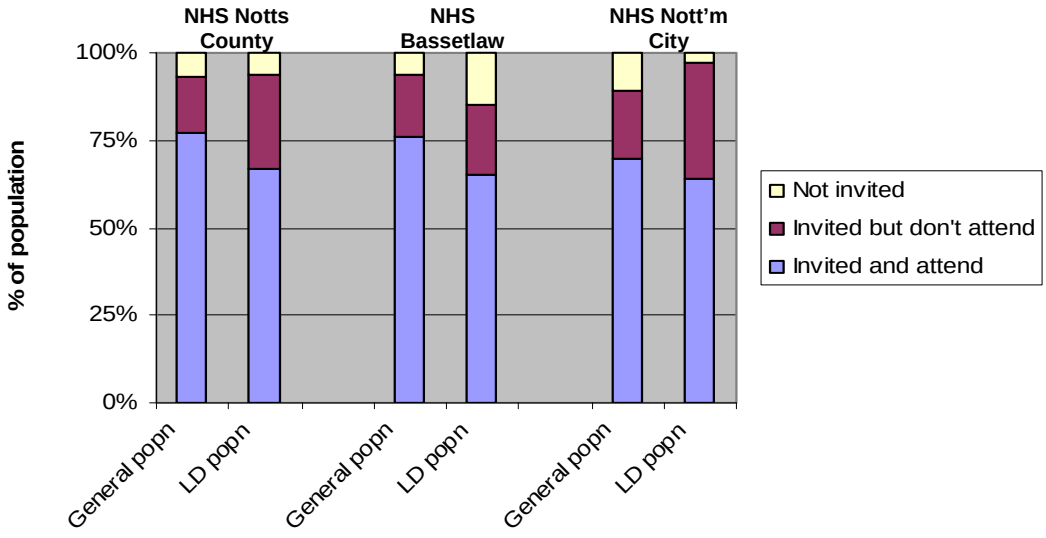
It should be noted that the population of adults with a learning disability used to assess screening coverage and uptake are those that are known to Adult Social Care services (see Section 6.4.1). Individuals within this group will be in contact with specialist services such as Community Learning Disability Teams who can provide assistance to attend screening appointments. Screening rates in the wider learning disabilities population could be lower than the figures stated here, particularly as adults with learning disabilities who are not known to specialist services may not have the support to attend screening appointments.

It should also be noted that due to the eligibility criteria for the screening programmes, only a small number of adults with learning disabilities known to Adults Social Care services are included when analysing the data by primary care organisation.

Breast cancer screening
The NHS Breast Screening Programme routinely invites all women aged between 50 and 70 for breast screening every 3 years. Women over the age of 70 are encouraged to make their own appointments for screening.[211]

In all 3 primary care organisations, a lower percentage of eligible females with learning disabilities attended a breast cancer screening appointment following an invite letter compared to eligible females in the general population (Figure 7.1). This is as reported in other localities (Section 4.1.4). Within NHS Nottinghamshire County and NHS Nottingham City, the difference was due to a higher percentage of eligible females with learning disabilities not attending a breast cancer screening appointment, despite having been invited. In Bassetlaw, the difference was due to a higher percentage of eligible females with learning disabilities not being invited to attend an appointment.

Figure 7.1: Percentage of eligible general population and adults with a learning disability (LD) population being invited and attending breast cancer screening appointments, by Primary Care Organisation, 2006-2008



Source: Exeter System

Bowel cancer screening

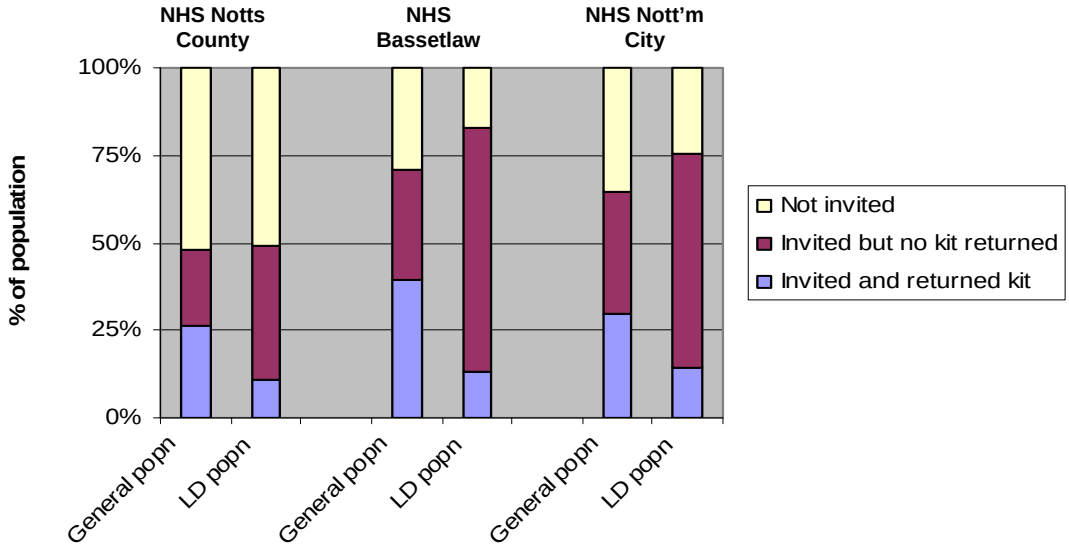
The NHS Bowel Cancer Screening Programme was launched in 2006, achieving nationwide coverage in late 2009. The programme offers screening every two years to all men and women aged 60 to 69. People in this age group will automatically be sent an invitation, then a screening kit, so they can do the test at home. Adults aged over 70 can request a screening kit.[212]

The number of screening kits returned between the start of the local screening programme in January 2008 and June 2009 was reviewed, and therefore not all eligible adults will have been invited within this time period. Invite rates will also vary between primary care organisation due to a staggered roll out of the screening programme.

In NHS Nottinghamshire County a similar proportion of eligible adults with a learning disability have been invited to participate in the screening programme compared to the general population (Figure 7.2). In NHS Bassetlaw and NHS Nottingham City a higher proportion of eligible adults with a learning disability had been invited to participate compared to the general population. However, in all 3 primary care organisations a much lower proportion of invited adults with a learning disability had returned their screening kits than the general population. The difference was greatest for NHS Bassetlaw where 13.0% of invited adults with a learning disability had returned a screening kit, compared with 39.4% of eligible adults in the general population.

Due to the recent implementation of the national Bowel Cancer Screening Programme, there has been no comparable data published from other localities.

Figure 7.2: Percentage of eligible general population and adults with a learning disability (LD) population being invited to participate in and returning bowel cancer screening programme kits, by Primary Care Organisation, January 2008 to June 2009



Source: Exeter System

Cervical cancer screening

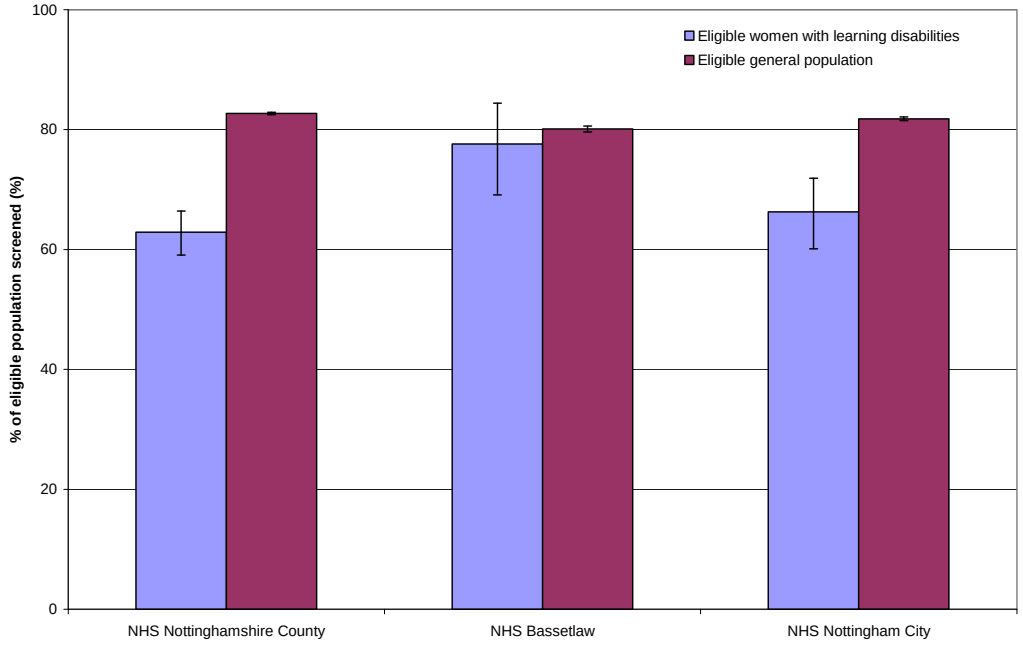
The NHS Cervical Cancer Screening Programme offers screening to all women aged between 25 and 49 every three years and to women aged between 50 and 64 every five years.[213]

Eligible women with a learning disability have a lower uptake of screening than the general population (Figure 7.3), but with approximately two thirds attending a recent appointment, this suggest a higher uptake than published rates from other localities (Section 4.1.4). The uptake was significantly lower in NHS Nottinghamshire County and NHS Nottingham City.

However, reviewing the eligible population does not include those women who have been coded as *suspended* or *ceased*. Suspensions are a temporary break in being called for a screening appointment (for example due to pregnancy). Women who are ceased are removed prior to being called for the first screening test or are removed from the recall list, with the decision generally made by the GP. Eligible women with learning disabilities have significantly lower rates of suspension than the general population in all three primary care organisations, but significantly higher rates of ceased women (Figure 7.4). In NHS Bassetlaw nearly 40% of the total female population aged 24-65 and with a learning disability had been ceased, with 33% in NHS Nottingham City and 30% in NHS Nottinghamshire County. This could account for the higher uptake rates of the eligible learning disabilities population in NHS Bassetlaw. It also suggests that women with learning disabilities may be systematically being removed from the cervical screening call/recall lists in some practices across NHS Nottinghamshire County, NHS

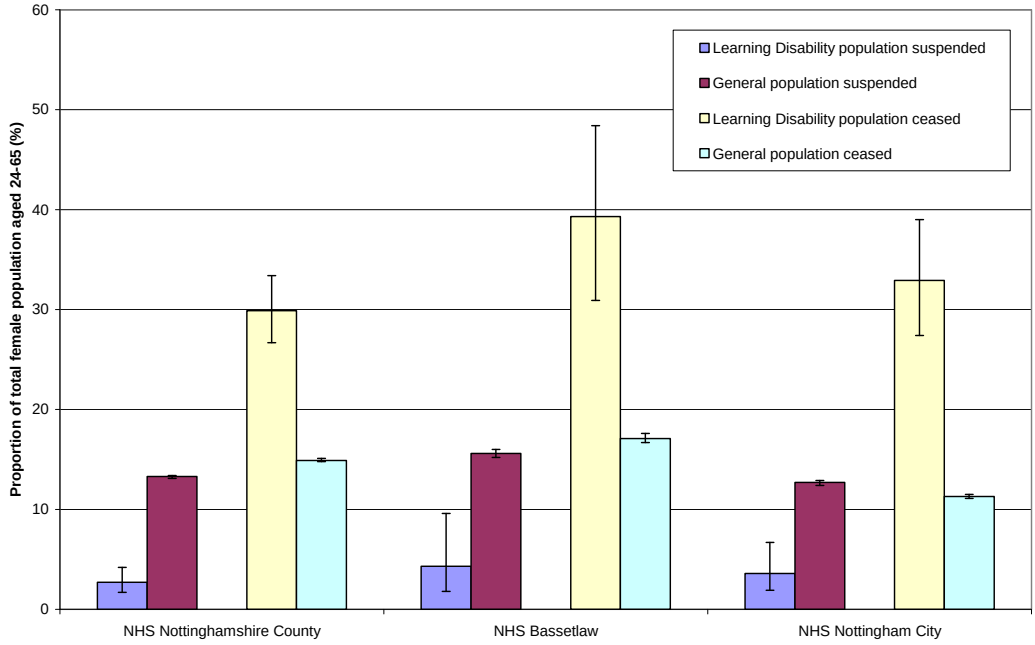
Bassetlaw and NHS Nottingham City. This may be because they have never been sexually active.

Figure 7.3: Proportion of eligible women attending cervical screening appointment between 1st April 2003 and 31st March 2008, by Primary Care Organisation



Source: Exeter System

Figure 7.4: Proportion of total female population coded as suspended or ceased for the cervical screening programme, by Primary Care Organisation



Source: Exeter System

7.2.3 Dental services

- Dental services for adults with learning disabilities are provided through general primary care dental services and Special Care Dentistry services.
- Approximately 95% of the population requiring Special Care Dentistry services are adults and children with learning disabilities.
- A Special Care Dentistry Review was established in 2009 to review current service provision in relation to need.

Within NHS Nottinghamshire, NHS Bassetlaw and NHS Nottingham City, dental services for adults with learning disabilities are provided through general primary care dental services and Special Care Dentistry services. It is estimated that approximately 95% of the population requiring Special Care Dentistry services are people with moderate, severe or profound learning disabilities.

In 2009, a Special Care Dentistry Review Group was established by the Oral Health Strategic Group to review the population needing to access special care dentistry, identify the services required, define a care pathway, outline a commissioning framework and identify information and communication processes. The Review Group also considered existing services and where possible activity levels, however this information was not available across all providers.

As the Review Group is considering the need for services, current activity levels amongst specialist dental services and is ensuring services provide care to the same standards across the whole of Nottinghamshire, dental services are not considered in more detail within this Health Needs Assessment.

7.3 Secondary care information

It was not possible to compare the secondary care activity levels between the population of adults with a learning disability and the general population to identify whether local needs matched the pattern of health need identified in Section 4. Unfortunately coding of learning disability as an admission sub-diagnosis is neither comprehensive nor consistent across local providers, and there maybe a number of reasons for this:

- If the reason for admission is not directly related to the individual's learning disability (for example an admission in relation to cancer or diabetes) then clinical staff may not state that the individual has a learning disability
- Staff may not identify patients with mild learning disability as having a learning disability

To test the completeness of coding at secondary care providers, we reviewed diabetes admission rates, comparing admission rates for those individuals known to Adult Social Care services (who had been matched to their NHS number) with admission rates across the whole population where learning disability had been included as a sub-diagnosis. In 2008, there were 13 admissions identified using NHS numbers of individuals known to Adult Social Care services, but only 8 using learning disability as a sub-diagnosis of the admission.[d]

A higher level of admission activity would be expected when reviewing sub-diagnoses for learning disabilities as the individuals known to Adult Social Care services are only a subset of the total adult learning disability population.

It was decided therefore that when reviewing secondary care activity, the learning disabilities population would be defined as those patients known to Adult Social Care services whose NHS numbers had been matched. The following sections therefore provide a picture of the local pattern of health need for adults with learning disabilities known to Adult Social Care services rather than the learning disabilities population as a whole.

Analysis of secondary care activity included the calendar years 2004 to 2008 inclusive. In order to reduce the impact of year-on-year fluctuations in activity, either 3-year rolling averages or a 5-year average was used.

Admissions to and attendances at all secondary care providers are included in the analysis, though for the local population of adults with learning disabilities the majority of secondary care activity will occur at Nottingham University Hospitals, Sherwood Forest Hospitals, Doncaster and Bassetlaw Hospitals and Nottinghamshire Healthcare Trust.

[d] ICD10 codes: F7* (mental retardation), F81 (Specific developmental disorders of scholastic skills), Q85.1 (tuberous sclerosis), Q86 (Foetal Alcohol syndrome), Q87.1 (Prader-Willi syndrome), Q90 (Down's syndrome), Q91 (Edwards and Patau's syndromes) and Q99.2 (Fragile X syndrome)

7.3.1 In-patient admissions

- Adults with learning disabilities have admission rates to secondary healthcare approximately 20% to 40% times higher than the general population.
- Admission rates are significantly higher for adults with learning disabilities for elective and emergency admissions than the general population, but significantly lower for maternity-related admissions.
- Adults with learning disabilities have a higher median length of stay than the general population.
- Adults with learning disabilities are significantly more likely to be admitted than the general adult population for epilepsy, an oral health condition, a mental health condition, diabetes and a hearing problem.
- Adults with learning disabilities were significantly less likely to be admitted than the general adult population for cancer, coronary heart disease, respiratory disease and gastro-intestinal disorders.

An admission is a generic term that refers to a stay in hospital as either an in-patient or day case. Admissions across all secondary care providers were included in the analysis, including acute providers and mental health trusts. Admissions were analysed for each calendar year, and 3-year rolling averages were calculated. If a patient had a number of different episodes within an admission spell (for example if they were referred to a different consultant team whilst an in-patient) then this was counted as a single admission.

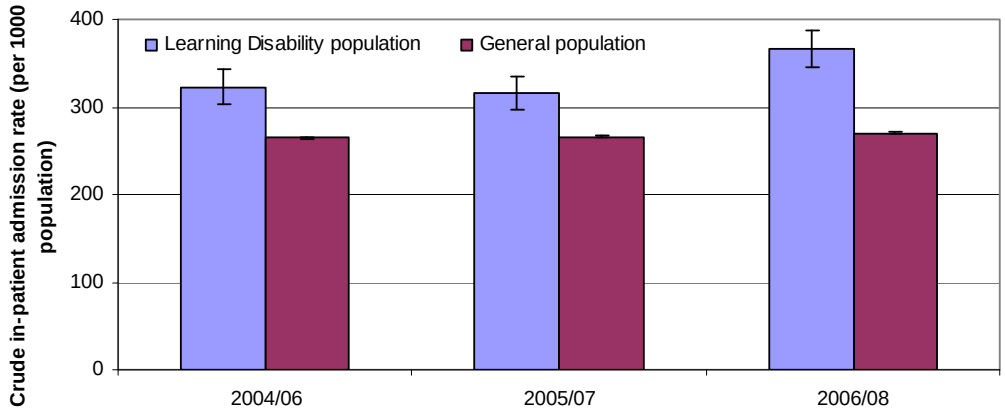
Crude admission rates for adults with a learning disability were similar in 2004/06 and 2005/07 (322 and 315 per 1,000 population), but increased in 2006/08 (368 per 1,000 population). This increase was due to an increase in the admission rates for patients registered with NHS Nottinghamshire County and NHS Nottingham City. In general, admission rates were significantly lower in NHS Nottinghamshire County than in NHS Bassetlaw and NHS Nottingham City.

Adults with learning disabilities in Nottinghamshire had a significantly higher in-patient admission rate between 2004/06 and 2006/08 than the general adult population (Figure 7.3), with an admission rate 1.2 times higher in 2004/06 and 2005/07 and rising to 1.4 times higher in 2006/08. NHS Nottingham City had the highest difference in admission rates between adults with learning disabilities and the general population (ranging from 1.23 times higher in 2004/06 to 1.92 times higher in 2006/08) and NHS Nottinghamshire

County had the lowest difference in admission rates (ranging from 1.03 times higher in 2005/07 to 1.16 times higher in 2006/08).

The evidence nationally suggests that people with learning disabilities have an admission rate 1.9 times higher than the general population.[171] The admission rates for Nottingham City are similar to this.

Figure 7.3: Crude in-patient admission rates per 1000 population (with 95% Confidence Intervals) for adults with learning disabilities and the general population in NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City combined, 3 year rolling average 2004/06 to 2006/08



Source: SUS data – Local Data Warehouse System

Directly standardised rates

As previously demonstrated, the population of adults with a learning disability within Nottinghamshire (including Bassetlaw and Nottingham City) has a younger age structure than the general population (Sections 6.4.1 and 6.4.2). As healthcare use tends to increase with age, a younger population would therefore be expected to have a lower admission rate. Admission rates for adults with learning disabilities and the general population were therefore age-standardised to adjust for the differences in age profiles. After standardising for age, similar patterns of admissions were observed as for the crude admission rates, but there was a greater magnitude of difference between adults with a learning disability and the general population for age-standardised rates compared to the crude rates, thereby emphasising the level of health need in this population.

It was not possible to use age-standardised rates throughout the analysis due to small numbers in the learning disability age bands, and technical issues in calculating confidence intervals when the number of cases was greater than the population (as was the case when reviewing all admissions rather than the number of admissions of unique people).

In-patient admission type

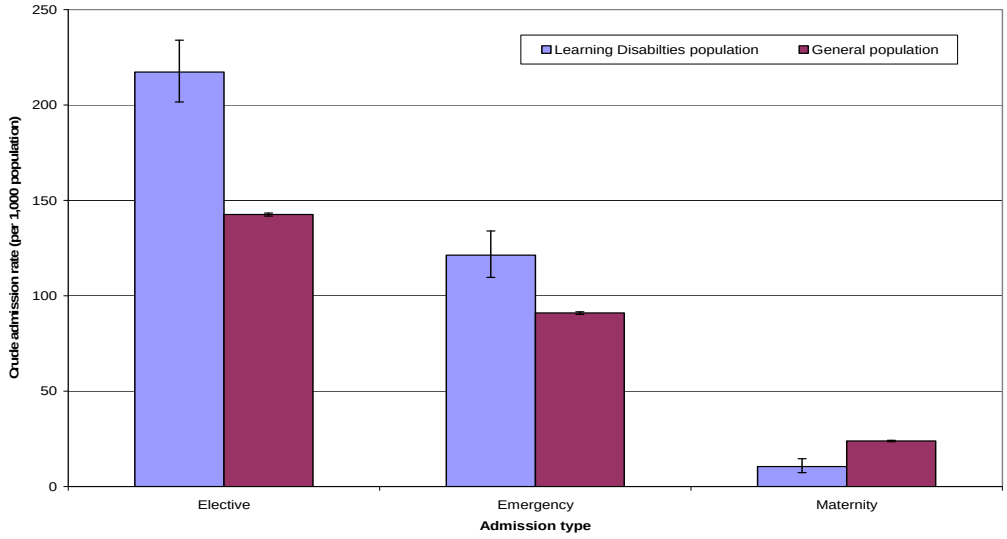
In-patient admission types can be classified as elective (an admission that is planned in advance), emergency (an unplanned admission at short-notice) or maternity (of a pregnant or recently-pregnant woman to a maternity ward).[214]

NHS Bassetlaw had a significantly higher rate of elective admissions for adults with learning disabilities than NHS Nottinghamshire County and there were no significant differences between the rates of emergency and maternity admissions between the primary care organisations.

Adults with learning disabilities were 1.5 times more likely to be admitted to secondary care as an elective admission than the general adult population, and 1.3 times more likely to be admitted as an emergency (Figure 7.4). However, adults with learning disabilities were 2.3 times less likely to be admitted as a maternity admission than the general adult population. NHS Nottingham City had the greatest differences in elective and emergency admission rates between adults with learning disabilities and the general population (2.0 and 1.5 times higher respectively) with NHS Nottinghamshire County having the least difference in admission rates (1.3 for both elective and emergency admissions).

No national data on the admission types has been found so it is not possible to compare this information.

Figure 7.4: Crude admission rates for the general adult population and adults with learning disabilities, 2004/8 average, with 95% confidence intervals



Source: SUS data – Local Data Warehouse System

Length of Stay

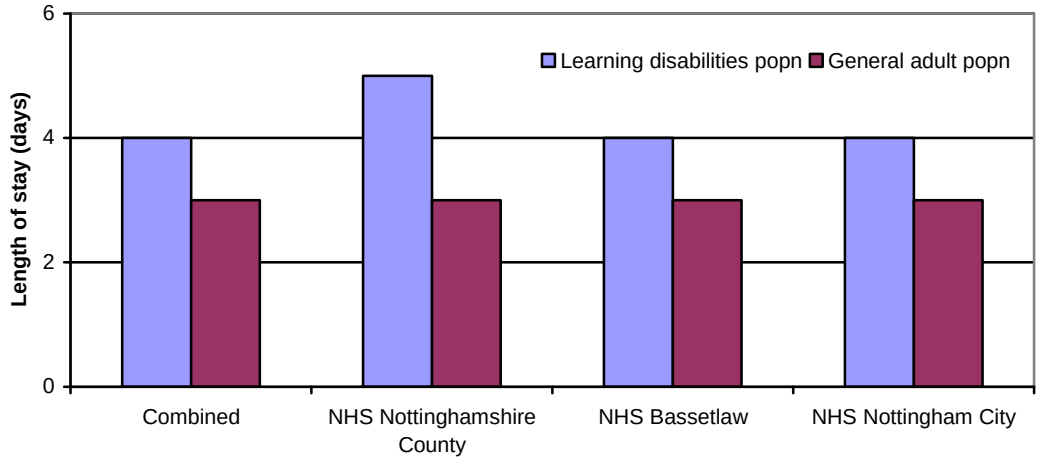
Length of stay (LOS) is the duration of a single period of hospitalisation. Reducing length of stay has been viewed as key to improve the efficiency of the NHS, as even small reductions in a patient's length of stay can have financial benefits.

The time period analysed for length of stay (2004 to 2008) included the discharging of a number of adults with learning disabilities from hospital into community accommodation under the campus reprovision programme, as outlined in Valuing People. As a number of these individuals had been in-patients for many years, inclusion of these patients in a mean length of stay would have skewed the figure for the learning disability cohort and therefore a median value was calculated. In addition, the high number of day cases (that are categorised as in-patient admissions) skewed the median value for both the general adult and learning disabilities populations, and therefore only those episodes with a length of stay of 1 day or more were included in the analysis.

Adults with a learning disability had a longer median length of stay than the general adult population in NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City (Figure 7.5). In all three primary care organisations the median length of stay for the general adult population was 3 days, however in NHS Bassetlaw and NHS Nottingham City the median length of stay for adults with learning disabilities was 4 days, and 5 days in NHS Nottinghamshire County.

National evidence suggests that people with learning disabilities tend to have a greater length of stay.[171] The longer observed length of stay could be positive due to recognition by ward staff of the more complex needs of adults with learning disabilities, or could be a reflection of adults with a learning disability not receiving a similar level of care as the general population.

Figure 7.5: Median length of stay for adults with a learning disability and the general adult population for all in-patient admissions between 2004 and 2008, by primary care organisation



Source: SUS data – Local Data Warehouse System

Reasons for in-patient admissions

The reasons for in-patient admissions were analysed to identify differences between the general population and adults with learning disabilities. As

admissions for individual conditions are relatively small and fluctuate on a yearly basis, an average rate based on admissions between 2004 and 2008 was used. Due to the small population cohorts of adults with learning disabilities in each primary care organisation, a combined admission rate has been included for each condition.

Adults with learning disabilities were significantly more likely to be admitted than the general adult population for epilepsy, an oral health condition, a mental health condition, diabetes, a hearing problem and diabetes (Table 7.1). Adults with a learning disability were significantly less likely to be admitted than the general adult population for cancer, coronary heart disease, respiratory disease and gastro-intestinal disorders (Table 7.2). Nationally people with learning disability have an increased uptake of medical and dental hospital services, but a reduced uptake of surgical specialities compared with the general population.[215] This is reflected to a certain degree locally.

Section 4.1.9 outlined the published pattern of health need, and in general adults with learning disabilities in Nottinghamshire experience a similar pattern. However, adults with learning disabilities in Nottinghamshire do experience a lower rate of admission for respiratory diseases and gastro-intestinal disorders which are unexpected as this population have a higher prevalence of these conditions.

Rates of admissions for dementia and fractures were also analysed, as the published literature suggests that adults with learning disabilities experience higher rates of these conditions than the general population (Section 4.1.8). However, there was no significant difference in admission rates for adults with learning disabilities and the general population for either dementia (0.3 and 0.5 per 1,000 population respectively) or fractures (4.8 and 2.8 per 1,000 population respectively).

Table 7.1: Conditions for which adults with learning disabilities were significantly more likely to be admitted, based on yearly average 2004 to 2008

Reason for admission	Rate ratio*	Crude admission rate for adults with learning disabilities (per 1,000 population)	Crude admission rate for general adult population (per 1,000 population)
Epilepsy	22.6	24.9[1,2,3]	1.1
Schizophrenia	4.6	2.3[1]	0.5
Oral Health	3.4	13.4[1]	3.9
Mental Health	3.1	4.7[1]	1.5
Diabetes	2.9	3.2[1]	1.1
Hearing problems	2.5	2.8	1.1
Bladder disorders	1.6	9.7[1]	6.2

* Rate ratio is calculated as (the admission rate for adults with learning disabilities) / (the admission rate for the general adult population)

1 rate is significantly higher for patients registered with NHS Nottinghamshire County

2 rate is significantly higher for patients registered with NHS Bassetlaw

3 rate is significantly higher for patients registered with NHS Nottingham City

Source: SUS data – Local Data Warehouse System

Table 7.2: Conditions for which adults with learning disabilities were significantly less likely to be admitted, based on average across 2004 to 2008 admissions

Reason for admission	Rate ratio*	Crude admission rate for adults with learning disabilities (per 1,000 population)	Crude admission rate for general adult population (per 1,000 population)
Cancer	3.7	5.5[1,2]	20.1
Coronary heart disease	1.8	11.2[1]	19.6
Respiratory disease	1.5	9.6	14.3
Gastro-intestinal disorders	1.2	30.4	37.7

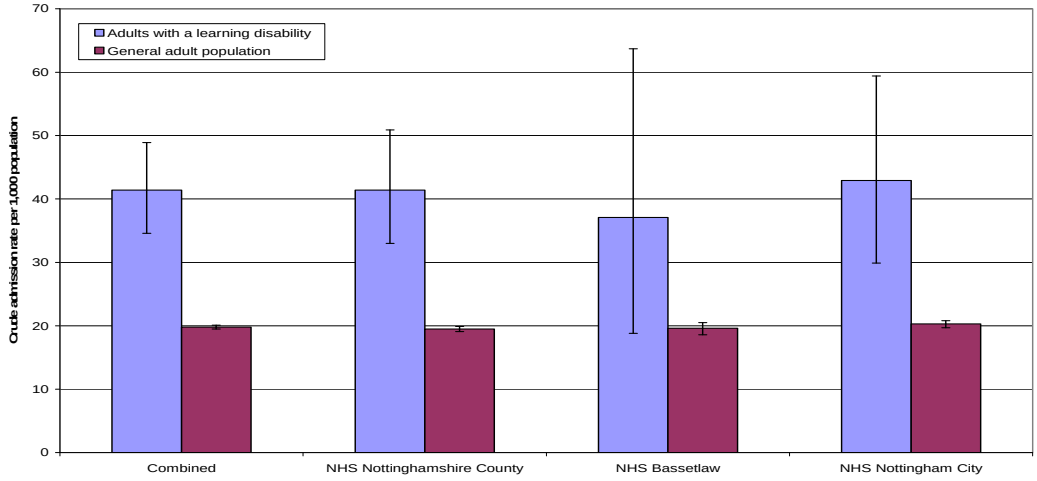
* Rate ratio is calculated as (the admission rate for the general adult population) / (the admission rate for adults with learning disabilities)
1 rate is significantly lower for patients registered with NHS Nottinghamshire County
2 rate is significantly lower for patients registered with NHS Bassetlaw
Source: SUS data – Local Data Warehouse System

Ambulatory Care Sensitive Hospitalisations

Ambulatory care sensitive (ACS) conditions are a number of illnesses (mainly chronic diseases) that have been identified as contributing most to unnecessary emergency hospital admissions. Adequate care can safely be provided in primary care for these conditions.

Rates of admissions for ACS amongst adults with learning disabilities were similar across NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City (Figure 7.6). Admission rates were significantly higher amongst adults with learning disabilities in NHS Nottinghamshire County and NHS Nottingham City compared to the general adult population. Rates were higher in NHS Bassetlaw as well, however due to the smaller population size the rate was not significantly higher.

Figure 7.6: Crude admission rates for Ambulatory Care Sensitive Conditions for adults with a learning disability and the general adult population, combined and by primary care organisation, 2004-08 average



Source: SUS data – Local Data Warehouse System

7.3.2 Out-patient clinic attendance

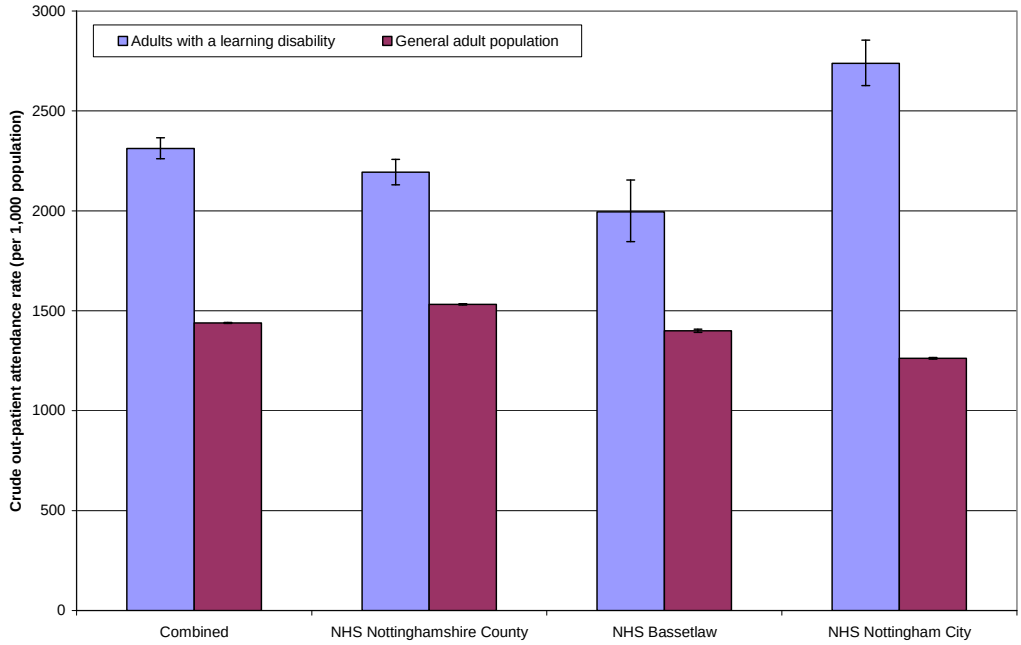
- Adults with learning disabilities have significantly higher attendance rates at out-patient clinics than the general population, ranging from 1.4 times higher in NHS Nottinghamshire County and NHS Bassetlaw to 2.2 times higher in NHS Nottingham City.
- Out-patient attendance rates were significantly higher for adults with learning disabilities in NHS Nottingham City than NHS Nottinghamshire County and NHS Bassetlaw.
- Adults with learning disabilities had significantly higher attendance rates than the general population for the following specialities: neurology, audiological medicine, oral surgery, rehabilitation, orthodontics, maxillo-facial surgery and mental illness.
- Adults with learning disabilities had significantly lower attendance rates than the general population for the following specialities: old age psychiatry, obstetrics, clinical oncology, gynaecology, dermatology, rheumatology and general surgery.

First and follow-up attendances at out-patient clinics across all secondary care providers were included in the analysis, including acute providers and mental health trusts. The total number of out-patient attendances was reviewed, rather than the number of unique individuals attending appointments. Due to incomplete data for previous years, attendances were analysed for 2007 and 2008 (as calendar years), and a 2-year average was calculated.

The out-patient attendance rate was significantly higher for adults with learning disabilities in NHS Nottingham City than in NHS Nottinghamshire County and NHS Bassetlaw (Figure 7.7). Adults with learning disabilities have a significantly higher attendance rate at out-patient clinics than the general population. The greatest difference in rates was observed in NHS Nottingham City, where adults with learning disabilities were 2.2 times more likely to attend out-patient appointments than the general adult population.

No national data on the out-patient attendance has been found so it is not possible to compare this information.

Figure 7.7: Crude out-patient attendance rates (with 95% confidence intervals) for adults with learning disabilities and the general population, by primary care organisation, 2-year average 2007 and 2008



Source: SUS data – Local Data Warehouse System

Attendance at out-patient specialities

Patterns of attendance at out-patient clinics were different between the general population and the learning disabilities population. Unsurprisingly, the out-patient speciality with the highest attendance rate for people with learning disabilities was Learning Disabilities, followed by Audiological Medicine, whereas the out-patient speciality with the highest attendance rate for the general population was Trauma and Orthopedics (Table 7.3).

Table 7.3: Out-patient speciality with the highest attendance rates (average rate/year based on 2007 and 2008 data)

Learning disabilities population		**General population**	
Out-patient speciality	Crude rate per 1,000 population (95% confidence intervals)	Out-patient speciality	Crude rate per 1,000 population (95% confidence intervals)
1. Learning Disabilities	206.4 (191.0-222.6)	1. Trauma and Orthopaedics	68.8 (68.3-69.4)
2. Audiological Medicine	73.7 (64.6-83.6)	2. General Medicine	56.4 (55.9-56.9)
3. Trauma and Orthopaedics	71.4 (62.5-81.2)	3. General Surgery	50.0 (49.5-50.5)
4. General Medicine	64.6 (56.1-73.9)	4. Ophthalmology	47.1 (46.7-47.6)

There are a number of out-patient specialities where adults with learning disabilities have significantly higher or lower attendance rates than the general population (Tables 7.4 and 7.5). In general, the pattern of attendance mirrors that of the published literature into the pattern of health need for people with learning disabilities (Section 4.1.9).

There were no significant difference in attendance rates between adults with learning disabilities and the general population for a number of specialities where the published literature highlights a potential higher need for adults with learning disabilities (Section 4.1.9). These include Diabetic Medicine, Ear, Nose and Throat, Gastroenterology, Geriatric Medicine and Ophthalmology.

Table 7.4: Out-patient specialities for which adults with learning disabilities were significantly more likely to attend, based on yearly average 2007 to 2008

Out-patient speciality	Rate ratio*	Crude attendance rate for adults with learning disabilities (per 1,000 population)	Crude attendance rate for general adult population (per 1,000 population)
Learning disabilities	206.4	206.4[1, 2, 3]	1.0
Neurology	5.5	63.0[1, 2, 3]	11.5
Audiological medicine	4.3	73.7[1, 3]	17.0
Oral Surgery	3.7	40.4[1, 3]	11.0
Rehabilitation	3.4	10.5[1]	3.1
Orthodontics	3.3	2.3[1]	0.7
Maxillo-facial surgery	2.6	6.2[3]	2.4
Mental Illness	1.6	18.3[1]	11.6

* Rate ratio is calculated as (attendance rate for adults with learning disabilities) / (attendance rate for the general adult population)

1 rate is significantly higher for patients registered with NHS Nottinghamshire County
2 rate is significantly higher for patients registered with NHS Bassetlaw
3 rate is significantly higher for patients registered with NHS Nottingham City

Source: SUS data – Local Data Warehouse System

Table 7.5: Out-patient specialities for which adults with learning disabilities were significantly less likely to attend, based on yearly average 2007 to 2008

Out-patient speciality	Rate ratio*	Crude attendance rate for adults with learning disabilities (per 1,000 population)	Crude attendance rate for adults with learning disabilities (per 1,000 population)
Old Age Psychiatry	4.1	1.4[1]	5.7
Obstetrics	3.1	5.2[1, 3]	15.9
Clinical Oncology	2.7	3.5[1]	9.4
Gynaecology	2.5	13.7[1, 3]	34.0
Dermatology	1.7	14.0[1]	24.1
Rheumatology	1.6	7.2	11.4
General Surgery	1.5	34.1[1]	50.0

* Rate ratio is calculated as (attendance rate for the general adult population) / (attendance rate for adults with learning disabilities)

1 rate is significantly lower for patients registered with NHS Nottinghamshire County
2 rate is significantly lower for patients registered with NHS Bassetlaw
3 rate is significantly lower for patients registered with NHS Nottingham City

Source: SUS data – Local Data Warehouse System

7.3.3 Accident and Emergency Department attendances

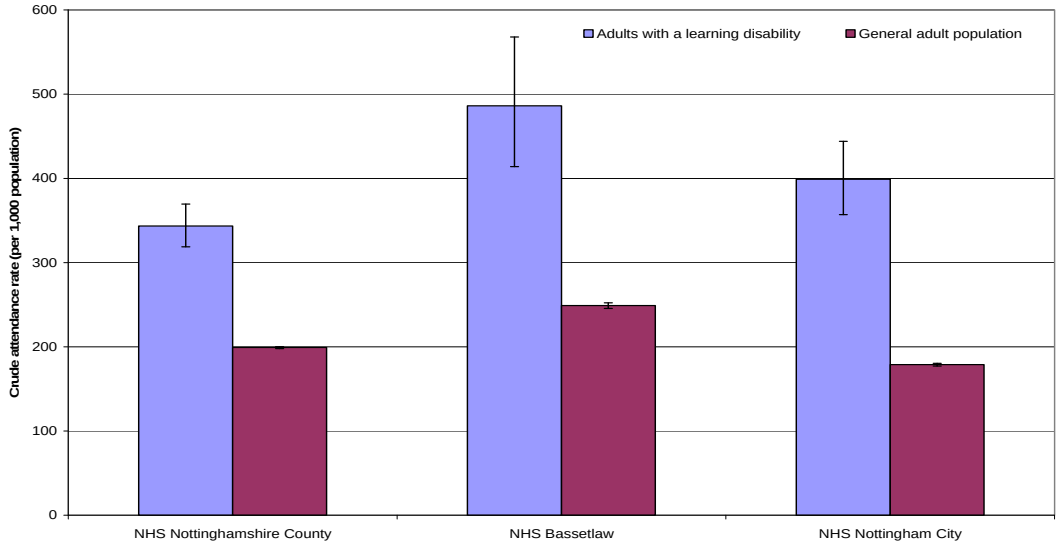
- Adults with learning disabilities had significantly higher attendance rates at A&E than the general population.
- Attendance rates for adults with learning disabilities were significantly higher in NHS Bassetlaw than in NHS Nottinghamshire County.
- Adults with learning disabilities were significantly more likely to attend at A&E and have their reason for attendance coded as nothing abnormal detected, the diagnosis code left blank or as diagnosis not classifiable than the general population.

All attendances at Accident and Emergency (A&E) departments were included in the analysis, rather than the number of unique individuals attending. For NHS Nottingham City, all attendances between 2004 and 2008 were reviewed and a 5-year rolling average used. Complete data was only available for NHS Nottinghamshire County and NHS Bassetlaw for 2007 and 2008. A single 2-year average has therefore been used for NHS Nottinghamshire County and NHS Bassetlaw

In NHS Nottingham City, A&E attendance rates for adults with learning disabilities increased slightly between 2004 and 2008, displaying a similar pattern to that observed in the general population. The highest rates were observed in NHS Bassetlaw, being significantly higher than the rates observed in NHS Nottinghamshire County (Figure 7.8). Attendance rates were significantly higher for adults with learning disabilities when compared to the general population, with rates approximately twice as high across all three Primary Care Organisations (Figure 7.8).

No national data on the accident and emergency admission has been found so it is not possible to compare this information.

Figure 7.8: Crude Accident and Emergency Department annual attendance rates per 1,000 population (with 95% confidence intervals) for adults with a learning disability and the general adult population, for NHS Nottinghamshire County, NHS Bassetlaw* and NHS Nottingham City***



* Average annual attendance rate for 2007 and 2008
** Average annual attendance rate for 2004 to 2008 inclusive
Source: SUS data – Local Data Warehouse System

Reasons for Accident and Emergency Department attendance

An analysis of the reasons for attendance at Accident and Emergency departments was undertaken. As 93.2% of A&E attendances for NHS Bassetlaw did not have a diagnosis classification associated with them, attendances by adults registered with a GP in NHS Bassetlaw were excluded from the analysis.

The most common reason for attendance at A&E amongst adults with a learning disability was contusion/abrasion. Two of the three most common reasons for attendance at A&E were the same for adults with learning disabilities and the general adult population (contusion/abrasion and dislocation/fracture/joint injury/amputation), although attendance rates were approximately twice as high amongst adults with a learning disability (Table 7.6).

Table 7.6: Reasons for attendance at Accident and Emergency Department with highest rates for adults with a learning disability in NHS Nottinghamshire County and NHS Nottingham City, 2007 and 2008

	Adults with learning disabilities (rate per 1,000 population)	General population (rate per 1,000 population)
1	Contusion/abrasion (30.4)	Dislocation/fracture/joint injury/amputation (15.9)
2	Cerebro-vascular conditions (27.6)	Sprain/ligament injury (15.0)
3	Dislocation/fracture/joint injury/amputation (25.0)	Contusion/abrasion (14.4)

Source: SUS data – Local Data Warehouse System

Due to the differences in the time periods analysed, the reasons for attendance at A&E departments were analysed separately for NHS Nottinghamshire County and NHS Nottingham City. There were a number of reasons for attendance that were significantly higher for adults with learning disabilities and the general population for both NHS Nottinghamshire County and NHS Nottingham City (Tables 7.7 and 7.8). These included cerebro-vascular conditions, central nervous system conditions, psychiatric conditions, contusions/abrasions, gastro-intestinal conditions, lacerations and dislocations/fractures/joint injury/amputations.

Adults with a learning disability were also significantly more likely to attend A&E departments and have their attendance recorded as *nothing abnormal detected*, *diagnosis not classifiable* or *diagnosis code left blank* (Tables 7.7 and 7.8). As discussed in Section 4.1.3, diagnostic overshadowing (when a presenting symptom of physical or mental illness is incorrectly attributed to the individual's learning disability) is common in adults with a learning disability and may explain the higher rates of non-diagnosis and nothing abnormal detected observed in A&E attendance rates.

Table 7.7: Conditions for which adults with learning disabilities registered with NHS Nottinghamshire County were significantly more likely to attend Accident and Emergency Departments, based on yearly average 2007 to 2008

Reason for attendance	Rate ratio*	Crude attendance rate for adults with learning disabilities (per 1,000 population)	Crude attendance rate for general adult population (per 1,000 population)
Central Nervous System conditions (excluding strokes)	9.8	15.6	1.6
Psychiatric conditions	6.5	6.5	1.0
Cerebro-vascular conditions	5.6	18.0	3.2
Social problem (including chronic alcoholism and homelessness)	3.2	2.9	0.9
Head injury	3.1	6.5	2.1
Poisoning (including overdose)	2.4	5.8	2.4
Gastrointestinal conditions	2.1	12.0	5.7
Contusion/abrasion	2.0	26.6	13.5
Laceration	1.9	20.9	11.2
Dislocation/fracture/joint injury/amputation	1.5	23.0	15.1
Nothing abnormal detected	3.1	14.9	4.8
Diagnosis not classifiable	2.2	53.2	24.3
Diagnosis code left blank	2.2	63.0	29.3

* Rate ratio is calculated as (attendance rate for the general adult population) / (attendance rate for adults with learning disabilities)
Source: SUS data – Local Data Warehouse System

Table 7.8: Conditions for which adults with learning disabilities registered with NHS Nottingham City were significantly more likely to attend Accident and Emergency Departments, based on yearly average 2004 to 2008,

Reason for attendance	Rate ratio*	Crude attendance rate for adults with learning disabilities (per 1,000 population)	Crude attendance rate for general adult population (per 1,000 population)
Cerebro-vascular conditions	8.7	39.1	4.5
Central Nervous System conditions (excluding strokes)	4.1	8.7	2.1
Psychiatric conditions	3.6	6.5	1.8
Contusion/abrasion	2.4	39.8	16.4
Gastrointestinal conditions	2.1	17.6	8.5
Lacerations	1.9	26.1	13.6
Dislocation/fracture/joint injury/amputation	1.7	29.9	17.7
Nothing abnormal detected	6.0	3.6	0.6
Diagnosis not classifiable	2.7	42.7	16.1
Diagnosis code left blank	2.1	27.3	13.3

* Rate ratio is calculated as (attendance rate for the general adult population) / (attendance rate for adults with learning disabilities)
Source: SUS data – Local Data Warehouse System

7.4 Analysis of secondary care activity by Practice-based Commissioning clusters

- Due to the small number of clusters and smaller population sizes of cluster populations there are very few significant differences in admission and attendance rates between clusters in NHS Bassetlaw and NHS Nottingham City when compared to the overall PCT rate.
- In NHS Nottinghamshire County the clusters in the north of the county have significantly higher in-patient admission rates than the overall PCT rate, and clusters in the south of the county have significantly lower in-patient admission and A&E attendance rates than the overall PCT rate.

Secondary healthcare use (in-patient admissions, out-patient clinic attendances and Accident and Emergency attendances) was reviewed by Practice Based Commissioning (PBC) cluster. PBC clusters are groups of GP practices that are collectively involved in commissioning health services for their patients.

In NHS Bassetlaw and NHS Nottingham City, rates of secondary healthcare use were similar between clusters. In NHS Nottinghamshire County however, there is variation in secondary health care use by adults with a learning disability between the GP clusters. PBC clusters in the north of the county in general had significantly higher rates of secondary health care use than clusters in the south of the county. As detailed in Section 6.3.3, clusters in the north of NHS Nottinghamshire County have a higher recorded prevalence of adults with learning disabilities. The rates of secondary care activity have been reviewed on a per 1,000 population with a learning disability basis, which would therefore standardise for differences in recorded prevalence rates between clusters.

Table 7.7: Crude in-patient admission, out-patient attendance and A&E attendance rates by Practice-based Commissioning clusters

	Crude in-patient admission rate per 1,000 population with a learning disability (95% confidence intervals), 2004-2008	Crude out-patient attendance rate per 1,000 population with a learning disability (95% confidence intervals), 2007-2008	Crude A&E attendance rate per 1,000 population with a learning disability (95% confidence intervals)*
NHS Nottinghamshire County	**323.4 (299.4, 348.7)**	**2193.4 (2130.3, 2257.9)**	**343.5 (318.8, 369.6)**
High Point	367.3 (324.9, 412.5)	2026.4 (1926.3, 2130.3)	426.8 (381.5, 475.9)
Middleton Lodge	760.6 (571.4, 992.4)	2197.2 (1865.9, 2570.3)	169.0 (87.3, 295.2)
Newark and Sherwood PbC Group	493.0 (419.5, 574.3)	2650.5 (2477.4, 2832.4)	437.7 (369.1, 515.3)
Nottingham East Consortium	175.6 (136.6, 222.2)	2104.3 (1963.3, 2252.8)	241.7 (195.6, 295.5)
Nottingham West	258.9 (196.3, 331.9)	2062.8 (1881.7, 2256.6)	324.7 (255.4, 407.0)
Principia	170.4 (124.6, 224.1)	2341.5 (2166.9, 2526.5)	230.6 (178.2, 293.7)
Unclustered	140.0 (20.8, 400.3)	2150.0 (1556.0, 2896.0)	75.0 (5.4, 320.8)
NHS Bassetlaw	**429.2 (360.8, 505.4)**	**1995.4 (1845.7, 2154.1)**	**486.3 (413.9, 567.8)**
Bassetlaw PbC Group	380.7 (296.5, 478.9)	1847.6 (1657.9, 2053.1)	318.2 (242.5, 410.0)
Unclustered	493.0 (384.3, 622.8)	2190.1 (1953.5, 2447.6)	707.7 (576.2, 860.4)
NHS Nottingham City	**388.4 (347.1, 433.2)**	**2738.2 (2626.7, 2853.3)**	**399.0 (356.8, 444.1)**
Chilvers McCrea	400.0 (178.9, 742.8)	4456.5 (3635.7, 5407.4)	556.5 (285.2, 939.0)
City Central	512.7 (355.1, 702.0)	2894.4 (2512.1, 3318.3)	431.0 (290.9, 611.5)
NorComm	392.3 (328.5, 465.0)	2610.6 (2441.4, 2788.4)	367.6 (305.6, 437.7)
Robin Hood	362.1 (304.4, 425.4)	2719.7 (2559.7, 2887.1)	411.1 (349.7, 478.5)
UniComm	No adults with learning disability registered at practices in this cluster		

*A&E attendance rate information relates to 2007-08 for NHS Nottinghamshire County and 2004-2008 for NHS Nottingham City

Crude rate significantly higher than Primary Care Organisation rate

Crude rate significantly lower than Primary Care Organisation rate

Source: SUS data – Local Data Warehouse System

7.5 Specialist learning disability services

- Currently differences exist in activity levels amongst community and in-patient specialist learning disability services provided by Nottinghamshire Healthcare Trust.

Data was received from Nottinghamshire Healthcare Trust detailing the number of individuals referred to specialist community learning disability services and admitted to specialist learning disability in-patient units between April 2009 and January 2010. This was the first time the monthly patient level data sets had been provided and there were some concerns about the data provided particularly to the number of repeat referrals received for some clients. Clarification is therefore required, and only a basic analysis of data was undertaken.

Community services
A total of 2,147 individuals were referred 5,394 times to specialist learning disability community services provided by Nottinghamshire Healthcare Trust. Referral rates to each community service were calculated based on the estimated population of adults with learning disabilities (Table 7.8).

The main differences in the referral rates between the three primary care organisations were as follows:

- A lower referral rate in NHS Bassetlaw for physiotherapy
- A lower referral rate in NHS Nottingham City for Speech and Language Therapy
- A lower referral rate in NHS Nottingham City for Short Breaks (Community Contacts)
- A higher referral rate in NHS Nottinghamshire County for Daycare
- A lower referral rate in NHS Bassetlaw for Community Assessment and Treatment Teams

Whereas some of these differences can be explained by differences in provision of services in each locality (for example NHS Bassetlaw have not had a Community Assessment and Treatment service), further exploration will be required to gain a better understanding of whether provision of services is appropriate for local need.

In-patient services
A total of 123 individuals were admitted 441 times to specialist in-patient units at Nottinghamshire Healthcare Trust. Referral rates to each community service were calculated based on the estimated population of adults with learning disabilities (Table 7.9).

Again whereas differences between referral rates can be explained by differences in provision of services in each locality (for example NHS Nottingham City do not commission Nottinghamshire Healthcare Trust for provision of continuing in-patient care services), further exploration will be required to gain a better understanding of whether provision of services is appropriate for local need.

Table 7.8: Referrals to Nottinghamshire Healthcare Trust specialist learning disability community services, by Primary Care Organisation, April 2009 – January 2010

Service	NHS Nottinghamshire County		NHS Bassetlaw		NHS Nottingham City	
	Number of referrals	Rate of referrals per 1,000 estimated total population of adults with learning disabilities*	Number of referrals	Rate of referrals per 1,000 estimated total population of adults with learning disabilities*	Number of referrals	Rate of referrals per 1,000 estimated total population of adults with learning disabilities*
Consultant Psychiatrists	734	68.9 (64.0 – 74.1)	122	69.2 (57.5 – 82.7)	361	67.9 (61.1 – 75.3)
Community Nursing	564	52.9 (48.7 – 57.5)	108	61.3 (50.3 – 74.0)	278	52.3 (46.3 – 58.8)
Clinical Psychology	429	40.3 (36.5 – 44.3)	71	40.3 (31.5 – 50.8)	168	31.6 (27.0 – 36.8)
Physiotherapy	374	35.1 (31.6 – 38.8)	10	5.7 (2.7 – 10.4)	176	33.1 (28.4 – 38.4)
Speech and Language Therapy	316	29.7 (26.5 – 33.1)	70	39.7 (31.0 – 50.2)	132	24.8 (20.8 – 29.5)
Occupational Therapy	271	25.4 (22.5 – 28.7)	44	25.0 (18.1 – 33.5)	159	29.9 (25.5 – 35.0)
Epilepsy Nursing Service	191	17.9 (15.5 – 20.7)	31	17.6 (12.0 – 25.0)	109	20.5 (16.8 – 24.7)
Short breaks (Comm Cnts)	148	13.9 (11.7 – 16.3)	40	22.7 (16.2 – 30.9)	43	8.1 (5.9 – 10.9)
Daycare	145	13.6 (11.5 – 16.0)	12	6.8 (3.5 – 11.9)	27	5.1 (3.3 – 7.4)
Community Assessment and Treatment Teams	89	8.4 (6.7 – 10.3)	<5	-	59	11.1 (8.5 – 14.3)
Music Therapy	39	3.7 (2.6 – 5.0)	<5	-	35	6.6 (4.6 – 9.2)
Art Therapy	31	2.9 (2.0 – 4.1)	<5	-	<5	-

* estimated population of adults with learning disabilities calculated as 2% of July 2009 PCT registered populations. NHS Nottinghamshire County n=10,654, NHS Bassetlaw n=1,762 and NHS Nottingham City n=5,314

Source: Nottinghamshire Healthcare Trust

Table 7.9: Admissions to Nottinghamshire Healthcare Trust specialist learning disability in-patient services, by Primary Care Organisation, April 2009 – January 2010

In-patient service	NHS Nottinghamshire County		NHS Bassetlaw		NHS Nottingham City	
	Number of referrals	Rate of referrals per 1,000 estimated total population of adults with learning disabilities*	Number of referrals	Rate of referrals per 1,000 estimated total population of adults with learning disabilities*	Number of referrals	Rate of referrals per 1,000 estimated total population of adults with learning disabilities*
Short Breaks	165	15.5 (13.2 – 18.0)	<5	-	186	35.0 (30.2 – 40.4)
Continuing In-Patient Care	29	2.7 (1.8 – 3.9)	8	4.5 (2.0 – 8.9)	0	0 (0 – 0.7)
Assessment and Treatment	25	2.3 (1.5 – 3.5)	5	2.8 (0.9 – 6.6)	11	2.1 (1.0 – 3.7)
Locked Rehabilitation	9	0.8 (0.4 – 1.6)	0	0 (0 – 2.1)	0	0 (0 – 0.7)

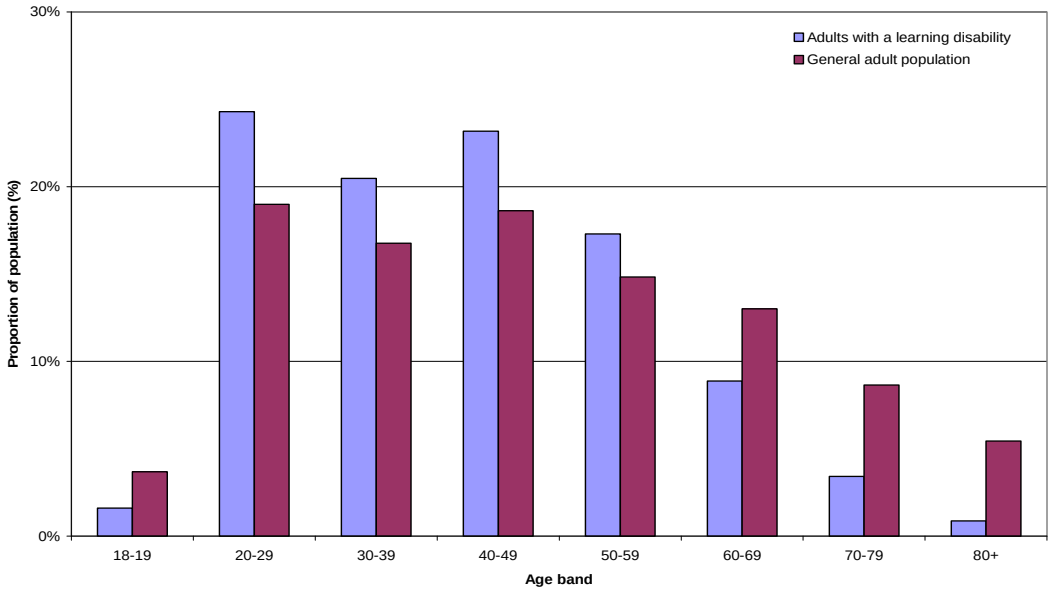
* estimated population of adults with learning disabilities calculated as 2% of July 2009 PCT registered populations. NHS Nottinghamshire County n=10,654, NHS Bassetlaw n=1,762 and NHS Nottingham City n=5,314
Source: Nottinghamshire Healthcare Trust

7.6 Mortality
7.6.1 Life expectancy

- The age profiles of adults with learning disabilities known to Adult Social Care services in Nottinghamshire suggest a shorter life expectancy than the general population.
- An analysis of death certificates demonstrated a median age of death of 56 years for adults with learning disabilities recorded on the death certificate, compared to 80 years for individuals with death certificates where learning disabilities was not recorded.
- Pneumonia was the most common cause of death in individuals with learning disabilities recorded on the death certificate, followed by aspiration pneumonia and cardio-respiratory failure.

The age profiles of the combined adult population of NHS Nottingham City, NHS Nottinghamshire County and NHS Bassetlaw and adults with learning disabilities known to Adult Social Care and Health show a distinct difference (Figure 7.9). A higher proportion of the learning disabilities population are aged 20-59 and a lower proportion aged 60 and above, compared to the general population. This would suggest that people with learning disabilities in Nottinghamshire die younger than the general population.

Figure 7.9: Age profile of general population and adults with learning disabilities known to Adult Social Care services



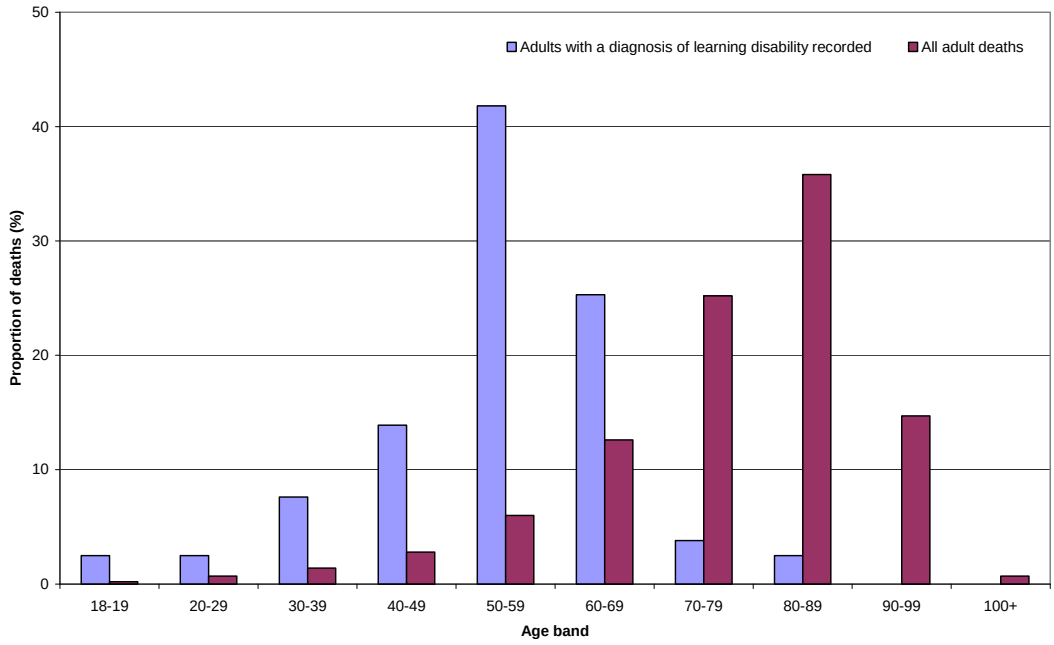
Source Adult Social Care services, Nottinghamshire County Council and Nottingham City Council. PCT population from registered population table July 09

Further evidence of adults with learning disabilities having a shorter life expectancy than the general population is demonstrated by reviewing the deaths of adults aged 18 or over that occurred within Nottinghamshire (including Nottingham City and Bassetlaw) between 2004 and 2008. Identification of all adults that had a learning disability recorded on the death certificate was undertaken, using the following ICD-10 codes: [216]

- F70-79 (mental retardation)
- Q85.1 (Tuberous Sclerosis)
- Q86 (Foetal Alcohol Syndrome)
- Q87.1 (Prader-Willi Syndrome)
- Q90 (Down's Syndrome)
- Q91 (Edwards Syndrome and Patau's Syndrome)
- Q99.2 (Fragile X Syndrome)

A total of 79 deaths were identified, with the majority occurring between 50-69 years of age, with a peak at 50-59 (Figure 7.10). The median age of death was 56, compared to the median age of death for the general population of 80.

Figure 7.10: Proportion of deaths by age band of adults that had a learning disability diagnosis recorded on their death certificate and all deaths in Nottingham and Nottinghamshire, 2004-08

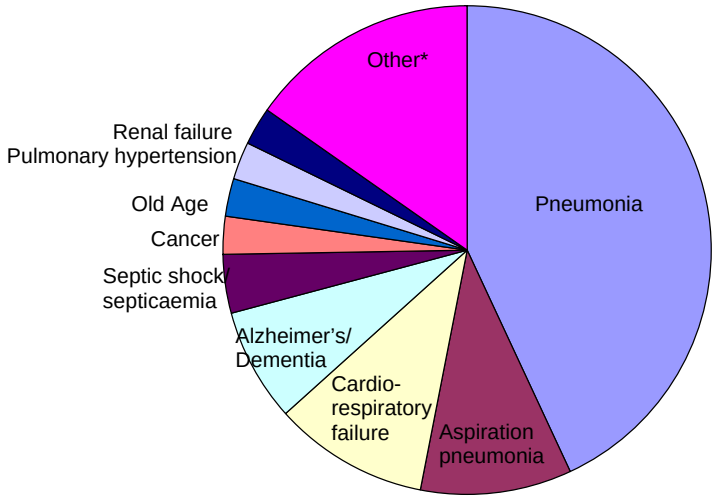


Source: Office of National Statistics

7.6.2 Causes of death

The majority of the 79 deaths identified were primarily caused by respiratory disease, in particular pneumonia which accounted for 43.0% of all deaths (Figure 7.11).

Figure 7.11: Causes of death of adults with a learning disability recorded on their death certificate in Nottingham and Nottinghamshire, 2004-08



*Other causes of death include cerebral atrophy, cerebral ischaemia, congenital heart disease, diabetes, Down's Syndrome, epilepsy, myocardial infarction, multi-organ failure, multiple strokes, peritonitis, pulmonary oedema and respiratory arrest
Source: Office of National Statistics

7.6.3 Recording of learning disabilities on death certificates

Using estimated age-specific mortality rates[217] and data provided by Adult Social Care services at Nottingham City Council and Nottinghamshire County Council the expected number of deaths per year amongst those known to Adult Social Care services is 48.3 (Table 7.10). As a total of 79 deaths between 2004 and 2008 were identified (see Section 7.5.1), giving a mean annual death rate of 15.8, this suggests that learning disabilities is only recorded on death certificates for 32.7% of the local population of adults with learning disabilities.

Table 7.10: Expected number of deaths per year of adults with learning disabilities in Nottinghamshire (including Bassetlaw and Nottingham City)

Age	Age-specific estimated annual mortality rate (per 1,000)*	Frequency**	Expected number of deaths per year
18-29	5.07	840	4.26
30-39	6.62	664	4.40
40-49	8.61	752	6.47
50-59	21.38	561	11.99
60-69	34.96	288	10.07
70-79	70.04	111	7.77
80+	118.59	28	3.32
Total		**3,244**	**48.29**

Source:* Emerson and Hatton (2008) *Estimating future need for adult social care services for people with learning disabilities in England*
** Data provided by Adult Social Care and Health, Notts County Council and Nottingham City Council

8 CURRENT SERVICES FOR ADULTS WITH LEARNING DISABILITIES

Findings

- Prevention initiatives are in place.
- There are relatively few specific health improvement projects for adults with learning disabilities and it is uncertain as to how many adults with learning disabilities access generic health improvement projects.
- All practices have a register of adults with a learning disability.
- All practices in Bassetlaw have signed up to deliver the Learning Disability Directed Enhanced Service (LD DES). Just under 90% of GP practices in Nottingham City and Nottinghamshire County have signed up to deliver the LD DES.
- All three PCT's have primary healthcare facilitators in post.
- Both Nottingham University Hospital Trust and Sherwood Forest Hospital Trust have acute liaison nurses.
- There are integrated Community Learning Disability Teams in Nottinghamshire County and Bassetlaw and co-located teams in Nottingham City.
- There are Assessment and Treatment beds and Community Assessment and Treatment Teams for all three PCT areas.
- Short break provision is available.
- The Lifestyles team is supporting campus re-provision.
- There are a number of care homes across the whole county providing places for adults with learning disabilities.
- There is a specialist epilepsy service for those with learning disability and complex epilepsy.
- Nottinghamshire County and Bassetlaw have high dependency/locked rehabilitation beds.
- A pilot project has taken place to address the needs of people with learning disability in prisons.
- Health actions plans are available to adults with learning disabilities.
- There is an agreed list of 400 symbols to support everyday words for adults with learning disability in Nottinghamshire.

Key issues

- It is unclear how prevention initiatives are targeted at high risk groups.
- It is unclear as to how many adults with learning disabilities access generic health improvement projects.
- The total number of people with a health action plan across Nottinghamshire is unknown.
- The total number of health checks that have been delivered and the quality of these is still unknown.
- There are currently no mechanisms in place at acute hospitals to proactively identify patients with learning disabilities.
- There is currently no acute liaison nurse for Bassetlaw District General Hospital.
- There are no processes in place to identify those adults that come into contact with the criminal justice system in Nottinghamshire.
- Although there is an agreed list of 400 symbols to support everyday words in Nottinghamshire, these are not consistently used across all organisations and the Learning Disability Partnership Boards.

The first part of this section considers what primary prevention services are being delivered at a local level (Table 8.1). The second part scopes service provision and interventions available across NHS Nottingham City, NHS Nottinghamshire and NHS Bassetlaw using the tiered approach to care for people with learning disabilities[64] as introduced in Section 5.1 (Table 8.2).

A Tiered Approach to Care for People with Learning Disabilities

Tier 0	Community resources and supports, housing and support packages, education and learning, employment, healthy lifestyle initiatives and policy development.
Tier 1	Primary health care services, directly accessed services and their supporting services.
Tier 2	Generic secondary (outpatient, inpatient and tertiary) health services accessed via primary health care services and their supporting services.
Tier 3	Specialist learning disabilities services provided by Local Authorities, NHS and the independent sector.
Tier 4	Supra-specialist (tertiary) learning disabilities services provided by Local Authorities, NHS, and the independent sector.

Source: Health Needs Assessment for Scotland (2004)

Table 8.1: Primary prevention services and interventions available in Nottinghamshire

Pre Tier 0 - Primary Prevention			
	NHS Nottingham City	**NHS Nottinghamshire County**	**NHS Bassetlaw**
Prevention prior to conception			
Genetic counselling	Genetic counselling is available at Nottingham University Hospital for both Nottingham City and Nottinghamshire County.		Genetic counselling is available at Sheffield or Nottingham University Hospitals
Prevention during pregnancy			
Down's screening	Current services are not to national standards – work is in progress to ensure that appropriate Down's screening services are available.		Screening services are available
Pregnancy screening	All women are screened for syphilis. All women are screened for rubella immunity and if not immune are offered vaccination after delivery.		
18-21 week foetal anomaly scan	All women are scanned. This may pick up physical problems that are often associated with learning disabilities.		
Prevention of prematurity	Implementation of Healthy Start to those pregnant women who are eligible.	Implementation of Healthy Start to those pregnant women who are eligible.	Implementation of Healthy Start to those pregnant women who are eligible.
Alcohol	Primary care staff trained in screening for alcohol and delivery of brief intervention.	Primary care staff trained in screening for alcohol and delivery of brief intervention.	Primary care staff trained in screening for alcohol and delivery of brief intervention.
Folic acid	NUH antenatal records – folic acid not included.	SFHT use the West Midlands Perinatal Institute notes. Option to record folic acid, however data not currently being collated on this.	DBH use the West Midlands Perinatal institute notes. Option to record folic acid, however data not currently being collated on this.
Prevention after birth			
New born blood spot testing	Every child is offered blood spot screening at 5-8 days of age and will be provided with treatment within 21 days if needed.		

Table 8.2: Scoping of service provision and interventions across NHS Nottinghamshire City, NHS Nottinghamshire County and NHS Bassetlaw

Tier 0 – Community resources and supports, housing and support packages, education and learning, employment, healthy lifestyle initiatives and policy development. (The wider determinants of health such as accommodation, education and learning and employment are acknowledged to play an important role in improving the health and well-being of people with learning disabilities; however this section will focus on health aspects only).			
Service	**NHS Nottingham City**	**NHS Notts County**	**NHS Bassetlaw**
Healthy lifestyle initiatives/health improvement projects	Pacesetter Project (Healthy Hearts) funded during 09/10 Plant Tastic allotment Directory of leisure services for adults with a learning disability Football for Fun – John Carroll Leisure Centre Smile: No Bullying scheme (Mencap)	Pacesetter Project (Healthy Hearts) funded during 09/10 Mansfield – Active Choices Allotment Active@arena – improving health through physical activity. Walking for Health group – Broxtowe Dig In community allotment – Broxtowe Forestry commission deliver woodland workshops for people with LD – Newark Nottinghamshire Supported Living Service – Basic Personal Care MOT Smile: No Bullying scheme (Mencap)	Pacesetter Project (Healthy Hearts) funded during 09/10 The Stage of Life – arts and wellbeing project Nottinghamshire Supported Living Service – Basic Personal Care MOT Smile: No Bullying scheme (Mencap)
Tier 1 – Primary health care services, directly accessed services and their supporting services and paid and family carers			
Service	**NHS Nottingham City**	**NHS Notts County**	**NHS Bassetlaw**
Quality Outcomes Framework LD register	All practices have LD register	All practices have LD register	All practices have LD register

Annual Health Checks (LD DES)	52/60 (87%) of practices signed up to deliver the LD DES (as of 31st March 2010). 348 health checks (40% of those eligible) were completed in 2009/10[e]	85/97 (87%) practices have signed up to deliver the LD DES (as of 31st March 2010). 1,275 health checks (54% of those eligible) were completed in 2009/10[f]	All practices have signed up to deliver the LD DES. 60 health checks were completed in 2009/10
Health Facilitators	3 wte[g] health facilitators employed by CitiHealth	4 wte[g] health facilitators employed by Nottingham Community Health to cover all PBC clusters	1 wte[g] health facilitator.
Tier 2 – Generic secondary (outpatient, inpatient and tertiary) health services accessed via primary care services, and their supporting services and paid family carers.			
Service	**NHS Nottingham City**	**NHS Notts County**	**NHS Bassetlaw**
Acute Liaison Nurses	2 wte[g]: 1 wte[g] Band 7 and 1 wte Band 6 employed by Notts Healthcare and deployed at NUH.	1.7wte[g]: 1wte[g] - Band 7 employed by Sherwood Forest Hospitals NHS Trust 0.7wte[g] Band 6 (part of a team for NUH) employed by Notts Healthcare Trust.	There is currently no acute liaison nurse for Bassetlaw District General Hospital.
Mechanism to identify and flag patients with learning disabilities.	NUH currently looking to develop a system	SFHT currently looking to develop a system	No information for Bassetlaw District General hospital

[e] Data from financial claims submitted by practices
[f] Data extrapolated from figures obtained from practices
[g] wte – whole time equivalents

Tier 3 – Specialist learning disabilities services provided by Local Authorities, NHS and the independent sector, and paid and family cares in support of these.			
Service	**NHS Nottingham City**	**NHS Notts County**	**NHS Bassetlaw**
Integrated Community Learning Disability Teams – multidisciplinary and multi-agency teams. This service is delivered by a range of learning disability specialist professionals including: • Registered Learning Disability Nurses • Speech & Language Therapists • Occupational Therapists • Physiotherapists • Psychiatrists • Psychologists • Arts Therapists • Administration support services	Three co-located CLDT across Nottingham (NHCT): Nottingham East CLDT, Nottingham North CLDT, Nottingham South CLDT.	6 integrated CLDT across Nottinghamshire (NHCT): Ashfield CLDT, Newark CLDT, Mansfield CLDT, Rushcliffe CLDT, Gedling CLDT, Broxtowe CLDT.	1 integrated CLDT in Bassetlaw (NHCT) Bassetlaw CLDT.
Day Services - Health	Horizon Day Treatment Hospital – NHCT Flexible Day Services – Broad Street, Nottingham (NHCT)	10 places at Horizon/Highbury (NHCT) Newark – Holly Lodge (NHCT) provides service for over 60's with learning disabilities that	Whitegates (NORSACA)

		are starting to experience age related health needs including dementia. Mansfield – Abbot Road and Springfield (NHCT) Flexible day services - jointly commissioned with Nottingham and Nottinghamshire Adult Social Care Services and NHS Nottingham	
Day services – Local Authority These offer a range of activities some of which are aimed at health improvement and healthy lifestyles.	Nottingham City Council – Springwood, Bestwood and Summerwood ▪ Leisure access programme ▪ Rebound therapy (trampolineing at Harvey Hadden) ▪ Football at Southglade ▪ Other work happening at Day Centres e.g. allotment project External – West Area Project, Norsaca and Mencap	Nottinghamshire County Council – Ernehale Lea (Arnold), Barnscroft (Beeston), Whitewater (Ollerton), Friary (Newark), Redoaks (Rainworth), Willowwood (Sutton in Ashfield), Rushcliffe.	Greenacres – 1 whole time equivalent nurse and 1 Health Care Assistant employed
Hearing service	Missing Out Hearing Service, Nottingham	Missing Out Hearing Service	

Tier 4 – Supra-specialist (tertiary) learning disabilities provided by Local Authorities, NHS and the independent sector, and paid and family cares in support of these.			
Service	**NHS Nottingham City**	**NHS Notts County**	**NHS Bassetlaw**
Community Assessment and Treatment teams – (CATT)	Nottingham CATT team (NHCT)	Covered by Nottingham and County CAT team. Art Therapy project in Mansfield and Ashfield CATT.	Covered by the County CAT team.
Assessment and Treatment Unit	NHCT	NHCT contract: Nottingham 12 beds at Highbury (jointly commissioned with Nottingham City) Mansfield – 6 beds at Lindsay Close	NHCT contract: Mansfield – 1 bed at Lindsay Close.
Short breaks – health and local authority (Planned residential breaks)	Hucknall House, Highbury Hospital (NCHT) Oakdene	Newark 8 beds (Newlands) (NCHT) Helmsley Road, Rainworth Kingsbridge Way, Chilwell Wynhill Court, Bingham Oaklands – independent care home in Warsop	Holles Street, Worksop
Campus beds	0 beds	25 beds - resettlement required by 2010 Lifestyles team supports people being discharged from campus.	All 8 resettled Lifestyles team set up to support people being discharged from campus.
Care Homes (Voluntary sector/Private/local authority)	27 care homes in total providing 299 places. (5 voluntary/charity (28 places); 20 private (224 places); 2 local authority (47 places)	81 care homes in total providing 863 places. (16 voluntary/charity (145 places); 56 private (611 places), 8 local authority (87 places) and 1 other (20 places)	12 care homes in total providing 108 places. (5 voluntary (47 places); 6 private (51 places); 1 local authority (10 places)

	Excellent rating (CQC) – 3 (All private)	Excellent rating (CQC) – 9 (4 voluntary/charity, 4 private and 1 local authority.	Excellent rating (CQC) – 4 (2 voluntary/charity and 2 private)
	Good rating (CQC) – 16 (3 voluntary/charity, 12 private and 1 local authority.	Good rating (CQC) – 47 (10 voluntary/charity, 31 private, 5 local authority and 1 other.	Good rating (CQC) – 6 (3 voluntary/charity, 2 private and 1 local authority.)
	Adequate rating (CQC) – 6 – 1 voluntary/charity, 4 private & 1 Local authority	Adequate rating (CQC) – 11 (1 voluntary/charity and 10 private	Adequate rating (CQC) – 0
	Poor rating (CQC) - 0	Poor rating (CQC) - 0	Poor rating (CQC) – 1 – (Private)
	Not yet rated (CQC) – 2 (1 voluntary/charity and 1 private)	Not yet rated (CQC) – 14 (2 voluntary/charity, 11 private and 1 local authority.	Not yet rated (CQC) – 1 (Private)
Out of Area placements	November 09 – 19 low secure (8 in region, 11 out of region)	November 09 – 23 locked rehabilitation/low secure/supported living for complex needs.	
Continuing Care	Numbers known to Continuing Care (as at 31st March 2010): Fully funded: 27 adults with LD Joint funded: 123 adults with LD	Numbers known to Continuing Care (as at 31st March 2010): Fully funded: 22 adults under 65 with LD and 1 adult over 65 with LD Joint funded: 216 adults under 65 with LD and 1 adult over 65 with LD.	Nurse assessor in post for continuing care for people with LD.
Specialist epilepsy service	Diagnosis and treatment for adults with complex epilepsy and LD. Partnership with the neurology services at NUH and specialist LD services.		
High dependency/locked rehabilitation	10 individuals placed in non-NHS placements	Mansfield 7 beds (Alexander House). Unit meets the needs of male adults with a learning	Mansfield 1 bed (Alexander House)

		disability who have high dependency /low secure needs detained under the Mental Health Act 1983	
Prisons	HMP Nottingham City – NHCT 6 month pilot project funded during 09/10 to address the needs of people with learning disabilities in prison.	HMP Whatton and Lowdham Grange - NHCT 6 month pilot project funded during 09/10 to address the needs of people with learning disabilities in prison.	HMP Ranby - NHCT 6 month pilot project funded during 09/10 to address the needs of people with learning disabilities in prison.
Work across the five tiers			
Function	**NHS Nottingham City**	**NHS Notts County**	**NHS Bassetlaw**
Health Action Plans / Personal Health File	Health plans are available. Uncertainty on uptake of these across Nottinghamshire.		
Communication	Agreed list of about 400 symbols to support everyday words. Consistent with the system used across Nottinghamshire schools. Identified that these are not used consistently.	Agreed list of about 400 symbols to support everyday words. Consistent with the system used across Nottinghamshire schools. Identified that these are not used consistently.	Agreed list of about 400 symbols to support everyday words. Consistent with the system used across Nottinghamshire schools. Identified that these are not used consistently.

9. HEALTH EQUITY AUDIT

Findings

- It has not been possible to undertake a health equity audit due to time limits of this health needs assessment.

Key issues:

- A health equity audit for both primary care and specialist services will take place in the future, which will outline the current inequalities in the provision of health care for people with learning disabilities and outline action for improvement. It is anticipated that a health equity audit for primary care will be completed by March 2011. Once completed it will be included as an appendix to this report.

Promoting equity involves minimizing inequity. Inequity means a difference (inequality) which is unfair. Typically, socially-marginal and economically-deprived groups have the greatest overall need for health care but are least able to obtain it.

Health Equity Audits (HEAs) assist with ensuring that resources are appropriately targeted. It is a process by which local partners can:

- Systematically review inequities in the causes of ill health and in access to effective services and their outcomes for a defined population.
- Ensure that action required is agreed and incorporated into local plans, services and practice.
- Evaluate the impact of the actions on reducing inequity.

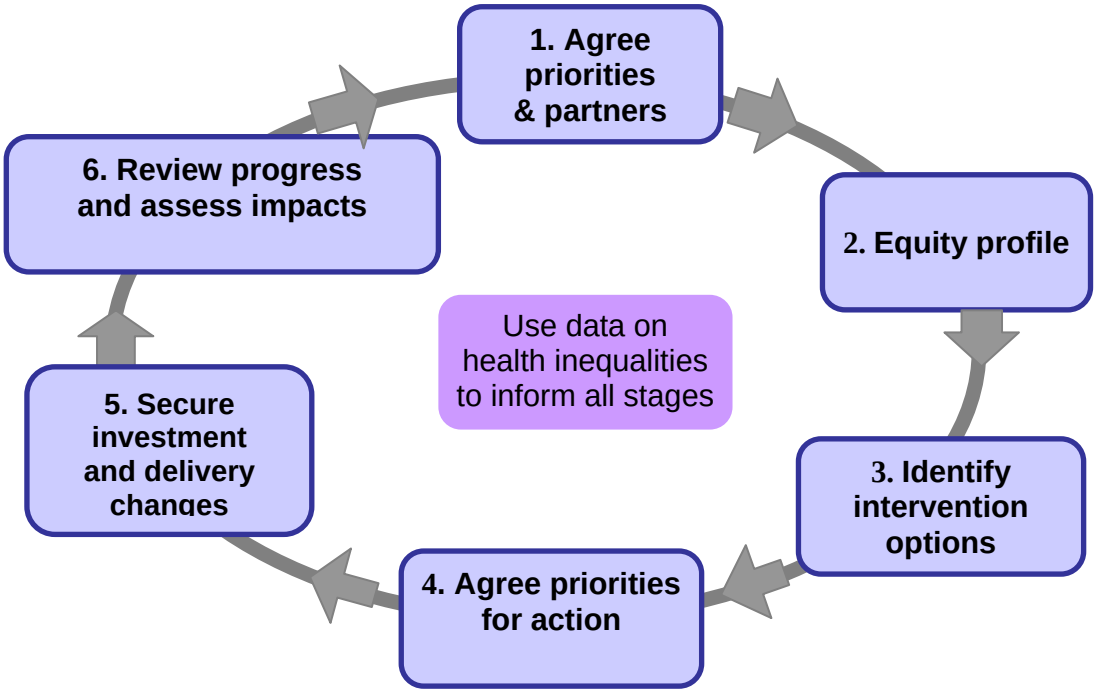
Equity audits can enable commissioners and providers of services to ensure that resources are directed towards tackling inequities and can:

- Inform the commissioning of services.
- Contribute to local performance management of public services.
- Support partnership working and the allocation of resources.
- Encourage community involvement in the NHS and across local strategic planning processes.

9.1 The Health Equity Audit cycle

The Health Equity Audit cycle has 6 stages as identified in Figure 9.1.

Figure 9.1 The Health Equity Audit cycle



When conducting a health needs assessment it is usual to undertake a health equity audit to identify any current inequalities that there are. It has not been possible to undertake a health equity audit due to the time limits of this health needs assessment. Health equity audit for primary care and specialist services will take place in the future, which will outline the current inequalities in the provision of health care for people with learning disabilities and outline action for improvement. It is anticipated that a health equity audit for primary care will be completed by March 2011. Once completed, it will be included as an appendix to this report.

9.2 Health Equity Audit of Quality and Outcomes Framework registers in NHS Nottingham City

In 2009, NHS Nottingham City was commissioned by the Health Inequalities National Support Team to review exclusion and exception[h] reporting from GP practice Quality and Outcomes Framework registers. The aim of the project

[h] **Exclusions** refer to patients who are unsuitable or ineligible for a disease domain, and are therefore excluded from all indicators relating to that register. **Exceptions** refer to patients who are recorded on the disease register and would be eligible for the care described in the indicator but are excepted from the indicator for one of the nine reasons defined in the QOF guidance.[207]

was to try and identify whether patients with certain characteristics were more likely to be excluded from QOF disease registers, or excepted from some of the management indicators associated with these chronic conditions. Patients recorded as being on the QOF learning disability register were analysed as one of the patient characteristics that may be more likely to be regularly excluded or exception reported.

The disease registers reviewed were:

- Chronic Obstructive Pulmonary Disease (COPD)
- Hypertension
- Coronary Heart Disease (CHD)
- Diabetes

The indicators reviewed were:

- BP5 The percentage of patients with hypertension in whom the last blood pressure (measured in the previous 9 months) is 150/90 or less.
- CHD 10. The percentage of patients with coronary heart disease who are currently treated with a beta blocker.
- CHD 8. The percentage of patients with coronary heart disease whose last measured total cholesterol (measured in the previous 15 months) is 5mmol/l or less.
- DM 20. The percentage of patients with diabetes in whom the last HbA1c is 7.5 or less in the previous 15 months.

Due to low numbers recorded on the disease registers it wasn't possible to calculate whether adults with a learning disability were more likely to be excluded from the COPD and CHD registers. Adults with a learning disability were not more likely to be excluded from the hypertension register, and there was a borderline significant increase in the likelihood of being excluded from the diabetes register.

Adults with learning disabilities were more likely to be excepted from the diabetes indicator, but not significantly so. Adults with learning disabilities were not more likely to be excepted from the other QOF indicators analysed.

The health equity audit suggests that adults with learning disabilities are not routinely excluded or excepted from QOF disease registers. However as observed in Section 6.3.3 then the QOF learning disability registers are not comprehensive and only record approximately one fifth of the estimated true prevalence of adults with learning disabilities, and this may impact on the analysis.

10 CORPORATE VIEWS

Findings

- Completion of the 2009 SHA performance and self assessment framework on the provision of health care/services identified that improvements are needed to mainstream healthcare service provision for adults with learning disabilities. Each PCT has identified targets to achieve. All include the provision of annual health checks and health action plans in primary care.
- All three PCTs have primary health care facilitators in post, although not all acute hospitals have acute liaison nurses in post.
- Priorities have been set by the Nottinghamshire Service Review for learning disabilities.

Key issues

- Diagnostic overshadowing is felt to be a problem.
- Systems are not in place to identify adults with learning disabilities in the criminal justice system.
- The Learning Disability Partnership Boards need to monitor health services in more depth than they currently do.
- It is difficult for people with a learning disability to complain about the services that they receive and systems do not enable health services to identify the number of complaints by this group.
- There are no processes in which commissioning groups and Partnership Boards review complaints from adults with learning disabilities and/or their carers/families.

This section is presented in four parts:

- An overview of the self assessment that each PCT conducted in 2009, in which views were obtained from health and social care staff along with those from people with learning disabilities and their families/carers.
- The views of key stakeholders, such as members of the Better Health group and Learning Disability Strategic Commissioning Groups.
- The priorities of the Nottinghamshire Service Review learning disability work stream.
- An overview of complaints made about health services by people with learning disabilities and their families.

10.1 Performance and self-assessment framework

As detailed in Section 3, in 2009 all NHS commissioners in the East Midlands were required to undertake a performance and self-assessment framework that provided a rating across a number of top targets. The assessment was undertaken in consultation with a range of stakeholders, including service-users and carers and has been validated by NHS East Midlands. The top targets assessed were:

Top Target 1: Campus homes will be closed by 2010 and people who lived in long stay hospitals will have moved into their new homes

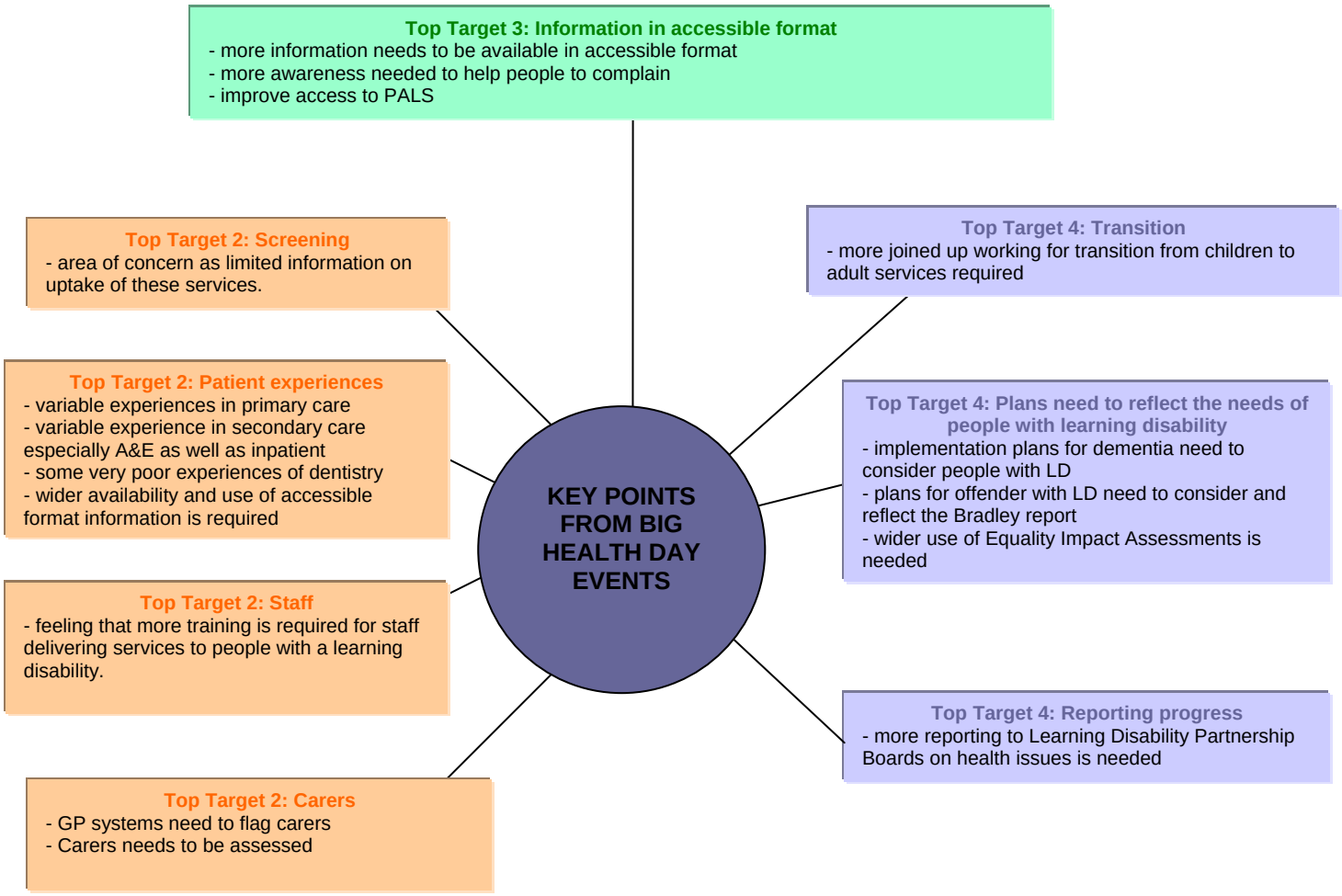
Top Target 2: The PCT is working closely with the Partnership Board and other partners. This means that people with a learning disability can use the same health services and get the same treatment as everybody else

Top Target 3: People with a learning disability are safe in NHS services

Top Target 4: Valuing People Now means we are making services better and creating more opportunities for people with a learning disability

All three PCT's organised 'Getting Ready' events and held a 'Big Health Check' event in June 2009. This, along with the Getting Ready Days, gathered the views and experiences of people with learning disability, family members and health and social care professionals on the provision of health care/services for people with learning disabilities locally. Figure 10.1 provides an overview of the key issues for Top Targets 2, 3 and 4.

Figure 10.1: Key issues in relation to the self assessment Top Targets 2, 3 and 4



Attainment by NHS Nottingham City, NHS Nottinghamshire County and NHS Bassetlaw for each of the Top Targets is shown in Table 10.1.

Table 10.1: Ratings for 2009/10 of local NHS commissioning organisations against the Performance and Self-Assessment Framework

	NHS Nottingham City	NHS Nottinghamshire County	NHS Bassetlaw
Top Target 1			
Top Target 2			
Top Target 3			
Top Target 4			

NHS commissioning organisations were also required to identify areas of work from the framework that would be prioritised locally. The priorities for 2009/2010 are detailed in Table 10.2.

Table 10.2: PCT priorities for 2009/2010 following the self assessment

NHS Nottingham City	NHS Nottinghamshire County	NHS Bassetlaw
Health actions plans and annual health checks	Primary healthcare – health actions plans and annual health checks	Communication and reasonable adjustments
Actions identified in relation to 'Six Lives' and 'Healthcare for all'	Actions to deliver the recommendations of 'Six Lives' and 'Healthcare for all'	Primary care and GP practice – up take of health checks
Prisons	Effective and comprehensive local specialist services	Acute care in hospitals
Training and workforce issues		Transition

The ratings attained in 2009 have provided a baseline measure on which future performance can be benchmarked.

10.2 Stakeholder views

As part of this Health Needs Assessment process a number of semi-structured interviews have also taken place to obtain additional views and thoughts about current service provision. Figure 10.2 provides an overview as to what people feel is working well in relation to health provision for people with a learning disability and Figure 10.3 provides an overview as to where people feel there is a gap or there are issues for people with learning disability.

Figure 10.2: What's working well in Nottinghamshire (including Bassetlaw and Nottingham City) in relation to health provision for adults with a learning disability.

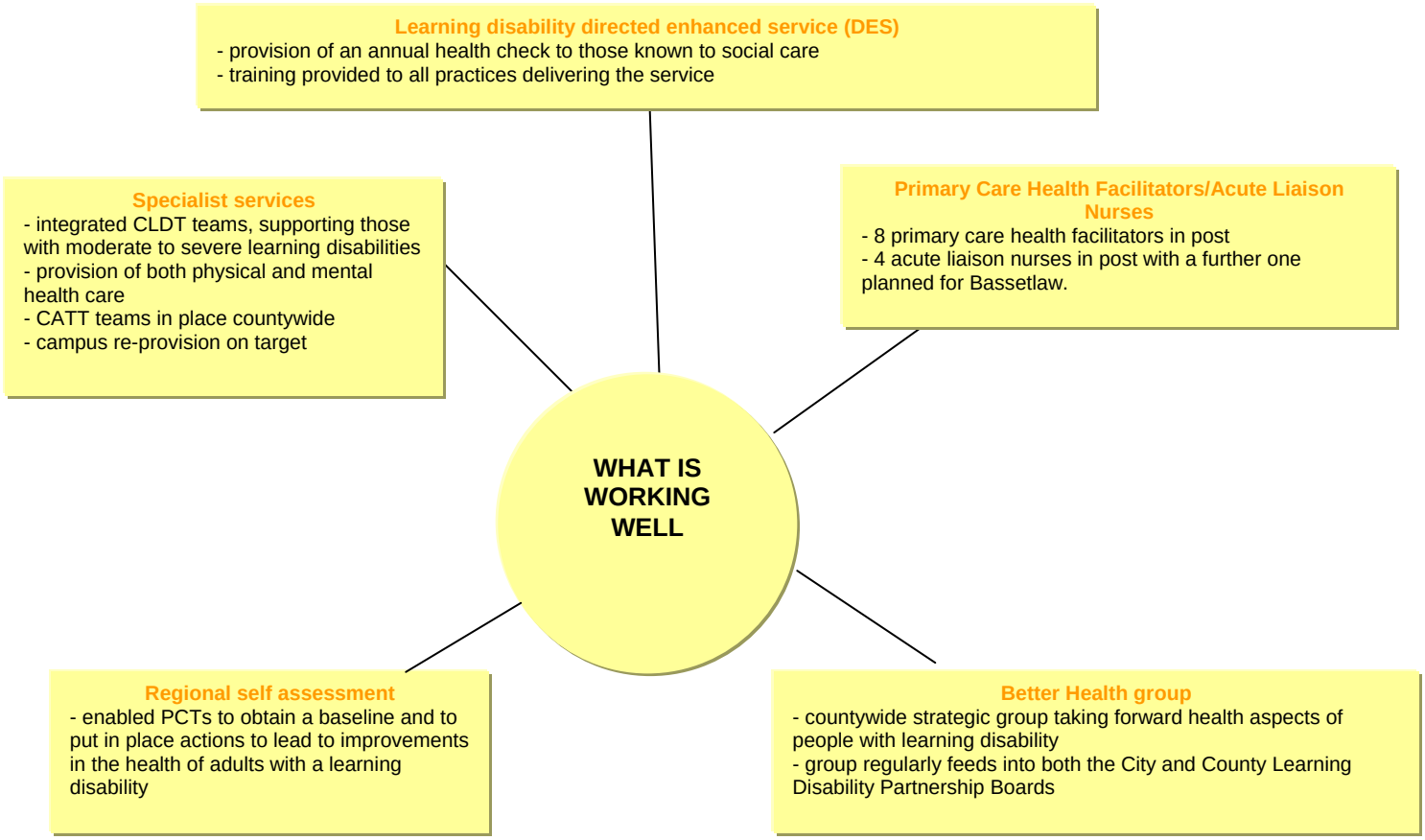
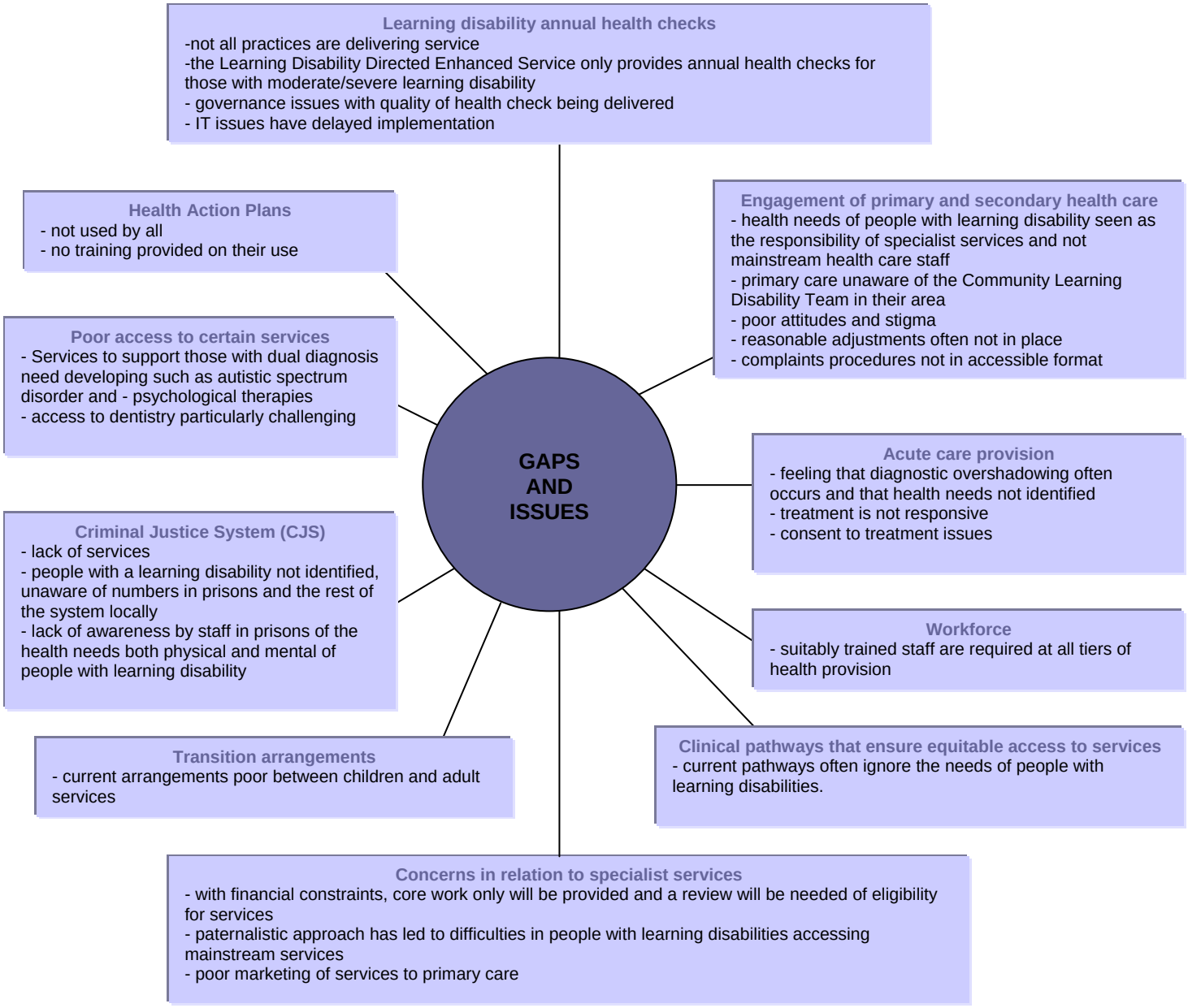


Figure 10.3: Issues and perceived gaps in service provision in Nottinghamshire (including Bassetlaw and Nottingham City) for adults with a learning disability



10.3 Nottinghamshire Service Review (NSR) learning disability workstream

The Nottinghamshire Service Review (NSR) priorities are given in Section 3.3.2. These priorities were submitted to and approved in 2009 by:

- NSR Clinical Leadership Group
- NSR Programme Board
- Nottingham City Learning Disability Partnership Board
- Nottinghamshire County Learning Disability Partnership Board
- Nottinghamshire County Learning Disability Strategic Commissioning Group

10.4 PALS enquiries and Complaints

PALS (Patient Advice and Liaison Service) and Complaints teams at NHS Nottingham City, NHS Nottinghamshire County, NHS Bassetlaw, Nottinghamshire Healthcare Trust, Nottingham University Hospitals and Sherwood Forest Hospitals were approached to determine whether PALS and Complaints teams record enquiries made by or on behalf of an adult with learning disability. The responses from the organisations are provided in Table 10.3.

Table 10.3: Summary of availability of complaints and enquiries made by or on behalf of adults with a learning disability, by NHS organisation

NHS Organisation	Response
NHS Nottinghamshire County	Not available. Information collected on whether individual has a disability, but system does not differentiate between physical and learning disabilities.
NHS Bassetlaw	The PALS team are unaware of any complaints made by or on behalf of an adult with a learning disability. They are currently developing an accessible complaints leaflet, to support complaints by this population group.
NHS Nottingham City	Not available. Information collected on whether individual has a disability, but system does not differentiate between physical and learning disabilities.
Nottinghamshire Healthcare Trust	Not available. Information collected on whether individual has a disability, but system does not differentiate between physical and learning disabilities. However, PALS/complaints team can extract information by team/ward/service and therefore information available on enquiries and complaints with regards specialist Learning Disability services.
Nottingham University Hospitals Trust	Information not routinely collected, though recently introduced a "special requirements" section in complaints management plan will capture presence of learning disability if made aware. More complex PALS enquiries could also use this process to capture information.
Sherwood Forest Hospitals Trust	Not available. Information collected on whether individual has a disability, but system does not differentiate between physical and learning disabilities. The Trust is working with Acute Liaison Nurse to identify enquiries and complaints from individuals with a learning disability.

Source: PALS/complaints teams at NHS organisations

11 COMPARATIVE ASSESSMENT

Findings

- All three PCT's compare favourably to other PCTs in both the East Midlands and Yorkshire and Humber regions for campus re-provision, being safe in NHS services and meeting the Valuing People Now recommendations. They compare less favourably with other areas on provision of mainstream health services for adults with learning disabilities.

Key issues

- Mainstream health care services for people with learning disabilities appear to be an area of priority for all 3 PCT's in Nottinghamshire.
- Specialist effective and comprehensive service provision for people with learning disabilities in Bassetlaw is also an area for improvement.

Across the country, PCTs have been undertaking the learning disabilities performance and self-assessment framework. This section compares how well NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City are doing to other PCTs in the East Midlands and to PCTs within the Yorkshire and Humber region which completed the self assessment for the first time in 2008.

Table 11.1 compares the performance of the three Nottinghamshire PCT's with those in the rest of the East Midlands (2009) and to PCT's in the Yorkshire and Humber region (2008). It has not been possible to obtain information for 2009 from other regions across the UK, so this has limited the ability to compare the three PCT's in Nottinghamshire with other parts of the country. It is hoped that in subsequent health needs assessments that these will be available to enable comparison to other PCT's across the whole of the England.

The three PCT's compare favourably to other PCTs in both the East Midlands and Yorkshire and Humber regions for the top targets on campus reprovision, being safe in NHS services and also meeting the Valuing People Now recommendations. They all compare less favourably to top target 2 which considers mainstream health services for people with learning disabilities. As discussed in Section 10, actions to improve mainstream services have been identified by all three PCT's for improvement in the next year.

Table 11.1: Comparison of performance of NHS Nottinghamshire County, NHS Bassetlaw and NHS Nottingham City with PCTs in the rest of the East Midlands (2009) and the Yorkshire and Humber region (2008)

	Very unhappy with this	Not happy with this	More work to do on this	Happy with this	Very happy with this
Top Target 1: Campus homes will be closed by 2010 and people who lived in long stay hospitals will have moved into their new homes					
Y&H Region^	2		4	1	10
EM Region*			2	1	6
City					✓
County					✓
Bassetlaw					✓
Top Target 2: The PCT is working closely with the Partnership Board and other partners. This means that people with a learning disability can use the same health services and get the same treatment as everybody else					
Y&H Region^	7	1	9		
EM Region*	2	3	4		
City		✓			
County		✓			
Bassetlaw	✓				
Top Target 3: People with a learning disability are safe in NHS services					
Y&H Region^	3	3	5	3	3
EM Region*		1	8		
City			✓		
County			✓		
Bassetlaw			✓		
Top Target 4: Valuing People Now means we are making services better and creating more opportunities for people with a learning disability					
Y&H Region^	2	7	6	2	
EM Region*	2	1	6		
City			✓		
County			✓		
Bassetlaw		✓			

^ Numbers indicate the number of PCTs that have attained this rating across the whole of the Yorkshire and Humber region in 2008
** Numbers indicate the number of PCTs that have attained this rating across the whole of the East Midlands region in 2009*

12 LIMITATIONS OF HEALTH NEEDS ASSESSMENT

Due to the scale of the information included, this Health Needs Assessment has taken much longer than originally anticipated and there are still areas in which it has not been possible to obtain information.

12.1 Literature review of health needs and effectiveness of services

The evidence base for both the health needs and effectiveness of services is limited and there are significant gaps. In general the quality of studies are poor, often due to poor sample sizes. There are very few systematic reviews that review all the research evidence available to provide a balanced view on what the studies have found. It is hoped that for future Health Needs Assessments that there will be more good quality research for the evidence base sections.

12.2 Epidemiological information

Information has been readily available for those with moderate/severe learning disabilities however it has not been possible to obtain information about the health needs of those with mild learning disabilities. This group are not known to specialist services and currently those with a mild learning disability are not being identified. It is hoped that as QOF registers improve that more information will become available about the healthcare needs of this group.

It has not been possible to obtain in depth information about transition between children's and adult health services. This is identified as being a piece of work that needs to be undertaken and will be considered in the future.

12.3 Pattern of health need

Due to time constraints, analysis of data extracted from primary care has not been undertaken. Therefore we have not been able to provide information on the prevalence and management of chronic conditions for adults with learning disabilities in primary care. This is a piece of work that will be undertaken in the future and will be included as an appendix in this report.

This Health Needs Assessment does not cover dental issues in great depth as a Special Care Dentistry Strategy has been developed, in which a needs assessment has been undertaken. This identifies the services required and has developed a care pathway.

12.4 Current services

Whilst every effort has been made to ensure that this report is as up to date as possible, due the time that it has taken to complete it, it may be possible that some of the information given may not reflect any new services/initiatives or any changes to existing projects that may have happened.

12.5 Health equity audit

It has not been possible to undertake a health equity audit due to time limits. Health equity audits for both primary care and specialist services will be undertaken in the future and included as an appendix to this document.

12.6 Corporate views

It has not been possible to analyse any complaints made by people with learning disabilities or their family/carers about health services as it is currently not possible to identify those complaints that are from this particular group of individuals.

12.7 Comparative assessment

There is very limited information available to compare the performance locally to other PCTs across the country. This has limited the ability to reliably compare ourselves to other PCTs. It is hoped that as the results of self assessments from PCT's across the country become more freely available that it will enable us to compare ourselves more robustly in the future.

13. GAPS

In the last few years it has become increasingly recognised that people with learning disabilities face many types of health inequalities as highlighted in this report. The health and health needs of people with learning disabilities is now a higher priority than it has been in the past. The evidence base regarding the nature and scale of health needs and strategies for addressing inequalities is small due to the lack of high quality research for this population group. Based on the literature review and analyses conducted for this health needs assessment, the gaps identified are given below. The recommendations of the Health Needs Assessment are given in Section 14.

Strategy/Policy

- There is no process locally to systematically identify and implement national policy documents relating to learning disability.
- Corporate strategies and plans of PCTs would benefit from considering and emphasising the health needs of adults with learning disabilities and the impact that improving the health of this population group can have in reducing the health inequality gap.
- The health needs of adults with learning disabilities in Nottinghamshire are not adequately reflected in both the Joint Strategic Needs Assessments (JSNAs).
- Reports on the health of adults with learning disability have not been presented regularly at the Learning Disability Partnership Boards.
- Performance management is currently not reviewed at Learning Disability Joint/Strategic Commissioning Groups.

Identification and recording of adults with learning disability

- The prevalence of learning disability on practice Quality and Outcomes Framework (QoF) learning disability registers is lower than expected and may be due to under-identification and/or under-reporting.
- There is limited knowledge on the health needs of adults with learning disabilities from Black and minority ethnic communities, older people and those with profound and multiple learning disabilities.
- There is currently little information on the health needs of adults with mild learning disability in Nottinghamshire
- For most health teams there is no mechanism to identify children coming through transition from children to adult health services.
- There are currently no processes in place locally to identify those adults that come into contact with the criminal justice system.
- Learning disability is not always used as a sub-diagnosis in secondary care and on death certificates making analysis of patterns of healthcare use incomplete.

Prevention

- Although there are prevention measures to reduce the incidence of learning disability it is unclear how these are targeted, particularly to high risk groups.

Healthy lifestyle initiatives

- There are few specific healthy lifestyle initiatives for this population group and very little information on the numbers of adults with learning disabilities accessing lifestyle interventions.

Primary care

- Not all GP practices across Nottinghamshire have signed up to deliver the Learning Disability Directed Enhanced Service (DES) which provides an annual health check to those adults with moderate to severe learning disability.
- It is currently not known how many of those adults with learning disabilities who are eligible for an annual health check are accessing this, the quality of the health checks offered and the physical / mental health outcomes.
- A lower proportion of eligible adults with learning disabilities are participating in cancer screening programmes than the general population.
- There is currently lack of evidence of the effectiveness of primary care health facilitators in improving the health outcomes of people with learning disability in primary care.

Secondary care

- There are currently no mechanisms in place at acute hospitals to proactively identify adults with a learning disability to ensure that pathways of care are reasonably adjusted to meet the health needs of these patients.
- All hospitals in Nottinghamshire need to ensure that suitable level of quality of care is provided to adults with learning disabilities, including the provision of reasonable adjustments.
- The appropriateness of acute admissions (including the lengths of stay) and attendances is unclear.

Specialist services

- The impact that specialist services have on the health outcomes of adults with learning disabilities is with learning disabilities is unclear.
- Further information is required on specialist services provided to adults with learning disabilities in each PCT.
- There is limited information and understanding about out-of-area placements for adults with learning disabilities.

- Current service provision may not be sufficient to meet the increasing numbers of adults with learning disabilities in the future.

Across all tiers

Health action plans

- The number of adults with learning disabilities that have a health action plan is currently not known.
- Health action plans are currently not being used effectively as a tool to either inform different services of a persons health needs or to help to inform future commissioning strategies.

Dental services

- Poor experiences of dental services both in the community and acute hospitals are reported.

Complaints

- For most health organisations there is very little information on the number of and types of complaints made by people with learning disabilities and their families/carers.

Patient and Public Involvement

- More in-depth views and experiences of people with learning disabilities and their carers in relation to access to health care are needed to shape services in the future.

Training and Workforce Development

- The awareness and knowledge of primary and secondary health care staff have of the issues for people with learning disabilities is currently low.

Clinical pathways

- It is unknown if local clinical pathways consider the needs of people with learning disabilities.

End of life

- It is unclear if the needs of adults with learning disabilities at the end of life are being met.

Communication

- There is no consistency in the use of aids to communicate with adults with learning disabilities across all organisations in Nottinghamshire.

Transition

- Transition between primary and secondary healthcare services is reported to be poor at times.

Safeguarding adults

- The effectiveness of systems that are in place to ensure that adults with learning disabilities are safe when they access and use health services is unclear.

Equitable access to health services

- It is unclear if there is equitable access to health services for adults with learning disabilities.

Improvement across all health services

- The SHA performance and self assessment framework has identified gaps in health services.

14 RECOMMENDATIONS

The gaps and recommendations identified during completion of this Health Needs Assessment have been reviewed by Nottinghamshire County and Nottingham City Learning Disability Partnership Boards, Joint/Strategic Commissioning Groups and the Better Health group. The Better Health Group is tasked with monitoring the implementation of the recommendations to further improve the health of adults with learning disabilities that live in Nottinghamshire, and reduce the health inequalities they currently experience.

Strategy/Policy

- Ensure suitable processes are in place locally to strategically take forward national policy documents.

- The Learning Disability Partnership Boards with support from the Better Health group should influence PCT corporate strategies to raise the profile of health issues for adults with learning disabilities, address ways to tackle those conditions that cause premature death in this population group, and support work to tackle inequalities in health.

- Information on the health needs of adults with learning disabilities in Nottinghamshire should be included in the Joint Strategic Needs Assessments.

- Joint commissioning strategies and plans should be developed and updated to reflect the health needs for adults with learning disabilities (taking into account national strategies and local current and projected need) and their implementation regularly monitored and reviewed.

- Joint commissioning groups should ensure that plans are in place to meet the needs of:

    - Increasing numbers of adults with learning disabilities.
    - Increasing numbers of older adults with learning disabilities.
    - Those coming through transition.

- Regular reports on health issues and the work of the Better Health group should be presented at Learning Disability Partnership Board meetings.

- Performance of providers should be reviewed at Learning Disability Joint/Strategic Commissioning Groups.

Identification and recording of adults with learning disability

- Primary care should be encouraged to identify and record people with learning disability across the whole learning disability spectrum to improve the completeness and quality of the registers.

- Local authority data should be used to identify those practices that under-report adults with moderate and severe learning disabilities and these practices should be prioritised for support.

- Primary care, secondary care and specialist services need to record ethnicity and severity of learning disability.

- Primary care data on ethnicity should be reviewed.

- Analysis of data is required to improve knowledge of the healthcare needs and treatment for those within Black and minority ethnic communities, older people and those with profound and multiple learning disabilities.

- Improved recording of severity of learning disability in primary care is required to further understand the health needs of those with mild learning disabilities.

- There should be improvement in and better management of continuity and co-ordination of care at transition between children and adult health services. Mechanisms need to be in place to identify children coming through transition from children to adult services to ensure they are recorded on learning disability registers.

- Systems need to be put in place locally to improve the identification and services provided for those adults with learning disability in the criminal justice system to ensure that their needs are recognised and met.

- Improving the recording of learning disability as a sub-diagnosis in secondary care coding and on death certificates will improve understanding in the health needs of adults with learning disabilities.

Prevention

- Prevention measures should be encouraged and targeted at those with a higher risk of having a child with a condition that is associated with learning disability. These include:
    - genetic counselling, including education on the risks of consanguinity.
    - screening (in pregnancy and in the first few days of life) and diagnostic tests (that meet national standards).
    - immunisation for rubella and measles.

- programmes to reduce alcohol consumption of women of child bearing age.
- folic acid supplementation.

Healthy lifestyle initiatives

- Ensure that all services promote the opportunity for healthy lifestyles for adults with learning disability.

- Ensure that all PCT commissioned lifestyle interventions (such as weight management and exercise referral schemes) are accessible to adults with learning disabilities and that this population group have comparable outcomes to the general population.

- Equality Impact Assessments should be completed for all services and monitored regularly.

Primary care

- All GP practices should be encouraged to provide annual health checks through participation in the Learning Disability Directed Enhanced Service.

- Alternative providers should be commissioned to provide annual health checks for those patients whose GP practice is not participating in the Directed Enhanced Service.

- The quality of health checks should be monitored.

- Systems should be set up to ensure regular monitoring of the numbers of people accessing an annual health check.

- A health equity audit should be conducted to identify any inequalities that there are in the provision of primary care services for adults with learning disability.

- Ensure that all eligible women with learning disabilities are offered and supported to attend breast and cervical screening.

- Adults with learning disabilities should be encouraged and supported to take part in the bowel cancer screening programme.

- The reasons why adults with learning disabilities are not being invited to participate in cancer screening programmes and why, if they are, they don't attend or participate needs to be better understood.

- The higher rates of women with learning disabilities who are ceased from the cervical screening programme should be explored further to determine whether individuals are being ceased appropriately or not.

- Commissioners should ensure that there are robust service specifications in place for primary healthcare facilitators that include agreed health outcomes.

- An evaluation of the effectiveness of primary care health facilitators in supporting the health needs of adults with learning disability in primary care should be undertaken.

Secondary care

- Systems should be put in place to proactively identify patients with a learning disability who enter acute hospital trusts so that reasonable adjustments are put in place to meet their health needs.

- Quality Panels should develop processes to inform relevant groups on the progress of acute hospitals in meeting the quality schedule measures.

- The quality schedule measures should be reviewed annually to encourage continued service improvement.

- All hospitals should have an acute liaison nurse in post to support adults with learning disability during their hospital care.

- Commissioners should ensure that there are robust service specifications in place for acute liaison nurse service that include agreed health outcomes.

- An evaluation of the effectiveness of acute liaison nurses in supporting the health needs of adults with learning disability in secondary care should be undertaken.

- Further work should be undertaken to review for adults with learning disabilities:
    - the appropriateness of higher rates of secondary care admissions and attendances.
    - the appropriateness of longer lengths of stay.
    - difference between clusters in secondary healthcare use.
    - reasons for higher rates of *nothing abnormal detected*, *diagnosis not classifiable and diagnosis code left blank* in Accident and Emergency attendances.

Specialist services

- Scope health improvement programmes currently occurring in specialist Learning Disability services.

- Commissioners should ensure that there are robust service specifications for all specialist learning disability services that include agreed health outcomes measures.

- The monthly dataset provided by Nottinghamshire Healthcare Trust should be regularly analysed to monitor provision of specialist services within each PCT and also to review patient pathways within the specialist services.

- Out of area placements should be mapped initially and, where possible, reviewed regularly to support future service planning and commissioning of services, in particular in attempting to support these individuals nearer to home.

- Plans need to be in place to consider the increased numbers of adults and older adults with learning disabilities in the future.

Across all tiers

Health action plans

- Systems should be put in place to monitor the number of adults who have a health action plan in Nottinghamshire.

- All adults with learning disabilities should be offered the opportunity to have a health action plan.

- Health action plans need to be promoted as the mechanism to enable all services/providers to be aware of an individual's health needs for all who come into contact with that person with a learning disability, particularly engagement of primary care in health action planning as part of person-centre planning.

- Processes should be put in place to monitor what is being recorded in health action plans to inform both the Joint Strategic Needs Assessment and commissioning strategies.

Dental services

- Commissioners and providers should consider how to ensure optimal opportunities for oral health promotion and improve access to dental services and the quality of care provided.

- The Special Care Dentistry Strategy should be implemented.

Complaints

- Systems should be in place to enable people with learning disability to complain about health services.

- Health organisations should be able to identify complaints from people with a learning disability or their families/carers.

- Service specifications should specify that providers report on complaints made by adults with learning disabilities and their carers.

- Complaints made by or on behalf of adults with a learning disability should be reviewed at Joint/Strategic Commissioning Groups.

Patient and Public Involvement

- Patient engagement and involvement with people with learning disabilities and their families should be ongoing to shape the services that are commissioned.

Training and Workforce Development

- Learning disability awareness training should be part of Equality and Diversity training in all organisations across Nottinghamshire.

- Frontline staff should be offered training on learning disability awareness and have the skills to meet the health needs of people with learning disabilities to enable them to have a much greater understanding and awareness of the health needs of people with learning disability.

Clinical pathways

- All new clinical pathways developed should have an Equality Impact Assessment (EIA) completed to ensure that any adverse impact that it may have on people with learning disabilities is considered.

End of Life

- Further work is needed to quantify and define the end of life care required for adults with learning disabilities.

Communication

- Whilst acknowledging that individuals with learning disabilities will have different ways of communication, to ensure consistency in communication across all organisations in Nottinghamshire an agreed set of symbols/system should be used.

Transition

- There should be an improvement in and better management of continuity and co-ordination of care at transition between primary and secondary care, especially for those with the greatest support needs.

- Implementation of Summary Care Records may assist in the sharing of information between primary and secondary care.

Safeguarding adults

- The Nottinghamshire Six Lives Action Plan should be implemented to ensure that adults with learning disabilities have equity of access to health services and are safe in them.

Equitable access to health services

- All service specifications should state that health services must be accessible for adults with learning disabilities. An Equality Impact Assessment should be completed on all service specifications and services to ensure that any adverse impact that it may have on people with learning disabilities has been considered.

- Health equity audits for both primary care and specialist services should be undertaken.

Improvement across all health services

- Each PCT should implement the action plan as required by the East Midlands Performance and Self Assessment Framework to ensure continuing improvement in health services for adults with learning disabilities.

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