

FINAL

Provision of mainstream healthcare for people with Learning Disabilities

Final Report and Recommendations

March 2009

Task Group Members

Councillor Ray Ballman

Councillor Jim Grant

Contents

- 1. Recommendations**
- 2. Foreword from the Task Group**
- 3. Introduction**
 - 3.1 Rationale for the Review
 - 3.2 Report Overview
 - 3.3 Review Structure
 - 3.4 Aims and Objectives
 - 3.5 Methodology
- 4. Background**
 - 4.1 What is a Learning Disability?
 - 4.2 The Health Needs of People with Learning Disabilities
 - 4.3 National Policy & Guidance
 - 4.4 Barriers to Accessing Healthcare
- 5. The Picture in Swindon**
 - 5.1 Evidence Gathering
 - 5.2 Summary of key issues arising from our consultation with schools
 - 5.3 Health Needs and Health Inequalities
 - 5.4 Current Local Policies and Practices
 - 5.5 Leadership and Ownership
 - 5.6 Health Education and Promotion
 - 5.7 Focussing on Individual Needs
 - 5.8 Care Pathways and Accessing Services
 - 5.9 Transition from Children and Young People's to Mainstream health Services
 - 5.10 Ensuring and Monitoring the Effectiveness of Services
- 6. Summary of Findings**
- 7. Appendices**
 - Appendix 1 Task Group Terms of Reference
 - Appendix 2 Sources of Evidence
 - Appendix 3 Questionnaire produced by the Task Group
 - Appendix 4 Response to Task Group Recommendations by Cabinet

1. Recommendations

Recommendations

Formatted: Bullets and Numbering

That the Cabinet be requested to approve the following recommendations:

1. That Swindon Borough Council be requested to ensure that local charities, community and voluntary groups are made aware of funding streams that they can access to promote healthy eating and physical activity amongst people with Learning Disabilities and their carers.
2. That the Final Report & Recommendations of the Provision of Mainstream Healthcare to People with Learning Disabilities be noted.

That the Health Overview and Scrutiny Committee be requested to approve the following recommendations:

3. That the Health Sub Group of the Learning Disability Partnership Board, local NHS Trusts, community and voluntary organisations that support people with Learning Disabilities and their families and carers are congratulated on the significant amount of work that is underway to reduce health inequalities for people with learning disabilities in Swindon.
4. That Swindon PCT, Great Western Hospitals NHS Foundation Trust and the Avon & Wiltshire Mental Health Partnership NHS Trust be requested to take steps to promote the importance of health professionals working in partnership with people who care for someone with a Learning Disability and to involve them in the care planning process as appropriate. Each Trust to present a summary of the action taken to promote the role of carers and the outcomes of this activity to the Health Overview & Scrutiny Committee in March 2010.
5. That the proposal submitted by the Health Sub Group of the Learning Disability Partnership Board to Swindon PCT and Great Western Hospitals NHS Foundation Trust to create a full time Health Facilitator post for Learning Disabilities be fully supported.
6. That the bid for funding for an e-learning training package that has been submitted by the Health Sub Group be fully supported and that partner organisations be strongly urged to identify suitable resources to meet this bid.
7. That the Health Sub Group of the Learning Disability Partnership Board be requested to investigate the feasibility of establishing a dedicated web page on an existing organisational website that can be used a resource for professionals, carers and members of the public regarding the support available for people with Learning Disabilities and updated on a regular basis. that it is relevant to their needs. An update report to be provided to a future meeting of the Health Overview & Scrutiny Committee.

8. That the Health Sub Group of the Learning Disability Partnership Board be requested to explore the feasibility of producing an Easy Read health and well being newsletter that is circulated to all known service users and their carers at least annually to keep them informed of new initiatives and to communicate health promotion messages. Service users and carers should be involved in the design and production of the newsletter to ensure that it is relevant to their needs. An update report to be provided to a future meeting of the Health Overview & Scrutiny Committee.
9. That the Task group endorses the efforts being made by the Great Western Hospitals NHS Foundation Trust to introduce a 'flag' system on electronic patient records to enable staff to be made aware of the needs of patients with a Learning Disability as soon as possible.
10. That the Great Western Hospitals NHS Foundation Trust be requested to explore the feasibility of introducing training to raise awareness of the needs of patients with Learning Disabilities and the importance of working in partnership with carers as part of its induction programme for all new staff.
11. That Swindon Primary Care Trust provides an update to the Health Overview & Scrutiny Committee in March 2010 regarding the outcomes of the GP Direct Enhanced Service for people with Learning Disabilities.
12. That Swindon PCT be requested to explore the feasibility of appointing a GP Champion for patients with Learning Disabilities to promote their needs amongst colleagues in general practice.
13. That Swindon PCT be requested to explore options to increase the take up of cervical and breast screening amongst women with Learning Disabilities living in Swindon.
14. That Swindon PCT and Swindon Borough Council be requested to ensure that local charities, community and voluntary groups are made aware of funding streams that they can access to promote healthy eating and physical activity amongst people with Learning Disabilities and their carers.
15. That the Public and Patient Involvement Leads from Swindon PCT and the Great Western Hospitals NHS Foundation Trust be requested to work with community and voluntary groups that support people with Learning Disabilities and their carers in Swindon to raise awareness of the Patient Advice and Liaison Service (PALS) and how to make a comment, query or formal complaint in relation to an NHS Trust.
16. That Swindon PCT and the Great Western Hospitals NHS Foundation Trust be requested to explore the feasibility of producing key information in an Easy Read format and to work with service users and carers to identify any other forms of communication that would benefit patients with Learning Disabilities.
17. That Swindon PCT and the Great Western Hospitals NHS Trust be requested to explore options to include symbols on medication labels to make it clearer to people with Learning Disabilities what time of the day the medication should be taken and whether it should be taken with meals.

2. Foreword from the Task Group

“...addressing the difficulties faced by people with learning disabilities in accessing general healthcare services does not require specialist knowledge about learning disabilities; the issues they face are relevant to all members of society¹.”

For many people, going to see their GP can be stressful. Making an appointment can be time consuming and some people find it awkward explaining to the receptionist why they need to see a doctor. The waiting room is often noisy and it is not always easy to work out when your name has been called. During the appointment, it can be difficult to remember all the questions you wanted to ask and to understand what the doctor is saying. Many people forget when they should take prescribed medication and when they should make another appointment to check up on progress in their treatment. Now imagine how difficult this whole experience is for someone with a learning disability.

National research has shown that people with learning disabilities not only experience worse health than the general population but also have poorer access to health services. This issue has been subject of many national reports and inquiries, including the most recent Chaired by Sir Jonathan Michael that concluded that more needs to be done to make NHS services equally accessible to people with learning disabilities².

This report is about the experiences of people with learning disabilities that access NHS services in Swindon. We have spoken to people with learning disabilities, their carers, community and voluntary groups that support people with learning disabilities and representatives from NHS Trusts and the Adult Community Learning Disability Service. We are extremely grateful to everyone who has given up their time to help us with this review.

Although this report only provides a snapshot of the picture in Swindon, it is clear that much exciting work is underway to ensure that people with learning disabilities not only have better access to healthcare but also that they are treated with dignity and respect.

However, people with learning disabilities in Swindon do still face challenges in accessing good quality healthcare. Commissioners, providers and their partners must continue to tackle this issue head on to ensure that everyone in our community can receive the care and treatment to which they are entitled.

Councillor Ray Ballman

Councillor Jim Grant

¹ *Healthcare for All: Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, Sir Jonathon Michael, July 2008

² *Healthcare for All: Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, Sir Jonathon Michael, July 2008

3. Introduction

3.1 Rationale for the Review

National research has found that people with learning disabilities face:

- Increased risk of early death
- Higher prevalence of certain medical conditions
- Having unequal access to mainstream health services
- Having unhealthy lifestyles
- Health inequalities

The role of the NHS in relation to people with learning disabilities should be the same as for the rest of the population to promote health and well-being and to provide treatment in a primary, community, acute or specialist setting.

However, national research suggests that people with learning disabilities often encounter health inequalities and difficulties in accessing local mainstream healthcare services.

The Health Overview & Scrutiny Committee commissioned this review to determine whether sufficient work is taking place in Swindon to reduce the health inequalities faced by people with learning disabilities.

The review was carried out under Section 7 of the Health and Social Care Act 2001, which sets out the power of local authority scrutiny committees to, "...review and scrutinise...matters relating to the health service in the authority's area and to make reports or recommendations on such matters..."

3.2 Report Overview

The report is divided into the following sections:

Recommendations	Details the recommendations from the review
Introduction	Outlines the aims and objective of the review and structure of the report
Background	Provides a background to the health needs of people with learning disabilities
Evidence Gathering	Outlines the approach taken to gather evidence and the evidence collected
Summary	Provides an overview of the review
Appendices	Contains appendices referred to in the main report

3.3 Review Structure

The review was carried out in three phases as outlined below:

Phase	Timescales	Activities
Phase 1 – Consolidation and Work Plan	July 2008	<ul style="list-style-type: none"> • Task Group established • Setting of Terms of Reference • Identification of internal advisors and witnesses • Identification of existing information
Phase 2 – Evidence Gathering	August 2008-February 2009	<ul style="list-style-type: none"> • Desk based research of national best practice • Questionnaires developed and circulated • Meetings with internal advisors and witnesses • Site visits
Phase 3 - Recommendations	February-March 2009	<ul style="list-style-type: none"> • Development of final report and recommendations prior to presentation to the Health Overview & Scrutiny Committee

3.4 Aims and Objectives

To carry out an objective review of the provision of mainstream healthcare services in Swindon to people with learning disabilities to determine what steps have been taken by all NHS bodies and their partners to reduce health inequalities and increase the accessibility of services for this group of patients.

See Appendix 1 for the Terms of Reference of the Task Group.

3.5 Methodology

Evidence was gathered during the course of the review through:

- Desk based research of national policy, guidance and best practice
- Interviewing identified advisors/witnesses
- A questionnaire that was sent to community and voluntary organisations that support people with learning disabilities and their carers
- Several visits to the Open Door Day Centre
- Attendance at a meeting of Better Lives in Swindon (BLIS)
- Attendance at the 'Big Health Day' service user consultation event

4. Background

4.1 What is a Learning Disability?

A learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)
- With a reduced ability to cope independently (impaired social function)
- Which started before adulthood and has a lasting effect on a person's development¹

There are 1.5 million people with a learning disability in the UK (approximately 2-2.5% of the population)³. Learning disabilities can be very mild where people live largely unsupported (approximately 85%). At the other end of the spectrum are people with profound and multiple difficulties who require a great deal of support (1-2%)⁴.

The term does not include people who have an illness or injury that affects the brain during adulthood. One of the criteria for diagnosis is an IQ below 70 but this alone will not dictate whether a person requires additional support. A learning disability is NOT mental illness or dyslexia.

People with a learning disability find it harder than others to learn, understand and communicate. Although a learning disability can never go away, a great deal can be done to support and enable people to live as full a life as possible.

4.2 The Health Needs of People with Learning Disabilities

People with learning disabilities have higher health needs than the general population, many of which are unmet. For example⁵:

- People with learning disabilities are 58 times more likely to die before the age of 50 than the general population⁶
- There is a higher prevalence rate of epilepsy
- Women with learning disabilities are much less likely to undergo cervical smear tests
- Women with learning disabilities are much less likely to engage in breast cancer examinations or receive invitations for screening
- Respiratory disease is the leading cause of death for people with learning disabilities

³ www.mencap.org.uk

⁴ www.patient.co.uk

⁵ *The Healthcare of People with Learning Disabilities in the East Midlands: A Report for the Next Stage Review*, East Midlands Next Stage Review Workstream Group, May 2008

⁶ *Equal Treatment: Closing the Gap*, Disability Rights Commission, 2006

FINAL

- Coronary heart disease is the second most common cause of death amongst people with learning disabilities
- People with learning disabilities are up to 200 times more likely to have vision impairment and 40% have a hearing impairment. Many people are not assessed for these impairments due to staff attributing lower levels of functioning to the person's learning disability and are unlikely to receive aids to vision or hearing.
- The prevalence of dementia is much higher amongst older adults with learning disabilities
- Prevalence rates for schizophrenia are three times greater than for the general population
- People with learning disabilities are much more likely to be either underweight or obese than the general population
- Less than 10% of adults with learning disabilities eat a balanced diet
- Over 80% of adults with learning disabilities engage in levels of physical activity below the minimum recommended by the Department of Health

Some people with learning disabilities may have particular difficulties in communicating with health professionals and others may have behavioural issues that can make it difficult to offer treatment and care.

4.3 National Policy and Guidance

4.2.1 Valuing People

In 2001, the Government produced its White Paper, '*Valuing People: a new strategy for learning disability in the 21st century*'⁷. It set out the Government's plan for making the lives of people with learning disabilities, their families and carers better.

The strategy is based on people with learning disabilities having:

- Their rights as citizens
- Inclusion in local communities
- Choice in daily life
- Real chances to be independent

In relation to health, the Government set the following objective:

"To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support when necessary".

The White Paper acknowledged the challenges facing people with learning disabilities in relation to their health and well being and recognised that the NHS had been slow in developing the skills and capacity to meet their needs.

⁷ *Valuing People: a new strategy for learning disability in the 21st century*⁷, Department of Health, 2001

FINAL

The key actions required by the White Paper to address these problems included:

- Establishing a confidential inquiry into the mortality of people with learning disabilities
- Challenging discrimination against people with learning disabilities from minority ethnic communities
- Identifying health facilitators for people with learning disabilities by 2003
- All people with a learning disability to be registered with a GP by 2004
- All people with a learning disability to have a Health Action Plan by 2005
- All mainstream hospital services to be accessible
- Developing local specialist services for people with severe challenging behaviour

4.2.2 Progress in implementing Valuing People

In 2004, the Government reviewed progress in the implementation of 'Valuing People'⁸. The review found that health inequalities were beginning to be successfully addressed where:

- The health of people with learning disabilities are included in mainstream plans and strategies
- Health action planning is linked to patient centred planning
- There are clear plans for improving health with strong links to the Learning Disability Partnership Board
- There is strong leadership for promoting the health of people with learning disabilities from Strategic Health Authorities and Primary Care Trusts

However, the review found that there was still some way to go to implement the actions outlined in Valuing People.

The Learning Disability Task Force was commissioned to produce Annual Reports reviewing progress in implementing 'Valuing People'. The latest report in 2007⁹ found that although some things had got better for people with learning disabilities, it was unacceptable that people with learning disabilities do not receive the same quality of treatment as other people. Many people with learning disabilities were still not registered with a GP or receiving regular health checks, despite 'Our Health, Our Care, Our Say: A new direction for community services'¹⁰ reaffirming the government's commitment to introducing regular and comprehensive healthchecks. Feedback from people with learning disabilities also suggested that they felt that healthcare professionals did not take them seriously. The Task Force recommended that the Government and NHS addressed the issues identified by the Task Force and by other national reports as a priority.

The enactment of the Disability Discrimination Act 2005 also required the NHS to show that it is taking positive action to address the health inequalities facing people with learning disabilities.

⁸ *The Story So Far... Valuing People*, Valuing People Support Team, 2004

⁹ *Could do Better: The Learning Disability Task Force Annual Report 2006-07*, Learning Disability Task Force, 2007

¹⁰ *Our Health, Our Care, Our Say: A new direction for community services*, 2006

FINAL

In 2007, the Department of Health published '*Valuing People Now*'¹¹ a consultation document outlining the government's priorities for embedding 'Valuing People' and the final 'Valuing People Now' document was published in 2009. 'Valuing People Now' acknowledges that improving the healthcare provided to people with learning disabilities has previously been a low priority for NHS organisations. It outlines national and local actions to help ensure that the NHS fully respects people with learning disabilities as equal citizens including¹²:

- Improved access and information for people with learning disabilities
- Clear identification of people with learning disabilities on GP registers
- Comprehensive annual health checks
- Health Action Plans
- Practitioners helping people navigate their way through primary and secondary care
- Strategic Health Facilitators to improve awareness and capability of health services
- Better communication by the NHS with people with learning disabilities to ensure that their and their carers' voices are heard by organisations and by individual practitioners
- Health services should undertake a Disability Equality Impact assessment in relation to the "choice" agenda for people with learning disabilities
- Training for staff in mainstream healthcare
- Improved links between specialist learning disability services and the rest of the health care system
- Mental health services should provide quality access and care for people with learning disabilities and collaborate with LD services through joint implementation of the Green Light Toolkit¹³.
- Hospitals should implement policies and procedures to support admission, treatment and discharge of people with learning disabilities
- Hospital Trusts should give consideration to recruiting acute liaison nurses for people with learning disabilities
- Public Service Agreement targets to reinforce the importance of promoting the health and well being of people with learning disabilities through mainstream services

4.2.3 Primary Care Service Framework

In July 2007, the Department of Health published the '*Primary Care Service Framework for the Management of Health for People with Learning Disabilities in Primary Care*'¹⁴.

¹¹ *Valuing people now: from progress to transformation – a consultation on the next three years of learning disability policy*, Department of Health, 2007

¹² *The Healthcare of People with Learning Disabilities in the East Midlands: A Report for the Next Stage Review*, East Midlands Next Stage Review Workstream Group, May 2008

¹³ *Green Light for mental health – how good are your mental health services for people with learning disabilities?*, Valuing People Support Team, 2007

¹⁴ *Primary Care Service Framework for the Management of Health for People with Learning Disabilities in Primary Care*, NHS Primary Contracting, July 2007

FINAL

The Framework aims to equip commissioners, practitioners and providers with the background knowledge, service and implementation details to safely commission and deliver a high quality, integrated service for people with learning disabilities in primary care.

Under the Framework, PCTs are required to commission an enhanced service for adults with mild, moderate or severe learning disabilities. The enhanced service aims to:

- Improve equality of access to primary, community and specialist services
- Provide regular, comprehensive healthchecks with appropriate treatment and follow up
- To provide individualised health action plans which help people with learning disabilities become more involved in taking care of themselves and which also involves their carers
- To improve access to health promotion and improvement programmes
- To reduce the need for hospitalisation or the length of stay
- To improve the support for, information, sharing and understanding of the needs of people with learning disabilities and their family carers

Commissioners must also be satisfied that service providers have a regular programme of education, training and support for their staff, extended team and community networks.

Service users and their families must also be involved in the planning, design and delivery of services.

4.4 Barriers to Accessing Healthcare

There have been several high profile national reports highlighting the difficulties that many people with learning disabilities face in not only accessing healthcare but also in receiving the same standard of care and treatment that is expected by the general population. These include:

- *Treat me Right!* (Mencap) that sought to improve the health and healthcare experiences of people with a learning disability
- *Death by Indifference* (Mencap) told the stories of six people with a learning disability who died unnecessarily while in the care of the NHS
- *Equal treatment: closing the gap* (Disability Rights Commission) outlined evidence that people with learning disabilities are more likely than other citizens to die young and to live with physical health problems, many of which are preventable
- *Joint Investigation into the provision of services to people with learning disabilities at Cornwall NHS Partnership Trust* (Healthcare Commission) investigated concerns regarding the care and treatment of people living in assessment and treatment centres provided by the Cornwall NHS Partnership Trust

FINAL

The key issues identified by these reviews included:

- That people with learning disabilities have poorer health than the general population and a lower life expectancy as a result
- That people with learning disabilities are more likely to lead unhealthy lifestyles than the general population, including a poor diet and lack of physical activity
- That mainstream health care professionals have limited understanding of the needs of people with learning disabilities,
- That many health professionals have not received training to help them better meet the needs of people with learning disabilities
- There is a low level of reporting amongst people with learning disabilities and when health screening is carried out, it often shows a high level of unmet needs
- In many cases hospitals expect parents or carers to provide basic care to patients with learning disabilities, even if this is not the wish of the carer
- Hospitals do not always provide appropriate levels of support to patients with learning disabilities
- The suggestion that there is institutional discrimination in the NHS towards people with a learning disability and that they receive worse treatment as a result
- People with learning disabilities experience 'diagnostic overshadowing', where reports of physical ill health are viewed as part of the learning disability and so not investigated or treated
- Evidence that primary care services are not generally making 'reasonable adjustments' as required by the Disability Discrimination Act for people with a learning disability including longer appointment times, providing treatment information in alternative formats or sending text or phone appointment reminders
- Partnership working between agencies and practitioners providing care, services for different age groups and across the NHS is poor in relation to services for adults with learning disabilities
- Parents and carers are not always treated as effective care partners
- Many healthcare professionals do not understand the law around capacity and consent to treatment
- Healthcare professionals rely inappropriately on their estimates of a person's quality of life
- The NHS complaints system is often difficult to negotiate, time consuming and ineffective

The most recent inquiry carried out by Sir Jonathan Michael¹⁵ was commissioned by the Government to respond to the findings of these reports and to identify the action needed to ensure that adults and children with learning disabilities receive appropriate medical treatment in the NHS. The inquiry concluded that:

- People with learning disabilities are not visible or identifiable to health services and their experiences are not assessed

¹⁵ *Healthcare for All: Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, Sir Jonathan Michael, 2008

FINAL

- There is a lack of awareness of the health needs of people with learning disabilities in primary care
- The health needs for people with learning disabilities do not appear to be a national priority for the NHS
- Compliance with disability discrimination and mental capacity legislation is not effectively monitored or performance managed across health and adult social care
- The lack of knowledge makes 'reasonable adjustments' as required under the Disability Discrimination Act hard to make
- Training and education regarding learning disabilities to clinical staff is very limited
- Lack of knowledge and training is reinforcing negative attitudes towards people with learning disabilities and their carers

5. The Picture in Swindon

5.1 Evidence Gathering

In 2008 the Centre for Public Scrutiny (CfPS) and Foundation for People with Learning Disabilities produced a guide to assist overview and scrutiny committees to carry out their scrutiny work in relation to the provision of mainstream healthcare to people with learning disabilities¹⁶. When planning this work, the Task Group decided to base its review around answering the ten questions identified in the CfPS Guide. The key findings of the Task Group are summarised in this section of the report.

In carrying out this review, the Task Group has met with a wide range of witnesses including people with learning disabilities, carers, support workers, representatives from primary, secondary and mental health NHS services, adult social care and the learning disability service. In addition, the Task Group developed a questionnaire that was sent to a wide range of community and voluntary groups that work with people with learning disabilities and their carers. More details regarding the evidence gathered by the Task Group is available from the Swindon Borough Council Scrutiny Unit.

In addition to this review, the Health Sub Group of the Learning Disability Partnership Board is also carrying out a comprehensive review of the provision of healthcare to people with learning disabilities in Swindon. The Task Group has worked closely with the Sub Group and the findings of this review are intended to supplement and inform the Sub Group's work.

5.2 Health Needs and Health Inequalities

The health needs of people with learning disabilities

The total population of Swindon is approximately 190,500. Nationally it is estimated that between 2-2.5% of the population may have learning disabilities. A large proportion may have a mild learning disability and live independent lives.

In Swindon 720 adults and children are currently known to the Learning Disability Service. This figure will fluctuate depending on service users moving into and out of the Borough.

¹⁶ *10 questions to ask if you're scrutinising...mainstream health services for people with learning disabilities*, Centre for Public Scrutiny and Foundation for People with Learning Disabilities, 2008

FINAL

Below is a table summarising the number of people from Black and Minority Ethnic communities who have learning disabilities:

Ethnic Origin	% Registered as having LD in Swindon	% of the total Population of Swindon
Black & Black British	1.1	0.7
Asian & Asian British	1.3	2.13
Mixed	0.7	1.14
Chinese	0.1	0.43
Other	0	0.4

Collecting and monitoring the health needs of people with LD

Swindon Primary Care Trust recently carried out a Health Equity Audit. The information used to inform the audit was a mixture of performance data and qualitative evidence from people with Learning Disabilities and their carers. The initial findings have been shared with the Task Group and once published, the final results of the audit will include an equity profile that aims to compare the needs and service provision for people with LD compared to the general population.

In 2006, 70% of people with a learning disability that were recorded on the Swindon Service Planning Database were recorded as having one or more health need, the most common being physical disability¹⁷

The LD Service manages a central register of all people known to the LD Service in Swindon. GPs may also advise the LD Service of any patients that they think may have LD that are not already on the register. A screening tool has also been developed for GPs to assist them to determine whether a person should be included on the register.

The LD Service notifies each GP practice of patients that have LD. Practices are required to maintain an LD register and this forms part of the Quality Outcomes Framework (QOF) under the GP contract.

There is not a lead GP with special interest for people with LD but 2 local GPs are involved in the work of the Health Sub-Group.

5.3 Current Local Policies and Practices

Swindon Community Strategy: A Shared Vision for Swindon 2008-2030

The Community Strategy aims to deliver a vision of a healthy, caring and supportive place, where people live a longer, healthier, happier and more active life. Working in partnership to reduce health inequalities, including those experienced by people with a LD, is a key part of achieving this vision.

¹⁷ *The Health of the Population of the Swindon Primary Care Trust 2007/08*, NHS Swindon & Swindon Borough Council, 2008

FINAL

NHS South West Strategic Framework 2008/09 to 2010/11

NHS South West published its Strategic Framework for the South West 2008/09 to 2010/11 in November 2008.

The Framework identifies the key priorities to improve health and wellbeing in the region over the next three years. One of the priorities is to ensure that people with a learning disability have the same opportunity as others to achieve their full potential for improved health outcomes.

As part of the development of the Framework, a series of stakeholder engagement events were held that including people with learning disabilities. In addition an Easy Read version of the written consultation document was produced and circulated via the Health Sub Group of the Learning Disability Partnership Board in Swindon. People with learning disabilities said that:

- They wanted to be at the centre of their care
- That health professionals should speak to them about their care and treatment first, not their carer
- That there should be more training for health staff in general around learning disabilities

The Strategic Framework aims to:

- Implement Valuing People (and Valuing People Now)
- Ensure 95% of GP practices can identify their patient population with LD by March 2009
- By 2010 ensure that people with a learning disability have access to the physical and mental health care that they need through an annual healthcheck and personal health plan
- Increase screening rates so that they are the same as for the general population (80% uptake for breast and cervical cancer screening by 2013)
- All people in NHS Campus provision to be housed in accommodation of their choice with appropriate level of care and support by March 2010

The ambitions outlined in the Framework inform each local area's Strategic Plan and the Annual Operating Plan of each PCT within the South West region.

Delivering Excellence for Swindon: Our Strategic Plan 2008-13

Swindon PCT and Swindon Borough Council have published a '*Strategic Plan for the Delivery of Excellence in Health and Wellbeing for the residents of Swindon*'¹⁸.

The Plan has been developed to build on the existing integrated and co-ordinated approach to the prevention of ill health and inequality. The Plan brings a particular focus to the contribution improving health and wellbeing can bring towards the achievement of the aims and ambitions for an improving Swindon.

¹⁸ *Strategic Plan for the Delivery of Excellence in Health and Wellbeing*, Swindon PCT and Swindon Borough Council, 2008

FINAL

The delivery of the ambitions outlined within the Plan will be focused through the Annual Operating Plans for both Swindon Primary Care Trust and Swindon Borough Council, which will set out expected outcomes and performance measures for each year.

The Plan has been developed following consultation with staff and members of the public.

The Plan includes the following vision for learning disability services:

“...to support people to embrace life’s challenges in order to lead full, rewarding and healthy lives by promoting opportunities for personal growth, positive health, high self esteem, participation and personal success.”

The Plan outlines key aims and targets and associated commissioning intentions in order to achieve this vision. Key aims include:

- Increasing access to Direct Payments for service users and carers
- People with a learning disability to have a personal care plan
- Re-provision of NHS Campus Beds
- Reducing out of borough placements
- Reduction of the number of adults requiring long-term institutional care
- Ensure appropriate training is in place to enable relevant NHS staff to work more effectively with people who have a learning disability
- Increase breast and cervical cancer screening
- Redesign of the Short Breaks Service
- Ensure people with learning disabilities have access to a range of opportunities including work, volunteering, education, social and leisure to reduce reliance on traditional centre based day services
- Ensure key stakeholders are involved in developing a clear communication strategy which facilitates partnership working
- Advice will be available in a range of formats, which must include telephone, face-to-face, digital and online as well as multi-lingual hard copies which are accessible to people with sensory impairment and learning disabilities

The Plan also acknowledges that the number of people with learning disabilities in Swindon is likely to increase over the next 10 years due to not only the growth of the town but also due to advances in medical technology. Stakeholders including service users and carers were involved in the development of the Plan through the stakeholder engagement process.

The BME Action Group was involved in the development of the Plan to ensure that the needs of people with learning disabilities from BME communities have been taken into account.

The Health Overview & Scrutiny Committee will monitor progress against the objectives outlined in the Plan.

FINAL

Swindon's Second Local Area Agreement

Swindon's Second Local Area Agreement (LAA) is a three-year agreement between a local area and central government. The LAA sets out how local priorities will be met by applying local solutions. It also contributes to national priorities set out by the government.

The second LAA includes 19 local indicators selected from a list of 198. Several of these indicators have direct implications for the health and well being of local people with learning disabilities including:

NI 120 – 'All age, all cause mortality' which includes actions to tackle obesity, increase physical activity, improving health screening and to improve health promotion.'

NI 124 'People with a long-term condition supported to be independent and in control of their condition' which includes providing people with the skills and knowledge to play a greater role in the management of their own condition.'

Swindon Action for Health Framework

The Swindon '*Action for Health Framework for Health Facilitation and Health Action Planning*' has been developed to outline progress to date in meeting the '*Valuing People*' and '*Valuing People Now*' standards and sets out a framework for continuing the implementation of Health Action Planning and Health Facilitation for people with learning disabilities living in Swindon. The Framework has been developed and maintained by the Health Sub Group of the Learning Disability Partnership Board.

The framework acknowledges the requirement of both the specialist learning disability services and generic healthcare services to work in close partnership to meet the needs of people with learning disabilities and identifies how this can be further developed. The Framework also includes details on how progress and quality will be monitored to ensure that organisations are complying with the framework and that it is achieving its desired outcome to help people with learning disabilities to be healthy.

Action Plans that were produced in response to Mencap's 'Death by Indifference Report' have also been updated and a separate action plan developed taking into account the findings of 'Healthcare for All'. These were approved by the Swindon PCT Professional Executive Committee (PEC) and Board in February 2009.

Swindon PCT's Disability Equality Scheme

The PCT's Disability Scheme acknowledges the health inequalities that are experienced by people with learning disabilities and the associated poor health outcomes.

The Scheme's Action Plan includes:

- Increasing health checks for people with learning disabilities
- Increasing health promotion at day centres
- Increasing physical activity

FINAL

- Improving access to key services including health screening and obesity
- Ensuring that communication is made in an appropriate format for people with a range of disabilities
- Increasing awareness of PCT staff regarding the needs of disabled people
- Increasing participation and involvement of disabled and vulnerable groups in the planning, design and delivery of health services

5.4 Leadership and Ownership

The Learning Disabilities Partnership Board has established a Health Sub-Group to oversee the local implementation of the health agenda as detailed in '*Valuing People*' and '*Valuing People Now*'.

The Sub Group aims to:

- To provide a decision-making forum in which health professionals, service users and their carers can work together to improve health outcomes and people's experiences of accessing and using services.
- Provide advice and direction to the Swindon Learning Disability Partnership Board, Local Commissioners and provider organisations/services on this important area of work.

Membership of the Sub Group comprises of representatives from commissioners, primary care provider arm (including GPs), acute care, adult social care, the Learning Disability service, community and voluntary groups, service users and carers. Councillor representatives on the Learning Disability partnership Board have an open invitation to attend.

The Sub Group is leading on the completion of Swindon's 'Learning Disabilities Performance and Self Assessment Framework'. The framework has been produced by the Strategic Health Authority to enable PCT/ local authority areas to assess their current progress against the standards outlined in '*Valuing People*' and '*Valuing People Now*' and to outline planned activity to meet all standards by 2010.

The Sub Group reports to the Learning Disability Partnership Board, which is Chaired by the Cabinet Member for Health, Housing and Adult Social Care. Members of the Sub Group are responsible for reporting back to their respective organisations. Annual progress reports are provided to participating organisations.

The Task Group is pleased that a great deal of work is taking place in partnership across health and adult social care and with the community and voluntary sector to ensure that health inequalities for people with learning disabilities are being tackled in a systematic way. The Task Group has been working in partnership with the Sub Group to share its findings to ensure that these are taken into account as part of the Self Assessment Framework. In addition, the Sub Group has been proactive in gaining commitment from all partnership organisations in responding to the findings of the independent enquiry into access for healthcare for people with LD that was led by Sir Jonathan Michael in 2008.

5.5 The Views of People with Learning Disabilities and their Carers

The Task Group met with a number of people with LD to find out their views regarding healthcare services. In addition, the Task Group produced a questionnaire that was circulated to several groups that work with people with LD and their carers in Swindon. A copy is attached at Appendix 3.

Members also met with a small number of family carers. Encouraging family carers to share their experiences was one of the biggest challenges of this review.

The key issues raised by people with LD and their family carers are summarised below

Making appointments at the GP

- The vast majority of people with LD would not make an appointment or attend a healthcare appointment without their carer or support worker
- Several people commented on the difficulties of making an appointment over the telephone, especially at surgeries where appointments cannot be booked in advance or where you have to ring at a certain time. They often felt that they were not understood and that they often had to wait a long time for an appointment
- Some carers felt that surgeries did not understand the need to make reasonable adjustments for their loved one, such as having quiet waiting areas or advising them of any long delays when they book in at reception
- One person said that they had to confirm their attendance for an appointment at their surgery using a computer. This makes it impossible to use for people who cannot read and they felt that it was difficult to ask the receptionist for help because they are so busy
- Several carers said that attending their GP was not a problem because they made and attended appointments with them

Attending GP Appointments

- Many people said that they did not understand what the doctor said to them
- Some people felt that the doctor or nurse would talk to their carer, rather than talking to them directly
- Some carers said that their loved one had a Health Action Plan but they felt that this made no tangible difference to their child's needs being met
- Many carers felt that their loved one would not be understood if they did not attend appointments with them
- One carer said that her son's behaviour became difficult when attending appointments and he required a support worker to accompany him
- Several carers had experienced difficulties because their child was over 18 and this raised issues regarding confidentiality and consent. As a result, they felt excluded and that their wealth of knowledge about their son or daughter was not being used effectively
- One of the carers that the Task Group spoke to felt that her GP surgery was unable to cope with her daughter's extremely challenging behaviour

FINAL

and that they were reluctant to examine her daughter. As a result, she only took her daughter to see a GP when absolutely necessary, despite her having a chronic physical health problem. She also felt that her surgery did not make any adjustments for her daughter's specific needs

- One person said that their GP only referred them to the hospital for treatment after they demanded it
- The majority of people that the Task Group spoke to did not think that they are treated any differently to patients who do not have LD
- Several carers commented that they had received good support from their GPs and that some GPs understand the needs of people with learning disabilities and are very helpful

Treatment at Hospital

- Some people thought that hospital appointment letters were confusing, especially if they are asking people to ring at a certain time to make an appointment. Several people have ended up going to the hospital instead because they did not understand the letter. There were several suggestions of alternative methods of communication being used.
- Several carers felt that staff in Accident & Emergency required more training in order to identify whether a patient has a learning disability and how to tailor their care accordingly. One carer said that staff did not acknowledge the needs of her daughter, even though she explained that she had a LD. One person with learning disabilities had been admitted to A&E but staff did not contact his family to let them know where he was. He was also discharged without his family or support worker being notified. This resulted in an additional trip to the GP to find out what a prescription was for and when medication should be taken.
- Several carers and people with learning disabilities said that they had received good care and treatment at hospital
- One carer had a bad experience when her 20-year-old daughter was admitted to hospital with a complex long-term condition. She felt that medical staff did not involve her in her daughter's treatment or check that her daughter understood what was happening. She found this extremely frustrating and felt that she was not being taken seriously
- Several people felt that hospital staff needed more training to be aware of the needs of people with learning disabilities in hospital and how they could best meet their needs.
- Communication was identified as a big issue. Examples were given of patients not being able to see because they didn't know where their glasses were, not being able to ask for a drink or knowing where the toilet was. One person with learning disabilities said that they felt that no one understood or listened to them
- One carer said that many people with learning disabilities are confused by new surroundings, often do not understand why they are in hospital and are too frightened to ask any questions
- Several people said that had not had any problems getting treatment at hospital, one following a car accident and the other as a planned admission

FINAL

Health Improvement and Promotion

- Some people had received health checks from their GP
- Several carers said that their GP had not offered any routine health checks
- One carer said that her adult daughter had been sent appointment letters for cervical screening and that she had rung and explained that her daughter had a severe LD. She was told that her GP would be contacted to consider the way forward but she never received any follow up
- One person with learning disabilities had received information from a dietician on healthy eating
- Several people said that they had received talks on healthy eating and exercise at the day centre that they attended and that the day centre also arranged physical activities both inside and outside of the centre (swimming and dancing)
- Several parents said that they would like more physical activities to be accessible to their loved one. One parent had tried to get their child to attend sports activities at the Link Sports Centre but it was not possible for them to attend with a support worker
- Some carers said that they provided advice themselves or could speak to their community learning disability nurse
- A group of people with learning disabilities said that they knew they could get information from the library, leisure centre, doctor and dietician but wanted more information in picture form or spoken versions

Other Primary Care Services

- Several people thought that the information on medication was confusing
- Many people use the community dentist, which they thought was a good service but some said that there was a long wait for appointments. One person said that the community dentist also visits their day centre once a year
- Some people thought that it was difficult to find a dentist but some had a family dentist that they went to
- Some people thought that using the Walk In Centre was not a problem, especially as they had used it before but one carer commented that you often had to wait a long time in the waiting room which could be problematic
- Several people and carers said that there is an issue in relation to nail cutting. Eligibility for this service is limited on the NHS and those people who are eligible said they had to wait 3 months for an appointment

Other Issues

- The majority of people with LD did not know how to raise a concern or make a complaint regarding the NHS
- Some carers had raised concerns with the relevant Patient Advice and Liaison Team (PALS). Some other carers did not know how they could raise a concern or make a complaint regarding healthcare services

Areas for Improvement

- Ensuring that people who live independently are adequately supported to make and attend appointments

FINAL

- To make the process for booking appointments at GP surgeries easier
- GP surgeries to consider the individual needs of patients before attending an appointment e.g. longer appointment times, try to reduce the time people with learning disabilities have to wait in the waiting room or provide a separate waiting area
- Providing more routine health checks
- Providing more information on health and well being in Easy Read formats
- Ensuring that family carers are involved in health planning and treatment and that their views are listened to
- Patient records should show whether a patient has a learning disability and any special needs that they may have. These should be available to all medical staff
- GPs could use pictures to explain what they are saying or other forms of communication such as signing
- Doctors, nurses, receptionists need to be trained in understanding people with learning disabilities and their needs. Medical staff also need to listen to patients with learning disabilities
- When someone is admitted to hospital there needs to be a designated support person, who is available 7 days a week, to ensure that the individual understands everything that is happening around them

5.6 Health Education and Promotion

Access to Health Promotion Programmes

The Health Equity Audit identified that more work is required to educate and support people with LD to access healthcare. For example, the audit suggests that people with LD have higher incidence of delayed diagnosis of long-term conditions such as diabetes. In addition, the Audit found that people with LD are less likely than the rest of the population to undertake preventative programmes, such as screening or health promotion activities.

The Learning Disability Service undertook an Obesity Audit in 2007 that found that half of those assessed were either overweight or obese (51 out of 89)¹⁹. To address this, there are some good examples of effective health promotion programmes for people with LD in Swindon. A programme has been developed as part of the Active Swindon initiative for people with LD to access exercise. No referral is required and people can attend on a voluntary basis. The programme is advertised via day centres and the Learning Disability Service and is generally well attended. The 'Help me to eat' scheme also that provides information on healthy eating and how to eat safely and service users are supported to access weight control programmes.

There are a low number of service users that are known to the LD Service who smoke, regularly drink alcohol or take drugs. Smokers should be offered support to quit via their Health Action Plan as part of the GP Direct Enhanced Service.

¹⁹ *The Health of the Population of the Swindon Primary Care Trust 2007/08*, NHS Swindon & Swindon Borough Council, 2008

FINAL

The Open Door Day Centre has also done a lot of work in relation to health promotion including being active and healthy eating.

A Draft Relationships Policy for people with Learning Disabilities is also being developed by the Learning Disability Partnership Board to promote healthy relationships and respect.

It is encouraging that the BME community have been engaged in the development of the Strategic Plan. However, it may be beneficial to build on this engagement with the Swindon Race Equality Council to consider the best way to raise awareness amongst BME communities regarding the support available for people with LD, even though a very small number of service users that are known to the LD Service are from a BME community.

Support for Carers

It is important that carers are made aware of the key symptoms of ill health so that they do not assume that behaviour is linked to the person's LD.

The Health Equity Audit also suggests that increased education for staff in residential care homes is required through the existing liaison nurses in the community to not only promote health and well being but to also recognise and act upon ill health.

Carers also need to be provided with information about healthy eating and exercise to ensure that they can support their loved one to lead a healthy lifestyle.

Accessibility of Written Information

The Health Equity Audit found that the health service does not always provide written information in Easy Read form or use alternative methods of communication that are more appropriate for people with LD, such as arranging face to face meetings.

Swindon PCT PALS Team has produced an Easy Read leaflet providing information about its services but there is a need to ensure that this is available in a wide range of places that are accessed by people with LD on a regular basis, such as day centres.

A wide range of information is available from the Community Learning Disability Service in an Easy Read format, including person centred planning and accessing health records.

The Great Western Hospitals NHS Foundation Trust currently produces some information in Easy Read format but work is underway to ensure that more information is easily accessible to patients with LD. The PALS Team is also going to work with the PCT PALS Team to develop a PALS Easy Read leaflet.

FINAL

Health Screening

The Health Equity Audit identified that people with LD are less likely to participate in screening programmes than the rest of the population.

A letter of invitation is usually sent to eligible patients. If a patient fails to respond on 3 occasions, this is usually recorded as the patient refused to undergo screening. This can create an issue in the case of people with LD, who may not understand the content of the letter or the reason for screening. This may put individuals at risk of breast or cervical cancer going undiagnosed.

The GP Direct Enhanced Service should ensure that Health Action Plans and annual healthchecks identify whether an individual is eligible for breast and cervical screening and support them to access screening services. In addition, the Health Action Plan also covers the issue of breast and testicular self-examination where appropriate.

The Community LD Service team emphasised that it is important that people with LD are able to make an informed choice about whether or not to undergo screening and are fully supported through the process.

5.7 Focusing on Individual Needs

A health lead has been appointed within the Learning Disability Service who is responsible for person centred planning and addressing health inequality.

Patient Records

The LD Service manages a central register of all people known to the LD service in Swindon.

The GP Direct Enhanced Service requires GP surgeries to keep their own register of patients with an assessed LD. GPs may also advise the LD Service of any patients that they think may have LD that are not already on the register but it is important that this only includes patients with a learning disability and not those with a learning difficulty. A screening tool has been developed for GPs that is not intended to diagnose a person as having a learning disability but that can help determine whether a person should be referred for a psychological assessment or be included on the register.

GP patient records should identify whether a patient has a LD and whether any 'reasonable adjustments' are required to meet their needs. However, it is not clear whether this is happening across all GP surgeries on a routine basis.

The Great Western Hospitals NHS Foundation Trust is exploring whether it is possible to add a flag to electronic patient records to identify whether a patient has a Learning Disability and if they have a carer. This would be particularly beneficial in the case of emergency admissions. This could also include a link to an existing Hospital Action Plan or prompt staff to complete an Action Plan with support from the LD Service. This would be limited to patients with an existing patient record.

FINAL

The Great Western Hospitals NHS Trust does not routinely receive information from GPs at the point of referral to alert clinicians as to whether a patient has a LD and if any reasonable adjustments are required as a result. As a result, hospital staff are likely to be unaware of whether a patient has a LD, especially if they do not have an existing patient record. When a patient has severe LD, GPs usually provide details of their needs in a referral letter.

Regular Healthchecks

The Health Equity Audit identified that a number of people with LD have one or more unmet health needs.

When this review started, Annual Healthchecks were not provided universally across Swindon.

The services provided by GP surgeries to patients with LD are monitored by the PCT via the Quality Outcomes Framework (QOF).

'Valuing People' requires Primary Care Trusts (PCTs) to commission services that provide an annual healthcheck for people with LD in their local community. In Swindon this service is now beginning to be rolled out with a view to being fully operational by April 2009. All but 1 GP practice has signed up to the Direct Enhanced Service.

The service will include:

- GPs will be responsible for leading the delivery of annual healthchecks and the majority of GPs are keen to provide this service
- Annual healthchecks will be offered to patients with 'moderate' to 'severe' LD as required nationally
- GP surgeries will be advised of patients registered at their surgery that are known to the LD Service and those that are eligible for an annual healthcheck. GPs should also have a copy of the summary sheet from each registered patient's Health Action Plan.
- GP surgeries will receive additional funding for patients on the LD register that are registered with their practice and for each annual healthcheck that they carry out, making it important that the right patients receive this service
- There is a need to agree with surgeries the process that will be used to notify patients of the date of their annual healthcheck and to support people to react to this information i.e. do they understand that they have an appointment and what it is for, who will support them at the appointment, how will they get to the surgery, is the appointment convenient for carers, how will they deal with the results etc.
- If a patient has a LD, this should be flagged on their electronic patient record
- A checklist has been produced, based on a checklist developed in Cardiff, to advise GPs of the content of the healthcheck

The Task Group has raised concerns that the healthchecks are not being offered to people with mild LD, especially as they are more likely to be living

FINAL

independently and will not have the same level of monitoring as people with more severe LD. This may result in them 'slipping through the net' and their health deteriorating before they actually go to see their GP.

Health Action Plans

The Health Equity Audit found that Health Action Plans are not widely used in primary care and work is required with GPs to encourage them to use them routinely.

Steps are now being taken to ensure that once the LD Service identifies someone as having a LD, they should be invited to participate in the development of a Health Action Plan to identify their health needs. The permission of the person with the LD or their carer is required to develop an Action Plan and some service users have declined to have one. Service users should be fully involved in the development of their Action Plan and the Learning Disability Service seeks their permission to retain a file copy and to share with other professionals as appropriate.

The Action Plan should 'follow the patient' and is used by all health professionals including dentists, opticians and pharmacists. Health Action Plans should also include information about a person's behaviour and how to manage challenging behaviour.

As at the end of February 2009, 370 service users had been offered a Health Action Plan by the LD Service.

Below is a summary of progress in completing Health Action Plans (as at February 2009):

Number of service users to which a Health Action Plan has been offered	370
Number of service users who have declined to complete a Health Action Plan	108
Number of service users who have yet to respond to the invitation to complete a Health Action Plan	50
Number of service users who are in supported accommodation but where it has not yet been confirmed that they have a Health Action Plan	44

In total, a health Action Plan has been offered to 95.5% of known service users. The LD Service is re-contacting those service users who have not responded to the offer to complete a Health Action Plan.

Some service users or their families have declined to participate in the development of a Health Action Plan. Where appropriate, the LD Service will support service users or their families to revisit this decision at a later date.

The LD Service is currently checking whether a group of service users that are living in supported accommodation have a completed Action Plan. As

FINAL

these service users are already known to healthcare services, it is assumed that the majority will have a Plan in place.

A small number of service users (4.5%) of the total known to the LD Service are on a waiting list for their Health Action Plan to be completed.

Overall, 61% of all service users that are known to the LD Service have a completed Health Action Plan. The LD Service works closely with Children's Services to ensure that young people have a completed Health Action Plan at the point of transition to Adult Services.

The Action Plan includes prompts for the carer and person with LD to complete, for example, 'I'm good at.....'.

The Task Group has suggested that a 'Checklist' could be developed for new referrals to the LD Service that outlines all of the actions that need to be completed once a person has been referred, such as the development of a Health Action Plan. This would be a useful monitoring tool for services, carers and clients. This would also be a helpful tool in residential homes.

A temporary Hospital Action Plan is also offered to any person with LD who is known to be going into hospital. The Action Plan can be completed by any service that works with people with LD. An electronic copy can also be accessed by staff at the Great Western Hospital that can be completed in the case of an unplanned admission or if a person forgets to bring their completed Action Plan with them. Hospital Action Plans are not kept on the end of patient beds and the Task group has suggested that it may be helpful to include a symbol on their notes to notify clinical and other staff that a patient has a LD.

The Hospital Health Action Plan is working well in most cases and staff have also made suggestions for amendments to the Plan as a result of training sessions that have been held at the hospital. There is also a LD Liaison Nurse from the LD Service that works with GWH to provide advice and guidance to staff but this support is only available Monday to Friday.

Strategic Health Facilitator

The Health Sub Group has developed a proposal to appoint a strategic health facilitator to work proactively with local services to ensure fair access to mainstream services for people with LD.

This role will provide co-ordinate the work already being progressed by professionals from a range of organisations and continue to champion the needs of people with LD in relation to healthcare.

The proposal is subject to the identification of suitable funding.

Support for Carers

The LD Community Team works closely with families to ensure that they receive the support that they need. However, the national agenda to deliver

FINAL

care closer to home and the modernisation of LD day services means that people with LD are more likely to remain in their family home than ever before.

The Swindon Carers Centre has an Outreach Carers Support worker who provides support to adult carers who care for adults with a range of needs, including LD. Her role is to work with carers to identify their support needs and to put support packages in place. She works with people who care for adults with learning disabilities, older people, people with dementia and those with physical disabilities. Approximately 15-20 new referrals are received a month and new clients are usually seen within 2-3 weeks of a referral being made.

There is no specific support group run through the Swindon Carers Centre for carers who care for someone with a learning disability

A Carers Support Group is in existence, which meets once a month and is moving to a 'self-help' model to enable carers to take a proactive role in supporting each other

The Task Group met with a small number of carers who were extremely grateful for the support they received from the Swindon Carers Centre. However, neither had received a Carers Assessment from their GP and were referred to the Carers Centre once they reached crisis point at home. They felt that carers need more practical support to help them negotiate the health and social care system. Not all of the carers were registered on the Carers Register at the GP practice and felt that they received limited support in terms of their own health and wellbeing.

The carers also felt strongly that healthcare professionals must recognise that they are often experts in meeting the needs of their loved ones. This includes how to manage challenging behaviour and communicate with their loved one. Many carers feel that healthcare professionals sometimes exclude them from decisions regarding their loved one's care. Concerns were also raised regarding the assessment of their loved one's capacity to make decisions regarding their treatment.

The Great Western Hospitals NHS Foundation Trust hosted 'Swindon Carers' Day' in December 2008 that was arranged by the Swindon Carers Centre. This emphasised the important role of people who care for loved ones with a LD.

The Trust has also developed an Action Plan in conjunction with the Princess Royal Trust for Carers to increase the support available to all carers from the Trust. This work is focussed on adult carers but representatives from the Trust have also met with a group of young carers.

If a patient has severe LD, ward staff will usually speak to the patient's carer to determine if they would prefer to stay in hospital with their loved one. The Trust has acknowledged that there have been instances where staff have not communicated effectively with carers and the carer has felt excluded as a result. The Action Plan should help to address this issue.

FINAL

Carers can stay overnight and reclining chairs are provided in each ward. Staff should have a discussion with the carer to agree whether they wish to carry out some caring tasks for their loved one e.g. washing, feeding or whether they would prefer that these tasks are carried out by hospital staff. However, staff should not assume that carers will carry out such tasks.

Training & Education for Healthcare Staff

The Task Group heard evidence that the majority of healthcare staff are keen to provide a good service to people with LD but do not always know how best to meet their needs, or sometimes what these needs are.

In addition, people with LD often get frustrated if they feel that they are not being understood and this can manifest itself as aggression or poor behaviour. As such, health professionals and carers need to be equipped to recognise and manage this behaviour

As part of the Direct Enhanced Service within GP surgeries, training is underway with senior partners, practice managers and reception staff. This has developed in conjunction with local GPs with an interest in LD. The training must meet national criteria. The training includes how GP surgeries can make reasonable adjustments to better meet the needs of patients with LD. All of the surgery staff that have attended the training to date have been keen to make adjustments and have been working with the LD Service to seek advice and guidance.

GPs have also been provided with an information pack that contains contact details of services that can offer support and advice on supporting people with LD, common conditions amongst people with LD, a top 10 tips for carrying out a consultation with a person with LD and a form that the patient can complete explaining why they have come to see the doctor and that the doctor can complete on the other side explaining any recommendations. The Task group thought that it may be helpful if the Swindon Borough Council website had a page with links to all of this information so that all healthcare staff could access it quickly and easily. The information could also be updated more readily.

The LD Service has also provided training to staff at the Great Western Hospital (GWH) regarding the use of Hospital Action Plans and the needs of people with LD when they are admitted to hospital. Training is also being developed as part of the junior doctor induction programme. This includes the implications of the Mental Capacity Act and the needs of patients with LD. There is an emphasis on how nurses can become more skilled in managing challenging behaviour within an acute setting. This work is being carried out in conjunction with the Mental Health Liaison Nurse from the Victoria Centre who specialises in working with older people with mental health problems. It is also important that staff fully understand the issues around confidentiality and the importance of involving carers in the care and treatment of their loved ones as fully as possible. Drop-in sessions have also been held for staff to raise any

FINAL

queries. Awareness raising sessions are also underway for A&E staff. Take up of this training has been good.

The Health Sub Group has submitted a bid for funding for e-learning training package that could be used by all healthcare staff to raise their awareness of the needs of patients with LD. This model has been used successfully in other local authority areas. The Great Western Hospitals NHS Foundation Trust are also interested in pursuing an alternative package. The Task Group is of the view that securing funding to increase local options for the learning and development of staff is essential to raise awareness, knowledge and skills across the health economy.

The Task Group would also encourage all NHS Trusts to include a session on LD as part of statutory and mandatory training days and staff induction training.

5.8 Care Pathways and Accessing Services

GP Surgeries

The majority of the people with LD who spoke to the Task Group said that they would not make an appointment to see their GP without support from their carer or support worker.

The support provided to people with LD who do not live with a carer is largely dependent upon GP's being proactive in promoting their health and wellbeing.

The Task Group heard evidence from the Learning Disability Service that when making appointments, staff at GP surgeries should be considering:

- How the person is going to get to the appointment
- Whether they would prefer to wait in a separate, quieter waiting area
- If a longer appointment is needed to ensure that the GP has enough time to explain everything to the patient
- If the patient requires their carer to attend the appointment with them, whether the appointment time is convenient for carer
- How will the outcome of the consultation be communicated to the patient e.g. does the GP also need to write down the outcome to allow the patient to show their carer
- Whether any information needs to be provided to the patient prior to the appointment and if so, in what format e.g. phone call, Easy Read leaflet

It has been difficult to ascertain whether all GP surgeries are consistently taking steps to increase the accessibility of their practices to people with LD as part of this review. However, the Direct Enhanced Service should ensure that GP surgeries are addressing these issues and staff training should also raise awareness of the type of needs that patients with LD should have. Once fully implemented, it is important that the PCT rigorously monitors compliance with the scheme, including feedback from patients and their carers.

FINAL

Dental Services, Optometry, Audiology, Chiropody & Podiatry

Dental Services, Optometry and Audiology appeared to be areas that have yet to receive a great deal of scrutiny from the Learning Disability Partnership Board Health Sub-Group or Learning Disability Service.

A hearing therapist is employed directly by the LD Service who does desensitising work with service users and works very closely with the audiology department at the Great Western Hospital. This service was recently increased to 2 days per week.

The LD Service is not aware of any feedback from service users who have had a poor experience of these services.

However, evidence from the Learning Disability Service suggests that there is a need to raise awareness amongst people with LD of the health promotion benefits of regularly getting their eyes tested and going to the dentist for check ups. An example was provided of a person with LD who was blind and did not realise that the optician could identify any health problems through an eye test.

Professionals, service users and carers have all raised concerns regarding toenail cutting. NHS Podiatry and Chiropody Services will not cut toenails when there is not an associated health need. In addition, adult care staff have also withdrawn this service. This issue has been discussed by the Vulnerable Adults Sub Group of the LD Partnership Board, which has received confirmation from the Commission for Social Care Inspection (CSci) that toenail cutting is not an invasive procedure and forms part of an individual's basic care. As a result, training on toenail cutting and foot care has been delivered to residential care home staff but this remains a significant issue for many service users.

The Task Group suggests that this is an area that requires attention from the Learning Disability Partnership Board Health Sub-Group to ensure that the same issues around access and 'reasonable adjustments' are addressed in the same way as more general medical issues. In addition, there is a need to ensure that health promotion messages are effectively communicated.

Other Primary Care Services

The Task Group heard evidence from the Primary Care Trust that there is a need to ensure that people with LD understand the services provided by the Walk-In Centre at Carfax Street and the Clover Centre in relation to out of hours treatment. In addition, clear communication is required regarding the establishment of the new GP-led Health Centre in April 2009 to ensure that people with LD and their carers understand that this will not impact on their ability to go to their usual GP.

Pharmacies

The Task Group heard evidence from some people with LD that they find the information contained on medication confusing.

FINAL

Some PCTs have introduced an Easy Read label for medication to explain when medication should be taken.

Great Western Hospitals NHS Foundation Trust (GWH)

The Trust's Board commissioned a review of the Trust's practices against the recommendations made in Mencap's "Death by Indifference" Report. The Trusts Mental Health Act Committee is responsible for issues in relation to the Mental Capacity Act and any other relevant legislation. This includes care for people with LD. An update report in response to "Death by Indifference" and 'Healthcare for All' has been presented to the Committee.

The Trust has made good progress on supporting patients with LD that attend as part of a planned inpatient admission. If a patient is admitted with LD, staff will assess the capacity of the patient to make decisions regarding their care and treatment. If a patient is assessed to not be capable of making such decisions, their carer will be asked to take on this role. If a patient does not have a carer, they should be referred to an Independent Mental Capacity Assessor (IMCA). In addition, they could be referred to the Swindon Advocacy Movement.

Every patient will receive an assessment that informs his or her Care Plan. This includes whether they are a carer or have a carer. Young carers should also be identified at this stage. The assessment should also ask about what the patient can and cannot do at home, their background, what support they receive at home etc. This is the first source of information from a patient and is sometimes double checked with a family member to ensure that the information is complete and accurate.

Work is underway with clinical managers to increase the number of appropriate referrals to the Swindon Advocacy Movement, that supports people with LD.

In the case of a planned admission, patients with LD should have their own Hospital Action Plan, which are discussed elsewhere in this report.

If a patient has complex needs, the Trust may consider hiring a specialist mental health or LD agency nurse. Discussions are taking place with Swindon Primary Care Trust regarding the funding for this specialist support. A member of staff may also accompany patients who already have a paid carer or live in a residential care home.

As discussed elsewhere in this report, the Great Western Hospital has worked with the Learning Disability Service to develop a Hospital Action Plan that it kept at the foot of a patient's bed. Training sessions have also been carried out to make staff aware of how to use the Action Plan.

There is a Lead Matron and a Ward Manager within the Trust who are available Monday-Friday to provide support and guidance to staff.

FINAL

Some carers have raised concerns with the Task Group that there is a lack of consistency in staffing on the Wards, which can be particularly confusing for people with LD. The Trust is currently reviewing shift patterns to address this issue.

Another issue raised was in relation to medication provided at the point of discharge. A pilot is currently underway where a pharmacist will meet with the patient on the day of their discharge from hospital to explain what medication they have been prescribed and when they should take it. The Task Group has suggested that the labels on medication could also use symbols to clearly indicate when medication should be taken. The Learning Disability Service also does this for patients in the community if appropriate.

In relation to unplanned admissions or emergencies, the 'Front Door Team' within Accident & Emergency includes a social worker, physiotherapist and occupational therapist and are available 7 days a week, ('on call' at weekends). Each ward should have a social worker Monday-Friday.

As discussed elsewhere in this report, the Trust is hoping to introduce flags on patient records to identify if a patient has an LD. This will significantly assist staff in tailoring services to meet the needs of LD patients.

Some carers had asked whether it would be possible to 'fast track' patients with a LD for outpatient appointments, so that they did not have to wait a long time in the waiting room, which can make some people very anxious. The timescale for appointments to be issued has been significantly reduced to several weeks over recent months and where possible, delays at clinics are kept to a minimum.

The Patient Advice & Liaison Service (PALS) currently does not routinely identify whether a person with a LD or their carer has made a contact with the service, even if their concern, praise or complaint is not overtly related to a LD. The Trust is working to develop a method of recording whether feedback relates to a patient with a LD.

5.9 Transition from Children and Young People's to Mainstream Health Services

The Health Equity Audit identified the transition from children's to adult services as a key issue for development, especially as there is a large group of young people due to move into adult services over the next few years.

Adult services currently meet with young people at the age of 14 but this is only an introductory meeting and they do not play an active role in planning or service delivery until the individual is just about to turn 18.

A Transition Sub-Protocol has been produced for the transfer of care from Children's to Adult services. The transition of care starts when the young person is 17 years and 9 months old. A joint visit to the family will be arranged between the Children's Service and Adult Services caseworker.

FINAL

During the transition phase the adult service can provide advice and guidance regarding care without assuming legal clinical responsibility for the service user. Once the service user has turned 18, the Children's Service can continue to provide advice and guidance for 3 months but the Adult Service will have assumed clinical responsibility. This ensures that the family and service user are fully supported during the transition process.

The LD Service particularly emphasised the importance of making sure that families are fully prepared for what will change when their son or daughter undergoes the transition into adult services

5.10 Ensuring and Monitoring the Effectiveness of Services

This report has tried to summarise the key activity that is underway in partnership across the Borough to review the service that is currently available to people with LD and to ensure that any health inequalities are addressed as a priority.

Monitoring the effectiveness of services

The Health Sub-Group of the Learning Disability Partnership Board is particularly active in driving this agenda forward. It is acknowledged that there are some gaps in the data that is currently collected and there is a need to continuously improve monitoring as initiatives such as the Direct Enhanced Service become more embedded across the Borough.

The involvement of service users and carers on the Learning Disability Partnership Board is particularly important to not only inform the commissioning of services but also to monitor the quality of service delivery.

The 'Big Health Day' was held in February 2009 as part of an initiative across the South West to seek the views of service users and carers on local healthcare services and to identify priorities for development. The outcomes, which are due to be reported by the end of March 2009, will further inform the development of services locally. The event will be repeated annually.

The Task Group welcomes the current involvement of service users and would encourage the more systematic collection of feedback from service users and carers by all healthcare providers in order to demonstrate the impact of all of the new initiatives that are currently planned or recently implemented.

Involving Black, Minority & Ethnic (BME) Communities

A BME consultation event was held in May 2008 with representatives from BME communities to better understand the needs of service users and families. This was organised with the support of Better Lives in Swindon (BLIS).

There are a small number of service users in Swindon from a BME community (approximately 10 are known to the LD Service). It is estimated that there are

FINAL

to up 40 people with LD living in Swindon from a BME community with some degree of LD

There is no specific strategy in place to highlight the needs of service users from BME communities but the LD Service aims to deliver a fully inclusive service. The service has access to translators and staff will work closely with families and service users to understand their specific needs. In addition, the methods of communication used by the LD Service, such as pictures, assists communicating with service users and their families even if English is not their first language or if the service user cannot communicate verbally.

Comments, Queries, Concerns and Complaints to NHS Trusts

The Task Group was pleased that the Swindon PCT PALS Team has produced an Easy Read leaflet explaining the role of PALS and how patients and their families can make a comment, raise a concern or make a complaint.

As part of the assessment process for new service users, the LD Service will explain the role of PALS and provide a copy of Swindon PCT's PALS leaflet to the service user.

The PCT PALS Team had only received 2 complaints in relation to the treatment of a person with a LD during 2007/08 and 2008/09. Both were made by the same person and were not upheld. The learning resulting from the complaints have highlighted the importance of healthcare professionals ensuring that they are providing the right information to patients and their carers and that this information is provided in the right format. In addition, healthcare professionals need to check that patients and their carers have understood what they have said.

Two PALS queries were received over the same period. Both were in relation to changes to respite care and were resolved to the satisfaction of the carer raising the concern. Again, both queries emphasise the importance of providing clear information to carers regarding any changes to services.

Adult social care will automatically pass any health-related concerns, queries or complaints to the PCT PALS team and vice versa.

The PALS Team at GWH had only received 2 contacts in the last year related to a patient with LD. Both contacts were made by a carer but did not relate specifically to the fact that the patient had a LD. No formal complaints were made in the last year but 1 was made in 2007/08. The complaint concerned a patient with LD but was due to the cancellation of an operation, which was in no way related to the patient's LD.

As discussed elsewhere in this report, the Task Group felt that the good work of both PALS Team could be built upon by undertaking proactive promotion of the PALS service with people with LD and their carers, especially through day centres and other services regularly used by people with LD. The Task Group would also suggest that the role of the PALS Team and how to contact them should be explained to clients when producing their Health Action Plan in

FINAL

addition to when a service user is first assessed by the LD Service. Information about PALS should also be available in a range of formats that are accessible to people with LD.

6. Summary of Findings

In summary, increasing the accessibility of mainstream healthcare to people with learning disabilities is a high priority for health and social care organisations in Swindon.

Much work is taking place in partnership to address many of the issues raised in national reports and to meet the requirements of national policy. This is reflected in local policy and guidance.

It has also been identified that people with LD are facing health inequalities and there is a need to actively promote their health and well being to enable them to live fulfilling lives.

This report fully endorses all of the activity that is taking place locally to ensure that people with LD have fair access and good quality treatment from mainstream health services that is tailored to their needs.

However, there are some issues that the Task Group wishes to highlight as key priorities for commissioner, providers and ongoing monitoring by the Health Overview & Scrutiny Committee:

- The importance of ensuring that family carers receive the support that they need to promote the health and well being of their loved ones but also to safeguard their own health
- That healthcare providers must ensure that all information that they produce is available in accessible formats for people with LD. This includes challenging the traditional written forms of communication for making appointments
- That the outcomes of the GP Direct Enhanced Service are closely monitored, including feedback from service users
- That training for acute care staff continues to be delivered and that mechanisms are put in place to ensure the swift identification of patients with LD and that their needs are taken into account throughout their treatment at hospital

Appendix 1

Task Group on Provision of Mainstream Healthcare Services to People with Learning Disabilities

Aim	To carry out an objective review of the provision of mainstream healthcare services in Swindon to people with learning disabilities to determine what steps have been taken by all NHS bodies to reduce health inequalities and increase the accessibility of services for this group of patients.
Rationale	<p>Research carried out by Mencap and the Disability Rights Commission found that people with learning disabilities faced:</p> <ul style="list-style-type: none"> • Increased risk of early death • Higher prevalence of certain medical conditions • Being part of a disadvantaged group and having unequal access to mainstream health services • Having unhealthy lifestyles • Reinforcing health inequalities <p>The role of the NHS in relation to people with learning disabilities should be the same as for the rest of the population to promote health and well being; providing treatment in a primary, community and acute setting and health promotion.</p> <p>However, national research suggests that people with learning disabilities often encounter health inequalities and difficulties in accessing local mainstream healthcare services. Ensuring that people with learning disabilities receive a high standard of care from the NHS as a whole is also an ambition within the Strategic Health Authority's Strategic Framework 2008/09-2010-11.</p>
Scope	<p>Includes:</p> <ul style="list-style-type: none"> • Consideration of the health needs of people with learning disabilities in Swindon • Locally, is there an overarching strategy to ensure that mainstream health services meet the needs of people with learning disabilities? • Is partnership working effective at a strategic and service delivery level? • Does the PCT's commissioning strategy address the needs of people with learning disabilities? • How much is spent on promoting the needs of people with learning disabilities in mainstream services? • What are individual NHS Trusts doing to promote the needs of people with learning disabilities? • What support is provided to people with learning disabilities and their families to take more control of their

	<p>own health?</p> <ul style="list-style-type: none"> • The adequacy the referral process to alert staff of any reasonable adjustments that may be required • How easy is it for people with learning disabilities to access mainstream services and what reasonable adjustments have been made? • What arrangements are in place to support children and young people with learning disabilities and their families to make the transition to adult services? • How is the effectiveness of services to meet the needs of people with learning disabilities monitored? • How are people with learning disabilities and their families involved in the commissioning, design, delivery and evaluation of services, as well as in planning their own care? <p>Excludes:</p> <ul style="list-style-type: none"> • In-depth review of specialist health services for people with learning disabilities, although these service have an important role in supporting and/or supplementing mainstream services 				
<p>Resources</p>	<p>Task Group:</p> <ul style="list-style-type: none"> • Councillor Ray Ballman • Councillor Jim Grant <p>Officer Support:</p> <ul style="list-style-type: none"> • Emma Powell, Scrutiny Officer 				
<p>Timescales</p>	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 15%; text-align: center;"><i>Start</i></td> <td>First meeting date to be arranged in July 2008</td> </tr> <tr> <td style="text-align: center;"><i>Finish</i></td> <td>Final report presented to the Health Overview & Scrutiny Committee in March 2009</td> </tr> </table>	<i>Start</i>	First meeting date to be arranged in July 2008	<i>Finish</i>	Final report presented to the Health Overview & Scrutiny Committee in March 2009
<i>Start</i>	First meeting date to be arranged in July 2008				
<i>Finish</i>	Final report presented to the Health Overview & Scrutiny Committee in March 2009				
<p>Outputs</p>	<ol style="list-style-type: none"> 1. Chair of the Task Group to provide an update to the Health Overview & Scrutiny Committee at its meetings in September and November 2008. 2. Chair of the Task Group to outline the review findings and recommendations to the Health Overview & Scrutiny Committee at its meeting on ??? 				
<p>Methodology</p>	<ul style="list-style-type: none"> • Desk based research of current policy and practice • Considering best practice nationally • Interviewing identified advisers/ witnesses • Consultation with service users and carers • Site visits 				

<p>Expert Witnesses/ Advisors</p>	<p>Internal</p> <ul style="list-style-type: none"> • Cabinet Member for Health, Housing & Social Care • Graham Pearson, Joint Director Service Delivery • Pauline MacDonald, Deputy Director of Primary Care & Community Services • Jane Leaman, Director Public Health <p>External</p> <ul style="list-style-type: none"> • Graham Walker, Manager Learning Disability Service • Representatives from Swindon & Marlborough NHS Trust, Avon & Wiltshire Mental Health Partnership NHS Trust, Great Western Ambulance Service NHS Trust • Swindon Local Involvement Network • MENCAP (Swindon & District) • MIND Swindon & District • Swindon & Wiltshire Users Network • Swindon Carers Centre • Upham Road Centre • Swindon LINK • Better Lives in Swindon Self Advocacy Group • One Step Ahead • SUNS • Enterprise Works • Ridgeway Partnership Oxfordshire Learning Disability Trust • The Open Door Centre • Age Concern • White Horse Care Trust
<p>Evidence Documents</p>	<ul style="list-style-type: none"> • <i>Valuing Health for All</i>, Foundation for People with Learning Disabilities, 2003 • <i>Treat Me Right!</i> Mencap, 2004 • <i>Equal Treatment: Closing the Gap</i>, Disability Rights Commission, 2006 • <i>Death by Indifference</i>, Mencap, 2007 • <i>Primary Care Service Framework, Management of Health for People with Learning Disabilities in Primary Care</i>, NHS, 2007 • <i>Improving the health of people with profound and multiple learning disabilities</i>, London Borough of Haringey, February 2007 • <i>10 Questions to Ask if You're Scrutinising Mainstream Health Services for People with Learning Disabilities</i>, Centre for Public Scrutiny & Foundation for People with Learning Disabilities, 2008 • NHS South West Draft Strategic Framework 2008/09-2010, NHS South West • <i>Healthcare for All: Independent Inquiry into Access to Healthcare for People with Learning Disabilities</i>, Sir

FINAL

	Jonathon Michael, July 2008
Site Visits	<ul style="list-style-type: none">• To be identified

Appendix 2

Sources of Evidence

Reports/ Briefings Produced for the Task Group

- *Other Overview & Scrutiny Reviews*, Scrutiny Unit, August 2008
- *National reviews regarding mainstream health care for people with Learning Disabilities*, Scrutiny Unit, August 2008
- *What is a "Learning Disability"?* Scrutiny Unit, August 2008

Minutes of Meetings

Evidence was heard from the following witnesses during Task Group meetings. Copies of available minutes are available from the Scrutiny Unit.

- Joint Director Service Delivery, Swindon Borough Council & Swindon Primary Care Trust
- Deputy Director of Public Health, Swindon Primary Care Trust
- Valuing People Project Worker
- Manager, Adult Community Learning Disability Service
- Chief Executive, Great Western Hospitals NHS Foundation Trust
- Director Nursing & Performance, Great Western Hospitals NHS Foundation Trust
- PALS Manager, Swindon Primary Care Trust
- Head of Patient Experience, Great Western Hospitals NHS Foundation Trust
- Learning Disability Carers & Adult Outreach Support Worker, Swindon Carers Centre
- Better Lives in Swindon (BLIS)
- The Open Door Day Centre

National Reports, Policy and Guidance

- *Could do Better: The Learning Disability Task Force Annual Report 2006-07*, Learning Disability Task Force, 2007
- *Death by Indifference*, Mencap, March 2007
- *Equal Treatment: Closing the Gap*, Disability Rights Commission, 2006
- *Green Light for mental health – how good are your mental health services for people with learning disabilities?* Valuing People Support Team, 2007
- *Healthcare for All: Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, Sir Jonathon Michael, July 2008
- *Healthy and Equal: Improving the health of people with profound and multiple learning disabilities*, Haringey Council Overview and Scrutiny Committee, 2007
- *Joint Investigation into the provision of services to people with learning disabilities at Cornwall NHS Partnership Trust*, Healthcare Commission, 2006
- *The Healthcare of People with Learning Disabilities in the East Midlands: A Report for the Next Stage Review*, East Midlands Next Stage Review Workstream Group, May 2008
- *The Story So Far... Valuing People*, Valuing People Support Team, 2004

FINAL

- *Treat me Right!*, Mencap, 2004
- *Valuing people now: from progress to transformation – a consultation on the next three years of learning disability policy*, Department of Health, 2007
- *Valuing People: a new strategy for learning disability in the 21st century¹*, Department of Health, 2001
- *Primary Care Service Framework for the Management of Health for People with Learning Disabilities in Primary Care*, NHS Primary Contracting, July 2007
- *10 questions to ask if you're scrutinising...mainstream health services for people with learning disabilities*, Centre for Public Scrutiny and Foundation for People with Learning Disabilities, 2008

Local Reports, Policy and Guidance

- *Swindon Community Strategy: A Shared Vision for Swindon 2008-2030*, Swindon Strategic Partnership
- *NHS South West Strategic Framework 2008/09 to 2010/11*, NHS South West
- *Delivering Excellence for Swindon: Our Strategic Plan 2008-13*, Swindon Borough Council and Swindon Primary Care Trust
- *Swindon's Second Local Area Agreement*, Swindon Local Area Agreement Partnership Board
- *Swindon Action for Health Framework*
- *Learning Disability Strategy*
- *The Health of the Population of the Swindon Primary Care Trust 2007/08*, NHS Swindon & Swindon Borough Council, 2008

Websites

www.mencap.org.uk

www.patient.co.uk

www.healthcarecommission.org.uk

www.learningdisabilities.org.uk

FINAL

Appendix 3

Your views on general healthcare for people with learning disabilities in Swindon

Swindon Borough Council's Health Overview and Scrutiny Committee **wants to hear your views** about general healthcare services for people with learning disabilities who live in Swindon.

Please send this form to:



Scrutiny Unit
Swindon Borough Council
Civic Offices
Euclid Street
Swindon
SN1 2JH

It would help if we could have your comments **by 19th December 2008.**

Thank you for your help



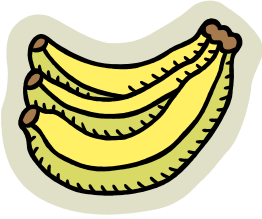
1. How easy is it for people with learning disabilities to get treatment from their GP?

Your comments:



2. How easy is it for people with learning disabilities to get treatment at hospital?

Your comments:



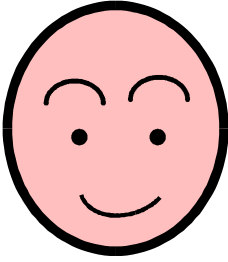
3. How easy is it for people with learning disabilities to get information about healthy eating, exercise and going to the doctor for health checks?

Your comments:



4. How easy is it for people with learning disabilities to use other health services like dentists, pharmacies and the Walk In Centre at Carfax Street?

Your comments:



5. What needs to change to improve local healthcare services for people with learning disabilities?

Your comments:



6. Is there anything else you would like to tell us?

Your comments:

Thank you for your help

Appendix 4

Response to the Task Group Report by Cabinet

CABINET

WEDNESDAY, 15 APRIL 2009

EXTRACT FROM MINUTES

135. References from Health Overview and Scrutiny Committee

The Cabinet Member for Health, Housing and Adult Social Care, and the Director of Law and Democratic Services submitted a joint report setting out references and recommendations arising from the meeting of the Health Overview and Scrutiny Committee held on 25th March 2009, concerning the final report and findings of the Provision of Mainstream Healthcare for People with Learning Disabilities Task Group, the Task Group on Local Accessibility of Radiotherapy in Swindon, and the Support Available for Carers in Relation to Mental Health Services Task Group.

Councillor Ray Ballman, joint Chair of the Mainstream Healthcare for People with Learning Disabilities Task Group, and Chair of the Support Available for Carers in relation to Mental Health Services Task Group, commented on the background to the two Task Groups and on their findings and recommendations. She drew particular attention to the problems faced by young carers dealing with people with mental health problems. Through work on the Carers in relation to Mental Health Task Group, she had been made aware of the existence of a policy developed nationally on the role and needs of young carers, and she believed that it would be helpful if the Children's Services team considered this policy to see if it, or something similar, could be adopted in Swindon. She asked for the Cabinet's support in seeking Health partners to give serious consideration to the Task Groups' findings and recommendations.

Councillor Garry Perkins, Cabinet Member for Children's Services, welcomed both Task Group reports, and advised that if Councillor Ray Ballman provided him with more information on the young carers policy he would be happy to discuss this with the Group Director, Children.

Councillor Mick Bray, joint Chair of the Local Accessibility of Radiotherapy in Swindon Task Group, commented on the Task Group's findings and recommendations. He referred to the media attention given to the findings of the Task Group, and to the impact on patients of having to travel out of the Borough for treatment on a daily basis. He noted the recent commitment given by the Prime Minister regarding Cancer treatment and the provision of local Radiotherapy services, and he hoped that this would be reflected in the provision of such facilities in Swindon in the near future.

Councillor David Renard, Cabinet Member for Health, Housing and Adult

FINAL

Social Care, welcomed all the Task Groups' findings and recommendations which he believed, if delivered, would have a significant impact for health care in the Borough, and for service users and their carers. He thanked all the Task Groups for their work.

Resolved – (1) That, further to Minute 62(1) of the Health Overview and Scrutiny Committee, and the findings of the Mainstream Healthcare for People with Learning Disabilities Task Group, (a) the Group Director, Housing and Social Care and the Director of Community be requested to ensure that local charities, community and voluntary groups are made aware of funding streams that they can access to promote healthy eating and physical activity amongst people with Learning Disabilities and their carers, and (b) the Final Report and recommendations of the Task Group, be noted.

(2) That, further to Minute 63 of the Health Overview and Scrutiny Committee, the Final Report and recommendations of the Task Group on Local Accessibility of Radiotherapy in Swindon, be noted.

(3) That, further to Minute 66 of the Health Overview and Scrutiny Committee, the Final Report and recommendations of the Task Group on Support Available for Carers in relation to Mental Health Services, be noted.

(4) That the Cabinet expresses its thanks to all the Councillors, partners and officers involved in the Task Groups referred to in (1) to (3) above, and to all those who contributed to the preparation of the Task Groups' reports, for their hard work and commitment to the production of these comprehensive and welcome reports.

The reasons for the decision and alternative options are as set out in the report to the meeting.