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1.1 Foreword

People with a learning disability and their carers have the same entitlement as anyone else to independent living and control of decisions about their lives, to participation in all the aspects of community life and access to health improvement services and to have the support to do so. These are the key values which underpin this health improvement strategy. Changed days from a generation or two ago when the standard model of care for many people with a learning disability was one based on lifetime institutional care.

This strategy is based on and driven by a needs assessment which takes account of the views of people with a learning disability and their carers - and therein lies one of its strengths. Another is its careful consideration of what the research evidence tells us is effective in promoting the health of this group of people.

It is rightly ambitious in its scope, covering as it does all of the various factors which impact on the health of people with a learning disability and their carers. Ambition brings challenges, and following the launch of this strategy close collaboration of all stakeholders will be essential in order to make the best use of the resources available to us to improve the health of people in Fife with a learning disability.

Dr Mike Roworth
Consultant in Public Health Medicine
May 2011
1.2 ACKNOWLEDGEMENTS AND FURTHER INFORMATION

Funding for this strategy was provided by the Scottish Government through the Equally Well Learning Disability Change Fund programme 2009-2011.

Essential information was collated from people with a learning disability, parents, carers and staff from multi-agencies; our thanks are extended to these contributors. Your comments and views have been invaluable for shaping the development of this Health Improvement Strategy for Adults with a Learning Disability in Fife.

This strategy has been produced under the direction of a multidisciplinary and multi-agency steering group (membership in Appendix 2) sponsored by the Adult Learning Disabilities Service and Dunfermline and West Fife Community Health Partnership (CHP).

The report is also available in easy read and audio formats. These were developed by the Dunfermline and West Fife CHP Improving Health Team with support from the Speech and Language Therapy Department and Communications for Health Project.

If you would like any further information and copies of the strategy, please contact Improving Health Team, Dunfermline and West Fife Community Health Partnership on 01383 565497.

For additional information on services provided by the Fife Learning Disabilities Service, NHS Fife please contact the Clinical Services Facilitator, on 01383 565280.

Photograph by Photosymbols 3. Cartoons by Graham Ogilvie.
1.3 Definitions

For the purpose of this report it has been assumed that in Fife the definition of a learning disability is as outlined in the *The Same as You?* report \(^1\) i.e.

A significant, lifelong condition: that started before adulthood that affected their development which means they need help to understand information, learn skills, and cope independently.

1.4 Abbreviations

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
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<tr>
<td>ASD</td>
<td>Autistic Spectrum Disorder</td>
</tr>
<tr>
<td>CHD</td>
<td>Coronary Heart Disease</td>
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<tr>
<td>CHP</td>
<td>Community Health Partnership</td>
</tr>
<tr>
<td>CLDN</td>
<td>Community Learning Disability Nurse</td>
</tr>
<tr>
<td>CLDT</td>
<td>Community Learning Disability Team</td>
</tr>
<tr>
<td>HEAT</td>
<td>Health, Efficiency, Accessibility and Treatment targets</td>
</tr>
<tr>
<td>GORD</td>
<td>Gastro-oesophageal reflux disease</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>JHIP</td>
<td>Joint Health Improvement Plan</td>
</tr>
<tr>
<td>LDMT</td>
<td>Learning Disabilities Management Team</td>
</tr>
<tr>
<td>LDS</td>
<td>Learning Disabilities Service</td>
</tr>
<tr>
<td>LD/ASD SIG</td>
<td>Learning Disability &amp; Autism Spectrum Disorder Strategic Implementation Group</td>
</tr>
<tr>
<td>PMLD</td>
<td>Profound and Multiple Learning Disabilities</td>
</tr>
<tr>
<td>PWLD</td>
<td>People with a Learning Disability</td>
</tr>
<tr>
<td>PFPI</td>
<td>Patient Focus Public Involvement</td>
</tr>
<tr>
<td>PAMIS</td>
<td>Profound and Multiple Impairment Service</td>
</tr>
<tr>
<td>QIS</td>
<td>NHS Quality Improvement Scotland</td>
</tr>
</tbody>
</table>
2 EXECUTIVE SUMMARY AND RECOMMENDATIONS

This strategy has been produced in response to reports and key documents which identified a need to deliver better health and care to people with a learning disability. The Scottish Government has provided funding to NHS Fife and their partners to address the health inequalities recommendations and respond to the findings of NHS Quality Improvement Scotland (QIS) Review of Health Care Services for People with a Learning Disability in Fife, held in August 2009.2

This strategy will outline and plan the priorities for people with a learning disability living in Fife with the aim to improve health, wellbeing and social inclusion and reduce health inequalities for this population.

2.1 BACKGROUND

Health needs of adults with a learning disability

Approximately 2% of the Scottish population have a learning disability with around 0.4% having severe or profound learning disability.3, 4

The number of people with a learning disability is projected to rise by 11% between 1998 and 2008.4 It is likely that the prevalence of this group will continue to rise at about this rate for the foreseeable future due to several societal factors such as increased longevity, better survival at birth, women deciding to have children later in life as well as increased alcohol consumption and teenage pregnancies among this group.3, 5

It is widely understood that the health needs of people with a learning disability are often unrecognised and unmet.4 In response to this, NHS Fife has worked with partners to develop this health improvement strategy for adults with a learning disability in Fife.

2.2 AIMS

The aims of this Health Improvement Strategy are to:

- Identify the health needs of adults with learning disabilities in Fife;
- Identify gaps in current service provision;
• Compile an action plan to address the significant health inequalities which can be experienced by this group of service users.

2.3 SUMMARY OF LITERATURE

A literature review of the health needs and health inequalities was conducted. This included mainly systematic reviews but also included non-systematic reviews and review of similar strategies produced by other NHS boards.

The literature review showed that the health statuses of those with a learning disability are distinct from those in the general population in respect of: lifestyle health issues, physical health needs, and mental health and behaviour. Their experiences in respect of access to and of the quality of healthcare are also different than for the general population.

2.4 CONSULTATION PROCESS

As part of the health needs assessment underpinning this health improvement strategy a broad consultation exercise was conducted to gather the views of stakeholders throughout Fife. This consultation aimed to answer the three key questions summarised in the pictures below.
In order to gather a broad range of views, our consultation process took three forms:

1. Three large consultation events (for parent carers, voluntary organisations, statutory organisations, advocacy services and service users)

2. Five smaller focus group sessions. As gatherings of smaller numbers of familiar faces, these aimed to provide a more relaxed opportunity for individuals with a learning disability to contribute their views.

3. An online questionnaire (primarily aimed at professionals who were unable to attend the other events).

Throughout the consultation process attendees were encouraged to think of health in its broadest terms:

In total approximately 150 people attended the large consultation events and focus groups with an additional 60 individuals responding to our online questionnaire.
2.5 Local Health Needs Identified

The needs assessment process highlighted a number of key themes in relation to the health needs of adults with a learning disability living in Fife which are further discussed in sections 5 and 6. These are outlined below with some illustrative quotes.


Health Needs: Learning disability often overshadows health needs.

Relationships: Adults with a learning disability have a right to relationships, good sexual health and wellbeing (including inpatients). ‘We are entitled to have sexual feelings too and to be able to express them’.

Access Issues: Physical barriers often prevent access to health care provision and leisure activities.

Communication: Difficulties were identified with understanding appointment letters, prescriptions, discharge letters, dietary and health improvement advice. Suggestions for improving content included: using accessible language, more pictures and larger text. Information sharing was also highlighted with suggestions on ways information can be better shared.

Carers: Carers are intrinsic to wellbeing of people with a learning disability. Support for carers is essential. They are relied upon for early identification of problems. They know the patient well, are able to support them in behaviour change and accessing services and can identify problems early. ‘Carers need the opportunities to learn - both from healthcare professionals and from other carers’.

Transitions: The transition from children’s to adult’s services and from adult’s to older person’s services stages were identified as a problem although there were some encouraging comments: ‘Transitions can be challenging but don’t be discouraged as people will surprise you as to how they can and will adapt with encouragement’.

Training: Existing training was felt to be good but insufficient. ‘There is a lack
of trained staff out with the learning disability service’. Training required for service users, family, carers and staff. More support groups and train the trainer events for carers are needed.

**Interventions and Services:** Services which suit the individual are required. Many existing services received positive comments. Suggested additions to existing services included:

- identification of hidden population for multidisciplinary health checks;
- awareness of screening programmes;
- expansion of schemes such as Disability Sport Fife;
- local area coordinator for learning disability;
- patient passports and essential life plans.

**Being a Citizen:** People with a learning disability have a right to access all avenues involved in being part of a community.

**Advocates:** There is a need for advocates for people with a learning disability. ‘It’s important that I have a voice’ service user.

### 2.6 Gaps and Recommendations

<table>
<thead>
<tr>
<th>Gaps</th>
<th>Recommendations</th>
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<tbody>
<tr>
<td><strong>Health Surveillance</strong></td>
<td></td>
</tr>
<tr>
<td>• There is little data on the local health needs of this population particularly those with a mild learning disability.</td>
<td>1. Establish learning disability registers at local level to identify health needs. This would support and improve strategic planning.</td>
</tr>
<tr>
<td><strong>National Screening Programmes</strong></td>
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| • A lower proportion of adults with a learning disability, in relation to the general population, and who are eligible for cancer screening programmes are not accessing these programmes. | 2. Make health screening programmes more accessible though better local information on:  
  • breast screening;  
  • cervical screening;  
  • bowel screening;  
  • osteoporosis screening. |
<table>
<thead>
<tr>
<th>Gaps</th>
<th>Recommendations</th>
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<tr>
<td><strong>Health Improvement</strong></td>
<td></td>
</tr>
<tr>
<td>• People with a learning disability have difficulty accessing the universal health prevention/improvement programmes currently in place.</td>
<td>3. Ensure there is proactive coordination of current and future health initiatives for people with a learning disability especially around sexual health, parenting, healthy eating; general health needs (&quot;Keep Well Checks&quot;), smoking, alcohol and substance use.</td>
</tr>
<tr>
<td><strong>Nutrition (Food and Health)</strong></td>
<td></td>
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<tr>
<td>• There is an inconsistent approach to the nutritional needs of this group resulting in higher levels of obesity and nutritional ill health.</td>
<td></td>
</tr>
<tr>
<td>• Service users and staff highlighted difficulties in accessing weight management intervention and nutrition supplement in form Vitamin D for this population in regards to osteoporosis prevention.</td>
<td>4. Develop and implement appropriate nutritional standards for residential supported living and day support services.</td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td></td>
</tr>
<tr>
<td>• Lack of training and competent staff.</td>
<td>5. Improve workforce competencies across all agencies around health needs for people with a learning disability.</td>
</tr>
<tr>
<td>Gaps</td>
<td>Recommendations</td>
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<tr>
<td>------</td>
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<tr>
<td><strong>Communication</strong></td>
<td></td>
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<tr>
<td>• Accurate and up-to-date, accessible information on services and health information for people with a learning disability, staff, carers and the community is not always consistent.</td>
<td>6. Provide accurate, up to date and accessible information on services available to people with a learning disability for all staff, carers, and the community.</td>
</tr>
<tr>
<td>• Service users identified difficulties in understanding communications with statutory agency.</td>
<td>7. Improve communication between agencies and services in order to provide a holistic health care approach.</td>
</tr>
<tr>
<td>• Currently there are no systems in place within the acute sector (hospitals) which identify and ensure adjustments are made for the patient with a learning disability in order to improve and respond to care needs.</td>
<td>8. Build on existing forums to ensure that health improvement is a focus for all key stakeholders. This will allow sharing, learning and developing of expertise.</td>
</tr>
<tr>
<td>9. Build on existing practice to proactively identify patients with a learning disability who enter the acute sector so that suitable adjustments can be put in place to meet their health needs.</td>
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<table>
<thead>
<tr>
<th>Gaps</th>
<th>Recommendations</th>
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<tbody>
<tr>
<td><strong>Active Citizenship</strong></td>
<td></td>
</tr>
<tr>
<td>• Gaps were identified in education, employment and social and leisure opportunities for the client group.</td>
<td>10. Develop in partnership with other statutory and voluntary organisations:</td>
</tr>
<tr>
<td>• Transitions were another area where further opportunities and coordinated approach is required.</td>
<td>• more opportunity for social and physical activities, employment opportunities and a greater breadth of educational opportunities for people with a learning disability;</td>
</tr>
<tr>
<td></td>
<td>• an active citizen charter for people with a learning disability which describes individuals' rights and responsibilities in relation to actively managing</td>
</tr>
</tbody>
</table>
their health needs;

• improve access to transportation services that assist people with a learning disability especially in relation to access for social and educational opportunities to maintain and improve their health.

11. Ensure that when a person is in transition from child to adult services or from adult to older people services there is sufficient attention given to their ongoing and future health needs.

<table>
<thead>
<tr>
<th>Gaps</th>
<th>Recommendations</th>
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<td>Strategy/Policy</td>
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<tr>
<td>12.</td>
<td>Develop further integration of services and pathways to ensure a holistic approach to the health needs of people with a learning disability.</td>
</tr>
<tr>
<td>13.</td>
<td>Review, develop and influence partnership strategies and action plans to ensure planning and commissioning of health issues is being carried out.</td>
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<tr>
<td>14.</td>
<td>Ensure Equality and Diversity is a priority in all health improvement activity intended for those with a learning disability.</td>
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<tr>
<td>15.</td>
<td>Ensure the Patient Focus Public Involvement strategy includes a focus on service users’ and families’ input to improving their health outcomes.</td>
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3 INTRODUCTION

Improved health for people with a learning disability is a key priority for NHS Fife, Fife Council and other agencies involved in providing care. Each person’s health is affected by a wide range of factors. These ‘determinants of health’ range from individual lifestyle to wider social, economic and environmental factors. People with a learning disability have the right to lead their lives fully with the same opportunities and responsibilities as other citizens. They deserve to be treated with the same dignity and respect as the general population. Evidence shows that people with a learning disability are known to experience significant health inequalities compared to the general population. They also suffer from increased barriers to accessing health promotion and preventative care and as a result have a shorter life expectancy.

This strategy has been produced in response to reports and key documents which identified a need to deliver better health and care to people with a learning disability. The Scottish Government has provided funding to NHS Fife and their partners to address the health inequalities recommendations and respond to the findings of the 2009 NHS Quality Improvement Scotland Review.²

This strategy will outline and plan the priorities for people with a learning disability living in Fife with the aim to improve health, wellbeing and social inclusion and reduce health inequalities for this population.

3.1 AIMS AND OBJECTIVES

The aims of this Health Improvement Strategy are to:

- identify the health needs of adults with learning disabilities in Fife;
- identify gaps in current service provision;
- compile an action plan to address the significant health inequalities which can be experienced by this group of service users.

The specific outcomes of this Health Improvement Strategy will be to identify areas of evidence-based good practice throughout the health improvement
arena in Fife. The approach includes:

- identifying key partners;
- gaining service users’ perceptions of health;
- identifying health needs and health inequalities;
- reviewing current NHS Fife local policies and practices;
- reviewing current health education and promotion for this population;
- providing baseline information on the population of Fife.
4 POLICY CONTEXT

4.1 SCOTTISH POLICY CONTEXT AND THE INEQUALITIES AGENDA

The *The Same as you?*¹ learning disability review was published in May 2000, setting out a programme of change to enable people with a learning disability to lead a full life and to ensure the provision of better health and care. This is the main strategic policy driver in developing services for people with a learning disability in Scotland. It recognised that more should be done to allow people with a learning disability to achieve a full life, including greater access to mainstream services. For this to occur the report further highlighted the need to improve, reshape and reorganise services as well as the need to increase public awareness of the needs of people with a learning disability. A shift towards person-centred and needs-led approaches was also recommended as was the need for agencies to be clearer about their role and opportunities for working with others.

In 2004 NHS Health Scotland published a Health Needs Assessment Report on People with Learning Disabilities in Scotland.⁶ This report summarised research showing the additional health needs that people with a learning disability have and how these health needs differ from those of the general population.

The *Equally Well: report of the ministerial task force on Health Inequalities Scottish Government (2008)*⁷ acknowledged the need for NHS Boards to target health promotion and health improvement action more effectively for people with a learning disability and others who may need support to access information.

In 2010 a UK briefing paper by Improving Health and Lives: Learning Disability Observatory⁸ summarised and highlighted the most recent evidence on the health status of people with a learning disability and determinants of the health inequalities they face.

These are the main national policies that emphasise concerns in regards to the health issues of adults with a learning disability. These reports, in
conjunction with the key government literature, outline a national commitment to improving the quality of life for people with a learning disability. These are the key drivers for taking forward work locally to improve the overall health, access to health services and services received for people with a learning disability throughout Fife.

4.2 FIFE POLICY CONTEXT

The Fife Health and Wellbeing Alliance (FHWA) provides the strategic lead for improving health and well being and reducing health inequalities for the population of Fife.

A key driver for this particular population is the NHS Quality Improvement Scotland (QIS) Review of Health Care Services for People with a Learning Disability in Fife, held in August 2009. This highlighted the following areas for local action in relation to adults with learning disability:

- There was no reference within the Joint Health Improvement Plan, ‘A Healthier Future for Fife’ (2007-2010) (JHIP) specifically to people with a learning disability. The JHIP is the foundation for developing and progressing health and wellbeing activities across all NHS Fife.

- Transport was highlighted as an issue and is being addressed locally within the NHS Quality Improvement Scotland Review action plan.

- A gap was identified around sexual orientation, sexuality, sexual health and relationship education for people with a learning disability. This is now being addressed by the Sexual Health Strategy Group.

- There was no identified person to provide specific disability awareness or disability training across NHS Fife. It acknowledged the work undertaken on an ad hoc basis by the Disability Liaison Nurses and Equality & Diversity general training. This issue is acknowledged within the strategy.

This strategy will link into other local and national documents and strategies for example:
• The recently launched (July 2010) “Caring Together”, a five year strategy outlining a shared vision for the future of carer recognition and support in Scotland is the first time carers are being recognised as equal partners in care. The adult strategy has a 10-point plan with specific commitments to help carers. A carer’s strategy for Fife is currently being developed by Fife Carers Strategy Group.

• The Fife Council Day Services Review.

• Guidelines for meeting audiology needs of adults with a learning disability.

• Promoting access to healthcare for people with a learning disability – a guide for frontline NHS staff, NHS Quality Improvement Scotland 2006.

• The Fife Health and Social Care Partnership Service Delivery Plan 2008-2011.

• The Fife Health and Wellbeing Plan 2011-2014, which is being developed and which will address these issues.

4.3 Equality and Diversity (E & D) Service in NHS Fife

Equality and Diversity is about equal treatment and equal opportunities and is at the heart of NHS Fife. NHS Fife is committed to inspiring a culture where people with a learning disability are respected and valued and their rights are promoted and supported. This will be done by ensuring that NHS Fife initiate and deliver appropriate services that respect the needs of people with a learning disability.

With the introduction of the Equality Act 2010 NHS Fife is required to pay due regard to:

• the need to eliminate discrimination;
• advancing equality;
• fostering good relations.

These three requirements apply to many aspects and this includes disability.
Collecting and analysing the evidence about the use and accessibility of our services to reduce health inequalities will ensure that services will be more accessible and inclusive for people with a learning disability.

4.4 **Governance and Accountability**

A working group consisting of the current steering group and additional key stakeholders will meet regularly to ensure that the recommendations and actions in this strategy are taken forward.

Governance and accountability of the working group will be provided through the Learning Disabilities Management Team (LDMT) and the Learning Disability and Autism Spectrum Disorder Strategic Implementation Group (LD ASDSIG).

Figure 1 shows the local strategic governance structure for adults with a learning disability in Fife.

4.4.1 **Performance Management**

NHS Fife recognises the strategy action plan needs to be appropriately linked with existing outcome frameworks for example, the NHS Fife Balanced Score Card, Health Efficiency Accessibility and Treatment targets (HEAT) and Single Outcome Agreements.

Figure 1 overleaf shows the structural arrangements in place to ensure the strategy is embedded within existing work streams and strategies.
Figure 1: NHS Fife and Fife Council Strategic Partnership Management Structure Overview

NHS Fife Board

Fife Council Social Work & Health

Health & Social Care Partnership Group
(Councillors, NHS Fife Board Members)
(Senior Managers, Fife Council in attendance)

Partnership Management Group
(Senior Officers – Social Work, Operational Division, Housing Service, Local Service Network, Voluntary Sector)

Strategic Groups
The Learning Disability SIG

Joint Resource and Joint Management Group
(Senior officers Health & Social Work)

Local Management Units
(Operational Managers)
- Glenrothes & North East Fife
- Kirkcaldy & Levenmouth
- Dunfermline & West Fife

Managed Clinical Network Learning Disability
The Fife LD Service continues to work with the South East Scotland Managed Clinical Network and is represented on various MCN groups.

The Advocacy Working Group
The Carers Working Group
The Supported Living and Short Breaks Working Group
The Children, Young People and Further Education Working Group
The Complex Care Joint Commissioning Working Group
The Good Health Care Working Group
5 SUMMARY OF LITERATURE

The review of literature presented in this section is not exhaustive but provides a summary of the health needs and health inequalities that people with a learning disability may encounter. The review mainly included systematic reviews but also included non-systematic reviews and grey literature including review of similar strategies produced by other NHS boards. Some of the electronic databases searched included: Ovid Medline and EMBASE. Search criteria were based on those used in the Cochrane Development Psychosocial and Learning Problems Group.16

5.1 EPIDEMIOLOGY (INCLUDING INCIDENCE AND PREVALENCE – PROJECTED NUMBERS FOR FIFE)

Approximately 2% of the Scottish population have a learning disability, with around 0.4% having a severe or profound learning disability.3,4 Applying the national Scottish prevalence figure to Fife it is estimated that approximately 6,000-7,000 adults have a learning disability.

At the time of the 2009 QIS review, NHS Fife had identified approximately 1,410 adults with a learning disability from GP registers held for people aged over 18. 51 of the 58 GP practices in Fife held such a register.

It should be noted that no local register of children with a learning disability existed at the time of the QIS review.

Epidemiological research on the specific health needs of people with a learning disability is limited due to difficulties in diagnosis, definition of cases and small study sizes.17

The number of people with a learning disability is projected to rise by 11% between 1998 and 2008.4 It is likely that the prevalence of this group will continue to rise at about this rate for the foreseeable future due to several societal factors such as increased longevity, better survival at birth, women deciding to have children later in life as well as increased alcohol consumption and teenage pregnancies among this group.3,5
5.2 Health Needs and Health Inequalities

Research had shown the main determinants of health inequalities experienced by people with a learning disability are potentially receptive to interventions. This chapter discusses these main determinants as well as the health needs of people with a learning disability.

5.2.1 The Social Determinants of Health

People with a learning disability, especially those with a less severe disability, have an increased risk of exposure to well established “social determinants”, these include poverty, poor housing conditions, unemployment and social isolation. Figure 2 below provides a valuable framework to demonstrate the many influencing factors contributing to health outcomes.

Figure 2: Social Model of Health - Dahlgren and Whitehead (1991)
The Main Determinants of Health

Dahlgren and Whitehead’s health model\(^8\) - A person’s health is influenced by the conditions in which they live. The social and economic conditions which include low income, social exclusion, unemployment and poor housing conditions are well known to influence health and length of life.

The World Health Organisation definition of health is:

‘Health is a state of complete physical, mental and social wellbeing and not
merely the absence of disease and infirmity.’

This emphasises the link to well being and associated focus on the mental and social aspects as well as physical.

Table 1: Provides an Overview of Some of the Evidence Supporting the Enhanced Risk of Exposure to the Social Determinants of Health People with a Learning Disability Experience.

<table>
<thead>
<tr>
<th>Factors having influence on health of people with a learning disability.</th>
<th>Some supporting evidence</th>
</tr>
</thead>
</table>
| Low income | • Severe learning disability is relatively evenly spread in the population. However mild to moderate learning disability rates are higher in some deprived and urban areas.\(^{19}\)  
• People with a learning disability living independently (private households) are much more likely to live in areas known to have higher levels of social deprivation.\(^{19}\)  
• People with a learning disability compared to the general population are more likely to experience income poverty and material hardship.\(^{20}\)  
• Increased risk of reduced health and mental health outcomes has been identified among British children and young people with a learning disability.\(^{21, 22, 23}\)  
• Higher rate of self–reported antisocial behaviour among adolescents with a learning disability.\(^{24}\) |
| Social exclusion | • Being subjected to bullying at school and blatant discrimination as an adult are independently related to poorer health outcomes for people with a learning disability.\(^{25}\) |
| Poor housing | • The majority of people with learning disability, whether mild or severe, live with a parent. The more severe the learning disability the higher chance of living in residential and NHS accommodation.\(^{26}\) |
| Education needs | • Only 9% of people with a learning disability are in further education in Scotland (2,524 people).\(^{26}\) |
5.2.2 Specific Genetic and Biological Causes of Learning Disability

Higher risk of death from congenital abnormalities occurs in people with moderate to profound learning disability compared to the general population.

Examples include:

**Table 2: Provides examples of specific genetic and biological mortality**

<table>
<thead>
<tr>
<th>Congenital abnormalities</th>
<th>Disease/Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down’s syndrome</td>
<td>Congenital heart diseases and early onset dementia.</td>
</tr>
<tr>
<td>Prader -Willi Syndrome</td>
<td>Higher incidence of obesity</td>
</tr>
<tr>
<td>Cohen Disease Syndrome</td>
<td></td>
</tr>
<tr>
<td>Bardet - Biedl Syndrome</td>
<td></td>
</tr>
</tbody>
</table>

5.2.3 Communication Difficulties and Reduced Health Literacy

People with a learning disability are unable to relate their health needs to individuals due to their limited communication skills. Carers are relied upon to identify and pass on clients’ health needs. Health problems can be overlooked because of lack of recognition by carers. Sensory impairment was not identified by carers in 50% of patients with difficulties in hearing and seeing.
5.2.4 **Lifestyle Health Issues**

**Diet and Exercise**

Diet has a significant role to play when considering lifestyle related risk factors with adults with a learning disability. Evidence suggests that less than 10% of those living in supported accommodation eat a healthy balanced diet. It is recognised that carers have poor knowledge about adult’s recommended daily allowance (RDA).

**Weight Problems**

People with a learning disability may experience a higher risk of being overweight or becoming obese due to physical impairments, the side effects of medication, dependence on others to regulate diet and reduced access to information on a healthy lifestyle. A greater prevalence has been reported in adults with a learning disability when compared with general population. The prevalence of obesity in males and females with a learning disability has been shown to be 26.5% and 44.2% respectively compared to a general population prevalence of approximately 20% for each gender. A significant number of people with a learning disability are underweight, with the prevalence of underweight increasing with increasing severity of learning disability. One cause of underweight is difficulty with swallowing, which can also lead to inadequate fluid intake.

**Smoking and Substance Use**

Several studies have reported that the smoking rates among adults with a learning disability are considerably lower than in the general population. The same studies have found that adults with a learning disability drink considerably less alcohol than the general population. However as those with a mild learning disability live longer, have less restricted lifestyles and exercise greater self-determination, it is thought that the rates of tobacco and alcohol use may increase.
Sexual Health

There has been little research conducted into the sexual health status of people with a learning disability in the UK. There is a misconception that this group is not sexually active. This misconception has been identified and challenged by others. High rates of unsafe sexual practices and sexually transmitted disease among men with a learning disability have been reported. It has been suggested that this group may face particular barriers in gaining access to sexual health services, and the informal channels through which young people learn about sex and sexuality. It is suggested here that the misconceptions about the sexual activity of those with a learning disability are significantly detrimental to this group gaining access to relevant services; therefore training should be provided to staff in order to break these misconceptions.

5.2.5 Physical Health Needs

The following section provides an overview of the physical health needs that are more common in people with a learning disability than the general population.

Respiratory Disease

Respiratory disease is a significant cause of death for people with a learning disability. The 2010 Department of Health update paper on Health Inequalities with People with Learning Disabilities stated that respiratory disease was the cause of death in 46-52% of this population, which is higher than for the general population at 15-17%.

Coronary Heart Disease

In the UK, coronary heart disease is a leading cause of death among people with a learning disability (14-20%), with rates expected to increase due to increased longevity and lifestyle changes associated with community living.

Further, 45-50% of people with Down's syndrome have congenital heart defects.
Cancer

Overall, the proportional mortality rate from cancer in the UK among people with a learning disability is currently lower than the general population: 12-18% compared to 26%. Moreover, people with a learning disability experience a different pattern of cancer compared to the general population. For example there is a decreased rate of prostate, lung and urinary tract cancers; but an increased rate of gastrointestinal cancer (48-59% vs. 25% for the general population).\textsuperscript{40 - 43}

An increased risk of leukaemia for people with Down’s syndrome has been observed, with the incidence being 10 to 20 times more than general population and presents typically in first four years of life. It has been suggested with Prader - Willi syndrome there is increased risk of myeloid leukaemia.\textsuperscript{6}

The incidence and pattern of cancer among people with a learning disability is rapidly changing due in part to longevity.\textsuperscript{6, 8, 40 - 42}

Epilepsy

Uncontrolled epilepsy can have serious negative consequences on both quality of life and mortality. The prevalence rate of epilepsy among people with a learning disability has been reported as at least twenty times higher than for the general population, with seizures commonly multiple and resistant to drug treatment.\textsuperscript{8, 44, 45} Freedom from seizures must be balanced with the impact on quality of life of the side-effects of antiepileptic drugs.

Oral Health

People with a learning disability have more untreated dental decay, more extractions, worse oral hygiene levels and more gum inflammation and periodontal disease than the general population; and are less likely to have consistent contact with dental services.\textsuperscript{46}

Uptake of dental screening services is lower than for the general population and dental work tends to be reactive rather than preventative as a result.\textsuperscript{47} One in three adults with a learning disability and four out of five adults with Down’s syndrome have unhealthy teeth and gums.\textsuperscript{8} People with a learning disability living in family homes in the community were found to have had
greater unmet oral health needs (more untreated decay and worse oral hygiene) than those living in residential homes.48

**Gastrointestinal disorders**

**Table 3: Summary of Gastrointestinal disorders**

| Swallowing and Feeding difficulties | Adults with a learning disability are at a higher risk of swallowing and feeding problems, putting them at higher risk of choking and other secondary complications.5 “Difficulties with eating, drinking and swallowing have implications for health, safety and wellbeing. A noticeable percentage of adults with a learning disability and dysphagia experience recurrent respiratory tract infections. Other negative health consequences of dysphagia include asphyxia, dehydration and poor nutritional status.” 8,49 |
| Gastro-oesophageal reflux disease (GORD) | Gastro-oesophageal reflux disease (GORD) often goes unnoticed in the learning disability population and if untreated there is an increased risk of oesophageal carcinoma.50 A Recent Department of Health Inequalities & People with Learning Disabilities in the UK: 2010 report states “we are not aware of any UK-based data on the prevalence of GORD among people with a learning disabilities”. However up to half of a sample of institutionalised people with moderate and severe learning disability in the Netherlands were found to have GORD.17 |
| Constipation | Constipation is more prevalent in people with learning disability than in those without. It is particularly likely in those who: have a profound and multiple learning disability; are less mobile; have inadequate hydration or limited food choice; and experience side effects of long term medication.51 In Britain there is limited research on this topic but one Dutch study found constipation in almost 70% of institutionalised individuals with learning disability compared with 15% in adults in the general population.51,8 |

**Sensory Impairment**

People with a learning disability have a higher prevalence of visual and hearing impairments than the general population. Approximately 40% of people with a learning disability are reported to have a hearing impairment, with people with Down’s syndrome at particularly high risk of developing vision
and hearing loss. Estimates from a Dutch study found a population prevalence of hearing loss of around 30% of adults with a learning disability (around twice that of the general population). In 47.6% of cases identified, the hearing loss had not been identified prior to the study. Hearing loss increases with age and is more common in those with Down’s syndrome. Carers frequently fail to identify sensory impairments, including cerebral visual impairment, among people with a learning disability that they support. Those living independently or with family are significantly less likely to have had a recent eye examination than those living with paid support staff.

**Metabolic and Endocrine Disorders**

**Table 4: Summary of Metabolic and Endocrine Disorders**

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Osteoporosis and fractures</strong></td>
<td>People with a learning disability are at higher risk of developing osteoporosis and fractures than the general population. Studies from Australia and the USA indicate that people with a learning disability may have increased prevalence of osteoporosis and lower bone density than the general population. Down’s syndrome is another risk factor for osteoporosis. Contributory factors include lack of weight-bearing exercise, delayed puberty, earlier than average age at menopause for women, poor nutrition and being underweight.</td>
</tr>
<tr>
<td><strong>Thyroid Disease</strong></td>
<td>Thyroid disease can develop at any age but is more common with increasing age and is more prevalent in those with Down’s syndrome. The 5 and 10-year incidence of definite hypothyroidism in adults with Down’s syndrome was 0.9%-1.64% and 13.6% respectively.</td>
</tr>
<tr>
<td><strong>Diabetes</strong></td>
<td>Prevalence of Type II diabetes is possibly higher in those with a learning disability due to lower physical activity and poor nutrition (hence high rates of obesity). Within the learning disabilities population, the diagnosis of Type II diabetes may be overlooked and therefore go untreated. A Welsh GP-based survey of adults with a learning disability demonstrated a prevalence of diabetes of 9% compared with approximately 4% in the adult population.</td>
</tr>
</tbody>
</table>

**Posture and Mobility**

There are high rates of mobility problems associated with more severe levels of learning disability. Among adults with a learning disability:
• being non-mobile has a sevenfold increase in death compared to being fully mobile;

• being partially mobile has been associated with a twofold increase of death when compared with being fully mobile.\textsuperscript{8}

High rates of accidents and injuries among people with a learning disability, including injuries from falls have been reported in various studies undertaken in Canada, Australasia, the Netherlands and the US.\textsuperscript{58 - 62} One study found a level of musculo-skeletal disability or impairment 14 times higher in people with learning disability compared with the general population.\textsuperscript{63} The recent Department of Health report however stated that “they are not aware of any UK-based data on the prevalence of injuries, accidents or falls among people with a learning disability”.

**Mental Health and Behavioural Needs**

*Prevalence of mental illness and health problems:*

People with a learning disability are more likely to experience mental health problems than the general population. Psychological problems in people with a learning disability can be masked by their learning disabilities and can go undiagnosed for considerable periods of time. This is further compounded by a number of factors including difficulties in expression and communication. It should also be noted that psychological health problems are more difficult to diagnose and can have varying degrees of severity.

**Table 5: Summary of Mental Health and Behavioural Problems**

| Challenging behaviour | Challenging behaviours, aggression, destruction and self-injury are shown by 10%-15% of people with a learning disability with age-specific prevalence peaking between ages 20 and 49.\textsuperscript{64 - 69}

The term ‘challenging behaviour’, in the absence of a psychiatric disorder, encompasses a wide range of behaviours that may be harmful to people or property, it may be difficult to manage and may limit access to community facilities.\textsuperscript{70}

Unsurprisingly, estimates of prevalence rates vary widely. A recent Cochrane Review reported rates of 7.6% and 55.3% from different studies.\textsuperscript{70} |
### Affective disorders

The prevalence of depression and bipolar disorder are approximately 25-30%: at least twice that of general population.\(^7^1\)

Reported prevalence rates for anxiety and depression among adults with a learning disability vary widely, but are generally reported to be at least as prevalent as the general population and higher among people with Down’s syndrome.\(^8\)

### Severe and enduring mental health problems

The reported prevalence of psychotic disorders is between 4.4% and 29% with a suggested rate of schizophrenia more than twice that of the general population.\(^7^1\)

### Dementia

Several studies have shown that the prevalence of dementia among those with a learning disability is considerably higher than for the general population for example, (22% versus 6% aged 65+).\(^8\), \(^7^2\), \(^7^3\) People with Down’s syndrome are at particularly at high risk of developing dementia, with the age of onset being 30-40 years younger than that for the general population.\(^7^4\), \(^7^5\)

### Autistic Spectrum Disorders (ASD)

ASD is the most common psychiatric disorder among people with a learning disability (10% overall and 30% of moderate to severe [IQ<50] group).\(^3\)

People with autistic spectrum disorders face similar barriers to accessing health care as those with a learning disability.

A review of specific needs has been comprehensively summarised in the Autistic Spectrum Disorder Needs Assessment document.\(^7^6\)

### Transitions

The transition from child to adult service user is a stage in the person’s life where key life choices and decisions are made. Yet it has been shown that for people with a learning disability this change transition is not always as smooth as it should be.\(^7^7\) - \(^8^0\) This appears to be due to poor planning, communication and coordination between care providers.\(^8^0\)

### Parenting

Research commissioned by NHS Fife in scoping services in Fife available for pregnant woman and parents with a learning disability with a child under five has found those with a learning disability can encounter many inequalities in accessing local services tailored to their needs.\(^8^1\) It has been highlighted that 40-60% of children born to parents with a learning disability are removed from
their care. This has enormous societal and financial impacts.\textsuperscript{82-85} There are several significant barriers faced by a parent with a learning disability including others’ beliefs, discouragement of motherhood, unavailability of resources, inaccessibility of environments and the unavailability of appropriate support.\textsuperscript{82-90} To increase the chance of avoiding family breakdown the Scottish Good Practice Guidelines on supporting parents with learning disabilities aims to help services improve their support for parents with a learning disability and their children.\textsuperscript{91}

5.2.6 Access to and the Quality of Healthcare

The 2007 Scottish Government literature review \textsuperscript{92} on multiple and complex needs summarised existing research into the processes which people engage or do not engage with services. The review further highlighted that:

- People with multiple and profound learning disabilities often do not know what services exist and face significant barriers in accessing services.
- Exclusion of this group occurred, with people with multiple needs being declined services for example being assessed as “too complex or challenging” for the service(s) reviewed.
- Inflexibility of service criteria prevented continuity of care.
- The following elements should be seen as good practice:
  - targeted and outreach information provision in accessible formats;
  - services and partners that address the person holistically;
  - outreach services that actively identify and targeted people that did not access services.

Health Promotion and Health Screening:

The learning disability population experience lower levels of health promotion intervention, preventative care and access national health screening initiatives less frequently.\textsuperscript{93} These have included: assessment for vision or hearing impairments routine dental care, cervical screening and mammography screening.
Health Checks:

A systematic review of evidence on health checks indicates that they are effective in identifying previously undetected health conditions in people with a learning disability.\textsuperscript{94} According to this review, "Only one of 38 publications included found that the intervention made no significant difference to outcome, however in this case the intervention used prompt cards in medical notes to promote opportunistic health screening by GPs rather than health screening \textit{per se}.". It is evident from the results of these studies that the introduction of health checks for people with a learning disability typically leads to:

- the detection of unmet, unrecognised and potentially treatable health conditions including serious and life threatening conditions such as cancer, heart disease and dementia;
- targeted actions to address health needs.

Some significant limitations to the evidence base however were noted:

- small number of randomised control trials having been done;
- sparse evidence on such issues as the costs of health checks;
- the acceptability of health checks;
- the optimal timing of health checks;
- the rate of implementation of targeted actions resulting from the health checks;
- the impact of health checks on future health and well-being;
- the extent to which any such effects may be moderated by health determinant factors.
6 Local Health Needs of Adults With a Learning Disability

6.1 Consultation and Involvement Process

In order to capture a breadth of opinions from all of those involved with adults with a learning disability, including service users themselves, three different methods of consultation were used:

1. Three large group consultation events (one in each Fife Community Health Partnership (CHP)) for parent carers, voluntary organisations, statutory organisations, advocacy services and service users.

2. Five smaller focus group sessions. As gatherings of smaller numbers of familiar faces, these aimed to provide a more relaxed opportunity for individuals with a learning disability to contribute their views.

3. An online questionnaire (Appendix 3). This was primarily targeted at a range of health and social care professionals who were unable to attend the other consultation events.

6.1.1 Questions

The consultation encouraged attendees to think of health in its broadest terms (i.e. not just healthcare but also the broader determinants of health, for example leisure activities, education and living conditions. The large events and focus groups gathered opinions on the following questions:

1. What are the health needs of adults with a learning disability in Fife?
2. How are they being met and are there barriers preventing them from being met?
3. What are the gaps and unmet health needs of adults with a learning disability in Fife?
4. How do partners bridge these gaps and improve the health of adults with a learning disability in Fife?

The questionnaire covered the areas above and also asked for examples of good practice and suggestions for staff employed in the field. It can be found
6.1.2 ANALYSIS

Analysis involved collating comments from the three methods of consultation and dividing them into key themes. Comments within each theme were divided into sub-themes and summarised. The consultation outputs were analysed and synthesised as per Figure 3.

Figure 3: Summary Diagram of the Three Forms of Consultation and Their Analysis

6.2 SUMMARY OF CONSULTATION FINDINGS

6.2.1 INTERPRETATION

Whilst this consultation process invited the opinions of a breadth of different stakeholders, the findings below only reflect the views of those who attended. As such these comments should not be assumed to be representative of the views of all stakeholders and should be considered alongside the evidence
collated from the literature summarised in Section 5.

In total, approximately 150 people attended the large consultation events and focus groups with an additional 60 individuals responding to our online questionnaire. The majority of questionnaire responses came from acute healthcare (42%), community based healthcare (25%) and social work (17%).

Key themes identified throughout the consultation process are summarised below with some illustrative quotes from stakeholders highlighted in boxes.

6.3 **LOCAL HEALTH NEEDS IDENTIFIED**

6.3.1 **THE HIDDEN POPULATION**

The consultation exercise identified an issue about how a learning disability is defined and how the hidden population of adults with undiagnosed learning disability health needs are being met. It was suggested that developing and maintaining a register of all people with a learning disability in Fife may be helpful.

6.3.2 **HEALTH NEEDS**

The health needs of adults with a learning disability identified in the consultation exercise included those listed in

> ‘*We are entitled to have sexual feelings too and to be able to express them*.’
Table 6. Adults with a learning disability have a right to relationships, good sexual health and wellbeing (including inpatients). The presence of a learning disability may sometimes overshadow other health needs.
Table 6: Some of the Health Needs of Adults with a Learning Disability Identified During the Consultation

<table>
<thead>
<tr>
<th>healthy living advice</th>
<th>sensory impairment</th>
<th>obesity</th>
<th>institutionalisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>heart disease</td>
<td>respiratory disease</td>
<td>forensic issues</td>
<td>osteoporosis</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>epilepsy</td>
<td>night seizures</td>
<td>thyroid disease</td>
</tr>
<tr>
<td>preventable and unrecognised mental health issues</td>
<td>gastro-oesophageal reflux disease</td>
<td>stomach cancer</td>
<td>bowel and cervical cancer screening needs</td>
</tr>
</tbody>
</table>

6.3.3 Access Issues

There are often physical barriers which prevent access to health care provision or leisure activities, for example a shortage of public transport options or a lack of appropriate equipment. This can be more evident for adults with a profound and multiple learning disability. Carers are often asked to provide equipment or to lift service users. Toilets and accessible changing facilities are often unsuitable. These are fundamental and need to be universally available.

Health care services need to be more co-ordinated e.g. GP, nursing and social work to make access to services easier and maximise effectiveness. It would be good practice to have a system which flags up a person with a learning disability and automatically books longer appointments. There is also a shortage of staff and time to accompany clients to activities.
6.3.4 Communication

NHS Fife and partners need to improve communication between service providers, carers, family, service users and the community to raise awareness of what information is available for and about adults with a learning disability.

Many service users don’t like it when professionals speak to other people in the room rather than to them. Many types of communication can be difficult to understand including: appointment letters, health improvement advice etc. Barriers to effective communication include: literacy issues, lack of appointment time, assumptions which lead to confusion, lack of service user or carer confidence to raise an issue, and leading questions. Automated telephone systems can be confusing.

Suggestions for improving communications included: using accessible language, more pictures, larger text, including maps with appointment letters and providing simple, targeted, unambiguous messages. Accessible information and communication skills should be universal (including online). Standard written appointments may be inadequate. Other approaches could include: texting, email, reminder phone calls and Braille (where appropriate). The dental and
mammogram DVDs were praised.

Proper informed consent is important, as is an understanding of what to do when an individual declines treatment. There are complex issues surrounding capacity to consent across the learning disability spectrum. Current systems can cause delays (e.g. the need for incapacity certificates).

6.3.5 Carers

Carers are pivotal and need to be supported. They know the service users well, can identify problems early and are able to support them in behaviour change and accessing services. Carers need opportunities to learn – both from healthcare professionals and from other carers for example family and carer support networks. Financial support, health and mental health support and respite care may be required.

In healthcare settings, carers may sometimes wrongly be assumed to understand service users’ problems better than others and are often relied upon to perform tasks for a patient when in hospital. Some agencies only have older carers. Young adults often want young carers. Older carers may keep some adults as ‘eternal children’ by being protective and reluctant to ask for help.
6.3.6 TRANSITIONS

The transitions from children's to adult services and from adult to older people's services were identified as a challenge. Whilst young people’s services are well coordinated, adults with a learning disability need to be more proactive to seek out care. Having a lead professional throughout the transition stages would be helpful.

The health needs of older people with a learning disability are different. Agencies need to establish suitable accommodation, social opportunities and better support for end of life care for older people with a learning disability.

6.3.7 BEING A CITIZEN

Table 7: Aspects of Being a Citizen which were Discussed at the Consultation Events

| Attitudes | The diagnosis of a learning disability as a label and some of its associated services can have stigma attached. Patronising attitudes are still problematic e.g. many staff do not recognise the right for adults with a learning disability to have sexual relationships. ‘It’s almost expected that you will be obese if you have a learning disability; but you’re made fun of by ‘normal’ people. You don’t fit in’. |
| Independence | Importance of service users rights to independence and encouragement to take responsibility for their own health. “I get my thyroid and heart checked” “working as a hospital volunteer is important to me.” |
| Vulnerability and choice | Service users’ rights to independence need to be balanced with their vulnerability to financial/sexual/physical abuse and to peer pressure/bullying. Our risk adverse culture has reduced the ability to meet their needs: ‘I don’t feel I always have choices”; ‘We are not letting people live their lives’. |
| Advocacy | There is a need for advocates for people with a learning disability like Citizens Advice; people who are well versed in filling in forms, utility bills and benefit applications. ‘It’s important that I have a voice’. Those with profound and multiple learning disability have insufficient advocacy and need a more coordinated approach. |
| Healthy eating | Service user focus groups identified healthy eating and weight |
loss as a challenge: ‘Lack of support to lose weight… it’s hard to do when living on your own’. Suggestions included: ‘Healthy eating classes to know how to cook healthier meals for myself… a chance to try different foods’.

**Financial**

Resources are scarce. There is a need to have good local policies and strategies so money is channelled to the right place. Health and social care funding needs to overlap; to enable partnership working and to smooth transitions. Funding is attached to various services and doesn’t follow the individual.

**Education**

Educational opportunities at colleges are polarised between those with and without a learning disability; there is little in between. ‘Inclusion is working well in education but I feel it is raising expectations with too little support/services to deal with students with learning disability once over 16.’

**Employment**

There is a lack of funding and support to access employment and hence opportunities are very limited. Fife Employability Organisation give a lot of support in this area but there is a lack of variety in jobs available. Many service users said they would like more chances to take part in both voluntary and paid work. ‘Make employment for people with a learning disability part of the core business of social work.’

**Housing**

There is limited suitable accommodation. New housing can be built in localised areas with less integration into the community. Housing is an increasing problem as adults with a learning disability get older.

**Leisure and socialising**

Service users identified a broad range of different activities which they participated in, including: swimming, aqua-aerobics, dancing, walking, holidays, horse riding, 10-pin bowling, helping family, yoga, cycling, gym, playing music, college courses. ‘Involvement in leisure activities can really change your outlook’. It was felt that there are insufficient funds to support social and leisure activities and often the activities are not supported appropriately for learning disability service users.

**Positive Mental Well being**

Despite positive influences mentioned above social isolation, loneliness and boredom were all identified as problems which impact on positive mental health. There is a need for more social opportunities for all ages with an emphasis on activities for older clients. Adults with profound and multiple learning disability have few places they can go to engage in activities or events.
6.3.8 TRAINING

Health Improvement training is needed for service users, family, carers and staff alike. The health needs of service users need to be understood by both service users and staff: ‘[What would help to make it better] …staff who understand your needs and behaviours’. More training for family and professional carers e.g. training about: health needs, screening, diabetes, moving and handling, oral health and healthy lifestyles. More support groups and ‘train the trainer’ events for carers is needed.

Among generic statutory and voluntary sector staff there can be limited knowledge/experience of the health needs of adults with a learning disability.

It was suggested that some areas to improve knowledge would be:

- training on the needs of people with a learning disability for all staff in protected teaching time (perhaps mandatory);
- flexible training (not just 6 week courses).

Training needs to move beyond addressing physical health needs towards consideration of a more holistic approach to care. Training materials should be centralised and shared. Examples of good practice include the Profound and Multiple Impairment Service (PAMIS) workshops and the Royal National Institute of the Blind (RNIB) course.

Other topics for staff training could include drugs and alcohol, diet, housing issues, living issues, changing lifestyle, safety, use of lifting equipment,
complex problems in and out of hospital, long term conditions, barriers encountered by people with a learning disability accessing services, mental health issues, autism spectrum disorder and management of challenging behaviours.

6.3.9 INTERVENTIONS AND SERVICES

Many existing services received positive comments, for example: the multidisciplinary Down’s syndrome screening clinic; the virtual baby for teaching parenting skills, learning disability liaison nurses, adult education, PMLD postural management team, GP home visits, Fife community dental service (has a dentist with a specific learning disability remit) and single shared assessments. Other examples of good practice included:

- Co-operation with Fife College to provide courses for adults with learning disability (provides an element of respite for carers also).
- The Family Health Project– vulnerable parents supported by midwife and nursery nurse in the community. Input from social work department and Health Visitors.
- Recent initiatives involving Social Work (Fife Employability Team ‘Work 4 You’ project and FACET ‘Transitional Planning’ project) working closely with education to support pupils with additional support needs who are approaching school leaving age.

Suggested additions to existing services included:

- Need to identify the hidden population with learning disability for
multidisciplinary health checks. Could reduce the age threshold for *Keep Well* checks for adults with a learning disability, although some felt existing *Keep Well* checks are not well explained and can cause anxiety.

- Ensure adults with a learning disability are aware of screening programmes. Bowel screening and *Keep Well* were thought unnecessary or confusing by some.

- Learning champions on wards and in care homes and universal one to one key workers.

- Extend existing learning disability liaison services.

- Disability Sport Fife should be expanded and have more investment.

- Care manager or local area coordinator in the community for learning disability.

- Longer hours at Day centres. ‘*Current hours are insufficient to allow carers a full day for either work or respite.*’

- Patient passports and essential life plans.

- Enhanced systems to flag up those with learning disability and provide double appointments.

- ‘Parenting pack’ for expectant and new mothers.

- Drop-in clinics, more men’s clinics, more clinics in the community.

Some learning disability services already work closely with other service providers – e.g. links between NHS Fife audiology services and RNIB. There were many calls for greater integration of all services (health, social work and voluntary organisations) and care pathways (e.g. ‘*link GP records with NHS 24*’; ‘*one-stop shops for healthcare*’). The way information is

‘*We need to have more integrated working across different services and teams to look at what people need to live successfully in their communities.*’

‘*There is an expectation that the person should fit the service and not vice versa*’
shared also needs to be reviewed. Currently it is difficult for agencies to obtain information about their clients. There were also concerns regarding communication when service users attend appointments on their own. There should be robust services in place for crises.

The strategies of different partners should be ‘joined up’ and partnerships need to be fostered to avoid frustration (e.g. comments like ‘This isn’t a health issue it’s a social issue’). The voluntary sector is under-valued and should be involved strategically.

Service users and carers should also be involved. Although there may be a need to be conscious of the burden of bureaucracy: ‘Need to have fewer diaries and forms. We need a certain amount of them but who else at 35 years old fills in a diary every day about what they did and how much money has been spent. Carers spend too much time filling forms in and not enough working with clients’.

There is a lack of continuity in health care for adults with a learning disability and a high turnover of care staff. There were concerns that with tighter budgets the greater demands on staff may be at the expense of service users. ‘It’s hard to make a difference seeing someone once a week’. Need to maximise the appropriate use of existing resources and have a clearly defined structure of how services work.

Now adults with a learning disability are living in the community; their wellbeing is not just the responsibility of the public services but also of carers, family, friends and the wider community.

Housing issues themselves can cause problems. ‘We can work on behaviours but it’s the environment that they’re living that’s the cause.’ ‘Even to get a ramp installed is really, really difficult and then people don’t get out’.

Funding does not currently follow the individual. Partnership commissioning is required to reduce wastage (e.g. ‘smoking cessation support is available but underutilised as additional support is required to administer treatment’).
7 CURRENT SERVICES FOR ADULTS WITH A LEARNING DISABILITY IN FIFE

7.1 KEY STAKEHOLDERS AND OTHER RESOURCES

This section includes key stakeholders who will be involved in implementing the strategy and what resources they can offer. This list is however not exhaustive and gives an indication of the range of stakeholders involved with the population group.

**NHS Fife**

- Adult Learning Disabilities Service
- Improving Health Service
- Allied Health Professionals
- Audiology Department
- Community Dental Service

**Fife Council**

- Social Work Services Adult Teams
- Accommodation Services
- Day Services
- Employability

- Education Services

**Voluntary and Private Care Providers**

- Various agencies throughout Fife

**Voluntary Organisations:**

- PAMIS
- Advocacy - People First, Equal Voice, Dunfermline Advocacy Initiative, includeMe
- Carers Centre

**Service Users and Family Carers**

- Diamond Association
7.2 **Specialist Health Learning Disabilities Services**

7.2.1 **Outline of Learning Disabilities Service**

NHS Fife provide a wide range of specialist health services for people with a learning disability who live in Fife, for example, in-patient admission, which cannot be provided by mainstream health services. The service works to help services users reach their true potential by providing the right level of care and support for each individual.

The service can be split into two main areas:

1. **Community Services**
   - Community Learning Disabilities Teams (CLDT)

There are three generic Community Learning Disabilities Teams based across Fife.

The CLDT provide specialist high quality, health care services for people with a learning disability that enable and support the individual to participate in the activities of everyday life.

For the majority of people with a learning disability living in the community, most of their health needs are met by their GP or primary health care team. Additional “specialist” health needs may be met by the CLDT.

Each CLDT includes dietetics, occupational therapy, speech and language therapy, clinical psychology, psychiatry, clinical pharmacy, physiotherapy, podiatry and nursing.

- **Specialist Services**

The service also benefits from various specialist nursing staff which includes: Acute Learning Disability Nurse, Primary Care Liaison Nurse, Transition Nurse, Challenging Behaviour Specialist Nurse, Epilepsy Specialist Nurse
• Fife Forensic Learning Disabilities Service

In addition to the three Community Learning Disability Teams, a specialist Fife Forensic Learning Disability Team (FFLDS) supports individuals with a learning disability and a history of offending and/or risk of offending that may result in significant harm to themselves or others. This team is multi-agency and multi-disciplinary with input from the various linked services mentioned above.

• Community Services Health Care Services Overview

An example of interagency joint working is the joint initiative between NHS Fife and Fife Council; it provides a service to clients with complex psychological needs for whom previous discharges to the community have failed. Social care workers are based in client’s flats and provide one to one support on a daily basis. In addition, a trained nurse is available within the staff base to provide professional advice and support to each of the five individual services.

2. Inpatient Services

The inpatient service, based in Lynebank Hospital, provides care for adults 18 - 65 years of age and currently comprises:

• An Admission and Assessment Unit - Mayfield
• A Step/Down Forensic Unit - Levendale
• A Regional Forensic Learning Disabilities Unit - Daleview
• A Therapy Unit

Profound and Multiple Learning Disabilities Team (PMLD)

Although working with clients in the community this service is managed by the Lead Nurse In-Patient Services. The Profound and Multiple Learning Disabilities team was established in 2006. It was set up in response to needs identified for
the transition of clients between Child services and Adult services. Clients have been identified as having a Profound and Multiple Learning Disability and Healthcare needs.

The team consists of a Charge Nurse and six Registered Nurses who are Learning Disability Nurses and/or Adult Nurses. The team have provided Home Care, Day Care, an Outreach service and Respite Care. The service aims to be flexible in response to client needs.

### 7.2.2 Overview of Current Health Improvement Initiatives in Fife

As indicated above there is a wide spectrum of stakeholders who will contribute to the strategy.

Described within this section are the particular projects, initiatives and services available through NHS Fife.

The Learning Disabilities Service continues to progress health improvement for people with a learning disability throughout Fife some examples of good practice are shown below:

**Health Improvement:**

**Healthy Living Project**

Fife Council Day Services offer a range of activities to those who attend their centres. Some of these activities are aimed at health improvement and healthy lifestyles.

The Healthy Living Project is an example of interagency working to improve the health needs of adults with a learning disability. The combined efforts of Day Centre Officers, Community Learning Disability Nurses and Community Dieticians who facilitated sessions to service users with a focus on weight, diet and exercise in an attempt to encourage those involved to adopt a healthier lifestyle.

**Oral Health**

The dental service has produced a series of DVDs addressing oral health.
Sexual Health Improvement

Fife Multiagency Sexual Strategy group action plan 2010-2012 aims to provide programmes for parents and carers to enhance communication skills around relationships and sexual health, providing targeted support for parents who may benefit from additional training/support for those whose children have a learning disability. Current liaison is ongoing to ensure adults with a learning disability and their carer’s needs are met in relation to this topic.

There is current delivery of ‘Sexual health matters for people with a learning disability’ Training by Community Learning Disability Nurse & Health Improvement Team throughout NHS Fife - Health Improvement Training Programme. Evaluations of the programme identify further training needs and support required from stakeholders. This training has strongly highlighted many issues surrounding this area of work. Participants often highlight a lack of understanding within their organisation, as well as a lack of clear and concise policies and guidelines to direct the approaches to sexual health and well being which would keep staff and clients’ safe as well as maintaining the rights of this population.

One to one sex education & relationships work through open referral to Community Learning Disability Teams for adults with a learning disability in Fife is also currently provided. The use of Sexual Knowledge Assessment Tools (ASK tool) as a pre/post measure of effectiveness of session work (1:1 & group) is being used throughout all the Community Teams.

Parenting Research

Parents with a learning disability are a vulnerable group who can face many inequalities in accessing services tailored to their needs. NHS Fife commissioned Research to review existing service provision in relation to pregnant women and parents with a learning disability with children under 5 years, and provide recommendations for improvement. The research consisted of qualitative and quantitative research with a range of stakeholders working with the client group across the NHS Fife area, and qualitative research with parents and pregnant
women with a learning disability. Overall, it would appear that much progress has been made in terms of services demonstrating good practice. However there remain many existing barriers and challenges linked to the complexity of meeting the needs of the client.

The next steps and actions arising from the research will include the formation of a multi-agency implementation group which will look at how locally the recommendations from the study can be taken forward.

**Nutrition (Food and Health)**

Local efforts around the provision of health enhancing activities and social inclusion include the Community Food Project. A 6-week pilot session on food, physical activity and healthy lifestyles was conducted for a group of people with a learning disability.

**Health Surveillance:**

**Mammogram DVD – DVD for Breast Screening Programme**

A local multi-agency group developed a DVD to enable and support women with a learning disability to access the breast screening programme. The resource has proved a valuable information tool for staff members to support women with a learning disability and has now been incorporated nationally.

**Accessing Primary Care**

In 2006, the best practice statement “Promoting access to healthcare for people with a learning disability - guide for frontline staff” was produced by NHS Quality Improvement Scotland. Locally a report was produced to identify the barriers which may be experienced by people with a learning disability when accessing primary health care. It is hoped that the recommendations made in this report will be actioned by members of the “Good Health Care Working Group”

**Health Screening Checks**

The Primary Care Division of the Primary and Community Care Directorate of the Scottish Government has highlighted a need to introduce a routine health check
for adults with a learning disability living in Scotland. In response to this the Adult Learning Disability Nursing Service has been offering health checks for this population at point of contact to the service.

*Keep Well* is an anticipatory care programme which aims to tackle health inequalities in targeted population of people aged 40-64 years. Integration of the *Keep Well* health checks within the learning disability population is under development. A pilot was held within a day centre by members of the Keep Well Team and Learning Disability Nursing Service and in partnership with Fife Council Day Services. It is hoped to extend this initiative Fife wide. This will help to identify which types of health improvement/health education are required locally.

**Down’s syndrome Health Screening Clinic**

The Down’s syndrome “One Stop Health Screening Clinic” runs across the three community team areas of Fife. A multidisciplinary group has been established to monitor and evaluate these clinics.

**Dementia Care Pathway**

Recent guidelines on diagnosis of dementia in people with a learning disability have been produced by NICE-SCIE, SIGN and jointly by the British Psychological Society and Royal College of Psychiatry. A short-life multidisciplinary group was convened to develop a pathway in the assessment of suspected dementia in adults with a learning disability in Fife.

**Communication:**

**Communication for Health Project**

NHS Fife Speech and Language Therapy Department have developed a new project using a more co-ordinated and strategic approach to making good quality information accessible across various services in Fife for adults who have a learning disability.

The project has developed a robust pathway for making information accessible that incorporates: building on staff’s knowledge, understanding & skills needed;
agreement on quality assurance measures; identification of resources and support for staff; development of a mechanism for sharing resources across services and engages with service users in a meaningful way.

A Communication for Health website (www.nhsfife.scot.nhs.uk/easyread) has been recently launched to effectively share good quality accessible information and to provide day-to-day and long-term support to staff when making information accessible. This website will continue to develop and more content will be added as it becomes available.

**Pregnancy Support Pack**

NHS Fife Speech and Language Therapy, Clinical Psychology with input from the community midwives have produced the Pregnancy Support Pack; an accessible resource that aims to support parents with a learning disability to engage in their experience of pregnancy. The resource has been used and positively evaluated by prospective mothers and people with a learning disability as being both acceptable and accessible with midwives also reporting that this resource supports engagement in the antenatal process.

**Active Citizenship:**

**Autistic Spectrum Disorder Learning Network**

Monies were also received from the Change funding to develop a learning network to improve the health and well being of people on the autistic spectrum disorder. A conference has been held which allowed stakeholders to share good practice and develop a learning network.

**Transitions**

NHS Fife have clearly made a commitment to the supporting transition care and support for young people who have a learning disability throughout Fife in conjunction with young people, their families and carers, social work, education and voluntary agencies.

A draft proposal for a TEEN (Transition Early Engagement & Networking) Health Forum, to look at young clients with complex health issues coming to the adult
service, is in progress and has been submitted to the management teams for review.

**Involving People Work**

NHS Fife strives to ensure the involvement of service users and families. Extensive Patient Focus Patient Involvement (PFPI) work has held around the development of the assessment and treatment and regional learning disability unit. In 2008 a project was conducted to gain a retrospective view of the experiences of people with a learning disability when they access acute health care in Fife. This health improvement strategy attempts to address the issues raised by this group.

There are also individual strands of work which support people with a learning disability which consider and address health issues. Tuesday Night Group (patient and staff group) which operates in Lynebank Hospital is an example of this.

**Areas of practice currently being developed:**

**Profound Multiple Learning Disabilities Health Screening Clinics**

There has been a growing awareness that services need to plan for the health needs of people with Profound Multiple Learning Disabilities (PMLD).

It has been proposed that a pilot service be looked at that could offer a health review in an environment that was accessible and considered the complexities that someone with a PMLD presentation may exhibit.

Due to demands on service, the potential start date for the pilot has been put back until mid 2011. Before this happens there are still consultation meetings and planning required as this is potentially the first screening clinic for this patient group within Scotland.

**Men’s Clinics**

West Fife area learning disability nurses are targeting issues of men’s health and are planning a men’s health group in this area due to identified need in the group
of men they currently work with. The groups are at the initial planning stage with a programme in the progress of being devised and suitable resources sought.

**Adult Autistic Spectrum Disorder (ASD) Diagnostic Pathway**

An ASD diagnostic pathway and post-diagnostic signposting is being developed and is being taken forward by the Adult ASD Steering Group.

**Improving Access to Psychological Therapies**

The national initiative to improve access to psychological interventions has recently been extended to include people with a learning disability. Fife is starting to implement this with a view to meeting a HEAT target to reduce waiting times.

### 7.3 Current Local Practices and Links Between Key Partners

The following projects are ongoing in Fife and all link to better health outcomes for people with a learning disability:

**Fife Council Social Work Service and Fife Employability Service**

Fife Employability Team, part of the Social Work Service is one of Scotland’s largest providers of employment services for disabled people and employers. Work Options, part of Fife Council Social Work Service and Fife Employability Team focus on supporting adults with a learning disability to access a range of work opportunities. The programme is specifically for people with a learning disability and prepared individuals for the world of work. They are then helped to find employers, given the chance to learn new skills, offered training and benefits advice and once in employment given job coaching.

**Enable Scotland – runs Employment Options programme**

Clients are learning disabled aged 16 to 60. Along with other agencies they assist people into work, training or college. Buzz club, the centre part of programme builds confidence and self esteem while looking at employment and further
education. The service operates on one to one outreach basis.

**FACET (Glenrothes)**

This organisation offers training in computing, and a range of arts and crafts including woodwork, gardening and ceramics along with work experience opportunities.

Projects such as ‘Work 4 you’ project (Fife Employability Team) and ‘Transitional Planning’ (FACET) through training courses and work experience placements provide pupils with pathways to employment opportunities. These services assist young people to continue on the education path.

Other projects involved in providing employment, training and further education include:

- F.E.A.T enterprises
- Fife Council - Workforce diversity programme
- Impact
- Kit for Work
- Matrix Fife
- Remploy
- SAY it’s Workable
- Shaw Trust Dunfermline

**Day Service Review**

The day services review undertaken by Fife Council Social Work Service Department provides opportunities to work in partnership to develop meaningful ways to engage with service users in the identification and management of their health care needs.
8 GAPS IDENTIFIED: CONSIDERING LOCAL NEEDS IN LIGHT OF THE EVIDENCE BASE AND POLICY CONTEXT

Based on the summary of the literature and information gathered from the consultation events the following main gaps have been identified and would need addressed to improve the health of people with a learning disability who live in Fife.

Health Surveillance:

The literature review clearly demonstrates that the health needs of people with a learning disability are distinct from those of the general population with this group experiencing significant health inequalities compared to the general population. A database system would help to ensure these unique health needs are met in this vulnerable group and support strategic planning. A consistent approach to regular health screening including physical examination will regularly identify morbidity and increase access to health promotion and improvement measures.

National Screening Programmes:

People with a learning disability participate less in cancer screening programmes than the general population.

Health Improvement:

People with a learning disability have difficulty gaining access to the universal health prevention/improvement programmes currently in place such as smoking cessation, Keep Well Health Checks, Winning by Losing weight management programmes and cardiac rehabilitation.

Nutrition (Food and Health):

There is an inconsistent approach among care providers towards meeting the specific nutritional needs of people with a learning disability. Service users and staff highlighted difficulties in accessing weight management intervention and nutrition supplement in form vitamin D for this population in regards to osteoporosis prevention.
Training:

Training was highlighted among stakeholders as playing an important role in helping to enhance knowledge and awareness of the health needs and associated issues of people with a learning disability. A key theme emerging from the consultations was the need for those working with people with a learning disability to have an awareness of these learning disabilities and how these impact on the client and also the service they require. Specific issues staff and carers identified are further described in section 6.3.8. A key theme emerging was that training needs to move beyond physical health needs towards a more holistic approach to care as well as training materials being more centralised and shared.

Another important issue raised was one of informed consent and understanding what to do when the individual declines treatment.

Communication:

Accurate and up-to-date accessible information on services and health information for people with a learning disability, staff, carers and the community is not always consistent. Service users identified difficulties in understanding communications with statutory agency. Several barriers were identified including lack of appointment time, difficulties understanding appointment letters and confusing automated telephone systems. During consultations with GPs it was highlighted not enough time is given for clients to discuss fully their health needs.

Currently there are no systems in place to ensure that in the acute sector (hospitals), people with a learning disability are proactively identified to ensure they gain the suitable adjustments to ensure their health needs are being met.

Active Citizenship:

Social isolation, loneliness and boredom were concerns identified as impacting on mental health and psychological wellbeing of this client group. There are significant gaps identified in educational and employment opportunities, courses are often limited with lack of resources or funding provided. Many service users
and support staff said they would like more chances to take part in both voluntary and paid work.

A gap exists in the coordination of medical and social services for those moving between children services through to adult services and from adult’s services to older people services. A more coordinated approach is required between GPs, medical professionals and social work services.

The service user’s consultation exercise identified a lack of advocacy provision for those with more profound learning disabilities.

Involving adults with a learning disability and their families in patient and public engagement/involvement models is imperative to improving their health. Although some of this work is ongoing, more needs to be done to improve the representation and inclusion in decision-making structures.

**Strategy/Policy:**

Service delivery could be further enhanced by improved communication between the different branches of the service and partners. Suggestions included use of e-health and having more opportunities for health improvement to be a focus and ensure sharing of expertise through forums events. There is a need to maximise the appropriate use of existing resources and have a clearly defined structure of how services work.
9 KEY RECOMMENDATIONS AND FUNDING IMPLICATIONS

9.1 KEY RECOMMENDATIONS

Health Surveillance:

1. Establish learning disability registers at local level to identify health needs. This would support and improve strategic planning.

National Screening Programmes:

2. Make health screening programmes more accessible though better local information on:
   - breast screening;
   - cervical screening;
   - bowel screening;
   - osteoporosis screening.

Health Improvement:

3. Ensure there is proactive coordination of current and future health initiatives for people with a learning disability especially around sexual health, parenting, healthy eating; general health needs (Keep Well Checks), smoking, alcohol and substance use.

Nutrition (Food and Health):

4. Develop and implement appropriate nutritional standards for residential supported living and day support services.

Training:

5. Improve workforce competencies across all agencies around health needs for people with a learning disability.
Communication:

6. Provide accurate, up to date and accessible information on services available to people with a learning disability for all staff, carers, and the community.

7. Improve communication between agencies and services in order to provide a holistic health care approach.

8. Build on existing forums to ensure that health improvement is a focus for all key stakeholders. This will allow sharing, learning and developing of expertise.

9. Build on existing practice to proactively identify patients with a learning disability who enter the acute sector so that suitable adjustments can be put in place to meet their health needs.

Active Citizenship:

10. Develop in partnership with other statutory and voluntary organisations:

   • more opportunity for social and physical activities, employment opportunities and a greater breadth of educational opportunities for people with a learning disability;

   • an active citizen charter for people with a learning disability which describes individuals' rights and responsibilities in relation to actively managing their health needs;

   • improve access to transportation services that assist people with a learning disability especially in relation to access for social and educational opportunities to maintain and improve their health.
11. Ensure that when a person is in transition from child to adult services or from adult to older people services there is sufficient attention given to their ongoing and future health needs.

Strategy/Policy:

12. Develop further integration of services and pathways to ensure a holistic approach to the health needs of people with a learning disability.

13. Review, develop and influence partnership strategies and action plans to ensure planning and commissioning of health issues is being carried out.

14. Ensure Equality and Diversity is a priority in all health improvement activity intended for those with a learning disability.

15. Ensure the Patient Focus Public Involvement Strategy includes a focus on service users’ and families’ input to improving their health outcomes.
9.2 Funding Implications

Many of the actions arising from the recommendations can be implemented within existing funding levels and through service redesign; however it is recognised there may be resource implications for some actions. Actions which require extra costs and resources should save money in the long term.

Appendix 4 shows the draft action plan arising from the 15 recommendations listed above with an assessment of whether or not each can be implemented within existing resources. Those that are likely to incur extra cost and resource are similarly highlighted. It is recognised given the current financial climate that this latter group of actions may not be achievable within the short to medium term future.

The implementation of this strategy will require the support and commitment from a range of individuals and agencies. It is also crucially important that people with a learning disability are empowered to be an active partner in the implementation of these recommendations, thus ensuring that the recommendations are implemented appropriately.
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Appendix 1 – List of Fife Council Services/ Voluntary Organisations – indication of range services provided (please note this is not exhaustive but an outline of current services)

Fife Council

Fife Employability Network
Sandra Wilson,
Development Co-ordinator
01592 415971 or info@fenlink.org.uk

Fife Action on Autism - www.fifeactiononautism.org.uk

Impact - Fife Employability Team - www.fifedirect.org.uk
sam.mclaughlin@fife.gov.uk

Mood café - www.moodcafe.co.uk - promoting mental health across the whole of Fife.

Nordoff-Robbins Music Therapy, Scotland - www.nordoffrobinsscotland.org.uk

Voluntary Organisation Services:

Respite Fife - www.respite-fife.org.uk

RNIB Information Office - www.rnib.org.uk

Aspergers Project - www.fifeactiononautism.org.uk

ASPIRE - www.fifedirect.org.uk

BILD www.bild.org.uk

Down’s syndrome Scotland - www.dsscotland.org.uk

Momentum Fife - www.momentumscotland.org

www.lookupinfo.org - an information service about eye care and vision for people with a learning disability (See Ability and RNIB).

Enable Scotland Fife – Trudy Doidge http://www.enable.co.uk
trudy.doidge@enable.org.uk

Advocacy Services:

People First - www.peoplefirstltd.com
Equal Voice (Central Fife) - equalvoiceincentralfife@yahoo.co.uk

Dunfermline Advocacy (West Fife) - www.dunfermlineadvocacy.org

IncludeME (North East Fife) - www.includeme.org.uk

**NHS Fife**

NHS Fife www.nhsfife.scot.nhs.uk

Apart from the links to websites further information on these and other services as well as useful contacts are available in “Where to find information on services” leaflet produced by Fife Learning Disabilities Information Group August 2008.

Contact Fife Carers Centre on 01592 642999
Appendix 2 – Health Improvement Strategy Steering Group

- Julie Burza, Health Promotion Officer, Dunfermline and West Fife CHP (Project Officer and main author of report)
- Philip Conaglen, Specialty Registrar in Public Health, NHS Fife
- Gail Crawford, Service Manager Social Work Service Fife
- Angela Heyes, Equality and Diversity Lead, NHS Fife
- Belinda Morgan, Head of Health Improvement, Dunfermline and West Fife CHP (Vice Chair)
- Sandra Morrison, Acute Learning Disabilities Liaison Nurse Learning Disabilities, NHS Fife
- Alan Roberts, Learning Disability Project Manager, NHS Fife (Chair)
- Mike Roworth, Link Consultant in Public Health Medicine, Dunfermline and West Fife CHP
- Aileen Smith, Primary Care Liaison Nurse Learning Disabilities, NHS Fife
Appendix 3 – Professionals’ Questionnaire

Introduction

NHS Fife are developing a health improvement strategy for adults with a learning disability and are eager to gain key stakeholder’s perceptions of health needs and any gaps in provision which could contribute to health inequalities.

We are asking you to complete this short questionnaire to seek your views on the broad range of health needs of adults with learning disabilities in Fife. We would like to learn more about these needs which extend beyond health and social care to housing, education, employment, leisure, recreation etc.

There are eight questions, and the whole questionnaire takes about 5-10 minutes to complete. Responses will be anonymous and your thoughts will help inform the Health Improvement Strategy for this important group within the Fife community.

The information from the questionnaire will add to information from a number of large events and focus groups which we have held (which were better suited to service users and family carers) and will help NHS Fife to know what’s working well and help identify areas for improvement.

Definition of learning disabilities
An estimated 6,000 adults in Fife have learning disabilities. We are defining learning disabilities as a significant, lifelong experience with three components:

1. Reduced ability to understand new or complex information or to learn new skills.

2. Reduced ability to cope independently.

3. Onset before 18 years of age with a lasting effect on the individual’s development.

Source: The Same as You, Scottish Executive, 2000
Question 1:
Which of the following best describes the area you work in:

1. Community based healthcare (e.g. general practice, public health nursing)
2. Acute healthcare
3. Social work
4. Housing
5. Education
6. Voluntary sector
7. Other (please specify)

<Free text box>

Question 2
Consultations to date have suggested that the following contribute to the health of adults with learning disabilities in Fife:
- Unrecognised physical, mental and sexual health issues, social isolation, physical activity and diet, housing and communication issues.

Please list any areas or give examples which, from your perspective, are missing from the list above.

<Free text box>

Question 3
A 2004 report by NHS Health Scotland categorised services available to adults for learning disabilities into different tiers (see below). What do you see as the main gaps in service provision for adults with learning disabilities within each tier?

Tier 0: Community supports, housing, education, employment, public
health initiatives, and policy development.

Tier 1: Primary health care, paid and family carers.

Tier 2: Generic secondary (outpatient, inpatient and tertiary) health services and paid and family carers.

Tier 3: Specialist learning disabilities services provided by Local Authorities, NHS Scotland, and the independent sector, and paid and family carers in support of these.

Question 4
From your own experience could you provide examples of good practice in relation to provision of services for people with learning disabilities?

You may wish to consider the type of service, information format and delivery, ways in which service was successful and effective etc.

Question 5
The following have been proposed as some of the many barriers to health which particularly affect adults with learning disabilities:

- poor access to suitable services
- professionals lack confidence/experience of treating people with learning disabilities
- concern about choice/consent issues
• lack of partnership approach (e.g. linking leisure and health)

From your experience, what are the greatest barriers to health for adults with learning disabilities in Fife? (NB: your responses do not need to come from the list of suggestions above).

<Free text box>

**Question 6**
Do you have any suggestions for how the barriers you have identified can be broken down?

<Free text box>

**Question 7**
From your experience, what do you see as the main gaps in training for people working with adults who have learning disabilities in Fife?

<Free text box>

**Question 8**
Is there anything else you want to tell us which you think would help to improve the health and wellbeing of adults with a learning disability in Fife?

<Free text box>

Thank you for taking the time to complete this survey, your input is appreciated. We will share the results of this consultation with you in due course.
Appendix 4 – Draft Action Plan

The implementation of this strategy will require the support and commitment from a range of individuals and agencies. It is also crucially important that people with a learning disability are empowered to be an active partner in these actions.

The below are some potential actions which may arise from the recommendations.

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<tr>
<td><strong>Health Surveillance</strong></td>
<td>1. Establish learning disability registers at local level to identify health needs. This would support and improve strategic planning.</td>
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<td></td>
<td>Improve databases kept by the Learning Disability Service so that NHS Fife can identify who the persons GP is to ensure that they are on the register.</td>
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<td></td>
<td>Liaise with the Single Point of Access To Referral Group who are currently developing a spreadsheet which includes who the persons GP is.</td>
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<td></td>
<td>Liaise with partner agencies to discuss the sharing of appropriate information.</td>
<td>No</td>
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<td></td>
<td>Explore over time research opportunities with local education establishments and expand on knowledge of the local health needs of the population. Continue to ensure regular review of literature and good practice guidelines is undertaken and appropriately disseminated.</td>
<td>Yes</td>
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<tr>
<td>National Screening Programmes</td>
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<tr>
<td>2. Make health screening programmes more accessible though better local information on:</td>
<td>Review communication and information sent in relation to these programmes and ensure it is accessible as possible.</td>
<td>No</td>
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<tr>
<td>• breast screening;</td>
<td>Raise awareness to care providers and families regarding support to the individuals who are identified for these programmes.</td>
<td>No</td>
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<td>• cervical screening;</td>
<td>Review accessibility of these screening programmes, for example the citing of mobile mammogram vans in Fife.</td>
<td>No</td>
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<td>• bowel screening;</td>
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<td>• osteoporosis screening.</td>
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<tr>
<td>Health Improvement</td>
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<td>3. Ensure there is proactive coordination of current and future health initiatives for people with a learning disability especially around sexual health, parenting, healthy eating; general health needs (Keep Well Checks), smoking, alcohol and substance use.</td>
<td>Highlight initiatives in relation to the particular needs of people with a learning disability.</td>
<td>No</td>
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<tr>
<td><strong>Parenting:</strong></td>
<td>Ensure that Learning Disability Parenting Implementation Group addresses the recommendations highlighted from commissioned research.</td>
<td>No</td>
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<td><strong>Healthy eating:</strong></td>
<td>Liaise with the Food and Health Strategy Group to ensure the needs of this population group are considered in action plans.</td>
<td>No</td>
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<td></td>
<td>Ensure that programmes such as weight management (Winning by Losing) and exercise referral schemes are accessible and tailored</td>
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to the needs of adults with a learning disability.

Consider the needs of the learning disability population in regards to additional vitamin supplement especially Vitamin D.

**Health Checks (Keep Well):**

Develop further the Keep Well Health Clinics in partnership between Adult Learning Disability Service, Improving Health Team/Keep Well Team, Residential and Day services and primary health care. Gather information from these health checks to agree health promotion priorities for the population.

**Smoking:**

Liaise with Smoking Cessation Service leads via the Smoking Cessation Operational Group and Tobacco Issues Group to ensure the needs of this population are considered in action plans.

**Alcohol and Substance Misuse:**

Liaise with Fife Alcohol and Drug Partnership to ensure the needs of this population are considered in action plans.

**Sexual Health:**

- Develop a LD sexual health forum to enable networking & assist staff providing direct support to people with a learning disability.
- Secure representation on Fife Sexual Health Strategy Group and link with local CHP sexual health groups by a designated member of Learning Disability Service.
- Establish best practice guidelines for Relationship, Sexual Health and Parenting education for young people with a learning disability.

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- Support the development of Sexual Health and Relationship Education (SHARE) Special Training for DSE and Special Needs Schools in Fife.
- Support the development of sexual health training in order to build capacity within all agencies that support people with a learning disability.
- Support developments that will improve accessibility of mainstream sexual health services, and initiatives such as the development of sexual health drop ins to deliver specialist sexual health services within residential units in community and inpatient settings.
- Develop a Fife-wide sexual health post (22.5 hours) with a specific focus on supporting the learning disability population, which will focus on building capacity of staff by supporting training needs as highlighted above.

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<tr>
<td><strong>Nutrition (Food and Health)</strong></td>
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<td>4. Develop and implement appropriate nutritional standards for residential supported living and day support services.</td>
<td>Adapt the Royal Environmental Health Institute of Scotland “Elementary Food and Health for carers for adults with a learning disability” 2008 course for local use. Liaise with the Food and Health Strategy Group to ensure the training needs of staff and carers are considered this population group are considered in action plans.</td>
<td>No</td>
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<tr>
<td><strong>Training</strong></td>
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<tr>
<td>5. Improve workforce competencies across all agencies around</td>
<td>Review existing and develop new training as appropriate.</td>
<td>Yes</td>
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<tr>
<td><strong>Communication</strong></td>
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<tr>
<td>6. Provide accurate, up to date and accessible information on services available for people with a learning disability, all staff, carers, and the community.</td>
<td>Review current information and revise appropriately.</td>
<td>No</td>
<td>No</td>
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<td></td>
<td>Distribute revised information to all sectors.</td>
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<td></td>
<td>Increase awareness of and encourage use of the Communication for Health website which provides support and resources to staff on producing more accessible information for the population.</td>
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7. Improve communication between agencies and services in order to provide a holistic health care approach.

- Review current systems and enhance systems to identify those that need additional support (learning disability) and provide double appointments were appropriate.

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<td>7. Improve communication between agencies and services in order to provide a holistic health care approach.</td>
<td>Review current systems and enhance systems to identify those that need additional support (learning disability) and provide double appointments were appropriate.</td>
<td>No</td>
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8. Build on existing forums to ensure that health improvement is a focus for all key stakeholders. This will allow sharing, learning and developing of expertise.

- Develop a role and remit for the forum.
- Submit a paper based on the role an remit to LD/ASD SIG.

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<tr>
<td>8. Build on existing forums to ensure that health improvement is a focus for all key stakeholders. This will allow sharing, learning and developing of expertise.</td>
<td>Develop a role and remit for the forum.</td>
<td>No</td>
<td>No</td>
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<tr>
<td>8. Build on existing forums to ensure that health improvement is a focus for all key stakeholders. This will allow sharing, learning and developing of expertise.</td>
<td>Submit a paper based on the role an remit to LD/ASD SIG.</td>
<td>No</td>
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9. Build on existing practice to proactively identify patients with a learning disability who enter the acute sector so that suitable adjustments can be put in place to meet their health needs.

- Explore the scope for actively utilising the use of the hospital patient passport system in sharing information regarding patients.

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<tr>
<td>9. Build on existing practice to proactively identify patients with a learning disability who enter the acute sector so that suitable adjustments can be put in place to meet their health needs.</td>
<td>Explore the scope for actively utilising the use of the hospital patient passport system in sharing information regarding patients.</td>
<td>No</td>
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10. Develop in partnership with other statutory and voluntary organisations:

- more opportunity for

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<tr>
<td>10. Develop in partnership with other statutory and voluntary organisations:</td>
<td>Work in partnership with Fife council to further develop actions coming from the day services review.</td>
<td>No</td>
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<tr>
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<td>10. Develop in partnership with other statutory and voluntary organisations:</td>
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<td>- more opportunity for</td>
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social and physical activities, employment opportunities and a greater breadth of educational opportunities for people with a learning disability;

- an active citizen charter for people with a learning disability which describes individuals' rights and responsibilities in relation to actively managing their health needs;

- improve access to transportation services that assist people with a learning disability especially in relation to access for social and educational opportunities to maintain and improve their health.

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<tr>
<td>11. Ensure that when a person is in transition</td>
<td>Review how the health needs are currently addressed through current transition structures and ensure the health needs are core</td>
<td>No</td>
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from child to adult services or from adult to older people services there is sufficient attention given to their ongoing and future health needs.

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<tr>
<td>12. Develop further integration of services and pathways to ensure a holistic approach to the health needs of people with a learning disability.</td>
<td>Develop collaboration between health, social work services and voluntary sector through the LD/ASD SIG to support people with a learning disability to develop and maintain healthy lifestyles.</td>
<td>No</td>
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<tr>
<td>13. Review, develop and influence partnership strategies and action plans to ensure planning and commissioning of health issues is being carried out.</td>
<td>Develop commissioning processes that give weight and priority to health needs and health improvement especially nutrition within care and support contracts. Further develop links between health and social work day services that support service users to lead healthier lifestyles.</td>
<td>No</td>
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<tr>
<td>14. Ensure Equality and Diversity is a priority in all health improvement activity</td>
<td>Develop staff awareness of the importance of this issue in relation to this client group, i.e. training, email reminders, poster and awareness campaigns.</td>
<td>No</td>
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<td>intended for those with a learning disability.</td>
<td>Ensure Equality Impact Assessments (EIA) are undertaken for all policies, procedures, service redesign and strategies in relation to adults with a learning disability.</td>
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<td>15. Ensure the Patient Focus Public Involvement strategy includes a focus on service users’ and families’ input to improving their health outcomes.</td>
<td>Review both learning disability and NHS Fife strategies and input to next strategy reviews.</td>
<td>No</td>
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