FOREWORD

I think that it is important for the NHS to improve the health of people with learning difficulties because we are as important as anybody else and should have the same rights and opportunities to access services.

Professionals should listen to people with learning difficulties because we are the experts. We know what our bodies need and require. It might take longer to know what is wrong with us but you have to be patient.

Fiona Wallace,
People First (Scotland).

I welcome the report. The health professionals need to learn from anyone with learning disabilities in any way that they can - by listening to them and speaking to them and also gathering information that is to do with the health needs of the person. Health professionals need to try to understand that not everyone has the same needs. I also feel that GPs do not always understand the person’s feelings, even if they are told them. A nurse may have to see a person with learning disabilities before the doctor does. The person might like to see the same doctor all of the time.

The patient (and he/she does not have to be in hospital) should know the best diet for them. The health staff should advise them on this. They should also learn about the side effects of any medication from health staff. If surgery is required, time should be spent explaining what is to happen and when this will be done and what will happen afterwards.

Douglas White,
Consortium Area Network, Scottish Consortium for Learning Disability.
The Health Needs Assessment is a very important document as it highlights the very real need for change within the health service for people with learning disabilities. It opens the way for a new system of health checks which can establish the real health issues people with learning disabilities face, along with the normal health problems which we all have to face each day.

Everybody needs to be healthy and feel good, not just the people who have no disability or learning disability.

I have been involved with the training relating to Promoting Health, Supporting Inclusion. I feel it is very important for health professionals to listen to the health needs of people with learning disabilities, their families and carers, as we are all citizens of this country, just like anyone else, and should not be treated any differently or discriminated against because we are different.

Margaret Reid,
Consortium Area Network, Scottish Consortium for Learning Disability.

Hi my name is Anne Haddow and I look after my daughter, Jennifer. Jennifer is twenty-four and has profound physical and intellectual disabilities, as well as complex healthcare needs. The views I express here reflect my experiences of caring for someone who has been labeled as having “profound and multiple disabilities” (PMLD), however, I suspect that some of the issues are relevant to all family carers who look after people with different kinds of learning disabilities.

Meeting the healthcare needs of Jennifer is an important issue for me. Adequate and appropriate healthcare is crucial to Jennifer’s survival, her life expectancy and her quality of life. Furthermore, failure to meet her healthcare needs has often resulted in her being excluded from day services, short break opportunities, leisure activities and educational pursuits. For Jennifer to live a full and active life she needs to receive services which will keep her healthy, enable her to reach her potential and access services and community resources. This involves accessing not only generic health services but specialist health services. It also involves her receiving the same levels of preventive healthcare, including screening and health checks, as the general population. If this does not happen her healthcare needs will go undiagnosed, unrecognized and untreated.

In my experience, there is a particular need to ensure a continuity between children and adult health services for people with learning disabilities. Often young people with complex healthcare needs, like Jennifer, lose contact with specialist health services when they cease to use paediatric services. Moreover, fragmentary and disjointed services at the transition stage often result in this group receiving treatment from an adult specialist for one aspect of their healthcare, whilst remaining with paediatric services for another. Sometimes there is no equivalent adult service for the young people to move on to and this often results in them receiving general services which do not have sufficient knowledge or understanding of their particular needs. There can also be difficulties surrounding the continuity of therapy services which results in the deterioration of the young people’s health and/or physical ability. For Jennifer to be socially included in society her healthcare needs must be met. If this does not happen she is in danger of being socially excluded. Therefore I welcome this report and hope that funding and resources will be provided to implement its recommendations. This report is an important step forward in promoting the healthcare needs of people with learning disabilities.

Anne Haddow,
Family Carer.
The time has come to ensure that the intentions within Scottish policy – reducing health inequalities, social justice, and ending discrimination – become a reality for persons with learning disabilities. The Health Needs Assessment has the opportunity to build upon work already in place, most importantly the developments in The same as you? Many individuals and organisations have contributed to the process of the Health Needs Assessment, the development of this report and its recommendations. This extensive collaboration demonstrates that there is the commitment in Scotland to getting it right for persons with learning disabilities. This is everyone’s responsibility – and everyone’s gain.

Sally-Ann Cooper,
Chair, Health Needs Assessment for People with Learning Disabilities in Scotland.
EXECUTIVE SUMMARY

- People with learning disabilities are individuals. They should be valued for their differences, respected as citizens, supported to speak for themselves and make their own choices. They should not experience discrimination, abuse, harassment or exclusion from the community, of which they are a full part.

- *The same as you? A Review of Services for People with Learning Disabilities* provides the framework for the development of supports and services for persons with learning disabilities in Scotland. This Health Needs Assessment is set firmly within the guiding principles and policy of *The same as you?*

- The Health Needs Assessment was undertaken in response to the first recommendation of *Promoting Health, Supporting Inclusion: The National Review of the Contribution of All Nurses and Midwives to the Care and Support of People with Learning Disabilities.*

- The recommendations within the Health Needs Assessment Report are aimed at reducing health inequalities, to promote social inclusion. They are informed by evidence that was gathered from across Scotland, the experiences of service users and their family carers, published research, and Scottish and international experience.

- The number of people with learning disabilities in Scotland is unknown: estimates are in the region of 20 people in every 1,000 with mild or moderate learning disabilities and 3 to 4 people in every 1,000 with severe or profound learning disabilities. About 18,000 adults with learning disabilities are currently known to Local Authorities in Scotland. The eSAY project co-ordinated by the Scottish Consortium for Learning Disability will lead to better information in future.

- The life expectancy of people with learning disabilities is increasing and in future there will be more people with learning disabilities, more older persons with learning disabilities, and more persons with the most severe learning disabilities in all age cohorts.

- Life expectancy for people with learning disabilities is lower than for the rest of the Scottish population. This is a key public health measure used to determine the relative health of a population.
• People with learning disabilities have a higher number of health needs, and more complex health needs than the rest of the population.

• People with learning disabilities have a higher level of unmet health needs compared with the rest of the population.

• People with learning disabilities have a different pattern of health need compared with the rest of the population. The types of health needs they most commonly experience differ from those most commonly experienced by the rest of the population, and some types of health needs are specific to persons with learning disabilities.

• The leading causes of death for people with learning disabilities differ from the leading causes of death for the rest of the population.

• Scottish policy is explicitly directed towards social justice and tackling inequalities. However, current public health initiatives and practices in Scotland will not close the gap and are likely to lead to a widening of the health gap for people with learning disabilities. Specific interventions and policy recognising the specific needs of people with learning disabilities can change this. This is because of the different pattern of health needs and causes of deaths.

• Persons with learning disabilities experience barriers in accessing appropriate services and supports for their health needs, health promotion needs and lifestyle choices. However, this only accounts for some of the health inequalities.

• There are many other factors that contribute to a person’s health, including biological factors, past experiences, social factors, and wider community and environmental factors including cultural, economic and religious factors, and Scottish industry and policy. However, the extent to which different factors impact upon the health of persons with learning disabilities and account for their health inequalities is unknown. Very little research has been undertaken to understand better these issues. Little is known of the health needs of persons with learning disabilities from ethnic minority communities.

• Family carers play a crucial role in supporting the health needs of their relative with learning disabilities. Their own needs are often not adequately supported.

• All long stay hospitals for people with learning disabilities should be closed by 2005. Community services and supports are developing, but there is considerable variation in quantity and scope of resource across Scotland. There is a need to continue to build capacity. This includes capacity within generic services to meet better the health needs of persons with learning disabilities and also capacity within specialist learning disabilities services.

• Persons with learning disabilities and family carers are a valuable resource for educating professionals and paid carers.
• It is explicitly unlawful in Scotland to discriminate against a person on the basis of their disabilities; reasonable adjustments must be made so that services are accessible. However, in addition to experiencing exclusion, people with learning disabilities experience both overt and more subtle forms of discrimination in NHS Scotland. This cannot continue to be tolerated.

• The Health Needs Assessment developed 25 recommendations to improve health for people with learning disabilities, and reduce inequality. These call for a series of specific actions in five areas:
  A. Leadership and accountability (both nationally and locally, and including health improvement strategy development).
  B. Infrastructure: development, planning and monitoring (including a programme of research focused on health improvement for people with learning disabilities, database development, and recommendations for NHS QIS and the Care Commission, and for S.I.G.N.).
  C. Specific interventions (including a health screening programme specifically for people with learning disabilities, development of national governance with an audit of all deaths of persons with learning disabilities, enhancing primary health care services, increased availability of advocacy, and specialist community-based services for children, adults and older persons with learning disabilities).
  D. Information (including dissemination of health improvement information, identification and networking of directly-accessed practitioners, and a better understanding of the needs of persons with learning disabilities from ethnic minority communities).
  E. Education (including work on staff induction in NHS Scotland, initiatives at pre and post registration / graduation, and with paid and family carers).
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PART ONE
INTRODUCTION
CHAPTER ONE
THE STARTING POINT

1.1 FUNDAMENTAL PRINCIPLES
People with learning disabilities are individuals. They should be valued for their differences, respected as citizens, supported to speak for themselves and make their own choices. They should not experience discrimination, abuse, harassment or exclusion from the community, of which they are a full part.

The same as you? A Review of Services for People with Learning Disabilities\(^1\) describes seven fundamental principles. These state that people with learning disabilities should be:

- Valued.
- Treated as individuals.
- Asked about what they need and involved in choices.
- Given the help and support to do what they want to do.
- Able to get local services, like everyone else.
- Able to get specialist services when they need them.
- Able to have services which take account of age, abilities and needs.

The work of this Health Needs Assessment is built around these principles.

Modern developments in services and supports for people with learning disabilities have sprung from the theory that, in order to overcome the history of segregation and discrimination they have experienced, it is not sufficient for them to be seen as part of the community if they are not valued members of society. Therefore, The same as you?\(^1\) lays great stress on people with learning disabilities having access to employment, to public life, to lifelong learning and to being active participants in the community. This is not only important directly to improve the lives of people with learning disabilities, as by experiencing people with learning disabilities in roles that are socially valued, the general public is less likely to view them as “outside society”. Increased expectation of what people with learning disabilities can achieve is likely to lead to more positive responses by, for example, employers. Reinforced by legislative demands such as the Disability Discrimination Act, 1995\(^2\), this will increase the opportunities available to people with learning disabilities. Therefore, openings previously closed to them – lifelong learning, employment and access to leisure - become real possibilities, making their rights as citizens a reality.
Recent research in Scotland showed that whereas a majority of Scots thought that they would be comfortable living next door to a person with learning disabilities, few thought that people with learning disabilities could exercise citizenship duties, for example, jury service. Now, expectations of people with learning disabilities may also affect the view of professionals about what can be achieved for their health status and quality of life. In order to implement a health improvement agenda, it is vital to demonstrate to health professionals, and others, that health gains can be made. Even for people with profound learning and multiple physical disabilities, such gains have a positive impact on social experiences and quality of life. This will also have benefits for families of people with learning disabilities.

Health improvements are essential if people with profound learning and multiple disabilities are to be included in community activities, to develop communication skills and the ability to make choices, and to participate in other opportunities such as lifelong learning and leisure activities.
CHAPTER TWO
THE HEALTH NEEDS ASSESSMENT

2.1 WHY IS THERE A NEED FOR THE HEALTH NEEDS ASSESSMENT?
There are four important reasons for undertaking the Health Needs Assessment now:
• The changing population demographics.
• The high prevalence of health need and, in particular, unmet health need experienced by persons with learning disabilities.
• The closure of long stay institutions for persons with learning disabilities.
• Many professionals working in generic services have limited experience and training relevant to the health needs of people with learning disabilities.

The demographics of the population with learning disabilities are changing. In the United Kingdom, the number of people with learning disabilities increased by 53% over the 35 year period 1960 – 1995, representing an increase of 1.2% per annum. This increase is thought to be due to a combination of improvement in socio-economic conditions and intensive neonatal care. A projected future prevalence for the ten-year period 1998 – 2008 was calculated from Leicestershire data, and predicted a further 11% increase over this period, due to increasing survival, particularly in old age. Whilst the introduction of antenatal screening programmes for Down’s syndrome has led to an increased rate of termination of pregnancy, birth prevalence for Down’s syndrome is still increasing due mainly to increased survival at birth particularly of children with Down’s syndrome who have congenital heart disease. Additionally, the improved life expectancy of people with learning disabilities has led to an increase in the number of older people with learning disabilities and an increase, at all ages, in the number of people with the most severe levels of disabilities. Birth rate also impacts on population demographics. Of note is the post war baby boom of adults now in their sixth decade and a further peak in birth rate in the 1960’s. These factors contribute to the age structure of the learning disabilities population as well as to the general population.

People with learning disabilities have higher levels of health needs than the general population. However, health needs are often not recognised and remain unmet. The pattern of types of health need experienced by people with learning disabilities differs from that of the general population; as do the main causes of death. This has important public health implications, and implications for developing the most appropriate community and service responses.

All Scottish long stay hospitals for persons with learning disabilities should be closed by
Whilst the majority of people with learning disabilities never lived in an institution, in the past most specialist health resources for people with learning disabilities were focussed or organised within the institutions. The development of community services is more recent and redesign of services is now essential, given the developments in Scottish policy. Whereas service commissioning has not always been evidence-based, there is robust evidence on the benefits and positive outcomes surrounding the development of community services. The Hospital Closure / Service Reprovision Working Group of The same as you? Implementation Group has already identified some areas that require to be addressed and specific recommendations to take these forward. The technology of a Health Needs Assessment enables this work to be built upon.

Many professionals providing generic services in community based and hospital settings, have received little or no training in working with people with learning disabilities. In addition, as they have infrequent contact with people with learning disabilities they have little opportunity to develop and maintain their knowledge base and skills. To bring about health improvement of people with learning disabilities it is important to tackle the unmet training needs of professionals providing services.

2.2 AIMS OF THE HEALTH NEEDS ASSESSMENT

The Health Needs Assessment aims to provide relevant information for the strategic planning and development of services. Therefore, it is primarily aimed at commissioners and providers of services for people with learning disabilities. However, it is hoped that it will also be useful for people with learning disabilities, their families and staff working in services used by people with learning disabilities.

The Health Needs Assessment focuses on the health of children, adults, and older adults with learning disabilities. This is in order to promote inclusion. It aims to provide a framework for the strategic development and commissioning of services in the future. To achieve this, it aims to identify:

- The current evidence about the health needs of people with learning disabilities.
- The existing patterns of service delivery in Scotland and other countries.
- The current strengths, gaps and inequities in services in Scotland.
- The future work required, formulated into a series of recommendations, in order to:
  - Reduce the health inequalities experienced by people with learning disabilities.
  - Enhance the provision of services and care for people with learning disabilities across their life course.
  - Improve the quality, range, consistency, accessibility and integration of services necessary to meet the health needs of people with learning disabilities.
  - Promote a broader understanding of the health needs of people with learning disabilities and their right to effective services and health care.
  - Enable everyone involved in the care and support of people with learning disabilities to acquire and maintain the attitudes and values necessary to improve health.

The recommendations in this report are not only relevant to strategies that directly concern people with learning disabilities and their families. Figure 1 illustrates how the proposed actions will impact upon key outcome targets and responsibilities for Joint Future local partnerships, NHS Scotland, Local Authorities, the independent sector and other stakeholders. In implementing health improvement initiatives Joint Future local partnerships...
THE HEALTH NEEDS ASSESSMENT

should seek to strengthen existing partnership arrangements, develop strong partnerships with independent organisations and promote greater public involvement. This will enable a wide range of agencies to achieve their goals of greater social justice, less discrimination, more citizen focused services and greater community capacity.

Figure 1: Everyone’s Responsibility - Everyone’s Gain

PARTNERS AND STAKEHOLDERS
People with learning disabilities and their families
Local communities
Independent organisations
Service provider organisations
NHS Scotland
Local Authorities
Universities
Scottish Executive
Industry

KEY ACTIONS AND PROCESSES
Health needs identification:
• local health needs assessments
• local and national databases
• increased research and development of the evidence base

Tackling the wider determinants of health e.g. lack of choice, poverty and unemployment

Public involvement

Development of strategic health improvement plan by NHS Scotland and Local Authorities

NHS Scotland and Local Authorities implement and monitor overall strategy, and support the development of best practice

OUTCOMES
Gains for people with learning disabilities, family carers and the whole community:
• greater autonomy and choice
• health improvement
• social inclusion

Partners assisted to identify relevant actions to achieve key policy objectives, such as reducing health inequalities and ensuring equitable access to services

Enhanced local capacity to respond to strategic policy and legislation such as the Disability Discrimination Act and Care Standards

Shared outcomes for the people of Scotland:
• greater social justice
• a healthier Scotland
• improved quality of life
• safer communities
• modernised public services
2.3 THE PROCESS – HOW THE HEALTH NEEDS ASSESSMENT WAS UNDERTAKEN

The Health Needs Assessment commenced in August 2002 and over a 18-month period gathered evidence to inform the development of recommendations. It adopted a systematic approach aimed at ensuring that resources are used to improve the health of the Scottish population of people with learning disabilities in the most efficient way. The process of the Health Needs Assessment was as follows:

• Establishment of a reference group.
• A series of literature reviews of published research and evidence.
• Review of existing Health Needs Assessments.
• Review of Scottish NHS Health Plans, Partnership-in-Practice Agreements (PiPs), NHS Quality Improvement Scotland (NHS QIS) and Scottish Health Advisory Service (SHAS) reports.
• Review of national and international policy.
• Establishment of working groups to focus on child health, primary health care, and mental ill-health of persons with learning disabilities.
• Extensive oral evidence and consultation with groups and individuals across Scotland.
• Four regional stakeholders’ events, to gather evidence and contribute to the formulation of recommendations.
• Five service user events focussing on health, well-being and experience of the NHS Scotland and its partners, organised by Capability Scotland, and NHS Lanarkshire.
• Reports from user and carer organisations.
• A series of surveys and studies across the NHS Scotland, social work, voluntary organisations, and independent provider organisations, regarding existing services, issues and trends in population migration.
• Links with other ongoing, relevant commissioned work.
• Establishment of a Scottish consensus group, to contribute to a consensus event and critically review the draft report.
• Establishment of a panel of international experts to critically review the draft report.
• Widespread consultation on the draft report of the Health Needs Assessment.

2.4 THE LAYOUT OF THE HEALTH NEEDS ASSESSMENT

The Health Needs Assessment collected evidence about health needs and supports. From this the recommendations presented in Chapter 7 were developed in order to address the findings from the evidence. Therefore, in part two of this report, the evidence that was drawn upon is provided systematically - including the evidence base from the scientific literature, and information on existing services in Scotland, and internationally.

Chapter 3 outlines the context of recent Scottish policy and legislation. Within this context, there is an opportunity to promote significant and lasting health improvement for people with learning disabilities.

Chapter 4 presents the existing research literature relevant to the health needs of people with learning disabilities. The initial focus is about everyone with learning disabilities, including what is known about the number of people with learning disabilities who may be living in Scotland and the life expectancy of people with learning disabilities. This Chapter then considers the health needs of different groups of people with learning disabilities, before describing the evidence on specific health needs. The order in which this information is presented is not intended to reflect the priority of one type of health need over another. Indeed these health needs often coexist, such that Chapter 4 aims to reflect the breadth
and complexity of the challenge for services addressing the health needs of people with learning disabilities.

Chapter 5 also presents evidence. As well as reviewing the research literature on service provision it also draws upon other important sources of evidence. As described in Chapter 2.3 above, the process in preparing the Health Needs Assessment involved consulting widely with users of services, their families, voluntary organisations, service providers and other key stakeholders. This provided valuable evidence on the progress being made by services in Scotland.

Chapter 6 provides additional evidence through an overview of the international context of services for people with learning disabilities.
3.1 THE SCOTTISH CONTEXT
Supporting health needs is an essential contribution towards achieving inclusion and social justice. Compared with other Western European countries, Scotland’s health is poor: life expectancy for women is the lowest of all European countries and life expectancy for men is the second lowest only after Portugal\(^{26}\). Health variations and inequalities within Scotland contribute to our comparatively low European standing. Scottish policy is explicitly committed towards social inclusion and tackling inequality. There is an aim to improve health and life expectancy for people in Scotland, particularly disadvantaged members of the community.

People with learning disabilities have a higher prevalence of health needs and unmet health needs than the rest of the general population. Scotland spends £365 million annually on service supports specifically for people with learning disabilities, in addition to the supports provided for everyone to use (2001 / 02 data). The time has come to deploy better all of Scotland’s resources to improve the health of people with learning disabilities and reduce the disadvantage and inequity that currently exists.

3.2 SCOTTISH POLICY FOR PEOPLE WITH LEARNING DISABILITIES
In Scotland, two key documents have provided a framework to begin to address the inequalities experienced by children and adults with learning disabilities:
- *The same as you? A Review of Services for People with Learning Disabilities*\(^1\).
- *Promoting Health, Supporting Inclusion: The National Review of the Contribution of All Nurses and Midwives to the Care and Support of People with Learning Disabilities*\(^27\).

The publication of *The same as you?*\(^1\) was a substantial and highly significant undertaking, and Scotland’s first major review of services for people with learning disabilities for decades. It outlines the core values that must underpin the care and support of people with learning disabilities and sets out the broad direction of travel for services and supports in the future. The essential message of *The same as you?*\(^1\) is that people with learning disabilities have the right to be supported to have the same opportunities as everyone else to live a full life, including something meaningful to do during the day, leisure, access to appropriate health care, and choices to make friends and have relationships. *The same as you?*\(^1\) sets out an agenda for change in services to make these opportunities possible.
BACKGROUND

*The same as you?* made 29 specific recommendations that have been implemented, or are in the process of implementation, across Scotland. These should lead to improved lives for people with learning disabilities and their carers. Recommendations for major new initiatives included the closure of all long-stay hospitals by 2005; the establishment of Partnership - in - Practice Agreements (PiPs); the setting up of The Scottish Consortium for Learning Disability (SCLD); the development of local databases to enable strategic service planning and monitoring; the establishment of direct payments; and the introduction of local area co-ordinators and personal life plans to improve people’s access to community supports to enable them to live the life of their choosing. *The same as you?* Implementation Group has been established by the Scottish Executive to take forward recommendations and support implementation across Scotland. This Health Needs Assessment is firmly placed within the policy context of *The same as you?* and builds upon its foundation.

The first recommendation of *Promoting Health, Supporting Inclusion*27 was to invite the then Public Health Institute of Scotland (now NHS Health Scotland) to: “undertake a Health Needs Assessment of the health needs of children and adults with learning disabilities in Scotland to inform the development and commissioning of services for the future.” This is the basis upon which the Health Needs Assessment was undertaken.

3.3 SCOTTISH POLICY AND LEGISLATION

The devolution of health issues from the U.K. to Scotland in 1999 created an opportunity for policy development to be more responsive to the needs of the Scottish population. A commitment to social justice and inclusion is underlined in a wide range of policies, with the growth of a “Scotland in which every person both contributes to, and benefits from, the community in which they live”28.

Partnership for Care29 has built upon the policy within *Our National Health: A Plan for Action, A Plan for Change*30. This aims to promote a culture of partnership working among organisations, and with service users, to bring about a continuous improvement in the health of the people of Scotland. The structures to support this include the establishment of unified NHS Boards, new Community Health Partnerships and a new Scottish Health Council, together with a Change and Innovation Fund. A key priority is to ensure that the health workforce is fit for purpose, with all professionals providing services and care based upon evidence-based practice, professional standards, and supported by professional development. *Joint Future*31 has already brought together organisations providing health, social work and housing in joint working arrangements, with joint resourcing and management. It seeks to develop a culture of partnership working. The direction of these developments was further supported by the framework of the *Community Care and Health (Scotland) Act, 2002*32, which also highlighted the need for Local Authorities to offer direct payments to eligible persons. The first step in the implementation of direct payments took place in 2003, with further extension planned for 2004. Work is in progress across Scotland to develop Single Shared Assessment tools and information-sharing protocols to progress the *Joint Future* agenda for people with learning disabilities. The PiPs (available at www.scotland.gov.uk) provide the framework to support partnership working, so that service planning and commissioning for people with learning disabilities can be responsive to local needs, whilst reflecting national policy.
The direction of Scottish policy was reinforced by the joint statement from the coalition following the May 2003 election, *A Partnership for a Better Scotland*. It emphasised the need for sustainable development for Scotland, including the delivery of excellent public services to support health, and a focus on social justice. Key themes within the statement included health promotion, health improvements, and the need for multi-agency innovative approaches to tackle the root causes of inequality, such as nutritional standards, and the role of health screening services. The recognised need for continuing professional development contained within the statement is in keeping with recommendations for nursing developed within *Promoting Health, Supporting Inclusion*.

A culturally competent service is one that recognises and meets the diverse needs of people of different cultural backgrounds. Within Scotland, ethnic minority communities comprise 2.01% of the population, with Indian, Pakistani, Bangladeshi, Chinese, Caribbean, African and South Asian communities being commonest. *Fair For All: Working Together Towards Culturally Competent Services* addresses the needs of ethnic minority communities, including the importance of language, religion, diet and culture on health beliefs and health lifestyle. Within ethnic minority communities, people with learning disabilities are often not visible, and little is known about their health needs. The National Resource Centre for Ethnic Minority Health was established in April 2002, as part of NHS Health Scotland. It supports and assesses NHS Scotland in meeting the requirements within *Fair For All*, and the *Race Relations (Amendment) Act, 2000*. The latter was enacted in Scotland in November 2002, and renders it unlawful for public authorities to discriminate on racial grounds: NHS Scotland must adhere to the Act, which is supported by a Code of Practice. The work of the National Resource Centre for Ethnic Minority Health has subsequently been extended to include the needs of gypsy travellers, asylum seekers and refugees, and people who are homeless.

The policy outlined within *Equality Strategy: Working Together for Equality* is also relevant for persons with learning disabilities. It acknowledges that many persons in Scotland experience discrimination, lack of opportunities or access to services and are under-represented in decision-making. The policy aims to remove discrimination, prejudice and ensure equity for all.

Significant changes are underway in education services, to ensure equality of opportunity for all. The legislative programme has addressed recommendations arising from the *Report into the Education of Children with Severe Low Incidence Disabilities*. A major emphasis is now placed on the notion of inclusion and Section 15 of the *Standards in Scotland’s Schools etc. Act, 2000* makes the presumption that all children should have their education provided in mainstream school, except in certain particular circumstances.

Other current and impending policy developments affect this presumption to mainstream. *The Children (Scotland) Act, 1995* already requires services for children with disabilities to “minimise the adverse effects of the disability” and to help the children live “as normal a life as possible”. *The Special Educational Needs and Disability Act, 2001* renders it unlawful to discriminate against pupils with disabilities and places a duty on Local Authorities to make reasonable adjustments to avoid placing pupils with disabilities at substantial disadvantage. In addition, *The Education (Disability Strategies and Pupils’ Educational Records) (Scotland) Act, 2002* was introduced to address the issues of accessibility to education and other services.
for pupils with disabilities. The new framework document, *Moving Forward! Additional Support for Learning* and new legislation about to go through the Scottish Parliament, will provide an overarching framework to address the individual needs of children who may have difficulty accessing and benefiting from learning, whatever the reason or cause may be for that difficulty.

These developments place a new duty on education authorities to identify and address additional support needs of pupils. The aims are wider than the current Special Educational Needs (SEN) framework and will require input from other agencies, such as NHS Scotland and social work services, to assist education authorities with this process. While input from other agencies already happens, the intention is to ensure that this is more consistent and promotes integrated working in supporting the needs of children.

Additionally, legislation within Scotland that is of importance to persons with learning disabilities includes the *Adults with Incapacity (Scotland) Act, 2000*, the forthcoming *Mental Health (Care and Treatment) (Scotland) Act, 2003*, *The Disability Discrimination Act, 1995*, and the *Human Rights Act, 1998*.

The *Adults with Incapacity (Scotland) Act, 2000* provides a legal mechanism for gaining consent or acting on a person’s behalf when the person does not have capacity to give or withhold consent. Part V of the Act relates to medical treatment and research, and became effective in 2002. It includes any procedure or treatment that seeks to promote physical or mental health. The accompanying Code of Practice is currently under review, following a recent consultation exercise. The remit of the *Adults with Incapacity (Scotland) Act, 2000* overlaps with that of the forthcoming *Mental Health (Care and Treatment) (Scotland) Act, 2003*, which will be effective from April 2005. The new Act legislates the criteria and procedures for compulsory detention and / or treatment of persons with mental disorders (which is defined to include “severe mental impairment”). It places a range of duties on organisations including NHS Scotland, the Mental Welfare Commission and the new Mental Health Tribunal. It will provide courts with more effective procedures for persons with mental disorders charged with offending. Importantly, persons with mental disorders are afforded new rights by the Act, including the right of access to independent advocacy.

The *Disability Discrimination Act, 1995*, is being introduced in three stages, with the final part effective from October 2004. The Act makes it illegal to discriminate against people who have disabilities in employment, access to goods, services, transport and education. This includes persons with learning disabilities. Service providers, including Local Authorities and NHS Scotland, are required to make reasonable adjustments for people who have disabilities. They cannot discriminate by refusing to provide a service, in the standard of the service provided, or the terms on which a service is provided. This includes policies and procedures, providing extra help, and removing physical barriers to access.

The *Human Rights Act, 1998* relates to public bodies, and protects human rights and the values of a democratic society. All of the Articles of the *European Convention on Human Rights and Fundamental Freedom, 1950*, are contained within the Act, and apply equally to persons with learning disabilities. This includes freedom from discrimination.
3.4 WHAT DOES THE TERM LEARNING DISABILITIES MEAN?
The Health Needs Assessment Report adopts the definition of learning disabilities used by *The same as you?*. This is equivalent to the term “intellectual disabilities”, which is commonly used internationally. Whilst considering this definition, it is of course essential to always consider that everyone is an individual, and will have individual needs, preferences and ambitions.

**The same as you? Definition of Learning Disabilities**

Learning disabilities is a significant, lifelong experience that has three components:
- Reduced ability to understand new or complex information or to learn new skills (in global rather than specific areas).
- Reduced ability to cope independently.
- Onset before adulthood (before the age of 18) with a lasting effect on the individual’s development.

The definition above is widely used within adult services. Within services for children the broader terms of learning difficulties and special needs are commonly used. These include a wider range of children who require support for learning for any reason, including specific developmental disorders such as dyslexia, problems with speech and language, and sensory impairments. Children with such needs often do not have associated learning disabilities as defined above, although they require support for learning in specific, rather than global aspects. Additionally, people with autistic spectrum disorders were included in *The same as you?*, to ensure that there was no omission of persons who wish to access a service to have their needs met. However, a proportion of people with autistic spectrum disorders do not have significant learning disabilities.

Clarity of definition is therefore important when considering the needs of persons who use a range of inter-related services, for example at times of transition. Clear definitions may avoid confusion in the provision of services and service planning for adults when based on childhood needs assessments or databases.

Natural variation between persons occurs in the population for most human characteristics and this is the case also for ability level. Additionally, there are hundreds of different specific causes of learning disabilities, some of which are exceptionally rare. Down’s syndrome is one of the most common specific causes of learning disabilities. When a child is first identified to have developmental delay, it is important that she / he has access to a comprehensive multi-disciplinary assessment via paediatric services. This includes determining the cause of the developmental delay. The reasons for this include the need to identify any causes that may be reversible; to provide accurate information for the family; to identify any health problems or needs for health screening that may be specifically associated with the child’s particular cause of learning disabilities, and which may bring benefits from early detection and intervention; to assess needs for educational supports and the family’s need for other supports. This Health Needs Assessment does not intend to review the many possible causes of learning disabilities; instead it focuses on the health needs of persons with learning disabilities.
PART TWO
THE EVIDENCE
4.1 THE POPULATION OF PEOPLE WITH LEARNING DISABILITIES IN SCOTLAND

*The same as you?* estimated that in Scotland, about 20 people in every 1,000 have mild or moderate learning disabilities and 3 - 4 people in every 1,000 have severe or profound disabilities. This suggests that there are about 120,000 people with learning disabilities in Scotland. However, there are no detailed studies specific to Scotland on which to base estimates and these figures are generalised from studies that took place in other geographical areas, using varying methodologies.

In a review of 43 papers measuring the prevalence of learning disabilities, it was found to vary from 2 to 85 per 1,000 of the population. This review produced an average prevalence of 34 per 1,000 for mild learning disabilities and 3.8 per 1,000 for more severe learning disabilities. The results of studies that have been published since then are shown in the table.

The comparison of studies that use variable methodologies across different geographical areas is problematic. More recent studies have described a lower overall prevalence of learning disabilities. Examining the four studies that provide a breakdown of figures, it appears that there is a marked difference in the prevalence of mild learning disabilities when compared to the average prevalence described previously. The prevalence of more severe learning disabilities varies from 2.7 to 3.64 per 1,000, which is marginally lower than the average prevalence reported in *The same as you*.

It is not surprising that the greatest variation between these studies relates to people with mild learning disabilities. Some persons who started life with mild learning disabilities, having benefited from support for learning in childhood and had the years to gradually learn skills, may not appear to have learning disabilities in adult life. That is, having learned the life skills to cope independently, the person may not require a lot of additional support and may not identify her/himself as having disabilities. People with more severe learning disabilities are more likely to require life-long support and so are more likely to be identified as having disabilities in population-based studies.

Whilst the differences between studies may represent genuine differences in prevalence between areas they could also reflect differences in study design, for example due to case ascertainment. Such variations affect the validity of applying findings from other studies to Scotland.
REVIEW OF RESEARCH

The extent to which demographic statistics can be generalised from other countries to Scotland also depends on the stability of populations. Population size in Scotland peaked in 1974. Since then there has been a gradually declining trend and a projection that this will continue. This is due to an excess of deaths over births, with net emigration being lower than 15 years ago. Net emigration is weighted towards males and younger age groups.

Reports from elsewhere in the U.K. have described how depopulation can be associated with the outward emigration of younger, mobile individuals rather than persons who are older or have disabilities: consequently the proportion of persons with learning disabilities within the population can rise and vary according to urban or rural factors. Other factors also determine population movement. Some individuals, or families, relocate for a variety of reasons. This might include employment or lifestyle choices. Some families with a family member who has learning disabilities may choose to relocate to an area in order to access a particular school or service with a good reputation. Other persons with learning disabilities may be moved with little choice if local services do not have a provision able to meet the person’s needs. In some areas of Scotland independent providers offer residential services for people with very specific needs and attract referrals from across Scotland. This may bring benefits for the person with learning disabilities if their needs are better met or, in some cases, it may be associated with a human cost of dislocation from families and familiar communities. Where residential services are established and attract inward migration to the area, this will require support from other local health and social work

Table 1: Studies of the Prevalence of People with Learning Disabilities in the Population

<table>
<thead>
<tr>
<th>Year</th>
<th>Age group</th>
<th>Geographical area</th>
<th>Study population with learning disabilities</th>
<th>Study type</th>
<th>Prevalence (per 1,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td>1997</td>
<td>Lifespan</td>
<td>Worldwide</td>
<td>N/A</td>
<td>Critical review of 43 prevalence studies</td>
<td>34</td>
</tr>
<tr>
<td>1998</td>
<td>Median age 10.8 years</td>
<td>Norway</td>
<td>185</td>
<td>Population based of 1980-1985 birth cohort</td>
<td>3.5</td>
</tr>
<tr>
<td>1999</td>
<td>Unspecified</td>
<td>France</td>
<td>1,150</td>
<td>Retrospective survey of 1976-1985 birth cohort</td>
<td>N/A</td>
</tr>
<tr>
<td>2001</td>
<td>Lifespan</td>
<td>U.S.A.</td>
<td>945,091</td>
<td>Non-institutionalised population, cross sectional survey in 1994-1995</td>
<td>N/A</td>
</tr>
<tr>
<td>2002</td>
<td>20 years and over</td>
<td>Leicestershire, England</td>
<td>105</td>
<td>Population based, cross sectional administrative prevalence in 1991</td>
<td>N/A</td>
</tr>
<tr>
<td>2002</td>
<td>14-20 years</td>
<td>Ontario, Canada</td>
<td>225</td>
<td>Population based screening study in 1994</td>
<td>3.54</td>
</tr>
<tr>
<td>2003</td>
<td>11.5 years</td>
<td>Northern Finland</td>
<td>105</td>
<td>Population based 1985-1986 birth cohort</td>
<td>7.49</td>
</tr>
<tr>
<td>2003</td>
<td>Children</td>
<td>Western Australia</td>
<td>3,426</td>
<td>Population based 1983-1992 birth cohort</td>
<td>10.6</td>
</tr>
</tbody>
</table>

The extent to which demographic statistics can be generalised from other countries to Scotland also depends on the stability of populations. Population size in Scotland peaked in 1974. Since then there has been a gradually declining trend and a projection that this will continue. This is due to an excess of deaths over births, with net emigration being lower than 15 years ago. Net emigration is weighted towards males and younger age groups.

Reports from elsewhere in the U.K. have described how depopulation can be associated with the outward emigration of younger, mobile individuals rather than persons who are older or have disabilities: consequently the proportion of persons with learning disabilities within the population can rise and vary according to urban or rural factors. Other factors also determine population movement. Some individuals, or families, relocate for a variety of reasons. This might include employment or lifestyle choices. Some families with a family member who has learning disabilities may choose to relocate to an area in order to access a particular school or service with a good reputation. Other persons with learning disabilities may be moved with little choice if local services do not have a provision able to meet the person’s needs. In some areas of Scotland independent providers offer residential services for people with very specific needs and attract referrals from across Scotland. This may bring benefits for the person with learning disabilities if their needs are better met or, in some cases, it may be associated with a human cost of dislocation from families and familiar communities. Where residential services are established and attract inward migration to the area, this will require support from other local health and social work
services. Whereas social work services are typically purchased as part of the contract, health services are free-at-the-point-of-delivery and there may be the expectation that local health services meet such needs. Indeed, it is the right of the person with learning disabilities to be able to access national health services locally. Providing for the health needs of persons moving into an area will increase demand on local health services and it is essential that such factors are included within local strategic planning.

Due to lack of pre-existing available data on migration within the Scottish learning disabilities population, a mapping exercise was undertaken as part of the Health Needs Assessment. This is reported in greater detail elsewhere. Health services, social work services and voluntary organisations were asked to indicate the number of people with learning disabilities moving in and out of their area. A detailed questionnaire was sent to all learning disabilities teams in Scotland. To identify the impact on service users, carers and services, focus groups were held in one NHS Board area identified to have a high level of inward migration.

An analysis of the results suggests that there are significant numbers of people with learning disabilities and complex needs who have migrated from their original area of residence. This figure includes children and adults from all four United Kingdom countries as well as other European Union countries. A picture emerges where originating areas are more characteristically urban, while the receiving areas are rural in nature.

The most common reason children and adults with learning disabilities are migrating from their area of origin is a lack of appropriate local services to meet their complex needs. The lack of appropriate services creates significant health impacts on receiving areas that are not strategically planned for. These include crisis admissions and readmission to Assessment and Treatment Units, disagreement or confusion over out-of-area financing, increased service demand on all tiers of the health service and ultimately failure effectively to meet the complex health needs of the individual with learning disabilities. This is highly unsatisfactory for the persons with learning disabilities and their families.

More boys are born with learning disabilities than girls. This is because some causes of learning disabilities which are genetically determined are specifically associated with male gender. Hence, unlike the general population, cohorts of children and younger adults with learning disabilities are about 60% male and 40% female. This changes in older age, as women typically live longer than men. Hence an equal gender ratio is seen in old age, and at extreme old age there is probably a greater proportion of women than men.

Temporal changes in the prevalence of learning disabilities amongst children have been examined by studies of successive birth cohorts. Social and medical changes have resulted in improved survival and outcomes for children with learning disabilities. However, different findings in the three studies demonstrate the difficulties in generalising results between countries and regions.

To allow strategic planning of services there is a need for the development of a system that can provide robust Scottish epidemiological data. The recommendation in *The same as you?* that the first PiPs should address the development of local databases, and the current eSAY project coordinated by SCLD and including work towards the development of a national database are significant developments in this respect.
4.2 LIFE EXPECTANCY AND MORTALITY

Life expectancy is one of the key public health measures used to determine the health of a population. The life expectancy of the whole population is increasing. For people with learning disabilities, life expectancy is also increasing, however it still remains lower than for the rest of the population.

In 1929, the life expectancy for an infant born with Down’s syndrome was only 9 years, and for persons with learning disabilities in general in the early 1930’s the average age of death for men was 15 years and for women was 22 years. In contrast to this, many persons with learning disabilities now achieve middle and older age (whereas achieving old age used to be rare). A Californian study calculated that up to the age of 35 years, mortality rates are similar for people with Down’s syndrome and people with learning disabilities of other causes. After 35, mortality rate doubled every 6.4 years for people with Down’s syndrome compared with doubling every 9.6 years for people with learning disabilities of other causes. Table 2 summarises recent studies providing data on life expectancy or mortality rates.

Life expectancy is shortest for people with learning disabilities who are least able. Some specific causes of learning disabilities, such as Down’s syndrome, are also associated with a reduced life expectancy when compared with other people with learning disabilities. Other health needs also covary with significantly reduced life expectancy, such as epilepsy and hearing impairment, reduced mobility, tube feeding and male gender. These associations are also found amongst children and adolescents with learning disabilities, who have higher mortality rates than do children and adolescents from the general population. Amongst children and adolescents with learning disabilities, shorter life expectancy is associated with lower ability level, presence of additional complex needs such as cerebral palsy or epilepsy, congenital malformations and infectious diseases.

Studies to understand better the multiple factors that contribute to a person’s final cause of death could help explain the increased mortality rate for people with learning disabilities. Furthermore, they could allow the development of interventions to increase life expectancy such as with the approaches underway in New South Wales, Australia (reported in Chapter 6). The profile of cause of death for people with learning disabilities differs from the general population. The most common causes of death for the Scottish population are firstly cancer, then ischaemic heart disease and thirdly cerebrovascular disease. The commonest cancers causing death are trachea, bronchus and lung, followed by prostate in men and breast in women. Public health strategies in Scotland are aimed at tackling and reducing deaths from these causes, and with some effect: deaths from ischaemic heart disease are falling such that this is no longer the leading cause of death in Scotland. Quit smoking campaigns, initiatives to encourage increased consumption of fruit and vegetables, and to reduce suicide, are all underway, with the explicit aim of improving the health of the nation.

In contrast, the leading cause of death for people with learning disabilities is respiratory disease, which relates to pneumonia and aspiration, posture, swallowing and feeding problems and gastro-oesophageal reflux disorder. This is followed by cardiovascular disease – but disease related to congenital heart disease rather than ischaemia. Cancer is a lower ranked cause of death than for the rest of the population, and the types of cancers most commonly experienced by people with learning disabilities also differ from the general population. In particular, people with learning disabilities have reduced rates of lung,
prostate and urinary tract malignancies but increased rates of oesophageus, stomach and gall bladder malignancies. These differences are partly explained by lower rates of smoking and high rates of untreated gastro-oesophageal reflux disorder. Importantly, there are often several factors which contribute to the cause of death of a person with learning disabilities, some of which are potentially preventable.

Table 2: Studies Measuring the Life Expectancy and Mortality of People with Learning Disabilities

<table>
<thead>
<tr>
<th>Geographical area</th>
<th>Population type</th>
<th>Study population with learning disabilities</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>U.K.</td>
<td>Individuals in a specified area of London</td>
<td>N/A</td>
<td>Mortality rates of adults with learning disabilities exceed those of the general population</td>
</tr>
<tr>
<td>Finland</td>
<td>Nation-wide population study</td>
<td>2,366</td>
<td>Mild learning disabilities population has similar life expectancy to general population. Reduced life expectancy with more severe learning disabilities</td>
</tr>
<tr>
<td>Israel</td>
<td>Individuals across the lifespan in residential centres</td>
<td>6,022</td>
<td>Overall mortality rate of 10.2 per 1,000 population with average age at death of 32.7 years. Mortality rate of general population of 5.1 per 1,000 population with average age of death of 71.0 years</td>
</tr>
<tr>
<td>U.S.A.</td>
<td>Individuals over 40 years old in New York state</td>
<td>100,000</td>
<td>Average age of death of 66.1 years for individuals with learning disabilities compared to 70.4 years for the population without learning disabilities</td>
</tr>
<tr>
<td>Western Australia</td>
<td>State wide population study</td>
<td>8,724</td>
<td>50% survival probability of 68.6 years for individuals with learning disabilities compared to Australian population figures of 78.4 years</td>
</tr>
<tr>
<td>U.S.A.</td>
<td>Population based cohort of 10 year olds</td>
<td>1,062</td>
<td>Standardised mortality ratio of 3.3 for children with learning disabilities, ranging from 1.4 amongst those with mild learning disabilities to 8.4 for those with severe learning disabilities</td>
</tr>
<tr>
<td>Sydney, Australia</td>
<td>Geographical area based study of 10-64 year olds</td>
<td>693</td>
<td>Overall standardised mortality ratio of 4.9 compared to figures for the area population without learning disabilities</td>
</tr>
</tbody>
</table>
These differences are important. Firstly, the lower life expectancy of people with learning disabilities demonstrates that they are disadvantaged compared with the rest of the population. They are therefore one of the groups that Scottish policy explicitly states an intention to improve health for, to reduce this inequality. Secondly, however, Scotland’s current public health initiatives will fail to achieve this intention. Indeed, instead of closing the gap, current initiatives are likely to widen the inequality gap. If actions are in place so that all current public health initiatives are accessible for people with learning disabilities, then the whole population is likely to gain some benefit from them – but people with learning disabilities will gain much less than the rest of the population as e.g. quit smoking initiatives are relevant to a much smaller proportion of all people with learning disabilities compared with the proportion of the rest of the population for whom they are relevant. The most effective public health initiatives for people with learning disabilities would be those that target their leading causes of ill-health and death; however, such initiatives do not currently exist – as they are not of particular relevance to the rest of the population.

Demography is changing due to increased life expectancy at all ages and all ability levels, including the survival of very premature and low birth-weight infants. This has resulted in a growing number of older adults with learning disabilities and also a growing number of persons with severe and profound learning disabilities in all age cohorts. Strategic planning is therefore required to address the changes in population needs that can be anticipated due to changing demography.

Many factors are contributing to the increase in life expectancy seen for the whole population and some special factors are relevant for persons with learning disabilities. The latter are likely to include the progress made towards community lifestyles for persons with learning disabilities, with more person-centred approaches to support and care, and reduction in the spread of infectious diseases. Improved access to health interventions, which evidence suggests may previously have been withheld from this population, includes antibiotic treatment for chest infections and cardiac surgery for congenital heart disorders, both of which occur more commonly in people with learning disabilities compared with the general population.

If data sources in Scotland do not record persons as having learning disabilities, it will not be possible to undertake studies to answer questions central to addressing the health inequalities experienced, and to strategically develop services. This is exemplified by a study which used central data sources at a large children’s hospital to identify children admitted over a three month period. It identified no children with learning disabilities, yet other methods identified admissions.

### 4.3 THE UNMET HEALTH NEEDS OF PEOPLE WITH LEARNING DISABILITIES

The health needs of people with learning disabilities can be conceptualised on 4 levels, shown in the box.

**A Model of the Health Needs of People with Learning Disabilities**

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

Adapted from *Promoting Health, Supporting Inclusion*[^27]
Health needs and health services cannot be considered in isolation. There are a number of factors that impact upon an individual person’s health, well-being, spiritual well-being and health choices. These may include biological factors such as age, sex and genetics, and also individual lifestyle (including lack of choice and information), social and community influences (including being dislocated from opportunities), living and working conditions (including housing, diet, employment, use of services), socio-economic, cultural and environmental factors which influence health and well-being. Ill-health in turn can impact upon a person’s behaviour, learning and expectations, can influence their environment, impact on community participation and lead to exclusion. These considerations are just as important for persons with learning disabilities, and maybe more so than for the general population.

Social deprivation and exclusion are associated with poorer health \(^{84,85}\). Persons with learning disabilities have been shown to be more likely to live in areas identified as socially deprived \(^{86}\). However, the measures used to categorise social deprivation in the general population are not necessarily the most appropriate for use with persons with learning disabilities (in view of e.g. previous institutional care, being placed rather than choosing locality, mismatches between deprivation scores of family of origin in past and current location; and currently if still in contact with family). People with learning disabilities have experienced multiple exclusions including the lack of opportunity to determine their own choices and futures. Factors other than social deprivation may be more powerful determinants of health and ill-health for persons with learning disabilities, whilst not being of particular relevance for the general population e.g. communication needs, psychological and social disadvantages, including adverse experiences in early life, and a history of discrimination within services, as well as experiencing exclusion in society at large. However, there has been such limited study of these factors and their potential impact on the health and well-being of people with learning disabilities that it is difficult to make evidence-based statements regarding their importance, from which recommended interventions could be developed. There is an urgent need for research on the wider determinants of health to benefit persons with learning disabilities.

What is clear, is that people with learning disabilities have greater health needs when compared with the general population \(^{7,13}\). Much of their health need is unrecognised and unmet \(^{7,8,14-18}\). They experience barriers to these needs being met by services \(^{16,18,87-90}\). This relates to a combination of factors affecting access.

Factors affecting access to services include:
- Issues related to the person with learning disabilities, and requiring services to make reasonable adjustments:
  - Communication needs.
  - Problem behaviours.
  - Multiple coexisting health needs.
  - Some types of health needs are distinct to people with learning disabilities and not experienced by the general population (e.g some types of self injury, behavioural phenotypes).
  - Low expectations of services due to previous bad experience of services.
  - High tolerance of pain associated with certain causes of learning disabilities may result in carers not being aware of health need.
• Health and social work professionals:
  ° Attribution of a person’s additional health needs to their learning disabilities.
  ° Presence of inappropriate stereotypes and negative assumptions about a person’s ability to maintain health and quality of life.
  ° Lack of pre-registration training in working with persons with learning disabilities.
  ° Inexperience in working with persons with learning disabilities, and low level of contact leading to difficulties in gaining experience.
  ° Lack of post-registration training in working with persons with learning disabilities.
  ° Knowledge, skills, and attitudes.
  ° Lack of confidence, fear, and feeling de-skilled.
  ° Lack of recognition of the contribution to personal knowledge and experience of family carers to their family member’s needs and behaviour.

• The structure of health and support services:
  ° Inflexible appointment systems.
  ° Short appointment times.
  ° Reliance on a person’s ability to read e.g. appointments, information sheets, leaflets and consent forms.
  ° Reactive, rather than proactive delivery of health care e.g. reliance on the individual seeking help, rather than routinely offering it.
  ° Physical barriers.
  ° Poor co-ordination and exchange of information between services and agencies.
  ° Ineffective communication and planning between services and agencies at times of transition.
  ° Exclusion from services that may be beneficial on the basis of a person having a learning disability e.g. services for older people or physical disability services.
  ° Institutional discrimination e.g. protocols to access treatments for dementia being based on average ability levels of the general population.
  ° Recording and sharing of health information within teams of paid support workers e.g. staff shifts, staff turnover, new and agency employed workers.
  ° Lack of healthcare training and education for family carers and paid carers to enable health promotion and identification of health needs.
  ° Limited availability of information from the person’s past.
  ° Limited information about available services.
  ° Limited availability of independent advocacy.
  ° Unclear complaints procedures.
  ° Lack of accountability of NHS Boards to explicitly address and report the needs of people with learning disabilities.
  ° Lack of systems in place to identify and record the number of people with learning disabilities and their health needs, to inform service delivery and planning.
  ° Limited quantity and quality of research supported to lead to developments for health improvements.

• Scottish legislation:
  ° The Adults with Incapacity (Scotland) Act, 2002 specifically excludes people who do not have ability to give or withhold consent, from participating in some types of research. It excludes everyone who cannot consent from taking part in research which could lead to health benefits, if they are not in contact with a relative.
Several of these factors are inter-related, such as:

- A person with learning disabilities may have limited verbal communication skills, but the structure of services impacts further upon the overall effectiveness of communication (short appointment times, noisy ward environment), as can the attitude and experience of the health professional. It is essential to remember that communication is a two way process. There is a responsibility on professionals and services to adopt approaches to communication in the most appropriate way for each person.
- The person may experience problem behaviours but only in certain situations – such as during appointments with under-confident, inexperienced professionals in clinical environments.
- Attitudes of professionals may be a component of the unintentional institutional discrimination within services, and compounded by low expectations of service users, which may be the result of previous bad experiences of services.

Within the framework of the Disability Discrimination Act, 1995 it is now the explicit responsibility of all those involved with provision of services to address these barriers.

Many services in Scotland adopt a reactive rather than proactive model of care. They rely on the person or their carer recognising that the person has a possible health need, and seeking input from the professional/service. Hence a person with communication needs is subject to health management by proxy. Persons supported by paid carers may also be affected by how long the paid carer has known the person, so that they recognise any change in the person, how well information is shared between members of the support team, and how much time the paid carers spend with the person. The reactive nature of service provision therefore disadvantages persons with learning disabilities. General Practitioners (GPs) are sometimes referred to as “gate-keepers” for the health service i.e. they restrict access to other parts of the health and social work service by managing need as much as possible within the primary care setting. This model is counter-intuitive for persons with learning disabilities who are known to have extremely high levels of unmet health needs, and who already face barriers even in accessing primary health care services. Added to this is the tradition necessarily adopted within primary care, where “common things are commonest”. One of the skills of the GP is distinguishing the person with health needs who requires intervention from the number of persons presenting to their service with time-limited problems or other concerns requiring reassurance or education. For example, a person presenting with a cough may be reassured at a first appointment, prescribed antibiotics if the person represents her/himself at a second appointment, and offered a chest X-ray if they return with the same complaint at a third appointment (as “common things are commonest” - a viral infection is the more likely cause rather than lung cancer or tuberculosis). Given the access barriers faced by persons with learning disabilities, how likely are they to go to the same GP with the same complaint on three occasions, having previously been given reassurance? Additionally, the pattern of ill-health experienced by persons with learning disabilities differs from the rest of the population - so whilst, “common things are commonest”, what is commonest differs for people with learning disabilities - hence a differing knowledge base is required to effectively operate the same model of care. This knowledge base does not exist at present in primary health care services in Scotland, for a variety of reasons. It is difficult to see how this capacity can be built within the existing model of primary health care services, given that each GP's opportunity to gain experience once in practice will be limited. On average, a GP will have
only about five persons with learning disabilities registered with her / him at any one time, each one of whom will have health needs differing from each other, and typically with lower consultation rates than the rest of the population. This is extremely low volume work compared with other work managed within primary care.

Both physical and mental ill-health problems can present with a change in behaviour, and so they can be misinterpreted. Additionally, some philosophies of care interpret challenging behaviour as an indicator that the way support is provided needs to change. Such best intentions are highly desirable for some persons with long-standing problem behaviours. However, they fail to identify that the person may be experiencing a problem or distress due to physical or mental ill-health. It has been demonstrated that for the majority of persons with learning disabilities who have mental ill-health, health professional input has not been sought and even where support workers were aware of symptoms they had failed to realise the significance of these. Health care training and education would help address this. Conversely, family carers have considerable personal knowledge and experience of their family member with learning disabilities, and are often able to detect subtle changes in the person or her / his behaviour. It is essential that professionals recognise and utilise this information.

It has been consistently found that there is insufficient attention to the health needs of people with learning disabilities, a lack of basic health promotion, support to achieve a healthy lifestyle and under-identification of specific ill-health. To suggest that people with learning disabilities are already included in all health improvement policy ignores their long history of unmet health needs, their additional specific health needs and the complex issues that prohibit effective use of and access to services and care. Inclusion in all health improvement policy will not happen automatically; it will need additional, specific actions.

To ensure that the wider determinants of health for persons with learning disabilities are addressed it is essential that their needs are highlighted across the full range of government departments and local agencies: strategic responses and corporate responsibility is required nationally and locally. Public health strategies provide an opportunity to enhance the health of people with learning disabilities, provided that their needs are not overlooked as a component of general population needs. Towards a Healthier Scotland and Improving Health in Scotland: The Challenge outline themes to improve the health of the whole of the Scottish population, and also recognise the need to improve the health of people who are most disadvantaged. For persons with learning disabilities, this will require additional, specific measures.

4.4 EVIDENCE ON THE TYPES OF HEALTH NEEDS OF PEOPLE WITH LEARNING DISABILITIES
The following sub-chapters summarise the research evidence about the health needs of people with learning disabilities and their carers.

4.4.1 PERSONS WITH PROFOUND LEARNING AND MULTIPLE PHYSICAL DISABILITIES
There are increased mortality rates and reduced life expectancies amongst persons with profound learning disabilities. Respiratory diseases, seizures, infections and gastrointestinal diseases are of particular significance in relation to this increased risk of premature death. Although this effect is seen across the lifespan, age related data
demonstrates that people with profound learning disabilities at the two ends of the age spectrum are comparably at particular risk of premature death. The reasons for the above findings are the complex health needs of persons with profound learning disabilities. They experience increased rates of epilepsy, swallowing problems, sensory impairments, gastrointestinal disorders, respiratory problems, low body weight requiring feeding via gastrostomy tubes, cerebral palsy, and posture and mobility problems when compared with other persons. Several of these disorders can be present in an individual, interacting to increase morbidity and the risk of premature death.

The complexity and potentially negative impact of the specific additional health needs of persons with profound learning and multiple physical disabilities are important for services to recognise. Effective provision of health care will require the involvement of multiple health care professionals e.g. GPs, speech and language therapists, physiotherapists, and partnership working between the tiers of the health care system with Local Authority employees and paid carers. Independent organisations also have an important role. Family carers have a crucial role to play in promoting and maintaining good health. It is essential that health information and training is available for family carers and paid carers; who, in turn, can make important contributions to training professionals.

4.4.2 CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES

All children and young people have important health needs that must be met to ensure they have the opportunity to develop. These can only be met by considering each child as an individual within the context of the surrounding environment. Of primary importance are a child’s parents and other family members. Additionally, factors such as social circumstances, friends, aspects of the community in which they live, educational opportunities, and other statutory services can all impact upon a child’s health, well-being and development. For example, a recent study demonstrates the impact of poverty and social disadvantage on families with a child who has learning disabilities. Lone parents and families from ethnic minority communities are at increased risk of experiencing severe social disadvantage.

Children with learning disabilities often have needs additional to the general health needs that are common to all children. This is recognised within the National Service Framework for Children currently under development in England. As part of the development process, an external working group is producing national standards for services for disabled children and their families. The working group has identified seven key areas for standards:

- Early diagnosis.
- Family support/ intervention.
- Equipment and adaptations.
- Therapy services.
- Transition services.
- Childrens’/ family participation.
- Children with complex and continuing health needs and / or life- limiting conditions.

(Details are available at www.doh.gov.uk/NSF/children.ewgdisabled.htm#progress)

4.4.2.1 ASSESSMENT AND DIAGNOSIS

Right from the Start describes the experiences of families when their child was first assessed
and how they were told about their child’s disabilities. The report made 21 recommendations, highlighting the importance of early, honest and empathic communication with families, the need to give consideration to the ongoing support families may require and the provision of helpful information for the family. The way in which a family was told about their child’s diagnosis had important consequences\textsuperscript{107,110}. In recognition of the importance of this time for children and families, a template outlining best practice for services has been developed\textsuperscript{111}, as have English guidelines for professionals working with children with disabilities and their families\textsuperscript{112}.

The initial assessment process is a key opportunity to identify the unmet needs of children and their families, leading to the provision of effective interventions and supports. Given the dynamic nature of childhood development the diagnosis of learning disabilities in children can be challenging and complex, and requires a comprehensive multi-disciplinary approach.

Although children with more complex needs are often identified in the neonatal period, children with less severe difficulties may not be identified until they start school\textsuperscript{113}. However, when specific problems are recognised, there is considerable opportunity for interventions to positively impact upon the longitudinal outcome\textsuperscript{114}. This dynamic nature of the developmental trajectory therefore emphasises the potential impact and importance of early interventions in the pre-school period\textsuperscript{115}.

Universal child health promotion activities, such as the screening programme, are an opportunity for the early identification of children that would benefit from further assessment and intervention\textsuperscript{116,117}. Whilst these can potentially identify children with developmental problems, systematic reviews conclude that they do not meet the rigorous criteria for screening\textsuperscript{116}. There are proposed changes to the universal health surveillance programme which will reduce its breadth to allow practitioners to concentrate on more specific areas of health promotion, such as universal neonatal hearing screening.

Once developmental delay has been recognised, careful assessment and evaluation is required. There is considerable debate about the components of the diagnostic assessment process and this will vary depending upon the age at presentation and other individual factors. American guidelines have been developed, but are not directly applicable to Scotland\textsuperscript{119,120}. It would be advantageous to develop guidelines for use in Scotland.

4.4.2.2 EARLY INTERVENTION

Over the past 20 years, there has been an increased provision of early intervention programmes to children with learning disabilities or other developmental disorders\textsuperscript{121}. These focus on children already diagnosed, or those thought to be at high risk of the child having a developmental problem, such as very low birth weight infants or families at severe social disadvantage. Interventions have been designed and evaluated for children diagnosed with learning disabilities\textsuperscript{122}, autistic spectrum disorders\textsuperscript{123} or delay in particular developmental domains, such as speech and language\textsuperscript{124}. Although positive effects have been reported\textsuperscript{122,125}, there is controversy about the reliability of study findings\textsuperscript{126}. The importance of the participation of, and promoting partnerships with, parents and the wider family in interventions has been emphasised\textsuperscript{127,128}.
In the U.S.A., the likelihood of having learning disabilities is greatest amongst children from socially disadvantaged families\textsuperscript{129,130}. Social disadvantage in childhood has also been shown to predict outcome in adulthood of people with mild learning disabilities\textsuperscript{131}. Preventative strategies targeting identified children were therefore established in the U.S.A. A systematic review of these early intervention programmes concluded they are effective in preventing developmental delay\textsuperscript{132} and have long term benefits for children from low income families\textsuperscript{133,134}. Similar intervention programmes have recently been established in the U.K.

4.4.2.3 SPECIFIC HEALTH NEEDS

About 20 – 25\% of children and young people with learning disabilities have epilepsy\textsuperscript{135-137}. Prevalence increases for children at lower ability levels and is over 50\% for children with profound learning disabilities. A high prevalence is also associated with cerebral palsy\textsuperscript{138}, fragile X syndrome\textsuperscript{139} and tuberous sclerosis\textsuperscript{140}. Epilepsy has a negative impact upon mortality in children with learning disabilities and other developmental disabilities\textsuperscript{5,72,141}. Compared with children who have epilepsy but not learning disabilities, children with learning disabilities and epilepsy are more likely to have earlier age of onset of seizures\textsuperscript{142}, treatment refractory seizures\textsuperscript{137}, higher seizure frequency\textsuperscript{143} and a lower health-related quality of life\textsuperscript{144}.

Children with learning disabilities are at increased risk of visual impairment\textsuperscript{101,145,146} and hearing impairment\textsuperscript{101,147}. Early detection and correction is important.

A wide range of mental ill-health and problem behaviours are experienced by children and young people with learning disabilities. The reported prevalence is high, at between 31 – 50\%\textsuperscript{148-158}. Comparison with children from the general population has demonstrated that children with learning disabilities have a 3 – 5 times higher prevalence of mental ill-health and problem behaviours\textsuperscript{156,158}. The factors associated with an increased risk of mental ill-health in children with learning disabilities are male gender and older age\textsuperscript{103,149,152,153}, social disadvantage, family characteristics and the occurrence of significant life events\textsuperscript{103,159}. The inadequate provision of services for children and young people with learning disabilities and mental ill-health has been demonstrated\textsuperscript{160} and is described in detail in the U.K. report \textit{Count Us In}\textsuperscript{161}.

As for adults, specific types of health problems are specifically associated with particular genetic causes of learning disabilities. Guidelines are available for some causes, such as Down’s syndrome (www.dsmig.org.uk) and health screening programmes are indicated. Some services provide specialist provisions for particular groups of children, such as children with Down’s syndrome, Prader-Willi syndrome, fragile X syndrome, Williams syndrome and tuberous sclerosis. Children with Down’s syndrome, for example, have increased risk of congenital malformations, mainly of the heart and gastrointestinal system\textsuperscript{162}, risk of developing childhood leukaemia\textsuperscript{163}, thyroid dysfunction\textsuperscript{164}, celiac disease\textsuperscript{165,166}, sensory impairments and ear nose and throat problems, including upper airway obstruction, otitis media with effusion and obstructive sleep apnoea\textsuperscript{167}.

4.4.2.4 TRANSITION

Periods of transition are important in the lives of all people within our community. Although most work has focussed on the transition from adolescence to adulthood, there are important periods of transition throughout the lifespan. At these times, there are clear issues that need to be considered and addressed to maintain and promote health and well-being\textsuperscript{98}. Work in this
area identifies partnership working and enabling young people with learning disabilities to be actively involved and exercise choice at the time of transition planning as key issues\textsuperscript{168-170}.

The transition from adolescence to adulthood is a time when young persons with learning disabilities and their families are faced with important choices. This is a period in life when young persons with learning disabilities can enjoy new opportunities and challenges, for example in education, employment and relationships. To promote a successful transition, it is crucial that effective supports and services exist.

Studies have documented the pitfalls around this period of transition\textsuperscript{170-172}. Young people with learning disabilities often lose many of their protective relationships and friendships\textsuperscript{173}. Often equivalents do not exist between services for adults and children. This can mean that young people continue to use services for children well into adulthood or have to manage without an appropriate resource. In addition, poor planning, communication and coordination between childrens’ and adult services - sometimes with disputes over provision and resourcing of services - can leave a young person without the services and supports required to maintain their health, well-being and development\textsuperscript{169}.

Active planning and preparation for transition is required. In partnership with young people and their families, support staff and professionals from across agencies have an important contribution to make in raising expectations of what can be achieved at the time of transition.

4.4.3 OLDER PERSONS WITH LEARNING DISABILITIES

People with learning disabilities are living longer than ever before, and older persons with learning disabilities have higher levels of health needs than the general population. This is because they have risk factors for:

- Health needs that can affect the whole population.
- Health needs related to ageing.
- Health needs related to having learning disabilities.

About two-thirds of older people with learning disabilities have an additional mental disorder\textsuperscript{93,174}. This can be any of the full range of mental health needs, including developmental disorders such as attention deficit hyperactivity disorder of adults and autistic spectrum disorders; problem behaviours that have persisted through adult life; mental ill-health either of recent onset or enduring mental ill-health; and acquired dementia.

Dementia is about four times more common in people with learning disabilities\textsuperscript{175-177}. It is particularly common in people with Down’s syndrome, about half of whom will acquire clinical dementia in middle or older age\textsuperscript{178,179}. There are advantages to detecting the onset of dementia as early as possible. This allows access to cognitive-enhancing drugs for which there is some evidence for effectiveness\textsuperscript{180,181}, and also to a range of other biological, psychological, social and developmental approaches designed to improve quality of life and to support carers. The specialist services provided through Community Learning Disabilities Teams can advise on assessment, interventions and supports.

Physical ill-health is also common amongst older persons with learning disabilities, who benefit from assessment and interventions. Some such needs are related to the person’s
underlying learning disabilities; other health needs relate to ageing and are similar to those experienced by older people of average ability. Older persons with learning disabilities have health needs that are higher than age-defined comparison groups without learning disabilities\textsuperscript{10,11,13,95,182-184}. The prevalence of common age-related disorders such as hypertension, stroke and ischaemic heart disease may be similar to that amongst people without learning disabilities. However, the rates of sensory impairments\textsuperscript{11,95,183,185}, thyroid disorders\textsuperscript{11}, obesity\textsuperscript{13}, non-atherosclerotic heart disorders\textsuperscript{10,11}, mobility impairment\textsuperscript{184}, osteoporosis\textsuperscript{13,186} and respiratory problems are higher amongst older persons with learning disabilities. The most prevalent causes of death are different for older persons with learning disabilities compared with the general population.

Older persons with learning disabilities live in a diverse range of settings where they are usually in a minority. Diagnostic overshadowing is a particular issue for the older person – in learning disabilities settings additional health needs are often inappropriately attributed to old age; whereas in old age settings additional health needs are often inappropriately attributed to the person’s underlying learning disabilities. This can result in failure to address needs. Older persons with learning disabilities are unlikely to report symptoms\textsuperscript{184}. There is a strong indication for proactive screening programmes.

Older persons with learning disabilities differ from the older general population and younger people with learning disabilities in usually not having close family supports. Service supports therefore must be robust\textsuperscript{187}.

4.4.4 CARERS
4.4.4.1 FAMILY CARERS
Family carers play a crucial role in the development, health and well-being of persons with learning disabilities. Many persons with learning disabilities receive support from family carers, typically mothers. They need access to information, training and support, and can also make valuable contributions to staff training. Many offer lifelong support to their relative, with 24-hour care, often carried out alone and in a less than ideal environment, with minimal training. It is important to consider the impact that providing care or support can have upon carers’ health and well-being. Studies have demonstrated the positive effects on the well-being of families, and persons with learning disabilities, of short breaks (respite)\textsuperscript{188,189}.

A consistent finding is that families with a child with learning disabilities are at greater risk of socio-economic disadvantage\textsuperscript{103,104}. Other studies have reported increased rates of stress\textsuperscript{190-192} and depression\textsuperscript{193} amongst parents. Many family carers give low priority to their own needs, yet health problems have been demonstrated to be more prevalent in family carers of working age compared with the general population of similar age. In particular, women who are family carers experience depression 3.7 times more commonly and men who are family carers report cardiovascular problems 2.5 times more commonly\textsuperscript{4}. A relationship between depression and caring for a person with problem behaviour has been demonstrated. Both poverty and having a child with learning disabilities experiencing problem behaviours or other psychopathology have a negative impact upon the mental well-being of parents\textsuperscript{103}. Carers of people with multiple physical disabilities also acquire musculoskeletal problems associated with moving and handling and other aspects of physical care. It is important to recognise the needs of the siblings of persons with learning disabilities\textsuperscript{194,195}. They often have
diverse and important roles in the lives of persons with learning disabilities, and there is a need to develop appropriate support and health information for siblings. The independent organisation Down’s Syndrome Scotland has developed material for this purpose.

A growing number of studies have considered the positive impacts reported by parents of children with learning disabilities. In these studies, parents report that bringing up a child with learning disabilities can strengthen relationships and improve the coping abilities of a family.

The needs of families change with time, according to the age of the person with learning disabilities. In particular, parents worry about the ongoing care of their child with the transition into adulthood, and also the time in the future when they will no longer be able to provide care. This brings stresses, and impacts upon health and quality of life when caring for an adult family member with learning disabilities. Forward planning for transition and for older family carers to reduce stress is important. However, studies have shown that only between one third and a half of parents make concrete plans for the future care of an adult with learning disabilities who is living at home.

4.4.4.2 PAID CARERS
A significant proportion of people with learning disabilities living in the community receive support from carers employed by provider organisations. The amount and type of support varies between individuals. Paid carers can have a positive impact upon the health of people with learning disabilities by recognising symptoms or signs of ill-health, facilitating access to services, and promoting healthy lifestyles amongst their clients.

Paid carers require effective and comprehensive training relevant to their area of work before starting to work with clients. Health is an area that should be covered in the training of paid carers. There is very little published research on this area. Carer training on health promotion has been found to influence healthy eating practices of clients. Similarly, the increase in the activity levels of people with learning disabilities resulting from carer training on a model of active support has positive effects on health. Appropriate training has also been shown to have a positive impact on carer knowledge and confidence in supporting people with problem behaviours.

4.4.5 COMMUNICATION
Communication difficulties are prevalent amongst persons with learning disabilities. These include problems with expression, comprehension, and pragmatic communication in social situations. Problems with communication may be related to problem behaviours and can be a significant barrier to accessing appropriate health care.

In considering the communication needs of persons with learning disabilities it is important to recognise that communication is a two way process. Therefore, both partners have the opportunity to consider the process involved and the means by which they can facilitate successful communication. Total Communication embraces these principles. This system emphasises the importance of the context in which communication takes place and modifying the means of communication to the developmental level of the communication partner with learning disabilities. There have been innovative advances in the development
of methods to augment communication with people with learning disabilities, such as intensive interaction and Talking Mats.

Early intervention programmes have been shown to be effective in promoting the development of communication in children with autistic spectrum disorders and learning disabilities. Involvement and training of parents and carers is a key principal in such programmes.

Studies have shown that paid carers of persons with learning disabilities overestimate the comprehension levels of persons with learning disabilities. As a result they use methods of communication and levels of complexity that are mismatched to a person's communication needs. Training programs that encourage carers to look at their own communication skills have been demonstrated to be effective in improving the quality of communication.

### 4.4.6 GASTROINTESTINAL DISORDERS

People with learning disabilities have a high prevalence of gastrointestinal disorders. Gastro-oesophageal reflux disease (G.O.R.D.) is particularly common and frequently overlooked. It has been reported to occur in 48% of people with learning disabilities. A large scale study in the Netherlands found 70% of persons with learning disabilities to have G.O.R.D., if they additionally had one of cerebral palsy, scoliosis, severe / profound learning disabilities, were taking antiepileptic drugs, had dental erosions or a history of haematemesis or rumination. G.O.R.D. causes pain that the person may not be able to describe and which conceivably may contribute to sleep disturbance or problem behaviours. It can also lead to anaemia and the person may not be able to report the malaise and tiredness which anaemia can cause. People with learning disabilities have an increased risk of oesophageal cancer compared with the general population and the likely cause of this is the high prevalence of untreated G.O.R.D. in the population. Once suspected, G.O.R.D. is highly treatable – proton pump inhibitor drugs are highly effective in both adults and children. Detection of G.O.R.D. requires 24 hour oesophageal pHmetry, which in practice is usually difficult to undergo: a proportion of cases will be missed on single oesophagoscopy. Clinicians and carers require a high index of suspicion for G.O.R.D. There is justification in some cases for a treatment trial of proton pump inhibitor without prior endoscopy. This differs from protocols developed for the general population.

Infection with Helicobacter pylori is endemic among the population with learning disabilities, and is particularly associated with group situations e.g. living in a learning disabilities hospital now or in the past, group homes or shared-tenancies, respite care units, adult day centres. This finding has been demonstrated in many countries, including the U.K., Netherlands, Australia, Russia. Its significance, however, is uncertain. Some persons find the diagnostic breath-test hard to use. Eradication therapy with antibiotic drugs can sometimes cause complications. Helicobacter pylori infection is associated with peptic ulceration and pain in the general population, and eradication is recommended if symptoms are present. However, it is important to remember that some persons with learning disabilities are unable to report pain and the first presentation of peptic ulceration in this population can be perforation. It has been postulated that the high prevalence of infection with Helicobacter pylori in people with learning disabilities leads to a higher prevalence of gastric carcinoma.
REVIEW OF RESEARCH

Reinfection or recrudescence after eradication therapy has been found to be seven times higher than for the general population, at 7% per year\(^{\text{232}}\), suggesting that retesting at a later date may be necessary, if eradication is considered necessary.

Constipation is a significant problem for many persons with learning disabilities. One study identified 69% of people living in an institution to be constipated\(^{\text{233}}\). Particularly at risk for constipation were persons who were non-ambulatory, had cerebral palsy, food refusal, severe / profound learning disabilities or who were taking antiepileptic drugs or prescriptions for other gastrointestinal disorders.

Swallowing is problematic for some persons with learning disabilities. This is considered further under the Chapter on nutrition.

4.4.7 MENTAL ILL-HEALTH AND PROBLEM BEHAVIOURS

The prevalence of mental ill-health / problem behaviours is higher for adults with learning disabilities than for other people, with a lifetime prevalence of about 50%\(^{\text{9,12,234}}\). This is because of the biological, psychological, social and developmental predisposing factors, all of which are in excess of those experienced by the general population. Some genetic causes of learning disabilities are associated with particular types of mental ill-health (a “behavioural phenotype”) e.g. Down’s syndrome is associated with depression\(^{\text{235}}\) and dementia\(^{\text{216}}\); Prader-Willi Syndrome is associated with an affective psychosis\(^{\text{237,238}}\); velo-cardio-facial syndrome is associated with psychosis\(^{\text{239}}\). An overview of the associations between genetic and psychiatric disorders amongst people with learning disabilities has recently been reported\(^{\text{240}}\) with the proposed term “psychiatric phenotype”. Children and young people with learning disabilities are also at a higher risk of experiencing mental ill-health than are other children\(^{\text{148-150,152-158}}\), yet a recent, UK-wide enquiry found that there was a significant lack of services for children with learning disabilities and mental ill-health\(^{\text{161}}\).

People with learning disabilities may experience the full range of problems that are seen in the general population, plus some additional types that are rare in the general population. Examples include schizophrenia, which occurs about three times more commonly\(^{\text{241,242}}\), depression\(^{\text{243,244}}\), severe anxiety disorders\(^{\text{245}}\), delirium\(^{\text{246}}\) and dementia which is more common in people with learning disabilities than in the general population\(^{\text{177}}\). Attention Deficit Hyperactivity Disorder (ADHD) occurs commonly in children and adults with learning disabilities and is largely overlooked and under-managed\(^{\text{247}}\). However, controversy exists on the reliability of diagnosing ADHD in persons with learning disabilities, and the utility of existing diagnostic criteria. Eating disorders are common and include a wide range of abnormal eating behaviours and feeding disorders not prevalent in the general population\(^{\text{248}}\). Severity of learning disabilities has a pathoplastic effect upon the psychopathology found within mental ill-health\(^{\text{249}}\). For that reason, standard rating scales and classificatory systems of mental ill-health developed for use with the general population lack validity for persons with more severe levels of learning disabilities. DC-LD has recently been published, and provides a classificatory system for mental disorders for use with adults with moderate to profound learning disabilities\(^{\text{250}}\). Its usage was developed to be complementary to DCR (ICD-10)\(^{\text{251}}\). The prevalence of mental ill-health is probably higher at lower ability levels\(^{\text{12,175,252,253}}\).
Little is known regarding the long-term outcomes of mental ill-health in adults with learning disabilities. Positive outcomes have been reported for adults with Down’s syndrome who experience depression\(^2^{34}\). More research is needed to understand the vulnerability factors and protective factors for mental ill-health in persons with learning disabilities.

Communication needs and lack of awareness by paid carers\(^93\) and professionals can lead to mental ill-health remaining undiagnosed, and therefore unmanaged, for long periods. Diagnostic overshadowing contributes to this\(^2^{55},2^{56}\). This refers to the phenomenon whereby debilitating emotional / psychological problems are assumed to be less important than they actually are, because of the context of the person’s learning disabilities. In view of its high prevalence, mental ill-health should always be considered as a possible cause of any change in the behaviour of a person with learning disabilities.

Problem behaviours are experienced by about 15% of people with learning disabilities although higher rates are reported if problem behaviours occurring as a symptom of mental ill-health are included\(^2^{12},2^{33},2^{37},2^{58}\). Variations between prevalence studies is explained by the definitions and methodologies used in the studies. Problem behaviours are persistent over time\(^2^{59},2^{60}\) and have significant negative impacts upon individuals and their families. Some genetic causes of learning disabilities are specifically associated with particular problem behaviours\(^2^{40}\), such as the skin picking in Prader-Willi syndrome, self injury in Smith-Magenis syndrome\(^2^{61}\) and Lesch- Nyhan syndrome and impulsivity in Angelman syndrome\(^2^{62}\). Other genetic causes such as Down’s syndrome are associated with a probable lower level of problem behaviours than for persons with learning disabilities of other causes\(^2^{63}\).

### 4.4.7.1 FORENSIC NEEDS

Several literature reviews have attempted to determine whether the rate of offending behaviour is higher amongst people with learning disabilities compared with the general population\(^2^{64}-2^{66}\). These reviews highlight the difficulties involved in research in this area, and to date there is not yet a reliable answer to this question. Several studies have found that severe social disadvantage is a risk factor for offending behaviour amongst people with learning disabilities\(^2^{67},2^{69}\).

People with learning disabilities are vulnerable within the criminal justice system\(^2^{70},2^{71}\). During interviews they are at risk of providing answers to please the interviewers (acquiescence) or can be led into providing particular information (suggestibility)\(^2^{72}\). Therefore, they are at risk of providing false confessions in order to bring the interview procedure to an end\(^2^{23},2^{74}\). As a safeguard against these risks, there needs to be early identification of people with learning disabilities by staff working within the criminal justice system and provision of supports such as an appropriate adult during the interview process.

There is a growing consensus that research should move away from prevalence studies\(^2^{66},2^{75},2^{76}\) to developing and evaluating effective interventions and services for this group. A wide range of treatment models employing psychological methods for the treatment of sexual offenders with learning disabilities have been described\(^2^{77}\), although randomised-controlled trials of the models of treatment and service provision are needed.
4.4.7.2 INTERVENTIONS
There are recognised difficulties in researching the effectiveness of interventions for people with mental ill-health, problem behaviour or forensic needs. The need to develop evidence-based practice requires innovative strategies to meet these challenges.

4.4.7.2.1 Psychological interventions
In the past, psychological interventions were used to help support persons with a wide range of problem behaviours, including self-injurious behaviour, physically aggressive behaviour and destructive behaviours. As research has delineated the complexity of each of these, intervention studies have increasingly been more specifically focussed, for example on the use of anger management to support persons with problems with aggression. Interventions adopting cognitive methods have gradually been incorporated into established behavioural methods of intervention.

There is considerable evidence for the effectiveness of behavioural interventions to help support persons with aggressive behaviours. A more recent review of a type of behavioural treatment called non-contingent reinforcement suggested there was evidence for its effectiveness in the treatment of aggression. Models of aggression of relevance to people with learning disabilities incorporating cognitive factors are at an early stage of development. There is some optimism for the success of treatment methods for anger informed by cognitive theories.

There is a growing literature on the use of psychological interventions for anger management in people with learning disabilities, particularly group interventions. A small randomised-controlled trial of a group intervention found it to be beneficial. All participants in the treatment group demonstrated further improvements over a three-month follow-up period. Additionally, psychological interventions have been found to be effective in the treatment of sleep disorders, bereavement and self-injurious behaviours. Given the success of psychological interventions for the treatment of mental ill-health for the general population, there have been surprisingly few studies examining their effectiveness for persons with learning disabilities and mental ill-health.

There is evidence for the effectiveness of psychodynamic models of psychotherapy for persons with learning disabilities and additional mental disorders although more studies are required.

4.4.7.2.2 Pharmacotherapy
Between 20 and 50% of people with learning disabilities are found to be prescribed psychotropic medication depending upon the population studied. The reason for its use is often unclear and sometimes it is used in the management of problems for which there is little reliable evidence of effectiveness due to lack of research. One study reported that 68% of paid carers felt they had not received sufficient training on the use of medication by clients. As people with learning disabilities experience high rates of mental ill-health there is a need to develop evidence-based prescribing.

A systematic review found that the effectiveness of antipsychotic medication in the treatment of schizophrenia in people with learning disabilities has not conclusively been studied.
There have been several open-label studies of anti-psychotic use that have included people with learning disabilities and schizophrenia but randomised-controlled trials are required.

The use of antipsychotic medication for the management of problem behaviours is controversial. A systematic review found its effectiveness has not conclusively been studied. However, several randomised-controlled trials have been published supporting the use of antipsychotics in the management of aggression and problem behaviours in children, adults or in people with autistic spectrum disorders. Many participants in these studies experienced significant side effects including weight gain and sedation.

Concerns about the appropriateness of prescription of antipsychotic drugs for people with learning disabilities have frequently been raised. Some research reports the outcomes of programmes aimed at the gradual withdrawal of antipsychotic drugs. Whilst a few individuals were successfully withdrawn from drugs in these programmes, others experienced the onset of significant problems and ill-health during the attempt. Problems occurred both for people prescribed antipsychotic drugs for either mental ill-health or to manage problem behaviours, and problems were more common for persons with more severe levels of learning disabilities.

Antidepressant drugs have been used in the treatment of depression, stereotypies, self-injurious behaviour and problems associated with autistic spectrum disorders. Randomised-controlled studies are required.

Acetylcholinesterase inhibitors for the treatment of dementia in people with Down’s syndrome may be effective. Naltrexone, an opiate antagonist, has been advocated for the treatment of self-injurious behaviour, although studies do not support its efficacy. There have been mixed results on its use by people with autistic spectrum disorders. Anti-libidinal medication have been used for the treatment of sex offenders but robust evidence of effectiveness is lacking.

4.4.8 EPILEPSY
The prevalence of epilepsy among people with learning disabilities is around 25% in comparison to 0.4%-1% in the general population. The prevalence is greater among people with more severe learning disabilities. In all age groups, seizure patterns are more likely to be multiple and complex when compared with the general population and children with learning disabilities and epilepsy are more likely to experience intractable seizures. This can significantly affect quality of life. Chronic epilepsy may also be associated with psychiatric, behavioural and socio-economic sequelae and with increased risk of hospitalisation and failures of community care. Seizures can be the cause of fractures and soft tissue injuries, and both epilepsy and antiepileptic drugs can affect learning and concentration. Epilepsy can also be a cause of mortality amongst people with learning disabilities. There is an increased risk of sudden unexpected death in epilepsy.

As epilepsy and mental ill-health are both so prevalent among people with learning disabilities (at about 25% and 50%), they often co-exist. Additionally, it is possible that some persons with epilepsy are more likely to experience mental ill-health. Some people with learning disabilities who have epilepsy also experience non-epileptic seizures which may have
a psychological origin\textsuperscript{330,331}. This comorbidity is important, as some types of seizures, mental ill-health and anti-epileptic drug side effects can appear to have similar presentations to non-specialist health professionals, and require accurate diagnosis, as the interventions that will be effective obviously differ. Anti-epileptic drugs and drugs used as treatments for mental ill-health can interact, and drugs used for mental ill-health can affect seizure control\textsuperscript{330}. The person with both types of health needs therefore requires carefully co-ordinated care, with a designated health professional responsible for leading this.

Specialist nurses trained in epilepsy care for persons with learning disabilities have an important contribution to make to the health care provision for this group\textsuperscript{332}. Care needs to encompass not only the balance between optimising reduced seizure frequency and seizure-related adverse events against drug side effects, but educational approaches, provision of information, risk management, and individualised plans for use of rescue medication, administration of which can be life saving. Family carers of persons with epilepsy and all paid carers, whomever their employer, should be trained in the appropriate use and administration of rescue medication if they work with people with learning disabilities who have epilepsy. Clinical guidelines for the management of epilepsy in adults with learning disabilities have been internationally produced\textsuperscript{333} and validated tools to measure psychosocial factors are available\textsuperscript{125}. Epilepsy can have a significant impact on family carers\textsuperscript{334}.

\textbf{4.4.9 AUTISTIC SPECTRUM DISORDERS}

The prevalence of autistic spectrum disorders in children is estimated as 60 per 10,000 children. Of these, 20 per 10,000 will have autistic disorder, and would be likely to have associated learning disabilities, and 40 per 10,000 have other autistic spectrum disorders not associated with learning disabilities, such as Asperger’s syndrome\textsuperscript{51}. There have been no studies that have measured the prevalence of autistic spectrum disorders in adults.

People with autistic spectrum disorders face the same barriers to accessing health care as other people with learning disabilities. They often have additional health needs related to communication\textsuperscript{333}, epilepsy\textsuperscript{336}, mental ill-health\textsuperscript{337}, problem behaviours and sleep disorders\textsuperscript{338}. Studies have reported that 10-30\% of people using learning disabilities services for adults have an autistic spectrum disorder\textsuperscript{339,340}.

The needs of persons with autistic spectrum disorder have been comprehensively reviewed in the \textit{Autistic Spectrum Disorder Needs Assessment}\textsuperscript{341}. This made a number of recommendations to improve services for people with autistic spectrum disorders which were accepted in principle by the Scottish Executive. A reference group has been established to take the work forward, and is working to deliver an information strategy, to improve consistency of assessment and diagnosis, to conduct further research, and develop training.

\textbf{4.4.10 SENSORY IMPAIRMENTS}

There is an increased prevalence of sensory impairments within the learning disabilities population compared to the general population\textsuperscript{37,13,95,101,183,185,342-344}. The reported prevalence of hearing impairment varies from 12.3\% to 47\%. For visual impairment reported prevalence varies from 19\% to 63\%. The variations in these figures are due to the use of different definitions, methodologies and study populations. In particular, some studies have relied on carers’ opinion as to whether or not the person with learning disabilities has sensory impairments.
impairment which leads to under-detection, whereas other studies have actually tested vision and hearing.

Sensory impairments may be present from birth, or may be acquired later in life. Many of the genetic syndromes which cause learning disabilities such as Down’s syndrome or mitochondrial disorders, are specifically associated with sensory impairments, through causing e.g. congenital cataracts, keratoconus, retinal abnormalities, optic atrophy, structural abnormalities of the eye, sensorineural damage, or structural abnormalities of the inner ear. In addition to genetic causes, ante-natal infections can also cause sensory impairments from birth e.g. congenital rubella, as can cranial nerve lesions which may form part of a profile of neurological damage associated with learning disabilities for some persons. Sensory impairments can also be acquired later in life, as part of the ageing process, including development of cataracts, degenerative corneal changes, presbyopia and sensorineural impairment. Some persons appear to be at accelerated risk of acquiring such changes, particularly persons with Down’s syndrome. Some causes of sensory impairments would be easily corrected, however the need is frequently not identified and therefore remains unmet e.g. refractive errors and impacted ear wax, which occur commonly in this population. A person with limited verbal communication skills may have difficulty in conveying a deterioration in hearing or vision and a person with a long-standing uncorrected refractive error may not be aware of the potential for its improvement. It has repeatedly been demonstrated that hearing and visual impairments are frequently unrecognised and are under-reported by paid carers. A large scale study in the Netherlands demonstrated that 41% of people had prescribed spectacles at the time of the research assessment, but these were inadequate for 10%. Of the 59% who did not have spectacles, 19% were assessed as requiring them. There was a higher level of unmet need among older persons in the study: only 45% of persons aged over 50 years who would benefit from spectacles had been prescribed them. Similar large scale work from Denmark has identified the most prevalent cause of visual impairment to be uncorrected ametropia. It is possible to assess vision and hearing in persons with profound learning disabilities, provided there is access to special equipment and specialist skills and the evidence points to the need for screening programmes. Impaired hearing impacts upon communication and development, in addition to affecting quality of life in other ways. These are indicators for sensory assessments early in life, and at repeated intervals during adult life.

Cerebral visual impairment is at particular risk of under-reporting by paid carers. The pattern of impairment differs from that seen in age-related acquired visual impairment, with colour vision well developed, normal or subnormal visual acuity, but with crowding and problems with fast eye movements and visual field defect. Hence the person with cerebral visual impairment may have a substantial impairment affecting their functioning and difficulty making sense of what they see, but with carers inadvertently attributing this to poor attention or motivation. Cerebral visual impairment is associated with cerebral palsy, but can have other causes. Early detection and intervention is beneficial.

### 4.4.11 Respiratory Disease

Diseases involving the respiratory system are consistently shown to be the commonest cause of death for people with learning disabilities. This differs from findings for the general population.
population. In particular, pneumonia and aspiration have a higher prevalence than in the general population. This may be related to swallowing and feeding problems and G.O.R.D. particularly among people with profound learning and multiple physical disabilities or cerebral palsy. Other groups are also at high risk of pneumonia: persons with Down’s syndrome have a genetic predisposition due to mucociliary anomalies, congenital heart disease, ENT problems and immunological factors. Persons with Down’s syndrome are also more likely to be mouth-breathe rs. General care and environmental factors may also be relevant. A lower risk of lung cancer amongst people with learning disabilities has been reported. This may be due to a lower incidence in view of lower levels of smoking and occupational causes, and the shorter lifespan of people with learning disabilities can contribute, when comparing non age-adjusted data.

4.4.12 CARDIOVASCULAR DISEASE
Congenital heart disease is common in persons with learning disabilities, and is genetically determined. For example, persons with Down’s syndrome have a high prevalence of septal defects, Fallot’s tetralogy, persistent ductus arteriosus, mitral valve prolapse, aortic insufficiency and pulmonary hypertension. It is essential that all babies born with Down’s syndrome are screened for heart disease, so that the appropriate interventions are offered. The provision of surgery for infants with Down’s syndrome and congenital heart disease is the most significant factor to have led to increased lifespan for this population.

Within the Scottish general population, the two most common causes of death are cancer and ischaemic heart disease. This profile differs from that seen amongst people with learning disabilities. Since 1981, the proportion of deaths in the general population caused by ischaemic heart disease has fallen from 29 to 21%. It is not known if this falling trend has occurred among people with learning disabilities, but it seems unlikely, due to changing lifestyles and barriers accessing health care, health promotion and health screening. It is possible that deaths due to ischaemic heart disease are rising for people with learning disabilities.

Cardiovascular disease has been reported to be the second most common cause of death in people with learning disabilities. Much of this relates to congenital heart disease, but as people with learning disabilities live longer they are at risk of acquired cardiovascular disease. People with Down’s syndrome have particularly low rates of atheroma and typically have low blood pressure, but other people with learning disabilities are not protected in this way. Lifestyle choices have a significant bearing on cardiovascular disease (e.g. nutritional choices, obesity and smoking) in addition to age and genetics. Hypertension is a risk factor for stroke, vascular dementia and myocardial infarction. Access to health promotion events, accessible materials and well-person clinics is important for people with learning disabilities.

4.4.13 CANCER
Cancer is a common cause of death amongst people with learning disabilities. However, people with learning disabilities are suggested to experience a different pattern of malignancies compared with the general population. In particular, there appears to be reduced rates of prostate, lung and urinary tract malignancies but an increased risk of tumours of the oesophagus, stomach and gallbladder. Data from the Netherlands demonstrates that the standardised mortality ratio for oesophageal cancer is 2.9 for people with learning disabilities. The increased prevalence of gastro-oesophageal reflux disease...
amongst individuals with learning disabilities may in part explain the increased rates of upper gastro-intestinal malignancies. There is a higher risk of leukaemia amongst people with Down’s syndrome\textsuperscript{162,163}, incidence is 10-20 times higher than in the general population and typically presents during the first four years of life. It has also been suggested that people with Prader-Willi syndrome have an increased risk for myeloid leukaemia but not other cancers, compared with the general population\textsuperscript{164}.

Since 1995, cancer has been the leading cause of death among the Scottish general population: the proportion of deaths attributed to cancer has risen from 22\% in 1981 to 26\%\textsuperscript{34}. Cancer of the trachea, bronchus and lung is the leading cancer for both men and women (increasing in prevalence among women, but decreasing among men) with the second most common being prostate in men and breast in women\textsuperscript{34}. This pattern is not seen in people with learning disabilities who experience premature death from respiratory disease and congenital heart disease.

4.4.14 METABOLIC AND ENDOCRINE DISORDERS

Persons with learning disabilities have increased prevalence of osteoporosis\textsuperscript{186,165} and lower bone density than the general population\textsuperscript{166,167}. There are several contributory factors, including impaired mobility (lack of weight-bearing exercise), genetic factors where some learning disabilities syndromes are associated with a failure of production of sex-hormones and delayed or lack of puberty, the earlier-than-average age at menopause for women with learning disabilities, particularly women with Down’s syndrome\textsuperscript{168-170}, and poor nutrition and underweight. Some antiepileptic and antipsychotic drugs can also affect bone architecture\textsuperscript{171,172}. Osteoporosis is asymptomatic, but predisposes to fracture of bones. Fractures can occur with only minor injury and can be multiple. This can lead to pain, progressive deformity, loss of function and even death. Detection / prevention of osteoporosis is important, and there are interventions that can prevent or delay further bone loss, including nutrition and exercise, prescribed hormones or drugs specifically for the treatment of osteoporosis. Methods of lifting and handling are important, and occasionally there is a role for orthotics.

Hypothyroidism occurs commonly in people with Down’s syndrome and its prevalence increases with age\textsuperscript{173-175}. An association has been found between carrier status for hepatitis B surface antigen and thyroid disorder in adults with Down’s syndrome\textsuperscript{176}. Hypothyroidism can present insidiously with lethargy, loss of skills and malaise, which could pass undetected until reaching a late stage in the disease. Treatment can be associated with improved adaptive functioning\textsuperscript{177}. Hypothyroidism is easy to test for, and once detected is easy to treat: annual screening is recommended for persons with Down’s syndrome.

Diabetes mellitus has been reported to occur commonly in people with Prader-Willi syndrome and may be due to a failure to manage over-eating, resulting in obesity\textsuperscript{178}. The high level of overweight amongst persons with learning disabilities is likely to be associated with an increased risk of diabetes. Diabetes is associated with certain mitochondrial disorders and hence there is a putative link with learning disabilities: whether or not this is the case is yet to be demonstrated. Specific associations between certain genetic causes of learning disabilities and other
endocrine disorders additionally occur e.g. hypopituitarism with CHARGE association; hypogonadal function with Turner’s syndrome and Down’s syndrome; reduced growth hormone secretory function with Prader-Willi syndrome. Some drug treatments which are commonly used by people with learning disabilities can cause endocrinological side effects in a small proportion of people e.g. the syndrome of inappropriate antidiuretic hormone with antiepileptic drugs and diabetes with antipsychotic drugs such as clozapine.

4.4.15 ORAL AND DENTAL HEALTH
Most persons with learning disabilities have dental disease, which occurs much more frequently than in the general population. Additionally, persons with learning disabilities have high levels of unmet oral health needs. They have a high prevalence of gum disease, untreated dental caries and missing teeth. G.O.R.D. is contributory to the development of dental erosions. Anticholinergic medication can also contribute to dental caries by inhibiting saliva production. The role of and training needs of paid and family carers to support oral health have been highlighted. Persons with learning disabilities are more likely to receive their dental health care from specialist community dental services, not within mainstream dental services, and local survey has demonstrated a high level of satisfaction with specialist dental services. Oral and dental health is an important area for health promotion.

4.4.16 NUTRITION
Individuals with learning disabilities are at increased risk of swallowing and feeding problems. These are significant risk factors for choking and secondary complications. This is often associated with profound learning and multiple physical disabilities, cerebral palsy or particular causes of learning disabilities, such as Down’s syndrome or Rett syndrome. There is a need for detailed, multidisciplinary assessment of swallowing and feeding problems to minimise secondary conditions such as dehydration, aspiration and respiratory infections.

Obesity is recognised as an important health issue for persons with learning disabilities. Studies have demonstrated higher rates of obesity and overweight in comparison to persons who do not have learning disabilities. The reported prevalence of obesity varies from 10 - 56% depending upon the population studied, and methodology, with higher prevalence in women than men.

The importance of obesity as an independent risk factor for cardiovascular disease, stroke disease, type II diabetes and various cancers is well recognised. Although most of these studies have not specifically examined groups of people with learning disabilities, there is evidence emerging of a link between obesity and cardiovascular disease for persons with learning disabilities.

There are multiple reasons for the increased prevalence of obesity amongst people with learning disabilities. Some genetic causes of learning disabilities, such as Prader-Willi syndrome, are also associated with obesity. In addition, many people with learning disabilities have poor nutritional practices, low levels of physical activity and significant barriers to exercise and recreation opportunities.

A significant proportion of people with learning disabilities are underweight to the extent that...
it affects their health and life-expectancy. Surveys of weight status have reported the prevalence of underweight as between 10-43%. The prevalence of underweight increases with more severe levels of learning disabilities and can be related to the presence of cerebral palsy or swallowing difficulties. Inadequate fluid intake is also a significant health need for some persons with learning disabilities.

Individuals who are underweight or obese have higher morbidity and mortality rates. Therefore, proactive screening of weight and nutritional status is recommended.

4.4.17 MOBILITY, BALANCE, CO-ORDINATION AND FOOTCARE
There are high rates of mobility problems amongst persons with learning disabilities. Mobility problems are associated with the presence of cerebral palsy and more severe levels of learning disabilities. The rate also increase with age; 29% of people over 55 have mobility problems compared with 58% of people over 75. Antipsychotic and other medications can impair mobility and contribute to falls through postural hypotension. As well as the impact upon social functioning, mobility problems can lead to secondary problems such as respiratory diseases, osteoporosis, chronic constipation, gastro-oesophageal reflux disease or pressure sores. Furthermore, severe mobility problems have been shown to have a negative impact upon mortality. In order to maximise quality of life and prevent secondary morbidity, children with learning disabilities and mobility problems or people whose mobility changes require detailed assessment and management by specialist services. Access to specialist physiotherapy, specialist occupational therapy and wheelchair services is essential.

Postural management is of particular value for people with multiple physical disabilities. It plays a significant role in prevention of deformities, joint problems, breathing or feeding difficulties, pain, discomfort and major difficulties in moving and handling. Some areas of Scotland provide specialist postural management clinics, where personal postural care pathways are developed.

People with learning disabilities have a higher prevalence of foot and toenail problems requiring the interventions of podiatrists and related specialities. Some genetic causes of learning disabilities are associated with foot anomalies, such as rocker-bottom feet for children with Edward’s syndrome, and so access to specialist footwear is required. Community studies have found that 25-40% of adults with learning disabilities have foot problems. If left untreated these can contribute to the high incidence of falls amongst people with learning disabilities. Toenail problems can cause both pain and significantly impede mobility if not managed appropriately. Frequent falls, problems with manual dexterity, ability level, problem behaviours and problems managing personal hygiene may all contribute to problems with foot and toenail care. Some genetic syndromes, such as Smith-Magenis syndrome, are associated with self-injury including toenail avulsion.

4.4.18 SLEEP DISORDERS
There is evidence that people with learning disabilities have sleep problems like everyone else. That means that more than 10% of adults have a sleep disorder, rising to 20% in later life. However, they have special problems in self-reporting these difficulties and they may only come to light if carers are affected. This is a particular issue where disorders of excessive sleepiness (D.O.E.S.), such as hypersomnia, are concerned because these disorders pose...
relatively fewer management difficulties, compared to disorders of initiating and maintaining sleep (D.I.M.S.), such as insomnia, where carer sleep is disrupted. Research suggests that in addition to the above, people with learning disabilities are at particular risk of developing circadian disorders of sleep\textsuperscript{414-416} where the endogenous sleep-wake rhythm (the body clock) is misaligned with local time. Such problems can result in either D.I.M.S. or D.O.E.S. or both, and can be extremely disruptive of quality of life. Sleep-related breathing disorders are also common in particular populations e.g. people with Down’s syndrome\textsuperscript{413}.

It is important that potential sleep problems are routinely and adequately screened, and that referral is made for expert assessment and advice where persisting sleep problems are suspected. The relationship between sleep-wake problems, behaviour and mental health should be considered in diagnostic formulation and in treatment planning. Evidence-based non-pharmacological interventions for sleep disorders (behavioural treatments, sleep rescheduling, light therapy) are preferable and hypnotic drugs should only be used for short-term insomnia, in courses no longer than 10 days\textsuperscript{288,417,418}. Appropriate interventions for sleep disorders will also be important for the design of support packages as sleep disorders may restrict a person’s life and increase their need for care.

4.4.19 HAEMATOLOGICAL DISORDERS
Some genetic causes of learning disabilities are specifically associated with blood disorders, such as the multiple coagulation anomalies which occur in Cohen syndrome. In addition to an increased risk for leukaemia compared with the general population, people with Down’s syndrome have an increased risk for transient leukaemoid reactions\textsuperscript{163}: there is extensive literature on this topic. White cell counts are lower in children with Down’s syndrome. Mean corpuscular volume tends to be elevated from infancy onwards in people with Down’s syndrome\textsuperscript{419,420}; this may relate to differences in cell membranes as opposed to deficiency of folate or vitamin B12.

People with learning disabilities often require drug treatments for health needs. A small proportion of people experience blood dyscrasias as a side-effect to certain drugs e.g. antiepileptic drugs can cause thrombocytopenia and rarely aplastic anaemia\textsuperscript{421-425}. Some antipsychotic drugs, particularly clozapine, can cause agranulocytosis\textsuperscript{230}.

Some haematological disorders can be nutritionally determined e.g. macrocytic and microcytic anaemias. Gastrointestinal disorders such as G.O.R.D. and peptic ulceration related to helicobacter pylori can also cause microcytic anaemia, as can other causes of blood loss such as menorrhagia. Duration of menses has been shown to be negatively correlated to serum ferritin in women with learning disabilities\textsuperscript{426}.

4.4.20 INFECTION
Infections occur commonly in people with learning disabilities. Respiratory infections are particularly common in persons with Down’s syndrome\textsuperscript{151} and Prader-Willi syndrome\textsuperscript{178} and persons with profound learning and multiple physical disabilities, due to G.O.R.D. and swallowing problems which can lead to aspiration\textsuperscript{427}. Urinary tract infection has a reported prevalence of 1.7% and 5.6% in men and women with learning disabilities, with highest prevalence among women aged 55-64 years\textsuperscript{428}. Persons with self-injurious behaviour are at risk of infection following soft tissue injury. Group care settings have been associated with
transmission of cytomegalovirus infection, pertussis, intestinal parasitic infections, hepatitis A and hepatitis B, whereas studies regarding hepatitis C provide inconclusive results.429-438.

4.4.21 SEXUAL HEALTH
The sexual health needs and the sexuality of people with learning disabilities have largely been overlooked. There is an increasing awareness that persons with learning disabilities have similar sexual health needs to all other people.439,440.

As discussed in Chapter 4.5.23 people with learning disabilities are vulnerable and may be subject to sexual abuse. There are important issues regarding protection and the capacity of people with learning disabilities to consent to sexual intercourse. However, as in all life domains, it is important for persons with learning disabilities to have opportunities to discuss, make choices about and enjoy their sexuality.442.

Persons with learning disabilities need accessible information about sexuality and sexual health to enable informed choices. Initiatives providing sex education for persons with learning disabilities and offering training for carers have been developed and evaluated. It has been advocated that sex education can help the development of a positive self-esteem for persons with learning disabilities.442.

Women with learning disabilities have additional sexual and reproductive health needs. Menstruation and the menopause are fundamental issues in the lives of women.445. There are accessible materials available to facilitate discussion on the need for breast and cervical screening for women. There has been little research involving women with learning disabilities who experience pregnancy and childbirth. Greater focus has been placed on supporting both men and women with learning disabilities in their role as parents.447,448.

Persons with learning disabilities are sexually active through choice and/or abuse, and so are at risk of sexually transmitted diseases. A study from USA reports that persons with learning disabilities who are infected with HIV are more likely to be female, black and have IV drug use as the cause compared with other people with HIV.449.

4.4.22 ACCIDENTS
High rates of accidents and injuries occur amongst people with learning disabilities. In particular, injuries due to falls are common. This may be attributable to increased rates of epilepsy, psychopathology, medication use, sensory and neurological impairments and balance problems. Some injuries are attributable to problem behaviours, such as pica, self-injury and destructive behaviours. In Denmark, accidents have been reported to be a more common cause of death than for the general population. The Disabilities Death Review Team in New South Wales, Australia found that deaths due to drowning, falls and self-harm occurred more commonly than in the general population; this has led to the introduction of preventative initiatives. Appropriate risk assessment and management could significantly reduce the morbidity from accidents and injuries.

4.4.23 ADVERSE EXPERIENCES AND ABUSE
Background information and life history information of adults with learning disabilities and limited verbal communication skills is often lost and unavailable and so adverse experiences
from the past may be overlooked\textsuperscript{452}. People with learning disabilities are at greater risk of sexual abuse than the general population, but the lack of accurate prevalence data has been highlighted\textsuperscript{453-455}. Childhood sexual abuse has been reported to be experienced by 39-68\% of girls and 16-30\% of boys with learning disabilities\textsuperscript{456}, and another study reported abuse to be 1.7 times higher in children with disabilities compared with children who do not have disabilities\textsuperscript{457}. Adults with learning disabilities are also at high risk of sexual abuse\textsuperscript{458}. Communication needs impact on the ability of persons with learning disabilities to disclose abuse. Sexual abuse is thought to be a cause of psychopathology, although the existing literature is limited\textsuperscript{459,460}.

Physical abuse, financial abuse, neglect, exploitation, discrimination, bullying and harassment are also experienced more commonly by people with learning disabilities than the general population\textsuperscript{461,462}. It is important to recognise the potential for abuse within support services, including the “corruption of care”\textsuperscript{463,464}. The Care Commission and National Care Standards provide helpful guidelines to prevent this. Aspects of practice and service delivery can contribute to increase the risk of abuse, whilst appropriate design and delivery of services with monitoring and evaluation can increase protection\textsuperscript{465,466}. An association has been demonstrated between adverse childhood experiences and adult personality disorder in adults with learning disabilities\textsuperscript{467}. A high proportion of adults with learning disabilities spent all or part of their childhood living outwith a family home, sometimes with restricted opportunities for individual attention and positive-parenting experiences. It is possible that this has a longer-term influence on development of personality characteristics, coping styles, confidence, esteem and expectations. Life events experienced by persons with learning disabilities often occur in multiples e.g. the death of a person’s mother may also trigger major changes in her / his home and social supports. Bereavement is associated with mental ill-health in adults with learning disabilities\textsuperscript{468,469}.

\textbf{4.4.24 HEALTH PROMOTION AND HEALTHY LIFESTYLES}

There is an increasing recognition of the importance of health promotion for people with learning disabilities\textsuperscript{398,399}. There is evidence for health promotion activity around nutritional practices, levels of physical fitness and activity, smoking, alcohol use, substance misuse, sexual health, immunisation, and support networks. However, there needs to be an additional emphasis beyond focussing on specific health promotion needs. People with learning disabilities experience a lack of opportunity to exercise self-determination across all aspects of their lives. This includes choices that directly affect health and well-being, such as eating or activity patterns\textsuperscript{470}. Therefore, a key focus of health promotion should be enabling choice for people with learning disabilities, as initiatives promoting empowerment and enabling choice will lead to health improvement. Accessible written materials to facilitate health promotion activities with people with learning disabilities are available\textsuperscript{471}. Family carers and paid carers have an important role to play and health promotional training should be available for carers as well as training and accessible resources for use with persons with learning disabilities.

As stated in the Chapter on nutrition, there are high rates of obesity amongst people with learning disabilities. People with learning disabilities have been found to have poor nutritional practices\textsuperscript{398,472} similar to those described in people without learning disabilities. Accessible nutrition education programmes for people with learning disabilities have been advocated\textsuperscript{197}. However, lack of nutritional knowledge was not found to be related to the presence of
obesity in adults with learning disabilities. Indeed, the description of the importance of social factors, such as living environment, friendships and social activity in health promotion emphasises the need to consider the needs of an individual within the wider context of their life. The provision of effective health promotion education to support staff can produce positive effects upon the nutritional practices of people with learning disabilities.

In relation to obesity and cardiovascular fitness, studies have found that people with learning disabilities have levels of physical activity below those recommended for health promotion. There are recognised barriers to exercise and recreation opportunities for people with learning disabilities. Furthermore, rather than prescribing activity programmes, providing a range of opportunities and enabling people to make positive choices about their own lives may be a more successful strategy in improving physical activity levels.

People with learning disabilities are less likely to smoke or drink alcohol than people without learning disabilities. Nonetheless, some persons with learning disabilities do smoke and drink to levels that are harmful to their health. Persons living with the least support are more likely to smoke and drink which highlights the importance of providing accessible health promotion in primary care. Pilot work has demonstrated beneficial early results of a smoking education course developed specifically for people with learning disabilities.

Persons with learning disabilities are less likely to be immunised against tetanus, poliomyelitis and influenza than are the general population. Given the high prevalence of respiratory infections and premature death from pneumonia, influenza immunisation is of particular importance for some high risk groups of persons with learning disabilities. Persons with learning disabilities who live in, or access services in group settings are at higher risk of acquiring hepatitis B infection: immunisation provides long term protection.

People with learning disabilities are sexually active and so are at risk of sexually transmitted diseases, including HIV. Effective education and prevention is not widespread and strategic planning of services should address how the sexual health needs of people with learning disabilities will be addressed.

Within the context of the Joint Future agenda in Scotland there is an opportunity to promote health improvement by tackling some of the wider determinants of the health and well-being of people with learning disabilities. Poverty and social disadvantage have been shown to have a significant impact upon the health and outcomes of people with learning disabilities. The impact of friendships and supportive social relationships on the well-being of people with learning disabilities has been demonstrated, but persons with learning disabilities may experience difficulties in establishing friendships and social networks. As employment has been shown to have a positive impact upon the quality of life of adults with learning disabilities initiatives to enhance the employment opportunities may bring health benefits. The spiritual needs of people with learning disabilities need to be recognised as an important aspect in promoting health and well-being.
4.4.25 Health Screening and Health Needs Associated with Specific Causes of Learning Disabilities

Health screening programmes provided for the whole population, such as cervical cytology and mammography have been consistently demonstrated to be poorly accessed by persons with learning disabilities. SHAS (now part of NHS QIS) reports have identified this as an issue in services across Scotland. This reflects the many access barriers already described which persons with learning disabilities experience. Additionally, attitudes and inappropriate stereotypes may affect the uptake of cervical screening with the incorrect assumption that women with learning disabilities are not sexually active. The NHS Cancer Screening Programme has published a best practice document on cervical and breast screening for women with learning disabilities. Many women with learning disabilities are sexually active through choice, and others are survivors of abuse. Given that the proportion of women who self-examine their breasts is probably lower among women with learning disabilities and any abnormal symptoms such as nipple discharge or irregular vaginal bleeding may pass unnoticed, access to screening tests is important.

The much higher level of health need among adults with learning disabilities compared with the general population, and more particularly, the very high level of unrecognised and therefore unmet health need that has been consistently described, provides overwhelming evidence to support health screening programmes (health checks) specifically for persons with learning disabilities. This recommendation has been made on numerous occasions and a range of possible models have been described.

Health screening programmes are more likely to be effective if they are delivered in a population-based, proactive, co-ordinated way, rather than relying on the individual to initiate the arrangements for the health check. The programme should screen those health needs which occur most commonly in the at-risk population, and for which interventions and supports can be made available. Some health needs are prevalent across the whole learning disabilities population and so warrant inclusion for everyone e.g. everyday health needs, vision and hearing, mental ill-health and problem behaviours, vascular risk factors, G.O.R.D., epilepsy, constipation, osteoporosis, oral health, sleep problems, nutrition, mobility and foot care, polypharmacy and health promotion initiatives. Other health needs are particularly associated with special groups within the population of people with learning disabilities, and a health screening programme for people with learning disabilities should include protocols to accommodate such special requirements e.g. persons with Down’s syndrome (including thyroid function testing, hearing assessment every three years, dementia assessment if 40 years or older, enquiry for sleep apnoea), older persons (including dementia assessment, assessment of age related vision and hearing impairment, mobility), persons with cerebral palsy (including assessment for cerebral visual impairment).

4.5 Conclusions from the Review of Research

- Life expectancy and mortality rates have improved but people with learning disabilities still experience significant health inequalities.
- Across the lifespan, people with learning disabilities have additional specific health needs, in addition to health needs experienced by all of the general population.
- The pattern of health needs, and the pattern of causes of death, of people with learning
disabilities differs from that of the general population.

- People with learning disabilities have increased health needs in comparison to the general population.
- There is overwhelming evidence that a significant proportion of health needs are unrecognised and untreated. The many barriers to health care experienced by people with learning disabilities contribute to this high level of unmet health needs.
5.1 THE DIRECTION OF SCOTTISH SERVICES

People with learning disabilities are one of the most disadvantaged groups of everyone in Scotland, and “if you can get services right for people with learning disabilities, then you can be sure that they will be o.k. for everyone else”\(^{502}\). Evidence about the current range of services and supports in Scotland for people with learning disabilities was collected from a variety of sources, including published research, and the experiences and views of service users, family and paid carers, professionals, academics, providers of statutory services and voluntary organisations. The methods employed are outlined in Chapter 2.3.

Across Scotland the development and provision of services to people with learning disabilities has already been driven forward by the *Joint Future* agenda and the recommendations of *The same as you?*. The aims and objectives set out in these documents for services are centred upon improved and more effective service provision for people with learning disabilities. Although the process of change is at different stages in different geographical areas, it is important to recognise that significant developments to improve the quality of life of people with learning disabilities have already taken place. The Health Needs Assessment Report aims to build on these developments by providing evidence-based recommendations to reduce the health inequalities experienced by people with learning disabilities.

The *Joint Future* agenda aims to promote partnership working between agencies, and service user involvement, as a means to improved outcomes and increased effectiveness of services. This is within the context of the global development of integrated models of care\(^{503}\). Whilst models vary across the country, the aim of *Joint Future*\(^{501}\) is to move to jointly managed, jointly resourced services - breaking down the barriers between services traditionally provided by Local Authorities and NHS Scotland. Each area must provide a PiP Agreement, laying out how services will be jointly managed and resourced, and the structures for making that happen. The *Joint Future* Unit has set up national groups to help to facilitate this process by considering issues of joint governance and accountability and human resources issues. The scope for further development of partnership working will be enhanced further with the introduction of Community Health Partnerships in 2004.

To oversee the *Joint Future* developments, each area has a *Joint Future* local partnership, comprising the NHS and the Local Authority, and including other key stakeholders. The
composition and name of this will vary from area to area. For example, in Dumfries and Galloway, it has been agreed that there will be one Executive Partnership Board to cover all the community care groups. This Board will consist of seven representatives from the NHS Board and seven Local Authority representatives. A range of committees for individual community care groups, including a Joint Learning Disability Board, will feed into the Executive Partnership Board. Within the Health Needs Assessment Report the Joint Future local partnership refers to the arrangements in each area that hold responsibility for overseeing Joint Future developments for all community care groups. The term Learning Disabilities Forum is an unofficial term adopted only for the purpose of this report, to refer to the local grouping with delegated responsibility for developing and implementing learning disabilities strategy, the Partnership-in-Practice agreement, and for learning disabilities service delivery on behalf of and in keeping with the strategy of the Joint Future local partnership. This is of greatest relevance in Chapter 7 when considering the recommendations.

There is a robust quality assurance framework for services provided to people with learning disabilities in Scotland. Various organisations contribute to the monitoring of services including NHS QIS, the Care Commission and the Mental Welfare Commission. The Care Commission has published standards for care homes for people with learning disabilities and NHS QIS will be publishing revised Learning Disability Quality Indicators on 23rd February 2004.

As described above, robust structures and strategic policies relevant to the health needs of people with learning disabilities are already in existence in Scotland. These have lead to positive developments in services for people with learning disabilities. In order to build upon this success, this Chapter describes the evidence on the effectiveness of services in meeting the health needs of people with learning disabilities.

5.2 A TIERED MODEL OF CARE
A five-tiered model for health care was proposed in Promoting Health, Supporting Inclusion and has also been utilised within other recent reports. Within the tiers (and across the tiers) one can expand this model to consider the range of services available within the community, voluntary and independent sector, NHS Scotland and Local Authorities. The tiers can be considered components of an integrated care pathway, and a person may access services at several tiers at the same time to meet their needs, or may access services at different tiers at different times, due to changing needs. At higher level tiers, services are more specialised and provide for a smaller number of people with increasingly complex needs. Such persons should also necessarily be accessing services at tiers 0 and 1. This model is used here to set out the existing evidence-base on services.

Throughout the Health Needs Assessment we have recognised the wider determinants of health, such as social disadvantage and lack of choice and empowerment. Therefore, it is important to emphasise the need to reframe the model within an integrated care framework. Both across and within the tiers, there needs to be a broader base of agencies and services focused on tackling the health inequalities of people with learning disabilities. As previously described, current policy in Scotland is actively promoting increased horizontal (within tiers) and vertical (between tiers) integration to improve outcomes and service effectiveness.
The recognition of the importance of the wider determinants of health further emphasises the breadth and complexity of services involved in addressing the health needs of people with learning disabilities. The current focus on integrated care aims to improve communication, effectiveness and outcomes. This can only be achieved by the development of effective systems for strategic planning, development and commissioning of services across the tiers, as well as coordinated research, education, staff development, workforce planning, advocacy, and governance. It is essential that the statutory health and social work services provided at the 5 tiers are managed as a whole system, as the provision available at each tier impacts upon the requirements at the other tiers. Part of the health improvement agenda should be to increase the effectiveness of services within tiers 0 and 1 in order to reduce the reliance on more specialised services at other tiers of care.

**A Tiered Approach to Care for People with Learning Disabilities**

| Tier 0 | Community resources and supports, housing and support packages, education and learning, employment, public health initiatives, and policy development. |
| Tier 1 | Primary health care services, directly accessed services, and their supporting services and paid and family carers. |
| Tier 2 | Generic secondary (outpatient, inpatient and tertiary) health services accessed via primary health care services, and their supporting 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. |
| Tier 4 | Supra-specialist (tertiary) learning disabilities services provided by Local Authorities, NHS Scotland, and the independent sector, and paid and family carers in support of these. |

**5.2.1. TIER 0**

At tier 0 there are important roles to be played by the statutory services, voluntary organisations, housing associations, communities, support providers, employers, policy makers, and persons with learning disabilities and their families.

The content and processes within tier 0 that impact upon the health and well-being of people with learning disabilities are far ranging. This breadth is increased further by the increasing recognition of the wider determinants of health. Examples range from global initiatives, such as the activities of the World Health Organisation, to community projects like the opening of a sports centre, employment initiatives, and community policing projects such as the work of Strathclyde Police against harassment. Local Authorities manage a range of services at tier 0 which can impact upon health status, and provide opportunities for contributions to health...
improvement e.g. education services, day opportunities, short breaks and funding for community-based support packages, working in partnership with support provider organisations and housing departments or associations.

There is a role for specialist learning disabilities health professionals to contribute their skills at this tier to meet the health needs of persons with learning disabilities utilising the wide range of resources and services. This includes supporting paid and family carers and community workers in health improvement initiatives and also in training to acquire specific skills necessary to maintain health e.g. emergency administration of stesolid for persons with epilepsy, PEG feeds.

As described in Chapter 3.2, the publication of policy documents of specific relevance to the lives of people with learning disabilities has been a feature of the Scottish Parliament.

The developments that stemmed from the publication of The same as you? have already produced significant benefits for the health and well-being of people with learning disabilities. The establishment of SCLD, the development of PiP agreements, the prioritisation of hospital closure, employment, and local area co-ordination are just a few examples.

With the introduction of direct payments (recommendation 5 of The same as you?), persons with learning disabilities and their families have a greater choice in selecting services at tier 0 and can manage their own services if they wish. Recent guidance was issued to Local Authorities on implementation. A direct payment is a cash payment made by a Local Authority to an individual who needs community care services. It is hoped their uptake will promote social inclusion, autonomy, and allow the provision of more person-centred services. This change is still at an early stage of development.

An important development at tier 0 that will impact upon services in all the tiers is the development of local databases of persons’ needs. A great deal of consideration was given to the objectives of this proposal of The same as you?, and there has been extensive consultation with stakeholders. The eSAY project, co-ordinated by SCLD, is working to develop the national database. This requires an agreed national core dataset, adopted for use by all local database projects, and possibly linked to the Single Shared Assessment. A consequence of the databases will be the means to make informed decisions about the strategic development of services and their progression, and reduce the health inequalities facing people with learning disabilities.

It is important to develop a knowledgeable and experienced public health capacity for people with learning disabilities. Informed public health initiatives specifically relevant to the different and specific pattern of health needs of people with learning disabilities will be crucial if the current health inequality is to be tackled, and must be developed.

There is clear recognition across Scotland for the need for a structured health screening programme specifically developed to address the relevant health needs of persons with learning disabilities. At present, there are some examples of local health surveillance activity, usually with Community Learning Disabilities Nurses in the lead: however, much of this work is not yet population-based or clearly co-ordinated. This is an area requiring development.
Nationally clear leadership to ensure the health improvement for people with learning disabilities must be maintained and developed further. Additionally, champions at all levels need to be encouraged and developed. A clear lead from the Scottish Executive is required, with a recognition that the specific health needs of persons with learning disabilities differ from the current national priorities. The role of the three Special NHS Boards – NHS Health Scotland, NHS Education for Scotland (NES) and NHS QIS are important in helping to lead and support NHS Scotland, Local Authorities and the Voluntary Sector in working with persons with learning disabilities, their families and communities to improve the health of people with learning disabilities.

Whilst it is recognised that the policy documents specific to the lives of people with learning disabilities have brought their needs into focus, this is not the case for policy documents of a more generic nature. For example, the unmet needs of older people with learning disabilities were described in Chapter 4.4.3. The publication Adding Life to Years reviewed the healthcare of older people and made recommendations about service developments. However, there was no specific mention of the needs of older people with learning disabilities. As this group has distinct health needs and difficulty accessing services it is wrong to assume that the generic recommendations will address their health inequalities.

The publication of the Child Strategy Statement addressed this issue in relation to the needs of children and young people. It provided guidelines to individuals involved in the development of policy initiatives to ensure that consideration was given to children. If similar guidelines were developed and implemented for children, adults and older adults with learning disabilities this would ensure that policy development was influential in addressing the health inequalities for people with learning disabilities.

**Best Practice Example: Recommendations From The Child Strategy Statement**

Anyone involved in policy making or the strategic development of services should consider the following questions:

- Does the policy have any direct implications for children and if so, what are they? How can the policy positively enhance opportunities for children in Scotland?
- Does the policy have any implications for the target to defeat child poverty in Scotland within this generation? Can it make a positive contribution to this?
- Does the policy have an indirect effect of any significance on children e.g. the development of traffic calming measures?
- What impact will the policy have on the general welfare of children e.g. changes to homelessness legislation which might affect children in a number of ways?
- Will the policy affect one group of children more than others, or will there be competing interests between different groups of children?
- Will the policy positively or adversely affect other policy areas, Local Authorities, voluntary organisations or others in their work with children, and is there scope for integrating the new policy with other measures in train or in prospect?
Of course, there are some examples where generic policy documents do make specific reference to the need of people with learning disabilities, for example *A Scottish Framework for Nursing in Schools*[^507], or where recommendations are of equal relevance for persons with learning disabilities as for other people. This needs to be consistent across departments and topics, nationally.

There are a number of implications at tier 0 due to the changes in educational services which are in progress. Education services provided by Local Authorities have far reaching effects on health and well-being. These range from the impact of early interventions in the pre-school period to the provision of adult education for older people with learning disabilities. Furthermore, these can influence an individual’s development or encompass important health promotion activities. Much has changed in the educational arena regarding special educational needs and disabilities in recent years. The aim of these developments is to encourage a more holistic system in education that identifies the educational needs of all children, supports those needs and promotes a culture that welcomes diversity. As such it is about equality of opportunity for all.

Educational developments place emphasis on the need to improve transition planning for all pupils who have additional support needs. The importance of effective transition planning for individual health and well-being has been emphasised. Transition planning needs actively to involve the young person with learning disabilities and their family or carers. Priority needs to be given to enabling choice and opportunity for the young person. In those instances where a person requires support, those persons involved in services have a responsibility to promote communication and partnership working with young people and families[^169-171]. Local area coordinators have an important role in promoting effective transition planning and enabling choice for young people with learning disabilities at times of transition.

### Best Practice Example: Transition Planning

In Ayrshire the model of transition planning gives the young person with learning disabilities a central role in the process. A key worker is identified to facilitate the transition process involving parents and staff from health, education and social work in the process. The process aims to:

- Facilitate the development of the young person with learning disabilities.
- Optimise health.
- Identify funding and provision of services and community support.
- Bridge the transition to new services and supports.

Co-ordinated Support Plans (CSPs) will be introduced. These are targeted to help children who face complex or multiple barriers to learning that significantly affect their educational development over the long term. This group of children often require frequent access to a diversity of services e.g. therapy services or short breaks. The aim of the CSP is to plan long-term and strategically for the achievement of learning outcomes, and to foster co-ordination across the range of multi-agency services and multi-disciplinary input required to support this.
These developments will lead to an increased number of children with learning disabilities, including those with complex care needs, in mainstream education settings. The overall effects will be:

- More children with learning disabilities will be found in mainstream pre-school and school settings. There will be an increased emphasis on how best to support curricular, physical and social needs in such settings.
- There will be an increasing number of children with complex care and health needs in such settings. Many will require interventions whilst at school, to maintain and promote their health.
- Support will be required for children with significant or chronic health needs who are absent from school through illness (particularly when either extended or frequent). This will be of particular significance for children in the final stages of palliative care and their families.
- There will be increased support required for teachers and other non-teaching staff in meeting the health needs of children in pre-school centres and at school, particularly in relation to invasive clinical procedures for children with complex needs. The increased numbers of children and the growing expectation on non-medical staff to undertake clinical procedures requires to be addressed.
- There will be an increased need for a range of equipment and resources to support the health needs of children in pre-school centres and schools.
- There will be an increased demand for a range of child health services such as nursing and provision of psychological therapies.
- Partnership working between education, social work and school services will require adequate resourcing. For example, access to up to date and reliable information systems will promote effective support for children and their families.

5.2.2. TIER 1

The primary health care team comprises a range of professionals such as GPs, practice nurses, pharmacists, therapists, podiatrists, opticians, and many others. Services provided by primary health care teams include general medical services, emergency 24 hour services, health promotion, health surveillance measures, registration medicals and referral to specialist care.

All people with learning disabilities should be registered with a GP. Studies show that members of the primary health care team are the health professionals most likely to be in contact with people with learning disabilities. There is agreement that the most appropriate services to meet the general health needs of people with learning disabilities are those provided by GPs and members of the primary care team within tier 1. However, GPs and the primary care team receive little training, if any, on the needs of persons with learning disabilities during their undergraduate and vocational training and as people with learning disabilities only comprise a small proportion of any GP’s list, it is difficult for them to gain experience once in practice. GPs and the primary care team are unlikely to be knowledgeable of the different pattern of health needs experienced by persons with learning disabilities and this will hinder their assessments. Additionally, people with learning disabilities have a wide range of highly complex health needs. Therefore, to manage health needs effectively requires special organisation of services and many health needs cannot be met within the context of the general medical service provision provided by GPs and primary care professionals. Many persons with specific health care needs will require referral to specialists working in other tiers.
As described in Chapters 4.4.25 and 5.2.1, the use of health screening programmes has been suggested as one way in which to reduce the health inequalities of people with learning disabilities\(^\text{18,402,498-501}\). Piloting of targeted health screening programmes was advocated in *A Partnership for a Better Scotland*\(^\text{33}\). Targeted health screening can be acceptable to people with learning disabilities and provide a range of tangible benefits\(^\text{511}\). For example, successful maintenance of weight has been reported after a period of dietary management following a health check programme\(^\text{512}\). The early detection of illnesses will lead to improved quality of life and reduce the risk of unidentified but treatable conditions developing into long-term chronic complaints\(^\text{88}\). Additionally, GPs’ experiences of targeted health check programmes produced positive changes in their attitudes to participating in future programmes, in partnership with learning disabilities services\(^\text{513}\). There are many potential benefits and further studies examining long term benefits are indicated\(^\text{91,499}\). Whilst development of a co-ordinated targeted health screening programme is a tier 0 function, its implementation would be best managed in tier 1 or tier 3, or some combination.

**Best Practice Example: Primary Care Liaison Team**

In Glasgow, the Learning Disability Partnership has established a multidisciplinary team working within primary care. The team includes nurses, GPs, a speech and language therapist and a senior health promotion officer and is an example of partnership working between primary care, the learning disabilities service and the Glasgow University Affiliated Programme. The team provides:

- Comprehensive structured health checks to all adults and older adults with learning disabilities in Glasgow.
- Training, support and advice to primary health care staff.

As outlined in Chapter 4.3, lack of training of health professionals can act as a barrier to meeting the health needs of people with learning disabilities. Several studies have highlighted the unmet training needs of primary health care professionals for their work with people with learning disabilities\(^\text{23,91,514,515}\). Less than a quarter of GPs said that they have any special expertise in working with persons with learning disabilities\(^\text{516}\). These findings suggest that meeting the training needs of primary care teams may assist them to meet the health needs of people with learning disabilities.

Recent work in Glasgow has identified that on average, each GP has five people with learning disabilities registered. However, 87% of GPs recognised that they were not fully aware of their patients with learning disabilities and their health needs. Of the Glasgow GPs, 83% thought that a special health screening programme should be available for their patients with learning disabilities, but only 15% thought it should be provided by the GP or Practice Nurse. Only a small minority reported having any training or experience at all in communicating or working with people with learning disabilities\(^\text{517}\). Typically, Scottish GP appointments are scheduled at 7.5 or 10 minute intervals; in 1997, the average duration of consultation for NHS GPs was reported to be 9.4 minutes\(^\text{518}\). The communication and other special needs of persons with learning disabilities can introduce stress into such tight appointment schedules. Whilst these data refer specifically to GPs, the issues are similar for other types of primary health care provision.
Ayrshire and Arran NHS Board undertook a mapping exercise of primary care service developments taking place across Scotland that impact upon the health of people with learning disabilities. The key issues that were identified from this survey were:

- There have been limited strategic needs assessments.
- There is a need to support and project manage local initiatives effectively and disseminate best practice.
- Primary care practices need to become more ‘friendly’ and accessible.
- Health screening is required across Scotland for people with learning disabilities who have additional needs beyond those that primary care alone can meet. In some areas, small scale health screening projects are being developed, but with no additional resource.
- There is a need for improved education, links and support for primary care teams from local learning disabilities teams.
- Additional health support models to work in partnership with primary care service, similar to the work being undertaken by the Greater Glasgow Primary Care Liaison Team, should be developed.
- A national programme to support carers should be developed, offering support, information and training in healthcare.
- A network of support for directly accessed health services needs to be developed to ensure that people with learning disabilities have access to optometry, dental care and podiatry services.

Many of these points highlight the potential benefits of partnership working within and between the tiers of the model. For example, greater integration between primary care and tier 3 learning disabilities services can improve access to the health care system, improve coordination of care and reduce health inequalities. Examples of such partnership working are already beginning to emerge in Scotland, such as the Greater Glasgow Primary Care Liaison Team and the Lanarkshire Health Care Coordinator model.

Health promotion can have a significant impact on the health inequalities of people with learning disabilities. Service delivery at tier 1 provides more specific health promotion activities than those in tier 0, including child health surveillance and promoting healthy lifestyles. Significant changes to the child health surveillance programme have been recommended. The universal screening of neonatal hearing will be implemented across Scotland by April 2005. This will lead to the earlier detection of hearing impairment and should have an important positive impact on the development of children with learning disabilities who are deaf.

There is a need for improved provision of relevant health promotion services to children, adults and older adults with learning disabilities. People with learning disabilities face significant barriers to accessing health promoting activities.

There are recognised barriers to people with learning disabilities maintaining good oral health. Services have a role in promoting the oral health of this group and it is important that mainstream dental services address the barriers that people with learning disabilities experience when accessing services. Where specialist dental services are available, these are highly valued by families but it is vital that people with learning disabilities and their carers are enabled to make choices relating to their dental and oral health needs.
5.2.3. TIER 2

People with learning disabilities often need to access the general hospital services that provide out-patient, in-patient, tertiary, and emergency health care for the whole of the population. In view of the wide range of health needs experienced by persons with learning disabilities they require access to the full range of general hospital services. However, persons with learning disabilities are in the minority when using these services, which are not geared to catering for their special needs related to communication, understanding behaviour, presentation-by-proxy, and multiple co-existing health needs. Many carers reported difficulties accessing and using general hospital services, and during the course of the Health Needs Assessment work, many examples of institutional discrimination were cited. As described in Chapter 4.4, people with learning disabilities have increased health needs and often have multiple, complex needs, and as a consequence they are high users of services within tier 2.

Several studies have reported that people with learning disabilities have significantly higher rates of in-patient admissions compared to general rates of hospitalisation. In addition, people with learning disabilities have high rates of injuries and use of accident and emergency services. Another study examined in-patient admissions for a defined Health Authority in Wales over a 6-year period. The standardised admission ratios for people with learning disabilities were 4.63 to dental specialities, 1.83 to medical specialities and to surgical specialities was 0.64. People with learning disabilities had a slightly shorter mean length of stay of 4.37 days compared to 4.94 days for admissions of people without learning disabilities.

Several studies have reported the difficulties experienced by people with learning disabilities during admissions to hospitals. The recurrent themes from these studies are the problems with communication, lack of staff training on working with people with learning disabilities and the perceived negative attitudes of staff.

### Best Practice Example: Learning Disabilities Liaison Service

Lothian Primary Care NHS Trust and Lothian University Hospitals NHS Trust jointly developed a liaison service for people with learning disabilities using tier 2 services. The service objectives are:

- Co-ordination of care - at points of attendance, admission and discharge.
- Support and advice for acute care staff in relation to care requirements and community services.
- Education of acute care staff in issues relating to the health and care needs of people with learning disabilities.
- Collaboration between the agencies involved in service provision to ensure effective, seamless care is provided for the person with learning disabilities whether in the acute hospital or in their community.
- Development of standards of care and audit mechanisms as a means to assist with evaluation of the effectiveness of the care of persons with learning disabilities.
A study of admissions to a hospital for children in Scotland reported that children were not recorded as having learning disabilities on centrally held admission records. Using alternative identification methods, the study found that admissions of children with learning disabilities accounted for 4% of the total admissions, over a three month period. Based on locally-informed estimates of the predicted number of admissions of children with learning disabilities this was 97% greater than expected. Several issues emerged from the staff survey:

- Only 40% of respondents had previous training relevant to their work with children with learning disabilities. Sixty five per cent of staff stated they felt they required additional training.
- Although 96% of staff felt comfortable working with children with learning disabilities, 68% reported intermittently feeling inadequate and 30% felt intimidated by this area of work.
- When asked what would improve services for children with learning disabilities, 75% suggested additional training for staff and 68% felt an advisory service for staff would improve services. Sixty three per cent of staff wanted a specialist service to provide care for children with learning disabilities.

The same study sought the experiences of parents. All parents highlighted the communication needs of their children and the impact these had upon their experiences during admission. It was recognised that staff required extra time to meet the additional needs of some of the children with learning disabilities. Similar to other studies, many parents commented about the negative attitudes of staff. Finally, it was clear that the admission of their child placed significant demands upon parents and their needs should be considered.

These studies offer limited basic information about the use of tier 2 services by people with learning disabilities. However, addressing the themes identified could lead to significant improvements.

The diagnostic services provided at tier 2 are of particular importance for children, for investigation of developmental delay and developmental problems. Several professionals have important roles to play at this stage, including paediatricians, clinical geneticists, paediatric neurologists, speech and language therapists, other therapists, childrens nurses, social workers, child and adolescent psychiatrists and psychologists.

For persons with multiple health needs, there is no adult health service equivalent to the coordinating role of the paediatrician. This can cause major difficulties for individuals - both during and after transition into adult services - and tends to leave families unsupported in the management of the component parts of a fragmented service. As a consequence of a lack of referral options within adult services many paediatricians retain “children” in their twenties on their case-load.

**Best Practice Example: National Learning Disabilities Palliative Care Network**

Professionals throughout the U.K., working in the field of learning disabilities or palliative care have formed a network. The aims of the network are to promote the palliative care needs of people with learning disabilities, disseminate best practice and provide training.
5.2.4. TIER 3

Tier 3 services are specialist learning disabilities services such as those provided by specialist community learning disability teams. The professionals working at this tier are locality based, and have specialist expertise allowing advanced practice at a level not available at tiers 1 and 2. They accept referrals from professionals working at tiers 1 and 2, and so support those services, often on a shared-care basis. Some tier 3 services will also accept self-referrals and other direct referrals from tier 0.

_The same as you?_ states that all persons with learning disabilities should be able to receive specialist learning disabilities services when they need them and where possible locally delivered. When compared internationally, Scotland is fortunate to have a history of specialist learning disabilities health service provision, as the experience of countries that do not suggests that this leads to increasing levels of unmet health needs (see Chapter 6). Some countries are learning from the Scottish model, and currently developing specialist learning disabilities health services.

A survey of specialist learning disabilities health services in Scotland highlighted the inequities in service provision between different geographical areas. Ninety three per cent of services were provided as part of a multidisciplinary team with varying patterns of service provision that included specialist learning disabilities professionals from the disciplines of nursing, psychology, psychiatry, speech and language therapy, physiotherapy, occupational therapy, dietetics, podiatry, dentistry and audiology. The study reported that only 15% of children had access to specialist learning disabilities health services, a finding supported by recent reports of visits to services for children across Scotland. All services reported that they provided for older adults with learning disabilities, adults with mental ill-health, problem behaviours and adults with epilepsy-related needs. However, only 79% of services provided any services to people with forensic needs.

As for persons with mental ill-health or problem behaviours, persons with epilepsy require services to be available at all tiers in the model, working in an integrated way. Specialist learning disabilities epilepsy nurses have an important and developing role to play, as do learning disabilities psychiatrists, neurologists, psychologists, neurophysiologists and others. In addition to services at tier 3 and at other tiers, a small number of children and adults with epilepsy may require access to specialists at tier 4, offering in-patient assessment and access to other highly specialised services.

The introduction of the _Joint Future_ agenda is bringing changes to the organisation of specialist learning disabilities services at tier 3. Effective working between Local Authority and health professionals is vital, and the structures are now developing to improve this. An efficient tier 3 can support persons with needs more complex than can be managed by tiers 1 and 2 alone, and professionals at tier 3 may also work into tier 4 services as people access services at that tier for finite periods of time. It will be essential that the Single Shared Assessment, when introduced, contains an adequate amount and appropriate type of detail to health improvement. The Single Shared Assessment tool should be suitably detailed to trigger the need for more specialist health assessments when these are required. The majority of more specialist health assessments would also be undertaken by professionals at tier 3. In some localities, where community learning disabilities teams are organised to cover small population sizes, some specialist learning disabilities professionals may work across several
teams. Such professionals are still providing a tier 3 function if they take referrals directly from tiers 1 and 2, and work to specified localities (“catchment areas”).

Tier 3 services may be delivered in a range of settings depending upon the needs being addressed and the resources required. These may include domiciliary work at the person’s own home, work at a person’s day centre or respite care unit, clinic-based work in general practice surgeries, or at community learning disabilities team bases, or clinic work in general hospital settings. The learning disabilities professionals at this tier usually work in a multi-disciplinary way, and may work in partnership with professionals from other health service units (such as the acute hospitals) and other organisations.

Despite the high rates of mental ill-health and problem behaviours experienced by children with learning disabilities, the provision of services to meet these needs requires considerable development. A UK-wide enquiry reported the relative absence of service provision as a national scandal. Reports published by SHAS / NHS QIS have highlighted that service provision across Scotland is patchy, ranging from provision of a specific multidisciplinary team in some areas to no services in others. In areas where there is no dedicated service, children and young people with learning disabilities are often excluded from accessing the services of generic Child and Adolescent Mental Health Teams. The training and recruitment of professionals to allow the development of these services requires strategic planning and will take time. Some localities have developed specialist child and adolescent mental health services for children and young people with learning disabilities, managed as an integral part of specialist child and adolescent mental health services. This is a model that could be developed across Scotland and supported by a Managed Clinical / Care Network approach. Two levels of response are necessary to address the gaps identified. The first involves immediate service responses to develop action plans to meet needs. The second response is longer term, requiring strategic planning and workforce development to ensure there are child and adolescent mental health services for children and young people with learning disabilities, and plans to enable doctors, clinical psychologists, nurses and therapists to develop their roles in this area.

In addition to services for children and young people with learning disabilities and mental disorders, inequities across Scotland in tier 3 provisions were identified for meeting the health and health improvement needs of people with profound learning and multiple physical disabilities; early intervention services for children with learning disabilities; transitional arrangements; services for older persons with learning disabilities and persons with learning disabilities and dementia; services for persons with forensic service needs; services for adults with learning disabilities and ADHD. It is recognised that older people with learning disabilities often fail to have needs met by either general or specialist services and as a consequence can experience high levels of unmet health needs. A cohesive national framework and national leadership to focus on priority areas and service gaps could address this.

To provide effective services for people with learning disabilities it is important to develop a workforce fit for purpose. Many of the issues of relevance to all professionals working with people with learning disabilities were highlighted in recent reports. These reports found that there are significant inequities in the numbers of specialist learning disabilities staff in different geographical areas in Scotland. The recruitment and retention of specialist staff is
problematic and particularly so in rural areas. These reports highlight the need for the strategic development of the workforce by establishing sufficient training places, ensuring training on learning disabilities is available and of a high standard and establishing staff in sustainable jobs with adequate resources and support.

5.2.5. TIER 4
The highly specialist tertiary learning disabilities services at tier 4 provide additional support to tier 3 services for persons with low incidence, highly complex needs, often for a finite period of time (rather than providing continuing care). By definition they are highly specialised and so provide services to a wider geographical area than services in the other tiers. They should be locally based, but provide an intensive service to a smaller number of people than at tier 3, and may serve several community learning disabilities teams in urban areas. As at other tiers, tier 4 services require partnership working with a wide range of services and providers, including health, social care, independent organisations, care providers and family carers.

Examples of these services include:
- Tertiary mental health and problem behaviour services, such as in-patient learning disabilities assessment and treatment units, and tertiary problem behaviour support teams.
- Tertiary learning disabilities epilepsy services such as for persons requiring in-patient investigation.
- Learning disabilities forensic services.

A limited number of studies evaluating services for persons with learning disabilities experiencing mental ill-health have been published. However, the difficulties of carrying out controlled studies evaluating services have been described\textsuperscript{278}. A controlled study evaluating an outreach model of care compared to specialist in-patient care for people with mental ill-health was carried out in the Netherlands\textsuperscript{535}. Over a 28 week period, it was found that treatment of people in their home environment was as effective as in-patient treatment. However, four of the people in the group receiving outreach care required admission during the study emphasising the need for different models of care. A Scandinavian study demonstrated the effectiveness of in-patient care in reducing symptoms of mental ill-health\textsuperscript{536}. At times of acute mental ill-health, it is sometimes just not safe or possible to manage the person’s care in their own home. This may be particularly so for persons living with family carers, and who are aggressive only during their short episodes of mental ill-health.

Post closure of the long-stay institutions, NHS Board / Community Health Partnership areas are required to have in place four learning disabilities assessment and treatment beds per 100,000 population to provide the short-term specialist care that a small number of persons periodically require and which cannot be provided in other aspects of the health services\textsuperscript{1}. A recent study found the mean number of learning disabilities assessment and treatment beds per 100,000 was 3.97, with a planned number post closure of all the long-stay institutions, of 4.29 per 100,000. Of these, 25% are in use by people ready for discharge but with no suitable discharge care arrangements in place, and most services have experience of difficulties when a person requires admission but there is no available bed. This suggests inadequacies in community based services at tiers 0 and 3, rather than an inadequate
number of beds, and the need to develop further community-based health supports for persons with mental ill-health or problem behaviours\(^\text{337}\).

Problem behaviours are experienced by a significant number of persons with learning disabilities. Problem behaviours are identified as a contributing factor to breakdown in the support arrangements for persons with learning disabilities. In addition, problem behaviours contribute to the stress and burnout experienced by family and paid carers\(^\text{103,192,538}\). Studies evaluating services for people with problem behaviours tend to focus on inpatient treatment models of services. Although the effectiveness of inpatient services has been shown\(^\text{539}\) questions remain about the longer term benefits of offering treatments outwith the home environment. There is however evidence for the longer term effectiveness of problem behaviour services operating in community services\(^\text{540}\). Reports by SHAS / NHS QIS have highlighted the need to develop robust, effective and flexible services for persons experiencing problem behaviours (available at www.nhshealthquality.org). Whilst much work with persons with learning disabilities and problem behaviours will take place at tier 3, there is a role for the provision of highly specialist community services at tier 4. Various models of best practice complex needs services (or intensive support services) exist around Scotland. To prevent social exclusion of persons with problem behaviours and promote access to services, it is important to provide appropriate training and support for family and paid carers, and proactively to develop models of partnership working with generic services at tiers 1 and 2.

Several authors have advocated the development of robust learning disabilities forensic services\(^\text{266,276,277}\). These services should include integrated services to support people living in the community, involved with police and judicial services or requiring a secure care environment. There is a role for community learning disabilities professionals with advanced practice skills in working with offenders, working in tier 3 services, but also at tier 4. Tier 4 services include step-down secure forensic services provided for a regional locality, and also the State Hospital at Carstairs which provides an essential service for Scotland and Northern Ireland. The Mental Health (Care and Treatment) (Scotland) Act, 2003\(^\text{48}\) will bring developments in forensic services, with strengthened processes between the criminal justice service and learning disabilities services, including an extension of court diversion schemes. A Managed Clinical Network for Learning Disabilities services is being developed across Lothian and Fife.

**5.2.6 WORK ACROSS THE FIVE TIERS**

An inherent feature of the tiered model is the need for an integrated approach across the tiers. Work at one level inevitably will impact upon the other tiers in the model. Some functions cut across all five tiers. A key focus of models of integrated care is on communication and systems to promote effective information sharing. Initiatives such as the development of health logs that a person with learning disabilities carries with him or her to facilitate communication, are effective\(^\text{541}\). Other examples of initiatives that need integration across the tiers include clinical governance, education and staff development, research, workforce planning, strategic service planning, advocacy, and external monitoring such as that provided by NHS QIS, the Care Commission and the Mental Welfare Commission.

All people with learning disabilities need to have access to care that can meet their needs and improve health. The most effective use must be made of the skills of professionals to improve
the health and well-being of people with learning disabilities. In addition, there are significant issues around the recruitment and retention of staff, a situation which is particularly marked in rural and remote areas. The role of effective workforce planning that is evidence-based, adequately resourced and sustainable, is viewed as central to improving the health of people with learning disabilities. As well as providing a clinical service for people with complex health needs, specialists working in Community Child Health and Learning Disability Teams will require support to develop their skills as health educators of colleagues in general health care settings, social work, and the independent sector. This needs to be linked to an increase in funding and career opportunities for health professionals and their colleagues in both generic and specialist roles.

One of the principle recommendations of The same as you? was the development of local area coordinators by NHS Boards and Local Authorities. The local coordination model already exists in some services in Australia, North America and Scandinavia. Local area coordinators provide a bridge to connect persons with learning disabilities to their communities and promote social inclusion. In addition, they enable persons with learning disabilities, and their families, to identify and access appropriate supports and services. The role of local area coordinators will produce significant benefits to persons with learning disabilities. By enabling persons with learning disabilities to make choices about their lives and facilitating access to services they will promote health improvement for persons with learning disabilities.

**Best Practice Example: Local Area Co-ordinators**

In Dumfries and Galloway, two local area co-ordinator posts were established in 2002. The local area coordinators aim to:

- Have a strong base in the community.
- Be available for children and adults with learning disabilities.
- Work directly with persons with learning disabilities and their families.
- Provide appropriate and accessible information to enable persons to make choices and gain more control over their lives.
- Support social inclusion.
- Enhance community support.

The evaluation of the first year outcomes found that persons with learning disabilities, and their families, accessed the new service and were positive about its merits. The local area coordinators were achieving the stated objectives and there are plans to increase the number of posts.

Clinical guidelines aim to promote best practice through all tiers of the model. There is recognition that clinical guidelines can act to increase the health inequalities experienced by disadvantaged groups, such as people with learning disabilities. Two processes contribute to this. Developers of guidelines may not specifically consider the health needs of people with learning disabilities, inaccurately assuming that the generic nature of the guidelines will automatically promote health improvement for persons with learning disabilities. Secondly,
there is a shortage of research relevant to the health needs of people with learning disabilities (see Chapter 7.3.2). Since the criteria for the selection of topics for guideline development necessarily gives consideration to the available scientific evidence-base, this means that, as the current evidence-base does not fulfil this criterion, guidelines specific to persons with learning disabilities are not selected for development.

Examining guidelines recently published by the Scottish Intercollegiate Guidelines Network (S.I.G.N.) lends support to this argument. The S.I.G.N. guideline on the Management of Osteoporosis had a remit to promote, “the timely identification of those individuals at highest risk of osteoporosis, as well as those who already have the disease”. However, there is no mention of the increased prevalence of osteoporosis in people with learning disabilities (see Chapter 4.4.14). Although some guidelines, such as Diagnosis and Management of Epilepsy in Adults do consider the health needs of people with learning disabilities, these are in the minority.

If the evidence-base relevant to people with learning disabilities was considered during guideline development, there would be opportunity to promote health improvement for people with learning disabilities. However, at present clinical guidelines appear to be adding to the health inequalities experienced by people with learning disabilities and other disadvantaged groups.

5.3 DISCRIMINATION
It is explicitly unlawful in Scotland to discriminate against a person on the basis of their disabilities. Services are required to make reasonable adjustments to their practice, policies and procedures to enable all persons with learning disabilities to receive appropriate care. This should lead to improved access to services. Discrimination is qualitatively different to the access difficulties that policy is currently and actively addressing in Scotland.

Discrimination can be overt, or it can be more subtle and unintentional from the perspective of an individual health professional, but equally damaging for the person with learning disabilities. Overt discrimination includes health professionals assuming that the most interventional treatments such as intensive care, surgery, transplants and resuscitation should not be offered to someone with learning disabilities. During the course of the Health Needs Assessment, several such examples were evidenced. Some professionals have negative assumptions of the potential for persons with learning disabilities to maintain health and quality of life, and are influenced by inappropriate stereotypes. More subtle and unintentional discrimination has been evidenced to be deeply ingrained within NHS Scotland. This includes nursing staff not realising the limitations of a person’s self-care skills during hospital admission (and not even considering, or being directed by a supervisor, to consider that attention should be paid to this). Some protocols and clinical guidelines developed by experts for the whole population also demonstrate the institutional discrimination in Scotland. Some protocols for accessing drugs for treatment of dementia rely on the mini-mental state examination score and therefore discriminate against persons with learning disabilities (who also have a higher age-adjusted prevalence of dementia compared with the rest of the population). Some protocols developed for the whole population result in the prevention of
effective treatment of commonly experienced gastro-oesophageal reflux disorder for persons with learning disabilities due to reliance on self-report of dyspepsia. Efforts within NHS Scotland to prevent osteoporosis inadvertently discriminate against persons with learning disabilities by not including the high risk cohorts. Whilst such examples of institutional practice may be unintentional, they highlight the lack of consideration given to the needs of persons with learning disabilities, and therefore the value placed on the quality and contribution of such persons with learning disabilities by some health professionals and health service managers, who make inappropriate judgements about a person’s health and well-being.

Whether overt or subtle, discrimination cannot continue to be tolerated or ignored in a nation where it is explicitly illegal, and where policy is committed to social justice, equity and inclusion.

5.4 SERVICES FOR PEOPLE FROM ETHNIC MINORITY COMMUNITIES
All services must be culturally competent and accessible to people from ethnic minority communities (c.f. Chapter 3.3). However, studies have found that people with learning disabilities from ethnic minority communities have difficulty accessing both general and specialist learning disabilities health and care services\textsuperscript{36,546,547}. Specific consideration is required in order for services to address this adequately. It is recognised that similar issues impact upon other minority groups, such as people who are gypsy travellers, asylum seekers, refugees or are homeless. This work cuts across all 5 tiers of the model of service delivery described above and could be supported by the National Resource Centre for Ethnic Minority Health.

Best Practice Example: Learning Disabilities Culture Liaison Team
Glasgow Learning Disability Partnership established a learning disabilities culture liaison team which offers:
• Hands on health assessments and interventions.
• Advice and support about services.
• Advocacy.
• Support and advice to families about their own needs.

5.5 PERSONS WITHIN REMOTE AND RURAL COMMUNITIES
There are specific issues regarding the development and delivery of services for persons with learning disabilities in more rural and remote areas. Areas of priority for development in rural and remote areas include health surveillance and services to enable access to health services and mental health care. The development of service models to meet the needs of people with problem behaviours, forensic and offending needs, and profound learning and multiple physical disabilities requires attention. The development of managed Clinical / Care Networks could offer support for rural and remote areas for people with complex, low incidence health needs. These would provide advice and support to locally-based professionals and maintain clear links with dedicated, specialist services that could be accessed when required.
5.6 THE SCOTTISH CONSORTIUM FOR LEARNING DISABILITY (SCLD)

A key development from *The same as you*? was the establishment of SCLD by the Scottish Executive. The SCLD works across boundaries and disciplines to support people with learning disabilities to lead the lives they want. The SCLD has a remit to build respect in the Scottish community by enabling people with learning disabilities and family carers to take on roles such as trainers, research champions and advisers. The work of the SCLD is built around the seven principles from *The same as you*?, outlined in Chapter 1.1.

With the growing recognition of the health needs of people with learning disabilities, there is a need to work with people with learning disabilities, their carers, the voluntary sector, social work and NHS Scotland to increase the awareness and importance of health improvement for all people with learning disabilities. The SCLD is central in taking forward this agenda by working in partnership with other stakeholder organisations to improve the health of people with learning disabilities in Scotland. Aspects of the work programme of the SCLD will impact on the health of children and adults with learning disabilities, and address some of the factors that influence and determine health and well-being.

The SCLD is one of the national centres of excellence in training set up by the Scottish Executive. It has a remit to develop and deliver courses and learning materials to equip health and social care workers with the values and skills to work in person centred ways in partnership with people with learning disabilities and family carers as recommended by *The same as you*?. The SCLD has developed a programme of courses which provides underpinning knowledge for national qualifications such as SVQs and aims to develop best practice in supporting people in the community. Courses are tailor made to organisations and include topics such as understanding *The same as you?, Whose Plan is it Anyway?, community bridge building, choice, empowerment and vulnerability, and relationships and sexuality. People with learning disabilities and family carers are trained and supported to take on valued roles as trainers. Training can be assessed and there is collaboration with workplace mentors to support the application of learning in the workplace. A variety of delivery routes are available: the induction course in working with people with learning disabilities is available as distance learning and training for trainers is offered to support the use of the training pack on communication.

**Best Practice Example: SCLD**

SCLD initiatives that will improve health include:

- SCLD is working in partnership with NHS Education for Scotland to implement recommendations from *Promoting Health, Supporting Inclusion*? to ensure that all nurses and midwives in Scotland receive education about the needs of people with learning disabilities.
- SCLD has established a research network that brings together interested parties from across Scotland. This aims to identify what research is saying about learning disabilities, to positively contribute, and to pass on good practice.
- The SCLD Health Working Group provides a national focus to ensure that national strategies are influenced by the views of people with learning disabilities and family carers.
5.7 INDEPENDENT ORGANISATIONS

Independent organisations make essential contributions within Scotland across all the tiers outlined in the model, to support the needs of people with learning disabilities. The independent sector includes voluntary organisations, not-for-profit companies, housing associations, and private agencies. They provide support, information and educational materials for persons with learning disabilities, unpaid and paid carers, and professionals and are significant providers of support services. Additionally, important contributions are made to inform the Scottish Executive on the needs and desires of persons with learning disabilities, lobbying for change, peer support and personal development, and to promoting community awareness and inclusion. Independent organisations contribute to the Cross Party Group on Learning Disabilities and the Learning Disability Alliance, which is represented on the *The same as you?* Implementation Group. Some organisations are service providers of supports and advocacy.

The range of services and supports delivered by the independent sector includes supported living, day opportunities, short breaks and employment. Independent organisations are providers of support packages commissioned by Local Authorities and the NHS. Other funding sources include the Change Fund, established as a result of *The same as you?*, grants, trust funds and fund-raising. ENABLE, Scotland’s largest independent organisation for people with learning disabilities and their families, is a campaigning organisation established by parents which is also now a service provider and developer of new initiatives such as children’s self advocacy. Many new providers have been established to provide supports for people discharged from long-stay hospitals. The work of the independent sector includes the provision of support for some persons with significant health needs such as the work of ENABLE, Key Housing, Elcap and PAMIS with persons with mental ill-health, problem behaviours, history of offending behaviours and people with profound learning and multiple physical disabilities. There are many examples of innovative approaches to support health and initiatives to impact positively on lifestyles, opportunities and social factors that are amongst the wider determinants of the health of people with learning disabilities.

Some organisations with a wider remit, such as Capability Scotland and Sense Scotland also provide supports for persons with learning disabilities. Other independent organisations provide a specialist resource for people with a specific cause for their learning disabilities e.g. Down’s Syndrome Scotland. For people with causes of learning disabilities which are rare, voluntary organisations can provide a unique resource for the person and families through information and contact with other persons with similar needs and experiences. Independent organisations also play an important role in the provision of information and training for family carers.

The Scottish Independent Advocacy Alliance is an umbrella group for advocacy projects in Scotland. Standards are monitored by the Scottish Advocacy Safeguards Agency. The range of advocacy projects includes citizen advocacy (such as Equal Say) and self advocacy, (such as People First, Scotland). However, advocacy services are under-developed across Scotland, and not everyone who wants an advocate is able to access one. The new *Mental Health (Care and Treatment) (Scotland) Act, 2003* will legislate on rights to advocacy, which will have implications within statutory learning disabilities services.
There are examples of independent organisations working with primary care and learning disabilities teams, predominantly on an individual case-by-case basis. However, voluntary organisations also reported that they are beginning to be included in the commissioning of local health services and the development of local PiP agreements. The involvement of the independent organisations in the strategic planning and commissioning of health services is at an early stage. One of the messages promoted by Partnership for Care\(^9\) is greater involvement of service users in the health service. Good practice in involving people with learning disabilities and family carers in strategic planning is provided by some of the PiPs. For example in West Dunbartonshire a group of people with learning disabilities are writing their own PiP. As the independent organisations are in close contact with people with learning disabilities and their family carers, more widespread participation and partnership working should be promoted.

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**Best Practice Example: PAMIS Workshops For Family Carers**

PAMIS run training and information workshops for family carers on topics they themselves have identified as priorities. Most are health-related. Recent examples include oral care, management of epilepsy, vision, eating and drinking issues, moving and handling and the impact of the *Adults with Incapacity (Scotland) Act, 2000*\(^{47}\). PAMIS works in partnership with specialist health professionals who act as workshop tutors. Family carers appreciate the practical help the training offers and the opportunity they provide to problem solve individual situations alongside other carers, with input from relevant professionals.
6.1 INTERNATIONAL EVIDENCE, POLICY AND PRACTICE

In addition to the review of the international research evidence, policies and service developments for people with learning disabilities in other countries were examined. The International Reference Group also provided relevant national reports that impact upon the health of people with learning disabilities in their country. The intention was to learn and translate success wherever possible.

An analysis of the existing evidence reveals that world-wide, people with learning disabilities have poor health and high levels of unmet health needs. In addition, irrespective of the policy intention and model of health care delivery, people with learning disabilities are excluded from many aspects of health services. These findings have resulted in a collective, international focus on the need to improve the health of people with learning disabilities.

At present, services in Scotland are similar to those in England, Wales and Northern Ireland. However, post devolution greater divergence is likely to emerge. Since the publication of The same as you?7, service provision for persons with learning disabilities in England and Wales has been comprehensively reviewed. This resulted in the publication of Valuing People: A Strategy for Learning Disability for the 21st Century548 and Fulfilling the Promises549. There are similarities in the principles, conclusions and recommendations contained within the three documents. They emphasise the high levels of unmet health need and the barriers to accessing primary and secondary health care services. To address these issues there is a focus on delivering flexible, quality services to meet individual needs with additional support available where necessary.

To improve health, in England each person with learning disabilities will have a Health Action Plan. The Health Action Plan will form part of the person-centred plan and include details of health interventions, fitness, mobility, dental health, health screening and other health needs. They must be reviewed at defined stages during the life course. A newly created Health Facilitator role for Learning Disabilities Teams is being developed in partnership with primary care services. This role will include responsibility for implementation of the Health Action Plan. In addition, Health Facilitators will identify people with learning disabilities, facilitate access to health care, advocate and ensure access to all aspects of health care. The Health Facilitators will work closely with the new Patient Advocacy and Liaison Service that will be in place in
secondary health care settings. At policy level, steps are being taken in England to ensure the needs of people with learning disabilities are included in National Service Frameworks for childrens’ services, cancer and mental health. As part of the new GP contract, work has begun on the development of protocols for locally enhanced services for people with learning disabilities.

Outside of the U.K., there are both similarities and differences in the extent to which the health needs of people with learning disabilities are addressed. Internationally, there is evidence to support the assertion that children and adults with learning disabilities have higher levels of health needs compared with the general population, higher levels of unmet health needs and experience barriers in accessing appropriate health supports.

Across the developed countries, policy has focussed on hospital closure. However, the extent to which this has been achieved is variable and there are still large institutional populations in Australia, the U.S.A. and Netherlands. Evidence has previously been submitted to the Scottish Executive from the State of Victoria, Australia outlining the policies, processes, successes and limitations over the last 25 years.

A particular difference between the U.K. and most other countries is the provision of specialist learning disabilities nurses, psychiatrists, clinical psychologists and allied health professionals in the U.K. In the State of Victoria, Australia, learning disabilities nurses were deregistered in 1993 with the aspiration that the needs of people with learning disabilities would be met by generic health services. DisAbility Services (similar to Social Work services) lead the development of social supports for persons with learning disabilities. Behaviour Intervention Support Teams were later developed in view of recognition of management challenges. Subsequently, the recognition of the barriers to accessing generic health services and an increased recognition of the special and complex health needs of the population led to the establishment of learning disabilities academic centres within Universities. These centres are primary care led, multidisciplinary and have contributed to the development of an increased capacity within primary care and development of the evidence base.

Examples of service developments that have emerged from the development of the academic centres include the State-wide health screening programme for persons with learning disabilities in Queensland and a dual-diagnosis service for persons with learning disabilities and mental ill-health in Victoria. However, the previous dismantling of specialist learning disabilities health services has had a significant impact. There is a lack of health professionals with expertise in the health needs of people with learning disabilities and a lack of training and career pathways for those health professionals who are interested in developing their skills. Therefore, many people with learning disabilities are reliant on private health care, which can be haphazard, uncoordinated, reliant on individuals and liable to sudden cessation.

Checks have been put in place to monitor priority areas, such as the mandatory auditing of persons requiring restraints. In New South Wales, the Disability Death Review Team examines the circumstances of deaths of people with disabilities. The Team was established in response to concerns from the community about the high number of deaths of people with disabilities in care settings. In the majority of cases, the people who died had learning disabilities, many
with severe and profound learning disabilities\textsuperscript{451}. Children accounted for 15\% of the 221 deaths between 1991 and 1998, with the largest single group being people between the ages of 25-44 years. Deaths occurred due to drowning, falls, self-harm, asphyxiation and respiratory disease in numbers well in excess of the general population. Underlying health conditions were also found to be contributory factors and included nutritional problems, respiratory conditions, gastrointestinal problems, mobility problems, dementia, mental illness and epilepsy related deaths. In an attempt to address these issues, a range of initiatives are being implemented. These aim to ensure there is a combination of specialist learning disabilities input that incorporates health screening, health monitoring, regular review of health care plans, staff training, supervision of vulnerable people and injury prevention programmes. Health screening and review by health professionals experienced in learning disabilities is considered essential to ensure the early detection of health needs and hence prevention of premature death.

In some countries, funding arrangements are also thought to contribute to service issues for people with learning disabilities. Separation of DisAbility services from health services in Australia is thought to have introduced an arbitrary service division and entrenched the exclusion of persons with learning disabilities from State health services (particularly mental health services). The introduction of managed care in some States in the U.S.A. fails to recognise the particular needs of people with learning disabilities, and the additional time that most health assessments and interventions require. It seems that institutional discrimination is not just a feature of Scottish services, but a world-wide problem.

Within the U.S.A., there has been recognition that the health needs of people with learning disabilities require attention. In an attempt to improve the current situation, a detailed review of health needs and services has made several recommendations\textsuperscript{383}. These include the need to address leadership at policy level, financial incentives for health providers, more continuity of care, development of health screening, health guidelines and health promotion, review of educational curricula for health care professionals, training for paid workers and the development of a population database to determine accurately the health needs of the population with learning disabilities. Subsequently, \textit{Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation}\textsuperscript{551} further acknowledges that people with learning disabilities in the U.S.A. have unmet health needs and experience disparities in health and health care. The report outlines a six-goal plan with action steps and strategies to improve the health of people with learning disabilities. The need for education, evaluation of training for health professionals and curricula development, together with funding for research to address the gaps in the understanding of health of people with learning disabilities are strongly endorsed. Like the University Centres for Learning Disabilities in Australia, all U.S.A. States have University Affiliated Programmes (U.A.P.) in learning disabilities. \textit{Closing the Gap}\textsuperscript{551} identifies the strengthening of the health component for people with learning disabilities within University research programmes as an important way to progress. Some States are developing specialist post-qualification training programmes in learning disabilities for psychiatrists, and the US Developmental Disability Nurses Association has developed a post-graduate qualification entitled The Certificate of Developmental Disability Nursing.

Universities are also developing the research base and training in the Netherlands. The Netherlands has a long tradition of providing health services for people with learning
disabilities; in the past this was via learning disabilities hospitals. With their closure, the specialist physicians remain to support the health needs of persons with complex needs and support mainstream primary health care services. In 2000, the Minister of Health in the Netherlands established a three-year training programme in the health care of people with a learning disability as part of the Institute of Training of General Practitioners at Erasmus, University of Rotterdam. At the end of the programme, the doctors are recognised as physicians for people with learning disabilities. Regarding future services, one option is for services to be provided in regional assessment centres with a specialist focus on the health of people with learning disabilities. Such centres could have a remit to provide multidisciplinary care to those with the most complex needs, irrespective of living situation.

Several European initiatives will have a positive impact upon the health needs of people with learning disabilities. The pan-European campaign against discrimination entitled For Diversity, Against Discrimination, was launched by the European Commission in 2003. Secondly, in parallel to the work to develop the European Community Health Indicators, the European Union Health Monitoring Unit has funded the Pomona project. This project will develop a set of health indicators for people with learning disabilities allowing unified public health monitoring across the European Community. Finally, in November 2003 a European Manifesto of Basic Healthcare Standards for People with Intellectual Disabilities was launched. This document was developed by the European Association of Intellectual Disabilities Medicine, the Netherlands Society of Physicians for Persons with Intellectual Disabilities, in collaboration with Erasmus MC, University of Rotterdam which offers specialist training for physicians providing services for people with learning disabilities. These initiatives will actively promote health improvement for people with learning disabilities.

6.2 IMPLICATIONS FOR SCOTLAND
Across the developed countries, and irrespective of funding methods, people with learning disabilities have not had their health needs met. Unlike Scotland, in some countries there was a determined philosophy to dismantle all forms of specialist health care services. This required mainstream health services to try and meet the diverse and complex health needs of all people with learning disabilities. However, this approach has been proven to be inadequate. As a result, to reduce the health inequalities experienced by people with learning disabilities there is a focus now on the need for integrated care involving partnership working between specialist learning disabilities services and mainstream services; development of the role of Universities; and specific interventions such as the effective New South Wales audit of deaths.
Internationally, services are being redesigned to:
• Address the health inequalities experienced by people with learning disabilities.
• Establish specific health screening programmes.
• Develop a clear framework for health improvement for people with learning disabilities, including specific interventions.
• Promote health choices and healthy lifestyles for persons with learning disabilities.
• Establish clear systems and databases for population-based identification of need for service planning, and also monitoring.
• Ensure health services meet the full spectrum of health needs of persons with learning disabilities across the lifespan.
• Improve health delivery systems by promoting partnership working between specialist learning disabilities health professionals and other health care providers.
• Improve health outcomes by developing evidence-based practice, and guidelines.
• Establish well resourced learning disabilities programmes of research to develop the evidence-base on the health needs of people with learning disabilities.
• Ensure all aspects of government policy reflect the needs of people with learning disabilities.
• Develop and utilise the skills of health professionals working with persons with learning disabilities.
• Develop training programmes on health promotion and health support for family carers of persons with learning disabilities.
• Develop education and training programmes for health care professionals and support staff on the needs of persons with learning disabilities.
PART THREE
IMPROVING THE HEALTH OF CHILDREN, ADULTS AND OLDER ADULTS WITH LEARNING DISABILITIES IN SCOTLAND
CHAPTER 7
RECOMMENDATIONS

7.1 REDESIGNING SERVICES AND SUPPORTS TO IMPROVE HEALTH

As highlighted in Chapter 5.1, the local management structures with responsibility for meeting the health improvement needs of people with learning disabilities are configured differently in different parts of Scotland. In this Health Needs Assessment Report the term Joint Future local partnership refers to the senior level grouping bringing together the partners in a locality responsible for overall strategy across all community care groups. The term Learning Disabilities Forum is an unofficial term adopted only for the purpose of this report to refer to the local grouping with delegated responsibility for developing and implementing learning disabilities strategy, the Partnership-in-Practice agreement, and for learning disabilities service delivery on behalf of and in keeping with the strategy of the Joint Future local partnership. It is recognised that across different parts of Scotland structures are configured differently, a variety of terminologies are used, and the two groupings described above may overlap or be the same in some areas. Community Health Partnerships are in the process of development across Scotland. In some but not all parts of Scotland there is coterminosity between the Community Health Partnership and Joint Future local partnership. A clear relationship between the two is important with defined responsibilities, though these may differ in different parts of Scotland, in order to meet local needs.

Government is signalling the need to improve the health of the Scottish population. The evidence about the poor health, different pattern of health needs, and premature death of persons with learning disabilities is clear. Whilst current Scottish public health policy and programmes of health promotion should improve the health of the whole Scottish population, they will not address the inequality experienced by people with learning disabilities. Indeed, instead of “Closing the Gap” between people with learning disabilities and the rest of the population, the health gap is likely to widen. This is because of the different pattern of health need and causes of death experienced by people with learning disabilities compared with the general population. For example, smoking is a leading cause of morbidity and mortality in the general population, but not so amongst people with learning disabilities, few of whom smoke. Investing heavily in smoking cessation programmes, even if provided in an accessible framework, therefore disadvantages the population with learning disabilities relative to others. Instead, we require a range of complementary approaches which are designed to improve the health of people with learning disabilities by addressing their specific needs. There are no “quick fix” solutions, as can be seen from the experiences elsewhere in
the UK and internationally. It is clear that significant health improvement for children, adults and older adults with learning disabilities will not just happen unless there are active and specific changes to available supports. The evidence that has been presented in this report provides a strong base to inform the further redesign of supports available for people with learning disabilities. The health of people with learning disabilities can be improved.

The recommendations of this report adopt an integrated approach, linking policy and practice locally and nationally to the needs of people with learning disabilities. This needs to be supported by people with learning disabilities, their families and carers, communities, schools, NHS Scotland, Local Authorities, voluntary organisations and the Scottish Executive. Five critical areas for success have been identified for further development:

1. The need for clear leadership and accountability.
2. The need for a strong infrastructure to allow development, planning and monitoring.
3. The need for specific targeted interventions.
4. The need for information about resources.
5. The need for education and skill development.

Several of the recommendations developed seek to build upon work already starting or in progress in Scotland, and reinforce recommendations presented previously\textsuperscript{1,2,7}. All new developments and interventions that are recommended are strongly supported by the evidence identified by the Health Needs Assessment.

7.2 LEADERSHIP AND ACCOUNTABILITY

7.2.1 A NATIONAL HEALTH IMPROVEMENT ROLE
Tackling the health inequalities experienced by people with learning disabilities cuts across all aspects of the work of the Scottish Executive, statutory and voluntary organisations, and communities. Improving the health of children, adults and older adults with learning disabilities needs to be integrated further into all aspects of Government and policy development. It is important that external to the Scottish Executive there is perceived clarity as to where lies the responsibilities for health improvement for persons with learning disabilities.

The Scottish Executive has driven forward the development of joined-up services, bringing benefits for people with learning disabilities. One of the outcomes from implementation of The same as you? has been a modernisation of services. The next step is to develop the role of national strategic leadership into the remit of an evidence-based framework for health improvement.

The Scottish Executive should take responsibility for ensuring national action to improve the health of people with learning disabilities. A named lead for health improvement should be identified / appointed and work with the responsible individuals within Departments across the Executive. Responsibilities include:

- Ensuring the health needs of persons with learning disabilities are considered in all policy initiatives and monitoring arrangements across the Scottish Executive.

- Developing and implementing a Learning Disabilities Health Strategy Statement, similar to that of the Child Strategy Statement, appropriate to the needs of children, adults and older adults with learning disabilities, and aimed at addressing health inequalities.
• Supporting and monitoring the implementation of the Health Needs Assessment across Scotland. Alternatively, consideration could be given to delegating this responsibility to NHS Health Scotland. In this case, clear links would need to be established with The same as you? Implementation Group and with the Scottish Executive’s named lead for health improvement.

• Introducing robust monitoring arrangements, by including the health improvement needs of people with learning disabilities and family carers appropriately within the NHS Performance Assessment Framework, NHS QIS and the Care Commission. This should be based on the recommendations within this report, work undertaken in collaboration with NHS QIS and the Care Commission, and linked to the NHS QIS learning disabilities quality indicators.

• Identifying, promoting and disseminating health improvement initiatives across Scotland, in partnership with SCLD and NHS Health Scotland.

• Issuing guidance to Joint Future local partnerships, Learning Disabilities Fora, and Community Health Partnerships on meeting the health needs of children, adults and older adults with learning disabilities, and development of a local health improvement strategy, including the need for local implementation of the health screening programme for persons with learning disabilities.

• Issuing guidance to NHS Scotland to stamp out institutional discrimination.

One Division of the Health Department could be charged with this lead, such as Health Improvement. Potentially all aspects of the work of The same as you? Implementation Group affects health, and an effective health improvement strategy will require an extensive breadth of resources and knowledge as found in The same as you? Implementation Group. A close and explicit collaboration with The same as you? Implementation Group would be essential from outset, to ensure a joined-up approach to the work: The same as you? Implementation Group would be recommended to extend membership to the named lead for health improvement. Alternatively, the health improvement functions bulleted above could become an explicit, and readily identifiable integral component of the on-going work of The same as you? Implementation Group. In this later arrangement, a named lead should be identified within or appointed to The same as you? Implementation Group to lead on the health improvement work as an explicit extension of the work of the Implementation Group. With either arrangement the scope and extent of the required health improvement work is such that the named lead, working within the existing structures, will need to draw upon the widespread existing expertise to continually drive forward the necessary health improvement initiatives.

7.2.2 LOCAL ACCOUNTABILITY FOR HEALTH IMPROVEMENT

The Joint Future agenda and anticipated development of Community Health Partnerships provides a real opportunity for partnership working towards health improvement, with clear local leadership cutting across traditional agency boundaries. To date the focus of much local work has been on the important task of closure of all long-stay learning disabilities hospitals by 2005. Now that that target is being reached, Joint Future local partnerships should have a clearly identifiable proportion of their work focused on a programme of health improvement for people with learning disabilities. This should be required within the PiP agreements. Components of the health improvement work should be monitored within the NHS Performance Assessment Framework, by the Care Commission, and NHS QIS, as well as via robust local mechanisms developed by the Learning Disabilities Fora and Community Health Partnerships.
There are several arrangements through which the Joint Future local partnerships could deliver the health improvement functions for people with learning disabilities, and this will depend in part upon other local arrangements. Critical factors for success will include there being:

- A named individual with responsibility for developing the local health improvement strategy for people with learning disabilities and leading this work, with transparent links within the Community Health Partnership and the partner organisations of the Learning Disabilities Forum.
- Senior level involvement from Health, Social Work, and Education.
- Involvement of voluntary organisations, persons with learning disabilities and family carers.
- A clear link to the local Community Health Partnership / NHS Board strategy, and the wider Joint Future local partnership strategy for health improvement for the whole population.
- Robust monitoring arrangements, with clear local responsibility at the Learning Disabilities Forum and Community Health Partnership, as well as external monitoring.

The health improvement work for people with learning disabilities should be an explicit, and readily-identifiable integral component of the work of Joint Future local partnerships. A named lead is required: one approach would be the appointment of a Learning Disabilities Health Improvement Co-ordinator to the Learning Disabilities Forum / Community Health Partnership. Local services have a statutory responsibility for Clinical Governance, and together with the maintenance and development of service standards across agencies, these functions contribute to the wider health improvement agenda. A Learning Disabilities Health Improvement Co-ordinator could combine the functions of developing and implementing the local health improvement strategy and leading on clinical governance and standards, establishing the relevant links to professional line management (this may require a subcommittee of the Learning Disabilities Forum / Community Health Partnership, or a development / extension of the role of an existing subcommittee). A Learning Disabilities Health Improvement Co-ordinator / subcommittee provides an easily externally-identifiable structure through which a number of the recommendations contained within this report could be implemented.

7.2.3 A LOCAL HEALTH IMPROVEMENT STRATEGY
All Learning Disabilities Fora / Community Health Partnerships should develop a health improvement strategy for children, adults and older adults with learning disabilities. This should explicitly be an integral part of the PiP, and relate to the wider strategy for health improvement for the whole population of the Community Health Partnership / Joint Future local partnership. The Scottish Executive’s named lead could provide central support where this was appropriate. There are several necessary strands in the health improvement strategy. These include:

- Ensuring that people with learning disabilities are included in all local health initiatives. This will require the specific issues and needs of the population with learning disabilities being addressed within the context of the health initiative (not an assumption that it automatically applies without any additional modifications or supports). It will be necessary to establish a mechanism whereby all local strategy and policy is reviewed during development, from the perspective of the needs of people with learning disabilities. A Learning Disabilities Strategy Statement for implementation throughout Community Health Partnerships would facilitate this.
- Development and implementation of local approaches, utilising Scottish Executive
guidance, to eliminate institutional discrimination within NHS Scotland. This includes the need for written policies on equality of access to services for persons with learning disabilities, including surgery and intensive care. Such policies should also include the requirement of induction training on the needs of persons with learning disabilities and relevant legislation for all staff. The provision of the required supports to enable equality of access and service delivery, and the responsibilities of individual staff should be highlighted within policies. This will require a partnership approach between several of the NHS operating units, Community Health Partnerships, and the Learning Disabilities Fora. It will help fulfil responsibilities outlined in Patient Focus, Public Involvement.

• Development of accessible health promotion materials and a programme of health promotion. It is essential that the health promotion work is appropriate to the needs of the local population of people with learning disabilities, and not just a “translation” of a general population approach into an accessible format. More of the latter is required, but must be added to. This should be informed by the evidence-base. Relevant examples for people with learning disabilities include promoting health choices, promoting awareness of the at-risk factors for gastro-intestinal disorders and osteoporosis, with healthy choices to address these, thyroid dysfunction, sensory impairments, aspiration and swallowing problems, accidents and injuries, early detection of dementia, mental ill-health, and nutrition, amongst others.

• Development and implementation of specific interventions to reduce health inequality, including local implementation of the health screening programme for people with learning disabilities, and procedures for the audit of deaths.

• Development of a robust framework for Clinical Governance and Standards.

• Identifying local factors and the health needs of the local population of people with learning disabilities, and identifying current service responses and service gaps to be addressed to improve health. The needs of children and of older adults with learning disabilities should specifically be addressed, as well as those of adults with learning disabilities.

• Development of the Single Shared Assessment to include health improvement.

7.2.4 SERVICE INTERFACES
At present, the many interfaces between services can mean that sometimes persons with learning disabilities can be caught in the middle and so fail to receive an adequate service. It is important that this is prevented and the current restructuring of health services provides an opportunity to ensure that access to and movement between health services is an integrated, seamless experience for the service-user. All NHS operating units and Local Authority services are responsible for addressing interfaces; but this work requires coordination. The Learning Disabilities Forum is in a position to provide such co-ordination within and between services. There needs to be clearly defined and agreed protocols which responsible general managers, clinicians and professionals are signed up to, and which are acceptable to service users and their family carers. As health professionals provide the day-to-day delivery of clinical services, and are knowledgeable of their own level of skills, potential development and limitations, it is essential that they are fully engaged in the development of health-service protocols so that the required outcomes can be successfully delivered. This is also true for professionals and paid carers working for Local Authorities and service-provider organisations. The result should be that all persons with learning disabilities can access the service most appropriate for their needs, and that there is a clear responsibility for services to
respond, with no potential service-user falling between services. Such protocols should define clear routes of access, the role of facilitation by specialist learning disabilities professionals to enable access to mainstream services, and the role of delivery of direct care by specialist learning disabilities services. This should specifically include access to supports required for persons with needs related to mental ill-health, problem behaviours, autistic spectrum disorders, ADHD, forensic needs, dementia, epilepsy, communication, nutrition, swallowing, mobility, co-ordination, balance and postural management and foot care, skill development, sensory impairments, optometry, audiology, dental health, multiple disabilities, palliative care, and sexual health. This will include addressing the Health / Local Authority / Service-provider organisation interfaces between, for example:

- Adult mental health services and learning disabilities services.
- Mental health services for older people and learning disabilities services.
- Child and adolescent mental health services and learning disabilities services and community child health services.
- Neurology and learning disabilities services.
- Primary Care Allied Health Professionals (AHPs), hospital AHPs and learning disabilities services AHPs.
- Primary care and learning disabilities services.

Interfaces between the health service and Local Authority directly provided or commissioned services should also be addressed where this has not already happened as part of Joint Future arrangements. Many users of schools, colleges, Local Authority and independently provided day opportunity services, respite care services and support packages have extensive, complex and sometimes multiple health needs. Clear agreement is required as to how such needs are met, by whom, and associated training requirements identified and addressed. This is essential to enable persons with learning disabilities to benefit from using such supports safely. Examples might include the role of NHS employed professionals in training social work staff and paid carers employed by independent organisations in the appropriate use and administration of rescue-medication for persons with epilepsy, and PEG feeds. Protocols should also identify how such joint-working arrangements are monitored.

The introduction of Community Health Partnerships will provide a new framework for the delivery and planning of services. It will be important that all Community Health Partnerships include the needs of people with learning disabilities within their operations. This has the potential to bring important health gain opportunities, such as with the development of primary care one-stop health clinics for people with learning disabilities. Specialist learning disabilities services should continue to develop as an integrated whole-system. This is because component parts of the system, operating at different tiers, are inter-related and linked: activity at one tier impacts on each of the other tiers. Therefore, the system needs to be managed and co-ordinated through all of the tiers. For example, day opportunities accessed at tier 0 may expand a person’s social network, allow skills development and confidence building. The extent to which this is available may impact upon the specialist therapist and social worker resource at tier 3. The skill and quantity at tier 3 of e.g. community learning disabilities nurses may affect the level of requirement for in-patient assessment and treatment beds at tier 4. Provision of robust individual support packages at tier 0 may reduce delayed discharges from tier 4. Adequate provision of in-patient assessment and treatment beds at tier 4 may prevent persons having to access specialist in-patient or residential provision out-of-
It will be essential that the Learning Disabilities Forum develops a clearly defined and close pattern of working with the Community Health Partnership. This is particularly important at the interface of primary health care services and the learning disabilities services, public health services for people with learning disabilities, and at the time of transition from children's to adult services. At some tiers, the specialist learning disabilities service is small, both with regards to professional groups of individuals and multi-disciplinary units / teams. Attempts to integrate the specialist learning disabilities service within Community Health Partnerships has a potential for service fragmentation. This could lead to difficulties in working across several Community Health Partnerships (which will be necessary at tier 4 and some tier 3 services), in monitoring and auditing services, and for individual professional development and continuing quality improvement within the service. Service commissioning and strategic developments at tiers 3 and 4, which are inter-related to work undertaken at tiers 0, 1 and 2, would also be more challenging. It is recommended that specialist learning disabilities services continue to develop and be managed within a single Joint Future model, with clear working relationships established between the Joint Future local partnerships, Learning Disabilities Fora and Community Health Partnerships particularly with regards to primary health care services, public health and transition. This provides a framework to address health inequalities.

Arrangements may differ in different parts of Scotland. If for local reasons, Community Health Partnerships assume management for specialist learning disabilities services, it is recommended that arrangements to address the above issues are made, and also the interface issues with other services (such as joint out-of-hours services with mental health services). This might involve one Community Health Partnership “leading” on learning disabilities on behalf of a larger group of Community Health Partnerships.

7.2.5 THE SINGLE SHARED ASSESSMENT
Health improvement is clearly a multi-agency responsibility. With Joint Future bringing community learning disabilities health and social work professionals together to work within joint team models, a framework is in place to optimise health improvement endeavours. Health improvement should be a component part of the Single Shared Assessment, and should include identification of an individual’s health needs, health screening needs and health promotion needs, and any need for more detailed assessment of these. This aspect of the Single Shared Assessment requires expansion and development, if it is to be of benefit to persons. It is of relevance to all persons, should be part of the core assessment, and should be detailed enough to trigger additional assessments where these are required.

Whilst it is not appropriate to include sensitive medical information within the Single Shared Assessment, a considerable amount of health information must necessarily be shared, if improvements are to be gained. For example, the findings from a person’s hearing test, and date at which this next requires repeating is important information for family carers, day centre officers and paid carers who must incorporate findings into their daily care of the person, and arrange appointments. The person’s care manager, local area co-ordinator, service commissioner or other person co-ordinating the person’s care review is required to monitor that findings have been actioned. Findings are also relevant to the work of the
health professionals such as a speech and language therapist advising carers on communication, or a psychologist or psychiatrist working with a person who has problem behaviours. A large proportion of health need, health monitoring need, health screening need and health promotion need requires such a multi-agency response. Development of the Single Shared Assessment provides scope to reduce both duplication and omission of important health issues.

7.2.6 HARNESSING VOLUNTARY SECTOR EXPERTISE
The voluntary sector organisations develop a good understanding of the needs and priorities of the group they have been established for / by. The extent to which this expertise is used by Joint Future local partnerships varies across Scotland. Consideration should be given to further development of mechanisms to work with voluntary sector organisations within local and national development of health improvement strategy, protocols and networks.

7.2.7 RECOMMENDATIONS: LEADERSHIP AND ACCOUNTABILITY
1. The Scottish Executive should take responsibility for ensuring national action to improve the health of people with learning disabilities. A named lead for health improvement should be identified / appointed and work with the responsible individuals within Departments across the Executive. Responsibilities include:
   • Ensuring the health needs of persons with learning disabilities are considered in all policy initiatives.
   • Development and implementation of a Learning Disabilities Health Strategy Statement (see reference to Childrens Strategy Statement on page 52).
   • Supporting and monitoring the implementation of the Health Needs Assessment Report recommendations (or monitoring a delegated responsibility for this to NHS Health Scotland).
   • Introducing robust monitoring arrangements, via the NHS Performance Assessment Framework, NHS QIS and the Care Commission.
   • Issuing guidance to Joint Future local partnerships, Learning Disabilities Fora and Community Health Partnerships including local development of a health improvement strategy, implementation of the health screening programme for people with learning disabilities, and stamping out institutional discrimination.

2. All Joint Future local partnerships should have a local health improvement strategy to meet the specific needs of children, adults and older adults with learning disabilities within their wider strategy for health improvement. This should be developed and implemented locally by the Learning Disabilities Forum and the Community Health Partnership. A named person should be identified / appointed to lead this work: consideration should be given to this role being combined with that of lead for clinical governance and standards within the local Learning Disabilities Service. Component parts within the strategy should include:
   • A mechanism to ensure inclusion of people with learning disabilities in all local health initiatives.
   • A local Learning Disabilities Health Strategy Statement.
   • Elimination of institutional discrimination within the local NHS Scotland.
   • A programme of health promotion appropriate to the needs of people with learning disabilities.
   • Specific interventions to reduce health inequalities.
   • Clinical governance and Standards.
• Local assessment of health needs and services.
• Development of the Single Shared Assessment to include health improvement.

3. The local health improvement strategy for children, adults and older adults with learning disabilities should be included explicitly within the Partnership-in-Practice agreement. The PiP should also address how the work to develop local protocols will be co-ordinated to address service interfaces and provide a clear description of accessible pathways of care. This will require integrated working locally between the Learning Disabilities Forum and the Community Health Partnership in each area.

4. Specialist learning disabilities services should continue to develop and be managed within a joint Future model of service delivery and planning across all of tiers 0 – 4. A clearly defined relationship should be established between Community Health Partnerships and the Specialist Learning Disabilities Service, particularly with regards to the development and operation of primary health care services and public health functions, and transition from children to adult services.

7.3 INFRASTRUCTURE: DEVELOPMENT, PLANNING AND MONITORING

7.3.1 POPULATION DATABASES
The infrastructure should be further developed in order to provide a framework to support evidence-based development and commissioning of services and to enable continuing improvement. Considerable efforts have started to address the level of information about current service provision and performance, and local population needs, and this should be developed further. This will improve the extent to which strategic planning can fully address the inequalities experienced by people with learning disabilities. There are several specific developments which can be implemented to provide a better supportive infrastructure.

As part of the Scottish Executive eCare programme (www.ecare-scotland.gov.uk), the Modernising Government Fund was launched to take forward the objectives of the 21st Century Government for Scotland project. The fund provides £26 million over 2 years for projects making beneficial and innovative use of information and communication technologies. The eCare programme emphasises information sharing across agencies providing health and social care, with new technologies offering the possibility of improved information sharing. The SCLD has been awarded a grant to facilitate the development of integrated health and social work databases at local level to enable a clearer picture of service users’ needs (the eSAY project). The SCLD is working with four pilot sites across Scotland. The eSAY project is committed to ensuring that database development will be meaningful, useful and acceptable to people with learning disabilities. It provides the basis for the development of an anonymised national database for people with learning disabilities in Scotland. It aims to provide information for planning, and also for monitoring of progression of services and communities towards the objectives outlined in The same as you?.

The work of SCLD should be resourced to allow the extension of the eSAY project across all parts of Scotland. This should incorporate a resource for development of information and guidance to joint Future local partnerships to facilitate local database development. The joint Future local partnerships are already charged with the tasks of developing a local database of
people with learning disabilities (recommendation 9 in *The same as you?*), and a Single Shared Assessment (*Joint Future*). Some areas have highlighted the need for guidance on information sharing, consent, the Data Protection Act, the core dataset for the database and the Single Shared Assessment and links to special educational needs databases. The development of local databases is crucial for local planning and will also be required for the co-ordinated local delivery of the health screening programme for people with learning disabilities, and other public health and health promotion activities.

This modernisation of information management will provide an important contribution towards the health improvement of the population over time. It will also enable the Scottish Executive and Community Health Partnerships to monitor progression towards targets; monitor progress in health improvement; and will support service redesign.

7.3.2 DEVELOPING THE EVIDENCE-BASE

For people with learning disabilities, there is a shortage of research literature in almost all health-related areas. We know that health needs are substantially greater for people with learning disabilities, that the pattern of health needs and causes of death differ from the general population, and that health needs are more likely to be unmet if the person has learning disabilities. However, it is difficult to quantify the exact extent of need and unmet need, or define the interventions, supports and preventative measures that can reverse this, due to lack of research evidence. Little is known about the wider determinants that may impact upon the health of persons with learning disabilities, such as deprivation, adversity, employment, social, cultural and economic environment factors. Support for research must be available if this situation is to change.

Scotland is unlike the U.S.A. where Kennedy’s initiative in the early 1960’s led to the development of a University Affiliated Programme (U.A.P.) in every State in order to progress services for people with learning disabilities. Scotland has benefited from the work of the U.A.P.s by being in a position to learn from them and other international research, but does not have a strong tradition of contributing health improvement evidence internationally. Some Scottish universities do have a learning disabilities theme within their research strategies; in other cases, academic posts exist in relative isolation within organisations with lack of sustainable critical mass, and hence having uncertain futures. There is the potential to change this.

The Chief Scientist Office was funding response-mode projects to a total cost of £4.5 million within the theme of “mental health” as at April 2002. Of these, just 11% were topics addressing the needs of people with learning disabilities, with a further 4.5% addressing the needs of people with autistic spectrum disorders. For 2001/02, Scotland spent £365 million on services specifically for adults with learning disabilities compared with £591.5 million for adults with mental health needs. Hence Scottish spend on services specifically for adults with learning disabilities or mental health needs is distributed so that 38% is for adults with learning disabilities, but research spend is distributed so that only 11% benefits adults with learning disabilities. The disproportionately lower level of research funding for people with learning disabilities does not make financial sense, and contributes to on-going health disadvantage. Additionally, a better understanding of how to improve health for people with learning disabilities, reducing inequalities and exclusion is likely to bring knowledge and benefits for the
whole population, particularly other groups who share disadvantages in access to health care.

The introduction of the *Adults with Incapacity (Scotland) Act, 2000* has had implications for research. It is now illegal to include persons with learning disabilities who do not have full capacity to give / withhold consent in research projects addressing the needs of the whole population. This has been introduced with the intention of protecting persons, but it is a questionable assumption whether exclusion from research for people without capacity to consent is protective. People with learning disabilities should be included in mainstream research, and want to be. Where research specifically addresses the needs of people with learning disabilities, persons who do not have full capacity to give / withhold consent can only be included if their nearest relative consents to it (as almost no-one has a welfare guardian). This means that persons who are not in contact with a relative cannot participate in research. The current status is hindering rather than enabling developments to improve health and supports for persons who experience exclusion.

The process of research is additionally hindered by a lack of valid research measures which are appropriate for use with people with learning disabilities. This relates to mental health, physical health and service access. Instruments designed for the general population are usually inadequate unless they use physical measurements or observable information. Almost all quantitative research, whether epidemiological, service evaluation or randomised controlled trials requires valid means of measurement.

The independent sector has an important role to contribute to research, in partnership with Universities and statutory agencies. This includes advising on research, undertaking research and disseminating research findings and best practice. Participatory / emancipatory research has to be properly supported and is expensive, but makes important contributions to the evidence-base. Within Scotland, there is considerable interest and growing expertise in research within the independent sector e.g. the work of the SCLD Consortium Area Network (C.A.N.) and Down’s Syndrome Scotland, as is the case in England with the work of e.g. Mencap and People First.

These issues must be addressed if advances are to be made in understanding the needs of the population and individual approaches for health improvement, and so we can make a difference to people’s lives.

### 7.3.3 CONTINUAL IMPROVEMENT IN QUALITY

The recent formation of NHS QIS has brought together the Clinical Resource and Audit Group, Clinical Standards Board for Scotland, Health Technology Board for Scotland, Nursing and Midwifery Practice Development Unit and the Scottish Health Advisory Service. Its role is to improve the quality of healthcare in Scotland by setting standards, monitoring performance and providing evidenced guidance across NHS Scotland. It has close relations with the Scottish Intercollegiate Guidelines Network (S.I.G.N.) and the Scottish Medicines Consortium. The Care Commission plays an essential role in monitoring care services to improve quality, and hence has an important role to play in health improvement. It is important that the Care Commission and NHS QIS work closely together to ensure that health improvement initiatives are developed across all care settings. NHS QIS’s national monitoring and reporting programme has expanded, in keeping with the
changed focus of service delivery from long-stay hospitals to the community. This now includes specialist learning disabilities health services, child health services, primary care, acute hospital care and relationships with social work, education, family carers and voluntary agencies. It will be important that it incorporates the recommendations of this Health Needs Assessment Report within its quality indicators and assessment framework. On the basis of its findings, and review of the implementation of recommendations from the reporting and reviewing of all deaths of persons with learning disabilities in care settings, NHS QIS and the Care Commission should identify an area for national focus and development every other year. This will support Joint Future local partnerships and the Community Health Partnerships to continually strengthen, modernise and redesign services. The identified area should be included within the NHS Performance Assessment Framework each following year, to ensure a link with the Scottish Executive and clear accountability for health improvement and equality for people with learning disabilities.

Information should be available for all Learning Disabilities Fora and Clinical Directors / Lead Clinicians for Learning Disabilities regarding the role of, and inviting proposals for health technology assessments. NHS QIS should examine the feasibility of a project on drug treatments and psychological interventions for adults with learning disabilities and problem behaviours, mental ill-health, ADHD or dementia.

S.I.G.N. plays an important role in developing clinical guidelines to promote evidence-based best practice and reduce variation in practice across Scotland. However, the current process for selection and development of guidelines may be adding to the health inequalities experienced by people with learning disabilities (see Chapter 5.2.6). S.I.G.N. Council should be invited to consider how these processes could be modified to address this issue, such as inviting the SCLD to identify a representative to sit on the S.I.G.N. Council. This person would have a role in ensuring that prior to guideline topic selection consideration is given to the impact of proposed topics on the health inequalities of people with learning disabilities.

To ensure that every proposal selected for guideline development takes the opportunity to promote health improvement for people with learning disabilities, the Mental Health and Learning Disabilities Specialty Subgroup of S.I.G.N. should be invited to consider the implications of each proposal selected for the guideline development programme for people with learning disabilities (whether related to mental health or physical health). Consideration should be given to the existing evidence-base surrounding the topic and the need for a representative with knowledge of the proposal and learning disabilities to be part of each guideline development group. If this is appropriate, the Chairman and programme manager of every guideline development group should liaise with the Mental Health and Learning Disabilities Specialty Subgroup when membership of the guideline development group is being decided in order that suitable individuals are proposed.

7.3.4 RECOMMENDATIONS: INFRASTRUCTURE: DEVELOPMENT, PLANNING AND MONITORING

5. Learning Disabilities Fora should each establish a continually updated local database for people with learning disabilities by 2006. Local databases must be compliant with the National Learning Disabilities Core Data Set developed by the eSAY project managed by SCLD. Learning Disabilities Fora should be required to export anonymised data from their local database to the national database developed by the eSAY project. The eSAY project
should be expanded to provide support for local database development across all areas of Scotland.

6. The Scottish Executive should establish a sustainable programme of research for health improvement for people with learning disabilities. The programme should be inter-disciplinary and cut across traditional boundaries, working across primary and secondary health care. The U.S.A. U.A.P.s provide a model for this which Scotland could adopt and develop.

7. The Scottish Executive should further support health improvement research by commissioning project research into the development of valid measures that can be used for health assessment, health outcome, quality of life, and service access; by resourcing further development of the SCLD C.A.N.; and reviewing the Code of Practice regarding the research component of Part V of the Adults with Incapacity (Scotland) Act, 2000.

8. NHS QIS and the Care Commission should work together to ensure that NHS Scotland and her partners develop health improvement initiatives across all care settings, and monitor implementation of the Health Needs Assessment Report recommendations. They should facilitate continual improvement by identifying a health improvement area for national focus and development every other year, to be included in the following year’s NHS Performance Assessment Framework, in addition to their own framework.

9. NHS QIS should explore the feasibility of a Health Technology Assessment on drug treatments and psychological interventions for adults with learning disabilities and problem behaviours, mental ill-health, ADHD or dementia.

10. S.I.G.N. should be invited to extend its membership of S.I.G.N. Council by inviting representation from SCLD of someone with knowledge of the health needs of people with learning disabilities. S.I.G.N. should be requested to amend its procedure, such that after a proposal is selected for the guideline development programme, the Mental Health and Learning Disabilities Specialty Subgroup of S.I.G.N. discuss the need for someone with relevant knowledge and experience to contribute to the guideline development group. Where appropriate, suitable individuals should be proposed to the Chairman and programme manager of the guideline development groups.

7.4 INTERVENTIONS

7.4.1 A HEALTH SCREENING PROGRAMME FOR PEOPLE WITH LEARNING DISABILITIES

There is overwhelming evidence across the developed countries endorsing the need for a health screening programme specifically for people with learning disabilities. Introduction of such a programme in Scotland will start achieving a reduction in health inequalities for people with learning disabilities. This evidence cannot reasonably be disputed, and is clearly outlined in Chapters 4 - 6 of this Health Needs Assessment. Critical factors for success in the implementation of a national screening programme will include:

- The way such a programme is implemented locally, and supported nationally.
- The component parts of the health screen which must be relevant to the particular health needs of persons with learning disabilities (rather than general population needs).
- The competencies of the professional staff undertaking the health screen.
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• The level of appropriate support the person with learning disabilities has during the health screen.
• The acceptability of the health screen to persons with learning disabilities and their carers.
• The local service’s ability to identify the whole population eligible for the health screen so that it can be offered to every eligible person.
• The extent to which information on the health screening programme is made available or advertised nationally or locally.
• The extent to which there is local engagement and partnership-working between the professionals undertaking the health screen and other support and professional staff, paid carers and organisations, to take forward recommendations identified from individual health screens. This includes the need for person-centred health management. The latter might include the need for further health promotion work, monitoring of health needs, health interventions or care or community supports.
• Appropriate monitoring of the health screening programme and the person-centred health management following an individual’s health screen.

Implementing a health screening programme across Scotland will be a significant undertaking, and will require considerable development work. There is no one organisation within Scotland that currently has the competency or capacity to develop the necessary technology that will be required to implement the programme locally. To avoid duplication of effort in all localities, it would be appropriate for the development work of the health screening programme to be undertaken centrally (in contact with local services), prior to local implementation. This will require co-ordination, utilising existing expertise from within the current small scale screening programmes that have been piloted in Scotland, primary and secondary health care staff, University staff and others engaged in such initiatives. If appropriately resourced, the SCLD is ideally suited to undertake this role in partnership with NHS Health Scotland and linked with the Scottish Executive lead for health improvement.

Aspects of the health screening programme for people with learning disabilities that could be supported nationally include support and guidance regarding:
• The way local databases might be used for identification of the population eligible for the health screen.
• Development of eligibility criteria.
• Guidance on possible methods for local implementation.
• Identification of staff competencies to undertake the health screen, the additional training programmes required, and access to these.
• Development of the health screening instrument, which must be determined by the population’s most prevalent, detectable and potentially correctable unmet health needs. No off-the-peg instruments are currently available to serve this purpose.
• Widespread dissemination of information / advertisement about the health screening programme for people with learning disabilities.
• Development of protocols for appropriate sharing of information from a person’s health screen.

Local implementation will require resourcing and will be a critical factor for success. Identified professional and administrative staff will be required to deliver the health screening programme, and networks of engagement for taking forward recommendations from the
health screens will be necessary. There should be an identified worker for each person with learning disabilities responsible for taking forward the recommendations from her / his health screen. This might be a care manager, local area co-ordinator, community learning disabilities nurse, or some other specifically named worker. This combination of person-centred health management, together with population-based health screening should optimise results, bringing added value that neither initiative would gain on its own. Health improvement outcomes could be further strengthened by the addition of robust monitoring of the person-centred health management following the health screen. Each person’s care review should include a review of the action points from her / his health screen, and any outstanding work. Local Learning Disabilities Fora could consider incorporating measures of percentage health screen uptake within the monitoring of commissioned support packages. Local acceptability, implementation and percentage uptake of the health screening programme for people with learning disabilities should be routinely monitored by NHS QIS as part of its programme of regular assessments across NHS Scotland, and by the Care Commission.

It is anticipated that approximately 18,000 adults and older adults with learning disabilities across Scotland would benefit from being offered access to the health screening programme. The exact number will depend on the eligibility criteria that are developed. A proportion of persons would of course decline to take advantage of this initiative, and such personal preferences should be respected. In the first stages of implementation, this programme should be offered to adults and older adults with learning disabilities. Consideration should be given to extending its remit to include children and young persons.

The Scottish Executive should additionally consider whether to extend the remit of the health screening programme for people with learning disabilities to take advantage of the opportunity it provides for longitudinal study. Such study could delineate the changes in health status of Scottish people with learning disabilities associated with starting to access a modernised, redesigned community service. The modernising policy changes introduced by The same as you?, now built upon with the health improvement agenda of this Health Needs Assessment Report, should start to improve health and reduce health disparity. Longitudinal study could start to understand how health improvement is achieved, and the successful components of this that could be further developed to the benefit of the Scottish population.

7.4.2 A NATIONAL AUDIT OF DEATHS

People with learning disabilities have a higher level of health need, often multiple and complex, than the general population, and importantly, these needs are often unrecognised by carers and professionals, and unmet. This failure to recognise and meet health needs where they are present has many causes and contributes to the health inequality, morbidity and premature deaths experienced by people with learning disabilities. Causes of deaths listed at death certification are recognised to be a poor marker of the factors which have contributed to the final cause of death, and indeed, the actual recorded cause of death is not infrequently inaccurate. In New South Wales, Australia, a mandatory requirement to report the deaths of all persons with learning disabilities in care settings, whatever the cause, was introduced. The factors surrounding and potentially contributing to the death were then retrospectively studied in each case. This initiative identified many contributory factors, from obviously preventable deaths due to injuries and accidents, to less obvious contributory factors such as poor service co-ordination and lack of access to trained professionals,
educational needs of staff, chronic neglect of health needs, and systemic failures such as in staff support and unit policies. Review of national and international research, policy and practice, has demonstrated that this is an outstanding initiative which has led to demonstrable improvements in systems and supports to reduce the likelihood of premature, preventable deaths in care settings.

Within Scotland, recent high-profile cases suggest that in some cases system-failures or other factors have contributed to some deaths. The experience in New South Wales suggests that many other cases will have passed unrecognised. The Mental Welfare Commission is responsible for protecting the welfare of people with learning disabilities when in hospitals, cared for by Local Authorities, the independent and private sectors or in their own homes. Revised guidance on reporting significant accidents and incidents was issued in November 2000. However, only a minority of deaths are reported and review of incidents is not comprehensive. Experience from New South Wales indicates that many apparent “natural deaths”, when reviewed, were found to have had potentially remediable or preventable contributory factors i.e. the deaths where lessons were learnt from the audit were not necessarily those where there had been any immediate suspicion of potentially preventable factors – as the relevant factors had been overlooked. Hence in Scotland, at present there would be no expectation that deaths similar to those in New South Wales are reported to the Mental Welfare Commission.

The Learning Disabilities Health Needs Assessment Reference Group were unable to find any data on the number of deaths of people with learning disabilities in care settings in Scotland. Estimates based on data from Greater Glasgow suggest a possible 240 deaths per year across Scotland of people with learning disabilities in care settings, but the accuracy of this figure is uncertain.

In order to learn and change the factors contributing to preventable premature deaths of people with learning disabilities in Scotland, a process similar to that in New South Wales should be established. This should be an integral part of standard good practice and governance (in the same way that critical incidents are already reviewed in NHS Scotland). This work should be led by the Mental Welfare Commission working with the Care Commission. All deaths of persons with learning disabilities in a care setting should be reported, regardless of the apparent cause or age of the person. The Mental Welfare Commission / Care Commission should be resourced to comprehensively review each individual case and make recommendations based on individual findings. This provides a framework for “external” review, which is important. Findings should be published. This work will contribute importantly to national governance, and will lead to improved quality of life of persons with learning disabilities, as well as longer life.

The individual reviews should adopt a learning model, and consider the wider whole-systems factors contributing to a person’s death, not just the role of individual staff. To ensure maximal co-operation of staff it is suggested that staff names should remain confidential, as well as the name of the person with learning disabilities, except in any small minority of cases where there are personal or professional inadequacies in standards requiring disciplinary procedures and / or reporting to professional regulatory bodies. Family carers of a person with learning disabilities who has died at home should be allowed to opt-in to this review.
process if they wish: reporting of all deaths that occur in non-family care settings should be mandatory.

It is suggested that these reporting / review arrangements should occur over a 2 year period, with an additional six month lead-in period to establish processes and to accurately predict and project in more detail the scale of such an audit.

Robust mechanisms will be required in each care setting to identify a manager responsible for reporting any deaths, and in each locality to provide any required professional, managerial or support staff to contribute to the reviews. Implementation of recommendations should be the responsibility of the Joint Future local partnership / Learning Disabilities Forum (due to their delivery, organisation or planning of services, and their commissioning and monitoring of supports from other providers) and Community Health Partnerships. NHS QIS, the Care Commission and Mental Welfare Commission will all have roles in reviewing local implementation of recommendations.

The audit will identify key issues contributing to deaths, which should be used to develop a wider work programme for improved quality of life and longer life for persons with learning disabilities. NHS QIS should take this forward with local services e.g. through guidance, standards, practice developments.

7.4.3 A REDESIGNED PRIMARY HEALTH CARE SERVICE

The evidence has demonstrated that people with learning disabilities have difficulties accessing primary health care services: there are many reasons for this. GPs and other primary care staff receive little or no training in working with people with learning disabilities during undergraduate training and postgraduate vocational training, and the small number of persons with learning disabilities on their lists at any one time means it is difficult for them to gain experience once in practice. The average GP will be unaware of the different pattern of health needs experienced by people with learning disabilities, compared with the general population (and most work on the incorrect assumption that “common things are commonest”). Problems are compounded by the complexity of health need, communication difficulties, the tight appointment systems and reactive rather than proactive care necessary in busy practices.

The new GP contract, the implementation of which is currently being negotiated across the four U.K. countries, presents an opportunity to change this disadvantage experienced by people with learning disabilities. It is important that within these contractual arrangements, the needs of people with learning disabilities are clearly addressed. Provision of service for people with learning disabilities is listed as a possible group in the new contract for a local “enhanced service”. Given the current extreme disparity in health indicators, and the need for a more equitable service, it is recommended that for people with learning disabilities, “local” refers to Scotland-wide, with a Scottish service specification for an enhanced service and funding made available for local implementation across Scotland (rather than at the discretion of each locality). The enhanced service specification should include the requirement for completing education on health needs of people with learning disabilities, a flexible approach to appointments, working with carers and other professionals, and implementation of Part V of the Adults With Incapacity (Scotland) Act, 2000. The provision of
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the enhanced service might be by all practices in the Community Health Partnership, or by selected practices, depending which model is best fitted to local needs.

In addition to the work with people with learning disabilities undertaken by all or most GP practices, the creation of Community Health Partnerships provides a locality structure for the development of one-stop health clinics for people with learning disabilities. These could provide on one site a group of primary care professionals with a particular interest in developing expertise in working with people with learning disabilities. This might include doctors, nurse practitioners, audiologists, opticians and therapists who could provide additional assessment, investigation, treatment and monitoring for physical health needs at a level beyond that appropriately managed within the enhanced GP service provided by all or most practices. Bringing together a number of professionals from cognate disciplines, interested in developing their learning disabilities expertise, will have the added value of team working and opportunities for professionals to learn from each others’ work. The one-stop health model would not be a replacement for existing GP and primary care services, it would be additional and complementary to them, bringing a greater level of expertise than that that can ever be available in ordinary primary care services. It also could develop as a training resource for GPs and primary health care professionals not employed to work in the one-stop health clinic, but working in practices providing an enhanced service for people with learning disabilities.

It is important that the specialist learning disabilities service works in partnership with primary care services to support the needs of persons with learning disabilities and their carers. There is a role for learning disabilities health professionals in facilitating primary care, through a range of approaches. These include offering education and training, promoting awareness of the needs of people with learning disabilities, and facilitating primary care to improve access for people with learning disabilities. It is likely that community learning disabilities nurses, together with other learning disabilities health professionals, have the required skills to develop and provide this role. This could be provided through the establishment of a dedicated team of learning disabilities professionals to support primary care, or through locating learning disabilities professionals within Community Health Partnerships / primary care services. In the latter case, arrangements for peer support, audit and continuing professional development would need to be explicit with clear arrangements to reduce the effects of service fragmentation. This partnership between learning disabilities health professionals and primary care also provides one of several possible models through which the health screening programme for people with learning disabilities could be delivered locally. It is recommended that these partnership arrangements are developed in addition to the enhanced GP service and one-stop health clinics.

The Centre for Change and Innovation (CCI) was established in November 2002 within the Scottish Executive to provide NHS staff with practical support and expertise to improve care. The CCI supports the development of solutions to problems and supports national initiatives and priorities. One of their project areas, The National Primary Care Collaboration, aims to improve the experience and outcomes of every person by identifying and removing the barriers that cause delay and restrict access to services in primary care. This collaboration should be charged to consider specifically the needs of people with learning disabilities within its work. The CCI should develop its work programme to include support for the development of integrated health and social care services for people with learning disabilities.
7.4.4 SUPPORTING PERSONS WITHIN HOSPITAL SETTINGS
The multiple complex health needs of persons with learning disabilities mean that they require assessment and interventions from all health service specialties. The difficulties people encounter in accessing primary care services are also experienced in secondary care settings. The difficulties are compounded when persons require a period of in-patient treatment. At such times, the discrimination experienced by persons with learning disabilities can be overt and deliberate, or may be more subtle and unintentional. Both types of discrimination result from ingrained institutional practices that have passed unchallenged for too long. The staff within the acute sector are largely caring, skilled and dedicated to their work – there just has not been the expectation that they think about and are educated on these issues. Additionally, the complex nature of health needs and the additional developmental and communication needs of persons with learning disabilities means that many acute sector staff feel out of their depth when working with the person.

Specialist learning disabilities staff have a role to play in supporting the health staff working in other sectors, to improve care. Agreement should be reached and protocols developed between the acute services operating units and learning disabilities service and Community Health Partnerships, so that specialist learning disabilities advice and support can be provided for all persons admitted to any hospital within 24 hours of admission in all cases and usually within 4 hours, if they require it. Such support should also enable the service to comply with the Disability Discrimination Act, 1995, Adults with Incapacity (Scotland) Act, 2000 and Human Rights Act, 1998. A learning disabilities liaison service should be resourced. The acute sector should additionally include the needs of people with learning disabilities, an appropriate value-base, and relevant legislation in its induction of all new staff (not just health professionals).

7.4.5 DEVELOPING SPECIALIST LEARNING DISABILITIES SERVICES
Specialist learning disabilities services are an essential part of the range of services that need to be available for persons with learning disabilities. Joint Future will lead to more integrated working of health and social work staff within joint community services. Specialist learning disabilities community teams must also work in partnership with the local community, primary care and other secondary care services. It is important that the experience of services from the user’s perspective is seamless. Specialist learning disabilities services have important roles to play in training, facilitating access to mainstream services, health promotion, health screening and provision of specialist assessments, interventions, and monitoring and where necessary redesigning these. Specialist assessments and interventions are most usually conducted in the community, but occasionally require admission of the person to a specialist in-patient facility. Access to both community team based and in-patient specialist services is therefore important. The current provision of specialist multidisciplinary services for adults and older adults with learning disabilities is variable in quantity and scope of resource across Scotland. For children with learning disabilities and mental health needs / problem behaviours there is a service gap in most areas of Scotland.

All Joint Future local partnerships / Community Health Partnerships should review the capacity and skill mix of specialist learning disabilities professionals within their childrens teams and adult / older adult learning disabilities teams. They should ensure there is an adequate
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quantity and range of skills within the teams from allied health professionals, nurses, clinical psychologists, social workers, paediatricians, and learning disabilities psychiatrists. There should be an explicit referral pathway to access the specialist learning disabilities skills required to assess and manage children and adolescents with learning disabilities and mental ill-health / problem behaviours in addition to such services being available for adults and older adults. This could be through the provision of dedicated child and adolescent learning disabilities teams, which would develop working relationships with child development teams, child and adolescent mental health services and the adult learning disabilities services (particularly to facilitate transition).

The public health capacity with specialist knowledge of the needs of people with learning disabilities should also be reviewed and developed, to improve this function within Community Health Partnerships. NHS Health Scotland should lead this work.

Access to a specialist learning disabilities in-patient provision for short term assessment and treatment should be available for persons living in the communities of all areas. These should be locally based, but arrangements contracted between NHS Boards may be necessary to accommodate the needs of people living in some island communities.

The Auditor General for Scotland is an independent person who reports to the Scottish Parliament and is responsible for the work of Audit Scotland. Audit Scotland works by investigating on behalf of the Auditor General aspects of how public bodies work, by conducting audit checks to ensure finances are managed to the highest standards and achieve best value for public money. This includes baseline reports and subsequent checks to assess improvement in performance.

Audit Scotland could provide a valuable role in reviewing services for people with learning disabilities across Scotland, the cost of services, the extent of evidence-based planning and commissioning of services, and advising Joint Future local partnerships and Community Health Partnerships to achieve best value for health improvement in future.

7.4.6 MANAGED CLINICAL / CARE NETWORKS

Scottish Executive policy supports the development of Managed Clinical Networks and Managed Care Networks. These comprise health professionals from primary, secondary and tertiary care, together with other partners, working in a co-ordinated manner, across organisational boundaries. This aims to enable equitable provision of high quality effective health care and services throughout Scotland. These arrangements are new, and hence an evidence-base on effectiveness has not yet been established. Outcomes should be evaluated. Managed Clinical / Care Networks could be further developed across Scotland and may include national Networks for highly specialised low incidence needs. Such arrangements may help offer a source of advice and expertise for people with learning disabilities living in rural and remote communities. Examples might be in facilitating access to primary care services; mental health services for children and adolescents with learning disabilities; people with forensic needs; people with profound learning and multiple physical disabilities; people requiring palliative care; older people with learning disabilities and people with dementia; people with learning disabilities who have epilepsy. This list is not exhaustive.
7.4.7 INDEPENDENT ADVOCACY
Raising the expectations of service users and their carers is an important contributor to continually improving services. Too often, people are grateful for receiving any service at all, and do not like to complain where there are shortcomings. High quality services provide robust complaints systems and are keen to learn from both positive and negative experiences brought to their attention by service users and carers. It can be difficult for persons to communicate their needs and wishes, to be assertive, or to complain, if they are in a dependant position, are unwell or vulnerable. The provision of independent advocacy is important, but is not widely available across Scotland. The impending change with the introduction of the Mental Health (Care and Treatment) (Scotland) Act, 2003 includes specific requirements for access to advocacy services. It is recommended that independent advocacy is made available for all persons with learning disabilities using any health or social work services, whether in the community or any hospitals. This will require an increase on current capacity.

7.4.8 RECOMMENDATIONS: INTERVENTIONS
11. A specific health screening programme for people with learning disabilities should be established and implemented locally to a set of national standards. Local responsibility should lie with the Learning Disabilities Forum and Community Health Partnership. National support should be resourced to co-ordinate the development of the necessary technology and guidelines required to implement the programme locally. This national role could be undertaken by NHS Health Scotland and SCLD in partnership. Local resourcing for implementation will also be required. In addition, person-centred health management should be in place locally for each person with learning disabilities from a named worker, who is responsible for actioning recommendations from the health screen. Robust monitoring of the person-centred health management following the health screen should be established locally, in addition to external monitoring via NHS QIS and the Care Commission and the NHS Performance Assessment Framework.

12. Over a 2 year period, national governance should be developed by all deaths of persons with learning disabilities that occur in any non-family care setting being reported and comprehensively reviewed, regardless of the immediately apparent cause of death. Each care setting should have an identified manager who has a mandatory responsibility for reporting any death in that setting during this period. The Mental Welfare Commission should work with the Care Commission to lead the individual comprehensive reviews, within a culture of learning and a whole-systems approach, and provide individual recommendations. Implementation of recommendations should be reviewed by NHS QIS and the Care Commission, and locally by the Joint Future local partnership and Community Health Partnership. NHS QIS should take forward the wider work programme once the key issues from the audit are identified e.g. through guidance, standards and practice development.

13. The Scottish Executive should develop a Scottish service specification for an enhanced service for people with learning disabilities, to be offered across all of Scotland as part of the new GP contract. This should include the need for additional education on the needs of people with learning disabilities, a requirement to work in partnership with others, implementation of Part V of the Adults With Incapacity (Scotland) Act, 2000, and a flexible approach to appointments.
14. One-stop health clinics for people with learning disabilities should be established within Community Health Partnerships. These should be staffed by primary health care professionals working in partnership with other professionals, allowing access to a higher level of expertise than that that can ever be available via ordinary primary care services. They are in addition to recommendation 13.

15. The Scottish Executive Centre for Change and Innovation should specifically consider the primary care needs of people with learning disabilities within its programme of work.

16. *Joint Future* local partnerships and Community Health Partnerships should ensure that specialist learning disabilities health professionals are available to facilitate access to primary care, through a range of educational and liaison approaches. A learning disabilities liaison service should also be established for all hospital settings. Protocols should be developed between the acute hospitals, specialist learning disabilities service and Community Health Partnerships so that specialist advice and support can be provided for all persons who require it, admitted to any hospital within 24 hours of admission in all cases and usually within 4 hours. This should be monitored by NHS QIS.

17. All *Joint Future* local partnerships / Community Health Partnerships should review the capacity and skill mix of specialist learning disabilities professionals within their childrens teams and adult / older person learning disabilities teams. They must have multidisciplinary specialist learning disabilities services in place and should ensure an adequate quantity and range of skills across disciplines. There should be in each locality an explicit referral pathway to access the specialist skills required to assess and manage children and adolescents with learning disabilities and mental ill-health / problem behaviours, as well as for adults and older persons. This should be reviewed by NHS QIS. The public health capacity with specialist knowledge of the needs of people with learning disabilities should be developed, to improve this function within Community Health Partnerships: NHS Health Scotland should support this development.

18. Audit Scotland should be invited to conduct an independent review of the variability across Scotland, of services designed specifically for use by persons with learning disabilities. This should consider the capacity and skill-mix to meet the health improvement needs of people with learning disabilities in services locally, and the extent of evidence-based planning and commissioning of services, as well as spending on resources. This should enable *Joint Future* local partnerships and Community Health Partnerships to achieve best value in future.

19. The Scottish Executive and Community Health Partnerships should support the development of Managed Clinical / Care Networks across Scotland, to improve the health of children, adults and older adults with learning disabilities. This should include national networks for highly specialised low incidence needs.

20. Independent advocacy should be available for all persons with learning disabilities using any health or social work services, whether in the community or hospital.
7.5 INFORMATION

7.5.1 HEALTH IMPROVEMENT INFORMATION AND NETWORKS
There are considerable efforts taking place across Scotland to identify, produce and disseminate health improvement information. This includes the work of many organisations e.g. F.A.I.R., Sense Scotland and R.N.I.B., in producing accessible health information; and the work of community learning disabilities teams and health promotion units in developing accessible health promotion materials. Establishing a library resource of accessible information would be beneficial. The SCLD are active in disseminating information on best practice. Health promotional activities need to be an integral part of Personal Life Plans. Considerable work is taking place within Community Child Health Services (see the Scottish Framework for Nursing in Schools and Promoting Health, Supporting Inclusion), and needs to be taken forward within adult learning disabilities services. Better co-ordination may also help maximise these endeavours.

NHS Health Scotland has developed Scotland-wide learning and support networks to share and develop evidence, best practice and policy. A co-ordinated Learning Disabilities Health Improvement Network with a Scotland-wide focus could contribute to establishing, supporting and sustaining best practice. The work will need to be linked to national health improvement priorities and supported locally by Community Health Partnerships, health promotion departments and Joint Future local partnerships. The SCLD C.A.N. and the NHS Health Scotland could jointly further develop this work.

7.5.2 DIRECTLY-ACCESSED HEALTH CARE PROVIDERS
In some parts of Scotland, carers report difficulty in obtaining directly-accessed health services such as podiatry, optometry and dental care. Sometimes the problem is due to staff feeling unskilled in working with persons with learning disabilities, lacking the additional support to facilitate access, lack of time and capacity, and problems implementing the Adults with Incapacity (Scotland) Act, 2000. Where there are directly-accessed health services that can be accessed and with staff willing and able to work with persons with learning disabilities, family carers value and appreciate them. Some such professionals are available within mainstream independently-contracted services; others are more specialist resources, employed and directly provided by NHS services such as specialist learning disabilities community podiatrists and specialist NHS dental services. These latter examples, where available in Scotland, were found to be highly valued by service users and carers. They have a wealth of experience that can be drawn upon and potentially shared with other colleagues to support education and development.

NHS Health Scotland should develop its Scotland-wide work together with Joint Future local partnerships and Community Health Partnerships to identify all directly-accessed health services in each area who provide a service to persons with learning disabilities. Initial work has already been undertaken. This information should be made available locally to persons with learning disabilities and their carers, and to community learning disabilities professionals and support workers. Responsibility for updating could rest with Community Health Partnerships, via the one-stop health clinics. Additionally, the mapping exercise will enable NHS Health Scotland to support the development of a network of practitioners with an interest in sharing experience, best practice, and developing their skills in working with people with learning disabilities.
7.5.3 THE NEEDS OF MARGINALISED GROUPS
People with learning disabilities from any background are at risk of exclusion, and having unmet health needs contributes to this. It is likely that persons with learning disabilities from ethnic minority communities or who are asylum seekers or refugees will have needs distinct from others, and may require particular types of supports to improve their health. This may also be true for persons with learning disabilities who are homeless. Work should be undertaken to identify the health improvement needs of such persons. The National Resource Centre for Ethnic Minority Health, within NHS Health Scotland has started to address this issue and to undertake an exercise to identify health experiences and needs.

7.5.4 RECOMMENDATIONS: INFORMATION
21. SCLD and NHS Health Scotland should be resourced to identify, evaluate, promote and disseminate health improvement information and co-ordinate initiatives across Scotland. This could take the form of a national learning disabilities health improvement network.

22. NHS Health Scotland should build upon its current work by leading an exercise for local usage, to identify the directly-accessed health services in each area that provide a service to persons with learning disabilities, and developing a network for directly-accessed practitioners working with persons with learning disabilities.

23. NHS Health Scotland should extend its work to identify the health experiences and needs of persons with learning disabilities from ethnic minority communities, or who are asylum seekers, refugees or are homeless.

7.6 EDUCATION
7.6.1 STAFF INDUCTION WITHIN NHS SCOTLAND
Induction programmes are provided for all new staff employed by NHS Scotland. An introduction to the needs of persons with learning disabilities, an appropriate value-base, available supports, disability equality training, the local discrimination policy, and the requirements to comply with the Adults with Incapacity (Scotland) Act, 2000*, Disability Discrimination Act, 1995* and Human Rights Act, 1998* could be incorporated into all induction programmes. This should include written information packs in addition to training time set aside as part of the induction programme. There are a variety of educational methods which could be employed. Training could be provided “in-house” by each NHS operating unit. There may be a role for the learning disabilities liaison service within the acute hospital and the learning disabilities liaison team within Community Health Partnerships, and community learning disabilities teams. The SCLD could be contracted to contribute to or provide training. Employing persons with learning disabilities to deliver induction training would provide a particularly valuable learning experience for newly appointed staff. All NHS operating units should include the needs of persons with learning disabilities within the induction of all newly appointed staff (not just health professionals). This should be robustly monitored within the NHS Performance Assessment Framework and by NHS QIS.

7.6.2 PREREGISTRATION TRAINING AND LIFELONG LEARNING
We need a workforce that knows about the needs of people with learning disabilities, is not afraid of disability, treats people with respect, and works in partnership with persons with disabilities, family carers and with other professions.
NHS Education for Scotland (NES) is working to implement the educational recommendations (16, 17 and 20) from *Promoting Health, Supporting Inclusion*. Common learning outcomes about people with learning disabilities have been set for the nursing common foundation programme across Scotland and new learning materials developed to enable all student nurses to achieve these outcomes. NES is developing learning outcomes for all levels of nurse education which are linked to the Scottish Benchmark Statement on Nursing. These developments should raise awareness of the values required of all nurses, develop specific health knowledge and competencies in learning disabilities nurses and child health nurses, and provide a framework for continuing professional development. NES is also developing a set of health competencies across diverse health needs for support staff. This work should be extended to include other groups of health professionals.

Central to the agenda for the improvement of health within Scotland is the recognition that there needs to be a workforce with the skill, knowledge and attitudes necessary to improve and promote health. This requires engagement with people with learning disabilities, their families and paid carers, learning disabilities health specialists working in the NHS, Local Authority professionals, academics, the voluntary sector, local and national government departments and other practitioners working directly with people with learning disabilities. The health outcomes should be geared to health improvement and reducing health inequalities and wherever possible supporting and enabling people with learning disabilities to promote and improve their own health. Both generalists and specialists have important roles to play in improving health, although the contributions and skills required will clearly vary.

Most health professionals come into contact with persons with learning disabilities as part of their everyday health role: this may be frequent, but for others it is infrequent. Except for specialist learning disabilities health professionals, preregistration and post registration educational programmes typically have no or very limited reference to the needs of persons with learning disabilities. Many health professionals recognise their limited knowledge and experience of working with people with learning disabilities. This requires strategic review, with a view to identifying and incorporating core learning disabilities issues within educational programmes. It is however also necessary to be clear what education prepares practitioners to do and the level at which they can practice safely and independently.

Education should focus on and equip practitioners and others to develop communication skills, to recognise the wishes of and the common health needs of people with learning disabilities, and when and how to access additional learning disabilities specialist support. Disability equality awareness is important as is awareness of legislative requirements. Programmes for specialist learning disabilities professionals will require a higher level of development of specific competencies and knowledge. In some circumstances, learning can be more effective when undertaken in a multi-disciplinary and multi-professional forum, and potential for such learning opportunities should be identified and utilised. Employing persons with learning disabilities to educate students and professionals can provide a particularly valuable learning experience. In this way, over a period of time, developing respect will replace discrimination.

The Scottish Social Services Council is a new organisation, responsible for raising and developing standards in the Scottish social service workforce. The Council aims to develop a
RECOMMENDATIONS

social care workforce that is competent, confident and able to deliver high quality services that have the confidence of the public, and those who use services and their carers. A national training strategy is being developed which will provide a framework for enhancing the skills and competencies of the social care workforce in a way appropriate to Scottish needs, drawing on existing good practice and compatible with the Scottish Credit and Qualifications Framework.

The care and support of people with learning disabilities is an area of practice where health and social work professionals have a history of joint working and collaboration. This has increased through the introduction of Joint Future®. There is a need to support social work professionals to continue to develop their understanding of the health issues that impact on people with learning disabilities as well as their capacity to contribute to the wider health improvement of the people of Scotland. Health professionals benefit from understanding the social work contribution to health improvement as well as that of family and paid carers. There is scope for collaboration between NES and the Scottish Social Services Council. This creates opportunities for development of educational material and shared learning between health and social care professionals around wider health improvement and the health needs of people with learning disabilities.

Few, if any, health care professionals have extensive experience and competence to meet the full range of health needs of people with learning disabilities. It is not possible or indeed appropriate to pretend that this can be achieved. The role of learning disabilities specialists is therefore important and they must be enabled to utilise their skills to support others both within and outwith NHS Scotland. It is important that there is an expansion of public health capacity, appropriate to the needs of people with learning disabilities. On-going professional and career development opportunities for specialists in Community Child Health teams and Learning Disabilities Services are necessary.

Directly accessed health care providers working with children, adults or older adults with learning disabilities should also have opportunity to participate in education and practice development initiatives that will better prepare them in their work. Education and support needs to be available locally. Local Community Learning Disabilities Teams may have a role to play to support this, linking with the important work of local area co-ordinators with families and individuals, working across local communities.

The national centres of excellence (Criminal Justice Social Work Development Centre for Scotland, Dementia Services Development Centre, SCLD, Scottish Institute for Residential Child Care, and Scottish Training on Drugs and Alcohol) provide a resource for training and best practice which is informed by research and knowledge of practice needs.

7.6.3 TRAINING FOR FAMILY CARERS AND PAID CARERS

Paid and family carers make important contributions to supporting and improving the health of persons with learning disabilities. It is essential that such roles continue and are enabled and developed. Family carers become highly experienced in providing health care for their family member with learning disabilities, and are usually the person most likely to detect ill-health at an early stage. It is important that professionals utilise the skills of carers when working with persons with health needs, and also support carers in continuing to develop their health care
skills. It is essential that employers of support and sessional workers induct and develop their staff: this should include recognition of contributions towards supporting health and enabling health improvement. Commissioners of support packages should specify the need for staff development, including health care responsibilities, within their contracts with providers: they should also maintain robust mechanisms for monitoring these. The SCLD has a training remit for paid and family carers: it is important that this work continues.

7.6.4 RECOMMENDATIONS: EDUCATION

24. All NHS operating units should include the needs of persons with learning disabilities within the induction of all newly appointed staff. These arrangements should be fully operationalised by 2005. There should be robust monitoring within the NHS Performance Assessment Framework, and by NHS QIS.

25. NHS Education Scotland should expand its work with the SCLD to review and develop the learning disabilities component of all preregistration health professionals’ training programmes building upon current competency framework developments. NHS Education for Scotland, the Scottish Social Services Council and the SCLD should work with Higher Education Institutions across Scotland to support the development and inclusion of learning disabilities modules within post qualifying and post graduate programmes, and to make available post registration educational programmes for directly accessed health care providers. The training remit of SCLD with paid and family carers should continue to be developed and supported.
CHAPTER EIGHT
SUMMARY OF RECOMMENDATIONS

Detail is presented on the recommendations in the text of Chapter 7. This Chapter contains only the list of recommendations without further explanation, or guidance. Several of these recommendations seek to build upon work already starting or in progress in Scotland, and reinforce recommendations presented previously\(^1\),\(^2\). All new developments and interventions that are recommended are strongly supported by the evidence identified by the Health Needs Assessment.

Structures are configured differently in different parts of Scotland. In this Health Needs Assessment Report the term Joint Future local partnership refers to the senior level grouping bringing together the partners in a locality responsible for overall strategy across all community care groups. The term Learning Disabilities Forum is an unofficial term adopted only for the purpose of this report to refer to the local grouping with delegated responsibility for developing and implementing learning disabilities strategy, the Partnership-in-Practice agreement, and for learning disabilities service delivery within the Joint Future agenda on behalf of and in keeping with the strategy of the Joint Future local partnership. It is recognised that across different parts of Scotland structures are configured differently, a variety of terminologies are used, and the two groupings described above may overlap or be the same in some areas. Community Health Partnerships are in the process of development across Scotland. In some but not all parts of Scotland there is coterminosity between the Community Health Partnership and Joint Future local partnership. A clear relationship between the two is important with defined responsibilities, though these may differ in different parts of Scotland, in order to meet local needs.

A. LEADERSHIP AND ACCOUNTABILITY
1. The Scottish Executive should take responsibility for ensuring national action to improve the health of people with learning disabilities. A named lead for health improvement should be identified / appointed and work with the responsible individuals within Departments across the Executive. Responsibilities include:
   • Ensuring the health needs of persons with learning disabilities are considered in all policy initiatives.
   • Development and implementation of a Learning Disabilities Health Strategy Statement.
   • Supporting and monitoring the implementation of the Health Needs Assessment
Report recommendations (or monitoring a delegated responsibility for this to NHS Health Scotland).

- Introducing robust monitoring arrangements, via the NHS Performance Assessment Framework, NHS QIS and the Care Commission.
- Issuing guidance to Joint Future local partnerships, Learning Disabilities Fora and Community Health Partnerships, including local development of a health improvement strategy, implementation of the health screening programme for people with learning disabilities, and stamping out institutional discrimination.

2. All Joint Future local partnerships should have a local health improvement strategy to meet the specific needs of children, adults and older adults with learning disabilities within their wider strategy for health improvement. This should be developed and implemented locally by the Learning Disabilities Forum and the Community Health Partnership. A named person should be identified/appointed to lead this work: consideration should be given to this role being combined with that of lead for clinical governance and standards within the local Learning Disabilities Service. Component parts within the strategy should include:

- A mechanism to ensure inclusion of people with learning disabilities in all local health initiatives.
- A local Learning Disabilities Health Strategy Statement.
- Elimination of institutional discrimination within the local NHS Scotland.
- A programme of health promotion appropriate to the needs of people with learning disabilities.
- Specific interventions to reduce health inequalities.
- Clinical Governance and Standards.
- Local assessment of health needs and services.
- Development of the Single Shared Assessment to include health improvement.

3. The local health improvement strategy for children, adults and older adults with learning disabilities should be included explicitly within the Partnership-in-Practice agreement. The PiP should also address how the work to develop local protocols will be co-ordinated to address service interfaces and provide a clear description of accessible pathways of care. This will require integrated working locally between the Learning Disabilities Forum and the Community Health Partnership in each area.

4. Specialist learning disabilities services should continue to develop and be managed within a Joint Future model of service delivery and planning across all of tiers 0 – 4. A clearly defined relationship should be established between Community Health Partnerships and the Specialist Learning Disabilities Service, particularly with regards to the development and operation of primary health care services and public health functions, and transition from children’s to adult services.

B. INFRASTRUCTURE: DEVELOPMENT, PLANNING AND MONITORING

5. Learning Disabilities Fora should each establish a continually updated local database for people with learning disabilities by 2006. Local databases must be compliant with the National Learning Disabilities Core Data Set developed by the eSAY project managed by SCLD. Learning Disabilities Fora should be required to export anonymised data from their local database to the national database developed by the eSAY project. The eSAY project should be expanded to provide support for local database development across all areas of Scotland.
6. The Scottish Executive should establish a sustainable programme of research for health improvement for people with learning disabilities. The programme should be inter-disciplinary and cut across traditional boundaries, working across primary and secondary health care. The U.S.A. U.A.P.s provide a model for this which Scotland could adopt and develop.

7. The Scottish Executive should further support health improvement research by commissioning project research into the development of valid measures that can be used for health assessment, health outcome, quality of life, and service access; by resourcing further development of the SCLD C.A.N.; and reviewing the Code of Practice regarding the research component of Part V of the *Adults with Incapacity (Scotland) Act, 2000*.  

8. NHS QIS and the Care Commission should work together to ensure that NHS Scotland and partners develop health improvement initiatives across all care settings, and monitor implementation of the Health Needs Assessment Report recommendations. They should facilitate continual improvement by identifying a health improvement area for national focus and development every other year, to be included in the following year’s NHS Performance Assessment Framework, in addition to their own framework.

9. NHS QIS should explore the feasibility of a Health Technology Assessment on drug treatments and psychological interventions for adults with learning disabilities and problem behaviours, mental ill-health, ADHD or dementia.

10. S.I.G.N. should be invited to extend its membership of S.I.G.N. Council by inviting representation from SCLD of someone with knowledge of the health needs of people with learning disabilities. S.I.G.N. should be requested to amend its procedure, such that after a proposal is selected for the guideline development programme, the Mental Health and Learning Disabilities Specialty Subgroup of S.I.G.N. discuss the need for someone with relevant knowledge and experience to contribute to the guideline development group. Where appropriate, suitable individuals should be proposed to the Chairman and programme manager of the guideline development groups.

C. INTERVENTIONS

11. A specific health screening programme for people with learning disabilities should be established and implemented locally to a set of national standards. Local responsibility should lie with the Learning Disabilities Forum and Community Health Partnership. National support should be resourced to co-ordinate the development of the necessary technology and guidelines required to implement the programme locally. This national role could be undertaken by NHS Health Scotland and SCLD in partnership. Local resourcing for implementation will also be required. In addition, person-centred health management should be in place locally for each person with learning disabilities from a named worker, who is responsible for actioning recommendations from the health screen. Robust monitoring of the person-centred health management following the health screen should be established locally, in addition to external monitoring via NHS QIS and the Care Commission and the NHS Performance Assessment Framework.
12. Over a 2 year period, national governance should be developed by all deaths of persons with learning disabilities that occur in any non-family care setting being reported and comprehensively reviewed, regardless of the immediately apparent cause of death. Each care setting should have an identified manager who has a mandatory responsibility for reporting any death in that setting during this period. The Mental Welfare Commission should work with the Care Commission to lead the individual comprehensive reviews, within a culture of learning and a whole-systems approach, and provide individual recommendations. Implementation of recommendations should be reviewed by NHS QIS and the Care Commission, and locally by the Joint Future local partnership and Community Health Partnership. NHS QIS should take forward the wider work programme once the key issues from the audit are identified e.g. through guidance, standards and practice development.

13. The Scottish Executive should develop a Scottish service specification for an enhanced service for people with learning disabilities, to be offered across all of Scotland as part of the new GP contract. This should include the need for additional education on the needs of people with learning disabilities, a requirement to work in partnership with others, implementation of Part V of the Adults with Incapacity (Scotland) Act, 2000 and a flexible approach to appointments.

14. One-stop health clinics for people with learning disabilities should be established within Community Health Partnerships. These should be staffed by primary health care professionals working in partnership with other professionals, allowing access to a higher level of expertise than that that can ever be available via ordinary primary care services. They are in addition to recommendation 13.

15. The Scottish Executive Centre for Change and Innovation should specifically consider the primary care needs of people with learning disabilities within its programme of work.

16. Joint Future local partnerships and Community Health Partnerships should ensure that specialist learning disabilities health professionals are available to facilitate access to primary care, through a range of educational and liaison approaches. A learning disabilities liaison service should also be established for all hospital settings. Protocols should be developed between the acute hospitals, specialist learning disabilities service and Community Health Partnerships so that specialist advice and support can be provided for all persons who require it, admitted to any hospital within 24 hours of admission in all cases and usually within 4 hours. This should be monitored by NHS QIS.

17. All Joint Future local partnerships / Community Health Partnerships should review the capacity and skill mix of specialist learning disabilities professionals within their childrens teams and adult / older person learning disabilities teams. They must have multidisciplinary specialist learning disabilities services in place and should ensure an adequate quantity and range of skills across disciplines. There should be in each locality an explicit referral pathway to access the specialist skills required to assess and manage children and adolescents with learning disabilities and mental ill-health /
problem behaviours, as well as for adults and older persons. This should be reviewed by NHS QIS. The public health capacity with specialist knowledge of the needs of people with learning disabilities should be developed, to improve this function within Community Health Partnerships: NHS Health Scotland should support this development.

18. Audit Scotland should be invited to conduct an independent review of the variability across Scotland, of services designed specifically for use by persons with learning disabilities. This should consider the capacity and skill-mix to meet the health improvement needs of people with learning disabilities in services locally, and the extent of evidence-based planning and commissioning of services, as well as spending on resources. This should enable Joint Future local partnerships and Community Health Partnerships achieve best value in future.

19. The Scottish Executive and Community Health Partnerships should support the development of Managed Clinical / Care Networks across Scotland, to improve the health of children, adults and older adults with learning disabilities. This should include national networks for highly specialised low incidence needs.

20. Independent advocacy should be available for all persons with learning disabilities using any health or social work services, whether in the community or hospital.

D. INFORMATION
21. SCLD and NHS Health Scotland should be resourced to identify, evaluate, promote and disseminate health improvement information and co-ordinate initiatives across Scotland. This could take the form of a national learning disabilities health improvement network.

22. NHS Health Scotland should build upon its current work by leading an exercise for local usage, to identify the directly-accessed health services in each area that provide a service to persons with learning disabilities, and developing a network for directly accessed practitioners working with persons with learning disabilities.

23. NHS Health Scotland should extend its work to identify the health experiences and needs of persons with learning disabilities from ethnic minority communities, or who are asylum seekers, refugees or are homeless.

E. EDUCATION
24. All NHS operating units should include the needs of persons with learning disabilities within the induction of all newly appointed staff. These arrangements should be fully operationalised by 2005. There should be robust monitoring of this within the NHS Performance Assessment framework, and by NHS QIS.

25. NHS Education Scotland should expand its work with the SCLD to review and develop the learning disabilities component of all preregistration health professionals’ training programmes, building upon current competency framework developments. NHS Education for Scotland, the Scottish Social Services Council and the SCLD should work
with Higher Education Institutions across Scotland to support the development and inclusion of learning disabilities modules within post qualifying and post graduate programmes, and to make available post registration educational programmes for directly accessed health care providers. The training remit of SCLD with paid and family carers should continue to be developed and supported.
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13. COVER PHOTOGRAPH

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14. ADDITIONAL CONTRIBUTORS

Approximately 600 people from across Scotland and further afield contributed to the process during their attendance at the stakeholder events, service user events and consensus event.

Numerous persons contributed individually through written or verbal communications to the Project Manager or other members of the Reference Group.

Numerous individuals and officials within a range of organisations and their divisions and departments contributed their opinions, experience and time to the process.
The Scottish Executive, the PiP Network, COSLA, and NHS QIS contributed including by supplying data.

Local Authorities, Health Services and many Voluntary Organisations contributed to the national surveys.

The Physical Health Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disability contributed through inviting presentation of the preliminary report at its Annual Meeting, 2003, which enabled international discussion and review.

15. LIST OF ABBREVIATIONS

A.H.P.  Allied Health Professional
CCI     The Centre for Change and Innovation
CSP     Co-ordinated Support Plan
D.I.M.S. Disorders of initiating and maintaining sleep
D.O.E.S. Disorders for excessive sleepiness
G.O.R.D. Gastro-oesophageal reflux disorder
GP      General Practitioner
NES     NHS Education for Scotland
NHS     National Health Service
NHS QIS NHS Quality Improvement Scotland
PiP     Partnership-in-Practice agreement
SCLD    The Scottish Consortium for Learning Disability
SCLD C.A.N. The SCLD Consortium Area Network
SEN     Special Educational Needs
SHAS    The Scottish Health Advisory Service
S.I.G.N. The Scottish Intercollegiate Guidelines Network
U.A.P.  University Affiliated Programme
U.K.    The United Kingdom
U.S.A.  The United States of America