Health Needs Assessment Report - Summary

PEOPLE WITH
LEARNING DISABILITIES IN SCOTLAND

February 2004
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\(^1\) 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?\(^1\).

• 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\(^2\).

• 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 20051. 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).
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 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.

2. UNDERTAKING THE HEALTH NEEDS ASSESSMENT
The Learning Disabilities 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 recommendation arose because of four important factors:
• The demography of the population with learning disabilities is changing, such that the number of people with learning disabilities is increasing. This includes an increase in the proportion of older persons with learning disabilities, and an increase in the number of persons with more severe learning disabilities in all age cohorts.
• Persons with learning disabilities have a high prevalence of health need and a particularly high level of unmet health need. 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 when
developing the most appropriate community and service responses.

- All Scottish long-stay institutions for persons with learning disabilities should be closed by 2005. There is a need to design robust, community-based services to more appropriately meet the needs of the population.
- Many professionals working in generic services have a lack of experience and training relevant to the health needs of people with learning disabilities.

The aims of the Learning Disabilities Health Needs Assessment were 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 inequalities in services in Scotland.
- The future work required to contribute to reducing health inequalities, in order to make a difference to the quality of life of persons with learning disabilities, that of their families and social experiences. From this a series of recommendations were developed.

A wide range of approaches were used to gather all the necessary evidence from across Scotland and internationally, including the experiences of service users and their family carers, published research, and existing services and policy. The recommendations of the Health Needs Assessment Report are supported by this evidence-base, presented in the full version of the Health Needs Assessment Report. They reflect the needs of the Scottish population and aim at delivering current Scottish policy to reduce inequalities and promote social inclusion.

The recommendations are not only relevant to strategies that directly concern people with learning disabilities and their families. Figure 1 illustrates how the proposed actions for health improvement for people with learning disabilities 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 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.

3. THE SCOTTISH CONTEXT

Scottish policy is explicitly committed towards social inclusion and tackling inequality. Supporting health needs is an essential contribution towards achieving inclusion and social justice. There is an aim to improve health and life expectancy for Scots, particularly disadvantaged members of the community.

Two key documents have provided a framework to address the inequalities experienced by children, adults and older adults with learning disabilities; the same as you? and Promoting Health, Supporting Inclusion. These documents are focussed within a broad policy aim of promoting a culture of partnership working across organisations and with service-users, to bring about a continual improvement in the health of the people of Scotland.

Discrimination is illegal in Scotland, and policy is aimed at removing discrimination and prejudice, and ensuring equity for all. Service providers, including Local Authorities and NHS Scotland, are required to make reasonable adjustments for people who have disabilities. They
### 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

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### 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

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**Figure 1: Everyone’s Responsibility - Everyone’s Gain**
cannot discriminate by refusing to provide a service, in the standard of service provided, or the terms on which a service is provided².

4. WHAT DOES THE TERM LEARNING DISABILITIES MEAN?
The Health Needs Assessment Report adopts the same definition of learning disabilities used by The same as you?¹ Whilst considering this definition, it is of course important to always consider that everyone is individual, and will have individual needs, preferences and ambitions. Learning disabilities is a significant, life-long experience that has three facets:
• A reduced availability to understand new or complex information or to learn new skills (in global rather than specific areas).
• A reduced ability to cope independently.
• Onset before adulthood, with a lasting effect on the individual’s development.

5. THE POPULATION OF PEOPLE WITH LEARNING DISABILITIES IN SCOTLAND
The same as you?¹ 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 learning disabilities. About 18,000 adults with learning disabilities are currently known to Local Authorities in Scotland. However, there are no detailed studies specific to Scotland on which to base estimates. Recent studies from other geographical areas using differing methodologies report a prevalence varying from 2 to 85 people with learning disabilities per 1,000 of the population. To facilitate strategic development of services, a system needs to be developed that can provide robust Scottish epidemiological data. The eSAY project coordinated by the Scottish Consortium for Learning Disability (SCLD) is a major advance toward this goal.

6. LIFE EXPECTANCY AND MORTALITY
Life expectancy is one of the key public health measures used to determine the health of a population. Although the life expectancy of people with learning disabilities is increasing, it still remains lower than for the rest of the Scottish population. In addition, the most common causes of death for people with learning disabilities differ from the rest of the population.

These differences are important. The lower life expectancy of people with learning disabilities demonstrates that they are disadvantaged compared with the rest of the population. Therefore, they are one of the groups for whom Scottish policy explicitly states an intention to improve health and reduce inequality. However, Scotland’s current public health initiatives will fail to achieve this intention. Indeed, instead of closing the gap, evidence suggests that current initiatives are likely to widen the health inequality gap.

7. THE UNMET HEALTH NEEDS OF PERSONS WITH LEARNING DISABILITIES
The full version of the Health Needs Assessment Report presents a detailed review of the known evidence regarding the types and extent of health needs experienced by persons with learning disabilities.

Persons with learning disabilities have more and more complex health needs when compared with the general population. Much of their health need is unrecognised and unmet. It is
important to recognise that the types of health needs experienced by people with learning disabilities differ from the general population. There are many factors that contribute to this, including biological factors, social factors, and wider community and environmental factors including cultural, economic and religious factors, and Scottish industry and policy. Very little research has been undertaken to understand better these issues. Persons with learning disabilities experience barriers to health needs being met.

It has been consistently found that there is insufficient attention to the health needs of people with learning disabilities. This includes a lack of basic health promotion, under-identification of ill health, and a deficit in meeting the health needs specific to people with learning disabilities. To suggest that persons with learning disabilities are already included in all health improvement policy and practice ignores their long history of unmet health needs, health needs specific to persons with learning disabilities, and the complex issues that prohibit access to and effective use of services and care.

Family carers play a crucial role in the development, health and well-being of persons with learning disabilities. Family carers are at greater risk of socio-economic disadvantage, and have more prevalent health needs compared with the rest of the population. Studies have also highlighted the positive impacts reported by parents of bringing up a child with learning disabilities, including strengthening relationships and a family's coping abilities. Families need access to information, training and support, and can also make valuable contributions to the training of paid carers and professionals.

8. SERVICES FOR PERSONS WITH LEARNING DISABILITIES IN SCOTLAND

The full version of the Health Needs Assessment Report outlines in detail the current range of services for persons with learning disabilities in Scotland that are available in addition to the services available for use by everyone. This abbreviated version provides a brief overview.

A five-tiered model of care was described in Promoting Health, Supporting Inclusion\(^2\), and has been utilised within other recent reports. Within and across the tiers one can consider the range of services available within the community, voluntary and independent sectors, NHS Scotland and Local Authorities. A person may access services at several of the tiers at the same time in order to meet their needs, or may access services at different tiers at different times, due to changing needs. Therefore, this is a flexible model with joint working between organisations together with persons with learning disabilities, their families, and communities at each tier and across tiers. The provision of services at one tier impacts upon the need for services at other tiers. Strategic planning, development, and commissioning of services across the tiers are required, as are research, education, and staff development, workforce planning, advocacy, and robust governance and external monitoring such as that provided by NHS Quality Improvement Scotland (NHS QIS), the Care Commission and the Mental Welfare Commission.

Effective systems to provide improved integration of services both within (horizontal integration) and across the tiers (vertical integration) are important. Greater integration promotes effective communication, improved clinical outcomes, user and carer involvement and cost effectiveness.
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. |

Current policy is actively promoting partnership working between organisations and services and is embraced in the tiered model presented above. The implementation of Joint Future is at different stages in different parts of Scotland, and the structures in place to deliver the required service-functions differ in different parts of Scotland. The development and implementation of the first Partnership-in-Practice agreements was a major advance in partnership working. The forthcoming development of Community Health Partnerships will further enhance partnership working and integrated approaches to care and support.

All services must be culturally competent and accessible to persons from ethnic minority communities. Studies have demonstrated that persons with learning disabilities from ethnic minority communities have difficulties accessing both general and specific learning disabilities health and care services. This needs to be addressed through services specifically considering the needs of persons from ethnic minority communities.

9. 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 receive appropriate care. This will lead to improved access to services. Discrimination is qualitatively different to the access difficulties that policy is currently and actively addressing in Scotland. During the course of the Health Needs Assessment, evidence was presented of both overt and more subtle and unintentional discrimination within NHS Scotland. Examples included 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, and clinical guidelines failing to consider the impact that their implementation will have on people with learning disabilities.
Whilst many examples of discriminatory institutional practices are unintentional, they highlight the lack of value placed on the quality and contribution of persons with learning disabilities by some health professionals and health service managers, who make inappropriate judgements about a person’s health and well-being.

Policy in Scotland is committed to social justice, equity and inclusion. Whether overt or subtle, discrimination cannot continue to be tolerated or ignored.

10. RECOMMENDATIONS
Detail is presented on the recommendations in the text of Section 7 of the full version of the Health Needs Assessment Report. This abbreviated version 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. 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 childrens 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 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.

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.

11. ACKNOWLEDGEMENTS
Many individuals and groups have contributed to the development of the Health Needs Assessment Report. A list of acknowledgements is included in the full version of the Health Needs Assessment Report.
12. REFERENCES