

Quality Indicators ~ *February 2004*

Learning Disabilities

Developed with support from People First Scotland



© NHS Quality Improvement Scotland 2004

ISBN 1-84404-257-X

First published February 2004

NHS Quality Improvement Scotland (NHS QIS) consents to the photocopying, electronic reproduction by 'uploading' or 'downloading' from the website, retransmission, or other copying of these quality indicators for the purpose of implementation in NHSScotland and educational and 'not-for-profit' purposes. No reproduction by or for commercial organisations is permitted without the express written permission of NHS QIS.

www.nhshealthquality.org

Contents

| | |
|---|----|
| 1. Introduction | 2 |
| 2. Background on NHS Quality Improvement Scotland | 3 |
| 3. Background on Quality Indicators – Basic Principles | 6 |
| 4. Revision of the Quality Indicators for Learning Disabilities | 8 |
| 5. Membership of the Learning Disabilities Quality Indicators Project Group | 12 |
| 6. Overarching Principles | 13 |
| 7. An Introduction to Learning Disabilities | 16 |
| 8. Quality Indicators for Learning Disabilities | 19 |
| 9. Membership of the Learning Disabilities Reference Group | 68 |
| 10. Glossary of Terms | 73 |
| 11. References | 95 |

1. Introduction

This document introduces the revised NHS Quality Improvement Scotland (NHS QIS) *Quality Indicators for Learning Disabilities*¹. They include sections on:

- Involvement of Children and Adults with Learning Disabilities and Their Family Carers through Self-Representation and Independent Advocacy;
- Promoting Inclusion and Wellbeing;
- Meeting General Healthcare Needs;
- Meeting Complex Healthcare Needs;
- In-patient Services - Daily Life; and
- Planning Services and Partnership Working.

The quality indicators will be used by NHS QIS to assess performance in NHS Board areas throughout Scotland.

The initial sections of this document provide background information on NHS QIS and on the process used to develop the quality indicators (Sections 2 and 3 respectively).

The revision process of the *Quality Indicators for Learning Disabilities* is outlined in Section 4, and the membership of the Project Group undertaking this work is given in Section 5. The overarching principles guiding revision of the quality indicators are provided in Section 6.

Section 7 provides basic information about learning disabilities.

Section 8 contains the revised *Quality Indicators for Learning Disabilities*.

The membership of the Learning Disabilities Reference Group involved in the revision of the *Quality Indicators for Learning Disabilities* is given in Section 9.

Section 10 provides a glossary of terms used in the quality indicators.

Finally, a list of references is provided in Section 11.

¹ An easy-read summary to describe the aims and purpose of the quality indicators has been developed with the Scottish Consortium for Learning Disabilities (SCLD).

2. Background on NHS Quality Improvement Scotland

NHS Quality Improvement Scotland (NHS QIS) was established as a Special Health Board on 1 January 2003 as a result of bringing together the Clinical Resource and Audit Group (CRAG), Clinical Standards Board for Scotland (CSBS), Health Technology Board for Scotland (HTBS), Nursing and Midwifery Practice Development Unit (NMPDU) and the Scottish Health Advisory Service (SHAS).

The purpose of NHS QIS is to improve the quality of healthcare in Scotland by setting standards and monitoring performance, and by providing NHSScotland with advice, guidance and support on effective clinical practice and service improvements.

A part of this remit is to develop and run a national system of quality assurance of clinical services. Working in partnership with healthcare professionals, users, carers and members of the public, NHS QIS sets quality indicators and standards for health services, assesses performance throughout NHSScotland against these quality indicators and standards, and publishes the findings. The quality indicators and standards are based on the patient's journey as he or she moves through different parts of the health service. A wide range of diseases and services are at present being addressed, including infection control and vascular services.

Project Groups

For each service in the work programme, NHS QIS appoints a project group comprising appropriate health and social care professionals, representatives of voluntary organisations, and members of the public to:

- oversee the development of, and consultation on, the quality indicators and standards;
- recommend an external peer review process; and
- report on its findings to the NHS QIS Board.

As part of their rolling programme, individual project groups ensure that the quality indicators and standards are regularly evaluated and revised so that they remain relevant and up to date (reflecting developments in policy, new procedures and treatments). They also ensure that targets of achievement are raised as performance improves.

Development of Quality Indicators and Standards

The way in which quality indicators and standards are developed is a key element of the quality assurance process. Groups working on behalf of NHS QIS are expected to:

- adopt an open and inclusive process involving a wide range of both members of the public and professional people through a variety of mechanisms;
- work within NHS QIS policies and procedures; and
- test quality indicators and standards through undertaking pilot reviews to ensure that they meet the principles of NHS QIS.

In addition to quality indicators and standards for specific services or conditions, generic clinical governance standards have been set which apply to all clinical services.

Review

The framework for the NHS QIS review process is as follows:

- Once the quality indicators or standards have been finalised, each relevant NHS Board/service is asked to undertake a self-assessment of its service against these.
- A review team visits the NHS Board/service on behalf of NHS QIS to follow up this self-assessment exercise with an external peer review of performance in relation to the quality indicators or standards.
- NHS QIS reports the findings for the NHS Board/service, based on the self-assessment exercise and on the external peer review.

Peer review teams are multidisciplinary, including healthcare professionals, local authority representatives, voluntary organisation representatives, users, carers, and members of the public. All teams are led by an experienced professional from the service and are supported by staff from NHS QIS.

All the processes being developed are subject to review and evaluation, and this will help NHS QIS improve its quality assurance system.

Further Information

For further information about NHS QIS, or to obtain additional copies of these quality indicators and the easy-read summary, please contact:

NHS Quality Improvement Scotland
Edinburgh Office
Elliott House
8-10 Hillside Crescent
Edinburgh
EH7 5EA

Tel: 0131 623 4300

Fax: 0131 623 4299

publications@nhshealthquality.org

www.nhshealthquality.org

Copies of all NHS QIS publications can also be downloaded from the website (www.nhshealthquality.org).

3. Background on Quality Indicators – Basic Principles

The quality indicators set by NHS Quality Improvement Scotland (NHS QIS) are:

- focused on health issues and include joint working arrangements that impact on the quality of care;
- written in simple language;
- based on evidence and best practice (recognising that levels and types of evidence will vary);
- written to take into account other recognised standards and clinical guidelines;
- clear and measurable;
- achievable but stretching;
- developed by users, carers, health professionals, professionals from other agencies, and members of the public;
- published on paper and electronically (on the Internet); and
- regularly reviewed and revised to make sure they remain relevant and up to date.

Some quality indicators and standards are common to all health services, others specific to particular needs.

Format of Quality Indicators and Definition of Terminology

Both quality indicators and standards are used by NHS QIS to review the quality of services provided by NHSScotland.

All quality indicators set by NHS QIS follow the same format:

- each quality indicator has a **title**, which summarises the area on which that quality indicator focuses;
- the **rationale** section provides the reasons why the quality indicator is considered to be important;
- this is followed by the **quality indicator statement**, which explains the level of performance to be achieved; and
- the quality indicator statement is expanded in the section headed **criteria**, which states exactly what must be achieved for the quality indicator to be reached.

As already mentioned, NHS QIS aims to set quality indicators and standards that are **achievable but stretching**. NHS QIS quality indicators differ from the clinical standards as they focus on the overarching principles that should be applied to a service as a whole, whereas standards are targeted, specific measurements of a particular service. The prescriptive nature of standards, suggests a level of performance that is either met or not met. As the criteria used within quality indicators are less specific than those within standards, it allows for a range of performance to be assessed, and promotes the continuous improvement of a service.

The criteria are numbered for the sole reason of making the document easier to work with, particularly for the assessment process. The numbering of the criteria is not a reflection of priority.

Generic Clinical Governance Standards

As mentioned earlier in this document, generic clinical governance standards have been developed which apply to clinical services generally.

Copies of the generic clinical governance standards are available on request from NHS QIS or can be downloaded from the website (www.nhshealthquality.org).

4. Revision of the Quality Indicators for Learning Disabilities

This document contains the revised *Quality Indicators for Learning Disabilities*. These quality indicators were first published in May 2000 and have been used to assess the quality of health services available to children and adults with learning disabilities in Scotland. Subsequently, there have been a number of developments in both policy and legislation relevant to the needs of children and adults with learning disabilities, and the quality indicators have been revised to reflect these.

Policy Framework

A fundamental theme arising from the recent policy developments is the need for joint working arrangements between health and social work, and between primary and secondary care. The lead on developing joint working arrangements was taken by the Joint Future Group, which was set up by the Scottish Executive Health Department in December 1999. Its primary task was to agree a list of joint measures which all local authorities, Health Boards and Trusts should have in place to deliver effective services, and to set deadlines by which this must be done.

This means of delivering services is evident in *Partnership for Care, Scotland's Health White Paper (2003)*, which outlines the future of the health service, emphasising the need to promote health in Scotland and create a health service that is fit for the 21st Century. National priorities for NHSScotland are identified in addition to the organisational change required to deliver such care. The approach to joint working and wellbeing is reiterated in the *Community Care and Health (Scotland) Act (2002)*, and the new *Local Government (Scotland) Act (2003)*. These specify the roles of health, local authorities and others in improving and delivering health services, whilst *Improving Health in Scotland - The Challenge (2003)*, sets out the challenge of the health improvement agenda.

Further to the progression of general policy as described above, there have been a variety of developments specifically relating to learning disabilities services. Of particular note is the publication of *The same as you?* in May 2000 which sets the national policy for health and social care services for children and adults with learning disabilities in Scotland. The contribution of nurses and midwives in the care and support of people with learning disabilities is described in the National Nursing Review *Promoting Health, Supporting Inclusion*, which is set within the policy context of *The same as you?* whilst also taking account of the changes being brought about by *Joint Future (2000)*.

The move towards providing care and treatment for people with learning disabilities in the community and general health settings, rather than long-stay hospitals, emphasises the increasing role of primary care and general hospital services in the future. The forthcoming *NHS Health Scotland Learning Disability Needs Assessment* report will identify actions and recommendations to ensure the health needs of people with learning disabilities are effectively addressed.

Policy developments specific to other groups, such as *For Scotland's Children (2001)*, *Adding Life to Years (2002)* and the *Right Time, Right Place (2002)*, also have an impact on learning disabilities services. The implementation of these policies by NHS Boards should take account of the needs of children and adults with learning disabilities.

Legislative Framework

In addition to the developments in policy, the revised *Quality Indicators for Learning Disabilities* also reflect the changing legislative environment. Such developments in legislation relate to people with learning disabilities, and are applicable across health, social and education settings.

Of particular importance is the *Adult with Incapacity (Scotland) Act (2000)* which provides a legal framework for gaining consent or acting on a person's behalf when the person does not have capacity to give or withhold consent. Furthermore, the new *Mental Health (Care and Treatment) (Scotland) Act (2003)* will be implemented from April 2005 and this places a range of duties on organisations, including NHSScotland. People with mental disorders, including those with learning disabilities, are afforded new rights by the Act, with a significant development being the right of access to independent advocacy.

Legislation regarding the prevention of discrimination is relevant to people with learning disabilities. The final part of the *Disability Discrimination Act (1995)(DDA)* is effective from October 2004 and this makes it illegal to discriminate against people who have disabilities, in employment, access to goods, services and education. Other legislation, including the *Race Relations (Amendment) Act (2000)* and the overarching *Human Rights Act (2000)* provides a framework for the delivery of services that are culturally competent, free from discrimination and recognise individual rights.

Separate legislation for children such as the *Children (Scotland) Act (1995)*, already requires services for children with disabilities to 'minimise disability' and to help children live 'as normal' a life as possible. Supplementary to this are the *Education (Disability Strategies in Peoples' Educational Records) (Scotland) Act (2002)* and the *Support for Learning Bill (2003)*, both of which provide an overarching framework to address individual needs of children who may have difficulty accessing and benefiting from learning. There are requirements on health services to support children within this framework.

It is important that the revised *Quality Indicators for Learning Disabilities* reflect such developments in this complex and changing environment, and recognise that this can only be achieved with co-operation and efforts of other agencies, such as local authorities and voluntary organisations.

Further information on the overarching principles used in the revision process can be found in Section 6.

Revising the Quality Indicators for Learning Disabilities

Following the developments in policy and legislation and the formation of NHS Quality Improvement Scotland (NHS QIS), it was considered timely to revise the quality indicators, bringing together the work of the previous organisations on quality indicators and standards.

In 2003, the European Year of Disability, a project group was appointed to oversee the revision of the *Quality Indicators for Learning Disabilities*. The Group was led by Dr Margaret Whoriskey, Advisor (Disability Services), NHS Quality Improvement Scotland and the first meeting was held in March 2003. The membership of the Group is given in Section 5.

There was significant liaison by the Group with members of the NHS QIS Learning Disabilities Reviewer Network, NHSScotland and others, during the revision process. The membership of this Learning Disabilities Reference Group is given in Section 9.

People First Scotland was involved in specific consultation on the quality indicators. Their role in providing individual experiences and aspirations was a valuable contribution to this process.

The consultation process demonstrated that both quality indicators and standards have a function in reviewing and improving the quality of

services. The difference between quality indicators and standards is described in Section 3, however, it is recognised that this is the first stage in exploring the links between quality indicators and standards within NHS QIS. Inevitably, the process will continue to evolve through initial experiences and the course of NHS QIS reviews.

The revised *Quality Indicators for Learning Disabilities* focus on six key elements of learning disabilities services that have an impact on the quality of care a person with learning disabilities receives on their journey through the service. The NHS QIS generic clinical governance standards apply to learning disabilities services and are subject to separate review. However, relevant aspects of clinical governance are included throughout the quality indicators.

The revised *Quality Indicators for Learning Disabilities* provide a robust framework of aspirational targets, which set achievable challenges for services. While focusing on the role and contribution of health services, the quality indicators also provide a foundation for the development of joint indicators and/or standards in due course.

5. Membership of the Learning Disabilities Quality Indicators Project Group

The membership of the Learning Disabilities Quality Indicators Project Group, chaired by Dr Margaret Whoriskey, Advisor (Disability Services), NHS Quality Improvement Scotland, is presented below:

| Name | Title | NHS Board Area/Organisation |
|---------------------|----------------------------------|--|
| Dr Neil Beattie | General Practitioner | Ayrshire & Arran |
| Mr Martin Campbell | Senior Teaching Fellow | University of St Andrews |
| Dr Sally Cheseldine | Consultant Clinical Psychologist | Lothian |
| Mr Alex Davidson | Head of Adult Services | South Lanarkshire Council |
| Dr Patricia Jackson | Consultant Paediatrician | Lothian |
| Miss Liz Kerr | Senior Occupational Therapist | Capability Scotland |
| Mr Michael McCue | Complex Needs Services Manager | Glasgow City Learning Disability Partnership |
| Mr Mike Martin | Independent Consultant & Trainer | West Lothian |
| | | People First Scotland |

The membership of the wider Learning Disabilities Reference Group involved in the revision of the *Quality Indicators for Learning Disabilities* is given in Section 9.

Support from NHS Quality Improvement Scotland is being provided by Ms Jan Warner (Director of Performance Assessment and Practice Development), Mr Sean Doherty (Review Team Manager), Mrs Sarah Brown (Senior Project Officer), Ms Jane Allen (Project Officer) and Ms Susie Forbes (Project Assistant).

6. Overarching Principles

As mentioned in Section 2, NHS Quality Improvement Scotland has developed generic clinical governance standards of care that underpin all clinical services provided by NHSScotland.

The following key points underpin the revised *Quality Indicators for Learning Disabilities*:

- The revised *Quality Indicators for Learning Disabilities* apply to all people with a learning disability, both children and adults. This is to ensure that the quality assurance process considers services for people with learning disabilities in their entirety, including the transition from children to adult services. The term ‘children and adults’ is used throughout, where the indicator is seen as appropriate for someone of any age. If ‘child’ or ‘adult’ is used singularly, the indicator is seen as specific to that category and is indicated by a ‘C’ or ‘A’ respectively.
- People with a learning disability who also have an Autistic Spectrum Disorder (ASD) are included within the quality indicators, all of which apply to this group. Additional reference is made to ASD as appropriate, within specific quality indicators. Whilst it is acknowledged that people with ASD who do not have a learning disability may be excluded by this approach, the quality indicators will address interface issues with mental health and other services. NHS QIS will consider the need to develop standards for specific conditions, such as ASD.
- It is recognised that people with learning disabilities may also have other additional or complex needs, eg epilepsy. The emphasis of the quality indicators is on how services respond to meet these needs.
- As learning disabilities services become more integrated with general health services, it will be important to include the needs of people with learning disabilities in other NHS QIS quality indicators or standards, such as children’s services standards. These quality indicators address how all health services should respond to meet the needs of children and adults with learning disabilities. The role of primary healthcare and general health services is crucially important to ensure health improvement.

6. Overarching Principles

- The quality indicators reflect the seven principles identified within *The same as you?* report. These principles are listed below and are considered to be important in helping people with learning disabilities lead full and active lives:

- People with learning disabilities should be valued. They should be asked and encouraged to contribute to the community they live in. They should not be picked on or treated differently from others.
- People with learning disabilities are individual people.
- People with learning disabilities should be asked about the services they need and be involved in making choices about what they want.
- People in learning disabilities should be helped and supported to everything they are able to do.
- People with learning disabilities should be able to use the same local services as everyone else, wherever possible.
- People with learning disabilities should benefit from specialist social, health and educational services.
- People with learning disabilities should have services which take account of their age, abilities and other needs.

- The model of healthcare identified in *Promoting Health, Supporting Inclusion* and the *NHS Health Scotland Learning Disability Needs Assessment* report supports a tiered approach to service delivery for people with learning disabilities. This ranges from the strategic and public health requirements of a service, to services for people with complex needs, and offers a framework for:

- providing support to enable healthy lifestyles;
- providing appropriate health improvement material and access to health screening programmes;
- addressing everyday health needs that require general practitioner services;
- addressing health needs related to learning disability, eg providing extra support for people with learning disabilities to ensure services are accessible; and
- providing services related to profound learning and multiple physical disabilities, epilepsy, mental health, challenging behaviour, or autistic spectrum disorders.

The revised *Quality Indicators for Learning Disabilities* complement this approach, and each quality indicator is referenced to the relevant tier. The tiers are:

- Tier 0 - Community resources and supports, public health and policy development;
- Tier 1 - Primary care and directly accessed health services;
- Tier 2 - Generic secondary health services accessed via primary care;
- Tier 3 - Specialist locality learning disability services; and
- Tier 4 - Specialist area health services.

7. An Introduction to Learning Disabilities

What Is a Learning Disability?

A learning disability is a significant, life-long condition that has three components:

- a reduced ability to understand new or complex information or to learn new skills;
- a reduced ability to cope independently; and
- it starts before adulthood (before the age of 18) and has a lasting effect on the individual's development.

This definition of a learning disability is provided by *The same as you?* report and has also been adopted by the *NHS Health Scotland Learning Disability Needs Assessment* report. The term learning disabilities and this definition is widely used, particularly in adult services. However, other terms such as learning difficulties or intellectual disabilities may also be used to describe the same population. The term intellectual disabilities tends to be used internationally and by the research community, however, within services for children, the broader term of learning difficulties and special needs are commonly used to include a wider range of people.

People with learning disabilities may also have other complex needs, which arise from:

- significant difficulties of communication, moving about, or physical or social development;
- the complicated nature of support and services needed to help a person with a learning disability cope with mental health problems or getting into trouble with the law;
- the difficulties to the person or families, carers and others caused by people who injure themselves, who are aggressive or destructive who display socially unacceptable behaviour or other challenges;
- the extraordinary services that may be needed to cope with unusual or rare conditions; and
- specific medical problems such as epilepsy, disruptive or disordered sleeping patterns, problems with eating and poor physical and mental health.

How Common Are Learning Disabilities?

UK studies suggest that in Scotland, 20 people in every 1,000 have a mild or moderate learning disability and three to four people in every 1,000 have a severe or profound disability. On this basis, it is estimated that there are around 120,000 people in Scotland with learning disabilities. Of these, about 25% are children and young people aged under 16; a further 25% are people with complex needs who need a lot of support.

Evidence suggests an increase of 1% a year in the prevalence of learning disabilities. This is due to improved survival rates of people with complicated medical and physical needs, along with increasing life expectancy in keeping with the general population.

The development of the national database for people with learning disabilities in Scotland, supported by the Scottish Consortium for Learning Disabilities (SCLD), will provide more robust data in due course.

What Are the Health Needs of People with Learning Disabilities?

There is significant evidence available which states that people with learning disabilities have greater health needs when compared with the general population. There are also barriers to these needs being met by services. It has been consistently found that there is insufficient attention to the general health needs of people with learning disabilities; a lack of basic health promotion and under-identification of ill-health. There are also problems in meeting the special health needs of people with learning disabilities.

While most people with learning disabilities have always lived within the community many of those requiring significant input from health services lived in hospitals. All long-stay learning disability hospitals will close in 2005, and this means that a wide range of health services will require to be in place to meet the health needs of all people with learning disabilities in local areas.

Health services for people with learning disabilities are now increasingly provided within a joint service with local authorities. Local joint partnership arrangements should provide clear leadership and direction for local services in order to meet the needs of people with learning disabilities.

The *NHS Health Scotland Learning Disability Needs Assessment* report will provide more detailed information on the needs of people with learning disabilities in Scotland.

7. An Introduction to Learning Disabilities



8. Quality Indicators for Learning Disabilities

QUALITY INDICATOR 1 - Involvement of Children and Adults with Learning Disabilities and Their Family Carers through Self-Representation and Independent Advocacy

QUALITY INDICATOR 2 - Promoting Inclusion and Wellbeing

QUALITY INDICATOR 3 - Meeting General Healthcare Needs

QUALITY INDICATOR 4 - Meeting Complex Healthcare Needs

QUALITY INDICATOR 5 - In-patient Services – Daily Life

QUALITY INDICATOR 6 - Planning Services and Partnership Working

QUALITY INDICATOR 1 - Involvement of Children and Adults with Learning Disabilities and Their Family Carers through Self-Representation and Independent Advocacy (Tiers 0-4)

Rationale

Actively involving children and adults with learning disabilities and their family carers in the planning and delivery of services helps to ensure that services are provided on the basis of their needs. Services have a legal obligation to make available information to children and adults with learning disabilities, and to ensure that advocacy services are available to support them during this process, if required.

Involving People in Planning Services

| Quality Indicator Statement | |
|---|----------|
| 1.1 The NHS Board and partner organisations effectively support and involve children and adults with learning disabilities and family carers in the planning and delivery of services. <i>References: 3, 5, 6, 7, 18, 33, 38, 57, 71</i> | |
| Criteria | |
| 1.1.1 The patient and public involvement strategy identifies how children and adults with learning disabilities, and their families are involved in planning of, and consultation on, services. | |
| 1.1.2 There is appropriate support available to ensure effective involvement in planning groups. | |
| 1.1.3 Children’s services planning fora include representation from children and young people and their families. | C |
| 1.1.4 Local user/carer groups for children and adults with learning disabilities are involved in consultation on an ongoing basis, and on how successful participation should be measured and monitored. | |

- 1.15 Planning groups and service planning processes take account of the needs of children and adults with learning disabilities from black and ethnic minority backgrounds and their families.
- 1.16 Planning information is accessible and available to children and adults with learning disabilities and their family carers.
- 1.17 NHS services invest in ‘capacity building’ training for children and adults with learning disabilities, parents and family carers.
- 1.18 NHS services follow good practice guidance on involving children and adults with learning disabilities.

Quality Indicator Statement

1.2 Children and adults with learning disabilities and their families, family carers or their representatives are involved in the planning and review of their care across all health services.
References: 7, 72

Criteria

- 1.2.1 The service has a written user involvement strategy.
- 1.2.2 Person centred plans, reflecting the active involvement of children and adults, through advocacy if appropriate, are in use and up to date.
- 1.2.3 Families, parents and siblings are involved, and are able to give their views, which are recorded as such.

Access to Health Records

| Quality Indicator Statement |
|--|
| <p>1.3 There is a policy on access to health records in primary care, community and hospital services that is accessible to, and can be used by, children and adults with learning disabilities. <i>References: 1, 5, 10, 16</i></p> |
| Criteria |
| <p>1.3.1 The policy is available in a range of accessible formats.</p> <p>1.3.2 There is active support (including support for communication and advocacy) available to enable children and adults with learning disabilities to access information.</p> <p>1.3.3 Data protection procedures are in place that take account of the needs and rights of children, young people and adults with learning disabilities.</p> |

Complaints

| Quality Indicator Statement |
|---|
| <p>1.4 There is a complaints procedure, a freedom of expressing policy, and systems in place for recording suggestions and assessing satisfaction to inform service delivery. These are appropriate, available and accessible to children and adults with learning disabilities in primary care, community, and hospital-based services. <i>References: 16, 69, 72</i></p> |
| Criteria |
| <p>1.4.1 The policy, procedure, and systems, with information on their use, are available to, and clear and appropriate for, children and adults with learning disabilities across all health settings.</p> <p>1.4.2 There is evidence of routine opportunities for children and adults with learning disabilities, and family carers to make observations, give views, express concerns about any aspect of their care and treatment, individually and/or collectively, and with support from an advocate, if necessary.</p> |

- 1.4.3 User satisfaction surveys are in use in Community Health Partnerships (CHPs), general paediatric hospitals, and learning disability services.
- 1.4.4 All user satisfaction surveys take into account the views of children and adults with learning disabilities and their carers where appropriate.
- 1.4.5 Staff are aware of policies, procedures and systems designed to handle complaints and record level of satisfaction, and receive appropriate training.
- 1.4.6 There is a system in place to ensure that appropriate actions follow from complaints and satisfaction surveys.

Advocacy

| Quality Indicator Statement |
|--|
| <p>1.5 There is an NHS Board strategy for the range of advocacy services, which addresses the individual needs of children and adults with learning disabilities and their family carers. <i>References: 16, 26, 37, 50, 52, 62, 67</i></p> |
| Criteria |
| <p>1.5.1 A plan is in place, and advocacy services are commissioned with partner agencies.</p> <p>1.5.2 Arrangements are in place to support the right to access independent advocacy in line with the Mental Health (Care and Treatment) (Scotland) Act 2003.</p> <p>1.5.3 There is an appropriate range of advocacy services (self, independent/citizen, collective, crisis, issue-based etc) available for children and adults with learning disabilities in all hospital and community settings.</p> <p>1.5.4 There is appropriate advocacy support available for parents, siblings and family carers.</p> |

1.5.5 There is evidence that the NHS Board is implementing Scottish Executive Health Department (SEHD)/Scottish Health Advisory Service (SHAS) Advocacy Good Practice guidance and other relevant standards.

1.5.6 Advice on, and promotion of, good quality, independent advocacy for children and adults with learning disabilities is sought from appropriate sources, eg through reference to the Advocacy Safeguards Agency, the Scottish Consortium for Learning Disability, the Scottish Independent Advocacy Alliance and specialist interest groups, eg Autistic Spectrum Disorder (ASD) as appropriate.

1.5.7 Advocacy services are monitored and evaluated.

1.5.8 There is an identified person responsible for the advocacy services commissioned by the NHS Board.

Quality Indicator Statement

1.6 The NHS Board promotes and supports advocacy services through ongoing training and ensuring accessibility to information and services.

References: 37, 50, 67

Criteria

1.6.1 There is an ongoing training programme for NHS staff on the role of independent advocacy.

1.6.2 Advocates and their partners can meet privately.

1.6.3 Advocates have access to training on health and social care issues relevant to children and adults with learning disabilities.

1.6.4 There is evidence of opportunities for advocates to raise issues of concern with managers/staff.

1.6.5 There is a referral protocol available setting out how the advocacy services may be accessed.

1.6.6 Information about advocacy services in a range of formats is made available to children and adults with learning disabilities across all NHS settings.

1.6.7 Staff across all NHS services (including paediatric, primary care and general hospital services) know about the range of advocacy services available, and how they are accessed.

QUALITY INDICATOR 2 - Promoting Inclusion and Wellbeing (Tier 0)

Rationale

People with learning disabilities should receive the same services and support that will keep them healthy and enable them to participate fully in society. Health promotion and/or health improvement programmes, to be effective must address diversity and be responsive to the range of needs.

Disability Awareness

| Quality Indicator Statement |
|---|
| 2.1 Staff are familiar with the <i>Disability Discrimination Act (1995)(DDA)</i> guidelines and legislation as it applies to children and adults with learning disabilities. <i>References: 16, 17, 48</i> |
| Criteria |
| 2.1.1 SEHD guidance and the Disability Rights Commission Codes of Practice are followed. |
| 2.1.2 Staff are aware of their responsibilities in relation to the Act. |
| 2.1.3 An audit of DDA compliance has been carried out, and there is an action plan for tackling any deficits. |

| Quality Indicator Statement |
|--|
| <p>2.2 There is an up-to-date strategy for disability awareness and disability equality training, which takes account of the needs of children and adults with learning disabilities, including those with associated needs such as ASD or mental health problems. <i>References: 28, 30, 87</i></p> |
| Criteria |
| <p>2.2.1 There is an identified person for disability awareness/equality training for the NHS Board area/Community Health Partnerships.</p> <p>2.2.2 There is ongoing awareness training which takes account of relevant national standards and the needs of children and adults with learning disabilities and their family carers.</p> <p>2.2.3 Children and adults with learning disabilities and their family carers are involved in the development and delivery of training.</p> |

| Quality Indicator Statement |
|--|
| <p>2.3 Children and adults with learning disabilities and their family carers can safely access health service settings. <i>References: 16, 32</i></p> |
| Criteria |
| <p>2.3.1 Arrangements are in place for personal support to be provided.</p> <p>2.3.2 There is child-friendly access, across the range of health services, which includes appropriate play facilities.</p> <p>2.3.3 There are adequate parking and designated drop-off points within reasonable reach of destinations.</p> <p>2.3.4 Environmental adaptations are in place, including adapted toilets and changing facilities for children and adults with multiple disabilities.</p> <p>2.3.5 There is clear sign posting and use of appropriate symbols, internal and external to the building, for children and adults with learning disabilities and their family carers.</p> |

Transport

| Quality Indicator Statement |
|--|
| <p>2.4 The needs of children and adults with learning disabilities are considered in relation to patient transport and general transport services. <i>Reference: 63</i></p> |
| Criteria |
| <p>2.4.1 The NHS patient transport service liaison group takes account of the range of needs of children and adults with learning disabilities.</p> <p>2.4.2 Appropriate arrangements are made for children and adults with learning disabilities and family carers, eg wheelchair accessibility, transport of carer.</p> <p>2.4.3 The NHS Board is involved in appropriate fora with local authorities and others, addressing general transport services, and the needs of children and adults with learning disabilities.</p> <p>2.4.4 Children and adults with learning disabilities and family carers are involved in consultation on transport matters.</p> |

Health Promotion and Health Improvement

| Quality Indicator Statement |
|--|
| <p>2.5 The NHS Board/Community Health Partnership has an agreed policy on health improvement and wellbeing activities, which takes account of the diverse general and complex needs of children and adults with learning disabilities and addresses health inequalities. <i>References: 29, 59</i></p> |
| Criteria |
| <p>2.5.1 There is a health improvement policy in place which ensures:</p> <ul style="list-style-type: none">• Educational materials are available in a variety of formats, eg leaflets, posters, CD-ROMs suitable to the needs of both professional and user groups.• Children and adults with learning disabilities and their family carers are involved in the development and evaluation of health improvement activities.• Information is available for children and adults with learning disabilities and their family carers about healthcare issues, and wellbeing, in appropriate formats, across all healthcare settings. |
| <p>2.5.2 Education and leisure settings have health improvement programmes, and health education materials and facilities suitable to the needs of children and adults with learning disabilities.</p> |
| <p>2.5.3 There is attention to gender issues, sexuality and sexual health.</p> |
| <p>2.5.4 Staff training programmes are in place.</p> |
| <p>2.5.5 There is evidence of inter-agency working with local authorities and other organisations which promotes health improvement.</p> |
| <p>2.5.6 There are opportunities for children and adults with learning disabilities to participate in activities, which promote inclusion, social capacity and a healthy lifestyle.</p> |
| <p>2.5.7 Healthy living indicators include children and adults with learning disabilities.</p> |

| Quality Indicator Statement |
|--|
| 2.6 Accessible information on the range of health services is available. <i>References: 16, 33, 38, 71</i> |
| Criteria |
| 2.6.1 Information is available with appropriate support in a range of formats suitable for children and adults with learning disabilities and family carers across all settings. |
| 2.6.2 There is active dissemination of information to children and adults with learning disabilities. |
| 2.6.3 There is an identified person within the NHS Board/Community Health Partnership who is responsible for co-ordinating, updating and disseminating information. |

Health Information and Cultural Sensitivity

| Quality Indicator Statement |
|--|
| 2.7 All services are culturally sensitive to and responsive to the needs of black and ethnic minority children and adults with learning disabilities and family carers. <i>References: 33, 53</i> |
| Criteria |
| 2.7.1 Information is available in a format which is responsive to the cultural needs of children and adults with learning disabilities. |
| 2.7.2 Staff training is provided on race, religion and culture, and the specific needs of children and adults with learning disabilities and their families. |
| 2.7.3 Staff, children and adults with learning disabilities and their families have access to specialist advice and support. |

Direct Payments

| Quality Indicator Statement |
|---|
| 2.8 Health services support people with learning disabilities to use direct payments. <i>References: 8, 5, 25</i> |
| Criteria |
| 2.8.1 Information on how to get direct payments is available, and promoted in health settings. This is supported by staff training. |
| 2.8.2 Care plans include consideration of direct payments. |
| 2.8.3 Support is available to adults with learning disabilities and family carers to use direct payments. |
| 2.8.4 There is information for parents of children (under 16) and support available to access direct payments. |

QUALITY INDICATOR 3 - Meeting General Healthcare Needs (Tiers 1 & 2)

Rationale

People with learning disabilities can experience difficulties when using primary care and general health and/or hospital services which can mean that health needs are not effectively assessed and met. The screening and assessment processes help to identify unmet need and prevent health problems, while person-centred care plans help to ensure that the general and additional health needs of children and adults with learning disabilities are addressed.

Assessment and Care Planning

| Quality Indicator Statement |
|--|
| <p>3.1 Children and adults with learning disabilities accessing health services have an up-to-date multidisciplinary care plan. <i>References: 2, 13, 16, 51, 52, 55, 60</i></p> |
| Criteria |
| <p>3.1.1 Single shared assessments are in place for children and adults with learning disabilities.</p> <p>3.1.2 The <i>Adults with Incapacity (Scotland) Act (2000)</i> (AWIA) is implemented and subject to audit and is supported by ongoing training programmes for staff.</p> <p>3.1.3 Personal life plans take account of an individual's health needs and inform the care plan.</p> <p>3.1.4 Care plans show evidence of access to a range of community health services, based on individual need, including:</p> <ul style="list-style-type: none"> • Audiology; • Dental services; • Dietetics; • Health screening; • Optometry; and • Podiatry services. |

3.1.5 There is evidence of children and adults with learning disabilities and families and/or advocates, being involved in reviewing care plans.

3.1.6 There is evidence of efforts to take account of any special communication needs in everyday interactions with children and adults with learning disabilities.

3.1.7 Communication needs are identified and met, including the provision of augmented communication aids.

Quality Indicator Statement

3.2 Assessment of health and capacity of family carers is considered, and linked to assessment of users' need.
References: 3, 7, 8

Criteria

3.2.1 There are policies and procedures in place to ensure family carers' capacity to contribute to plans for users is assessed, including reference to their own needs in line with the *Family Carers (Recognition and Services) Act (1995)* and the *Community Care and Health Act (2002)*.

3.2.2 Needs of the whole family are given consideration within service user plans for children with learning disabilities (*Section 23, Children (Scotland) Act (1995)*), including family support and respite care.

3.2.3 Family carers' needs are identified within service user plans.

Primary Care and Community Services

| Quality Indicator Statement |
|--|
| <p>3.3 There is a named specialist practitioner known to each primary care team. <i>References: 19, 36, 59</i></p> |
| Criteria |
| <p>3.3.1 An appropriate health professional is available, to support access to specialist health services for children with learning disabilities.</p> <p>3.3.2 There are community learning disability nurses based in, and working collaboratively as, integrated members of primary care teams/Community Health Partnerships.</p> |

| Quality Indicator Statement |
|--|
| <p>3.4 Primary care services are responsive to the needs of children and adults with learning disabilities and their family carers. <i>References: 19, 29, 36, 52</i></p> |
| Criteria |
| <p>3.4.1 Children and adults with learning disabilities registered with the practice are identified, as is the degree of their support needs.</p> <p>3.4.2 Specific arrangements are in place to support children and adults with learning disabilities and their family carers using primary care services, eg flexible appointment arrangements, home visits, communication support, and accessible information.</p> <p>3.4.3 Patient/parent-held records/communication passports are used.</p> <p>3.4.4 Communication needs are recognised and addressed.</p> |

| Quality Indicator Statement |
|------------------------------------|
|------------------------------------|

| |
|---|
| 3.5 Children, young people, and adults with learning disabilities are included and supported to participate in national screening programmes. |
|---|

References: 2, 13, 29, 52

| Criteria |
|-----------------|
|-----------------|

| |
|--|
| 3.5.1 SEHD guidelines and AWIA legislation on consent to treatment/screening/examination are followed. |
|--|

| |
|--|
| 3.5.2 Adults and young people with learning disabilities attend Well Woman/Well Man clinics. |
|--|

| |
|--|
| 3.5.3 Personal support and information is provided for children with learning disabilities and their parents/carers to ensure maximum participation in child health surveillance programmes. |
|--|

| |
|---|
| 3.5.4 Personal support and information is provided for adults and young people with learning disabilities to ensure maximum participation in national screening programmes. |
|---|

| Quality Indicator Statement |
|---|
| <p>3.6 Specific health needs are assessed and monitored, including:</p> <ul style="list-style-type: none"> • Cardiac defects; • Drug or alcohol abuse; • Dysphagia; • Endocrine disorders; • ENT problems; • Epilepsy; • Hearing impairment; • Mental health; • Mobility; • Side-effects of medication; • Smoking; • Visual impairment; and • Weight. <p><i>References: 29, 31, 59, 60, 75</i></p> |
| Criteria |
| <p>3.6.1 Specific health needs are identified and addressed in case records/care plans for people who are in hospital as well as children and adults living in the community.</p> <p>3.6.2 Specific health needs are monitored and children and adults with learning disabilities are supported to attend specialist clinics as appropriate.</p> <p>3.6.3 Healthcare workers (eg GP, practice nurse, learning disability nurse) use appropriate health checks.</p> <p>3.6.4 There is evidence of health assessment, health promotion and audit in these areas.</p> <p>3.6.5 There is evidence of enhanced health surveillance of children with learning disabilities as appropriate. C</p> <p>3.6.6 There is information available in appropriate formats for children and adults with learning disabilities and their family carers in these areas.</p> |

| Quality Indicator Statement |
|--|
| 3.7 There is an agreed approach to joint working with social work and other agencies in line with <i>Joint Future (2000)</i> recommendations. <i>References: 51, 52, 60, 64</i> |
| Criteria |
| 3.7.1 There are jointly developed assessment tools incorporating inter-agency assessments. |
| 3.7.2 There is a forum or recognised system to share relevant information about children and adults with learning disabilities such as shared records. |
| 3.7.3 NHS services contribute to the development and implementation of local area co-ordination in line with national guidance. |
| 3.7.4 Joint equipment stores/arrangements are in place. |
| 3.7.5 There are agreed joint protocols for risk assessment and critical incidents. |

Services for Older People with Learning Disabilities

| Quality Indicator Statement |
|--|
| 3.8 There is appropriate health and social care intervention for older people with a learning disability. <i>References: 29, 52, 58</i> |
| Criteria |
| 3.8.1 Appropriate health screening is in place which takes account of specific health needs of older people with learning disabilities. |
| 3.8.2 There are clearly defined criteria for healthcare intervention and long-term care agreed jointly between health and social care providers. |
| 3.8.3 There is joint working between learning disability and older people's services. |

Wheelchair and Seating Services

| Quality Indicator Statement |
|---|
| <p>3.9 Wheelchair and seating services are provided which meet the needs of children and adults with learning disabilities. <i>References: 2, 59, 60, 72</i></p> |
| Criteria |
| <p>3.9.1 Children and adults with learning disabilities are involved in the selection of their wheelchairs.</p> <p>3.9.2 There is a local user group which involves children and adults with learning disabilities and their family carers.</p> <p>3.9.3 There is systematic reassessment for children and adults with learning disabilities.</p> <p>3.9.4 Provision and repair of wheelchairs/specialist seating is provided within agreed waiting times.</p> <p>3.9.5 Local clinics are provided that meet the needs of children and adults with learning disabilities.</p> |

General Health and Hospital Services

| Quality Indicator Statement |
|---|
| <p>3.10 There is a programme of education and training for healthcare professionals in primary, secondary, and tertiary settings with regard to the rights and needs of children and adults with learning disabilities. <i>References: 26, 29, 59, 72</i></p> |
| Criteria |
| <p>3.10.1 Induction training for health staff includes material on the needs and rights of children and adults with learning disabilities, including the role of the Mental Welfare Commission (MWC).</p> <p>3.10.2 The AWIA legislation is implemented and subject to audit and is supported by training programmes for staff.</p> |

3.10.3 The implementation of the *Mental Health (Care and Treatment) (Scotland) Act (2002)* is supported by appropriate training.

3.10.4 Attendance at training events related to the needs and rights of children and adults with learning disabilities by a range of health professionals is documented.

3.10.5 Users and family carers are involved in staff training.

Quality Indicator Statement

3.11 There is a system in place to ensure that paediatric and general hospital services can get advice and support from specialist staff in learning disabilities.

References: 52, 59, 72

Criteria

3.11.1 Staff are aware of the referral systems in place, and how to access information and specialist advice on learning disabilities.

3.11.2 Referral systems, and how to access information and specialist advice on learning disabilities are included in induction training and ongoing training programmes.

| Quality Indicator Statement |
|--|
| <p>3.12 General hospital services and services provided by paediatric hospitals/units are aware, and give attention to, the needs of children and adults with learning disabilities, and meet them appropriately. <i>References: 29, 72</i></p> |
| Criteria |
| <p>3.12.1 There are agreed protocols and appropriate staff in place to support children and adults with learning disabilities whilst attending general hospitals as out-patients, or as in-patients.</p> <p>3.12.2 Hospital appointments are made at times and locations that suit the needs of children and adults with learning disabilities and their family carers.</p> <p>3.12.3 Arrangements are in place to ensure that staff can get specialist advice and support within 4 normal working hours of a person with a learning disability being admitted to a general hospital.</p> <p>3.12.4 The communication needs of children and adults with learning disabilities are identified, and arrangements are in place to support communication throughout their hospital stay.</p> <p>3.12.5 General hospital services take account of any additional needs that children and adults with learning disabilities may have, and this is documented in the case record.</p> <p>3.12.6 There is a specialist learning disability nursing service within acute/general hospitals, to support children and adults with learning disabilities and their families.</p> |

| Quality Indicator Statement |
|--|
| <p>3.13 Palliative care services are able to take account of the needs of children and adults with learning disabilities. <i>Reference: 29</i></p> |
| Criteria |
| <p>3.13.1 There is effective liaison between palliative care, primary care and children's learning disability services.</p> <p>3.13.2 Where appropriate, children and adults with learning disabilities are supported to access specialist palliative care services, including hospice care.</p> <p>3.13.3 Palliative care specialists receive training regarding the needs of children and adults with learning disabilities.</p> |

| Quality Indicator Statement |
|---|
| <p>3.14 Clinical guidelines for specific illnesses are followed and take account of the needs of children and adults with learning disabilities, eg Scottish Intercollegiate Guidelines Network (SIGN), NHS Quality Improvement Scotland (NHS QIS).</p> |
| Criteria |
| <p>3.14.1 The clinical governance process incorporates the appropriate guidelines.</p> <p>3.14.2 There is multidisciplinary clinical audit of guideline implementation.</p> |

QUALITY INDICATOR 4 - Meeting Complex Healthcare Needs (Tiers 3 & 4)

Rationale

Children and adults with learning disabilities have a range of additional and complex needs, often life-long that require good integration of general and specialised services, across different age and service transitions. Services to meet complex needs are best delivered through evidence-based practice, tailored to individuals.

Service Integration

| Quality Indicator Statement |
|---|
| 4.1 There is functional integration of specialised and general health services. <i>References: 29, 55</i> |
| Criteria |
| 4.1.1 There is evidence of joint care planning and joint clinical review activity between primary, general and specialist health services for children and adults with learning disabilities. |
| 4.1.2 There is ease of access to specialist advice by other agencies and family carers. |

Transitions

| Quality Indicator Statement | |
|---|---|
| <p>4.2 There is continuity of healthcare through age-related transitions from pre-school to school, primary to secondary education, youth to adult learning disability services and adult to older people's services. This is ensured by liaison between paediatric services, primary care, education services and other specialists. <i>References: 15, 22, 29, 44, 45, 52, 55, 58, 60, 63</i></p> | |
| Criteria | |
| <p>4.2.1 There are policies and protocols to support age transitions within health services and between health, education, social work and other agencies.</p> | |
| <p>4.2.2 There is clear evidence of communication between services and agencies and agreed procedures for when and how information is shared and exchanged.</p> | |
| <p>4.2.3 Early information and support is available to children, young people and their families in preparation for the different transitions.</p> | C |
| <p>4.2.4 Recommendations about transitions from national reports are being implemented.</p> | |
| <p>4.2.5 Appropriate healthcare professionals are available to participate in co-ordinated support plans (CSPs).</p> | |
| <p>4.2.6 Representatives from adult learning disability services should be available to participate in additional support plans/future needs assessment meetings for young people with learning disabilities.</p> | C |
| <p>4.2.7 The relevance of adult focused legislation such as the AWIA and Community Care (Direct Payments) Act (1996) is considered and included in care plans, as appropriate, for young people approaching child to adult transitions.</p> | |
| <p>4.2.8 The needs of adults with learning disabilities approaching 65 years of age are identified in care plans with consideration, as appropriate, to accessing older people's services.</p> | A |

| Quality Indicator Statement |
|--|
| <p>4.3 There is continuity of healthcare in service transitions within, and to and from health services such as community, hospital, respite care, and locality transitions. <i>Reference: 60</i></p> |
| Criteria |
| <p>4.3.1 There are policies and protocols in place between health, education, and social work to support the range of transitions, within and between services.</p> <p>4.3.2 There is clear evidence of communication between services and agreed procedures for when and how information is shared and exchanged.</p> <p>4.3.3 Information and support is available to people and their families in preparation for the different transitions.</p> <p>4.3.4 There is continuity of the provision of aids and equipment for children and adults with learning disabilities.</p> <p>4.3.5 There is evidence of continuity of general and of specialist health services.</p> |

Specialist Services

| Quality Indicator Statement |
|---|
| <p>4.4 Children with learning disabilities have access to specialist multidisciplinary/multi-agency community services. <i>References: 4, 7, 14, 28, 29, 45, 47, 55, 59, 60, 63, 68</i></p> |
| Criteria |
| <p>4.4.1 There are local early diagnostic and early intervention services for children with learning disabilities. C</p> <p>4.4.2 Child development centres/teams provide a multi-agency focus for the early years. C</p> |

4.4.3 A community paediatric nursing service provides support to children, families and relevant agencies/staff on discharge from hospital, and ongoing support, as required. C

4.4.4 A range of paediatric clinical services is available, including:

- Clinical psychology;
- Dietetics;
- Orthotics;
- Nursing;
- Occupational therapy;
- Physiotherapy;
- Podiatry;
- Psychiatry; and
- Speech and language therapy. C

4.4.5 There is timely access to services within agreed waiting times. C

4.4.6 Health services contribute to the development and implementation of local area co-ordination for children and young people. C

4.4.7 The range of health services is provided to support children and young people with learning disabilities attending mainstream schools. C

4.4.8 Single shared assessments are in use. C

8. Quality Indicators for Learning Disabilities

| Quality Indicator Statement | |
|---|---|
| <p>4.5 Adults with learning disabilities have access to specialist multidisciplinary/multi-agency community services. <i>References: 29, 59, 60</i></p> | |
| Criteria | |
| 4.5.1 Community learning disability services are available to provide expert assessment and early intervention and support. | A |
| <p>4.5.2 A range of clinical services is available, including:</p> <ul style="list-style-type: none"> • Clinical psychology; • Creative therapies; • Dietetics; • Learning disability nursing; • Occupational therapy; • Physiotherapy; • Podiatry; • Psychiatry; and • Speech and language therapy. | A |
| 4.5.3 There is timely access to services within agreed waiting times. | A |
| 4.5.4 Arrangements for joint working are agreed in line with <i>Joint Future (2000)</i> . | A |
| 4.5.5 Single shared assessments are in use. | A |
| 4.5.6 There is liaison between community learning disability and homelessness services. | A |

Quality Indicator Statement

4.6 NHS Boards have identified specialist service needs and the range of services for children and adults with complex needs is provided across the NHS Board area.

References: 29, 34, 39, 45, 47, 68

Criteria

4.6.1 Specialist services are provided locally which can support good mainstream practice across health education and social work services as well as directly serve the small number of children and adults with the most complex needs.

4.6.2 Specialist assessment is available within agreed waiting times for the following complex needs:

- Autistic spectrum disorder;
- Challenging behaviour;
- Dementia;
- Epilepsy;
- Mental ill-health;
- Offending behaviour;
- Older age learning disabilities;
- Profound and multiple impairment;
- Sensory impairment; and
- Specific syndromes and genetic conditions.

4.6.3 Managed Care Networks are in place.

Services for Children and Adults with Challenging Behaviour

| Quality Indicator Statement |
|--|
| <p>4.7 There are community-based services to meet the needs of children and adults with challenging behaviour. <i>References: 9, 11, 24, 26, 27, 29, 45, 52</i></p> |
| Criteria |
| <p>4.7.1 Services for children and adults with challenging behaviour are jointly commissioned, based on needs assessment.</p> <p>4.7.2 For children there are appropriate crisis response services involving health, education, and social work</p> <p>4.7.3 There are staff across the range of disciplines with appropriate training in this area in community and in-patient assessment and treatment services.</p> <p>4.7.4 Health staff contribute to the training of support staff to meet the needs of children and adults with challenging behaviour.</p> <p>4.7.5 The support needs of family carers are addressed, including respite.</p> <p>4.7.6 There is evidence that there is capacity and competence within local services to understand and respond to the needs of children and adults with challenging behaviour.</p> <p>4.7.7 Community-based crisis and planned assessment and intervention services are in place.</p> <p>4.7.8 In-patient services should provide short-term, highly focused assessment and treatment. Any in-patient treatment is linked with the provision of future community-based resources for the individual.</p> |

| Quality Indicator Statement |
|--|
| <p>4.8 Management and treatment of challenging behaviour is practised, and approaches used have proven, evidence-based effectiveness and social validity. <i>References: 9, 24, 26, 29, 52</i></p> |
| Criteria |
| <p>4.8.1 All staff have knowledge and understanding of policies on: risk assessment; management of aggression; communication strategies; moving and handling; and safe use of restraint (eg British Institute of Learning Disability guidelines, Mental Welfare Commission, National Autistic Society guidelines).</p> <p>4.8.2 Policies are supported by training and audit.</p> <p>4.8.3 Communication needs are identified and addressed as a major underlying cause of challenging behaviour.</p> <p>4.8.4 Specific training is available to staff in treatment approaches, which reduce the likelihood of challenging behaviour in the future, and such approaches are evident in care plans.</p> <p>4.8.5 Training needs of staff working in educational settings are supported by health professionals. The treatment plan should be part of Individual Education Plans (IEPs) or co-ordinated support plans. C</p> <p>4.8.6 For children and adults with seriously challenging behaviour there is proactive risk management in a least restrictive setting.</p> |

Services for People with Offending Behaviour

| Quality Indicator Statement |
|--|
| <p>4.9 There is a service to meet the needs of people with learning disabilities with offending behaviour. <i>References: 24, 26, 29, 34, 52, 76</i></p> |
| Criteria |
| <p>4.9.1 There are local professionals with expertise in working with offenders with learning disabilities in community and in-patient services.</p> <p>4.9.2 There is evidence of joint working with social work staff and other agencies such as police, probation services, and the children's reporter service.</p> <p>4.9.3 There are protocols in place regarding risk assessment, access to, and discharge from, in-patient provision, and appropriate secure service provision.</p> <p>4.9.4 Community-based services are in place which support people, prevent admissions where possible, and facilitate discharge from inpatient and other secure settings. The least restrictive options for individuals should be available.</p> <p>4.9.5 There are clear procedures allocating responsibility to individuals for arranging proper assessment, treatment and care of offenders with learning disabilities.</p> <p>4.9.6 Local services are part of appropriate care networks and the needs of people with learning disabilities are addressed within the National Managed Care Network.</p> |

Services for People with Mental Health Problems

| Quality Indicator Statement | |
|-----------------------------|--|
| 4.10 | The mental health needs of children and adults with learning disabilities are met in the most appropriate setting. <i>References: 24, 26, 29, 40, 52, 68</i> |
| Criteria | |
| 4.10.1 | There is a range of appropriately trained health staff in community and in-patient services to meet the mental health needs of people with learning disabilities. |
| 4.10.2 | There are jointly agreed admission protocols between learning disability and mental health services, which aim to support people with learning disabilities who may be admitted to psychiatric services. |
| 4.10.3 | There is an identified mental health service for children with learning disabilities within child and adolescent mental health services. C |
| 4.10.4 | Age appropriate in-patient services are available for children and young people with learning disabilities. C |
| 4.10.5 | In-patient services provide short-term, highly focused assessment and treatment. Any in-patient treatment is linked with the provision of future community-based resources for the individual. |
| 4.10.6 | The Care Programme Approach (CPA) is used, when appropriate, for adults with learning disabilities. A |
| 4.10.7 | There are jointly agreed liaison arrangements between child health, child and adolescent mental health services, and learning disability services. |

Services for People with Autistic Spectrum Disorder

| Quality Indicator Statement |
|---|
| <p>4.11 The assessment and treatment needs of children and adults with learning disabilities who have an ASD are met in accordance with national guidelines. <i>References: 28, 29, 52</i></p> |
| Criteria |
| <p>4.11.1 There is a lead person/autism co-ordinator for children and adults identified to co-ordinate and support access to services.</p> <p>4.11.2 Early diagnostic services are available locally, and appropriate intervention services involve health, social work, and education.</p> <p>4.11.3 There are multidisciplinary care plans in place that take account of the specific needs of children and adults with ASD.</p> <p>4.11.4 There are identified staff with expertise to assess and provide appropriate services for people with ASD, including those with Asperger's Syndrome.</p> <p>4.11.5 Training programmes are in place for health staff across primary and secondary care services, education and social care staff.</p> <p>4.11.6 Specialist care pathways are provided for people with ASD and these give particular attention to supporting transitions.</p> <p>4.11.7 Managed Care Networks are in place.</p> <p>4.11.8 There is a system in place to consider national standards/ guidance relevant to the needs of children and adults with ASD.</p> |

Services for People with Dementia

| Quality Indicator Statement | |
|--|---|
| <p>4.12 There is an appropriate range of services to meet the needs of people with dementia. <i>References: 29, 52</i></p> | |
| Criteria | |
| 4.12.1 | There is access to appropriate assessment and early diagnostic services. A |
| 4.12.2 | People with learning disabilities who have dementia have access to the full range of therapeutic interventions, including cognitive enhancing medications. A |
| 4.12.3 | There are staff training programmes, including dementia awareness, to meet the needs of adults with learning disabilities who develop dementia. A |
| 4.12.4 | There is liaison with older people's and mental health services. A |

Services for People with Profound and Multiple Impairment

| Quality Indicator Statement | |
|---|--|
| <p>4.13 There is an appropriate range of services to meet the needs of children and adults with profound and multiple impairment and their family carers. <i>References: 20, 29, 47, 52</i></p> | |
| Criteria | |
| 4.13.1 | Specific health needs are assessed and appropriate interventions are in place (eg respiratory disease, gastrointestinal diseases, epilepsy, scoliosis). |
| 4.13.2 | There are agreed protocols and training in place for the administration of healthcare procedures, eg rectal diazepam, tube/PEG feeding, suction, oxygen and midazelan and these are used by all providers. |

- 4.13.3 Specialist healthcare staff provide training to staff in social care and education settings, and to family carers.
- 4.13.4 Specialist equipment and training for personal care, moving and handling, and eating is provided, as necessary.
- 4.13.5 Children and adults with profound and multiple impairments can access social day services or respite, with healthcare procedures delivered in those settings.

Services for People with Learning Disabilities and Epilepsy

| Quality Indicator Statement |
|---|
| <p>4.14 Services for children and adults with learning disabilities who have epilepsy are available. <i>References: 52, 73, 74</i></p> |
| Criteria |
| <p>4.14.1 Children and adults with learning disabilities have access to a specialist epilepsy clinic for assessment and ongoing review.</p> <p>4.14.2 There are joint treatment plans as part of the care plan, involving the individual, carer, GP and relevant specialists.</p> <p>4.14.3 Services provided are evidence-based from SIGN and other relevant guidelines.</p> <p>4.14.4 Nurse specialists in epilepsy provide advice and support to children and adults with learning disabilities, family carers, and staff.</p> <p>4.14.5 Information on epilepsy, medication, seizure management etc, is available to children and adults with learning disabilities in accessible formats.</p> <p>4.14.6 Training is provided to staff and family carers.</p> <p>4.14.7 Epilepsy audits are undertaken.</p> |

QUALITY INDICATOR 5 - In-patient Services – Daily Life (Tier 4)

Rationale

The quality of accommodation and services is a key contributor to quality of life. People who use services are entitled to make choices and decisions about their life and to live in the least restrictive setting.

Environment

| Quality Indicator Statement |
|--|
| 5.1 The NHS Board and Community Health Partnerships plan and implement a programme to manage the physical internal and external environment to reduce hazards, and manage the degree of risk to ensure personal safety. <i>References: 26, 27</i> |
| Criteria |
| 5.1.1 Environmental risk assessment audits are in place that take account of the needs of children and adults with learning disabilities. |
| 5.1.2 Audit results are collated centrally and these results influence preventative policies. |
| 5.1.3 There is a policy on environmental restrictions, including locked doors, in line with the Mental Welfare Commission guidance which is subject to audit. |
| 5.1.4 Children and adults with learning disabilities are able to move around the accommodation safely with minimal risk of harm to themselves and/or others. |

| Quality Indicator Statement |
|--|
| <p>5.2 The NHS Board/ Community Health Partnership ensures that in-patient accommodation is suitable to the needs of people with learning disabilities and aims to meet the appropriate standards for care homes. <i>Reference: 54</i></p> |
| Criteria |
| <p>5.2.1 The general environment provides domestic style accommodation.</p> <p>5.2.2 In paediatric services there should be appropriate and safe areas for play for children with learning disabilities. C</p> <p>5.2.3 There is adequate storage, and all items of furniture and equipment are stored appropriately.</p> <p>5.2.4 The accommodation is clean and free from offensive smells and intrusive noise throughout.</p> <p>5.2.5 Bedrooms are personalised to meet the needs and wishes of individuals.</p> <p>5.2.6 People can control the heating, light and ventilation in their room.</p> <p>5.2.7 Rooms and corridors are in good decorative order, and furniture and furnishings are of a good standard.</p> <p>5.2.8 There is a furniture and equipment replacement programme in place, and staff understand the procedure for requesting repairs and replacements.</p> |

Privacy and Personalisation

| Quality Indicator Statement |
|--|
| 53 People with learning disabilities have their privacy and property respected, and are free from unnecessary intrusion. <i>References: 26, 54</i> |
| Criteria |
| 53.1 People have their own bedroom, if they wish, which they have free access to. |
| 53.2 People have a lockable space and adequate storage space for personal belongings. |
| 53.3 People are able to bathe, use the toilet, and receive care in privacy. Risk assessment procedures are in place. |
| 53.4 People have access to personal toiletries, which they do not share. |
| 53.5 People are able to have visitors and are consulted with about visits and visitors. |
| 53.6 People are able to make phone calls in private and receive mail, including e-mails in private, unless there are clinical reasons to prevent this which are recorded in their care plan. |
| 53.7 People have their own clothes which staff can help to care for. |
| 53.8 People have easy access to areas for personal privacy. |

| Quality Indicator Statement |
|--|
| <p>5.4 The NHS Board/Community Health Partnership ensures that accommodation provides an environment supportive of individual needs, choice, privacy and dignity. <i>References: 33, 54, 62, 66</i></p> |
| Criteria |
| <p>5.4.1 People with learning disabilities, who are in longer term NHS care, have influence in the choice of people with whom they are currently living.</p> <p>5.4.2 People with learning disabilities, in NHS care are involved in selection of décor, furniture and personal effects.</p> <p>5.4.3 Environment/accommodation is adapted to take account of individual needs, eg children and adults with challenging behaviour and/or ASD.</p> <p>5.4.4 People moving between units/wards/social care resources should do so on the basis of individual choice and/or clinical grounds. Such moves are kept to a minimum.</p> <p>5.4.5 Good practice standards/guidance for ward/unit moves are in place and monitored.</p> <p>5.4.6 Mixed gender guidance is in place and is followed.</p> <p>5.4.7 Non smokers can expect to be in a smoke-free environment, and smokers to have access to suitable facilities.</p> |

Daily Life

| Quality Indicator Statement |
|---|
| <p>5.5 In line with the National Care Standards, the NHS Board/Community Health Partnership ensures people with learning disabilities are supported to make choices and decisions about day-to-day aspects of their life, and about how to spend their time. <i>References: 2, 31, 33, 53, 54</i></p> |
| Criteria |
| <p>5.5.1 Care plans/personal life plans identify opportunities for education, training and work, and people are supported to participate.</p> |
| <p>5.5.2 There is a range of leisure, recreation and relaxation activities available to meet people's needs.</p> |
| <p>5.5.3 People with learning disabilities are supported to make choices about day-to-day activities and to use local services such as hairdressers, shops, banks etc.</p> |
| <p>5.5.4 There is a varied choice of food, which meets individual preferences and dietary needs in line with relevant standards.</p> |
| <p>5.5.5 People have snacks, and hot and cold drinks as they wish.</p> |
| <p>5.5.6 Arrangements are in place for people's finances in line with AWIA legislation. Information is available to people about their benefits and allowances.</p> |
| <p>5.5.7 People are able to spend their money to do things that they want unless there are clinical reasons to prevent this.</p> |
| <p>5.5.8 People can choose their clothes and personal items, and are involved in buying them.</p> |
| <p>5.5.9 People have their ethnic background and religious beliefs acknowledged and respected, and have the opportunity and support to practice their faith. This is identified in their care plan.</p> |

QUALITY INDICATOR 6 - Planning Services and Partnership Working (Tier 0)

Rationale

To address health inequalities and plan services for children and adults with learning disabilities, information on the needs of the population is essential. A strategic approach across NHS Boards, Community Health Partnerships and local authorities is required for effective partnership working. The needs of children and adults with learning disabilities should be part of all planning activity and strategy documents.

Strategic Health Improvement and Needs Assessment

| Quality Indicator Statement |
|--|
| 6.1 Health improvement strategies take account of the needs of children and adults with learning disabilities and their family carers. <i>References: 23, 29, 43, 52, 56, 61, 63</i> |
| Criteria |
| 6.1.1 There is a continuing programme of health needs assessment, informed by <i>NHS Health Scotland Learning Disability Needs Assessment</i> recommendations and undertaken by the NHS Board and Community Health Partnerships together with local authorities, voluntary sector and people with learning disabilities and their family carers. |
| 6.1.2 The health needs assessment informs the Health Plan, Community Plan, Joint Health Improvement Plan (JHIP), and the range of strategic plans, eg child health, older people, mental health. |
| 6.1.3 The needs assessment includes children and adults in out of area placements. |
| 6.1.4 NHS Boards take account of the needs of children and adults moving to the NHS Board area on a temporary or longer term basis (including travelling people). |
| 6.1.5 The health and homelessness action plan takes account of the needs of people with learning disabilities. |

| Quality Indicator Statement |
|--|
| <p>6.2 Joint Partnership Boards have processes in place that address health inequalities in services for children and adults with learning disabilities in line with the <i>NHS Health Scotland Learning Disability Needs Assessment</i> report. <i>References: 23, 29, 43, 52, 61, 62, 63</i></p> |
| Criteria |
| <p>6.2.1 Social inclusion policies take account of the needs of people with learning disabilities.</p> <p>6.2.2 There is evidence of work being undertaken to improve equity of access to all services for children and adults with learning disabilities across the area.</p> <p>6.2.3 The needs of children and adults with learning disabilities in areas of deprivation and rural and remote areas are specifically addressed.</p> <p>6.2.4 Health improvement strategies take account of the needs of children and adults with learning disabilities, and there is a lead person identified within the joint partnership arrangements. There is partnership working within an agreed accountability framework.</p> <p>6.2.5 Joint Partnership Boards co-ordinate the development of local protocols to address the interface between health and local authority services.</p> |

Database Developments

| Quality Indicator Statement |
|--|
| <p>6.3 The E-Care strategy supports the planning and review process in line with joint partnership arrangements. <i>References: 29, 52</i></p> |
| Criteria |
| <p>6.3.1 Appropriate information is recorded on individual and collective needs in the local area.</p> <p>6.3.2 Databases are developed and maintained in line with national guidelines.</p> <p>6.3.3 There is a single shared assessment used as the basis of the database in line with the Joint Performance Information and Assessment Framework (JPIAF).</p> |

Healthcare Planning

| Quality Indicator Statement |
|---|
| <p>6.4 The NHS Board has healthcare provision plans for children and for adults with a learning disability. These plans inform the Partnership in Practice agreement (PiP) and other strategies. <i>References: 4, 12, 29, 34, 52, 55, 58, 68, 76</i></p> |
| Criteria |
| <p>6.4.1 There is a strategic plan/framework for learning disability services which addresses general and specialist health needs, and which has funding in place.</p> <p>6.4.2 The plan has been agreed with partners and is publicly available and accessible to children and adults with learning disabilities.</p> <p>6.4.3 The plan includes specific strategies that address the range of conditions as identified in the <i>NHS Health Scotland Learning Disability Needs Assessment</i> report.</p> |

- 6.4.4 Children's services plans, child health strategy, and child and adolescent mental health strategy address the needs of children with learning disabilities. C
- 6.4.5 Children's services and community care planning identify strategic objectives around transitions. C
- 6.4.6 Health representatives from the range of services (eg children, primary care, general and learning disability) are involved in the Same As You?/PiP planning implementation groups.
- 6.4.7 The PiPs include healthcare action and timescales in line with *Promoting Health, Supporting Inclusion*.
- 6.4.8 There is financial investment in health service plans to meet local needs, with a timetable for implementation.
- 6.4.9 There is evidence that the needs of adults with learning disabilities are taken into account within other strategies or plans such as mental health, older people, and physical disability. A

Quality Indicator Statement

6.5 Workforce planning and the education and training needs of staff are identified and addressed in collaboration with NHS Education for Scotland.
Reference: 59

Criteria

- 6.5.1 A training needs analysis has been undertaken across all NHS services, which take account of the needs of children and adults with learning disabilities.
- 6.5.2 Workforce planning takes account of the service planning for children and adults with learning disabilities.
- 6.5.3 NHS staff across all health settings (and jointly commissioned services) access appropriate educational and training opportunities.
- 6.5.4 A programme of training supports service changes and is subject to review and audit.

| Quality Indicator Statement |
|--|
| 6.6 Community Health Partnership planning processes take account of the needs of children and adults with a learning disability within their area. <i>References: 29, 61</i> |
| Criteria |
| 6.6.1 The Community Health Partnership plans relate to and inform the JHIP/Community Plan and overall planning at NHS Board level and of partner agencies. 6.6.2 There is evidence that plans address identified needs. |

| Quality Indicator Statement |
|---|
| 6.7 The NHS Board has plans to develop services for children and adults with complex needs. <i>References: 24, 29, 34, 55</i> |
| Criteria |
| 6.7.1 There is joint commissioning for children and adults with learning disabilities who have complex needs. 6.7.2 There is agreement on how complex care packages are funded. 6.7.3 There are plans for specialist services to support local mainstream practice to serve the small number of people with the most complex needs. |

| Quality Indicator Statement |
|---|
| <p>6.8 NHS Boards utilise up-to-date, evidence-based outcome and health gain information in their decision-making for commissioning health services, in line with the <i>NHS Health Scotland Learning Disability Needs Assessment</i> recommendations. <i>Reference: 29</i></p> |
| Criteria |
| <p>6.8.1 Services are commissioned according to best practice guidelines.</p> <p>6.8.2 Evidence-based practice is adopted in operational policies and regularly updated.</p> <p>6.8.3 There is a named person with responsibility for researching and recommending evidence-based outcomes.</p> |

Hospital Closure and Service Reprovision

| Quality Indicator Statement |
|---|
| <p>6.9 The NHS Board has an agreed plan on hospital closure/service reprovision that takes account of the Same As You? Implementation Group (SAYIG) report. <i>Reference: 62</i></p> |
| Criteria |
| <p>6.9.1 There is an agreed implementation plan with local authorities for hospital closure/service reprovision which addresses financial investment, user involvement, human resource strategy, communication strategy, site retraction plan.</p> <p>6.9.2 Joint assessments are undertaken and commissioning plans in place for all people who are in hospital/NHS units who do not have a home in the community. This includes people in out-of-area placements.</p> <p>6.9.3 Services are planned and commissioned with local authorities for children and adults who use hospital for short breaks/respite care.</p> |

- 6.9.4 There are housing plans for all people living in hospital.
- 6.9.5 Assessment and treatment services are developed in line with *The same as you?* objectives.
- 6.9.6 There is a joint accountability framework in place.

Partnership Working

| Quality Indicator Statement |
|---|
| 6.10 There are joint arrangements in place for learning disability services and these take account of the <i>Joint Performance Information and Assessment Framework</i> (JPIAF). <i>References: 39, 41, 46, 51, 64, 65, 77</i> |
| Criteria |
| 6.10.1 There is an agreed and documented approach to joint working, in line with the Joint Future and other policies relevant to children and adults with learning disabilities. |
| 6.10.2 There are jointly commissioned services with financial plans in place. |
| 6.10.3 There is a joint training strategy, secondment opportunities for staff and joint training budgets. |

| Quality Indicator Statement |
|--|
| 6.11 There is a joint approach to the evaluation of services. <i>References: 29, 41, 46, 52, 77</i> |
| Criteria |
| 6.11.1 Multi-agency teams are established to undertake evaluation of services. |
| 6.11.2 Evaluation is used to inform services. |

| Quality Indicator Statement | |
|--|---|
| 6.12 The NHS Board and partners have established a multidisciplinary group for the protection of vulnerable adults. | |
| Criteria | |
| 6.12.1 There is an inter-agency policy for the prevention and reporting of abuse of vulnerable adults. | A |
| 6.12.2 Staff are trained in the use of guidelines, and procedures and understand and use them. | A |
| 6.12.3 There is evidence of a lead agency health service involvement in the use of guidelines on Appropriate Adults. | A |
| 6.12.4 Disclosure Scotland and SEHD guidelines on staff checks are used. | A |
| 6.12.5 Policies on vulnerable adults are in place, supported by training and are monitored. | A |

| Quality Indicator Statement | |
|---|---|
| 6.13 The NHS Board and partners have established a multidisciplinary group for the implementation of child protection policies. <i>References: 88, 89</i> | |
| Criteria | |
| 6.13.1 There is an inter-agency policy on child protection in place which takes account of the needs of children and young people with learning disabilities. | C |
| 6.13.2 Staff are trained in the use of guidelines and procedures, and understand and use them. | C |

9. Membership of the Learning Disabilities Reference Group

The membership of the Learning Disabilities Reference Group is presented below:

| Name | Title | NHS Board Area/Organisation |
|----------------------|---|--|
| Mrs Alison Aitken | Nursing Director/ Child Health Commissioner | Borders |
| Mr Robert Aitken | Hospital General Manager | Lothian |
| Mrs Linda Allan | Lead Nurse - Primary Care Liaison Team | Greater Glasgow |
| Mr A Bruce Anderson | Project Director (Priority Services & Community Care) | Grampian |
| Mr David Anderson | Independent Social Work Consultant | Fife |
| Ms June Andrews | Director, Centre for Change and Innovation | Scottish Executive Health Department |
| Dr Ken Black | Senior Registrar, Public Health Medicine | Scottish Executive Health Department |
| Ms Anne Brown | Carer | Profound and Multiple Impairment Service |
| Mr Michael Brown | Health Needs Assessment Project Manager | NHS Health Scotland |
| Mr Ian Cairns | Principal Planning Officer | Angus Council |
| Mr John Cameron | Clinical Director - Psychology | Greater Glasgow |
| Mrs Susan Carr | Learning Disability Joint Future Manager | Grampian |
| Mr Victor Chlebowski | Assistant Director | Scottish Consortium for Learning Disability |

| | | |
|----------------------------|---|-----------------------------|
| Mr William Clark | Head of Strategy | West Dunbartonshire Council |
| Professor Sally-Ann Cooper | Professor of Learning Disabilities/Honorary Consultant Psychiatrist | University of Glasgow |
| Mrs Rosslyn Crockett | Director of Nursing | Greater Glasgow |
| Ms Lisa Curtis | Director, Scottish Consortium for Learning Disabilities | Greater Glasgow |
| Dr David Easton | General Practitioner | Grampian |
| Ms Anne Edmonstone | Speech & Language Therapy Adviser | Lothian |
| Mr John Foley | Epilepsy Specialist Nurse | Lothian |
| Mr William Gent | Independent Nurse Consultant | Tayside |
| Ms Margaret-Anne Gilbert | Social Work Officer | Mental Welfare Commission |
| Mr William Gorman | Head of Strategy and Development | Renfrewshire Council |
| Mrs Janice Gow | Director | Care Solutions Ltd |
| Ms Sandra Greer | Head of Service | Argyll & Bute Council |
| Dr Hamish D Greig | General Practitioner | Tayside |
| Mrs Linda Headland | Director, East Lothian Care & Accommodation Project | Lothian |
| Dr John Hislop | General Practitioner | Renfrewshire & Inverclyde |
| Professor James Hogg | Director, White Top Research Unit | Tayside |
| Ms Susan Hunter | Lecturer | University of Edinburgh |

9. Membership of the Learning Disabilities Reference Group

| | | |
|------------------------|---|----------------------------------|
| Mr Tom Keenan | Independent Social Care Consultant | Glasgow |
| Mr Ian Kerr | Inspector, Social Work Services Inspectorate | Ayrshire & Arran |
| Dr Malcolm Kerr | Chair, Arran LHCC | Ayrshire & Arran |
| Mrs Sally Lee | Joint Future Manager | Lothian |
| Mrs Meg Lindsay OBE | Independent Consultant | Glasgow |
| Mr Alistair Littlejohn | Clinical Service Development Manager | Lothian |
| Dr Ros Lyall | Consultant Psychiatrist | Lothian |
| Dr Robert MacIntosh | Senior Lecturer | University of Glasgow |
| Ms Fiona Mackenzie | Chief Executive | Forth Valley |
| Dr Shiona Mackie | Director of Clinical Standards & Health Improvement | Lanarkshire |
| Dr Grant McHattie | General Practitioner | Ayrshire & Arran |
| Dr Ronnie McVicker | Consultant Psychiatrist - Psychiatry of Learning Disability | Forth Valley |
| Mr Robert Marshall | Head of External Relations and Marketing | University of Glasgow |
| Dr John Martin | Consultant Psychiatrist | Ayrshire & Arran |
| Mr Malcolm Matheson | Director | Key Housing Association |
| Mr Alistair Matheson | Clinical Projects Manager | Argyll & Clyde |
| Dr Tom Murphy | Consultant Psychiatrist in Psychotherapy | Lothian |
| Ms Julie Murray | Head of Strategy & Development | East Renfrewshire Council |
| Mr John Paterson | Senior Operational Manager | The Richmond Fellowship Scotland |
| Ms Moira Paton | Head of Community Care & Community Development | Highland |

| | | |
|------------------------------|---|--------------------------------------|
| Dr Robert Peat | Acting Director of Social Work | Angus Council Social Work Department |
| Mr David Pigott | Chief Executive | Lanarkshire |
| Ms Marcia Ramsay | Locality Manager | Care Commission |
| Mrs Nan Reid | Assistant Director - Planning | Lanarkshire |
| Dr Julie Ridley | Senior Researcher | Scottish Health Feedback |
| Mr Denis Rowley | Director | Choices Foundation |
| Mr Robert Samuel | Nursing Officer | Scottish Executive Health Department |
| Ms Maggie Scrugham | Service Manager | Community Integrated Care |
| Dr John C Shemilt | Consultant Psychiatrist | Greater Glasgow |
| Dr Gordon Sim | General Practitioner | Borders |
| Dr Neill Simpson | Consultant Psychiatrist | Greater Glasgow |
| Mrs Lesley Smith | Director of Nursing and Allied Health Professions | Argyll & Clyde |
| Mr Tommy Stevenson | Professional Nurse Advisor | Ayrshire & Arran |
| Mr Hugh Stewart | Lay Representative | Glasgow |
| Mr Jack Stuart | General Manager | Grampian |
| Mr William Swan | Assistant Service Manager | Fife Council |
| Mrs Jenny Thompson | Head of Social Work | South Ayrshire Council |
| Professor Christopher Turner | Deputy Chair | Capability Scotland |
| Dr Robert Wagner | Chairman of Irvine, Kilwinning & Dundonald LHCC | Ayrshire & Arran |
| Dr Iain White | Associate Specialist in Learning Disability | Highland |

9. Membership of the Learning Disabilities Reference Group

| | | |
|---------------------|--|---------------------------------------|
| Dr Peter Williamson | Director of Planning & Development | Tayside |
| Mrs Gillian Wilson | Professional Head of Occupational Therapy Services | Yorkhill |
| Dr Steven Young | Consultant Psychiatrist | State Hospitals Board for Scotland |

10. Glossary of Terms

| | |
|-----------------------------------|--|
| accreditation | A process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation. |
| Acute sector | Hospital-based health services which are provided on an in-patient or out-patient basis. |
| Adults with Incapacity Act (AWIA) | The Adults with Incapacity Act was passed by the Scottish Parliament in May 2000. It introduces flexible options for dealing with situations where someone might need help with decision-making if they do not have the capacity to do so for financial, welfare or medical reasons. |
| advocacy | Where an individual acts independently on behalf of, and in the interests of, patients/users. |
| Advocacy Safeguards Agency (ASA) | The Advocacy Safeguards Agency is funded by the Scottish Executive Health Department in furtherance of the Executive's commitment to independent advocacy. ASA's purpose is to make sure that good quality independent advocacy is available to anyone in Scotland who needs it. It assists health and local authority commissioners to develop independent advocacy across Scotland and across all health and social care groups. It also ensures that the principles, practice and outcomes of the work done by advocacy organisations are meeting the needs of the people who use them. |
| AHPs | See allied health professions. |
| allied health professions (AHPs) | These are physiotherapy, occupational therapy, chiropody, radiography, dietetics, remedial gymnastics, orthoptics, art, music and drama therapies. |
| Asperger's Syndrome | This is a type of autism that some people of average intelligence have. They find it particularly difficult to understand what other people think, and this makes it hard for them to communicate and act appropriately. |
| assessment | The process of measuring patients' needs and/or the quality of an activity, service or organisation. |
| audiology | Audiology is the measurement of hearing. |

| | |
|----------------------------------|--|
| audit | Systematic review of the procedures used for diagnosis, care, treatment and rehabilitation, examining how associated resources are used and investigating the effect care has on the outcome and quality of life for the patient. |
| autistic spectrum disorder (ASD) | Autism can happen in people with different degrees of learning disability as well as in people of average intelligence, for example, those who have Asperger's Syndrome. Because of this wide range, we talk about a spectrum of autistic disorder. |
| AWIA | See Adults with Incapacity Act. |
| capacity building training | Capacity building training helps people with learning disability, and family carers, to develop their own leadership abilities. |
| Care Commission | <p>The Scottish Commission for the Regulation of Care (The Care Commission) is a national organisation set up under the Regulation of Care (Scotland) Act 2001 to regulate and inspect Scottish care services. Previously, regulation of care services was carried out by registration and inspection units covering 32 local authorities and the 12 mainland Health Boards, all operating to different standards and procedures.</p> <p>The Care Commission is working towards putting in place a new, unified and effective system of care regulation that puts the safety and wellbeing of people who use care services at its heart. Website: www.carecommission.com</p> |
| care programme approach (CPA) | Legislation requires that when a person is admitted or discharged from either a mental health unit or from mental health out-patients, they receive the care under the CPA. This is a means of co-ordinating, and monitoring of all aspects of care, which may be provided by a variety of agencies at any one time. |

All people accepted for treatment by specialist psychiatric services should be assessed for the level of care that they need. The level of CPA will be determined by the complexity and disabling effects of the psychiatric condition, the risk factors and level or complexity of aftercare needed for the future. As part of CPA rules, the service user will also be assigned a care co-ordinator.

There are two levels of CPA: Standard and Enhanced. Standard means that there will be minimal intervention, however, the client does need to be in contact with specialist mental health services. Enhanced level means that there are more complex issues that need to be addressed.

As part of the CPA rules each client will receive a care plan, which should cover both health and social care needs as well as their proposed management. The service user, along with all other relevant people involved in their care, should agree with the care plan.

The care plan will be reviewed regularly after an agreed time period. This is called a CPA review. All relevant people should be present at a review. All service users should be given a copy of their care plan.

carer

A person who looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

challenging behaviour

A term used to describe when someone accreditation
A process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.

| | |
|------------------------------|--|
| children's reporter services | A Reporter is a person employed by the Scottish Children's Reporter Administration (SCRA) to whom referrals about children are made and who makes decisions on whether to refer a child to a hearing. The SCRA is a non-departmental public body whose statutory function is to manage the reporter service and to provide suitable accommodation and facilities for children's hearings. |
| Children's Act 1989 | The Children's Act 1989 covers childminding and the implications for both Social Services and the childminder. The Children's Act seeks to offer greater protection to children. The main principles are: to make children's welfare a priority; recognise that children are best brought up within their families wherever possible; the local authority can provide services for children and families in need; to promote partnership between children, parents and local authorities; to improve the way courts deal with children and families with rights of appeal against court decision; and to protect the rights of children. |
| CHP | See Community Health Partnerships. |
| CLDT | See community learning disability teams. |
| clinical governance | A framework through which NHS organisations are accountable for both continuously improving the quality of their services, and safeguarding high standards of care, by creating an environment in which excellence in clinical care will flourish. Management of clinical risk at an organisational level is an important aspect of clinical governance. Clinical risk management recognises that risk can arise at many points in a patient's journey, and that aspects of how organisations are managed can systematically influence the degree of risk. |

| | |
|--|---|
| Clinical Resource and Audit Group (CRAG) | CRAG was the lead body within the Scottish Executive Health Department promoting clinical effectiveness in Scotland. The main committee, together with its subcommittees provided advice to the Health Department, acted as a national forum to support and facilitate the implementation of the clinical effectiveness agenda and funded a number of clinical effectiveness programmes and projects. On 1 January 2003, CRAG was merged with four other clinical effectiveness bodies to create NHS Quality Improvement Scotland. See NHS Quality Improvement Scotland. |
| Clinical Standards Board for Scotland (CSBS) | The Clinical Standards Board for Scotland was a statutory body, established as a Special Health Board in April 1999. Its role was to develop and run a system of quality control of clinical services designed to promote public confidence that the services provided by the NHS met nationally agreed standards, and to demonstrate that, within the resources available, the NHS was delivering the highest possible standards of care. On 1 January 2003, CSBS was merged, along with four other clinical effectiveness bodies, to form NHS Quality Improvement Scotland (NHS QIS). See NHS Quality Improvement Scotland. |
| Community Care & Health Act 2002 | The Community Care & Health (Scotland) Act 2002 has delivered some major improvements in community care services, including free nursing and personal care. It has also: broadened access to direct payments for home care services; extended the right to assessment for informal carers; enabled local authorities to provide care home places elsewhere in the UK; and ensured high standards among non-principal GP's. |
| community learning disability teams | Groupings of multidisciplinary staff providing specialised services and support to a geographical area or population. |

| | |
|---|--|
| Community Care (Direct Payments) Act 1996 | The Act which empowers local authorities to make direct payments to people with disabilities to employ their own carers rather than rely on local authority or independent sector providers. See direct payments. |
| Community Health Partnerships (CHP) | Where Trusts/NHS Boards commit themselves to work in ways that complement the care given by GPs, Social Services, acute hospitals, mental health, education and the voluntary sector. |
| community plan | The Local Government in Scotland Act 2003 made it a duty from 1 April 2003 for each local authority to initiate, facilitate and maintain a process (called 'community planning') through which the public services in the area of the local authority must be provided. The local authority must consult with public bodies and community bodies about the provision of services. It makes it a duty for the NHS Board, emergency services and Scottish Enterprise, amongst others, to participate in this community planning process. |
| complex needs | The needs a person has over and above their learning disability, eg extra physical or mental health problems, challenging or offending behaviour. |
| co-ordinated support plan (CSP) | The draft (2003) Education (Additional Support for Learning) Scotland Bill introduces a statutory Co-ordinated Support Plan (CSP). 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 services required to support this. |
| CRAG | See Clinical Resource and Audit Group. |
| creative therapists | This refers to drama, art and music therapies. |
| criterion(s)/criteria(pl) | Provide the more detailed and practical information on how to achieve the standard, and relate to structure, process or outcome factors. |
| CSBS | See Clinical Standards Board for Scotland. |
| data source | The source of evidence to demonstrate whether a standard or criterion is being met. |

| | |
|--|---|
| DDA | See Disability Discrimination Act 1995. |
| deaf-blindness (dual-sensory impairment) | Deaf-blindness (or dual-sensory impairment) is a unique disability which brings enormous challenges to the individual and those who support them. Many people will not be totally deaf and totally blind, but will have some remaining use of one or both senses. Others will also have additional physical and/or learning disabilities. |
| dementia | An illness that affects the brain and which usually causes symptoms such as confusion and loss of memory. |
| desirable (criterion/criteria) | Good practice that is being achieved in some parts of the service and demonstrates levels of quality to which other providers of a similar service should strive. |
| diagnosis | Identification of an illness or health problem by means of its signs and symptoms. This involves ruling out other illnesses and causal factors for the symptoms. |
| direct payments | From 1 April 1997, local authorities have been able to offer some people a cash payment instead of arranging community care services directly for them. People who get this money use it to arrange services for themselves to meet their community care needs. When an authority gives someone money in this way, it is known as a direct payment. Direct payments can be made to help disabled people, carers of disabled people and families with disabled children to have more control over their lives. From June 2003, local authorities in Scotland have had a duty to offer direct payments in place of providing services to all eligible disabled people, aged 16 and over. Parents of disabled children will also be able to receive direct payments to buy the services their children need. |

| | |
|---|---|
| Disability Discrimination Act (DDA) | The Disability Discrimination Act (1995) (DDA) gives disabled people rights in the areas of employment, access to goods, facilities and services, and buying or renting land or property. The employment rights and the first rights of access came into force in December 1996; further rights of access came into force on 1 October 1999; and the final rights of access will come into force in October 2004. |
| Disability Rights Commission (DRC) | The Disability Rights Commission is an independent body set up by the Government to help secure civil rights for disabled people. Its statutory duties are: to work to eliminate discrimination against disabled people; promote equal opportunities for disabled people; encourage good practice in the treatment of disabled people; advise the Government on the working of disability legislation (the Disability Discrimination Act (1995) (DDA) and the Disability Rights Commission Act (1999)). Website: www.drc.org.uk/ |
| Disability Rights Commission (DRC) Codes of Practices | A number of Codes of Practice, explaining legal rights and requirements under the Disability Discrimination Act 1995, have been produced by the DRC. These Codes are intended to be practical guidance - particularly for disabled people, employers, service providers and education institutions - rather than definitive statements of the law. However, courts and tribunals must take them into account where relevant. |
| discharge | A discharge marks the end of an episode of care. Types of discharge include in-patient discharge, day-case discharge, day-patient discharge, out-patient discharge and allied health professions (see AHPs) discharge. |
| Disclosure Scotland | The aim of Disclosure Scotland is: "To enhance public safety and help employers and voluntary organisations in Scotland to make safer recruitment decisions". The services provided are three levels of criminal history system check, known as 'disclosures', provided to registered agencies and individual applicants on submission of a fee. Website: www.disclosurescotland.co.uk |

| | |
|--|--|
| dysphagia | Difficulty in swallowing. |
| eCare | eCare is about better and more joined up care, advice and assistance to the people of Scotland through the use of computers and communication technology. With the individual's consent eCare enables secure information-sharing between professionals - such as doctors, nurses, social workers and teachers - in public and voluntary agencies. Website: www.ecare-scotland.gov.uk |
| Education (Additional Support for Learning) Bill | This draft Bill, proposed by the Scottish Executive for implementation in the 2003-04 Scottish Parliament, seeks to update the system for children in Scotland who need additional support at school. It represents a change from special educational needs (SEN) terminology to the new concept of Additional Support for Learning. |
| endocrine disorders | Diseases which affect those parts of the body which produce and secrete (release) hormones. |
| epilepsy | People with epilepsy are prone to recurrent seizures. A seizure is caused by a temporary change in the way their brain cells work. Sometimes an upset in brain chemistry causes the messages in the brain to become scrambled. When this happens, the neurons fire off faster than usual and in bursts. It's this disturbed activity that triggers off a seizure. |
| essential (criterion/criteria) evaluation | A criterion that should be met wherever a service is provided. The study of the performance of a service (or element of treatment and care) with the aim of identifying successful and problem areas of activity. |
| evidence-based medicine | Evidence-based clinical practice is an approach to decision making in which the clinician uses the best evidence available, in consultation with the patient, to decide upon the option which suits that patient best. |

| | |
|---|---|
| family carer | The term 'family carer' is used to distinguish a relative from a paid or professional carer. The term 'families' is used in recognition that people other than parents may have a contribution to make to consultations. |
| Family Carers (Recognition and Services) Act 1995 | This Act came into effect on the 1st April 1996, and covers adults who are providing or intend to provide care, children and young people who provide or intend to provide care for a parent or other members of the family, and parents who provide or intend to provide care for a disabled child. The Act gives the above people the right to request a social services assessment of their ability and willingness to cope with their caring role. The Act does not place any duty on Social Services to provide services to carers, but does give them the duty to take the circumstances of the carer into consideration when decisions are being made about the care of the person being cared for, and the support services they require. |
| future needs assessment | The future needs assessment (FNA) process is part of educational legislation covering pupils with a record of needs. A future needs assessment is initiated at the child's secondary year, reviewed in fourth year and until leaving school. This information should then be transferred to the community care team for forward planning of the needs as a young adult. |
| generic standards | Standards that apply to most, if not all, clinical health services. |
| GP | General Practitioner. |
| guidelines | Systematically developed statements which help in deciding how to treat particular conditions. |
| HDL | See Health Department Letter. |
| Health Department Letter (HDL) | Health Department Letter (formerly known as Management Executive Letter - MEL), formal communications from the Scottish Executive Health Department to NHSScotland. |

| | |
|---|---|
| health improvement programme (HIP) | Each Health Board produces a HIP which sets out the strategic framework for improving health, reducing inequalities and delivering faster more responsive services of a consistently high standard. The Government requires that each HIP be underpinned by a comprehensive 3 year human resources and organisational development action plan, signed up to by all participant organisations. |
| Health Technology Board for Scotland (HTBS) | The Health Technology Board for Scotland (HTBS) worked to improve Scotland's health by providing evidence-based advice to NHSScotland on the clinical and cost-effectiveness of new and existing health technologies (medicines, devices, clinical procedures and healthcare settings). On 1 January 2003, HTBS was merged, along with four other clinical effectiveness bodies, to form NHS Quality Improvement Scotland (NHS QIS). See NHS Quality Improvement Scotland. |
| healthcare professional | A person qualified in a health discipline. |
| HTBS | See Health Technology Board for Scotland. |
| ICP | See integrated care pathway. |
| ILP | See Individual Learning Plan |
| Individual Learning Plan (ILP) | This sets out agreed learning targets and additional assistance students need to support learning, eg transport, adapted materials, personal care. An ILP provides a mechanism for establishing and monitoring collaboration. Partners involved in supporting students are invited to help establish appropriate learning targets and to contribute regularly to student reviews. In addition, ILP partners are involved in collaboration with regard to curriculum delivery. |
| induction programme | Learning activities designed to enable newly appointed staff to function effectively in their new job. |

| | |
|--|--|
| Information and Statistics Division (ISD) | The Information and Statistics Division is part of the Common Services Agency, NHSScotland. Health service activity, manpower and finance data are collected, validated, interpreted and disseminated by the division. This data is received from NHS Boards, NHS Trusts and general practices. Website: www.isdscotland.org |
| integrated care pathway | An integrated care pathway is an explicit agreement by a local group, both multidisciplinary and multi-agency, of staff and workers to provide a comprehensive service to a clinical or care group on the basis of current views of good practice and any available evidence or guideline. It is important that the group agree on communication, record keeping and audit. There should be a mechanism to pick up when a patient has not received any care input specified by the pathway so that the omission can be remedied. The local group should be committed to continuous improvement of the integrated care pathway on the basis of new evidence of service developments or of problems in implementation. |
| International Association for the Scientific Study of Intellectual Disabilities (IASSID) | The International Association for the Scientific Study of Intellectual Disabilities is an international and interdisciplinary scientific organisation that promotes worldwide research and exchange of information on intellectual disabilities. Website: www.iassid.org/ |
| ISD | See Information and Statistics Division. |
| Island NHS Board | There are three Island NHS Boards (Orkney, Shetland and the Western Isles). They have always had a combined strategic and operational role. See NHS Board. |
| Joint Health Improvement Plan (JHIP) | In 2002 the Scottish Executive asked each local authority to take the lead in setting out a “shared vision for health” through a Joint Health Improvement Plan. |
| Joint Partnership Boards | Joint Partnership Boards co-ordinate the development of local protocols to address the interface between health and local authority services. |

| | |
|--|--|
| Joint Performance Information and Assessment Framework (JPIAF) | The Joint Performance Information and Assessment Framework assesses local partners' performance of joint services. It focuses initially on how local authorities (both social work and housing) and NHSScotland implement key parts of the Joint Future agenda, namely, joint resourcing and joint management, and single shared assessment. |
| JPIAF | See Joint Performance Information and Assessment Framework. |
| learning disability | A learning disability is a significant, lifelong condition which has three facets: reduced ability to understand new or complex information or to learn new skills; reduced ability to cope independently; and a condition which started before adulthood (before the age of 18) with a lasting effect on the individual's development. |
| Learning Disability Reviewer Network | People from health, local authority, voluntary organisations, dealing with users and carers and other independent societies who are involved in the NHS QIS review network. Reviewers are involved in visits and services as part of a team. |
| LHCC | See Local Health Care Co-operative. |
| local area co-ordinators | A recommendation from <i>The same as you?</i> , this is a method of supporting disabled people and their families. A local area co-ordinator's job is to build partnerships with individuals and families to assist them to pursue their goals and aspirations for a good life. They work on the basis that individuals with disabilities have a contribution to make. They ensure that services and solutions are available to people, and they build relationships with people over time. Local area co-ordinators know their local community and are well connected themselves. |
| Local Government in Scotland Act 2003 | From 1 April 2003 this Act introduced community planning and the power to advance wellbeing as duties for Scotland's local authorities. |

| | |
|---------------------------------------|---|
| Local Health Care Co-operative (LHCC) | In Scotland, Local Health Care Co-operatives are voluntary groupings of GPs and other local healthcare professionals intended to strengthen and support the primary healthcare team in delivering local care. |
| Managed Care Network | Similar to Managed Clinical Network but involving health, local authorities and other staff. |
| Managed Clinical Network (MCN) | A formally organised network of clinicians. The main function is to audit performance on the basis of standards and guidelines, with the aim of improving healthcare across a wide geographic area, or for specific conditions. |
| Management Executive Letter (MEL) | Formal communications from the Scottish Executive Health Department to NHSScotland, now known as Health Department Letters (HDLs). |
| MEL | See Management Executive Letter. |
| mental ill-health | 'Mental ill-health' or 'mental illness' are broad terms used to describe a wide range of psychiatric illnesses, from anxiety and depression to eating disorders and schizophrenia. |
| Mental Welfare Commission (MWC) | An independent organisation set up by Parliament with the responsibility of protecting the welfare of people with mental disorder (including learning disabilities and dementia) in Scotland. The Commission has a duty to anyone with a mental disorder whether they are in hospital, in local authority, voluntary run or private accommodation or in their own homes. The Commission's work includes visiting people in hospital and in the community, investigating cases of deficiency in care or treatment, and providing information and advice. Website: www.mwscot.org.uk |
| monitoring | The systematic process of collecting information on clinical and non-clinical performance. Monitoring may be intermittent or continuous. It may also be undertaken in relation to specific incidents of concern or to check key performance areas. |

| | |
|------------------------------------|---|
| multidisciplinary care plan | A plan for the integrated provision of services from the relevant range of professionals. Such a care plan should be made following an assessment at a case conference or review and should, as appropriate, involve users, carers and their families as well as professionals. |
| multidisciplinary team | A multidisciplinary team is a group of people from different disciplines (both healthcare and non-healthcare) who work together to provide care for patients with a particular condition. The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition; the scale of the service being provided and geographical/socio-economic factors in the local area. |
| National Care Standards Commission | The National Care Standards Commission regulates social care and independent healthcare services in England in accordance with statutory regulations and national minimum standards that have been issued by the Department of Health. Website: www.carestandards.org.uk |
| NHS | National Health Service. |
| NHS Board | NHS Boards are responsible for strategic planning, performance management and governance of each of Scotland's 15 local health systems. Most NHS Board areas (excluding Island NHS Boards) contain one Acute and one Primary Care Trust, with operational and employment responsibilities, but since 2001 they have operated within a strategic framework drawn up by the NHS Board. By 2004 Trusts will have been abolished and replaced by operating divisions of the NHS Board (see also NHS Trust). |
| NHS QIS | See NHS Quality Improvement Scotland. |

| | |
|---|--|
| <p>NHS Quality Improvement Scotland (NHS QIS)</p> | <p>NHS Quality Improvement Scotland is a statutory body, established as a Special Health Board in January 2003. Its role is to focus on improving the quality of patient care and the health of patients. It has a particular emphasis on the quality of care and the patient journey for vulnerable groups. NHS Quality Improvement Scotland has been created by the merger of five organisations: Clinical Standards Board for Scotland (CSBS); Health Technology Board for Scotland (HTBS); the Scottish Health Advisory Service (SHAS); Nursing and Midwifery Practice Development Unit (NMPDU), and the Clinical Resources and Audit Group (CRAG). Website address: www.nhshealthquality.org</p> |
| <p>NHS Trust</p> | <p>A Trust is an NHS organisation responsible for providing a group of healthcare services for the local population. An Acute hospital Trust provides hospital services. A Primary Care Trust provides primary care/community health services. Mental health services (both hospital and community based) are usually provided by Primary Care Trusts. Since 2001 Trusts have operated within an overall framework drawn up by their NHS Board. Subject to legislation, Trusts will be dissolved by April 2004, becoming operating divisions of the NHS Board. The NHS Board will be the single employer for the local system. In two areas - Borders and Dumfries & Galloway - since April 2003 there have been no Trusts or operating divisions with the NHS Board fulfilling a dual strategic and operational role (like the three Island Boards). The term 'Trust' is retained in NHS QIS publications during the period of Trust abolition. Where unification has occurred, the term 'Trust' should be taken to signify an operating division of the local NHS Board. See also NHS Board.</p> |
| <p>NHSScotland</p> | <p>The National Health Service in Scotland.</p> |
| <p>NMPDU</p> | <p>See Nursing and Midwifery Practice Development Unit.</p> |

Nursing and
Midwifery Practice
Development Unit
(NMPDU)

NMPDU was set up in December 1999 in response to the White Paper 'Designed to Care' (1997). The overall aim of the Unit is to ensure that practice/role development is taken forward across Scotland in a consistent and cohesive way, so that benefits gained from new practice in one area can be easily identified and shared within the profession. On 1 January 2003, NMPDU was merged with four other clinical effectiveness bodies to create NHS Quality Improvement Scotland. See NHS Quality Improvement Scotland.

outcome

The end result of care and treatment and/or rehabilitation. In other words, the change in health, functional ability, symptoms or situation of a person, which can be used to measure the effectiveness of care and treatment, and/or rehabilitation.

palliative care

Palliative care is the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment.

Partnership in
Practice agreement
(PiP)

The same as you? report makes a recommendation that local authorities, NHS Boards, and Primary Care Trusts prepare partnership in practice agreements for learning disability services in their area. The PiP should draw together the information that is already in existing plans, to make sure that all the agencies involved in planning services for adults and children with learning disabilities can come to an agreement.

patient

A person who is receiving care or medical treatment. A person who is registered with a doctor, dentist, or other healthcare professional, and is treated by him/her when necessary. Sometimes referred to as a user.

patient journey

The pathway through the health services taken by the patient (the person who is receiving treatment), and as viewed by the patient.

| | |
|--|--|
| PCT | Primary Care Trust. See NHS Trust and primary care. |
| peer review | Review of a service by those with expertise and experience in that service, either as a provider, user or carer, but who are not involved in its provision in the area under review. In the NHS Quality Improvement Scotland approach, all members of a review team are equal. |
| Performance Assessment Framework (PAF) | The method used within NHSScotland to measure the performance of Trusts (see NHS Trust) and NHS Boards against agreed indicators. |
| personal life plan | <i>The same as you?</i> identifies the need for better longer term planning for people with learning disabilities. A personal life plan should describe how the person, his or her family, and professionals, will work together to help that person lead a fulfilled life. |
| physician | A specialist in medicine. |
| podiatry services | The community podiatry service aims to provide assessment, diagnosis and treatment of lower limb and feet pathologies, enabling patients to attain mobility. The range of services provided cover routine maintenance, palliative care, biomechanics (many clinics are run jointly with the physiotherapy service), and nail surgery. |
| prescription | Usually a written recipe of treatment. |
| primary care | The conventional first point of contact between a patient and the NHS. This is the component of care delivered to patients outside hospitals and is typically, though by no means exclusively, delivered through general practices. Primary care services are the most frequently used of all services provided by the NHS. Primary care encompasses a range of family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners. |
| professions allied to medicine (PAMs) | Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dieticians etc. Now called allied health professionals (AHPs). See allied health professions. |

| | |
|---|--|
| protocol | A policy or strategy which defines appropriate action in specific circumstances. Protocols may be national, or agreed locally to take into account local requirements. |
| quality assurance (QA) | Improving performance and preventing problems through planned and systematic activities including documentation, training and review. |
| quality indicators | Both quality indicators and standards are used by NHS QIS to review the quality of services provided by NHSScotland. NHS QIS quality indicators differ from the clinical standards as they focus on the overarching principles that should be applied to a service as a whole, whereas standards are targeted, specific measurements of a particular service. The prescriptive nature of standards suggests a level of performance that is either met or not met. As the criteria used within the quality indicators are less specific than those within the standards, they allow for a range of performance to be assessed, and promote continuous improvement within the service. |
| rationale | Scientific/objective reason for taking specific action. |
| referral | The process whereby a patient is transferred from one professional to another, usually for specialist advice and/or treatment. |
| review | See peer review. |
| Same As You? Implementation Group (SAYIG) | A group set up by Ministers to oversee the implementation of <i>The same as you?</i> recommendations. |

| | |
|---|---|
| <p>Scottish Consortium for Learning Disability (SCLD)</p> | <p>SCLD is made up of 13 partner organisations who have joined together with funding from the Scottish Executive to become the Scottish Consortium for Learning Disability. SCLD's main areas of work are: offering consultancy and support to implement <i>The same as you?</i>; bringing together, developing and passing on information and advice; promoting joined up services; letting people know about useful research; undertaking public education campaigns; developing a skilled and confident workforce by improving training standards; and providing training. Website: www.sclد.org.uk</p> |
| <p>Scottish Executive Health Department (SEHD)</p> | <p>The Scottish Executive Health Department is responsible for health policy and the administration of NHSScotland. Website address: www.show.scot.nhs.uk/sehd</p> |
| <p>Scottish Health Advisory Service (SHAS)</p> | <p>The Scottish Health Advisory Service was an independent body, originally set up in 1970, and reporting to the First Minister. SHAS existed to help to improve the quality of health service care and the quality of life for people with a mental illness; people with a learning disability or physical disability; and frail older people. On 1 January 2003, SHAS was merged with four other clinical effectiveness bodies to create NHS Quality Improvement Scotland. See NHS Quality Improvement Scotland.</p> |
| <p>Scottish Independent Advocacy Alliance (SIAA)</p> | <p>The Scottish Independent Advocacy Alliance provides information, advice and support to local Advocacy organisations; undertakes training on advocacy and related issues for agencies in the statutory and voluntary sectors; and aims to ensure that the 'voice' of the Advocacy Movement is heard at a national level to influence current and future practice and policy. Website: http://members.lycos.co.uk/powerfulpartnerships/siaa/pages/</p> |

| | |
|--|--|
| Scottish Intercollegiate Guidelines Network (SIGN) | SIGN was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland, to sponsor and support the development of evidence-based clinical guidelines for NHSScotland. Where a SIGN guideline exists for a specialty or service for which CSBS had set standards, or NHS QIS is taking forward standards, it will be referenced. For further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed, contact: SIGN Executive, Royal College of Physicians, 9 Queen Street, Edinburgh EH2 1JQ. Website: www.sign.ac.uk/ |
| secondary care | Care provided in an acute sector setting. See acute sector. |
| SEHD | See Scottish Executive Health Department. |
| self-assessment | Assessment of performance against standards by individual/clinical team/Trust providing the service to which the standards are related. |
| sensory impairment | Reduction of the input from the senses. |
| SHAS | See Scottish Health Advisory Service. |
| SIGN | See Scottish Intercollegiate Guidelines Network. |
| SIGN guideline | Scottish Intercollegiate Guidelines Network guideline. See also guideline. |
| single shared assessments (SSA) | Guidance introduced in Scotland from April 2002 means that by April 2004 all people needing care will receive an SSA. SSAs are intended to simplify assessment processes, to be person-centred and to clarify responsibilities for providing care. |
| Special Health Board | The name is given to Health Boards with a national remit. These boards are focused on specific areas, eg NHS Education for Scotland, or NHS Quality Improvement Scotland. Special Health Boards match regional NHS Boards in terms of administrative grading. |
| standard | Required level of quality. |
| standard statement | An overall statement of desired performance. |
| statutory | Enacted by statute; depending on statute for its authority as a statutory provision. Required by law. |
| unified Board | See NHS Board. |

10. Glossary of Terms



11. References

1. UK Parliament. Access to Health Records Act 1990. London: HMSO (1990). www.legislation.hmsso.gov.uk/acts/acts1990/Ukpga_19900023_en_1.htm [full document] url cited 08/04/03.
2. Scottish Parliament. Adults with Incapacity (Scotland) Act 2000. Edinburgh: HMSO. www.scotland.gov.uk/health/cmo/incapacity_act_toc.asp [official website for the incapacity act] /www.scotland-legislation.hmsso.gov.uk/legislation/scotland/acts2000/20000004.htm [full document] www.scotland.gov.uk/health/cmo/mcpasprint.pdf [Code of Practice] url cited 08/04/03.
3. UK Parliament. Social Work (Scotland) Act, S.12aa (Assessing Carers). London: HMSO (1968).
4. Audit Scotland. Moving to Mainstream: The Inclusion of Pupils with Special Educational Needs in Mainstream Schools. Edinburgh: Audit Scotland on behalf of the Accounts Commission and the Auditor General in partnership with HMIE (2003). <http://www.audit-scotland.gov.uk/publications/pdf/2003/03pf09as.pdf> [full document] url cited 11/12/03.
5. Department of Health (DoH). Report on the Review of Patient Identifiable Information. London: DoH (1997).
6. Children in Scotland. Something to Say - A Report from the Citizen in Practice Project. Edinburgh: Children in Scotland (July 2003). www.childreninscotland.org.uk [organisation information] <http://www.childreninscotland.org.uk/docs/projects/Something%20to%20say.pdf> [full document] url cited 19/12/03
7. UK Parliament. Children (Scotland) Act 1995. London: HMSO (1995). www.legislation.hmsso.gov.uk/acts/acts1995/Ukpga_19950036_en_1.htm [full text] url cited 17/12/03.
8. Scottish Parliament. Community Care and Health (Scotland) Act 2002. Edinburgh: HMSO. www.scotland-legislation.hmsso.gov.uk/legislation/scotland/acts2002/20020005.htm (full document) url cited 18/03/03.
9. Cullen C. A Review of Some Important Issues in Research and Services for People with Learning Disabilities and Challenging Behaviour. Scottish Executive Review of Services for People with a Learning Disability. Edinburgh: Scottish Executive (2000).
10. UK Parliament. The Data Protection Act. London: HMSO. www.legislation.hmsso.gov.uk/acts/acts1998/19980029.htm [full document] url cited 08/04/03.
11. Department for Education and Skills (DFES) and Department of Health (DoH). Guidance for Restrictive Physical Interventions. How to Provide Safe Services for People with Learning Disabilities and Autistic Spectrum Disorder. London: DFES & DOH (2002). www.doh.gov.uk/learningdisabilities/physicalintervention.pdf [full publication including cover letter] url cited 11/12/03.

11. References

12. Department of Health. *The Health of the Nation - A Strategy for People with Learning Disabilities*. London: HMSO (1995).
13. Department of Health (DoH). *Guidelines on Consent to Treatment*. DoH (active web page with guidance for patients and healthcare professionals). www.doh.gov.uk/consent/guidance.htm url cited 12/12/03.
14. Department of Health. *External Working Group (EWG): Disabled Children - National Service Framework*. DoH (active web page with access to a range of publications: note that on the 1 July 2002, the EWG established seven task groups to address specific issues identified as central to services for disabled children and their families). www.doh.gov.uk/nsf/children/externalwgdisebled.htm url cited 12/12/03.
15. UK Parliament. *Community Care (Direct Payments) Act 1996*. London: HMSO (1996). www.hmso.gov.uk/acts/acts1996/1996030.htm [full document] url cited 19/12/03.
16. UK Parliament. *Disability Discrimination Act 1995*. London: HMSO. www.legislation.hmso.gov.uk/acts/acts1995/Ukpga_19950050_en_1.htm [full document] url cited 03/09/02.
17. Disability Rights Commission (DRC). *Policy Statement on Health*. DRC (active web page). www.drc-gb.org/campaigns/campaigndetails.asp?id=110 [full text] url cited 12/12/03.
18. Herd D, Stalker K. *Involving Disabled People in Services: a Document Describing Good Practice for Planners, Purchasers and Providers*. Edinburgh: Social Work Services Inspectorate for Scotland (1996).
19. Espie C, et al. *The Role of the NHS in Meeting the Health Needs of People with Learning Disabilities*. Report for the Scottish Executive Learning Disability Review. Edinburgh: Social Work Services Inspectorate of the Scottish Executive (1999). www.scotland.gov.uk/about/HD/CCD1/00017548/ColinEspieReport.pdf (full document) url cited 12/12/03.
20. Hogg J. *People with Profound Intellectual and Multiple Disabilities. Understanding and Realising Their Needs and Those of Their Carers*. Paper Prepared for the Scottish Executive Review of Services for People with Learning Disabilities. Edinburgh: Scottish Executive (1999). www.scotland.gov.uk/about/HD/CCD1/00017548/DundeeUniResearch.pdf (full document) url cited 12/12/03.
21. UK Parliament. *Human Rights Act 1998*. London: HMSO (1998). www.legislation.hmso.gov.uk/acts/acts1998/19980042.htm [full document] url cited 19/12/03.
22. Johnston L, MacDonald R, et al. *Snakes and Ladders: Young People, Transitions and Social Inclusion*. Bristol: The Policy Press in association with Joseph Rowntree Foundation (2000). www.jrf.org.uk/bookshop/details.asp?pubID=314 [summary and ordering information] url cited 12/12/03.
23. Scottish Parliament. *Local Government in Scotland Act 2003*. Edinburgh: HMSO (2003). www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2003/20030001.htm url cited 19/12/03.

-
24. Mansell J. Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs: Report of a Project Group. London: HMSO (1992). www.doh.gov.uk/vpst/documents/MansellReport.pdf [full document] url cited 19/12/03.
 25. Foundation for People with Learning Disabilities. Count Us in. London: (2002). www.learningdisabilities.org.uk/page.cfm?pagecode=AUOUP2 [summary and ordering information] url cited 19/12/03.
 26. Scottish Parliament. Mental Health (Care and Treatment) (Scotland) Act 2003. Edinburgh: HMSO (2003). www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2003/20030013.htm [full document] url cited 19/12/03.
 27. Mental Welfare Commission for Scotland (MWC). Risks, Rights and Limitations of Freedom. Edinburgh: MWC (2002).
 28. Ann Le Couteur - Chair - Core Working Group. National Autism Plan for Children (NAPC). Plan for the Identification, Assessment, Diagnosis and Access to Early Interventions for Pre-School and Primary School Aged Children with Autism Spectrum Disorders (ASD). London: Published by The National Autistic Society, for the National Initiative for Autism: Screening and Assessment (NIASA), in collaboration with The Royal College of Psychiatrists (RCPsych), The Royal College of Paediatrics and Child Health (RCPCH) and the All Party Parliamentary Group on Autism (APPGA) (March 2003). www.cafamily.org.uk/NAPFront.PDF [full document] url cited 12/12/03.
 29. NHS Health Scotland. Learning Disability Needs Assessment Report. Edinburgh: NHS Health Scotland (due by end 2003).
 30. Public Health Institute of Scotland (PHIS). Autistic Spectrum Disorders Needs Assessment Report. Glasgow: PHIS (2001). www.phis.org.uk/pdf.pl?file=publications/Autistic%20Spectrum%20Disorders.pdf [full document] url cited 12/12/03.
 31. NHS Quality Improvement Scotland (NHS QIS). Clinical Standards: Food, Fluid and Nutritional Care in Hospitals. Edinburgh: NHS QIS (2003). www.nhshealthquality.org/nhsqis/files/F18/12/03. url cited 19/12/03
 32. Profound & Multiple Impairment Service (PAMIS). Time for a Change - The Need for Adult Changing Facilities in Accessible Loos. Dundee: PAMIS (2003). www.dundee.ac.uk/pamis/pamis.html [organisation information] url cited 12/12/03.
 33. UK Parliament. Race Relations (Amendment) Act 2000. London: HMSO (2000). www.legislation.hmso.gov.uk/acts/acts2000/20000034.htm [full document] url cited 12/12/03.
 34. Scottish Executive Health Department (SEHD). Right Place - the Right Time: Improving the Patient Journey for Those Who Need Secure Mental Health Care. A Review of the Governance and Accountability of the State Hospital Board: Proposals for Consultation. Edinburgh: SEHD (2002).

11. References

35. United Nations. Convention on the Rights of the Child. Office of the High Commissioner for Human Rights (1989). www.unhchr.ch/html/menu3/b/k2crc.htm [full text] url cited 12/12/03.
36. Royal College of General Practitioners (RCGP) Working Party. Primary Care for People with a Mental Handicap: Occasional Paper 47. London: RCGP (1990). www.rcgp.org.uk/publications/catalogue/occasional/handicap.asp [ordering information] url cited 19/12/03.
37. Advocacy Safeguard Agency. Good Practice. Edinburgh: Advocacy Safeguard Agency (2003). [Advocacy Safeguards Agency, 91 Hanover Street, Edinburgh, EH2 1DJ, Tel: 0131 718 4373. Contact person: Adrienne Sinclair Chalmers, Director, at adrienne@advocacysafeguards.org. Background information at: www.scotland.gov.uk/about/DD/EqualityUnit/00016097/SteeringASA.aspx url cited 06/01/04]
38. Scottish Accessible Information Forum [SAIF]. Standards for Disability Information and Advice Provision in Scotland. SAIF (1999). www.saifscotland.org.uk/publications/standrds/0stndrs.htm [full text] url cited 15/12/03.
39. Scottish Office. NHS Responsibility for Continuing Health Care. NHS MEL(1996)22. Edinburgh: Scottish Office (March 1996). www.show.scot.nhs.uk/sehd/mels/1996_22.pdf [full text] url cited 15/12/03.
40. Scottish Office. Framework for Mental Health Services in Scotland. Edinburgh: Scottish Office (1997). www.show.scot.nhs.uk/publications/mental_health_services/mhs/index.htm [full electronic document/website] url cited 18/12/03.
41. Scottish Office. Interviewing People Who Are Mentally Disordered: "Appropriate Adult" Schemes. Edinburgh: Scottish Office (1998). www.scotland.gov.uk/library/documents5/aas-00.htm [full document] url cited 16/12/03.
42. Scottish Office. Social Inclusion - Opening the Door to a Better Scotland. Edinburgh: Scottish Office (1999). www.scotland.gov.uk/library/documents-w7/sima-00.htm [full document] url cited 19/09/02.
43. Scottish Office. Working Towards a Healthier Scotland - A Green Paper on Health. Edinburgh: Scottish Office (1998).
44. Scottish Executive. Implementing Inclusiveness: Realising Potential - The Beattie Committee Report. Edinburgh: Scottish Executive (1999). www.scotland.gov.uk/library2/doc04/bere-00.htm [full document] url cited 16/12/03.
45. Scottish Executive. The Riddell Advisory Committee Report on Education of Children with Severe Low Incidence Disabilities. Edinburgh: Scottish Executive (1999).

-
46. Scottish Executive. Protecting the Vulnerable: Caring Enough? Guidance for Nurses, Midwives and Health Visitors. Edinburgh: Scottish Executive (1999). www.scotland.gov.uk/library2/doc09/pvce-02.asp?textonly=FALSE [full document] url cited 19/12/03.
 47. Scottish Office. Helping Hands - Guidelines for Staff Who Provide Intimate Care for Children and Young People with Disabilities. Edinburgh: Scottish Office (1999).
 48. Scottish Executive Health Department (SEHD). Good Practice - Equality for Disabled People in the NHS: Access to Services. Edinburgh: SEHD (1999). www.show.scot.nhs.uk/publications/me/pcap/b-2_.pdf [full document] url cited 19/12/03.
 49. Scottish Executive. Our National Health: a Plan for Action, a Plan for Change. Edinburgh: Scottish Executive (2000). www.scotland.gov.uk/library3/health/onh-00.asp [full document] url cited 24/07/03.
 50. Scottish Executive. Advocacy - A Guide to Commissioners. Edinburgh: SEHD (2000). www.scotland.gov.uk/library3/health/iagc-00.asp [full text] 16/12/03.
 51. Joint Future Group. Report of the Joint Future Group. Edinburgh: Scottish Executive (November 2000). www.scotland.gov.uk/library3/social/rjfg-00.asp [full document] url cited 19/12/03.
 52. Scottish Executive: Working Group - Review of Services for People with a Learning Disability. *The Same as You?* A Review of Services for People with Learning Disabilities. Edinburgh: Scottish Executive (May 2000). www.scotland.gov.uk/ldsr/docs/tsay-00.asp [full document] url cited 19/12/03.
 53. Scottish Executive. Fair for All: Working Together Towards Culturally Competent Services. NHS HDL(2002)1. Edinburgh: Scottish Executive. www.scotland.gov.uk/library3/society/ffar-00.asp [full report] url cited 24/07/03.
 54. Scottish Executive. National Care Standards: Care Homes for People with Learning Disabilities. Edinburgh: Scottish Executive (2001). www.scotland.gov.uk/library3/health/pwld-00.asp [full document] url cited 18/12/03.
 55. Scottish Executive Health Department. For Scotland's Children Report: Better Integrated Children's Services. Edinburgh: SEHD (2001). www.scotland.gov.uk/library3/education/fcsr-00.asp [full text] url cited 19/12/03.
 56. Scottish Executive. Health and Homelessness Guidance. Edinburgh: Scottish Executive (2001). www.scotland.gov.uk/library3/health/hahg-00.asp [full document] url cited 18/12/03.
 57. Scottish Executive Health Department (SEHD). Patient Focus and Public Involvement. SEHD (2001). www.scotland.gov.uk/library3/health/pfpi-00.asp [full text] url cited 06/10/03.

11. References

58. Expert Group on Healthcare of Older People. Adding Life to Years., Edinburgh: Scottish Executive (2001). www.scotland.gov.uk/library3/health/alty-00.asp [full document] url cited 19/12/03.
59. Scottish Executive Health Department (SEHD). Promoting Health, Supporting Inclusion: Summary of The National Review of the Contribution of All Nurses and Midwives to the Care and Support of People with Learning Disabilities. Edinburgh: SEHD (2002). www.scotland.gov.uk/library5/health/phsi-00.asp [full document] www.scotland.gov.uk/library5/health/phsis-00.asp [summary] url cited 19/12/03.
60. Scottish Executive Health Department (SEHD). Building on Success - Future Directions for the Allied Health Professions in Scotland. Edinburgh: SEHD (2002). www.scotland.gov.uk/library5/health/bos-00.asp url cited 06/10/03.
61. Scottish Executive. Partnership for Care: Scotland's Health White Paper. Edinburgh: Scottish Executive Health Department (SEHD) (2003). www.scottishexecutive.gov.uk/library5/health/pfcs-00.asp [full document] url cited 06/11/03.
62. Scottish Executive. Home at Last? A Report on Progress with the Closure of Learning Disability Hospitals in Scotland. Edinburgh: Scottish Executive (2003).
63. Scottish Executive. Improving Health in Scotland - the Challenge. Edinburgh: Scottish Executive (2003). www.scotland.gov.uk/library5/health/ihis-01.asp [full document] url cited 19/12/03.
64. Scottish Executive. Equipped for Inclusion. Report of the Strategy Forum: Equipment and Adaptations June 2003. Edinburgh: Scottish Executive (2003). www.scotland.gov.uk/consultations/social/efir-00.asp [full text] url cited 16/12/03.
65. Scottish Executive Health Department (SEHD). The Joint Performance Information and Assessment Framework (JPIAF). NHS CCD(2003)1. Edinburgh: SEHD (2003). www.show.scot.nhs.uk/sehd/publications/CC2003_01.PDF [full document] url cited 16/12/03.
66. Scottish Executive Health Department (SEHD). Achieving Better Services for Patients (See Section 10. on Mixed Sex Accommodation). Clinical Resource and Audit Group website (CRAG - now part of NHS QIS) (1999). www.show.scot.nhs.uk/crag/topics/Patient%20safety/april99.htm [full text] url cited 18/12/03.
67. Scottish Health Advisory Service (SHAS) and The Scottish Office. Advocacy: A Guide to Good Practice. Edinburgh: Scottish Office (1998).
68. Scottish Needs Assessment Programme (SNAP). Needs Assessment Report on Child and Adolescent Mental Health. Edinburgh: Public Health Institute of Scotland (March 2003). www.phis.org.uk/pdf.pl?file=pdf/CAMH%20final%20report.pdf [full document] url cited 19/12/03.
69. Scottish Office Department of Health (SODH). The NHS Complaints Procedure: Revised Guidance for Family Health Service, Hospital and Health Board Complaints. NHS MEL (1999)49. Edinburgh: SODH. www.show.scot.nhs.uk/sehd/mels/1999_49.doc url cited 06/10/03.

-
70. Scottish Parliament. Education (Additional Support for Learning) (Scotland) Bill [as Introduced]. Scottish Parliament (2003). www.scottish.parliament.uk/bills/pdfs/b11s2.pdf [full text] url cited 16/12/03.
 71. Scottish Working Group on Information Services for People with Disabilities (for the Scottish Office). 'Enabling Information: A Report on Improving Access and Raising Standards in Information Services for Disabled People and Their Carers in Scotland'. Scottish Accessible Information Forum (1995). www.saifscotland.org.uk/publications/EnablRpt/ExecSmry.html [full text] url cited 19/12/03.
 72. Dunbar I. Determination by Ian Duncan Dunbar, Solicitor, Sheriff of Tayside, Central and Fife, in the Inquiry under the Fatal Accidents and Sudden Deaths Inquiry (Scotland) Act 1976 into the Death of James Mauchland. Sheriffdom of Tayside, Central and Fife at Dundee (March 2003). www.scotcourts.gov.uk/opinions/cb12_02.html [full text] url cited 16/12/03.
 73. Sheriffdom of Glasgow and Strathkelvin. Sheriffdom of Glasgow and Strathkelvin at Glasgow Inquiry Held under Fatal Accidents and Sudden Deaths Inquiry (Scotland) Act 1976 Section 1(a) Section 1(1)(B) (September 2002). Epilepsy Fatal Accident and Sudden Deaths Inquiry. Glasgow: (2002).
 74. Scottish Intercollegiate Guidelines Network (SIGN). SIGN Guideline 70: Diagnosis and Management of Epilepsy in Adults. Edinburgh: SIGN (July 2003). www.sign.ac.uk/guidelines/published/index.html [access to full document] url cited 17/12/03.
 75. Social Work Services Inspectorate. Sensing Progress : Social Work Services for People with a Sensory Impairment. Scottish Office (1998). www.scotland.gov.uk/library/documents-w1/spmai-00.htm url cited 17/12/03.
 76. The Scottish Office. Health, Social Work and Related Services for Mentally Disordered Offenders in Scotland. The Scottish Office (1999). www.scotland.gov.uk/library/documentsw6/mdoh-00.htm [full document] url cited 17/12/03.
 77. Williams C. Invisible Victims: Crime and Abuse against People with Learning Disabilities. London: Jessica Kingsley (1996).
 78. Powell A. Taking Responsibility: Good Practice Guidelines for Services - Adults with Asperger Syndrome. London: National Autistic Society (2002).
 79. Whitaker P. Challenging Behaviour and Autism: Making Sense-Making Progress A Guide to Preventing and Managing Challenging Behaviour for Parents and Teachers. London: National Autistic Society (2002).
 80. UK Parliament. Carers (Recognition and Services) Act 1995 (C. 12). London: HMSO (1995). www.legislation.hms.gov.uk/acts/acts1995/Ukpga_19950012_en_1.htm [full text] url cited 19/12/03.
 81. Scottish Executive. Moving Forwards - Additional Support for Learning. Edinburgh: Scottish Executive (2003).

11. References

82. Commission for Racial Equality (CRE). The Duty to Promote Race Equality. Performance Guidelines for Health Organisations in Scotland. CRE (2002). www.cre.gov.uk/duty/scotland/pdfs/scot_pg_health.pdf [full document] url cited 17/12/03.
83. Scottish Parliament. Education (Additional Support for Learning) (Scotland) Bill [as Introduced]. Scottish Parliament (2003). www.scottish.parliament.uk/bills/pdfs/b11s2.pdf [full text] url cited 16/12/03.
84. Scottish Parliament. Freedom of Information (Scotland) Act 2002. Edinburgh: HMSO (2002). www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2002/20020013.htm [full document] url cited 17/12/03.
85. Working Group of IASSID. Clinical Guidelines for the Management of Epilepsy in Adults with an Intellectual Disability. *Seizure* (2001); 10: 401-409.
86. Fitzpatrick J. Improving Disabled People's Access to Health Provision. Edinburgh: SHS Trust (2003). www.shstrust.org.uk/pdf/drcreport1.pdf [full document] url cited 17/12/03.
87. Playback. Equality in Diversity [Video Resource Pack]. Edinburgh: Playback - 489 Lanark Road, Edinburgh, EH14 5DQ (2002). http://www.scottishsecretary.gov.uk/News_2002/ss0130.htm [background information] url cited 06/01/04.
88. Scottish Executive. Protecting Children: A Shared Responsibility. Guidance for Health Professionals in Scotland: September 1999. Edinburgh: Scottish Executive (2000). www.scotland.gov.uk/library2/doc11/pcsr-00.asp [full document] url cited 29/01/04.
89. Scottish Office. Protecting Children - A shared Responsibility - Guidance on Inter-Agency Co-operation. Edinburgh: Scottish Office (1998). www.scotland.gov.uk/library/documents-w3/pch-00.htm [full document] url cited 29/01/04.

Our Commitment

Our work will be undertaken in line with the following values:

- **patient and public focus**
 - ~ promoting a patient-focused NHS that is responsive to the views of the public
- **independence**
 - ~ reaching our own conclusions and communicating what we find
- **partnership**
 - ~ involving patients, carers and the public in all parts of our work
 - ~ working with and supporting NHS staff in improving quality
 - ~ collaborating with other organisations such as public bodies, voluntary organisations and manufacturers to avoid duplication of effort
- **evidence-based**
 - ~ basing conclusions and recommendations on the best evidence available
- **openness and transparency**
 - ~ promoting understanding of our work
 - ~ explaining the rationale for our recommendations and conclusions
 - ~ communicating in language and formats that are easily accessible
- **quality assurance**
 - ~ aiming to focus our work on areas where significant improvements can be made
 - ~ ensuring that our work is subject to internal and external quality assurance and evaluation
- **professionalism**
 - ~ promoting excellence individually and as teams and ensuring value for money in the use of public resources (human and financial)
- **sensitivity**
 - ~ recognising the needs, opinions and beliefs of individuals and organisations and respecting and encouraging diversity

This document can be viewed on the NHS Quality Improvement Scotland website. It is also available, on request, from NHS Quality Improvement Scotland in the following formats:

- Electronic
- Audio cassette
- Large print

NHS Quality Improvement Scotland

Edinburgh Office ~ Elliott House 8-10 Hillside Crescent Edinburgh EH7 5EA Tel 0131 623 4300

Glasgow Office ~ Delta House 50 West Nile Street Glasgow G1 2NP Tel 0141 225 6999

comments@nhshealthquality.org www.nhshealthquality.org