

Best Practice Statement ~ *February 2006*

**Promoting access to healthcare for  
people with a learning disability –  
a guide for frontline NHS staff**

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## **Introduction**

NHS Quality Improvement Scotland (NHS QIS) was set up by the Scottish Parliament in 2003 to take the lead in improving the quality of care and treatment delivered by NHSScotland.

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

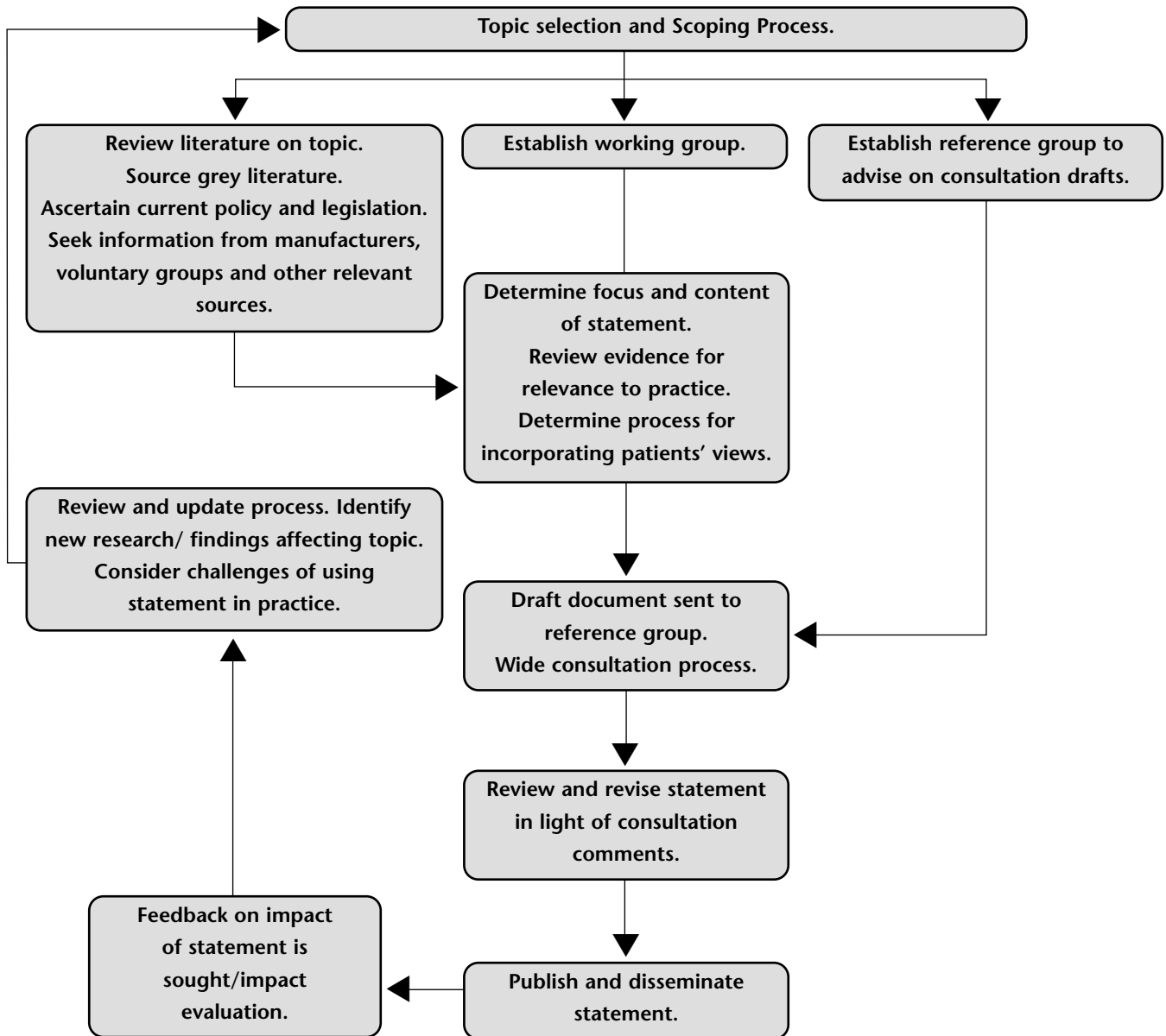
A series of best practice statements has been produced within the Practice Development Unit of NHS QIS, designed to offer guidance on best and achievable practice in a specific area of care. These statements reflect the current emphasis on delivering care that is patient-centred, cost-effective and fair. They reflect the commitment of NHS QIS to sharing local excellence at a national level.

Best practice statements are produced by a systematic process, outlined overleaf, and underpinned by a number of key principles:

- They are intended to guide practice and promote a consistent, cohesive and achievable approach to care. Their aims are realistic but challenging.
- They are primarily intended for use by registered nurses, midwives, allied health professionals, and the staff who support them.
- They are developed where variation in practice exists and seek to establish an agreed approach for practitioners.
- Responsibility for implementation of these statements rests at local level.

Best Practice Statements are reviewed, and, if necessary, updated after 3 years in order to ensure the statements continue to reflect current thinking with regard to best practice.

## Key Stages in the development of best practice statements



## **Best practice statement on promoting access to healthcare for people with a learning disability – a guide for frontline NHS staff.**

This best practice statement is designed to improve access at the point of entry into NHSScotland for children, adults and older people with a learning disability, by providing guidance for healthcare staff.

This statement endorses the values of social justice, promoting equalities and inclusion as outlined in Scotland's policy and legislative framework. The Scottish Executive notes that 'Social inclusion is about reducing inequalities between the least advantaged groups and communities and the rest of society by closing the opportunity gap and ensuring that support reaches those who need it most.'<sup>1</sup>

The NHS has a range of staff who are the first point of contact for members of the public entering the healthcare system. They may, for example, handle a telephone call, assist a person to secure an appointment, or make arrangements for the person to proceed within the system. While all NHS staff have a responsibility to ensure that the delivery of healthcare is equitable and that all patients can proceed to the most appropriate part of the service, the group acknowledged that staff at first point of contact are in a position of considerable responsibility in assisting with access.

This statement is therefore designed to point to best practice and to give guidance to those NHS staff at the interface with the public, and also for those who are in a position to improve access within the service. It is envisaged that the first four sections will be used by those wishing to engage with the principles of access and that the appendices could be used by frontline staff, either in training or to be copied as an aide memoire.

Although the patient journey and discharge, in particular from the acute sector to primary care, could be considered a form of access these were not included in the brief of the project.

A learning disability can be defined as '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.'<sup>2</sup>

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Learning disability ranges from reduced cognitive ability with limited impact on independence to profound disability often associated with complex and multiple physical needs. Discrimination, both conscious and unintentional, directed towards people with a learning disability is well documented. Across the UK there is recognition of the health disparities and inequalities experienced by people with a learning disability that should be addressed.<sup>3</sup> People with a learning disability may find it a challenge to enter the health service, since it may require, for example, coping with brief, formal telephone calls, or complex procedures and language used in appointment systems. They may have to cope with queuing procedures or waiting in what could be an unfamiliar and intimidating environment with inadequate facilities to meet their needs.

The Scottish Executive has identified it as a core principle that people with a learning disability have the right to live inclusive lives and has made it an obligation of NHS Boards to ensure that they fulfil their duty of care to enhance access as part of the inclusion agenda. This is supported by legislation which includes the principles of the European Convention on Human Rights, The Adults with Incapacity (Scotland) Act 2000, the Disability Rights Commission (DRC) Act, (1995) and the Disability Discrimination Act (1995) and the Disability Discrimination Act (2005), which makes it illegal to discriminate against a person with a disability. This Act requires public services to make a *reasonable adjustment* to meet the needs of people with disabilities.

Three important principles underpin the statement:

**1 The health needs of people with a learning disability are greater and more complex and often present differently from those of the general population.**

Some conditions, for example, vision and hearing impairments, mental ill-health and problem behaviours, vascular risk factors, gastro-oesophageal reflux disease (GORD), and epilepsy, occur more frequently than in the rest of the population. Other health needs are particularly associated with particular groups; persons with Down's syndrome are more prone to dementia, depression, thyroid function disorders and hearing impairment. It is important that those working in healthcare understand this. A full account of these differing and greater needs appears in the Health Needs Assessment Report; People with Learning Disabilities in Scotland, published in February 2004, by NHS Health Scotland.<sup>4</sup>

Heightened awareness of the distinct needs of people with a learning disability could do much to reduce what is often unintentional discrimination and to enhance access.

**2 People with a learning disability are more likely than the rest of the population to have an impairment to communication and therefore require special consideration.**

Central to access is the necessity for good communication. This document supports the principle of total or inclusive communication: ‘an overall awareness, by all communicators, of those strategies, both verbal and non-verbal, which may assist a client to understand and express needs, feelings and choices.’<sup>5</sup> The working group producing this statement highlights the fact that there is no one recommended system of symbols for the NHS in Scotland.

During consultation the place of the carer, which could be a professional carer or a parent or other family member, was emphasised as a potential source of health information especially for people with profound learning disability. Professional judgement on the part of NHS staff will be required to ascertain at what point communication should be initiated with the third party.

**3 People with a learning disability have a right to access health services and these should be provided within the current legislative framework and in a way which upholds the principles of inclusion and respect, and conforms to professional standards.**

This best practice statement outlines the principles which ought to be honoured not only at the first point of contact but throughout the healthcare system. It is not intended to give detailed guidance on informed consent or on assessing incapacity. Further information on this will be issued by the Scottish Executive in 2006. Consent, and the understanding which informs it, however, are linked to access. The chief principle affecting access and, indirectly, informed consent, identified by focus groups, is the necessity for awareness and appropriate and effective communication. Sensitivity and respect for the individual should always be a first principle.

The evidence base in the field of access to healthcare for people with a learning disability is evolving. The working group has been informed by often small scale qualitative research studies and the consensus of professionals using evidence from local examples to identify good practice. The measures recommended in this document have been accepted by healthcare and other professionals after wide consultation, but should nevertheless provide a stimulus for further formal research



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and evaluation. It will be necessary to evaluate developments that seek to remove or reduce barriers to accessing healthcare. People with a learning disability are disadvantaged by a range of social, physical, psychological and economic barriers that limit their full participation in society,<sup>7</sup> and healthcare is one area in our society where discrimination exists. Research should thus focus upon the identification and elimination of such barriers if the principles of inclusion are to be upheld.

## Core principles: Section 1: Attitude and identification of additional need

### Key Points ~

- 1 *Attitudes, consciously or unconsciously held, can shape the approach to other people.*
- 2 *Awareness of communication difficulties or additional needs can help the healthcare worker accommodate these needs.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>All staff at the first point of contact in the NHS are responsible for ensuring people with a learning disability have equal access to healthcare and have a responsibility to promote inclusion.</p>	<p>There are many points of entry into the NHS.</p> <p>'Persons with learning disabilities experience barriers in accessing appropriate services and supports for their health needs, health promotion needs and lifestyle choices. However, this only accounts for some of the health inequalities.'<sup>8</sup></p> <p>Staff should be aware of potential discrimination towards people with a learning disability.<sup>9</sup></p> <p>'People with learning disabilities should have the same opportunities as other people to lead full and active lives and should receive the support necessary to make this possible.'<sup>10</sup></p> <p>The principle of inclusion is supported by policy and legislation.<sup>11,12</sup></p> <p>Staff at the points of first contact eg, medical secretaries, receptionists, ward clerks and call handlers have a particular responsibility to ensure that their attitudes and behaviour support inclusion and allow people to proceed to appropriate healthcare.</p>	<p>Training and awareness-raising are available for all staff at induction and on subsequent occasions.</p>
<p>A learning disability is seen as one of a variety of additional needs for which communication and approach should be adapted to ensure equality of access.</p>	<p>Staff should be aware of potential conscious or unintentional discrimination leading to inequalities. It is explicitly unlawful in the United Kingdom to discriminate against a person on the basis of their learning disability.<sup>13</sup></p>	<p>Systems are in place to accommodate people with additional needs including those with a learning disability eg, there are arrangements for appointment times, there is access to appropriate help (see section 3).</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>Staff take account of the full range of needs across the learning disability spectrum: mild, moderate, severe and profound.</p>	<p>There is a spectrum of learning disabilities. Some learning disabilities may be associated with distinct physical and behaviour characteristics, but not all. Awareness of the spectrum of need will help staff to identify in particular those with a mild learning disability, where speech and manner might be confused with other conditions such as alcohol abuse.</p>	<p>There are systems to alert staff to additional needs. There is information on learning disabilities available for staff.</p>
<p>Staff have the means of identifying a person with a learning disability.</p>	<p>'Hospitals .... should review how they deal with the admission of patients with learning disability ..... and devise a protocol for identifying such patients and to ensure that there is proper communication with them not only on admission but throughout their stay in such hospitals.'<sup>14</sup></p> <p>Sensitivity is important to recognise that a person with a learning disability may not acknowledge or recognise their disability; communication strategies should accommodate this.</p> <p>Identification of a need is the first step to assistance. Some people with a learning disability</p> <ul style="list-style-type: none"> <li>• have difficulty in telling the time and in judging the passage of time<sup>15</sup></li> <li>• have a supporter or carer.</li> </ul> <p>Simple, closed questions constructed around these facts could help to identify a person with a learning disability.</p>	<p>There are means of identifying people with a learning disability eg, they possess a simple 'communication passport,' or a health log, or a patient information card is in use, or the patient health record, if the patient agrees, is flagged to alert staff to additional needs.</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>Staff are aware that a person with a learning disability will benefit most from contact with a known and trusted member of staff.</p>	<p>Continuity inspires confidence within the patient and eases communication.            When unwell or under stress, a person's communication may be altered.            Someone familiar to the patient will be more aware of the extent to which communication is altered because of illness or distress.            'The best available form of pain assessment is skilled clinical assessment combined with familiarity and understanding of the person.'<sup>16</sup></p>	<p>The patient health record may indicate the name of the GP, nurse, or other member of staff whom the patient prefers to see, if possible. Some services offer liaison staff to provide this continuity.            Communication protocols alert staff to this.</p>

#### Key Challenges ~

- 1 Extending awareness of unintentional discrimination amongst healthcare workers and ensuring an appropriate response.
- 2 Extending awareness of all additional needs, including the needs of people with a learning disability.

## Core principles: Section 2: Communication

### Key Points ~

- 1 *Many barriers to healthcare can be overcome by effective communication.*
- 2 *Healthcare workers will be required to communicate effectively not only with the person with a learning disability but advocates, family members, parents, carers and supporters.*
- 3 *Time will be required to communicate effectively with a person with a learning disability and to check the person understands the information.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>Staff at the first point of contact and subsequent contacts are able to identify and access the most appropriate and effective method of communication for the person.</p> <p>This could include;</p> <ul style="list-style-type: none"> <li>• asking the patient simple closed questions,</li> <li>• using simple language with facial expression and supporting gestures,</li> <li>• using an interpreter,</li> <li>• using photographs, pictures or symbols, or</li> <li>• signing or accessing someone with this skill.</li> </ul>	<p>'Communication difficulties are prevalent amongst persons with learning disabilities. These include problems with expression, comprehension, and pragmatic communication in social situations. Problems with communication may be related to problem behaviours and can be a significant barrier to accessing appropriate healthcare.'<sup>17</sup></p> <p>At least 50% of people with a learning disability have significant communication difficulties.<sup>18</sup></p> <p>Some people with a learning disability have limited reading skills.</p> <p>It is good practice, when first approaching patients, to assess their communication needs. People with a learning disability may have specific needs, which will vary from individual to individual. This is also only one group amongst many with special communication requirements.</p> <p>'The preferred means of communication must be practical and relevant to the environmental contexts in which people live their lives...'<sup>19</sup></p>	<p>Services have a system in place to identify and access appropriate means of communication and encourage a diversity of approaches to communication.</p> <p>The patient health record highlights if a particular approach to communication is required.</p> <p>Personal communication dictionaries, passports, charts or boards may be in use.</p> <p>There is evidence of a training plan which helps staff to respond to different communication needs.</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>Good practice is observed when communicating (see Appendices 1, 2, 3 and 4).</p>	<p>Many people with a learning disability have communication impairment and find complex language confusing. Appendices 1, 2, 3 and 4 are examples of tools outlining simple practices which could enhance communication.</p>	<p>There is local training for staff and carers in how to communicate. Appointment cards and letters of invitation are available in a variety of formats (see Appendix 3). Patient information is available in a variety of formats. The availability of these formats is advertised.</p>
<p>If the member of staff needs to approach a third party for help with communication, there is a robust and simple system in place to obtain this help.</p>	<p>'Given that communication is a two-way process it is important to avoid locating all the difficulty with the person with learning disabilities and rather to consider what the other party to the communication can do to maintain or extend communication.'<sup>20</sup> Appropriate communication or swift contact with someone with more specialist communication skills, if these are required, reduces waiting time, frustration and anxiety, which many people with a learning disability find difficult to manage.</p>	<p>Staff are able to demonstrate that there are robust links between staff at the first point of contact for patients, and specialist assistance from an advocacy worker, learning disability nurse or a speech and language therapist. There is evidence that staff use specialist link or liaison nurses, advocates or other supporters. The Advocacy Action Plan held by the NHS Board will contain reference to this.</p>
<p>Staff working with a person with a learning disability are aware of the various members of the person's support network. They are able to communicate, at an appropriate level, with these supports.</p>	<p>People with a learning disability often require support. 'Staff should be aware that family carers have a crucial role in the development, health and well-being of persons with learning disabilities.'<sup>21</sup> 'Paid carers can have a positive impact upon the health of people with learning disabilities by recognising symptoms or signs of ill-health, facilitating access to services, and promoting healthy lifestyles...'<sup>22</sup></p>	<p>Care plans identify the routes for communication with support networks. Examples of these supports include parents and family carers, social workers, members of the community learning disability team, voluntary organisations and independent advocates.</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>Staff talk directly to the patient and may have to include the advocate or carer, if one is present. The member of staff asks the patient for permission to talk to the other person if necessary, and continues to involve the patient using eye contact.</p>	<p>This is in keeping with the principles of respect, dignity and choice which should be extended to all patients.<sup>23,24</sup> Responses from focus groups and a consensus method of qualitative research to identify successful or preferred communicative techniques, and advice given to professionals, identify this as preferred practice.<sup>25,26</sup></p>	<p>The importance of this is emphasised in communication training sessions. There will be guidance on the circumstances when information may be sought from a parent, carer or other third party. This guidance to staff could be contained in a handbook or leaflet.</p>
<p>Healthcare staff allow time for people with a learning disability to give and receive messages.</p>	<p>Some people with a learning disability take longer and are less likely to be precise when describing symptoms.<sup>27</sup></p>	<p>Accommodation of this may be reflected in appointment times, or the provision of additional support. Arrangements which support effective use of time are suggested in section 3.</p>
<p>Staff are aware that a person's ability to give and receive messages may vary.</p>	<p>An individual's capacity to understand and to communicate can be affected by a number of factors. These can include the experience of pain and distress, the introduction of a new member of staff or an unfamiliar environment. The Adults with Incapacity (Scotland) Act 2000 Part 5 requires staff to be aware of variation in a person's capacity.</p>	<p>Staff will be alerted to this principle in communication protocols. Prompts in the protocol for obtaining consent alert staff to this.</p>
<p>Staff do not assume that if a person is unable to communicate through the spoken word that the person is</p> <ul style="list-style-type: none"> <li>• unable to understand</li> <li>• unable to agree to healthcare processes.</li> </ul>	<p>It is easy to make assumptions on appearances and behaviours. Appropriately trained healthcare staff should ascertain the incapacity of the person and ensure compliance with the principles of The Adults with Incapacity (Scotland) Act 2000 and subsequent amendments. (See Appendix 5)</p>	<p>Local protocols remind staff of this important principle in communication and the associated principle of consent. This guidance to staff could be contained in a handbook or leaflet. Prompts in the protocol for obtaining consent alert staff to this.</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>Staff are aware that the person accessing healthcare may carry a statement of healthcare preferences. If an emergency situation arises this is accessed by the relevant carer.</p>	<p>If a care plan or agreement exists it is considered good practice that this is handed over to the relevant member of staff as soon as possible.</p>	<p>Handover arrangements are in place.</p>
<p>Staff are aware that people unable to make decisions on medical treatment may be able to make decisions on other aspects of their care, and are encouraged to do so.</p>	<p>An important principle of the Adults with Incapacity (Scotland) Act 2000 is to encourage the adult to 'exercise residual capacity'. It is good clinical practice for all healthcare staff to be aware of this principle and apply it as appropriate.</p>	<p>There is evidence of the person having been consulted and exercising choice in appropriate aspects of care eg, nutrition, sleeping patterns.</p>
<p>Good practice is observed when reference is made to time<sup>28</sup> (see Appendices 1, 2 and 3).</p>	<p>The use of simple language, targeted to the particular person, to explain what is going to happen will be helpful for those who have difficulty with the concept of time. The use of pictures or photographs to explain a sequence of events is also helpful. References to time should be used with caution. If at all possible, explanations should be given using the present tense.</p>	<p>Information is designed to accommodate additional needs eg, appointment cards, letters of invitation or instructions on labels contain spaces for symbols or drawings in addition to written times.  Staff training programmes or awareness-raising sessions contain advice on how to structure information for people with a learning disability.</p>
<p>Good practice is observed when reference is made to place and directions (see Appendices 1, 2 and 3).</p>	<p>People with a learning disability can find directions difficult to follow. Colour coding and other signs can assist people to negotiate a complex environment. Staff should know, and be able to use, these prompts.</p>	<p>Induction programmes give staff familiarity with the healthcare environment and signs used. Staff should be aware of, and able to refer to, signs in their particular environment when communicating directions and instructions. Staff are informed if signs are changed.</p>



Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>After information has been given, staff ascertain that it has been understood.</p>	<p>Asking a person to repeat or read a message does not guarantee understanding. The person should be asked to rephrase the information or answer simple questions to ascertain the meaning has been understood. A short note may supplement verbal information and be helpful for future reference. This can also be useful for a parent or carer (See Appendix 3).</p>	<p>Accommodating the time required for patient feedback may be reflected in the appointment system. Local protocols determine that key messages are handwritten.</p>

**Key Challenges ~**

- 1 *Identifying appropriate methods of communication.*
- 2 *Utilising naturally occurring opportunities for informal awareness-raising and allocating time for appropriate awareness-raising and training*
- 3 *Producing accessible information within resource allocations.*

## Core principles: Section 3: Structures and arrangements to facilitate access

### Key Points ~

- 1 *It is possible to make physical changes to arrangements around appointments to assist access to healthcare.*
- 2 *The physical environment can be adjusted to promote access.*
- 3 *Where necessary, specialist learning disability nurses, advocacy workers, a speech and language therapist, or a parent or carer should be available for people with a learning disability at the point of entry to the healthcare system. The person working at the point of entry should be able to access the people offering help swiftly.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
Aspects of the healthcare system provide flexibility to allow extra time for people with a learning disability to give information, and receive and understand messages. Effective mechanisms could include:		
<ul style="list-style-type: none"> <li>• A double appointment time for a person with a learning disability.</li> </ul>	This gives more time for communication. Focus groups recommend this as a useful mechanism. <sup>29,30</sup> In some conditions such as Down's syndrome, pain or other symptoms may be described with less precision or slowly. This information may take time to interpret. <sup>31</sup>	There is a local operational policy to accommodate such arrangements. Information about this is contained in local leaflets. Local audits monitor this provision.
<ul style="list-style-type: none"> <li>• Arranging for appointments to be early in the consultation session.</li> </ul>	Some people with a learning disability find it difficult to manage waiting, and become anxious. Anxiety may compromise the capacity to communicate, or to maintain appropriate behaviour. An early appointment reduces potential time spent in waiting rooms.	There is a local operational policy to accommodate this. Local audits monitor this.
<ul style="list-style-type: none"> <li>• Arranging for the person to wait in an environment other than a formal waiting room.</li> </ul>	The waiting room environment may cause stress and agitation for those who find the understanding and management of waiting a challenge. The identification and adapting of particular waiting areas and treatment rooms can facilitate access to those with specific needs eg for those with autistic spectrum disorder, or complex physical needs.	There are arrangements to allow people to wait outside the waiting room in a more appropriate environment and call the person when the appointment is ready.

Statement	Reasons for statement	How to demonstrate statement is being achieved
<ul style="list-style-type: none"> <li>Securing appropriate additional support for the appointment scheduled if indicated (eg, advocate, parent or other carer).</li> </ul>	<p>'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.'<sup>22</sup></p> <p>This assists with interpretation and negotiation.</p>	<p>Operational policies reflect this.</p> <p>There is a flagging system to which the patient has consented.</p> <p>At induction, staff are given information on the support systems available in their particular healthcare environment.</p>
<ul style="list-style-type: none"> <li>Confirming arrangements and directions beforehand by telephone where available.</li> </ul>	<p>This supplements written information and encourages confidence within the patient and carer.</p>	<p>There is a local system, or a procedure to alert staff to do this.</p>
<ul style="list-style-type: none"> <li>Supplementing directions to a large or confusing environment for the first appointment with a telephone call to alert someone to meet the person on arrival.</li> </ul>	<p>This can reduce fear of a complex environment.</p>	<p>The facility is advertised in a pre-appointment letter.</p> <p>Volunteers act as guides or hosts.</p>
<ul style="list-style-type: none"> <li>For elective care, arranging a pre-admission visit to the hospital department.</li> </ul>	<p>For some individuals, this may allay anxiety, assist with orientation to a new environment, raise awareness of staff, and assist with planning.</p>	<p>Operational policy reflects this.</p> <p>Information leaflets make explicit the arrangements for people with additional needs.</p>
<ul style="list-style-type: none"> <li>Circulating appropriate information in a systematic way to alert those on the care team to the needs of the person admitted to hospital.</li> </ul>	<p>'Where such a patient is admitted to a general hospital more care should be taken to make sure that everyone who might be involved with his or her care is fully aware of how the patient's learning disability .....presents and of any specific problems which may be encountered as a result of such disability, illness or presentation.'<sup>23</sup></p>	<p>There are systems to disseminate appropriate referral information eg, pre-admission team meetings, 'dependency rating scales' or the use of learning disability liaison nurses.</p>
<p>There is consistent appropriate signage to give directions.</p>	<p>Signs, colour coding, and common symbol sets (see Appendix 4) are ways of ensuring information is shared and access enhanced.</p>	<p>Clinical governance initiatives may enhance accessibility.</p> <p>Directions may include visual material such as diagrams or photographs.</p>
<p>The physical environment is accessible to those with physical and additional sensory needs.</p>	<p>This accommodates people who may have limited mobility and a sensory impairment.</p>	<p>The physical environment is compatible with the requirements of the Disability Discrimination Act (1995) eg, there are fully accessible toilets or changing facilities, height-adjustable examination couches and lifts.</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>There are appropriate transport arrangements in place for people to attend healthcare appointments.</p>	<p>This fulfils the requirements of The Mental Health Act (1983), the Disability Discrimination Act (1995) and the Mental Health (Care and Treatment) (Scotland) Act 2003.</p>	<p>Transport services are offered, comply with the requirements of the Acts, and are advertised in patient information leaflets.</p>
<p>On some occasions and for some procedures a home visit to the patient, instead of a visit to the healthcare setting could be considered as a 'reasonable adjustment.'</p>	<p>In response to consultation, several professionals noted that a home visit can reduce risk of challenging behaviour. It was also noted that, with co-ordination and planning, several procedures eg blood test, catheter change, suture removal, diabetic support or changing of a PEG tube, could be conducted simultaneously in a familiar environment to avoid the need for multiple visits to a clinic or GP surgery.</p>	

#### Key Challenges ~

- 1 Using appropriate symbols when there is not a nationally recognised common set or source of such symbols.
- 2 Although the Scottish Consortium for Learning Disability agrees with making arrangements around appointment times, evaluation of this type of adjustment has occurred only at the local level. This could be a stimulus to further research.

## Core principles: Section 4: Education and training

### Key Points ~

- 1 *All healthcare workers need to have some knowledge of learning disabilities and protection of vulnerable adults and children.*
- 2 *Different levels of awareness, and therefore training, are required for healthcare workers; from those who are taught how to 'meet and greet' appropriately, to those who will be involved in assessment, and therefore need more specialist knowledge. All will require communication skills of differing levels.*
- 3 *Advocacy and specialist learning disability nurses or other specialists should be available for people with a learning disability, if desired, at the point of entry to the healthcare system. Staff at the first point of entry should be able to access these people swiftly.*
- 4 *Awareness-raising, informal education opportunities, and formal training could be approached from a variety of perspectives including risk management, equality and diversity training, and customer care.*

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>All staff working at the point of entry to healthcare are made aware of their responsibilities to support inclusion.</p>	<p>To fulfil legal obligations, staff need to be appropriately prepared for all patients entering the healthcare system. Although a single approach will not be appropriate for all, training to raise awareness and encourage positive behaviour among staff seems highly desirable by service users.<sup>3,4</sup></p>	<p>This will be reflected in training, induction programmes and 'refresher' courses. The inclusion agenda could be promoted through formal and informal programmes on risk management, customer care, and awareness raising for equality and diversity.</p>
<p>All staff working at the point of entry to healthcare have access to training, to ensure their communication and care is appropriate for people with an additional need, and in particular to ensure that a person with a learning disability is</p> <ul style="list-style-type: none"> <li>• welcomed into the service</li> <li>• put in contact with the appropriate people</li> <li>• able to leave the service with an understanding of the right information and the 'next steps' to take.</li> </ul>	<p>This supports principles of social inclusion and equity. The NHS QIS Quality Indicators – Learning Disabilities, 2 and 3<sup>3,5</sup> support principles of equity of access social justice and involvement of service users.</p>	<p>Personal Development Plans of relevant staff reflect these priorities. Audits of orientation and induction programmes will show that these elements of communication and good 'customer care' are addressed.</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>In addition to communication skills, healthcare workers require, within their range of competence, and according to the nature of their work, training to enhance skills;</p> <ul style="list-style-type: none"> <li>• in using the telephone (see sample telephone protocol Appendix 1)</li> <li>• in assessment of patient need</li> <li>• in negotiating issues around consent (see Appendix 5)</li> <li>• in helping to create an environment which encourages positive attitudes and behaviour.</li> </ul>	<p>Access to healthcare outside business hours or during an emergency is often dependent on the effective relaying of a message by telephone.</p> <p>This is a professional responsibility.</p> <p>It is a professional responsibility to be aware of the issues around consent.</p> <p>It is possible to avoid challenging behaviour which is associated with the capacity to manage waiting or handle fear.</p>	<p>There are arrangements for training staff in telephone techniques.</p> <p>Training requirements of professional staff reflect this.</p> <p>Training requirements of professional staff reflect this.</p> <p>Arrangements are in place to avoid unnecessary waiting, pain or distress eg, early appointments, dentistry using anaesthetic, etc.</p>
<p>Staff at the first point of contact know to whom the person with a learning disability should be referred for additional support, over and above scheduled care. Where required, staff are able to access independent advocacy or specialist learning disability nurses easily.</p>	<p>This complies with the NHS QIS Quality Indicator – Learning Disabilities which states that ‘Arrangements are in place to support the right to access independent advocacy in line with the Mental Health (Care and Treatment) (Scotland) Act 2003.’<sup>36</sup></p> <p>This complies with the recommendation from the Promoting Health Supporting Inclusion report which states that ‘All people with learning disability who have complex healthcare needs, wherever they live, should have a named children’s or learning disability nurse as a member of a specialist team to liaise, co-ordinate and link with all tiers of healthcare and other care systems.’<sup>37</sup></p> <p>‘People with learning disabilities should be helped and supported to do everything they are able to.’<sup>38</sup></p>	<p>Staff at points of entry to the healthcare system have rapid access to advocacy or other specialist help.</p> <p>There are examples of the use of specialist services eg, through the link nurses, local champions or personal health records. These demonstrate access to advocacy or specialist help.</p>

Statement	Reasons for statement	How to demonstrate statement is being achieved
<p>Those carrying out assessments are aware of:</p> <ul style="list-style-type: none"> <li>the differing and additional healthcare needs of people with a learning disability</li> <li>the policy and legislative framework, and</li> <li>the effect that fear and lack of understanding may have on behaviour, and the incidence of problem behaviour in people with a learning disability.</li> </ul>	<p>'People with learning disabilities have a higher number of health needs and more complex health needs than the rest of the population.'<sup>39</sup></p> <p>Policies and legislation outline the obligations which healthcare workers have to support inclusion. (See introduction )</p> <p>'Problem behaviours are experienced by about 15% of people with learning disabilities, although higher rates are reported if problem behaviours occurring as a symptom of mental health are included.'<sup>40</sup></p>	<p>This should be reflected in the curricula for professional training courses, and update information for existing members of staff.</p>
<p>Community learning disability teams, and staff providing children's services are involved in the education of carers, to assist them and the people for whom they care, in accessing healthcare as easily as possible.</p>	<p>These members of staff are best placed to inform carers how to access healthcare.</p>	<p>Systems are in place to ensure this topic is discussed in home visits.</p>

**Key Challenges ~**

- 1 *Raising awareness of the need for and extending training both formal and informal to all levels of healthcare workers.*
- 2 *Extending awareness of the differing and greater healthcare needs of people with a learning disability.*
- 3 *Accommodating different training levels for different groups of staff.*

## Appendix 1

### Telephone protocol –

Speak slowly in a calm, clear voice.
Introduce yourself and confirm the patient's name.
Be aware of the minimum information you require to access patient information on your system. Most database systems can retrieve a record with only two variables.
Initially, ask short, closed questions to gather this essential information and identify the caller. The person's name, date of birth, or home address, or hospital appointment number could be used to verify the caller. If your telephone system shows the caller's number, this information could be used to minimise the number of questions asked and retrieve the patient's details from a database. Try and establish the caller's identity using the minimum information.
Establish the reason for the call eg, if asking for an appointment, sick or wishing advice, by asking straightforward direct questions. A simple first question would be 'Why are you calling today?'
Use this information to ask the next appropriate question.
'Signpost' the course of the call by noting significant facts and agreements.
If you have difficulty in understanding the caller, ask a second person to listen in, to assist with interpretation. The person may require language interpretation.
If you have excluded an emergency situation, but you are aware further help is required, attempt to find out via the patient if there is anybody with them or if they can contact a third party.
If at any time during the call you are unable to obtain information it may be necessary to involve a third party.
Repeat and reinforce information and instructions. This can be done by rephrasing or using different vocabulary.
Ask the caller to re-iterate the information to ensure understanding. It may not be sufficient to ask for information to be repeated; understanding might be better ascertained if the patient can re-iterate this in his or her own words.
Avoid reference to time if possible, or supplement this with other information eg, it might be appropriate to say 'after breakfast' in addition to '9 o'clock.'
Only simple, short and clear messages should be set up on automated systems. User groups report that they have particular challenges with automated telephone systems.



## Appendix 2


### Tips for effective spoken communication with people with a learning disability.

Introduce yourself and use the person's name.
Speak clearly, maintain eye contact, and allow the person to see your lips move.
Use gestures, facial expression and body language to supplement words, but be aware that these do not always have the same meanings across cultures.
Use simple language, and short sentences.
Avoid the use of jargon and abbreviations eg, say 'hospital' rather than 'DGH.'
Avoid using negatives eg, say 'this afternoon' rather than 'not this morning.'
Be specific in making requests and avoid giving spatial directions eg, 'here's a chair for you to sit while you wait' rather than 'please use the waiting room on the left.'
Avoid idioms, or metaphors which could be taken literally eg, 'wait a minute.'
Use vocabulary and a style appropriate to the person's age eg, an older person may appreciate a formal title rather than a first name.
Be prepared for silences. Talking whilst the person is trying to formulate a message may cause distraction.
Reduce/eliminate distractions. Noise from televisions, telephones and the presence of other people can add to confusion and inhibit the capacity to receive and give messages.
Identify stress triggers and avoid them. Use information from the carer or family member to interpret non-verbal signs, and be alert to sudden changes of behaviour indicating distress. There is a high incidence of communication difficulties among people regarded as having challenging behaviour. ,
If the person has to take a message, or take a further step in a process, use simple questions to ensure the person has understood. The person's capacity to repeat a phrase may not indicate understanding.
Verbal instructions should be supplemented with written information or symbols eg, medication to be taken every evening could be identified with a symbol for bedtime, or a handwritten note of what has been agreed in a consultation.
Prewarn the person about procedures and explain simply why they have to be done eg, 'I am going to phone the liaison nurse who will help us get ready for the visit to the doctor.'
If the person is not able to receive verbal information it may be necessary to approach the carer or a family member. Always seek permission to do this, and continue to include the person in the dialogue with eye contact. <sup>45</sup>

## Appendix 3

### Tips on preparing written communication for people with a learning disability.

<p>Keep the layout simple with a lot of space. Too much text puts people off. Allow 60-70 characters per line and at least 2 times the space between words and between each line.</p>
<p>Use a large font (RNIB suggest 12 as a minimum and 14 for people with a visual impairment). A sans serif style allows the reader to distinguish more easily between letters so should be used in a short document. Use only one font in a document.</p>
<p>Do not justify typewritten documents. The length and spacing of words provide visual clues to the reader. For the same reason, do not hyphenate words at the end of a line.</p>
<p>The RNIB recommends using white or pale yellow matt paper with black ink. Avoid coloured inks and coloured papers.</p>
<p>Use lower case letters where possible since shapes of words give visual clues. Avoid</p> <ul style="list-style-type: none"> <li>• whole words or titles in capitals and italics</li> <li>• underlining - use <b>bold</b> instead</li> <li>• acronyms and jargon</li> <li>• abbreviations eg, 'doesn't' should be 'does not,' 'Tue' should be 'Tuesday'</li> </ul>
<p>Use short, simple sentences containing only one idea. Use simple vocabulary and don't use different words for the same thing. Avoid</p> <ul style="list-style-type: none"> <li>• complex punctuation symbols</li> <li>• negatives</li> <li>• too much detail</li> </ul>
<p>Keep the writing style active and personal eg, 'Come to meet the nurse at 4 ' rather than 'The appointment with the nurse is scheduled at 4'</p>
<p>User groups in Lothian<sup>46</sup> reported that they preferred appointment cards to contain, in addition to the time, day and date;</p> <ul style="list-style-type: none"> <li>• the name of the professional they would be seeing and</li> <li>• the reason for the appointment.</li> </ul> <p>This is particularly important for a person with many health needs and frequent appointments.</p>
<p>Write dates out in full and include the day of the week eg, Tuesday 23 May 2005 rather than 23/05/05 or Tue 23rd May 05</p>
<p>Write times with numbers rather than words. Supplement with a clock face if possible, and avoid using the 24 hour clock.</p>
<p>Include symbols or sketches where possible.</p>
<p>Use bullet points rather than numbers for lists. Never use Roman numerals.</p>



If writing by hand, observe the points above. Use a firm hand and a felt-tipped pen for a clear line. Ensure vertical strokes are extended beyond the height of the letters which have no vertical strokes.

Remember - not everyone can read. If possible an alternative format should be offered eg, a taped version of instructions.

This is based on advice from RNIB<sup>47</sup>, ENABLE<sup>48</sup> and the Plain English Campaign<sup>49</sup>

## Appendix 4

### Using symbols and visual materials

Many people with a learning disability show a preference for visual and diagrammatic information.<sup>50</sup> Signs or symbols are a more permanent form of communication and allow the person to process information more easily than listening to the spoken word. People with autism prefer symbols because of their concrete nature, allowing repeated examination over time, and the likelihood that using symbols involves less intense interaction with others.<sup>51</sup>

There are several systems of symbols in use. The working group producing this Best Practice Statement identified it as a challenge that there is no one preferred or recommended system of symbols for NHSScotland, and would recommend that a single system is adopted, to simplify learning and accommodate movement of staff, service users and carers between regions.

It is important that everyone using symbols should feel confident about their use. It is evident individuals use signs most when led by example; in the presence of others who also use them. Information at induction and at refresher courses for existing members of staff, on the symbol or picture system in use in that particular area could help promote their use. Some symbol sets are extended to other groups in addition to people with a learning disability. For example, the Makaton vocabulary,<sup>52</sup> using speech, signs and symbols, is sometimes employed with people who have communication problems following a stroke or in areas where different languages are spoken. An example of a common symbol set developed by health and social services within a region is that developed by the Good Information Group in the Scottish Borders, which has developed a dictionary of symbols for people with a learning disability, called 'I'll show you.'<sup>53</sup> This incorporates Picture Communication Symbols, published by Mayer-Johnson LLC,<sup>54</sup> with symbols from Bonnington<sup>55</sup> and People First.<sup>56</sup>

Picture books for people with a learning disability can be used by anyone who prefers pictures rather than words. Titles such as 'Going into hospital,' 'Going to the doctor,' and 'Going to out-patients' in particular promote and enhance access to healthcare.<sup>57</sup> Talking Mats™ an entirely visual resource, originally developed for people with complex communication needs, has been extended and a package has been prepared for people with a learning disability.<sup>58</sup>

In order to encourage the development of support materials to help people with learning disabilities to access healthcare services, two examples of symbolised materials have been included. The first example,

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the Health Advice Sheet, comes from the Better Health through Better Communication pilot project in NHS Lothian.<sup>59</sup> This project aimed to improve access to healthcare services for people with a learning disability in participating GP locations in NE and NW Edinburgh. This sample used Bonnington Symbols and was used to support service users to understand advice given by their GP during a consultation. A second example from this project is the Appointment Card which has been modified to include information for service users about the out-of-hours telephone contact number for their general practitioner, access to interpreting services, details of who the appointment is with, and what the appointment is for. This sample uses Picture Communication Symbols.

User groups have identified photographs as being the most desirable visual material.<sup>60</sup> The working group noted that the relatively low cost and ease with which digital cameras can be used means this medium has huge potential to convey information to people with a learning disability. Photographs could be particularly useful to prepare the person for a new and unfamiliar situation or in giving directions. The example shows how several key photographs presented with text could be used by a member of the ambulance team to allay fear and encourage the person to enter the ambulance. A colour version of this example can be downloaded from the website version at [www.nhshealthquality/publications/best-practice-statements](http://www.nhshealthquality/publications/best-practice-statements)

# Expressive Board

- Ask the patient to show you what they want to say
- The board is laid out in four sections
  - Area of life/events
  - Physical feelings
  - Emotions
- Figure outlines (over the page)
- Some people may find it helpful to look at the board one section at a time

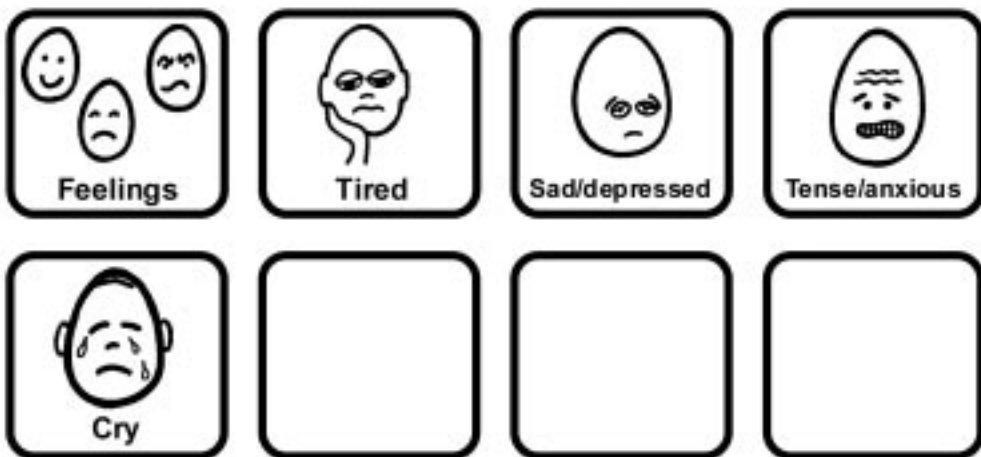
## Areas of life/events

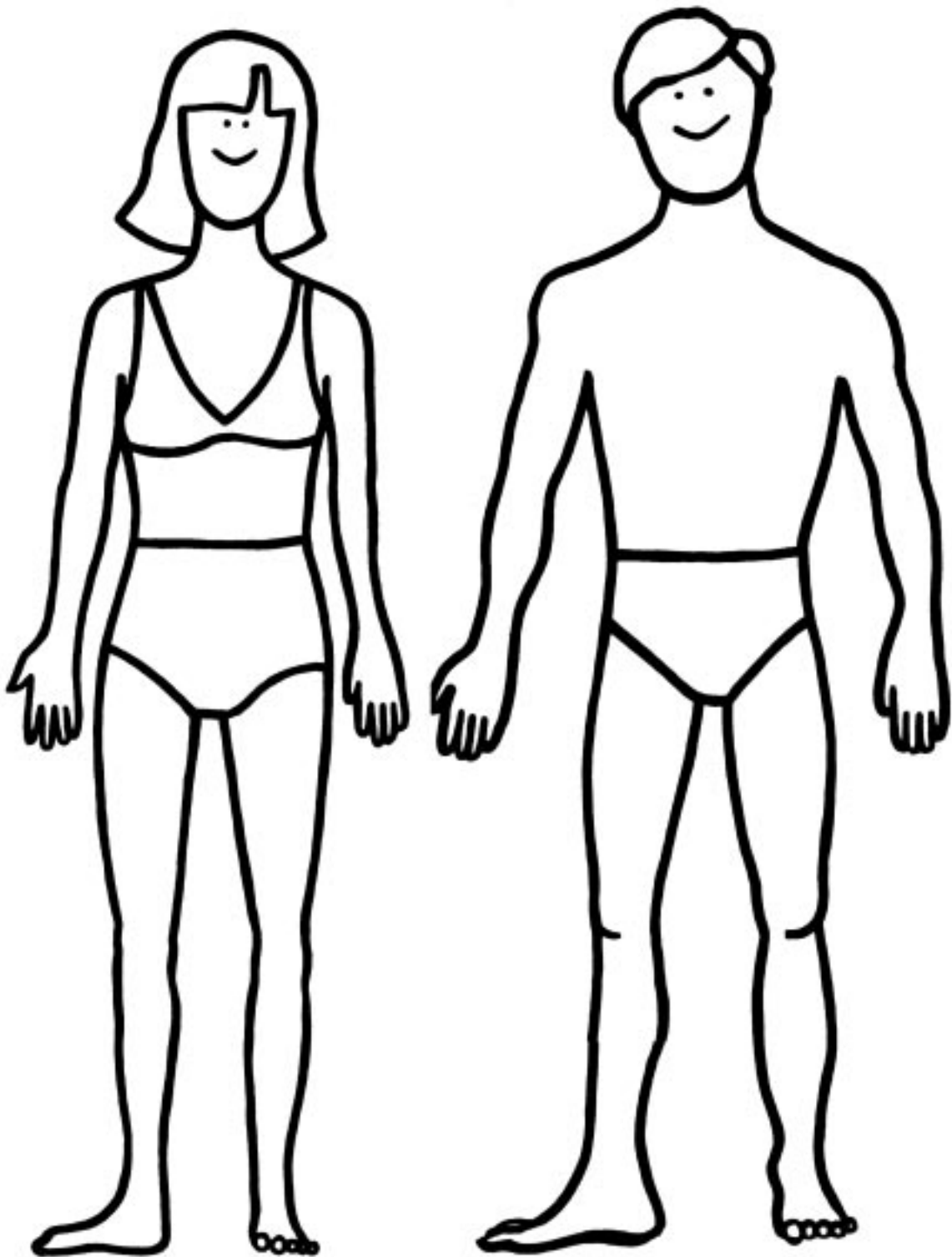


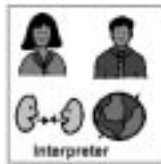
## Physical Feelings



## Emotions



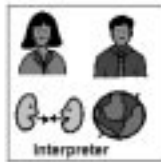




Interpreter required  
(please tick a box)

Male

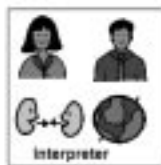
Female



Interpreter required  
(please tick a box)

Male

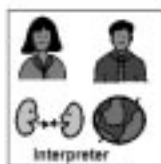
Female



Interpreter required  
(please tick a box)

Male

Female



Interpreter required  
(please tick a box)

Male

Female



Doctor



Surgery



Daytime Telephone

Out of Hours Telephone



## Appointment Card



Doctor



Surgery



Daytime Telephone

Out of Hours Telephone



## Appointment Card



Doctor



Surgery



Daytime Telephone

Out of Hours Telephone



## Appointment Card



Doctor



Surgery



Daytime Telephone

Out of Hours Telephone



## Appointment Card





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## Going in an ambulance in an emergency

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When someone dials 999 in an emergency, an ambulance like this might come.

The person helping you is called a paramedic and he or she will be wearing a green uniform.



The paramedic will take you into the ambulance in a chair or on a stretcher, which is like a bed.



The paramedic will ask you some questions.

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**You might need to wear a mask like this to help you breathe.**



**If you are very ill the paramedic may need to use a machine which helps your heart to beat properly. This is called a defibrillator.**



**The paramedic may need you to remove some of your clothing. The paramedic will also check that you are breathing ok.**

**Try not to worry about going in an ambulance. The paramedic will take good care of you.**

## **Appendix 5**

### **Principles of informed consent**

#### **Adults with Incapacity (Scotland) Act 2000**

A fundamental issue when addressing access to healthcare for people with a learning disability is the concept of consent.

Firstly there is the consent to involve a third party (such as a family member or a professional carer) in the discussion or disclosure of the individual's health needs. No one can speak on behalf of the patient after the age of consent (16 years) has been attained. The professional judgement of the healthcare worker will be critical in ascertaining not only how best to communicate with the patient but also in assessing at what point to involve a third party. An important principle to bear in mind is that in people with a learning disability the capacity to communicate can vary over time and with circumstances.

In addition, there is the concept of informed consent, where the patient over 16 agrees to medical treatment or research. At the time of going to press, a 'Good practice guide on consent for health professionals in NHS Scotland' was being prepared by the Scottish Executive. In addition, guidance on the amendments to Part 5 of the Adults with Incapacity (Scotland) Act 2000, contained within the Smoking, Health and Social Care (Scotland) Act 2005 will be issued from the Scottish Executive in 2006. It is intended that information in this appendix will identify principles which complement the more detailed guidance in the Scottish Executive publications.

The Adults with Incapacity (Scotland) Act 2000 is designed to ensure equity of treatment and choice for adults with incapacity. The general principles of this Act and how these should be considered by all healthcare professionals are outlined below.

Part 5 of The Adults with Incapacity (Scotland) Act 2000 sets out the principles that should underpin the assessment of incapacity to consent to medical treatment or research, and how to proceed where an individual is incapable of giving informed consent.

Within Part 5 of the Act 'medical treatment' includes any procedure or treatment designed to safeguard or promote physical or mental health.

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## General Principles

If the individual adult patient cannot give consent to treatment, then consent for treatment cannot be sought from the carer or supporter. No one can give consent for an adult with a learning disability unless the person is subject to the Adults With Incapacity (Scotland) Act 2000 (AWI) eg, a guardianship. If the individual does not have capacity to consent to treatment then the AWI Act should be implemented and a Section 47 must be completed.

All decisions made on behalf of an adult with impaired capacity (for whom a Section 47 has been completed) must observe the principles of the Act that any course of treatment should:

- benefit the adult
- be the most minimally invasive course of action to achieve the desired treatment outcome
- take account of the adult's wishes, both past and present, if these can be ascertained
- take account of the views of relevant others, as far as it is reasonable and practicable to do so
- minimise the restriction of the adult's freedom, while achieving the desired benefit
- encourage the adult to make decisions on other aspects of their care, if unable to make decisions on medical treatment.

## Incapacity

Incapacity is defined within the Act as being incapable of any of the following:

- acting
- making decisions
- communicating decisions
- understanding decisions, or
- retaining the memory of decisions.

by reason of mental disorder or of inability to communicate because of physical disability.

## Assessment of Incapacity

Assessment of incapacity was, until the amendment of the Adults with Incapacity (Scotland) Act 2000, the responsibility of the physician primarily in charge of the patient's care. The amendment to the Adults with Incapacity (Scotland) Act 2000 contained in the Smoking, Health and Social Care (Scotland) Act 2005 has extended this responsibility to those defined as 'a dental practitioner, ophthalmic optician, a registered nurse or a person who falls within such description of persons as may be prescribed by Scottish Ministers, who satisfy such requirements as may be so prescribed, and who is primarily responsible for the medical treatment of the kind in question.' (Amendment of Adults with Incapacity (Scotland) Act 2000: Part 6 authorisation of medical treatment Section 35) The assessment of incapacity should seek to determine whether the adult:

- is capable of making and communicating their choice
- understands the nature of what is being asked and why
- has memory abilities that allow the retention of information
- is aware of any alternatives
- has knowledge of the risks and benefits involved
- is aware that such information is of personal relevance to them
- is aware of their right to, and how to, refuse, as well as the consequences of refusal
- has ever expressed their wishes relevant to the issues when greater capacity existed
- is expressing views consistent with their preferred moral, cultural, family and experiential background
- is making a choice which is free of coercion.

In many NHS Boards in Scotland, a Learning Disability Liaison Service has been established to support people with a learning disability when they access services in general hospitals. These services are further supported by protocols, or agreed arrangements, which should honour the principles relating to informed consent.

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## **Principles of informed consent:**

- Patient consent is required in all areas of care/treatment.
- Consent cannot be given on behalf of another.
- All patients must be treated as equal, having the same rights to care.
- Patients with a learning disability should not be excluded from treatment unless this has been clinically indicated.
- It should not be assumed that patients with a learning disability cannot give informed consent.
- Medical and nursing staff should assess the incapacity of the patient to give consent in line with the Adults with Incapacity (Scotland) Act 2000. Capacity to consent may vary over time.
- All care given must clearly be in the patient's best interests; ultimately the attending doctor may make a decision to proceed without consent if deemed necessary.
- There should be liaison with the people who know the patient eg, the main carer or parent.
- The need to involve a learning disability liaison nurse, patient liaison officer or other such professional should be assessed.
- An independent advocate might help to assist a patient with a learning disability decide whether to proceed with a procedure or not.

## Appendix 6

### **Audit tool: assessing access to healthcare for people with a learning disability.**

The Quality Indicators (QIs) for learning disabilities published by NHS Quality Improvement Scotland (2004) provide a background to this best practice statement. It is mandatory for NHS Boards to comply with these indicators and NHS Quality Improvement Scotland has already conducted peer review visits to assess performance of NHS Boards against QIs 1, 4, 5 and 6, with a particular focus on hospital closure.

This best practice statement supports Quality Indicator 2, Promoting Inclusion and Well being, and 3, Meeting General Healthcare Needs.

This simple audit tool is an example of a check list which could be devised to allow staff in any healthcare setting to conduct a simple self-assessment. Healthcare units may already use a tool similar to this. The tool could be used to assess whether the most significant aspects of best practice identified in this statement are being observed in a particular environment. It lists the activities and arrangements which, if in place, and followed through, would contribute both to implementing the requirements of the QIs, and to promoting access to healthcare for people with a learning disability.

When a NHS QIS peer review visit takes place, NHS Boards are required to provide evidence of compliance with the QIs. It might be a step towards fulfilling the requirements of a peer review if healthcare staff were confident that this, or a similar audit tool, could be evidenced. This tool is intended only for internal self-assessment, however. Its use could stimulate further work in promoting access.

No assessment of 'access,' would be comprehensive without the voice of the user. This audit tool could be supplemented with qualitative evidence from focus or user group work to assess the effectiveness of arrangements and activities set up to promote access. This could target groups or individuals outside the healthcare setting, perhaps identified by social services or voluntary groups, rather than approaching those who have already accessed the service. Guidance on involving people with a learning disability and their carers in improving the quality of health services can be found in 'It's our Health Service!' (NHS QIS May 2005)<sup>60</sup>.



Self-assessment, to identify areas of good practice in a healthcare setting, as outlined in the Best Practice Statement on Promoting access to healthcare for people with a learning disability; a guide for frontline NHS staff.

<b>1)</b>	<b>Induction Sections 1,2,3 and 4</b>	<b>Y</b>	<b>N</b>	<b>Action</b>
	Induction programmes for staff include;			
<b>a</b>	Awareness of the principles of and responsibilities to promote inclusion			
<b>b</b>	Awareness and identification of additional needs, including learning disabilities			
<b>c</b>	Awareness of the additional support needs of a person with learning disability			
<b>d</b>	Information on the sources of support available in the local area eg advocacy, a liaison service, communication guides			
<b>e</b>	The principles of communication, and availability of communication resources			
<b>f</b>	Awareness of the physical environment, directions and signage			
<b>g</b>	Awareness, at a level commensurate with duties, of principles of inclusion and consent			
<b>h</b>	Awareness, at a level commensurate with duties, of principles and issues associated with the vulnerable adult and child protection			
<b>2)</b>	<b>Training Sections 1 and 2</b>			
	Staff have access to ongoing training opportunities to develop their knowledge and skills in relation to:			
<b>a</b>	Communication			
<b>b</b>	Equality and Inclusion			
<b>c</b>	Awareness of and access to local resources to support people with a learning disability			
<b>3)</b>	<b>Arrangements and protocols Sections 1 and 2</b>			
	Protocols and policies are available to support:			
<b>a</b>	The identification of learning disability			
<b>b</b>	The use of 'flagging' systems and communication tools such as patient passports, special notes to NHS 24			
<b>c</b>	The identification and use of a range of communication techniques that encourage a diversity of approaches			
<b>d</b>	Contact with local support systems (Community Learning Disability Teams, Liaison Nurses, Advocacy Services)			
<b>e</b>	The involvement of carers in providing health information			
<b>f</b>	The flexibility of appointment times to respond to individual need			
<b>g</b>	Pre-admission /attendance preparation for elective appointments			
<b>h</b>	Consent issues including Adults with Incapacity (Scotland) Act 2000			

4)	<b>Physical resources – the healthcare setting</b> <b>Section 3</b>	Y	N	Action
	The health setting has:			
<b>a</b>	Appropriate signage			
<b>b</b>	Provision of alternative waiting areas or arrangements for waiting and recall			
<b>c</b>	Access to appropriate toileting and changing facilities			
<b>d</b>	Areas of minimal distraction for clinical assessment			
<b>e</b>	Systems in place to bring about compliance with the requirements of Disability Discrimination Act(1995)			
<b>f</b>	Transport arrangements which comply with the Mental Health Act			
<b>5)</b>	<b>Information resources</b> <b>Section 2</b>			
	A range of information resources is available to foster effective communication: eg,			
	<ul style="list-style-type: none"> <li>• Large print and easy read leaflets</li> </ul>			
	<ul style="list-style-type: none"> <li>• Audio and Video resources</li> </ul>			
	<ul style="list-style-type: none"> <li>• Visual materials such as diagrams, symbols and photographs</li> </ul>			

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## References

- <sup>1</sup> Scottish Executive 2005 [www.scotland.gov.uk/Topics/People/Social-Inclusion](http://www.scotland.gov.uk/Topics/People/Social-Inclusion)
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This outlines core values that should form the basis for all service provision, including health.

<sup>24</sup> Under Agenda for Change the majority of posts held in the NHS will have a framework which describes how knowledge and skills are applied in the post. One of the core dimensions of knowledge and skills, which applies to all posts, is Equality and Diversity. Fully competent post-holders must attain at least level one of this dimension, which states that the person will 'act in ways that support equality and value diversity.'

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<sup>49</sup> The Plain English Campaign. The Plain English Campaign promotes the use of clear English without jargon or legalese in public communication. Further information can be obtained from: [www.plainenglish.co.uk](http://www.plainenglish.co.uk) [URL accessed 01/09/05].

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Further information from [heather.jones@borders.scot.nhs.uk](mailto:heather.jones@borders.scot.nhs.uk) or [pprice@scotbordeers.gov.uk](mailto:pprice@scotbordeers.gov.uk)



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<sup>54</sup> Mayer-Johnson LLC Picture Communication Symbols © 1981 - 2004 All Rights Reserved Worldwide. P O Box 1579, Solana Beach, CA 92075, USA  
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## **Networks and organisations consulted**

Allied Health Professionals Clinical Effectiveness and Practice  
Development Networks  
Community Practitioners' and Health Visitors' Association (Scotland)

Delegates at 'Celebrating success. Supporting people with Learning  
Disabilities - rhetoric to reality' National Nursing and Midwifery  
Conference 18 February 2005 This conference included service users and  
health professionals

Practice Nurses Association

NHS QIS Clinical Governance Network

NHS QIS Practice Development Nurse Network

NHS QIS Practice Development Midwives' Network

People First, Scotland

Parents contacted by PAMIS, Glasgow

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