

SCOTTISH EXECUTIVE HEALTH DEPARTMENT

GOOD PRACTICE

Equality for disabled people in the NHS in Scotland

**Access to services**

NHS in Scotland Management Executive

Archive document  
may contain outdated information

## **Purpose of this document**

This document provides essential background and guidance for senior NHSiS managers with specific responsibility for advising on access for disabled patients to services. It can also be used as a source of information on general disability issues for all staff.

Service providers and employers in the NHSiS will wish to consider the implications for them of the Disability Discrimination Act 1995 and of any other legislation. They are also advised to seek their own legal advice.

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Also available on floppy disk, on request, suitable for transcribing into braille and large type formats and can be accessed on Scottish Health on the Web ([www.show.scot.nhs.uk](http://www.show.scot.nhs.uk)).

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## **Acknowledgements**

This is a Scottish Executive Health Department edition of a UK-wide guide originally edited by: Melanie Henwood, Visiting Fellow at the Nuffield Institute for Health Community Care Division; Chris Norris, Communications Consultant, and Dave Thompson, Disability Services Adviser, Warrington Community Health Care NHS Trust. It builds upon two national UK conferences on the care of disabled people in hospital. We are grateful to all those who participated in those conferences, and to the individuals and organisations who commented on earlier drafts of this good practice guide.

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## **Foreword**

Disabled people often face unacceptable difficulties when they try to use NHSiS services. These difficulties can be caused by a variety of factors, including the lack of understanding of disability by some staff, and poor physical access to buildings and environments that make it difficult or impossible for disabled people to find their way about or communicate with staff. At the same time, there are examples of excellent practice, where hospitals and other health care providers have made enormous improvements to their services and to the general awareness of the needs of disabled people.

In future years it will be essential that such practice becomes the standard everywhere. Legislation - such as the Disability Discrimination Act - has already placed new duties on employers and service providers, and will create further requirements that will oblige providers to take greater account of the needs of disabled patients and staff. The Government wishes to encourage the development of a culture within the new NHSiS that supports the expansion of good practice.

Services that are accessible for disabled people are accessible for everybody. Doorways wide enough for wheelchairs, for example, are also much easier for people with small children in prams or pushchairs. Environments that are well designed, well decorated and clearly sign-posted are easier for everyone to find their way around.

In Scotland today it is estimated that over 800,000 people have some sort of disability. It is likely that many of us will experience disability at some time in our lives, particularly in later life. We are also likely to find ourselves temporarily disabled if we spend time in hospital, so we need to do all we can to ensure that the time a disabled person spends in hospital does not cause them additional problems.

The Government is committed to addressing health inequalities and tackling any unfairness which disabled people may meet in using the NHSiS must be central to any strategy for greater equality. This objective is consistent with the other medium-term priorities for the NHSiS, set out within the Government's Priorities and Planning Guidance. The Scottish Health White Paper "Designed to Care" makes clear the importance of giving greater voice and influence to the users of NHSiS services, and to their carers, and must be central to any approach that seeks to improve services and opportunities for disabled people.

This good practice guide has been produced to help improve the standards of support and care that the NHSiS offers to people with disabilities.

We are grateful for the assistance provided by Scottish disability groups who took part in a seminar hosted by the Scottish Office Department of Health earlier this year. The comments and advice received were most helpful in finalising the guide.

JACKIE BAILLIE MSP  
Deputy Minister for Communities

## Executive Summary

This guide is to help NHSiS managers and front line staff to improve their awareness of, and response to, the needs of disabled people – whether they are patients, carers or employees. Such awareness is not simply good practice, it is essential for the Health Service in meeting its responsibilities under the 1995 Disability Discrimination Act (DDA). Each section of the guide includes suggestions for specific issues that require particular attention.

**Section 1** begins by setting the **policy context**. NHSiS managers will be aware of the general context of community and continuing health care policy, and of the requirements of the Priorities and Planning Guidance, which addresses the overall context for the planning and delivery of health services for the next three years. Alongside these requirements are those of the 1995 Disability Discrimination Act. This is a wide-ranging Act that gives disabled people new legally enforceable rights. The Act covers all walks of life and has implications for the Health Service, both as a service provider and as an employer.

**Section 2** considers approaches that might be adopted in ensuring that the NHSiS provides equal access to services for disabled people. A local strategy needs to be developed, and there are particular strengths in designating a person or persons as a **disability services adviser**. This person can assume responsibility for co-ordinating and advising on services and policies, and for developing the necessary liaison both within and outside the NHSiS.

**Section 3** examines some of the issues that need to be addressed in the way NHSiS staff interact with disabled people. In particular, material is presented to help non-disabled people improve their **communication** with disabled people. The use of language and terminology is examined, and the Section promotes improved **awareness of disability** in general and specific situations.

**Section 4** addresses the range of issues that need to be tackled, and provides pointers to more detailed information and specifications. In parallel with this good practice guide, disability access guidance has been developed in Scotland by the NHSiS Estates Environment Forum and in England by the Department of Health. This guidance will enable access audits to be carried out on NHS buildings across the UK. The environments provided by buildings and other infrastructure can be highly disabling. The performance of the NHSiS is improving but there is still much to be done to improve **physical access**.

**Section 5**. It is not only buildings which can be disabling. The same can be true of **procedures and routine practices**. This section addresses such matters and considers ways in which appointments, hospital admissions and discharges,

outpatient and primary care consultations, can all be organised in ways that make them more accessible for disabled patients.

The NHSiS is the largest employer in Scotland, and the NHS Management Executive is committed to developing the NHSiS as a good employer. This includes the importance of developing equal opportunities policies and practices. The provisions of the DDA also introduce further requirements of the NHSiS as an employer, and there must be no discrimination in the recruitment or employment of people with disabilities. This area is being addressed through project groups which have been set up under the auspices of the NHS Scottish Partnership Forum as part of the work being undertaken following commitments in the April 1998 Human Resources Strategy publication "Towards a new way of working". It is expected that the project groups will publish their reports in the autumn.

## **Introduction**

### **Objectives and scope**

This good practice guide has been developed to help NHSiS managers and staff to improve the quality of their services. A comprehensive approach to access, including awareness and physical access, benefits everyone. It helps to create an inclusive environment that supports all NHSiS employees, patients and visitors where patients get fair access to consistently high quality, prompt and accessible services across the country. These principles also cover disabled people's access to the entire range of health services. The Disability Discrimination Act requires an end to discriminatory policies, practices and procedures and this guide identifies the sort of changes that will be required, and how to go about putting them in place.

To help NHSiS managers and staff develop such an approach this guide focuses on awareness of, and services for, disabled patients and employees. It is a resource document designed to inform the development of coherent local strategies that will ensure these matters are properly addressed.

In developing a local strategy, Trusts may find it useful to designate a senior manager (or part of the time of a senior manager) as a disability services adviser who can take responsibility for overall strategy design and co-ordinating implementation. The guide provides information about what it means to be disabled, what changes need to be made to services, and how this might be approached. Further detailed information on contacts and relevant organisations is included in Appendix II.

### **How to use this guide**

The guide is written particularly for health service managers with specific responsibility for advising on equality issues for disabled people. They may have different levels of awareness and experience of disability issues, so it includes much basic information. It also has a broader scope, and includes material that will need to be disseminated throughout the Service.

A wide variety of disabled service users, healthcare professionals and managers, and voluntary workers have contributed to this guide. The advice and ideas it contains are based on practical experience which has been proved to work, and which can contribute to improving practice throughout the NHSiS.

## **1. Policy context**

## 1.1 Review of current policy

The NHS in Scotland (NHSiS) has always had a responsibility to meet the health care needs of all its citizens but since its inception this has tended to have a two-fold effect on the way services have been delivered for disabled people. First there has been a focus on what disabled people tend to see as the "medical model" of disability and second, in the early years of the NHS, there was a high level of in-patient care for disabled people. Put together, these two trends have meant that NHSiS has tended to adopt an organisational approach to disability where the individual, rather than the environment, is "enabled" and where remnants of an institutional response to the needs of disabled people linger.

Now the vast majority of disabled people live in their own homes in the community, rather than in hospitals or in residential accommodation. The policy of community care has been an objective for many years, but particularly so since the 1990 NHS and Community Care Act, which came into effect on 1 April 1993. People, who in the past might have spent their lives in long stay institutions or hospitals, are now able to live in the community, with the support of health and social care and housing services, and often with support from family and friends. One effect of this trend is that more disabled people now make use of mainstream health services.

The responsibilities of the NHSiS for arranging and funding services to meet "the needs of people who require continuing physical or mental health care" therefore include not only care under specialist clinical supervision in a hospital or a nursing home but also include responsibilities around rehabilitation, palliative health care, respite health care, community health services support, and specialist health care support in different settings. Scottish Office Department of Health, 1996, *NHS Responsibility for Continuing Health Care* NHS MEL (1996) 22 dated 6 March 1996 refers.

Like everyone, disabled people use facilities such as: GP surgeries and primary health care services; dentists and opticians; community pharmacies; accident and emergency units; in-patient and out-patient hospital services. It is vital that all NHSiS services are accessible, so that disabled people are able to receive the same services that are available to other people. The Disability Discrimination Act 1995 (DDA) already addresses these issues and disabled people will have further rights from October 1999. Paragraph 1.2 goes into more detail.

If the NHSiS is to provide a fair service for disabled people, it has to be taken seriously by senior managers in Health Boards and Trusts. For many years, lip service has been paid to the idea of involving patients and users in planning services. This must now become a reality. Managers and service

providers must listen and respond appropriately; disabled people are the experts in their needs. The White Paper *Designed to Care* emphasised the shared responsibility of everyone working in the NHSiS to provide good quality health care which is responsive to patients' needs and wishes. It highlighted five key objectives essential to achieving this:

- co-ordination and reliability of care;
- clinical effectiveness;
- more effective care;
- patient involvement; and
- patient information.

A new NHS Charter is being developed in Scotland in partnership with NHSiS users, carers and staff. The aim is to consult on the contents with a formal launch in 1999. The development of Charter issues will continue to be pursued at local level with Boards and Trusts expected to develop meaningful local commitments which should address the specific needs of disabled people.

Improvements in the quality and efficiency of the NHSiS will be assessed through the new National Performance Framework, and this provides a further incentive for Health Boards and Trusts to ensure that services are responsive to individual needs.

**A service that is poorly suited to the needs of disabled patients is not a responsive or quality service. NHSiS services will need to be able to demonstrate how they meet the needs of their patients (including those with disabilities), and the plans they have in place for further progress.**

## **1.2 The Disability Discrimination Act 1995 (DDA)**

The Disability Discrimination Act defines disability as "**a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities**". This includes physical and sensory impairments, but also other impairments including learning disabilities and mental health problems. People with a progressive condition are also included if their condition affects normal day-to-day activities.

'Long term' in this regard means lasting, or likely to last for at least 12 months or the remainder of the life of the person concerned. 'Adverse effects' refer to effects in one of a number of areas listed in the Act: mobility; manual dexterity; physical co-ordination; continence; ability to lift, carry or move ordinary objects; speech, hearing or eyesight; memory or ability to concentrate, learn or understand; being able to recognise physical danger. Examples of circumstances that would be likely to be considered 'substantial' include:

- inability to see moving traffic clearly enough to cross a road safely;
- inability to turn taps or knobs; and
- inability to remember and relay a simple message correctly.

Some types of disability clearly fit into such a definition, but this may be less obvious in other cases. Severe disfigurements, for example, are treated as disabilities by the Act, although they might not have any effect on physical capacity to carry out normal day-to-day activities. Duties under the DDA also apply for people who have had a disability in the past (for example, someone who has had a mental health problem).

The DDA gives disabled people new rights in the areas of:

- access to goods, facilities and services;
- buying or renting land or property; and
- employment.

Since 2 December 1996, the DDA has made it unlawful for disabled people to be treated less favourably than other people, without justification, in areas such as buying goods, using services, finding somewhere to live and getting a job. The DDA only recognises very limited circumstances in which there may be 'justification' for treating a disabled person less favourably than other people. However 'justification' must not be used as an excuse for inaction. Less favourable treatment may be possible if a service provider reasonably believes that one of the following circumstances applies:

### **Health or safety**

No one is required to do anything that would endanger the health or safety of any person, including the disabled person.

### **Making contracts**

A trader can refuse to enter into a major or complex contract with someone who does not understand the nature of the contract because of their disability.

### **Providing a service to others**

A disabled person could be refused a service if it would mean that the service could not be provided to others.

### **Charging more**

A disabled person cannot be charged more for the same goods or services than anyone else. However, if a special service is provided or goods which cost more to produce, the disabled person can be charged more.

## **1.3 What does the DDA mean for the NHSiS?**

The DDA makes it unlawful for people who provide goods, facilities or services to the public to discriminate against disabled people. Service providers must not treat disabled people less favourably than they would treat other people when they are providing a service or facility. At present, a service provider cannot for reasons of their disability:

- refuse to serve a disabled person
- offer a disabled person a lower standard of service
- offer a disabled person less favourable terms.

On 9 June the Government announced the timetable for implementing those rights of the DDA affecting disabled people's access to goods and services. These provisions are to be implemented in two stages:

**From October 1999** service providers will have to take reasonable steps to change practices, policies or procedures which make it impossible or unreasonably difficult for disabled people to use their service; provide auxiliary aids or services which would enable or facilitate disabled people to use a service; and overcome physical barriers by providing a service by a reasonable alternative method.

**From 2004** service providers will have to take reasonable steps to remove, alter, or provide reasonable means of avoiding physical features that make it impossible or unreasonably difficult for disabled people to use a service.

Implementation of these provisions on access to goods and services (Section 21) will be phased in over a period from October 1999 to December 2004. Section

21 refers to a “service provider being under a duty to take such steps as is reasonable, in all circumstances of the case”. The Act does not specify that any particular factors should be taken into account. In the absence of a legal definition it would seem appropriate to apply an everyday meaning. Any guidance required on the interpretation of the DDA should be sought from Health Boards’/Trusts’ legal advisers.

### **The NHSiS as an employer**

The DDA covers all aspects of employment. This includes recruitment, doing the work, promotion, career development and redundancy or dismissal.

Employers have a duty to make 'reasonable adjustments' in the workplace where employment arrangements substantially disadvantage a disabled person compared with a non-disabled person, unless they can justify not complying with the duty. These adjustments apply to the physical features of premises, but also to fixtures and fittings, furnishings, equipment and materials, and also to the way in which a job is organised. The 'reasonableness' of an adjustment will depend amongst other things on the cost in relation to the size and resources of the employing organisation, but many adjustments (such as in improving lighting or re-arranging a layout) can be achieved at little or no extra cost.

#### **Working example**

**Monklands Hospital** has introduced a ‘What is reasonable adjustment’ policy for managers. This provides:

- detailed information for managers to help them assess whether employees/prospective employees are covered under the scope of the DDA
- workgroup case studies to illustrate the type of cases that may arise in the future.

Individual members of staff also have responsibilities not to discriminate. Employers can be held responsible for an employee's conduct unless they have taken such steps as were reasonably practicable to prevent such conduct. The employer can also be held responsible for anyone acting on their behalf and with their authority. A manager is responsible for ensuring staff know what actions may be unlawful.

## **2. Management and organisation**

### **2.1 Where to start**

How do you know whether or not your service is meeting the needs of disabled patients?

Although not focusing specifically on disability issues, the annual patient survey will generate invaluable information which for the first time will provide a

national picture (compiled at Health Board level) and enable the Health Service to measure itself against the aspirations and experience of its users. At local level Health Boards and Trusts need to undertake additional monitoring and evaluation of services, including for example:

- How accessible are local hospitals and other NHS facilities to disabled people?
- Have you undertaken an access audit, or spoken to disabled patients about their experiences?
- What does the Disability Discrimination Act mean for your service, and are you sure that you meet the requirements?
- What consultation processes exist that engage disabled people? How do you ensure that disabled people have full access to these processes?
- Have you a policy in place, which enables users and carers to be fully involved in strategic planning and service delivery?
- What is your strategy for disability awareness and disability equality training?
- Is there a pattern in complaints made about services, and is the complaint procedure equally accessible for disabled people?
- Are staff who have relevant expertise of disability fully involved in the development of a strategic plan?

## **2.2 Developing a local strategy**

Disability issues need to be recognised as everybody's business within the NHSiS. However, unless a particular person is given lead responsibility on such matters, there is a risk that they may never achieve the priority required. There also needs to be a recognised level of decision making which has been endorsed at board level.

Different models and approaches exist in different Health Boards, but there are strengths in appointing a senior clinician or manager to be **disability services**

**adviser or co-ordinator.** Similar lead responsibilities might also be assigned within acute and primary care trusts, and in primary care settings. The tasks that Health Boards need to address in developing a local strategy include the following:-

- ensure commitment to the general principles of placing disabled people (and all patients) at the centre of service planning and provision.
- develop a programme of staff training on disability awareness and equality (in partnership with disabled people and local organisations) among Health Boards and Trusts. This should involve staff with relevant expertise, such as hearing therapists for people with deaf communication skills and occupational therapists who have experience on environmental design.
- develop information on the incidence of different types of disability, and the implications for health services and budgets. There needs to be a strategy for overall improvement and equality of access for all disabled people;
- consult a disability advisory group(s) to agree achievable targets for services which include the requirements of the DDA;
- include in relevant strategy/strategies proposals for implementing the requirements of the Disability Discrimination Act, and ensure that all those providing health care facilities understand their responsibility to address disabling features of their services;
- monitor performance of Trusts through the Health Improvement Plan/Trust Implementation Plan Process; engage a monitoring group of disabled people to help conduct the review process;
- adjust targets and commissioning as necessary.

It may be helpful to base any strategy on a clear set of principles, such as those developed by the Living Options in Practice initiative, published by the Prince of Wales' Advisory Group on Disability.

#### **Living Options Principles**

**Choice** as to where to live and how to maintain independence without over-protection, or the risk of unnecessary hazards, including help in learning how to choose.

**Consultation** with disabled people (and their families if appropriate) on services as they are planned.

**Information** clearly presented and readily available to all disabled people, including people with the most severe impairments, in minority languages including British Sign Language. Information should also be available in Braille (or large print) for people who require this.

**Participation** in the life of local and national communities in respect of both responsibilities and benefits.

**Recognition** that long-term impairment is not synonymous with illness. The medical model is therefore not appropriate for impairment, but may be appropriate if a disabled person is ill.

**Autonomy:** that is, freedom to make decisions regarding the way of life best suited to an individual person's circumstances.

*SOURCE: North West Regional Health Authority (1995), Breaking Down Barriers: Guidelines for purchasers of services for disabled adults aged 16-64 with physical and sensory impairments. Companion Volume.*

Many issues raised in consultation, for example an access audit of older buildings, could involve major changes and financial outlay which can only be achieved over time. This should not lead people to think they cannot do anything in the short term. Consultation with disabled groups has also highlighted the degree to which small changes in an organisation's attitudes, culture and procedures can make a difference. These should be encouraged while planning more physical changes for the mid and longer term.

### **2.3 Disability services adviser**

Everyone in the Health Service will have a responsibility for disability issues, including the executive boards of NHS Trusts and individual departments such as human resources, quality, estates etc. However there are benefits for patients and for the Health Service in designating a senior person as a disability services adviser who can co-ordinate and/or advise on services and policies that are needed. Their role will be enhanced if they have a budget for key disability issues.

This person would be responsible for liaising with voluntary, statutory and business organisations that work with and for disabled people and disseminating key messages resulting from that liaison throughout their organisation. Many of

these disability organisations have experience that is extremely valuable for the Health Service. Different models of disability advisers might be developed. The particular roles and responsibilities would vary, but the principle requirements would be:

- a clear understanding of, and real empathy for, the issues faced by disabled people, which could, but not necessarily come from personal experience of disability;
- knowledge of local networks of support agencies and how to access them; and
- skills as a facilitator and co-ordinator.

Main responsibilities of a disability services adviser would include:

- raising awareness of disability issues leading to a greater understanding of the needs of disabled people by management and staff. This in turn, should lead to more informed identification of the steps that need to be taken to promote accessibility of the service. Taking these steps, where it is reasonable to do so, should help to avoid the potential for litigation under the DDA and lead, consequently, to a more positive image of the service; and
- providing an information link to staff and an advisory role for management on relevant policy and procedures in areas such as human resources, quality, estates, training etc.

### **Where should a disability services adviser be located?**

There is a case for a post-holder, or part of the time of a post-holder, to be dedicated to disability services adviser responsibilities at different points within the NHSiS. For example:

#### **Health Board/commissioner level**

Lead responsibility should be assigned to a senior manager who could establish a group of disabled people and carers whose remit would include influencing strategy and planning, and arrangements for monitoring and reviewing service plans.

#### **Acute NHS Trust**

Within an acute hospital there is likely to be enough work to justify a full time post if the responsibilities include human resources and estates as well as patient

services. Alternatively, responsibilities might be shared between different departments under the lead responsibility of a senior manager.

### **Primary Care Trust**

Potentially a full-time post, especially if the role is integrated with social services. There may also be scope for developing a partnership with an existing disability information service in the community. Within general practice the role of disability services adviser might be part of the responsibilities of the practice manager, or this could be shared between a number of practices within the Local Healthcare Co-operative. Other primary care practitioners need to consider how this role should be discharged within their own service.

### **Resource implications: costs and benefits**

The development of designated posts with disability services adviser responsibilities has resource implications that need to be considered:

The costs incurred in funding the posts need to be off-set against possible savings such as in the retention of staff who have become disabled during their working lives.

The costs of the post (or part of a post) can be spread across departments and agencies who will have a share in the post holder's expertise.

There is scope for maximising value for money by entering into partnerships with external agencies which may wish to invest in the advice and training developed by the disability services adviser.

### **Working example of co-operation between agencies.**

**Borders Health Board**, in association with the Social Work and Housing Departments, jointly fund a Disability Development Project under the management of the Borders Disability Forum, a local user-led voluntary group. The Health Board has pledged financial support for the provision of a Development Worker post, which will be managed by the Forum. The objectives of the Forum are:

- To raise awareness about disability matters;
- To promote a network in order to represent interests across the Region;

- To act as a focal point for consultation and action on issues;
- To seek representation on Council committees and other bodies;
- To provide information about issues of concern to disabled people;
- To provide support and training.

### **3. Approach and awareness**

#### **3.1 Implications of disability**

This section addresses some of the practical implications for those working with disabled people, whether as patients or colleagues. Most people working in the Health Service will meet disabled people regularly and need to be aware of obstacles that can, unwittingly, be put in their way. It is important to create an enabling environment which benefits everyone, incorporating a quality approach to diversity and equality. Many people are concerned that it is the environment that disables them – and this is as commonly through staff awareness and attitudes as through physical access and facilities.

There are a wide variety of impairments that can cause disability, which can vary in severity and complexity. Some people are born with impairments while others

acquire them at a later stage, either because of an accident or because of a medical or other condition. Some impairments will remain unchanged, some will fluctuate and others will steadily deteriorate. Some people live with multiple impairments. Individuals will have different perceptions about their impairment and how it affects their life.

Not all impairments are obvious to other people; many impairments are hidden and/or intermittent. Not all disabled people use a wheelchair, carry a white stick, or display any obvious sign that they have an impairment.

The term 'sensory disability' refers to a visual and/or hearing impairment; dual sensory impairment refers to a combination of visual and hearing impairment. People, particularly as they get older, may have more than one impairment or disability.

### **3.2 Attitudes**

This section is designed to help non-disabled people improve their communication with disabled people. It covers the language we use, people's perceptions and attitudes, and some simple advice.

The way in which people respond to and treat disabled people has a major effect. Attitudes influence the way we behave, and can either help to reduce the disabling effect of a person's impairment, or can intensify it.

#### **Medical and social models of disability**

Different approaches to defining and understanding disability have been dominant at different times. A distinction is often drawn between 'medical' and 'social' models of disability.

The medical model focuses on individual impairment, and on the treatment and other interventions which may be employed to reduce the impairment.

Today there is a different approach within society to equality of opportunity, and this is reflected in the social model of disability.

The social model emphasises the disabling effects of the environment rather than individual impairment. The social model evolved from the development of rights for disabled people, and originated from the disability movement. Many of the key ideas have acquired a much wider recognition – such as in

the concept of independent living whereby people make meaningful choices and exert control over their lives.

### 3.3 The use of terms

Terminology is important, because words reflect our attitudes and beliefs. However, some of the terms we tend to use in the Health Service may not reflect how some disabled people see themselves. Using the right words matter. This is not about 'political correctness', but using words and language which disabled people find acceptable, are not judgmental and do not reinforce negative or stigmatising images and discriminatory attitudes.

There has been a major change over the last couple of decades in the words that are considered preferable by disabled people themselves, and in those which are regarded as inappropriate and offensive. The following preferred terms, most of which also appear in Capability Scotland's 'Plain Talking' leaflet are suggested:

<b>Don't say</b>	<b>Do say</b>
The word 'disabled' as a noun (e.g. "the disabled") This implies that all disabled people are the same, and are a separate group from the rest of society.	Disabled people/people with disabilities.
the deaf.	Deaf people, if they are profoundly deaf, or people with impaired hearing, when people have some loss of hearing, or deafened people, if they have lost their hearing later in life (this term does not include people who have lost their hearing through age).
the blind.	Blind people, partially sighted people, or people with a visual impairment.
Handicapped/cripple	Disabled/has a disability

Call people by their conditions; for example someone is ‘a mongol’ or ‘a Spastic’.	People who have Down’s Syndrome or have cerebral palsy or have a learning disability.
Mental handicap.	Learning disability or learning difficulty.
Mental illness/mentally ill.	Person with mental health problems, mentally/ emotionally distressed person.
Words and terms that reinforce negative images or which are dehumanising. For example, don’t say ‘victim of’ or ‘suffering from’.	‘a person who has.....’ or ‘a person with....’.

People with disabilities have relationships and families; work; experience frustrations and ambitions, just like everybody else. The following general principles and ways of behaving should help counter the discrimination experienced by disabled people:

- Always see a disabled person first and foremost as a person to be respected and valued, rather than in terms of their disability.
- Meeting a disabled person’s needs should be seen as normal practice, rather than a problem to overcome.
- Listen carefully and give people time to respond to what you say. Talk to the person, not about them.
- Ensure people are able to maintain their dignity, self-respect and privacy. If you have to ask questions about their impairment that are relevant to the situation, then do it discreetly and privately. Don’t make assumptions about the people who are with them – they may simply be accompanying the patient but on the other hand could be an interpreter or a paid personal assistant.
- Being physically unable to do something does not necessarily cause dependency. People may simply require services to be provided differently. It is only if services are not accessible that they experience greater dependency.
- Some people experience physical contact as an intrusion of their personal space and will be upset by contact with people they do not know. Be cautious in your approach and find out if they object to being touched.

- In addition to general awareness of disability it also helps to know how best to support people who have specific impairments, and how to communicate most effectively with them. Annexes A and B offer specific advice on this.

### **3.4 People with mobility problems**

Not all people who have physical disabilities use wheelchairs. Some use other mobility aids (such as walking sticks), and people may use wheelchairs for different reasons. Some people use them some of the time because they find walking difficult or painful, while other people use wheelchairs all the time because they are essential for their mobility and they would not be able to get about without them. Some people are able to get out of their wheelchair and move to a bed or chair, whereas other people cannot do this independently or without using particular equipment. All wheelchair users are different. Points to bear in mind include:

- People are not 'wheelchair bound' - they are permanent, part-time or occasional wheelchair users. A wheelchair enables people to get around, although they may be restricted by environments that have been designed only for non-disabled living and are not readily accessible by wheelchair.
- A person's wheelchair is often an extension of their person, and as important and personal to them as their shoes or car. Do not touch it, lean on it or move it without asking permission, even if they are not using it at the time.
- When talking to someone who is in a wheelchair, try to place yourself at their eye level by sitting or kneeling by them, and do not stand where they have to look up or turn around to maintain eye contact.
- Do not assume that someone who is using a wheelchair will want you to push them - ask them if they need any help, particularly if there are obstacles in the environment (such as doors, kerbs, slopes or rough terrain or floor surfaces) which they may find awkward.
- To ensure the health and safety of everyone involved, staff should be trained, probably by the occupational therapy department or the local wheelchair service, to follow correct procedures when assisting wheelchair users. This should include knowledge and adherence to the Trust's policy on the maintenance and use of wheelchairs (such as the routine use of footplates) and to all aspects of supporting individual users, including lifting, moving and transferring. Do not forget that everyone is different – the best people to ask whether they need any help with their wheelchairs are the users themselves.

- Similar principles apply to assisting those who use other mobility aids such as sticks, walking frames or rollators. They are equally personal to the user and should not be removed or exchanged without their permission.

### 3.5 Deaf and hard of hearing people

Deaf people are not all the same. Some have no hearing at all, while others have different degrees of hearing loss. Most deaf people you are likely to meet will be older hard of hearing people who may or may not use hearing aids, and may rely largely on lip-reading and residual hearing.

It is estimated that there are around 8.7 million deaf and hard of hearing people in the UK – this means that one person in seven in Britain has a hearing impairment. Hearing impairment is not just a feature of old age; in the UK 1,000 children a year are newly diagnosed as having a permanent hearing impairment.

Many deaf people rely on lip-reading, if only unconsciously, whilst about 60,000 in the UK use British Sign Language (BSL) as their first or preferred language. Deaf people whose first language is BSL may have difficulties with speech or written language skills due to lack of educational opportunity and appropriate communication support. People who are severely deafened through accident or illness may rely on a combination of communication techniques, including written information. In all cases the important thing is to ask the deaf person about their communication requirements and to respect their choice.

- A **hearing aid** does not restore normal hearing. It amplifies all available sounds, so it can often be difficult to distinguish conversation from background noise, particularly in areas where there is a lot of human or mechanical activity.
- An **induction loop** is an electronic device to assist hearing aid users. When used in conjunction with the “T” switch on the user's hearing aid, it cuts out background noise and amplifies sound via a microphone. To protect confidentiality in reception areas, the loop should only be installed at the desk. **Portable miniloops** are also available and can readily be moved between locations by the user. Meeting and conference rooms can have a room loop that is accessible to all hearing aid users in the vicinity.
- **Text phones** are sometimes referred to as Minicoms, which is a trade name. The text phone is an electronic keyboard that enables deaf people to access the telephone system. Text phones can communicate directly with one another, but in order to communicate with voice telephones, it is necessary to relay through Tynetalk, the national text phone relay service. The access number for hearing people using voice telephones is 0800

515152. An operator transfers the call, typing the spoken message and relaying the response back to the hearing caller. Typetalk operators undergo training and abide by a code of conduct covering confidentiality.

Not all deaf people are able to lip-read. This requires intensive concentration and can be tiring when it has to be maintained for long periods of time. When talking to a deaf person observe the following principles:

- Ask the deaf person about ways to communicate which suit them best.
- Make sure the deaf person is looking at you before you speak. If necessary, attract their attention by touching their arm or shoulder.
- Ensure your face is well lit. Do not stand with your back to a bright light source such as a window or lamp.
- Reduce background noise and visual disturbance as much as possible.
- Look directly at the deaf person. Speak clearly and at an even pace. Do not shout or exaggerate your lip movements. Use natural gestures and facial expressions to support what you are saying.
- Stop talking if you have to turn away or write notes.
- Do not wave your hands about or cover your mouth. It can be difficult to lip-read people whose face is obscured by hair. It helps if long hair is drawn back from the face, and beards and moustaches are kept well trimmed.
- Allow time for the deaf person to absorb what you have said, and check that they have understood. If there seems to be any misunderstanding relax, repeat what you have said, rephrase (use plain words - avoid jargon). Write things down if needed, but ask the deaf person first.
- Where the deaf person uses British Sign Language check if they require a BSL interpreter for meetings, interviews or consultations. Qualified BSL interpreters should be used in any situations where complex and/or technical information needs to be communicated such as in formal consultation with medical staff. Videotelephony linked to remote on-line BSL interpreters might be an option to consider. Some patients prefer standard signed English (SSE).

- When using an interpreter you should speak directly to the deaf person and not to the interpreter. The interpreter facilitates equal communication between deaf and hearing people and should not be perceived as the deaf person's 'helper'. It is usual practice for the interpreter to stand or sit beside you, facing the deaf person.
- For medical consultations it is essential that someone with the proper level of interpreting skills is used and not a member of staff with basic knowledge of BSL.
- Hospitals and health centres should maintain an up-to-date list of accredited interpreters they can call upon.
- Qualified and accredited interpreters minimise the risk of misunderstanding. They are required to hold public liability insurance and are bound by a professional code of practice which includes confidentiality about assignments.
- The Scottish Association of Sign Language Interpreters hold the Register of Interpreters for Scotland and can offer advice on interpreters for deaf people, including some advice on deafblind interpreters and lip-speaking. There may be a local independent interpreting service, details of which will be available through disability advice centres or the local sensory impairment service (see appendix for addresses).
- Letter headings, leaflets and information sheets should include text phone, fax and e-mail numbers to facilitate responses from deaf people. Additional information and advice can be obtained from RNID Scotland whose 'Louder than Words' charter is available on request.

### **3.6 Blind and partially sighted people**

The RNIB estimates that there are over one million blind or partially sighted people in the UK, and a further 700,000 who have difficulty reading newsprint, even when wearing glasses. Fewer than five per cent have absolutely no vision at all, and most are partially sighted or have some perception of light and dark. In Scotland alone there are approximately 22,000 people who are registered blind, and a further 9,700 people are registered partially sighted. 6,400 of those people registered blind and 2,500 of those people registered partially sighted have an additional disability. The incidence of many eye conditions increases with age, and because of the ageing of the population the total numbers of people with vision loss can be expected to increase substantially over the coming years.

Some visually impaired people carry a short **white stick** (like a white walking stick). This is called a symbol cane and is mainly intended to indicate to other people that they cannot see very well. Other blind people may use a long cane to scan the area in front of them and find obstacles at low level, but only around four per cent of blind and partially sighted people have had long cane mobility training.

Only a minority of blind people use a **guide dog** (in the UK there are 4,500 working guide dogs at present). Many blind people will not use any mobility aid and will rely instead on their residual vision. However many of these people will find it difficult to move around independently in this way. It is untrue that visually impaired people develop a 'sixth sense' to compensate for their loss of sight. Nevertheless audible and tactile clues can be useful in assisting visually impaired people.

When meeting or offering to support a blind person it will help them if you follow these guidelines:

- Introduce yourself by name, even if you know the person (they may not immediately recognise you just by your voice).
- When you offer to support a blind person ask them exactly what they need you to do. If you are guiding them they will usually want to take your arm, and you should guide them rather than attempt to lead them or propel them. Do not drag someone by holding onto their clothing. Give adequate warning of any steps or other hazards that you approach. When entering unfamiliar surroundings or going somewhere for the first time describe the environment in terms of furnishings, obstacles, and any other people who are present.
- If you are doing things which will affect the person (for example, preparing to give them an injection, or leaving food for them on a tray), tell them what you are doing. Make sure you announce when you are leaving the room and how long it will be before you return or someone else comes in, so they know whether or not they are alone.
- Ensure that any other staff who enter or leave the room also announce their arrival and departure.
- If the person has a guide dog do not interfere with it doing its job, and always speak to the person, not the dog. Do not touch, feed or distract it; when a guide dog is wearing its harness it is at work and should not be treated like a pet.

- Information for blind people, most importantly information of a sensitive and confidential nature, should be provided in the patient's preferred format (for example, auditory or tactile forms). Telephone help lines can be useful, as can information recorded onto audiocassette (further information and advice on where to source transcription into alternative formats can be obtained from RNIB Scotland. See Appendix II).
- Many visually impaired people can read large print - 16 point text is a recommended standard (the RNIB Scotland booklet "See It Right" gives guidance on clear print).

The Braille alphabet is a series of raised dots that are recognisable by touch. Rolled up Braille documents can be sent through the post free of charge. Enlarged photocopies can be used in emergencies. Text can easily be converted by computer from a floppy disk. To obtain a copy of this document on disk, please see inside front cover.

### 3.7 Deafblind people

A person is regarded as deafblind if he/she has a severe degree of combined visual and auditory impairment resulting in problems of communication, information and mobility. Deafblindness is a particular impairment and, because it is relatively rare, the needs of deafblind people, which are more complex than other disabled people, are often overlooked. They often present as sighted hearing people, or as people who have a single impairment. It is extremely rare for an individual to confess to being deafblind. Great sensitivity is required. It is unusual for people to be congenitally deafblind, but many people (especially those who are elderly) will experience some impairment of both hearing and sight. Some 1,500 people in Scotland who are registered blind are also deaf, with an additional 500 people registered partially sighted who are also deaf.

A deafblind person may carry a **red and white cane**, or wear a red and white armband, as an indicator of their disability. Deafblind people may also need to be guided differently from blind and partially sighted people, since you cannot verbally warn them of hazards. Check with the deafblind person how they prefer to be guided. Always give the deafblind person some indication of your presence as they may not be aware of people approaching.

Deafblind people use a whole range of communication methods, often employing more than one method at a time to receive or give information. You should always check with the deafblind person what is their preferred method of communication.

**Deafblind manual** is a tactile communication method used by some deafblind people. It involves spelling out words onto the left hand of the deafblind person using a manual alphabet, which comprises a tactile sign for each letter. The basic approach can be learned in about half an hour, but needs regular use to maintain familiarity. The deafblind manual is also often called finger spelling. Service providers should be aware how to book a deafblind manual interpreter for a deafblind person. Other methods include small frame signing (within a small area close to the person's face) and hands-on signing (where the person feels the signs being made by the interpreter).

**Visual Frame or Hands-on British Sign Language** involves a skilled interpreter providing a voice-over for a deafblind person and interpreting to them what is being said.

**Block letters** involves tracing block capital letters to spell words onto the palm of a deafblind person. Deafblind people who are skilled in use of the English language may accept brief information using this method.

**Communication using residual sight and hearing.** Some deafblind people continue to use speech, hearing and sight to try to communicate. This can be assisted by ensuring **good lighting** is available and is directed at the speaker in a **quiet room** with a **loop system**. **Plain English** should be used and information **written down** using a thick, black felt tip pen on white paper printed in large clear lower case letters.

Some deafblind people use a modified form of **British Sign Language (BSL)**.

Other **practical steps** can be taken to assist deafblind people in identifying people, objects and locations. This often involves the use of tactile '**clues**' or '**objects of reference**' associated with a particular activity, for example handing a deafblind person a spoon to indicate mealtimes.

Some deafblind people may be able to use **Typetalk** (see above under item 3.5 “Deaf and hard of hearing people”) with an adapted text keyboard and braille printout.

NHS MEL (1998) 4 drew attention to the responsibility of service providers to have appropriate arrangements in place to ensure that deafblind people are afforded the services of a guide/communicator when they attend hospital or GP surgery. Any communication is of value to deafblind people and staff should be encouraged to use whatever skills they have to alleviate the isolation a hospital visit/GP visit may cause.

### **3.8 People with communication difficulties**

Some people have speech or communication difficulties that are associated with deafness. Others can develop speech and comprehension difficulties as the result of a brain injury, or neurological damage caused by a stroke. This is called **dysphasia**. It causes problems in both understanding and speech because words no longer convey meaning. People are affected to different degrees; some may be able to understand most of what is being said to them but be unable to find the words to respond. In severe cases people have no comprehension of spoken or written words.

Because of their difficulties with communication people with dysphasia are often treated by others as if they were stupid, or people make inappropriate assumptions about the reasons for their behaviour - slurred speech for example can give the misleading impression that someone is under the influence of alcohol or drugs. When communicating with someone with dysphasia or other communication difficulties talk to them slowly in short clear sentences using simple words. They may not be able to write down what they want to say (as, for example, a deaf person might do), because dysphasia affects understanding of language.

Other communication difficulties may be associated with **dyslexia**, which can make it difficult to make sense of written and spoken information, and is sometimes also associated with problems in putting spoken words together. One person in 25 is affected but the type of difficulty varies, so do not make assumptions. The following can be helpful:

- As far as possible give information that the patient needs in advance.
- **Writing**

Don't expect forms to be completed in your presence.

Spelling may be erratic and handwriting hard to decipher.

- **Spoken information**

Do not give too much information at once.

Ask direct rather than oblique questions.

Allow thinking time before the response.

- **Reading**

Written material should be well-spaced, of a reasonable font size and justified left only.

Avoid glossy white paper that could appear to glare; pale colours often offer a good contrast.

- **General**

Use landmarks in addition to left/right directions.

Be aware of possible distractibility and limited attention span.

Try to establish whether a person with impaired speech has lost verbal understanding. The best way of communicating will vary accordingly. Use appropriate gestures and facial expressions. Do not shout, but try to reduce background noise. Be patient and do not rush someone who is trying to communicate. Repeat instructions or questions as necessary. Do not give too much information at once.

### **3.9 People with learning disabilities**

It is not always obvious that a person has a learning disability. People with learning disabilities may also have additional physical and/or sensory disabilities. It is estimated that 20-30 per cent of people with learning disabilities also have a physical disability, and 15-30 per cent have epilepsy. Approximately 30-40 per cent of people with a learning disability also have some degree of sensory impairment that may compound their learning disability. The physical health needs of people with learning disabilities are often overlooked because of the difficulties they may have in drawing attention to or communicating these needs.

**Autism and Asperger Syndrome.** Autism is an invisible disability affecting around 36,000 children and adults in Scotland. People with autism often find it difficult to understand the spoken language or the meaning behind information. For young children the difficulty in lack of understanding of the world around them and problems of coping can produce behavioural problems. A doctor's surgery or hospital unit can be extremely traumatic and waiting in a room with others can be very upsetting both to the individual and to other patients. The National Autistic Society can provide further information and offer awareness training for staff (the address is listed in Appendix II).

Mental health problems can also accompany learning disabilities and it is estimated that 6 per cent of people with learning disabilities have severe challenging behaviour. However the label of 'challenging behaviour' is sometimes mistakenly applied to people with learning disabilities who have limited

communication skills and whose behaviour is an expression of frustration because they feel they are not being listened to, are being mistreated, or being ignored. Many people with learning difficulties have been badly treated at some time in their lives, ranging from bullying and name calling to very serious abuse and care should be taken not to reinforce existing feelings of alienation.

- First find out how best to communicate with the disabled person and their carer. If possible talk directly to the person with learning disabilities (including the use of signs and symbols), rather than to their carer, personal assistant or advocate.
- Ask the person what support, if any, they need (for example, do they need an interpreter or advocate?).
- Make the person feel welcome and respected. Don't patronise them and don't speak to adults with learning disabilities as if they are children.
- Avoid the use of jargon - use plain language with familiar words and short sentences.
- Some people may welcome information provided on audio tape, which they can replay at a later stage as often as necessary.
- It can be useful to support verbal or written information with drawings or pictures.
- Some people with learning disabilities communicate using systems of signs and symbols. Several different systems are in use, such as 'Makaton'.
- Check for understanding and be prepared to repeat information if requested.
- Provide time and opportunities for questions.
- Some people with learning disabilities will also have sensory impairments. They should be asked about their preferred communication and support needs.

### **3.10 People with mental health problems**

Like physical illness there are many different forms of mental illness and surveys of self-reported illness suggest that approximately one in four adults experience some level of mental health problem. Often these involve feelings of depression, anxiety and confusion - all of which most people get at some time or another,

particularly after a distressing life event such as a bereavement. But with mental illness these feelings occur to such an extent or over such a long period that they make it difficult for a person to cope with everyday life. There is now a much better understanding of mental illness so that we can investigate problems and treat them more effectively. But we do need to remember that, like everyone else, people with mental health problems have physical illnesses too, which may be unconnected with their mental illness.

Mental illness severe enough to need professional assistance is as common as heart disease and three times as common as cancer. It is one of the three national clinical priority areas for the NHSiS. One in ten people suffer from it and up to one in five children.

Despite the widespread incidence of mental health problems, the idea of 'mental illness' remains remote from many people's experience and often conveys images associated with more severe conditions, such as schizophrenia. People who have a mental health problem are very rarely dangerous, despite well publicised cases that may cause fear and misunderstanding among the public. Like any other illness people with mental health problems should be treated as individuals with unique circumstances, not according to others' perceptions of their illness.

Features of different mental illnesses include:

*Psychosis* - At some stage in their lives many people develop psychotic symptoms which mean that their ability to distinguish between what is real and what is imaginary is seriously affected. Psychotic disorders include schizophrenia and manic depressive illness.

*Schizophrenia* - this affects the most basic functions that give people their sense of individuality, uniqueness and direction. It can cause them to hallucinate (eg hear voices), develop feelings of bewilderment and fear, and to believe that their deepest thoughts, feelings and actions may be known to or controlled by others. People often become withdrawn and lethargic.

*Manic-depressive illness* (also known as bipolar affective disorder) - this often causes profound changes in mood from severe depression and lethargy to elation and over-activity. These severe mood swings significantly affect a person's ability to function, concentrate and participate in their normal personal relationships. These mood swings can affect people's judgement so that they make decisions or act in ways they regret later.

*Neurosis* is a broad term previously used to describe anxiety, stress-related disorders and depression, but it has been used in such a vague way for so long that it is now used less and less;

*Depressive disorder* – this is a condition in which feelings like depression, loss of interest, reduced energy, suicidal thoughts and sleep and appetite disturbances go beyond normal mood changes. Children get depressed too.

*Anxiety states* – these include phobic, panic and general anxiety disorders in which anxiety symptoms such as worry, tension, over-breathing, and giddiness cause significant distress and disability.

*Dementia* – this leads to a decline in a person's intellectual functioning and memory. People, particularly older people, can become very confused; their memory for current events is impaired but they may be able to recall events from many years before with great clarity.

The label of mental illness is one that is often perceived as stigmatising and people with mental health problems may therefore be reluctant to disclose their condition.

For mainstream health services the following questions might need to be considered:

- Is the person's mental health a relevant consideration? The need to alert staff to the person's particular condition must be weighed alongside other considerations, including the person's right to confidentiality and privacy. People should be aware if others are informed of their diagnosis, and this should only happen after discussion.
- People with mental health problems are not 'stupid'. They may behave in different or unusual ways, or exhibit fears and anxieties that others regard as unfounded, but this doesn't mean that their intellectual functioning is impaired.
- Someone with a mental health problem may be perceived by others as 'difficult', or may not be taken seriously. If someone behaves in a way that seems unusual or different, don't assume that they are deliberately doing so, or that they are trying to cause trouble. Keep calm and treat them with respect and dignity. It may provide valued reassurance and familiarity if there are staff present who know the person and who have dealt with them before.

- Don't assume that any reported physical symptoms are necessarily associated with a person's mental health problems. They are real and distressing for the patient, whatever the cause, and should not be dismissed.

### **3.11 Hidden disabilities**

It is not always apparent that a person has a disability and some are more 'hidden' than others. Disabilities such as dyslexia, epilepsy, multiple sclerosis, autism, diabetes, asthma or incontinence may not be evident but will nonetheless have implications for the needs of a person using the services of, or working within, the NHSiS. Do not make assumptions about whether or not a person has any disabilities.

### **3.12 Carers**

While the primary focus of this good practice guide is on disabled people it is also important to be aware of the significant role of carers and the way in which care provided for disabled people is significantly improved through the access which carers' facilitate.

The term 'carer' has become widely used by professionals and policy-makers over the last decade or so. It is generally used to refer to people (usually close relatives) who care for someone (usually without payment) who needs various kinds of help and support. There are approximately six million people in Britain who are carers. They are likely to be the parents, children/children in law, spouse or sibling of the disabled person. Many carers, particularly elderly spouse carers, are themselves disabled.

However do not assume that someone accompanying a disabled person is necessarily their carer. They might not be - they could be a friend, a neighbour, a volunteer helper, a paid personal assistant or even a taxi driver. Check first with both the disabled person and their companion and do not automatically involve people in discussions or situations as this may not be appropriate. It is important to ask the disabled person if they want their carer to be present at any consultation. The carer should also have the opportunity to be seen separately.

People who are carers often do not recognise themselves as such and might not understand the use of the term 'carer'. It is well documented that caring and supporting another person can be stressful emotionally, psychologically and physically. Carers often have to deal with feelings of isolation, frustration, anger, guilt, grief and embarrassment. By providing accessible care the NHSiS can help to minimise these feelings. Carers may suffer from back injuries and other

physical strains from lifting and may experience stress-related illness, lack of sleep and exhaustion.

Although carers are most likely to be middle-aged, 20 per cent of them are aged at least 65 and this is true of 27% of carers who are spending at least 20 hours a week as a carer. (Office for National Statistics, Social Survey Division, 1998, *Informal Carers*, London: The Stationery Office). It is often a crisis in the health of a carer that leads to a disabled person being admitted to hospital.

The relationship between a carer and the person they are caring for is not necessarily an easy one and their needs will not always be complementary. A disabled person may experience the relationship as claustrophobic or controlling and might prefer not to have them acting as carer. These difficulties can be particularly apparent in relationships between parent carers and their, often adult, children.

It should be remembered that sometimes it is the carer who is attending the clinic or hospital for treatment and the disabled person is accompanying them. This may be either to help them (many elderly carers and their adult learning-disabled children, for example, have a mutually dependant relationship) or because they cannot be left on their own.

### **Carers' needs**

Disabled people and their carers should have choices. Carers' needs are often simple and they are usually the best placed to determine what help and support they need.

Managers and professional staff must listen to the patient and to the carer. Consulting carers as a group can be difficult, either because they do not always know they are carers or because they are too busy caring to fill in forms or come to meetings. Monitoring complaints is not the best way to find out about carers' needs.

The 1995 Carers (Recognition and Services) Act entitles carers to an assessment by the local authority of their "ability to provide and continue to provide care". The result of the carer's assessment must be taken into account when the local authority is deciding what services to provide to support the person being cared for. Policy and practice guidance also underlined the responsibilities of NHSiS staff in collaborating with local authority staff in implementing the Act and in informing carers of their rights to request an assessment. (Social Work Services Group No 11/1996, Carers (Recognition and Services) Act 1995, Policy and Practice Guidance).

After a sudden disabling accident or illness, a newly disabled person is likely to need immediate counselling and advocacy. This will also be the case for the carer. Carers, or potential carers, will probably need someone in the hospital to help them cope with the shock and to make the decision on whether or not to take on caring responsibilities.

The needs of carers and disabled people are linked, but some of the things the carer wants may be in conflict with what the disabled person wants. If these conflicts are not addressed the potential for a stressful or even an abusive relationship may develop.

Carers can feel isolated, guilty, and disempowered, and be seen by service providers as a problem, rather than partners in care. Networking is important for morale, information and ideas.

Children (even very young children) sometimes find themselves as carers to a disabled parent (it has been estimated that there are 40,000 child carers under 16 years of age). A child may become used to helping a parent and acting as an interpreter, but his/her wishes may be contrary to the parent's wishes. It is unprofessional, inappropriate and exploitative to place a child in a position of responsibility where they are party to information of a personal or intimate nature. Some children may sometimes hide the amount of care they are providing for fear that they will be seen as 'at risk' and likely to be taken into care.

The carer may feel that they are marginalised while the disabled person is in hospital. On the other hand, do not assume that a carer will remain responsible for the disabled person's needs, whether a relative or not. It is important that they are kept in the picture and that they are appropriately involved in discharge planning.

#### **4. The environment**

## 4.1 Is it accessible or disabling?

Awareness of the needs of disabled people has implications for many areas of the NHSiS. One of the most tangible of these is the physical environment of hospitals and other health care facilities that determines whether they are accessible or disabling.

When new buildings are being designed there is much that can be done to avoid creating potential barriers. It is obviously easier (and cheaper) to address such matters in new facilities than it is to redress poor design when buildings are being refurbished. NHSiS premises that have been built since 1991 must comply with Part T of the 1990 Building Standards (Scotland) Regulations.

There is a wealth of guidance available on design issues and thinking should not be limited by the few examples given below. It is essential to obtain the appropriate expert advice, such as may be available from the Joint Mobility Unit, RNIB Scotland (see Appendix II for address).

**Estates departments should refer to Part T of the Technical Standards for compliance with the Building Standards (Scotland) Regulations 1990 which gives exact specifications to allow access for disabled people to buildings and facilities. However this should be regarded as a minimum standard and may not necessarily address many issues regarded as best practice. Disability access guidance (Scottish Health Facilities Note 14) has been published by the NHSiS Estates Environment Forum. SHFN 14 complements a further Estates Environment Forum publication – Access audits of primary healthcare facilities (SHFN 20), which enables detailed access audits to be conducted on NHS primary healthcare facilities. The guidance is based on Part T of the Technical Standards but also addresses additional access issues that need to be considered.**

## 4.2 Transport, cars and parking

- There should be conveniently placed ‘dropping off’ and collecting points designated for disabled people, especially as some disabled people will not be able to use public transport.
- Access to parking areas that are barrier controlled and have an intercom for communication with the control office will present a barrier to deaf and hearing-impaired drivers and those with speech difficulties.
- Car parking spaces for drivers with disabled badges should be close to the appropriate entrance, and the parking bays should be suitably sized. It is

essential that these designated spaces are protected from misuse by non-disabled patients or staff members. It is good practice to exempt disabled people from parking charges.

- Some disabled people may need help in transferring from their car to a wheelchair before they can get into the hospital.
- A blind person may require an escort into an unfamiliar building. Ensure that necessary arrangements can be made in advance.

### **4.3 Building fixtures and fittings**

Routine fixtures and fittings, such as light switches, door bells and handles, telephones, coat hooks and notice boards, all need to be in accessible locations, highlighted from the background against which they are located, at a suitable height for wheelchair users, and without being hazardous to other people. Entry phones are often positioned too high for anyone who is seated and such a system creates a further obstacle for deaf people if it relies solely on audible communication. The following list identifies other aspects of building interiors that need to be considered when considering access:-

- **Windows or glass screens on reception counters.** These can reflect the light and cause difficulties to people with impaired vision; they can also make lip reading difficult for deaf people, and hard of hearing people may be unable to hear anything through the screen.
- **The height of the reception counter.** If the counter is at a level that assumes people will always approach it on foot it will be too high for those in a wheelchair. A section at the correct lower level will help (while ensuring there are no projections underneath that would prevent a wheelchair user from utilising the counter).
- **The design of doorways.** Door return springs make doors very heavy and, subject to the requirements of fire officers, may need to be adjusted to make opening easy for disabled people, ideally by either pushing or pulling, and with handles within easy reach, or incorporating automatically released hold-open devices. Doors that are designed not to close completely can be a particular hazard to blind people. Doorways should be wide enough for wheelchairs, or for someone to pass through alongside a companion or a guide dog (on a double doorway, at least one side should be wide enough).
- **Automatic doorways.** These can be helpful so long as it is clear which way the doors operate (with visual and audible warnings) and people are not startled by doors which suddenly open towards them. Automatic

sliding doors are preferable to those that swing or rotate, as they allow unobstructed access. Other mechanised devices, such as escalators or moving walkways, can be hazardous for some disabled people and visually confusing for people with limited vision. If these are in place, non-mechanised alternatives should be available.

- **Ramps.** For lengths of 10-15 metres ramps should provide an even slope of 1 in 15 to 1 in 20. For ramps not exceeding 5 metres the slope should not exceed 1 in 15 to 1 in 12. Handrails should be provided and resting-places may be required on longer ramps. Temporary (or moveable) ramps may be used and should comply with the spirit of the building regulations. These may be inaccessible to people using motorised (three wheeled) chairs. Approaches to ramps need to allow adequate turning space.
- **Lifts.** To be fully accessible to disabled people lifts need to have Braille pads alongside the usual keypad; visible and audible warnings of floor levels and doors closing/opening; visible indicators to show that any call for assistance is answered; appropriate delays on door operation; and accessible buttons.
- **Stairs.** The space underneath a flight of stairs can be particularly dangerous if it is not boxed in. People with impaired vision may otherwise be unaware of any obstacle at head height. The approach of stairs needs to be indicated by a change in floor texture, and the edges of each stair tread should be clearly marked. Handrails should be fitted.

#### 4.4 Public spaces

Getting about hospitals, particularly those on large sites, can be confusing for many people and these difficulties can easily be compounded for disabled people. The following are important considerations for minimising the difficulties that might be encountered by disabled people:

- **Easy access around the building** - hold-open devices for fire doors which allow passage through corridors.
- **Signposting and way finding.** Clear signposting in NHS buildings is essential in helping people to find their way around. It is important to ensure the removal of obstructions and to design environments that can be navigated safely by disabled people. Are signs clear and simple? Are signs easy to read and sufficiently large? Are they well lit, with non-reflective surfaces and good colour contrast? High visibility and Braille or other tactile signs may also be appropriate. Colour coding or pictorial signs

representing different departments can also be helpful for people who have difficulties with reading or when English is not a first language.

- **Use of floor textures.** Changes in floor textures can indicate a change in direction or route. Many hospitals use coloured lines on floors to indicate routes to various departments but for people with limited vision this will be less helpful than following a path along a textured surface. Different surfaces can mean different things, for example a ribbed floor surface may signal the approach to a flight of stairs - but this approach needs to be sensitive to all groups - some people in wheelchairs will find some tactile surfaces difficult to move across.

*Building Sight: a handbook of building and interior design solutions to include the needs of visually impaired people*, published by RNIB. This book demonstrates how blind and partially sighted people may perceive the world about them, and shows how simple and low cost solutions can make the environment more accessible.

- **Toilets.** Are these adequately signposted and accessible for both males and females at the same time? Unisex wheelchair accessible toilets are essential; wheelchair users are often accompanied by a family member, spouse or friend. If the only accessible toilet is located in the ladies or gents it is embarrassing and frustrating for those needing assistance from an opposite gender companion. It may be necessary to provide separate toilets for independent use by wheelchair users. A toilet designed for independent use is not suitable for assisted use. Advice on accessibility of facilities is contained in NHS Health Building Note 40 Volumes 1 – 4, which should be read in conjunction with Health Building Note/Scottish Planning Note 40 Volume 5: “Scottish Appendix” which can be obtained from The Stationery Office. This is also an area in which first-hand consultation with disabled people should be undertaken to ensure the accessibility of facilities.
- **Wheelchairs.** While some people will attend appointments in their own wheelchairs others will need to be able to use a wheelchair while at the hospital, particularly if they need to move between locations or departments. Clearly distinguished and protected obstacle-free passages should be maintained to provide easy through-routes for wheelchair users and other patients.
- **Telephones.** Public spaces, including waiting areas, may include pay-phones for patients. Many people with hearing difficulties are able to use a telephone if it is suitably amplified and fitted with an induction loop coupler for hearing aid users. However these will be of no help to patients

who are profoundly deaf and there should preferably be a dedicated text phone line (see Section 3) with the number well advertised and highlighted in the telephone directory. Staff should be trained in text phone use. Wheelchair users will need telephones to be located at an appropriate height. A seat by the telephone will be welcome for some people.

## 4.5 Waiting areas

While waiting for appointments people want to be comfortable. This has implications for seating, for facilities and for the way in which appointments are controlled or announced. The following considerations are particularly important:

### **A calm and pleasant environment?**

Is the environment a calm and pleasant one? Waiting areas do not need to be uncomfortable places and many hospitals have developed facilities that include informal coffee shops and lounges for the use of both in-patients and out-patients.

Such facilities may help to reduce the stress that most people experience in hospitals. They may be particularly useful to people with mental health problems who find waiting areas stressful. A separate and more private quiet waiting area may help people who find a public area too distressing. Background noise can be very uncomfortable and intrusive for hearing aid users.

- **Lighting.** Lighting should be suitable for the area and techniques should be used to reduce glare. People with epilepsy may be distressed by flashing or flickering lights.
- **Seating.** Chairs in waiting areas need to be of various sizes and heights, and should be available with and without arms.
- **Floor and wall coverings.** Colour and contrast should be used to distinguish floors and walls. Avoid heavily patterned designs, which can be distressing to people who have a visual impairment, epilepsy, or experience confusion (for example, people with dementia). Heavy patterns can also make communication difficult for deaf people who lip read or use BSL.

*A design guide for the use of colour and contrast to improve the built environment for visually impaired people* has been developed by the Joint Mobility Unit, ICI Dulux and University of Reading. 'Project Rainbow' is

available (price £15) from RNIB/G13BA Joint Mobility Unit, 224 Great Portland Street, London W 1 N 6AA. Tel 01713 912002.

## **Announcements**

Announcements will often need to be made, either for the attention of all patients waiting or to call a particular person to their appointment. Systems that rely exclusively on either visible or audible messages will create problems for people with visual or hearing impairments. How does someone who is deaf or blind know when it is their turn? Visual electronic notice boards or ticketing systems can be helpful for a deaf person, but alternatives will be needed for people who are blind or deafblind.

Albert is deaf and uses a hearing aid. He has an outpatient appointment at his local hospital for a check up on a digestive problem. When he arrives for his appointment he informs the receptionist that he is deaf and will not be able to hear his name called. He sits down to await his appointment. Other patients go into appointments and leave, and after two hours Albert has still not been seen. He approaches the appointments desk to ask when it will be his turn. The receptionist responds angrily and asks where he has been as they have been calling his name for ages.

## **4.6 Fire precautions and other emergencies**

Meeting the needs of disabled people must be an integral part of health and safety procedures and staff training. General fire safety policy with regard to healthcare buildings is contained within The Scottish Executive Health Department Fire Safety Policy [NHS MEL (1998) 8]. Technical guidance additional to the mandatory requirements set out in Part D and E of the Technical Standards for compliance with the Building Standards (Scotland) Regulations 1990 is contained within the National Health Service in Scotland Firecode suite of documents, as published by the Estates Environment Forum. Further guidance on emergency egress particular to disabled people can be found in BS5588: Part 8 (1998).

- Obviously people who are profoundly deaf will not hear a fire alarm. Audible signals should be accompanied by visual ones (such as a flashing light), and/or a vibrating pager to be carried by all deaf patients, visitors and staff while on the premises. This is especially important in areas where people may be unaccompanied (such as toilets or bathrooms) and where they would otherwise be unaware of any emergency.

- If a building has to be evacuated because of a fire alarm arrangements may be needed to ensure the safety of wheelchair users. This may require evacuation to a 'safe refuge' on the same level of the building to avoid the use of stairs.
- Hold-open devices for fire doors, which allow wheelchairs and trolleys passage through corridors, must release in the event of a fire alarm sounding.
- Fire exits should have level or ramped thresholds.
- Emergency procedures in the event of a fire alarm should be clearly communicated, understood and well rehearsed by staff.

## **5. Procedures**

### **5.1 Outpatient clinics, GP surgeries, health centres, other primary care services and home visits**

Disabled patients will use NHSiS facilities other than hospitals and awareness of their specific needs should be integral to the delivery of all health services. This should also apply to contact with social services.

GPs who refuse to register a patient or to continue treating them because of their disability (including a mental health problem) may be committing an offence under the Disability Discrimination Act 1995.

The points made in earlier sections about disability awareness, needs of disabled people and accessible environments (including provision of interpreters) are all relevant to NHSiS services in different settings, including primary health care. The following points should also be considered:

- If a disabled person wants to make an appointment don't automatically assume that they would prefer a home visit. If the surgery (or other premises) are accessible it may be easier for them to come to the practice.
- Services for people with mental health problems may sometimes need to be provided differently in order to compensate for their particular disability. This might include willingness to make a home visit where a visit to the health centre would cause distress.
- When referring a disabled patient to another service make that service aware of the disability (with the patient's permission). While the patient may be referred for something that is unrelated to his/her disability, the service should be aware of the needs he/she might have as a disabled patient and be prepared to respond appropriately.
- Queuing systems should be both visible and audible but receptionists need also to be aware of patients who may not see or hear adequately or know when they are being called.
- Appointments need to be appropriately scheduled to ensure that sufficient time is allowed for a patient who may have additional needs, and also that any extra facilities (such as interpreters) can be arranged in advance. It is helpful for deaf people if they know in advance who will be interpreting.
- Sign language interpreters are usually booked for a two-hour period. If there are delays in appointments and clinics are running late this can lead to an interpreter having to leave for their next booking, leaving the deaf person without an interpreter. If there is a deaf person with an interpreter on the appointments list check how long the interpreter can stay and if appointments are running late be prepared to move the deaf person up the list to ensure they have use of the interpreter. The Scottish Association of Sign Language Interpreters and the RNID can give some advice on making bookings. However it is important that hospitals and other NHSiS facilities become familiar with local provision in their area as booking procedures may vary.
- People with communication difficulties, whether due to physical, sensory or mental impairments, may require longer than usual consultation periods.

- A disabled person may want to have an independent advocate present, particularly if a diagnosis or treatment is likely to be distressing. Some hospitals have an independent advocacy service available for patients.
- If it becomes apparent that patients will not be seen at their given appointment time it would be helpful and reassuring to let them know that there is a delay and how long they can expect to wait to be seen. If there are lengthy delays information on the availability of refreshments would be helpful.
- A disabled person may depend on the punctuality of routine home visits by community health staff in order to maintain a normal routine. For example, a delayed visit by a district nurse to carry out essential daily care could mean that the disabled person is late for work or misses transport to the day centre.

## **5.2 Patient administration in hospital**

Disabled people suffer the same illnesses and injuries as the able population. We should not assume that contact with the Health Service is as a result of their disability. Disabled people are just as likely to attend hospital for reasons unconnected with their disability.

Good practice in the organisation of arrangements for hospital appointments, and in particular for admission and discharge, should be followed for all patients. The *Discharge from Hospitals – A Guide to Good Practice*, published by the Scottish Office Department of Health in 1995, summarises the key elements of such practice.

Communication and co-ordination are critical to effective admission and discharge arrangements, and particularly for disabled people with special needs.

In emergency situations it is important to make a rapid assessment of a person's needs and to respond accordingly. People with mental health problems are likely to find the pressures of an Accident and Emergency department particularly distressing and it is important to be alert to their possible needs, whilst also maintaining confidentiality about their illness. Check for any cards that people may carry relating to mental health advocacy or crisis care, just as you would be alert to SOS indicators for diabetes or epilepsy.

Elective admissions provide a greater opportunity to ensure that pre-admission procedures identify the particular needs or requirements that a patient is likely to have during their stay in hospital (for example, in respect of communication, medication or mobility). The referring GP should discuss with patients their

needs and highlight them to the hospital. Patient administration systems should identify disabled patients to ensure that staff are aware of their needs.

**Some patients may bring their own 'admission form' with them. For example, the Multiple Sclerosis Society produces an A5 leaflet for people with MS to complete prior to a hospital admission. This includes personal information and also information about their condition. This recognises that the symptoms and effects of MS can vary widely between individuals and is intended to provide hospital staff with an idea of how much assistance the person is likely to require during their time in hospital.**

In making arrangements for appointments or for admission care should be taken to ensure that communication and information is in the most appropriate medium for the needs of a particular patient. This should include attention to the needs of different ethnic minorities, who may otherwise face additional difficulties. For example, how are the communication needs of a deaf and non-English speaking person addressed?

### **5.3 Admission and hospital stay**

The admission of all patients should follow a standard procedure and include the completion of an admission form with a record of any needs of which a person wishes the hospital to be aware. Policies need to be as inclusive as possible so that all patients are treated with dignity with respect to their privacy.

Many disabled people who live independently at home find that they cannot do so in hospital because facilities are not suitable or accessible. A period as an in-patient can be disabling and could create dependency and loss of confidence. It is particularly important that disabled people are enabled to continue to do things for themselves that they would normally do. For this to be the case:

- Some disabled people may find it difficult to cope with being in a public ward and some separate rooms should be available if preferred. However these facilities should not be used simply for the convenience of staff or other patients and should reflect the genuine wishes of the disabled patient.
- personal aids **and equipment** (such as spectacles, hearing aids, walking sticks etc.) should be kept in a visible place that is easily accessible to the disabled person, and not tidied away in a drawer or locker without the disabled person's knowledge or agreement;
- disabled patients may wish to bring items of specialist equipment into hospital with them, particularly if they are uncertain that equipment that they are used to using will be available in hospital. Discuss their

requirements in advance and make the necessary arrangements for equipment to be supplied in hospital or for disabled patients to bring their own with them;

- disabled people often need to keep to their own routines. For people with physical disabilities this is likely to include pressure care, bowel and bladder routines, pillow layouts etc.;
- arrangements should be made for carers or advocates to be present when wanted by a disabled person;
- bathrooms and toilets must be accessible for disabled people, whether this is for wheelchair users and people with physical disabilities or for people with limited vision or impaired hearing etc.

George is paralysed from the waist down as the result of an accident 20 years ago. He uses a wheelchair and lives alone. He is able to bath himself and see to his own toilet needs as he has a specially adapted bathroom. He is admitted to hospital for treatment of a pressure sore. The bathroom on the ward is not wheelchair accessible and George needs the help of three members of staff and a hoist to get him in and out of the bath. He is also unable to use the toilet without help because he cannot get his wheelchair close enough to transfer across. Over a six-week hospital stay huge amounts of staff time have been used in helping George. He feels depressed by his hospital stay, which has left him with little dignity and little confidence that he can return to living independently at home.

Disabled people must have the same rights to privacy and confidentiality as any other patient.

- there needs to be sufficient space for wheelchairs to be used, and chairs and beds need to be of suitable height and design to allow people to transfer from a wheelchair;
- fixed and/or individual portable loops should be in place to allow hearing aid users access to the same TV and video facilities as other patients. For people who are deaf or hard of hearing Teletext subtitles are necessary; and

- portable textphones (e.g. Minicomms) should be available in exactly the same way that a telephone trolley is available on the ward. It may not be necessary to have a minicom located on every ward, but one should be available (it might, for example, be shared between two or three wards as needed).

In addition:

A deaf person may need a sign language interpreter or lip-speaker, and it is the Trust's responsibility to arrange this (NHS MEL (1998) 4). Reliance on relatives for important consultations, such as the first visit to a consultant, information about diagnosis and treatment, or discharge plans, should be agreed in advance with the patient. Arrangements should be in place for an appropriately qualified sign language interpreter to be available. Inform the deaf person in advance who will interpret for them and find out if they have a preference for a BSL or Standard Signed English (SSE), male or female interpreter (this can be particularly important for matters of a personal nature).

You will need to explain the lay-out and arrangements of a ward to a blind or partially sighted patient:

- let them know who their neighbours are and show them the way to the day room and other facilities.
- Find out if they need help in orientating themselves and ensure that staff on the ward are all aware of their needs, such as explaining what and where things are on their meal tray. Awareness should extend to all staff, including auxiliaries and cleaners who might otherwise inadvertently create obstacles by moving furniture or leaving cleaning equipment in the way.
- a sign at the end of a person's bed may be appropriate to alert staff to the patient's visual impairment. They should agree to the wording.
- Staff need to know what to expect when a patient is admitted. A blind person would not normally expect their guide dog to stay with them in hospital, for example, but they would expect the dog to be with them if they were attending as an out-patient. Staff should be aware that the dog may need to be taken outside to relieve itself and that it may need a bowl of water, although it should not be fed. Detailed advice on helping visually-impaired people in hospital is available from RNIB.

Lillian is aged 87 and blind and is admitted to hospital for some tests. When her visitors come she always appears to be hungry but because she is a little confused no one takes much notice. One day her daughter is visiting and notices that her mother's lunch is sitting untouched on the table by her bed. When she asks her mother why she hasn't eaten it she discovers that Lillian did not know it was there, because nobody had told her.

People with learning disabilities may need particular support in hospital, either from their carer, an advocate or from hospital staff. Hospitals can be alarming places and it helps to explain what is happening in plain language that is easily understood and friendly.

People with learning disabilities (or indeed any other disability) must not be segregated against their wishes from other patients. Any discriminatory behaviour on the part of other patients should be discouraged by staff.

Extra time may be needed to allow for adequate explanation of any treatment and to provide reassurance to a patient with learning disabilities. It is preferable for patients to be cared for by the same staff whom they come to know and trust rather than to be confronted with a series of strangers.

Boredom can be a particular problem for people with learning disabilities who have nothing to do and may not be able to read or entertain themselves in the same way as other patients. They may need more individual interaction and there may be ways of using their own wider social networks to help with this. It can also be useful to ask them, and their carers if appropriate, for advice on any belongings from home that they might want to bring with them.

John is 24 and has learning disabilities. He is admitted to hospital for an operation. When his mother visits she finds him excited and he tells her that there is a train in the hospital and he is going to see the pantomime tomorrow. Puzzled by this news his mother speaks to the nursing staff and discovers that a nurse has told John that he will be going to the theatre tomorrow and that if he needs anything she will be at the station just around the corner.

#### **5.4 Discharge from hospital**

As with hospital admission, discharge arrangements should follow a standard procedure. However such procedures may be more complex in the case of a disabled patient and it is all the more important that arrangements, and responsibilities for carrying out such arrangements, are clear. When a patient has

continuing needs for health and/or social care these will need to be addressed through careful multi-disciplinary assessment and care planning, which will involve different personnel in different circumstances. The NHSiS *Discharge from Hospitals: A Guide to Good Practice* and NHS MEL (1996) 22: 'NHS Responsibility for Continuing Health Care' detail the key stages that need to be addressed. These can be obtained from the Scottish Executive Health Department at the address given in Appendix II. The following are of particular importance:

- Have any necessary aids or adaptations been supplied and fitted, and have the patient and their carer (where relevant) been trained to use them correctly?
- Have steps been taken to activate or reactivate any services such as home care, or meals on wheels, and has confirmation been received that these will commence on the required date?
- If the patient lives alone have arrangements been made to make their home ready for their return?
- Have take-home medicines and any dressings been given to the patient? Have they been given clear instructions on their use in the most appropriate format?
- Has the patient been given information about any follow-up appointments? Is this in a form that is best suited to their need, and that they can understand?
- Has appropriate transport been organised for the patient where necessary, possibly including someone to accompany the patient home and to ensure they are properly settled before leaving them?
- Has the patient's GP been notified of their discharge from hospital and of any changes to medication?
- Has the patient been given a named contact person and telephone number in the event of any difficulties or concerns following their discharge?

A person who is newly disabled will have different needs from someone who has been disabled for some time, or who has had a life long disability. All newly disabled people should be given appropriate information about their disability and about possible relevant organisations and support groups, as well as information about entitlement to any benefits and how to obtain support and equipment.

In addition to practical help disabled people may also need access to counselling support. This may be especially important when disability is sudden in onset, such as the result of an accident or trauma.

## **5.5 Handling complaints**

Complaints mechanisms should be viewed in a positive light and seen as an important part of the process for ensuring feedback and information from patients and their families. People should be given opportunities to comment on the service they receive, both positively and negatively.

Complaints procedures need to be fully accessible to disabled people. This may include making arrangements for an appropriate sign language interpreter or lipspeaker to be available, or enabling sign language users to make their complaints on video if they find this easier than expressing their complaint in writing. Information about complaints procedures should be available in plain language, using short sentences and easy words, supported by pictures. It should also be available in appropriate formats, such as large print versions, audio tape and braille.

Disabled people may have low expectations of a service because of previous negative experiences, or may be reluctant to comment for fear of reprisals or the loss of support.

It is important that all patients, but particularly those who are disabled, are reassured that their comments are valued and will be listened to and acted on as appropriate; that they will be supported in making a complaint; and that there are mechanisms for this to be anonymous if necessary.

## **Appendix I: Further information**

For detailed information on the Disability Discrimination Act, see the following:

- A range of leaflets about various aspects of the Act is available. To obtain copies telephone 0345 622 633, or textphone 0345 622 644. Copies of the leaflets are also available in alternative formats and from the Internet ([www.disability.gov.uk](http://www.disability.gov.uk)). The priced publications are available from The Stationery Office or from the Internet.
- Statutory guidance is available on the definition of disability in the Act. *Guidance on matters to be taken into account in determining questions relating to the definition of disability*, Department for Education and Employment, 1996.
- *Disability Discrimination Act 1995 Code of Practice: Rights of access, goods, facilities, services and premises*. Department of Social Security, 1996.
- *Disability Discrimination Act 1995 Code of Practice: for the elimination of discrimination in the field of employment against disabled persons or persons who have had a disability*. Department for Education and Employment, 1996.
- A new Code of Practice which takes into account the remaining provisions of Part III of the DDA that will come into effect in October 1999 and 2004 was published by the Department of Education and Employment on 29 June 1999. Available from the Stationery Office.

### **Other useful publications**

*See it Right* (1993), Available from RNIB, 224 Great Portland Street, London W1N 6AA.

*Discharge from Hospitals: A Guide to Good Practice* (1996), Scottish Executive Health Department.

*The Informability Manual* (1996), Central Office of Information. Available from the Stationery Office (Internet address [www.TSOnline.co.uk](http://www.TSOnline.co.uk)).

*Patients Disabled? The care of disabled people in hospital - Conference Report* (1997), available from Continuing Health Services, Room 5W20, Quarry House, Quarry Hill, Leeds LS2 7UE.

*Signposts for Success in Commissioning and Providing Health Services for People with Learning Disabilities* (1998), NHS Executive. Available from: Department of Health, PO Box 410, Wetherby, LS23 MN.

*Disabled People Using Hospitals - a charter and guidelines* (1998), Royal College of Physicians, 11 St Andrew's Place, London NW1 4LE.

*Courses by trainers in Visual Impairment* (1998), Department of Health. Available from Department of Health, SC6A, Room 228, Wellington House, 133-155 Waterloo Road, London SE1 8UG.

*Directory of training opportunities and materials for staff working with deaf people* (1997), Council for the Advancement of Communication with Deaf People (CACDP). Available from Department of Health, PO Box 410, Wetherby LS23 MN.

## **Appendix II: Contacts and associations**

For information on local organisations you can contact your Council for Voluntary Services (see the Phone Book). The following are mostly national organisations, some of which have regional and local branches. They are listed in alphabetical order.

**Action for Blind people**

14 – 16 Verney Road  
LONDON, SE16 3DZ

Tel: 0171 732 8771

Fax: 0171 639 0948

e-mail: [info@afbp.org](mailto:info@afbp.org)

web site: [www.demon.co.uk/afbp](http://www.demon.co.uk/afbp)

**Action for Dysphasic Adults**

1 Royal Street  
LONDON, SE1 7LL

Tel: 0171 261 9572

Fax: 0171 928 9542

e-mail: [adanation@aol.com](mailto:adanation@aol.com)

web site: [ada-uk.org](http://ada-uk.org)

**Alzheimer's Scotland Action on Dementia**

22 Drumsheugh Gardens  
EDINBURGH, EH3 7RN

Tel: 0131 243 1453

Fax: 0131 243 1450

e-mail: [alzheimers@alzscot.org](mailto:alzheimers@alzscot.org)

web site: [www.alzscot.org](http://www.alzscot.org)

**Arthritis Care**

68 Woodvale Avenue  
Bearsden  
GLASGOW, G61 2NZ

Tel/Fax: 0141 942 2322

**Assist**

46a Channel Street  
GALASHIELS, TD1 1BA

Tel/Fax: 01896 759 700

e-mail: [assist@netcomuk.co.uk](mailto:assist@netcomuk.co.uk)

**British Council of Disabled People (BCODP Ltd)**

Litchurch Plaza  
Litchurch Lane

DERBY, DE24 8AA

Tel: 01332 295 551

Fax: 01332 295 580

e-mail:[bcodp@bcodp.org.uk](mailto:bcodp@bcodp.org.uk)

web site:[www.bcodp.org.uk](http://www.bcodp.org.uk)

INFORMATION LINE (Mon – Fri, 13:30 – 16:30): 01332 298 288

### **British Deaf Association (BDA) Scotland**

Princess House

3<sup>rd</sup> Floor

5 Shandwick Place

EDINBURGH, EH2 4RG

Tel: 0131 221 1137

Text: 0131 221 1145

Fax: 0131 221 7960

e-mail:[bdatwo@dircon.co.uk](mailto:bdatwo@dircon.co.uk)

web site:[www.bda.org.uk](http://www.bda.org.uk)

### **British Diabetic Association Scotland**

4<sup>th</sup> Floor

34 West George Street

GLASGOW, G2 1DA

Tel: 0141 332 2700

Fax: 0141 332 4880

e-mail:[scotland@diabetes.org.uk](mailto:scotland@diabetes.org.uk)

web site:[www.diabetes.org.uk](http://www.diabetes.org.uk)

### **Capability Scotland**

Advice Service

11 Ellersly Road

EDINBURGH, EH12 6HY

Tel: 0131 313 5510

Minicom:0131 346 2529

Fax: 0131 346 1681

e-mail:[capability@capability-scotland.org.uk](mailto:capability@capability-scotland.org.uk)

web site:[www.capability-scotland.org.uk](http://www.capability-scotland.org.uk)

### **Carers National Association**

3<sup>rd</sup> Floor

91 Mitchell Street

GLASGOW, G1 3LN

Tel: 0141 221 9141  
Fax: 0141 221 9140  
e-mail:[internet@carerscotland.demon.co.uk](mailto:internet@carerscotland.demon.co.uk)

**Central Office of Information**

Communication Agency

Hercules House

Hercules Road

LONDON, SE2 7DU

Tel: 0171 928 2345

Fax: 0171 928 5037

**Centre for Accessible Environments**

Nutmeg House

60 Gainsford Street

LONDON, SE1 2NY

Tel: 0171 557 8182

Fax: 0171 357 8183

e-mail:[cae@globalnet.co.uk](mailto:cae@globalnet.co.uk)

web site:[www.cae.org.uk](http://www.cae.org.uk)

**Council for the Advancement of Communication with Deaf People (CACDP)**

Durham University Science Park

Block 4

Stockton Road

DURHAM, DH1 3UZ

Tel: 0191 383 1155

Text: 0191 383 7915

Fax: 0191 383 7914

e-mail:[durham@cacdp.demon.co.uk](mailto:durham@cacdp.demon.co.uk)

web site:[www.cacdp.demon.co.uk](http://www.cacdp.demon.co.uk)

**Deafblind UK**

21 Alexandra Avenue

LENZIE, G66 5BG

Tel/Text:0141 777 6111

Fax: 0141 775 3311

e-mail:[info@deafblindscotland.org.uk](mailto:info@deafblindscotland.org.uk)

web site:[www.deafblindscotland.org.uk](http://www.deafblindscotland.org.uk)  
24 HOUR FREE HELPLINE: 0800 132320

### **Disability Alliance**

Educational and Research Association

1<sup>st</sup> Floor East

Universal House

88 – 94 Wentworth Street

LONDON, E1 7SA

RIGHTS ADVICE HELPLINE (Mon + Wed, 14:00 – 16:00): 0171 247 8763

Publication orders (Mon – Fri, 10:00 – 16:00): 0171 247 8776

### **Disability Discrimination Act Helpline** (calls charged at local rates)

Tel: 0345 622 633

Text: 0345 622 644

Fax: 0345 622 611

web site:[www.disability.gov.uk](http://www.disability.gov.uk)

### **Disability Scotland**

Princess House

5 Shandwick Place

EDINBURGH, EH2 4RG

Tel/Minicom: 0131 229 8632

Fax: 0131 229 5168

e-mail:[disability.scotland@virgin.net](mailto:disability.scotland@virgin.net)

web site:[dis\\_scot.gcal.ac.uk](http://dis_scot.gcal.ac.uk)

### **The Dyslexia Institute**

74 Victoria Crescent Road

Dowanhill

GLASGOW, G12 9JN

Tel: 0141 334 4549

Fax: 0141 339 8879

e-mail:[enquiries@glasgow-di.freemove.co.uk](mailto:enquiries@glasgow-di.freemove.co.uk)

web site:[www.dyslexia-inst.org.uk](http://www.dyslexia-inst.org.uk)

### **East of Scotland Deaf Children's Society**

5 Coates Place

EDINBURGH, EH3 7AA

Tel/Text/Fax: 0131 220 5189

### **Edinburgh and East of Scotland Deaf Society**

49 Albany Street

EDINBURGH, EH1 3QY

Tel: 0131 556 3128

Text: 0131 557 0419

Fax: 0131 557 8283

e-mail:admin@escotdeafsoc.demon.co.uk

**Enable** (formerly Scottish Society for Mentally Handicapped)

National Office

6<sup>th</sup> Floor

7 Buchanan Street

GLASGOW, G1 3HL

Tel: 0141 226 4541

Tel: 07000 362253 ENABLE

Fax: 0141 204 4398

e-mail:enable@enable.org.uk

**Enlighten - Action for Epilepsy**

5 Coates Place

EDINBURGH, EH3 7AA

Tel: 0131 226 5458

Fax: 0131 220 2855

e-mail:enlighten@cableinet.co.uk

**Epilepsy Association of Scotland**

48 Govan Road

GLASGOW, G51 1JL

Tel: 0141 427 4911

Fax: 0141 419 1709

e-mail:admin@epilepsyscotland.org.uk

web site:[www.epilepsyscotland.org.uk/epilepsy](http://www.epilepsyscotland.org.uk/epilepsy)

HELPLINE (09:00 - 16:30): 0141 427 5225

**Guide Dogs for the Blind Association (GDBA)**

Princess Alexandra House

Dundee Road

FORFAR, DD8 1JA

Tel: 01307 463531

Fax: 01307 465233

**Hearing Concern**

The British Association of Hard of Hearing  
7-11 Armstrong road  
LONDON, W3 7JL  
Tel/Text:0181 743 1110  
Fax: 0181 742 9043

**Joint Mobility Unit**

RNIB Scotland  
2<sup>nd</sup> Floor  
Dunedin House  
25 Ravelston Terrace  
EDINBURGH, EH4 3TP  
Tel: 0131 311 8526  
Fax: 0131 311 8529  
e-mail:rnib@rnib.org.uk  
web site:www.rnib.org.uk

**Mental Welfare Commission for Scotland**

K Floor  
Argyll House  
3 Lady lawson Street  
EDINBURGH, EH3 9SH  
Tel: 0131 222 6111  
Fax: 0131 222 6112

**The Multiple Sclerosis Society in Scotland**

2a North Charlotte Street  
EDINBURGH, EH2 4HR  
Tel: 0131 225 3600  
Fax: 0131 220 5188  
e-mail:info@mssociety.org.uk  
web sit:[www.mssociety.org.uk](http://www.mssociety.org.uk)  
HELPLINE: 0131 226 6573

**The Murray Foundation**

2<sup>nd</sup> Floor  
Argyle House  
Ibrox Stadium  
GLASGOW, G51 2XD  
Tel: 0141 427 8564  
Fax: 0141 427 7241  
e-mail:[susan\\_shaw@rangers.co.uk](mailto:susan_shaw@rangers.co.uk)

**The National Autistic Society Scotland**

111 Union Street

GLASGOW, G1 3TA

Tel: 0141 221 8090

Fax: 0141 221 8118

e-mail:[nas@nas.org.uk](mailto:nas@nas.org.uk)

web site:[www.oneworld.org/autism\\_uk/](http://www.oneworld.org/autism_uk/)

**National Deaf Children's Society**

Scottish Development Officer

293 – 295 Central Chambers

93 Hope Street

GLASGOW, G2 6LD

Tel/Text:0141 248 2429

Tel/Text:0141 248 4457

Fax: 0141 248 2597

e-mail:[ndcs.scotland@ndcs.org.uk](mailto:ndcs.scotland@ndcs.org.uk)

HELPLINE (Mon – Fri, 10:00 – 17:00 + Tues 10:00 – 19:00): 0171 250 0123

**National Development Team (NDT) for People with Learning Disabilities**

St Peter's Court

8 Trumpet Street

MANCHESTER, M1 5LW

Tel: 0161 228 7055

Fax: 0161 228 7059

e-mail:[office@ndt.org.uk](mailto:office@ndt.org.uk)

web site:[www.ndt.org.uk](http://www.ndt.org.uk)

**National Information Forum**

Post Point 10/10

BT Burn House

Bell Street

LONDON, Nw1 5BZ

Tel: 0171 402 6681

Fax: 0171 402 1259

e-mail:[niforum@talk21.com](mailto:niforum@talk21.com)

**National Disability Council**

web site:[www.open.gov.uk/ndc/ndchome.h.t.m](http://www.open.gov.uk/ndc/ndchome.h.t.m)

**National Schizophrenia Fellowship (NSF) Scotland**

Clairmont House

130 East Clairmont Street

EDINBURGH, EH7 4LB

Tel: 0131 557 8969

e-mail:[info@nsfscot.org.uk](mailto:info@nsfscot.org.uk)

web site:[www.nsfscot.org.uk](http://www.nsfscot.org.uk)

**The NHSiS Estates Environment Forum**

Healthcare Engineering and Environment Unit

Room 8.51

Graham Hills Building

50 George Street

GLASGOW, G1 1QE

Tel: 0141 548 3446

Fax: 0141 553 4109

e-mail:[heeu@strath.ac.uk](mailto:heeu@strath.ac.uk)

**Partially Sighted Society (PSS)**

PO Box 322

Queen's Road

DONCASTER, DN1 2NX

Tel: 01302 323 132

Fax: 01302 368 998

**People First (Scotland)**

107 Macdonald Road

EDINBURGH, EH7 4NW

Tel: 0131 478 7708

Fax: 0131 478 7404

e-mail:[pfirstscot@aol.com](mailto:pfirstscot@aol.com)

**Royal Association for Disability and Rehabilitation (RADAR)**

12 City Forum

250 City Road

LONDON, EC1V 8AF

Tel: 0171 250 3222

Fax: 0171 250 0212

e-mail:[radar@radar.org.uk](mailto:radar@radar.org.uk)

web site:[www.radar.org.uk](http://www.radar.org.uk)

**Royal National Institute for the Blind (RNIB) Scotland**

Dunedin House  
25 Ravelston Terrace  
EDINBURGH, EH4 3TP  
Tel: 0131 311 8500  
Fax: 0131 311 8529  
e-mail:rnib@rnib.org.uk  
web site:www.rnib.org.uk

**Royal National Institute for Deaf People**  
RNID Services to Scotland  
9 Clairmont Gardens  
GLASGOW, G3 7LW  
Tel: 0141 332 0343  
Text: 0141 332 5023  
Fax: 0141 331 2640  
web site:[www.rnid.org.uk](http://www.rnid.org.uk)

**Scottish Association for the Deaf (SAD)**  
Clerwood House  
96 Clermiston Road  
EDINBURGH, EH12 6UT  
Tel: 0131 314 6075  
Text: 0131 314 6078  
Fax: 0131 314 6077

**Scottish Association of Health Councils**  
24a Palmerston Place  
EDINBURGH, EH12 5AL  
Tel: 0131 220 4101  
Fax: 0131 220 4108  
e-mail:sahc@sol.co.uk

**Scottish Association for Mental Health (SAMH)**  
Cumbrae House  
15 Carlton Court  
GLASGOW, G5 9JP  
Tel: 0141 568 7000  
Fax: 0141 568 7001

**Scottish Association for Sign Language Interpreters (SASLI)**  
54B Queen Street  
EDINBURGH, EH2 3NS  
Tel/Minicom: 0131 225 9995  
Fax: 0131 225 9932

e-mail:[mail@sasli.freeseve.co.uk](mailto:mail@sasli.freeseve.co.uk)

**Scottish Council for Equal Opportunities for the Disabled**

90 Mitchell Street

GLASGOW

Tel: 0141 221 1429

Fax: 0141 221 3049

**Scottish Downs Syndrome Association**

158-160 Balgreen Road

EDINBURGH, EH11 3AU

Tel: 0131 313 4225

Fax: 0131 313 4285

e-mail:[info@sdsa.org.uk](mailto:info@sdsa.org.uk)

web site:[www.sdsa.org.uk](http://www.sdsa.org.uk)

**Scottish Dyslexia Association**

Unit 3

Stirling Business Centre

Wellgreen

STIRLING, FK8 2DZ

Tel: 01786 446650

Fax: 01786 471235

e-mail:[dyslexia.scotland@dial.pipex.com](mailto:dyslexia.scotland@dial.pipex.com)

**Scottish Executive Health Department**

NHS Management Executive

St Andrew's House

Regent Road

EDINBURGH, EH1 3DG

Tel: 0131 244 8400

e-mail:[ceu@scotland.gov.uk](mailto:ceu@scotland.gov.uk)

Scottish Executive web site: [www.scotland.gov.uk](http://www.scotland.gov.uk)

Department of Health web site: [www.doh.gov.uk](http://www.doh.gov.uk)

**Scottish Society for Autistic Children**

Hilton House

Alloa Business Park

Whins Road  
ALLOA, FK10 3SA  
Tel: 01259 720 044  
Fax: 01259 720 051  
e-mail: [ssac@autism-in-scotland.org.uk](mailto:ssac@autism-in-scotland.org.uk)  
web site: [www.autism-in-scotland.org.uk](http://www.autism-in-scotland.org.uk)

### **Sense Scotland**

The National Deafblind and Rubella Association  
5<sup>th</sup> Floor  
45 Finnieston Street  
Clydeaway Centre  
GLASGOW, G3 8JU  
Tel: 0141 564 2444  
Text: 0141 564 2442  
Fax: 0141 564 2443  
e-mail: [kas51@dial.pipex.com](mailto:kas51@dial.pipex.com)

### **Spinal Injuries Scotland**

Festival Business Centre  
150 Brand Street  
GLASGOW, G51 1 DH  
Tel: 0141 314 0056  
Fax: 0141 314 0082

### **West of Scotland Deaf Children's Society**

100 Norfolk Street  
GLASGOW, G5 9EJ  
Tel: 0141 420 3388  
Text: 0141 420 3388  
Fax: 0141 420 3442  
e-mail: [w\\_scot\\_deaf\\_children\\_soc@compuserve.com](mailto:w_scot_deaf_children_soc@compuserve.com)

### **West Lothian Epilepsy Resource Centre**

Bloom House  
10 main street  
Livingston Village  
LIVINGSTON, EH54 7AF  
Tel: 01505 464446

Fax:

01506 464466

### **Appendix III: Example of Disability Awareness Training**

The following example of a disability awareness training programme was provided by Dave Thompson, Disability Services Adviser, Warrington Community Health Care NHS Trust. It builds on his own experiences as a person with a severe disability, and on those of others he works with. Non-disabled trainers may sometimes fail to emphasise the true impact of disability. However being disabled does not of itself qualify a person to be a trainer.

Variations of this template have been used for training a wide variety of staff groups. A mix of disciplines within a group can enhance the learning process.

#### **Programme**

9.15 am     **Arrival and registration.**

- 9.30 am **Introductions:** Trainers and group introduce themselves, ice-breaking exercise.
- Aims:** To give participants a general understanding of disability and the main barriers that concern disabled people.
- Objectives:** To improve the provision of services for disabled people through a greater awareness on the part of those who develop and provide those services.
- Participants' expectations:** In a letter confirming their place on the programme participants have been asked to give some thought in advance to what they want from this session.
- 10.00 am **Disability - what does it mean?** Participants discuss their thoughts about disability, with guidance from the facilitator to get them beyond the obvious images of wheelchairs, white sticks, guide dogs and hearing aids.
- Perceptions:** Participants break into small groups for 20 minutes to discuss an or from previous research.
- 11.00 am **Coffee break.**
- 11.15 am **Barriers - physical and sensory:** Divide into two groups to discuss and list barriers to access: one group considering physical disability, the other sensory disability. On return, each group considers solutions to solve the other group's problems.
- 12.30 **Lunch**
1. 15 pm **Language and terminology:** Split into groups to discuss and list words and phrases relating to disability that are offensive or inappropriate (see Section 3.3). On return, discuss issues surrounding myths and misconceptions that can lead to prejudice and discrimination.
- Effective communication:** Discuss when and how to help people with sensory impairments, learning disabilities or mental health problems.
- 2.15 pm **The business case:** Presentation of statistics and their implications.

- 2.30 pm **Tea break.**
- 2.45 pm **The Disability Discrimination Act 1995.** Presentation and discussion about specific implications for participants.
- 3.45 pm **Conclusions:** Refer back to participants' original expectations. Pick up on any gaps (such as social security benefits information, or local support networks), and any unanswered questions.
- 4.15 pm **Handouts, evaluation and close.**