

National Disability Authority

**Review of literature and guidelines on accessibility in  
healthcare that underpin the National Guidelines on  
Accessible Primary, Community and Hospital  
Services**

Dr Jane Pillinger, Independent Researcher and Policy Advisor

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<b>Section 1: Introduction.....</b>	<b>4</b>
1.1 Overview .....	4
1.2 Legislative and policy context.....	4
1.3 Key themes from the review of literature, review of guidelines and consultations on accessibility in healthcare services for people with disabilities ...	5
1.4 Methodology .....	6
<b>Section 2: Review of literature .....</b>	<b>7</b>
2.1 Introduction.....	7
2.2 Access to all healthcare settings .....	8
2.3 Access to hospital care .....	17
2.4 Access to emergency care.....	19
2.5 Access to maternity services .....	20
2.6 Access to primary care and GP services.....	21
<b>Section 3: Guidelines on access to healthcare.....</b>	<b>27</b>
3.1 Introduction.....	27
3.2 Guidelines on access to all healthcare services .....	27
3.3 Guidelines on access to hospital, emergency, maternity, GP/primary care services.....	30
3.4 Cross cutting guidelines on physical, information and communications accessibility .....	38
<b>Section 4: Consultations with the HSE and disability organisations in drawing up the guidelines.....</b>	<b>47</b>
4.1 Introduction.....	47
4.2 Initial consultations with disability organisations to inform the content of the guidelines.....	47
4.3 Consultations and feedback on draft guidelines .....	53

**Section 5: Policy issues and recommendations .....57**

**Appendix 1: List of individuals and organisations who participated in the consultations to inform the draft guidelines.....60**

**Appendix 2: List of individuals and organisations who gave feedback on the draft guidelines .....61**

**Bibliography .....63**

**Guidelines cited in Section 3.....70**

## **Section I: Introduction**

### **1.1 Overview**

The National Guidelines on Accessible Primary Community and Hospital Services provide guidance to increase disability awareness and the capacity to develop accessible health services for people with disabilities. The aim of the guidelines is:

- To enable health care providers meet their statutory responsibilities under the Equal Status Acts, the Disability Act 2005 and associated statutory Code of Practice.
- To provide practical information to staff working in healthcare so they can meet the particular needs of service users with disabilities, including those relating to the service itself, to communication, to information, and to premises and equipment.
- To serve as a reference manual for staff.
- To be used in education and training in relation to disability, accessibility and customer care.
- To assist Access Officers in public health services in their statutory role to provide, arrange for and coordinate assistance and guidance to persons with disabilities who want to access their services.

The objective of recent reforms in the delivery of healthcare is for services to be of high quality, appropriate, safe, available when and where they are needed and coordinated to meet individual needs in keeping with standards, professional practices and ethics. The objective is to improve the delivery, provision and outcomes of healthcare by improving access to healthcare and to enhancing the sensitivity and adaptability of the services provided.

A clear message coming through the literature review, the review of existing guidelines and from the consultations is the need for disability access to take a universal approach that takes account of the fact that people with disabilities have unique and individual needs. A person's disability may result in different capacities in relation to communication, mobility, decision-making and self-care. It is also important to recognise that healthcare providers need to identify and respond appropriately to the needs of people with disabilities by taking account of the disadvantage and discrimination they experience.

### **1.2 Legislative and policy context**

The UN Convention on the Rights of Persons with Disabilities (Article 25) sets out the right of people with disabilities to attain the highest standard of healthcare and non-discrimination. In an Irish context, the Equal Status Acts and the Disability Act have a core purpose to promote non-discrimination and a proactive approach to

equality in health. The Disability Act 2005 requires organisations providing services and information to accommodate the needs of people with disabilities. Health service providers are required to accommodate the needs of people with disabilities, including the provision of information in formats accessible to disabled people. The Equal Status Acts 2000 to 2011 prohibit discrimination in the provision of goods and services on the grounds of disability. The Acts require that service providers accommodate the needs of people with disabilities by making reasonable changes to the service, including special treatment and special facilities, where this is necessary.

### **1.3 Key themes from the review of literature, review of guidelines and consultations on accessibility in healthcare services for people with disabilities**

There is an extensive body of evidence on the factors that impact on a person's ability to access health services and health facilities. Access is widely defined to include:

- Physical access and the physical design of healthcare facilities, including access to buildings, reception desks or accessible treatment facilities. Physical access is also a factor affecting access to information; for example, because information display boards or leaflets that are displayed are out of reach for a wheelchair user. It is also relevant to accessible treatment facilities such as height adjusted examination tables and weighing scales and accessible changing rooms.
- Accessible information that can be accessed by a person who has a vision impairment or a person who has literacy difficulties, or because information could not be provided to a person who is a wheelchair user, because the reception desk was not accessible to enable the person to communicate with a member of staff.
- Accessible communications, for example, asking a person with a disability about their preferred communication methods.
- Using 'person first' language – e.g. a person who is deaf
- Reasonable accommodation, and awareness and skills of staff about practical ways to accommodate the needs of people with disabilities. As an example, receptionists should sit at eye level with wheelchair user, rather than sitting behind a reception desk that is too high.
- Awareness of specific healthcare needs and risks of people with disabilities. This includes understanding of and attention to preventable secondary conditions that arise from a person's disability or primary health condition, such as pressure ulcers experienced by people with spinal cord injury, urinary tract infections, osteoporosis or pain. Similarly, co-morbid conditions may also be neglected, for example, in relation to a higher prevalence of diabetes amongst people with schizophrenia and people with intellectual disabilities compared to

the general population, or in relation to premature ageing and higher rates of premature death amongst people with intellectual disabilities and people with mental health difficulties.

- Participation in consultations about a health service may be inaccessible because user consultations may exclude people with disabilities because information is not accessible or because the venue was not accessible to a person with a disability.
- Barriers arising from the prohibitive costs of healthcare, a lack of availability of services to people in the locality in which a person lives, or poor coordination between hospital and primary care services.
- Health inequalities experienced by people with disabilities, arising from poverty or a lower level of access to health promotion and prevention, for example, cancer screening services, checks for diabetes or heart health.

The research, policy documents and guidelines that have been reviewed stress the importance of reasonable accommodation and the promotion of the rights and dignity of people with disabilities in a healthcare setting. Reasonable accommodation covers a wide range of modifications and adjustments to facilitate access to healthcare services, for example, by changing the physical layout of healthcare facilities to provide access for people with mobility difficulties or in providing health information in accessible formats. Promoting reasonable accommodation also requires that disability education be integrated into undergraduate and continuing education for healthcare professionals, the development of evidence-based guidelines for assessment and treatment, policies and protocols on access and inclusive healthcare policies. This is particularly relevant as rates of disability are increasing because of population ageing and an increase in chronic health conditions; however, people with disabilities experience unmet healthcare needs arising from barriers in accessing health services (World Health Organisation 2011).

#### **1.4 Methodology**

The guidelines were drawn up using the following methodology:

- A review of literature on how to improve accessibility for people with disabilities when accessing healthcare. This encompassed academic articles, research reports, reports of government agencies and disability bodies in Ireland and internationally. The following literature searches were carried out with assistance from the NDA library:
  - NDA research database
  - NDA library catalogue
  - two electronic databases: Science Citation Index and Social Sciences Citation Index.

Section 2 provides the literature review. In addition, further searches were made of key journals on-line and in paper.

- An Internet search of government reports, consultations and published and unpublished reports of NGOs and disability organisations on accessibility in hospital, emergency, maternity and primary care services; and physical accessibility, communications accessibility and information accessibility.
- A review of practical guidelines on accessibility in healthcare was carried out. This was carried out through an Internet search of guidelines on accessibility in health care in the English language. This included searches that followed up references to guidelines in the literature and references to guidelines made by disability organisations in Ireland during the consultations. Section 3 provides an overview of the guidelines from Ireland and internationally that were reviewed.
- Consultations with disability organisations and HSE service providers were held to inform the content of the guidelines, which are documented in Section 4. The first stage of consultations involved a letter sent to the main disability organisations in Ireland, requesting information about any consultations with service users or reports that had been drawn up on accessibility in healthcare. The letter was followed up with telephone calls and emails to the organisations concerned. In some cases interviews were held either in person or by telephone with organisations that preferred to give feedback in this way.
- A second stage of consultations took place once the draft guidelines had been drawn up. The guidelines were circulated to disability organisations that had been involved in the initial consultations, to HSE service providers and disability organisations through the HSE's Universal Access Steering Group, and feedback from the NDA Senior Management Team. Feedback was collated and revisions made to the draft guidelines, resulting in the drawing up of the final guidelines.

## **Section 2: Review of literature**

### **2.1 Introduction**

This section provides an overview of the findings from the literature review on how to improve accessibility for people with disabilities when accessing healthcare. Much of the research literature draws on the barriers experienced by people with disabilities and highlights specific and practical accommodations that need to be made to improve accessibility.

The literature review covers studies on:

- access to all healthcare settings,
- access to mental health services for people with disabilities,
- access to preventative care,

- access to primary care and GP services,
- access to hospital services,
- access to emergency care services, and
- studies on access to maternity services.

Disability access is widely recognised as being central to the achievement of equity and equality in health (Whitehead 1991, Goddard and Smith 2001, World Health Organization 2001, Equality Authority 2006, D'Eath et al 2006, British Medical Association 2007) and can be viewed as an overall indicator of equity within a healthcare system (Maclachlan et al 2011). This also arises in the need to address and provide accessible services within the broader context of the social model of disability.

## **2.2 Access to all healthcare settings**

There is a wide range of recommendations in the literature of how healthcare services can be made accessible, safe, equitable and efficient for people with disabilities. These range from accessible buildings, equipment and examination tables to accessible communications between healthcare professionals and patients and addressing misconceptions held by healthcare professionals about the lives, preferences and abilities of people with disabilities. While it is evident from the literature that some elements of physical accessibility have been implemented in a healthcare setting, an important starting point is to ask a person with a disability about workable solutions (Iezzoni and O'Day 2006) and to widen awareness that disability access is more than ramps (Panko et al 2004).

Five characteristics of access to healthcare, developed by Simeonsson et al (1999) include the availability (type and extent of services), accessibility (physical barriers), accommodation (sensitivity to individual differences and disabilities), affordability (financial, time or energy costs) and acceptability (mutual acceptance and reciprocity). In a healthcare context accessibility includes the provision of physically accessible services, the provision of accessible information and communications and an awareness of how to accommodate the needs of people with disabilities in the provision of services (Michaels 2008, Coursen 2009, British Medical Association 2007). In particular, improving the awareness of disability and challenging any negative attitudes on the part of staff can help to avoid a situation where health needs are not identified, or 'diagnostic overshadowing' when a person's health problems are viewed as part of the person's disability (Alborz et al 2005, Krahn et al 2006, Smith and Pressman 2010, Mason and Scior 2004, Royal College of Nursing 2011). Some issues are raised in the literature about capacity and consent, including confusions and difficulties faced by healthcare staff in this area, and the need for clear procedures and protocols (Royal College of Nursing 2011). Specific issues are also highlighted about the need to provide equal access to healthcare, improve the knowledge of healthcare professionals of the health needs of people with



disabilities, provide accessible communications between the patient and the healthcare practitioner and promote positive images of people with disabilities (Sowney and Barr 2004, Hatton et al 2011). Key issues are raised about the duty of care address the healthcare needs of people with disabilities, and about staff attitudes towards people with disabilities (Jenkins and Davies 2006).

lezzoni & O'Day's (2006) book on improving the quality of healthcare, particularly in community-based outpatient care and primary care settings for people with physical and sensory disabilities sets out the challenges involved in providing accessible healthcare. The guidelines contained in the book are drawn from the experiences of people with disabilities documented in national surveys, interviews with service users and published literature. They have a particular focus on physical access, institutional policies and procedures, the assumptions, attitudes and awareness of healthcare staff to changing societal views of people with disabilities. Suggestions are given to address practical needs and clinical issues in order to improve healthcare delivery and client-clinician communication and to ensure that healthcare services are physically accessible, as well as comfortable and welcoming for people with disabilities. Three core messages are presented for providing accessible and patient-led care. First, assumptions should never be made about a person's abilities, preferences, expectations or wishes; second, that clinicians should 'just ask them' about how they can assist a person and about what they prefer and expect; and third, to respect and comply with their expressed preferences.

More detailed guidelines cover

- providing disability awareness training to all healthcare staff
- communicating with patients,
- accessible information and communication methods,
- clinical and technical communication,
- physical accessibility,
- specialist facilities and services
- awareness of accessibility of transport
- developing organisational policies and procedures for
  - complaints,
  - evacuation in case of an emergency,
  - administration and carrying out paper work in privacy,
  - communicating with patients through email and electronic communications,
  - providing sign language interpretation,

- gaining service user feedback on the experiences of care.

Additional supports for people with disabilities to address access to and the quality of healthcare provision are highlighted in a number of studies (Emerson and Baines 2010, Krahn et al 2006, Northway 2011). For example, Northway (2011) identifies four key domains for change covering practice, education, policy and research. This study offers practical strategies for achieving equality and equity of access to healthcare for people with intellectual disabilities. Coordination and quality are themes that appear in the literature as being key elements of the provision of accessible services. According to Hwang et al (2009) people with disabilities experience multiple and complex medical and non-medical needs, which healthcare providers may not be equipped to respond to in coordinated and appropriate ways. These authors stress the importance of a consumer-led approach to healthcare, (rather than one that is facility-led) to overcoming structural and procedural barriers to healthcare, to improving consumer satisfaction, quality health outcomes and to providing cost-effective and effective healthcare.

### **People with intellectual disabilities**

A number of reports and inquiries into poor access to healthcare for people with intellectual disabilities in the UK have led to policy changes that focus on improving access to healthcare (Disability Rights Commission 2007, Mencap 2007, Michael 2008, Parliamentary and Health Services Ombudsman 2009, Department of Health 2008). The report 'Six Lives' (Parliamentary and Health Service Ombudsman 2009) of the investigation into the deaths of six people with learning disabilities recommended that effective systems be put in place for services to plan to meet the full healthcare needs of people with disabilities. Similarly, Michael (2008) documented examples of discrimination and neglect across health services and recommended that standards should be adjusted to reflect the reasonable adjustments that need to be made for people with disabilities and that clinical training should include mandatory training in learning disabilities. Recommendations for reasonable adjustments included the provision of annual health checks, the provision of support when a visit to hospital is made, help in communications, better information and improved regulation and inspection to reduce inequalities in access to healthcare. Recommendations were also made for the training of staff in general hospitals and collaborative working with family members and carers, The National Patient Safety Agency in the UK (2004) also concluded that patients with learning disabilities were particularly vulnerable when in acute hospital settings leading to varying degrees of harm as a result. The introduction in the U.K, of an annual health check with their general practitioner for people with learning disabilities is a response to the evidence of poor access to healthcare.

Other studies have shown the importance of targeting resources and improving the awareness of healthcare staff to address accessibility and the poorer health experienced by people with intellectual disabilities and people with mental health

difficulties (Emerson and Baines 2010, Northway 2011, Alborz et al 2005, Chapman and Mitchell 2009, While and Clark 2009, Leeder and Dominello 2005, Krahn et al 2006, National Patient Safety Agency 2004, Parliamentary and Health Service Ombudsman 2009, Royal College of Nursing 2011). Specific measures to remove accessibility barriers include the need for better clarity of responsibilities, giving priority to a person's health when in healthcare settings as compared to social and residential aspects of life, improve measures used with carers and individuals with intellectual disabilities to explore their health, as compared with the general population, and improve communications so that effective decision-making can be made on health issues (Ruddick 2005). Emerson and Baines' (2010) review of literature on health inequalities experienced by people with learning disabilities made recommendations for improved access to services. These include addressing the health needs of people with a learning disability in the broad framework of the social determinants of health; improvements in the prevention and early identification of illness; enhancing the health literacy of people with learning disabilities and of family carers and paid carers/supporters; making 'reasonable adjustments' in all areas of health promotion and healthcare; and monitoring progress to reduce health inequalities experienced by people with learning disabilities. Sweeny (2004) suggested that Registered Mental Health Nurses were key drivers for change and that policy developments in Scotland under the 'Promoting Health, Supporting Inclusion' initiative that considered the needs of both individuals and families should be replicated in Ireland in order to address inequalities in health service provision. Research gaps were identified in Alborz et al's 2005 review of literature on access to healthcare for people with learning disabilities, who are more prone to a wide range of additional physical and mental health problems than the general population. Suggestions were made for improvements in communication and inter-personal skills, improved facilities and flexibility in procedures. Good practice innovations cited include use of communication aids, a prompt card to support general practitioners, health check programmes and walk-in clinics.

### **People with mental health difficulties**

With regards to the accessibility of mainstream health services to people with mental health difficulties, one European survey, healthQuEst, (Wahlbeck and Huber 2009) found that stigma and an absence of targeted services seriously limits accessibility to general healthcare. The study's recommendations called for better targeting and coordination of resources to improve access to mainstream health services, including health promotion. Specific studies on accessibility of hospital and primary care services can be found below. Goodard's (2008) UK study and literature review on access to mainstream health services for people with mental health difficulties found that many of the identified barriers in access to services could be overcome. Practical issues highlighted include the introduction of better systems for accessing primary care and booking appointments at times that suit people with mental health difficulties, the provision of quiet waiting areas, better

training to address negative attitudes by reception and clinical staff and in understanding the stigma and fear experienced by service users.

### **Irish studies on access to health care**

Studies carried out in Ireland have highlighted a range of improvements that are needed to remove barriers to access. In relation to the experiences of older people living with a disability, research has shown the importance of person-centred care in service planning and service delivery that embed equity, age awareness, consultation and advocacy (Murphy et al 2006 and 2007). Pillinger's (2003) study for the National Disability Authority on health services for people with disabilities stated that information was seldom made available in accessible formats, while attitudinal barriers and lack of disability awareness training among staff were significant issues impacting on the quality of care available to people with disabilities. The National Disability Authority's 'Recommendations for improving the accessibility of health services for people with disabilities in Ireland' (2007), in partnership with the HSE Disability Legislation Implementation Overseeing Group, aimed to provide healthcare providers and planners with information about the barriers to accessing health services faced by people with disabilities and to suggest practical ways of overcoming these barriers. Recommendations include the provision of accessible and appropriate information, services located within accessible buildings, disability awareness training for staff and to address the needs of people with disabilities in the event of emergencies.

The research by D'Eath et al 2006, for the National Disability Authority, on inequalities of health and the experiences of people with disabilities in accessing health services in Ireland, found significant barriers in the quality of care available to people with disabilities. Some people with disabilities reported they could only access with the assistance of their family and friends or with the added goodwill of individual health workers who could work to compensate them for the deficiencies of the system. Fragmentation of services and lack of coordination made a person-centred approach difficult to achieve. Lower proportions of people with disabilities were found to have accessed preventative and screening services than the general population. Some people with disabilities reported having been denied access to in-patient hospital services unless they were accompanied twenty-four hours a day, highlighting a considerable lack of confidence or competence among hospital staff. Key issues were raised about the exclusion of people with disabilities from preventative services; inadequate public provision of certain services including speech therapy and physiotherapy; gaps in mental health services available to people with disabilities; and continuing physical, communication and attitudinal barriers experienced by people with disabilities. Although all research participants reported having experienced barriers to their use of the health services, the greatest difficulties were reported by people with intellectual disabilities and Deaf people.

The study concluded that there was “at best a ‘poor fit’ between the system and many people with disabilities” and that healthcare services were accessible “with considerable support from friends and relatives and from the informal support and good will of individual health workers who try to personally compensate for the deficiencies, inefficiencies and injustices of the system” (D’Eath et al 2006: 110). Recommendations were made for coordinated, person-centred services. Specific issues were also raised about the need to develop mental healthcare services so that they fully include the needs of all people with disabilities, not just those with intellectual disabilities.

Specific recommendations in the report cover:

- A ‘synchronised and person-centred health service, based on a social model of disability’, in order to address the fragmented and medicalised model of healthcare provision, improve the quality of care and address the complex and multiple needs of people with disabilities. Avoid ‘pathologising’ people with disabilities into specific medical conditions. However, the study did find some good examples of how General Practitioners had adopted partnership approaches and inclusive practices.
- Improved access to person-centred health services, and particularly to addressing access to preventative and screening services.
- Enhance independent living through the provision of Home Help and Personal Assistance services and a social model of health that leads to a partnership with the service users who have expertise in their own needs and lives.
- Remove financial barriers to accessing services and particularly to enable medical card holders and non-medical card holders to access support such as chiropody, counselling, speech therapy or physiotherapy.
- Address communication, attitudinal and physical barriers to healthcare through the use of alternative forms of communication and information, mandatory training of all health service personnel, including induction training and professional training, and the greater involvement of people with disabilities in the development of all plans, policies and strategies.

Two studies carried out by Spinal Injuries Ireland (2004 and 2009), based on consultations with service users, have detailed the barriers to access that are experienced by people with spinal cord injury, including issues such as pressure sores and bowel care that impact on a person’s quality of life in hospital. Recommendations from the consultations highlight the importance of staff awareness of the specific care needs of people with spinal cord injury, and the need for better procedures and policies on physical accessibility.

### **Health literacy, information and communications of healthcare staff**

Many studies address the importance of accessible information and communications for people with disabilities. Improving health literacy for service

users and carers/family members is a key element of accessible communications. Accessible information and communications is vital in influencing people's choices and health seeking behaviour. Research and guidance on health literacy by the National Adult Literacy Association (NALA 2002) has emphasised the importance of guidance for health professionals in improving health literacy for people with disabilities and in developing accessible communications. Health literacy has become an increasingly important element of healthcare policy, particularly in promoting health and well being. NALA uses the definition of health literacy made by the USA Institute of Medicine and the Department of Health and Human Services: "Health literacy emerges when the expectations, preferences and skills of individuals seeking health information and services meet the expectations, preferences and skills of those providing information and services". (Cited in NALA, 2010: 2)

Two factors impact on accessible information for people with disabilities, which have implications for the delivery of accessible information in order to improve access to health services (Gulliford et al 2001). On the one hand, the 'information age' has led to a rapid growth in access to information, while on the other hand, there is a widening gap between the 'information-poor' and 'information-rich'. Some people with disabilities have much better access to information arising from new technology and assistive technologies, but others may experience greater difficulties in accessing information because they do not have access to technology.

An Irish review of literature shows the absence of research on communications between nurses and people with an intellectual disability who communicate non-verbally (Martin et al 2010). Issues highlighted in the review include knowledge of the person with intellectual disability, knowledge of communication methods and mismatch of communication ability. A follow-up exploratory study (Martin et al 2012), based on the experiences of Registered Intellectual Disability Nurses revealed the complexity of communication and the importance of building service-user relationships, with users, families and disability providers, based on knowing the person and valuing their experiences.

There are a number of studies on improving accessible communications for people who are Deaf or hard of hearing. In one UK survey of 305 service users who use British Sign Language as their preferred language of communication, poor access to sign language interpretation and communication support was found in GP surgeries and in hospitals (Action on Hearing Loss et al 2012). The survey highlights the importance of implementing procedures for booking and communication through sign language interpreters in GP surgeries and hospitals and improved access to interpreters to avoid confusion about medication and medication errors and to avoid service users' reliance on friends or family members to provide interpretation. Other studies that relate specifically to accessible communications

with people who are Deaf or hard of hearing are documented in the sections below on Access to GP and Primary Care Services and Access to Hospital Services.

### **Access to mental health services for people with disabilities**

A number of studies have identified the changes that need to be made to raise awareness of staff and improve the accessibility of mental health services for people with disabilities. The National Disability Authority's Review of Access to Mental Health Services for People with Disabilities (2003) found that the specific needs of people with a dual diagnosis, i.e. intellectual disability and mental health difficulty, were not fully met and that this group of people were unable to fully exercise their rights in accordance with Ireland's international obligations with regard to the rights of people with disabilities. These rights include the right to acceptable levels of access to appropriate mental health services that are suited to their need and provided in a respectful manner. The report found the absence of a defined service appropriate to meeting the needs of people with a dual diagnosis. This resulted in the health of people with a dual diagnosis suffering. In its recommendations, the report called for services to be developed to cater to the specific needs of people with a dual diagnosis and called for the Department of Health to issue a national policy statement and service framework for mental health services which could adequately address the needs of people with a dual diagnosis. The report called for a strategy for the development of these services, and for their funding and management.

Checklists for GPs for the diagnosis and management of depression in adults with intellectual disability were evaluated in a study carried out in Australia with 49 adults with intellectual disability, their paid carers and GPs (Torr et al 2008). The checklist used by carers was shown to be a useful tool for GPs in diagnosing depression in adults with intellectual disability. However, the checklists used by GPs were not seen to be fully comprehensive to enable a full assessment to be carried out. The study highlighted the importance of improving GP awareness of mental health issues and specifically in relation to people with intellectual disability.

Zhang Hampton et al's (2011) study in the USA on access to social and psychological health services for women with neurological disorders drew on evidence from interviews with 23 women with neurological disorders. The study found that participants often did not have access to social and psychological services. It recommended that more was needed to raise the awareness of disability issues amongst mental health service providers, to improve access to counselling services and informal support to help people cope with mental health difficulties and to improve physical accessibility to services, including accessible transport. The implications for service providers were highlighted in relation to the need to improve outreach programmes, improve information dissemination and links between service providers and disability organisations, improve the training

and education of mental health professionals and improve the choices available to women with neurological disorders.

A study in the USA (O'Day et al 2005) identified how barriers experienced by 16 participants with mental health difficulties could be overcome in accessing primary health care services. The study is part of a larger project that examined the health care experiences of a range of people with disabilities. The following barriers were identified by the participants: poor communication skills and lack of empathy, misunderstandings and lack of awareness of mental illness, inadequate information about the side effects of medication and financial burden due to inadequate insurance coverage. Suggestions were made for improving patient-physician communication skills and putting in place a respectful and patient-focused approach, improving knowledge, and implementing strategies for improved personal care and the empowerment of people with mental health difficulties in their relationship with physicians. First, it was suggested that physicians need up-to-date knowledge on the changing nature of mental ill health over time and how it can be managed through medication, therapy and other interventions. Second, training and awareness is needed for primary care physicians, including medication and the side effects of medication. Third, having improved access to physicians who do not have stigmatizing attitudes. Fourth, the need for a supportive environment to disclose a mental health difficulty was seen as particularly important in managing medication. Fifth, provision of support groups and practical information such as finding sensitive doctors and community resources. Sixth, opportunities for patients to be empowered to be their own advocates in having their health care needs met and in promoting their own health and well-being.

### **Deaf Service Users**

In 2002 a consultation exercise with health professionals and service users was carried out by the Department of Health in the UK on Deaf services users with mental health difficulties. The consultation report, 'A Sign of the Times' (Department of Health 2002) found a lack of awareness and an absence of services for Deaf people with mental health difficulties, including appropriate communication support and access to sign language interpretation.

Recommendations were made to improve Deaf awareness training, the development of a national strategy for Deaf mental health services, better procedures regarding emergency admissions and improved systems for identifying and responding to the needs of Deaf service users. Following this the Department of Health made recommendations to Primary Care and Hospital Trusts to improve access to services for Deaf people with mental health difficulties (Department of Health 2005). Recommendations included developing local Needs Assessments of the mental health of Deaf people, the provision of Deaf awareness training for front line staff, in partnership with local voluntary groups and local authorities, the piloting of a telemedicine service to provide medical information at a distance,



improve the availability of sign language software, specialist sign language interpreters and the use of video-links. Specific recommendations were made to improve needs assessments of and service provision for Deafblind people, Deaf prisoners and older Deaf people requiring residential care.

Islington LINK's (2011) on-line survey of local health providers on reducing communication barriers for Deaf service users accessing mental health services aimed to find out how they were implementing the government's 2005 guidelines on 'Mental Health and Deafness, Towards Equality and Access'. Of the 242 providers responses it was found that hospital staff often did not have the capacity to communicate with Deaf people and many lacked Deaf awareness. Recommendations were made for all frontline staff to participate in Deaf awareness training. Practical suggestions included ensuring that staff know how to use a loop system for hearing aid users, providing visual display alert systems, whiteboards or number systems in waiting areas to call a patient who is waiting to see a clinician, systems in place for booking an interpreter, and for service users to have access to a minicom or email to book and change appointments.

### **2.3 Access to hospital care**

There is a paucity of literature on access to hospital care for people with disabilities. A literature review of access to secondary healthcare for people with intellectual disabilities (Backer et al 2009) found a limited range of research studies on the issue. From the fourteen published studies some key factors impacting on the experience of people with disabilities in a hospital setting included individual factors, the role of the carer, attitudes and knowledge of staff, communications and the physical environment. Recommendations were made for more research to improve access to healthcare and for initiatives to improve access to be evaluated so that they inform the development of services.

#### **Intellectual disability**

Good practice examples from the UK can be found in the work of Learning Disability Hospital Liaison Nurses in UK hospitals. These nurses provide help with planning and preparing for coming to hospital, during treatment and in providing support when the person is in hospital and in planning discharge. These initiatives have resulted in a better capacity to identify healthcare needs and risks, make reasonable adjustments in the provision of services and provide better information for service users with an intellectual disability (Northway 2011). However, these examples are not universal and there is a need for change to take place in four areas. First is the domain of professional practice, which requires increased awareness of barriers to healthcare, awareness of specific healthcare needs, and addressing of negative and discriminatory attitudes. The second domain that needs attention is professional education. The needs of people with intellectual disabilities should be addressed in in-service, undergraduate and continuing education programmes including developing positive attitudes, communication skills and

improving competence, and by directly involving people with intellectual disabilities in education programmes. The third domain is that of policy formulation, ensuring that people with intellectual disabilities are named in wider healthcare policies and specific policies; and that all new policies should be assessed for their impact on the health of people with intellectual disabilities. Fourth, is the domain of research and data collection so that people with intellectual disabilities are included in public health surveys and in carrying out research in areas such as the role of support workers in promoting access to healthcare.

The importance of accessible communications with family members in acute hospitals is highlighted by Barr (2004). Gibbs et al (2008) carried out focus groups with eleven adults with intellectual disability, nine parents and five paid carers of adults with intellectual disability. The study found that participants often experienced fear and anxiety in a hospital setting and communication barriers were not uncommon. The findings led to recommendations for further research and policy to address awareness and training of staff, improved communications and protocols in a clinical setting and in the provision of local services.

Research on access to hospital care for people who are Deaf or hard of hearing shows that difficulties arise in making and changing appointments, non-attendance at appointments due to dissatisfaction with a previous visit and poor procedures on using interpreters. The Royal National Institute for Deaf People (RNID) (2004a and 2004b) for example, has suggested that better use can be made of existing technology such as visual alert displays and loop systems, the introduction of Deaf awareness training and training in communication skills, provision of written information in plain English, guidance on using interpreters and access to video interpreting technology. Practical suggestions include keeping a file of written questions in plain English to use when a Deaf patient is admitted to hospital, produce a short video to help orientate a Deaf patient to a hospital ward, provide access to a minicom, text television or computer, and ensure that there is access to communication tools and sign language interpretation.

The publication in Northern Ireland of *Equal Lives: Review of Policy and Services For People with a Learning Disability in Northern Ireland* (Department of Health, Social Services and Public Security, DHSSPS 2005) led to an objective to improve access to healthcare of people with a learning disability' (Objective 7) and fourteen recommendations for implementation. The number of people with learning disability is projected to increase by 1% each year over the next 15 years and it is anticipated that the number of children and older adults with complex physical health needs will be significant (DHSSPS 2005). The Guidelines and Audit Implementation Network (GAIN) (2010) guidelines (discussed in Section 3) also reviewed the literature in relation to access to hospital services for the 26,500 people with learning disabilities in Northern Ireland and found evidence of the need

for a wide range of improvements to be implemented in order to enhance access to hospital care.

In relation to research on accessibility for people with acquired brain injury, one study in Queensland, Australia, of 20 people with acquired brain injury and 18 family carers of the service highlighted the support needs of people with acquired brain injury and their family carers during the transition from hospital to home (Turner et al 2011). The study found varying levels of support during the transition from hospital to home, difficulties in negotiating the rehabilitation process between hospital and home and in access to support after discharge from hospital. The findings of the study highlight the importance of providing better coordination of care between inpatient and community based services.

## **2.4 Access to emergency care**

The literature review found few specific studies of accessibility in emergency care services. One study has shown the difficulties experienced by Deaf patients in using Accident & Emergency (Reeves et al 2002 and 2004b). Many of the problems experienced by Deaf patients arose from staff not understanding the communication needs of Deaf people. The lack of visual patient call systems led to difficulties for Deaf people knowing it was their turn to be seen, and problems occurred even when staff had been informed that the individual was Deaf. Even where people could lip read they found that staff spoke too quickly and some patients had difficulty in understanding what was written down because it was too complex. Service users identified the need for staff to learn some basic sign language, that sign language interpreters should be provided and for staff to be trained in Deaf awareness. The research recommended that A&E departments should have a system for obtaining qualified sign interpreters and that they should offer to provide an interpreter if this is requested. Practical recommendations included installing a textphone, putting in place a visual patient call system and to provide accessible written information about after-care. Further recommendations were made about staff having access to Deaf awareness training, on consulting with Deaf people about the services they received and for A & E departments to put in place a policy on access for Deaf people.

Another study found that providing more continuity of care between primary and specialist care for people with disabilities was crucial (Wood and Hall 2007). Better coordination of care was found to be important to reducing the deterioration in the general health of people with intellectual disability and/or development disability, and thereby reducing the need for attendance in emergency services.

A focus group with four women with intellectual disabilities who had repeat visits to emergency departments due to a mental health or behavioural crisis reported on negative experiences (Lunsky and Gracey 2009). These included not being respected, trauma associated with restraint and staffs' lack of awareness. A number

of recommendations were made for improving the experiences of women requiring emergency services.

Focus groups with 27 nurses in accident and emergency departments in five hospitals in Northern Ireland found a lack of knowledge about how to care for people with intellectual disabilities, leading to an over-dependence on service users carers/support persons (Sowney and Barr 2006 and 2007). The study recommended that staff in emergency departments have training and awareness raising about the abilities and needs of people with intellectual disabilities.

## **2.5 Access to maternity services**

Begley et al (2010) interviewed 78 women with disabilities (20 in the mental health group, 18 each in the physical disability, hearing impairment, vision impairment groups and 4 in the intellectual disability group of the study). A further 30 people participated in focus group discussion and focus groups were also held with health care professionals. While some of the issues raised were specific to maternity and infant care services, others would apply to health services generally. People with physical disabilities commented on distance to parking, the importance of automatic entrance doors, internal steps which made areas of a hospital inaccessible, the importance of having accessible bathroom and shower facilities on wards, the need for adjustable height examination couches, and difficulty reaching to lift a baby from a hospital cot. People who used crutches commented on being expected to carry their hospital notes from one area to another which they found difficult. People with sight or hearing difficulties underlined the importance of being able to make appointments via accessible means of communication, and of having suitable ways to know when it is your turn to be seen. Visually impaired mothers spoke of the importance of orientation to know where things were (such as different facilities, seats, the bedside light and alarm switch, where to go to eat.). Being told to 'take a seat' is difficult if you can't see where the seats are. Women with vision impairments were at a disadvantage because they were unable to see their baby's ultrasound, and staff often did not take the time to talk them through it. Women who were Deaf reported difficulties around communication, availability of sign language interpretation, not knowing what technical or hospital jargon meant ('gynae ward'), and issues around confidentiality when relying on others to interpret or transmit information. Antenatal classes were problematic for women who had difficulty with vision or hearing. The report documented good practice where a maternity unit liaised with a person's mental health team, and conversely bad practice where there was no link-up at all. The question of taking medication in pregnancy was also reported as an area of difficulty by mother with mental health conditions. Some participants reported the lack of understanding or appreciation of a person's disability were cited by some staff, and experiencing negative attitudes. Some professionals conveyed a negative attitude towards women with disabilities becoming pregnant. Taking the baby into care was a major issue for mothers with intellectual disabilities.

The authors called for more direct involvement of service users in the improvement of healthcare services, for the provision of specialist services for women with mental health difficulties and for continuity of care between hospitals, primary health care teams, community-based health services and general practitioners. Practical suggestions were made for improving accessibility through better awareness of staff, greater flexibility in service provision, accessible communications and information, improved physical accessibility and the use of aids and adaptations during all stages of pregnancy, childbirth and early motherhood.

## **2.6 Access to primary care and GP services**

There is an extensive literature on how to improve access to primary and preventative healthcare for people with disabilities (Kirschner, Breslin and Iezzoni 2007, Parish and Huh 2006, Drainoni et al 2006, Scheer 2003, World Health Organisation 2011, Jones et al undated, Larson et al 2002). The literature on access to primary care and GP services shows that health professionals often have to spend extra time providing a service to a person with a disability in order to ensure accessible consultations and communications. McColl et al's (2010) study in Northern Ireland found that the quality and accessibility of primary care for adults with disabilities was affected by the workloads of health professionals, levels of patient contact and whether GP practices were salaried or funded through the capitation system. Those that were salaried were much more likely to provide an accessible service and to be willing to accommodate the healthcare needs of people with disabilities. This is an important issue because GPs and other healthcare professionals often face constraints on their time.

The barriers faced by people with intellectual disabilities in accessing primary healthcare were identified in a UK study of service user and social care staff, based on interviews and focus groups (Webb and Stanton 2009b). Three key themes emerged from the study relating to access to the GP surgery, communication issues and waiting to be seen. Social care staff highlighted attitudes and behaviour of primary care staff and the importance of knowing the service user. Service users identified issues related to their concerns about going to see a doctor, health education and making changes. The perspectives of service users and social care staff were seen as an important precondition for improving access to primary healthcare. Research also points to the need to develop the evidence base on meeting the healthcare needs of people with learning disabilities, to enhance the care experience, enhance the practice of learning disability liaison nursing services and reduce the risk of harm (Brown et al 2010). A further UK survey of forty-nine adults with learning disabilities found that the needs of people with learning disabilities often go unmet, despite the fact that their primary health care needs tend to be higher than those of the general population (Lennox et al 2003). Specific health care needs that were often neglected included foot problems, incontinence,

vision impairments and specific medical conditions. Recommendations are made for improved service planning to meet the needs of people with learning difficulties.

Research in the USA (Morrison et al 2008) on how family physicians address the accessibility needs of people with physical disabilities was based on six focus groups carried out with health professionals in primary care and three focus groups with adults with physical disabilities. The objective was to gain greater insights into some of the barriers identified from other studies about access to preventative care and dissatisfaction with the provision of care. The study found that research has not focused on the relationships between disability and quality of care, and the importance of raising awareness of disability access in medical education. The key finding was that physicians and other health professionals require better awareness of disability issues, on the basis that knowledge and attitudes of health professionals impact on accessible communications and physical access. In relation to service users, physical access issues that were identified for improvement were the provision of high-low examination tables, wide automatic doors, high-contrast signs and lighting, wheelchair scales. Quality of care issues included effective referral systems and discharge planning, coordination of care, longer appointment times and the need to see the person and not the disability. Suggestions by service users to improve communications included the need for better training, with a focus on the need to communicate directly with the service user, to take time during consultations and to provide relevant clues to vision impaired patients. Healthcare staff and clinicians identified the need for coordination of care and a team approach, information on how to access disability resources, how to adapt services, access medical equipment, provide accessible forms for disability status and plan for discharge. Specific needs were identified for training for all healthcare staff. Overall recommendations included the need for more training for staff, better knowledge of disability, better physical access, improved disability focussed systems for ensuring quality care and positive attitudes towards people with disabilities.

Physical accessibility to primary care services has been highlighted in a number of studies. Surveys of the physical accessibility of primary care facilities, using the American with Disabilities Act Accessibility Guidelines, shows that health care facilities often lack key elements of accessibility (Yee and Breslin 2010). Key elements of physical accessibility identified in one survey of physicians' practices in South Carolina included accessible parking, lever door handles, clear floor space and grab bars in the restroom, hearing aid-compatible telephones, wheelchair accessible scale, and an adjustable-height examination table (Leigh Graham and Mann 2008). In another study, using focus groups with people with physical disabilities, specific issues highlighted were low levels of accessibility and usability of examination tables, imaging equipment, medical chairs, and weight scales (Story, Schwier and Kailes 2009). The findings from the focus groups found that lack of accessible medical equipment and technology impacted on patient safety and accessibility. Specific issues were raised about lack of physical support for patients

with disabilities to transfer on and off equipment and in maintaining body positions while on the equipment, limited access to wheelchair scales and an absence of voice outputs on wheelchair scales for people with vision impairments.

Mudrick (2007) in the USA identified specific areas that needed to be addressed to remove access barriers in access to primary and preventative care. These include financial (access to treatment and specialists), structural (access to buildings) and programmatic (accessible equipment and expertise of healthcare staff in providing an accessible service). Although financial and structural barriers are generally well understood, this is often not the case regarding programmatic access barriers. Mudrick goes on to outline how medical practice, policies and procedures can be developed to enhance programmatic access to healthcare for people with disabilities. These encompass policies and procedures regarding communicating with people with disabilities, making appointments, accessible treatment and equipment, staff training and awareness, coordination and flexibility and disability cultural competence. A research audit on the accessibility primary care provider facilities in California (Mudrick et al 2012) found significant physical access barriers. 2,389 accessibility site reviews were analysed in areas such as parking, exterior access, building entrance, interior public spaces, doctor's office interior, and the presence of accessible examination equipment. The highest prevalence of barriers to access was found in the relation to the provision of accessible weighing scales, available in only 3.6% of premises and height adjustable examination tables, available in only 8.4% of premises. Barriers to access were also widespread in bathrooms and examination rooms. Parking, exterior access, building access and interior public spaces were more likely to meet accessibility requirements.

The importance of awareness raising and training for staff in primary care services is highlighted from consultations with service users and practitioners in a number of other studies. An evaluation of a project to raise awareness, improve training and adaptations to working practices in three primary care practices in North-Essex in the UK found an association between poor health of people with a learning disability and the inadequate accessibility provided by primary care practitioners (Webb and Stanton 2009a). The research showed that the individual's experience of healthcare can affect their future engagement with services. The production of Practice Development Plans had helped to improve access for people with learning disability and further recommendations were made for further improving awareness and training of staff.

Evidence from a Scottish nurse-led education programme on promoting accessible primary care for people with learning disability in one primary health care practice shows the positive impact of continuing training (Jones et al undated). In the pilot site evaluated in this study there was a positive impact on improving accessibility, inclusivity, knowledge, attitudes and behaviour of staff in primary care. Outcomes from the continuing training led to the development of planning, a programme of

regular health checks for people with learning disability and consultations with service users. The study built on evidence collected from focus groups and interviews with 25 service users (Jones et al 2008) which highlighted the importance of awareness raising for staff and changing attitudes towards people with disabilities, improving accessibility and helping people to access the surgery and enhancing communications. Melville et al's (2005 and 2006) study called for additional training for service providers and recommended that training initiatives be directed at practice nurses due to the fact that they were found to have positive attitudes and high self-efficacy scores in their work with people with intellectual disabilities. Awareness training on supporting people with intellectual disabilities had a positive impact on the work of practice nurses, with 61% of the sample stating that they had applied the training in their work and 69% saying that there had been a change in their view of their role as practice nurses in supporting people with intellectual disabilities.

Accessible communications and good interpersonal skills are common themes identified in research documenting consultations with service users and health practitioners. Research by Murphy (2006) on communications between people with a communication disability and General Practitioners found that poor communications impacted on access to health services and the dignity of the person with a communication disability in multiple ways. The need for training and simple communication tools were identified by General Practitioners. People with a communication disability emphasised the importance of continuity of staff, trust, better staff communication skills and less reliance on carers. Communications is also a key theme arising from service user consultations on the difficulties experienced by Deaf patients in using GP services in the UK (Reeves 2002, Reeves et al 2004a, Dye et al 2001). This recommends that GP practices should be aware of how to book a qualified sign language interpreter and that they should offer to book an interpreter if a Deaf patient requests one. Further recommendations made for GP practices, were to have a system to enable a Deaf person to contact a GP practice directly to make an appointment; the introduction of visual patient call systems; and for Deaf people to have information about after-care provided in writing and in plain English. Specific issues were raised about the need for staff to receive Deaf or disability awareness training, for Deaf people to be asked their views about existing services and for policies and guidelines to be put in place for staff.

In another study, based on interviews with service users with communication difficulties and carers in a primary care setting, Law et al (2005) identified key themes of inclusion, participation in society and access to healthcare; the process of communication itself; and continuity in the relationship between service users and providers. Another USA study carried out consultations with people with disabilities to identify their perceptions about the quality of care received in a primary health care setting (Bowers et al 2003). A key finding from the study was



that expertise in the provision of health care is not just technical, but benefits from a combination of knowledge and expertise from people with disabilities and through collaboration in the patient-provider relationship.

There is an extensive literature on the provision of GP and primary care services for people with dementia in a general healthcare setting (National Audit Office 2007, Henderson et al 2007, Sheard 2011, NICE 2006, Argle et al 2010, Alzheimer's Society of Ireland 2006, O'Shea 2007). Around 40,000 people in Ireland have a diagnosis of dementia. Research and guidelines from the Alzheimer's Society of Ireland and Alzheimer's Society (UK) focus on the fear and ignorance of the disease. This may create barriers to people and unpaid carers approaching their GP about suspected dementia. GPs' own attitudes could impede an early diagnosis. Focus groups of people with dementia and unpaid carers participating reported that diagnosis of dementia is often poorly communicated. Some other health or social care professionals lack the training and knowledge to provide advice on services and support that may help improve people's quality of life.

### **Access to preventative healthcare**

The need for innovative strategies to promote the health and well-being of people with disabilities has been highlighted in consultations with people with disabilities and health providers. For example, Rimmer and Roland's (2008) USA study suggest that attitudinal, programmatic and architectural accessibility are important to creating disability friendly environments, as is the need to empower and support people with disabilities to manage their own health.

Analysis of the results of the USA 2006 National Health Interview Survey found that women with disabilities, compared to women without disabilities and men with disabilities have lower access to healthcare, including preventative healthcare (Smith 2008). In relation to women's access to preventative healthcare two studies document the findings of consultations with women with intellectual disabilities (McCarthy 2010, Woods and Douglas 2007). McCarthy's (2010) study of the experiences of women with learning disabilities in accessing contraception involved interviews with 23 women with learning disabilities and a postal survey of GPs. The study highlighted the need for women with learning disability to make informed choices about contraception, and particularly to find alternatives to contraceptive implants and Depo-Provera, which are often prescribed to women with intellectual disability. Similarly, the research also points to the need for better awareness of practitioners in ensuring that when a woman with learning disability has capacity and refuses contraception, her wishes should be respected. Suggestions coming from the study include the need for flexibility and sufficient time to be given to communicate with women with intellectual disability, for example, through a series of short visits to a family planning clinic or GP, and through the provision of support during appointments. Information in an accessible format is also needed for women to take away and consider, and where this is not possible for decisions

about consent to be made on the basis of 'best interest'. The study also suggests the need for GPs and practice nurses to be aware of the lives, needs and capabilities of people with learning disabilities. The study suggested the participation of people with learning disabilities in education, training and in drawing up accessible information.

A survey of 24 GPs in Scotland, including follow-up interviews with six GPs, examined access to cervical screening for women with learning disability (Woods and Douglas 2007). The survey found that many doctors were unable to identify which of their patients had a learning disability. It found that women with learning disabilities were not invited to have smear tests. The findings suggest that there is a need for doctors and nurses to do more to encourage women with learning disabilities to take up smear tests, including the need to identify patients on their list who have a learning disability, and for greater guidance and support in how to provide screening to women with learning disability.

Other research has pointed to the need to improve access to health screening, immunisation and health promotion for people with disabilities. For example, Jones' (2005) study found that people with disabilities did not receive blood pressure checks and cholesterol checks to the same extent as non-disabled people. Women with mobility disabilities had poor access to pap smears, breast examinations and mammograms. Such women could be consulted about oestrogen therapy to prevent bone loss, which is of importance to women with mobility disabilities who are unable to carry out weight bearing exercise. This was also found to be the case in Parish and Huh's (2006) US study on access to preventative healthcare for women with disabilities. Mele et al (2005) study showed that women with disabilities in the USA faced barriers in access to breast screening services that may result in delayed detection and poorer outcomes from treatment.

Recommendations were made to improve the training and awareness of staff in working with and communicating with women with disabilities, in line with the guidelines drawn up under the Americans with Disabilities Act of 1990 which call for all screening services to comply with accessible design standards. A partnership approach was recommended which allows women with disabilities to be partners in their own care. O'Connor, Barry and Murphy's (2006) literature review on women and disabilities similarly found that women's access to sexual and reproductive services was impeded by poor communications, attitudinal barriers and a double burden of inequality faced by women with disabilities.

Specific recommendations made in the literature include the need to target people with disabilities more effectively to take up health promotion, health screening and cancer screening programmes. Women with intellectual disabilities could miss out on being offered cervical screening (Royal College of Nursing 2011), or sex education and sexual health programmes (O'Connor, Barry and Murphy 2006),

based on assumptions that they were not sexually active. Such assumptions and attitudes needed to change.

## **Section 3: Guidelines on access to healthcare**

### **3.1 Introduction**

In addition to the review of literature outlined in Section 2, the development of the HSE/NDA guidelines drew on information resources and guidelines that have been drawn up to improve accessibility of healthcare services. Some guidelines focus on people with specific disabilities, whilst others cover access for all people with disabilities. They include guidelines drawn up by government agencies to implement legislation or standards on accessibility, guidelines drawn up by professional bodies on accessibility and guidelines drawn up by NGOs and disability organisations.

For the purposes of presentation, the guidelines reviewed are separated into those on:

- Access to all healthcare services
- Access to hospital services, emergency services, maternity services and GP/primary care services
- Cross-cutting guidelines on physical, information and communications accessibility.

### **3.2 Guidelines on access to all healthcare services**

- Guidance from the UK General Medical Council's Good Medical Practice (Equality and Human Rights Commission 2008), produced with the Disability Rights Commission (now Equality and Human Rights Commission) draws out specific examples for disability equality and for the full implementation of the then Disability Discrimination Act 1995. The guidelines are intended to help inform both people with disabilities about what they can expect and medical practitioners how they can improve the accessibility and quality of their services. Practical examples on how accessibility can be implemented are detailed under each of the Good Medical Practice guidelines.
- Guidance on Rights of access to health and social care have been drawn up under the Disability Discrimination Act (Northern Ireland) (NI Direct undated). The Disability Discrimination Act (DDA) specifies the rights of people with disabilities in relation to access to health services, including access to information in an accessible format. This also specifies that disabled people have important rights of access to health services and social services, such as doctors' surgeries, dental surgeries, hospitals and mobile screening units. The anti-discrimination provisions of the DDA mean that your GP should not refuse to register, or to continue treating you, because of your disability. The DDA

also means that you have a right to information about healthcare and social services in a format that is accessible to you where it is reasonable for the service provider to provide it in that format. For example, a hospital may provide forms and explanatory literature in large print or Braille to assist people with visual impairments, or arrange for an interpreter for someone with a hearing impairment.

- NHS Scotland / Disability Rights Commission (2007) *Achieving Fair Access: Improving NHS Services for people with disabilities*, provides detailed guidance covering disability equality, accessible service delivery, accessible communications, accessible estates and buildings and putting the guidance into practice.

### **People who are Deaf or hard of hearing**

- Guidance on providing accessibility for people who are Deaf or hard of hearing are found in Disability Services Commission Western Australia (undated), *An introduction for management on the needs of people who are deaf or have a hearing impairment (under the You're Welcome initiative: Community access for all ages and abilities)*.
- RNID *Guidelines on accessibility of health services: Tips to Make Your Service Accessible*, provide guidance on being prepared, being flexible, deaf awareness, being understood, how to book communication support and use equipment and staying in touch and involving patients.
- Irish guidelines developed by a group comprising the Citizens Information Board, deaf community interests and the Health Service Executive (2012) on health services for people who are Deaf and hard of hearing.

### **People with intellectual disabilities**

- Royal College of Nursing (2011) *Meeting the health needs of people with learning disabilities: RCN guidance for nursing staff*. The guidance document states that learning disability services in the UK have moved from a medical model towards a social model of care. The emphasis in the guidelines is on promoting social inclusion, choice, independence and rights. The guidance covers consent issues, specific healthcare needs, the provision of specialist services in the community, supporting access to services by creating an accessible environment, verbal communications, written information and inpatient care.
- Royal College of Nursing (2009) *Dignity in health care for people with learning disabilities: Guidance for nurses*, provides guidance for nurses on how to provide dignity in care in areas such as understanding a person's health, giving respect, getting to know the person, having choices and enabling people to make decisions, feeling safe and communicating in accessible and dignified ways.

- Guidelines for health professionals in providing healthcare to people with learning disabilities (Mencap undated). The guidelines are part of Mencap's Getting It Right Campaign and contains suggestions on how to make reasonable adjustments when providing health services to people with learning disabilities.
- Guidance drawn up by Imperial College NHS Trust (2010) on Supporting patients with learning disabilities: Good practice guidelines. This covers guidance on supporting effective communication, admissions and discharges, preparing individuals for admissions or clinical interventions, clinical tools, supporting family or familiar carers, consent to treatment, involving specialist teams, creating accessible information and quality assurance.
- Inclusion Ireland (undated) Intellectual disability: causes and prevention – your questions answered, provides information on the causes, diagnosis and prevention of intellectual disability, and gives information about organisations to contact.
- Inclusion Ireland (formerly NAHMI) (1999) recommended that standards should be set for service providers and in relation to the health of people with intellectual disabilities "Each service provider should have in place a written policy that identifies their procedures in monitoring the health needs of people in their care". Some people with intellectual disability may have specific health needs arising from their syndrome, age, life needs or gender. A small but significant number of people, because their level of intellectual disability is so profound, are not in a position to indicate their specific needs, discomforts, and / or pain. Services in collaboration with parents and families should monitor the general health needs of service users and should pay particular attention to reviewing medication and eye care.

### **People with impaired vision**

- NCBI Guidelines for all health professionals: Guiding a person with a vision impairment, provide guidance on what to do prior to an appointment, going for an appointment, in the waiting room, offering medical advice, providing medical information, being admitted to hospital and going home.
- NCBI Guidelines for nursing staff: Assisting adults with sight loss in hospital, provide guidance on what to do prior to an appointment, going for an appointment, in the waiting room, offering medical advice, providing medical information, being admitted to hospital and going home.
- NCBI Guidelines on Meeting and greeting people with sight loss, provide guidance on what to do and what not to do when meeting a greeting a person.
- Disability Services Commission Western Australia (undated) An introduction for management on the needs of people who are blind or who have vision impairment (under the You're Welcome initiative: Community access for all ages and abilities).

### **People with mental health difficulties**

- Shine (2010) Taking Control of Your Mental Health, which provides a wide range of information about different mental health disabilities, medication, recovery and contact information.

### **People with dementia**

- National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (2006) Dementia: Supporting people with dementia and their carers in health and social care, NICE Clinical Guideline 42, London: NICE/SCIE
- Alzheimer's Society of Ireland: Information Pack containing information resources for people whose lives are affected by Alzheimer's.
- Alzheimer's Society (UK) guidelines on How Health and Social Care Professionals can Help, covers practical information and factsheets on community care assessments, the role of GPs, diagnosis and assessment, the standards of care people expect from a care home, hospital discharge and care on a hospital ward.
- The Social Care Institute for Excellence on-line resources on dementia care.
- The Scottish Dementia Working Group (2007) a group of people with dementia produced a document What disempowers us, with suggestions about improving communications, awareness and sensitivity in care settings.
- Neill M (undated) Alzheimer's Dementia: What You Need To Know, What You Need To Do Guidance and Resources on Alzheimer's Dementia for Carers of People with Down's Syndrome.

## **3.3 Guidelines on access to hospital, emergency, maternity, GP/primary care services**

### **3.3.1 Guidelines on access to hospital**

- You can make a difference Improving access to hospital services for disabled people (Disability Rights Commission/NHS 2006 edition), provide practical guidelines on making appointments, arriving at hospital, reception areas, waiting areas, initial assessment and treatment areas, referral onto a ward and other treatment areas and discharge from hospital. Find out how disabled people want you to assist them first. Never simply take hold of a disabled person. Five key messages for a quality service, based on consultations with service users, are given in the guidelines:
  - Use an everyday tone of voice. Do not shout at or patronise a disabled person.
  - Ensure that disabled people are not pulled backwards in their wheelchairs.
  - Make sure that you enable people to communicate in their own way, and in their own time.

- Take the time to explain to people what is going on and check that they understand, to avoid unnecessary anxiety.
- Don't make assumptions. For instance, avoid assuming that someone's impairment is the cause of the problem.
- Center for Universal Design and The North Carolina Office on Disability and Health (undated) Removing Barriers to Healthcare: A Guide for Health Professionals. The guidance has a specific focus on universal design and recommends designing the built environment and products to be useable by everyone wherever possible, regardless of their age, status or ability.
- USA Guidelines on completing the Federal guidelines on Outpatient Health Care Usability Profile (Drum et al 2008), provide a checklist for providers to assess accessibility issues. These cover patient arrival (entrance ramps and doors, controls and signage), public facilities (telephones, water fountains, waiting room seating and reception counters, passageways, emergency egress and restrooms), and examination rooms and access to primary care services (accessibility of examination rooms and restrooms).
- Guidelines and Audit Implementation Network (GAIN) (2010) Guidelines on Caring for People with a Learning (intellectual) Disability in General Hospital Settings set out twelve areas for improvement in relation to the person's journey through a general hospital. It is argued that many of the issues that are dealt with in the guidelines can be delivered through better individual care planning, improved communication and effective liaison within and between services, and within existing resources. Each guideline covers a best practice statement and guidance in relation to:
  - Attitudes and values: every individual with a learning disability using hospital services should have equitable access. Staff in a general hospital setting should demonstrate behaviours that are respectful, which include seeing the person not the disability; ensuring that communication is sensitive to the needs and preferences of the person; person centred care; dignified, respectful and compassionate care; and non-judgemental attitudes.
  - Communication: people with learning disabilities and their families/carers should experience effective and meaningful communication to support safe and person-centred care.
  - Training: every individual with a learning disability has the right to receive care and services from knowledgeable, competent and skilled practitioners, in a timely, safe and caring environment that takes account of their specific needs. The training to support this care must be available to and accessed by all professional and non-professional staff who potentially deliver services to people with a learning disability in the general hospital setting.
  - Legal issues: staff working in general hospitals will understand and apply the relevant legal and professional framework(s) and principles in the delivery of

care to children and adults with a learning disability, ensuring that care is delivered in a safe, effective, personalised and non-discriminatory manner.

- Outpatients: all people with a learning disability who have an outpatient appointment at a general hospital will have an opportunity to be supported in preparing for this. Account should be taken of their abilities and needs, together with the implications of these to facilitate examination, treatment and care.
- The admission process and support during the hospital stay: when a person with a learning disability needs to be admitted to hospital, steps should be taken to prepare them, the hospital staff and the ward to ensure that they receive safe and effective care during their hospital stay.
- Discharge planning: individuals with a learning disability and where appropriate, their family/carers, will have a thorough and coordinated approach to discharge planning that meets their specific needs. Discharge planning will begin on the day of admission and will be evidenced within the patient's plan of care.
- Support for carers: when a person with a learning disability is required to use the general hospital setting, carers should be engaged as healthcare partners throughout the pathway of care alongside, not instead of, healthcare staff.
- Nutrition and hydration: people with a learning disability will receive high quality nutritional care based on individually assessed needs, which may be additional and more complex than that required by the general population. Quality nutritional care will involve appropriate screening, assessment, planning, monitoring, serving and, where necessary, safe practical help with eating and drinking.
- Assessment and management of pain: people with a learning disability will be assessed for pain, with attention focused on both verbal and non-verbal indicators of pain and/or distress. Their pain should be fully investigated and treated according to clinical need.
- Children in hospital: children and young people with a learning disability who use general hospitals will receive coordinated, safe, effective and child/family centred services that are age appropriate and based on assessed needs.
- Mencap (2008) Advice for hospitals and health professionals. Provides practical tips on detecting health problems, communicating in accessible ways by asking, listening to parents and carers, not making assumptions about a person's quality of life and capacity to consent.
- One method to improve access to healthcare for people with intellectual disabilities is through the development of specific hospital patient pathways for adults with intellectual disabilities. See for example the NHS East of England



Learning Disability QIPP<sup>1</sup>, Improving Acute Hospital Patient Pathways for Adults with a Learning Disability and Adults with Autism (NHS East of England 2011). This covers high level pathways for Acute Hospital in-patient, out-patient and accident and emergency services for adults with a learning disability and adults with autism, guidance for more effective alert and information system, a Quality Assurance Framework and models for self assessment and an Improvement Plan, a framework for workforce development, model role and reporting structure for Learning Disability Liaison Nurses, recommended protocols and joint agreements, an index of good practices and indicative levels of activity and possible savings.

- Many hospitals in the UK have developed protocols for supporting people with learning disabilities in a hospital setting. For example, a protocol developed by a multidisciplinary group addresses a number of issues for people with learning disabilities who access services at the Hillingdon Hospital (2012). This includes equality of access, easy to understand information, best interest decision-making and the role of the Community Learning Disability Teams and support staff. Similarly the introduction of Patient Passports has been one way to improve communications. An example of this is the Hillingdon Patient Passport (Hillingdon Hospital, undated).
- Imperial College Healthcare NHS Trust (2010) Supporting patients with learning disabilities: Good practice guidelines, gives examples of reasonable adjustments that may be required by patients with learning disabilities which include offering an extended or double appointment where this would assist to support effective communication, offering a choice of appointment times, use tools such as the hospital passport, use pictures and diagrams, record individuals specific access needs and review patient information leaflets. The guidelines cover the following areas:
  - Supporting effective communication
  - Supporting admissions and discharges
  - Preparing individuals for admissions or clinical interventions
  - Clinical tools
  - Supporting family or familiar carers
  - Consenting to treatment
  - Carrying out care or treatment in an individuals best interest. Involving specialist learning disability teams
  - Using and creating accessible information
  - Quality assurance (Essence of Care)

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<sup>1</sup> Quality, innovation, productivity and prevention

- Royal College of Nursing (undated) guidelines Commitment to the care of people with dementia in general hospitals. Guidance is provided on staff awareness and skill, having time to care, to support family carers and friends as partners in care, dementia assessments, person-centred care plans and creating dementia friendly environments. The guidance is contained in a checklist (Royal College of Nursing 2011) Commitment to the care of people with dementia in general hospitals.

### **3.3.2 Guidelines on access to emergency care**

- Guidelines and Audit Implementation Network (2010) Guidelines on Caring for People with a Learning Disability in General Hospital Settings, provide comprehensive and practical guidance and cover a best practice statement and guidance in relation to emergency care: every person with a learning disability using the emergency care service should receive timely, safe and effective care that takes account of their specific health needs.
- Guidelines for Managing the Patient With Intellectual Disability in Accident and Emergency (Bradley 2002). Provides guidance on how to communicate effectively, reduce anxiety in an unfamiliar environment, practical tips on making individuals comfortable and finding a quiet place to wait and be treated, and giving extra time to communicate and build a positive relationship with the patient.
- Your next patient in A&E may have an Intellectual Disability (Stevens and Bush 2011). Provides guidelines on communicating in a quiet place, capacity and consent, history taking, examinations, treatment and discharge.
- Pressman H and Schneider J (2009) Overcoming barriers in emergency situations: Some basic tools. International Patient-Provider Communication
- Blackstone SW (2009) Emergency preparedness and Augmentative Communication. International Patient-Provider Communication

### **3.3.3 Guidelines on accessible maternity care**

- Royal College of Nursing (2007) Pregnancy and Disability: RCN Guidance for Midwives and Nurses. The guidance covers the statutory framework in the UK on disability and consent to treatment. Practical issues in service provision cover disability awareness, use of terminology and disability etiquette, the impact of pregnancy on disabled parents, knowledge, skills and attitudes for effective care and communication skills. Case studies and examples of good practice are cited.
- An Bord Altranais (2010) Practice standards for midwives state that health professionals should enhance their knowledge of the services and supports available to women with disabilities, in line with the Royal College of Nursing's (2007) guidelines.

- Irish Deaf Society Pushing for Equality – Maternity Care DVD, to create awareness for Deaf mothers and their needs in relation to maternity services.
- NCBI Guidelines for Public Health Nurses: Practical tips for parents with sight loss, provide guidance on knowing where your children are, safety, changing and dressing a baby or toddler, feeding, lighting and colour, aids and appliances, bottle making and bathing a baby.

### **3.3.4 Guidelines on accessible primary care/GP services**

Guidance by the Disability Rights Commission/NHS (2004) on improving primary care services for people with disabilities, covers guidance on making an appointment, accessible entrance, reception and waiting areas, accessible assessment and treatment areas, referrals to other services and leaving the service. Five key areas, based on what disabled people say about a quality service, include:

- Find out how disabled people want you to assist them first. Never simply take hold of a disabled person.
- Use an everyday tone of voice. Do not shout at or patronise a disabled person.
- Make sure that you allow people to communicate in their own way, and in their own time. Allow someone with a disability extra time to explain their symptoms rather than appearing impatient.
- Take the time to explain to people what is going on and check that they understand, to avoid unnecessary anxiety.
- Don't make assumptions. For instance, avoid assuming that someone's disability is the cause of their present health problem. The two may not be connected.

### **People with intellectual disabilities**

- Royal College of General Practitioners (undated) Vision and People with Learning Disabilities: Guidance for GPs. This document for GPs and primary health care teams provides guidance on how to identify sight loss and visual impairment in patients with learning disabilities and to provide information about appropriate specialist services.
- Royal College of General Practitioners (2010) A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability. Guidance on providing annual health checks by GPs for people with a learning disability. It includes information and guidance in carrying out health checks, awareness about the healthcare needs of people with learning disabilities and how to provide an accessible service. The guide highlights the specific healthcare needs of people with learning disabilities in relation to the complex health problems experienced in areas such as mental ill health, chronic health problems, epilepsy, and physical and sensory problems, as well as the need to improve access to routine health screening and regular health checks and avoid 'diagnostic

overshadowing' of people with learning disabilities. The objective of the annual health checks is to improve health outcomes, early diagnosis and treatment of medical conditions, improve screening of health issues that are particular to people with a learning disability, improve access to health promotion and develop relationships with GPs, practice nurses and primary care staff. Specific guidance includes having a clinical lead for learning disabilities within a GP Practice.

- Primary Care and Intellectual Disability (McCourbie and Baines 2011). Provides guidance on health screening, health checks, booking longer appointments and accessible communications using plain English and pictures.
- The British Psychological Society and the Royal College of Psychiatrists (2009) Dementia and People with Learning Disabilities Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia. The guidance stresses the importance of multi-disciplinary assessments.
- The NHS Website for Primary Care Commissioning (undated) on the management of health for people with a learning disability provides GP Information Systems e-templates for annual health checks.
- Specific guidelines have been drawn up in Canada on the role of primary care services in addressing the healthcare needs of people with intellectual disabilities (Sullivan et al 2006). These cover first, the dignity of people with learning disability, based on their intrinsic value as human beings, requires respect and does not diminish with the absence or reduction of any ability. Second, people with LD are nurtured throughout life by human relationships. Third, primary care providers need to take into account health issues particular to adults with learning disabilities. Sullivan et al (2011) recommend that guidelines should be updated regularly in order to keep up to date with new findings in practice and research.
- Guidelines have been developed by the Centre for Disability Studies for the New South Wales Department of Health (2006a) for GPs in improving accessibility for people with an intellectual disability. These cover specific health issues such as dental health, screening, sensory impairment, nutrition, mental health, women's health and a range of specific medical conditions experienced by people with intellectual disabilities.
- Guidelines drawn up in the Netherlands (Wullink et al 2007) to facilitate the movement of people with intellectual disabilities from residential care facilities to community settings, including the transfer of care to general practitioners, highlights the importance of overcoming communication and organisational barriers. The draft guidelines were drawn up through information collated from interviews and discussions with health care staff. The guidelines cover the handing over patient files to general practitioners, including case histories,

arrangements of out-of-hours house calls, practice visits, medication and other medical treatments.

### **People who are Deaf and hard of hearing**

- The Deaf Mental Health Charter drawn up by Sign and the Mental Health Foundation (undated) in the UK aims to remove barriers in access to health services and promote the mental health and well-being of Deaf people. It builds on recommendations in Towards Equity and Access, the Best Practice Guidance on mental health and deafness (Department of Health & National Institute for Mental Health in England 2005). The Charter gives guidance on working with deaf people and giving extra time to communicate, better understanding of deafness and communications, effective engagement and communication during a diagnosis, access to information in accessible formats, access to sign language interpretation and knowledge of the words and tools necessary for communication with deafblind people, and having awareness of Deaf culture and communication styles.
- RNID web page on GP support to ensure that services are accessible, covering appointments, communication support, patient records, deaf awareness and equipment for hearing aid users.
- Irish Deaf Society Breast Awareness DVD, developed in partnership with Action Breast Cancer, aims to raise awareness of Deaf women.
- Irish Deaf Society Men's Health – Cancer DVD, developed in partnership with the Irish Cancer Society, aims to raise awareness of Deaf men's health issues and cancer prevention.

### **3.3.5 Guidelines on capacity and consent**

- Two resources drawn up by Inclusion Ireland: Legal Capacity and Decision (2008) and Making Medical Decisions: Who Decides and How? (2003) are of relevance (Note – the legal position will change following enactment of mental capacity legislation).
- Guidance from the UK, includes a Mental Capacity Act toolkit, guidance on a bioethics memory aid for healthcare professionals in England, Scotland and Wales for use in patients aged 18 or over in an emergency situation (RCGP 2011). It is based on four criteria of assessment about whether a person can communicate their decision, understand the information being given to them, retain the information given to them and balance or use the information. If the person does not have capacity, a further assessment is recommended to consider if a decision can be made after reviewing best interests, appointment of a lasting power of attorney, involvement of an independent mental capacity advocate or the appointment of a proxy.

## **3.4 Cross cutting guidelines on physical, information and communications accessibility**

### **3.4.1 Guidelines on physical accessibility**

Many of the guidelines reviewed stress the importance of universal design on the basis that the design of healthcare facilities for use by the general public takes account of the needs of people with disabilities and benefits all healthcare users. Guidelines on the design of healthcare facilities stress the importance of clear pathways of access by avoiding steps or steep slopes, correct height of a reception desk to enable a wheelchair user to have eye contact with a receptionist, accessible treatment/examination tables that are height adjusted, enabling sufficient space under wash hand basins or reception desks to accommodate a wheelchair, sufficient space in reception areas or around beds to enable a person to turn and move a wheelchair without barriers, and floor surfaces that may impede wheelchair mobility, such as deep pile carpets or polished surfaces.

There are specific issues of access to healthcare facilities, particularly hospitals, which may require people to walk considerable distances from a car park to an outpatient facility or a ward. This may affect older people, people with cerebral palsy, people with Parkinson's disease, people with multiple sclerosis and people with arthritis. People may use a walking aid, such as a walking stick, crutches, walking frame or a guide dog, and may also experience limitations on their physical stamina or may experience balance problems. As a result, guidelines that address accessibility issues for people with walking difficulties, give particular attention to the design factors regarding the height of steps and handrails, the provision of seating in reception and waiting areas and along a walkway, provision of lifts, avoidance of hazards, or difficulties in opening doors.

Some guidelines give specific attention to the problems that people may experience with hand movement and holding objects. This may include people with arthritis, people with injuries to the nerves in their fingers or hand or amputation of their fingers or hand. Guidelines that refer to the specific design factors for people who have difficulty with hand movement include the operation of fittings such as taps, switches and buttons on lifts, door handles and difficulties that may be experienced in accessing leaflets from a leaflet stand.

### **Guidelines reviewed**

- The Irish Wheelchair Association's (2010) best practice access guidelines which are informed by service users' experiences and which can be applied to a healthcare setting: Best Practice Access Guidelines – Designing Accessible Environments. The guidelines provide detailed guidance on all areas of physical accessibility, which in some cases go beyond those contained in the statutory requirements. These guidelines have been developed since the Irish Wheelchair Association's (2004) guidelines Access for All was published.

- National Disability Authority publication *Building for Everyone: A Universal Design Approach* (2012) defines what is required for buildings and facilities to be accessible and provides guidance and information about universal design of goods, services and buildings.
- National Disability Authority (2006) *Guidelines on planning accessible health service buildings*. The guidelines are premised on the argument that poor access does not make sense economically. The guidelines cover external approach; building approach; lighting; parking; specification for ramps; doors and entrances; specification for steps and lifts; signage; internal spaces. These guidelines were intended to be used as a reference for HSE staff when either planning new buildings or renovating existing buildings).
- National Council for the Blind of Ireland (undated) *Making Hospitals Accessible* and (undated) *Accessible Signage*, provide specific guidance on how to make hospitals and signage accessible to people with vision impairments.
- Equality Authority (2005) *Reasonable accommodation of people with disabilities in the provision of goods and services*, with suggestions on how service providers can improve accessibility for people with disabilities.
- *Guidelines on Access to Health Care for People with Physical Disabilities* (Isaacson Kailes 2008) sets out practical suggestions across “5 G’s” in the following areas: getting to, into and through a health care facility; getting access to medical equipment; getting what you need during your visit; and getting changes made.
- Accessibility guidelines have been drawn up under the Americans with Disabilities Act and Architectural Barriers Act (USA Access Board 2004). They cover technical requirements for accessibility of buildings and facilities by individuals with disabilities under the Acts. They cover the design, construction, and alteration of buildings and facilities.
- Disability Services Commission Western Australia (undated) *An introduction for management on providing access to health and medical services for people of all ages and abilities* (Western Australia, You’re Welcome initiative: Community access for all ages and abilities). The guidelines provide simple tips to make health services accessible to all people regardless of their age or disability. Specific issues covered include: accessible parking, accessible entrances and doors, accessibility for people who use mobility devices such as wheelchairs in reception and waiting areas, accessible specialised equipment, treatment rooms, changing rooms and examination tables, accessible toilets, accessible documents, forms and signs for people with a vision impairment and training to staff on disability awareness. This forms part of a wide range of short guidelines for managers in a range of different services to promote accessible services and facilities.

- Under the You're Welcome Initiative, healthcare facilities are encouraged to publish the accessibility of their services for inclusion on the web site of the You're Welcome initiative. Another example of is that service providers are encouraged to display a Better Hearing card on reception desks and counters so that service users know that the staff are aware of how they can communicate with a person who is deaf or hearing impaired.

### **3.4.2 Accessible communications**

There is a wide range of guidelines that deal with communications. These emphasise the importance of active listening skills and provide guidance on techniques for communications such as facing the speaker, maintaining eye contact, minimising external distractions, focusing on what the speaker has to say, responding appropriately, empathising, engaging with the person, giving feedback and deferring judgement. In addition, guidance documents are also listed on health literacy and communication aids.

#### **Guidelines reviewed**

- Power to Change Ten Tips to Effective and Active Listening Skills.
- Department of Health (New York) People First: Communicating with People with Disabilities.
- Guidelines drawn up in Victoria, Australia on inclusion, consultation and communication with people with disabilities (Department of Planning and Community Development 2008), provide practical tips on making written information more accessible to people with a disability and on how to communicate and actively involve people with disabilities in the planning, development, delivery, monitoring and review of services.
- International Patient-Provider Communication website provide a wealth of resources on different aspects of communications, including facilitation and communication strategies, communicating in emergency situations, training for nurses, as well as resources in the form of health symbols and the hospital communication book. See, for example, Pressman H and Newman H (2009) Communication Access Within Healthcare Environments. A Call for Action.
- Clinical Communication (Thacker 2002). Presents guidelines based on the General Medical Council's recommendations on effective and sensitive communication. The guidelines spell out the importance of listening skills and the provision of accessible and comprehensive advice and information for patients and their relatives.
- Government of Ontario Accessibility Directorate (2009) Communicating Access for People who have communication disabilities.



- Office for of Disability Employment Policy/National Centre for Access Unlimited (USA) (1995) Ten Commandments of Etiquette for Communicating with People with Disabilities.
- National Adult Literacy Agency (NALA)/MSD's (undated) publication Time to Talk: Help your patients achieve better health through more effective communication aims to bring a 'Time to Talk...health literacy' approach in to the medical practice of health professionals. An implementation guide has been produced for health professionals to assist them in implementing the approach. Educational materials, patient brochures, posters and goal-setting work sheets have been developed under their dedicated web site [www.healthliteracy.ie](http://www.healthliteracy.ie). Specific guidance is given on strengthening the therapeutic relationship between a patient and health professional by building trusting relationships and improving communication skills. The LEAPS approach aims to assist healthcare professionals in five key areas through Listening, Educating and Counselling, Assessing, Partnering and Supporting and Building rapport. Practical tips are given to help people understand health information, for example, by speaking slowly and giving patients time to digest information, using non-medical language, using pictures and illustrations, limiting the amount of information in order to promote recall and providing a supportive environment where a patient feels comfortable to ask questions.
- Guidance on health literacy from the American Medical Association includes Health Literacy: A manual for clinicians (Weiss B 2003).

### **Communication books/passports**

Communication passports, including guidance on templates and using communication passports.

- Learning Disability Partnership Board in Surrey (undated) Hospital communication book.
- Balandin S (2009) The Hospital Communication Book. A Useful Resource for Patients, Providers and Family Members.

### **Communications with people who are Deaf or hard of hearing**

- Irish Deaf Society poster Communicating with Deaf People. This gives guidelines on working with an ISL Interpreter and in communicating with Deaf People.
- Irish Deaf Society Basic Medical Signs: A guide for all Irish medical institutions on common medical sign-language for patient care. This includes a CD and booklet with photographs on signs that can be used in healthcare settings.
- Irish Deaf Society Some Sound Advice: Improving access to and utilisation of health services for the Deaf in Ireland. This is a booklet containing information about how to improve the quality of communications and information for Deaf people.

- National Deaf Children's Society (NDCS) (2011a) Deaf Children with additional needs, with guidance on specialist approaches to communication (Makaton, Signalong, Augmentative and Alternative Communication (AAC), Picture Exchange Communication, Widgit and Bliss symbolics).
- Royal National Institute for Deaf People (2004) Guidance on Providing British Sign Language/English Interpreters under the Disability Discrimination Act 1995 for Employers, Trade Organisations and Service Providers.
- National Deaf Children's Society NDCS (2011b) Communicating with your Deaf child. Provides guidance to parents on language and communication development and different communications approaches. Although targeted to families, the guidance has useful practical suggestions that are relevant for healthcare staff.
- Equality Commission Northern Ireland (undated) Communication support for deaf people in healthcare and other settings. The guidance covers professional sign language interpretation, deafblind interpreters, lipspeakers, note takers, speak-to-text reports and communication supports that can be provided in a health care setting. The guidance states that Deaf people have the right to have a qualified interpreter for medical appointments and that children and family members should not be used as interpreters. It does acknowledge that it may be appropriate for an adult to act as an interpreter.

### **3.4.3 Accessible information**

A large number of guidelines were reviewed on accessible information. Overall, guidelines focussed on how barriers can be removed to enable people with disabilities to access public information. These guidelines cover the specific information needs of people who are Deaf or hard of hearing, people with vision impairments, people with literacy difficulties and people who have difficulty in processing information such as people with an intellectual disability, people with an acquired brain injury or people with a mental health difficulty.

In summary the guidelines reviewed covered the following key areas:

- Printed information provided in plain English, clear text, colour contrasted backgrounds, information provided in bold or different print sizes
- Information provided in different formats, through the Internet, email, audio cassette/file and large print text, captioning of videos or DVDs or Braille format, if requested
- Information provided verbally and through sign language interpretation
- Accessible signage
- Internet and accessibility of web sites

## Guidelines reviewed

- In Ireland, the National Disability Authority's (2006) Code of Practice on Accessibility of Public Services and Information provided by public bodies provides statutory guidance to public bodies on how to improve access to written information. The National Disability Authority (2005) First Steps in Producing Accessible Publications, provides guidance on how to draw up accessible publications by planning accessibility through single source publishing.
- MacDougall (1998) Well Read: Developing Consumer Health Information in Ireland, Library Association of Ireland.
- NALA's initiative on health literacy includes a literacy audit tool for healthcare settings (NALA 2010). Health literacy aims to enable a person to understand health information, whether this is provided in person, over the telephone or in a written format. This is very relevant for some people with disabilities who experience literacy difficulties or who may have difficulties in understanding, processing or retaining information. NALA has produced two booklets on health conditions in plain English setting out key words and information, one on asthma and allergies and a second on arthritis.
- NALA's (2009) publication on Writing and Design Tips provides guidelines on how to produce documents in plain English so that information can be easily and quickly understood and provided in the correct order. This is very relevant to a healthcare setting, particularly because a lot of information is very complex and often provided at a time of stress or ill health for the person receiving the information. Reference is made in the Accessibility Guidelines to this and other reports produced by NALA. Similarly, NALA's Plain English Guidelines provide guidance on writing in plain English.
- The Citizens Information Board has a statutory responsibility to provide information to the public on state services and has developed guidelines on accessible information. It operates the national advocacy service for people with disabilities, on the basis that advocacy is one element of the continuum of information. The guidelines on Accessible Information for All produced by the Citizen's Information Board set out what public bodies need to do to implement the requirements of the 2005 Disability Act (Pillinger 2009). This sets out how to overcome information barriers and how accessible information can enhance the quality and effectiveness of services for different audiences, different uses and through different information channels. Specific guidance is given on:
  - Carrying out an information access audit to ensure that accessibility is written into policies on information accessibility, that written information is provided in accessible formats and that information centres are accessible and methods are in place for consulting with service users and that staff received training on information accessibility.

- Consulting with services users when planning, developing, managing and reviewing information services. This includes the development of accessible feedback and complaints procedures. This draws on the National Disability Authority's Ask Me: Guidelines for Effective Consultation with People with Disabilities (2002) which states: "Getting the consultation process right for people with disabilities means getting it right for everybody." Suggestions are given of how services users can be involved in monitoring information and an information service at individual, operational, strategic and governance levels.
- Working in partnership with representative and advocacy organisations to deliver information when it is needed, to identify gaps in information, have a reliable source of referral to more specialist advice; and in sharing and coordinating information provision.
- Designing information for accessibility on the basis that the content of information, whether it is written information, an audiotape, a DVD or a video, is clearly structured and that it is produced from a single source. Creating a single source avoids duplication and enables information to be updated easily and adapted to different formats and for the web. Specific guidelines are given on creating an accessible design, structuring a document, layout of a document, using images and tables and on producing electronic publications for web sites. Specific guidelines are also provided on single source publishing, using Xtensible Markup Language (XML) so that information from a single source can be easily adapted to other formats such as Braille, HTML for the web or PDF for printing.
- Providing information in different formats: with guidance on Braille transcription, information in audio on CDs, audio cassettes and sound files, video and DVD and audio description of visual information. Guidance is also given on writing documents in plain English and in Easy to Read formats, electronic documents, accessible emails, using pictures and symbols to make information easy to understand, text messaging, information in Irish Sign Language.
- Making websites accessible: guidance is given on how to make websites and digital electronic information accessible by designing for universal access. Accessible websites enable people with disabilities to use assistive technologies, for example text-to-speech software used by web users who are blind and vision impaired. Specific guidance is given on making website conform to the Web Content Accessibility Guidelines (WCAG).
- Accessibility of face-to-face and telephone based information: this is a key to quality customer services to ensuring that information they need is complex or hard to understand is accessible. The guidelines suggest a number of practices that can be put in place for effective and accessible communications with people with disabilities.

- Accessible information centres: guidance is given on the physical accessibility of information centres including parking, getting into a building, location of the service, height of the reception desk and information signs, audible and visible fire alarms, signage, access for wheelchair users, accessible toilets, hearing loop system and place a 'Guide Dogs Welcome' sign in a prominent place. Suggestions are also made about training for staff and in drawing up a disability access plan to improve the physical accessibility of an information centre.
- Accessible events and meetings: guidance is given on having a planned approach to events and meetings in order to avoid key elements of accessibility being overlooked. Specific guidance is given on what to take into account in planning events and meetings so that they are accessible to everyone.
- Developing an information accessibility policy: this provides guidance on drawing up an information accessibility policy in order to set out the vision and the goals of the organisation and how an information service can be developed and managed. This is an important way to engage senior managers by placing information accessibility at the centre of their organisation.
- Rewarding and encouraging good practice: the guidelines stress that an important part of improving information accessibility is to encourage and reward good practice. For example, this could include an internal award or merit system for staff working to promote information accessibility or an external award scheme, such as the National Adult Literacy Agency's Plain English Awards and the O2 Ability Awards. The NCBI's Media Centre has developed a clear print quality mark in order to recognise and acknowledge businesses and other organisations that use clear print design in their written information.
- Publicising the service and disseminating information: this stresses the need to let the public and service users to know about information resources that are provided and where they can find accessible formats, for example, by publicising the information service locally and running local information campaigns.
- Disability Services Commission Western Australia (undated) Accessible Information (under the You're Welcome Initiative)
- Scottish Accessibility Information Forum (SAIF) provides a wide range of guidelines and resources on accessible information, including Standards for Disability Information and Advice Provision in Scotland and A Brief Guide to Making Your Information Accessible.

### **Guidelines on plain English**

- The Plain English Campaign has produced a number of guidelines on working in plain English, including Plain English Guide to Design and Layout, How to write in Plain English and Tips for Clear Website.
- Two plain English guides have been produced by NALA/MSD. These are Asthma and Allergies: Key words in plain language and Arthritis: Key words in plain language

### **Guidelines on Easy-to-Read documents**

- **Make it Easy:** a guide to preparing easy to read information, prepared by the Accessible Information Working Group (2012) made up of Speech and Language Therapists who work with adults with intellectual disabilities in Ireland. The document spells out all the steps that need to be taken when writing an easy to read document or leaflet.
- **Easy Info** - resources to help make information accessible information for people with intellectual disabilities, including guidance on how to use symbols and pictures and making documents Easy-to-Read.

### **Guidelines on accessible information for people with vision impairments:**

- NCBI guidelines Making Print Accessible cover NCBI services on Braille transcription, audio recording, clear print advisory service and mark, Braille training for the pharmaceutical sector, Braille advisory and proof reading service, audio-description).
- Royal National Institute for the Blind (RNIB) guidelines include Clear print guidelines on accessible documents and See it Right covering accessible information, including information on making audio recordings and video for people with vision impairments.

### **Guidelines on Internet accessibility:**

- NCBI Centre for Inclusive Technology: Making Websites Accessible.
- Web Aim, provides guidance on how to structure a Word document, different text for images and save files to HTML.
- Web Content Accessibility Guidelines (WCAG) from the Web Accessibility Initiative (WAI).
- National Disability Authority: Web accessibility guidelines.

## **Section 4: Consultations with the HSE and disability organisations in drawing up the guidelines**

### **4.1 Introduction**

Consultation was carried out with individuals within the HSE and disability organisations in the preparation of the guidelines and in gaining feedback on the draft version of the guidelines. This section gives an overview of issues highlighted by individuals and organisations that participated in the initial consultations and who gave feedback on the draft guidelines.

### **4.2 Initial consultations with disability organisations to inform the content of the guidelines**

During the research phase, prior to drawing up the draft guidelines, consultations were carried out with disability organisations to inform the content of the guidelines. These consultations sought to identify:

- Documentary evidence and reports from previous consultations that had been collated by organisations on accessibility for people with disabilities (which have been included in the content of Section 3).
- Priorities for issues and themes to include in the guidelines. Appendix I lists the organisations that responded to the consultations.

Specific issues highlighted by disability organisations are summarised as follows:

#### **Irish Deaf Society**

Consultations with service users who are Deaf and hard of hearing reveal experiences of patronising attitudes towards Deaf and hearing impaired people and a lack of awareness of the communication needs of people who are Deaf or hard of hearing. Some service users were referred to as 'deaf and dumb' because they could not communicate with the health practitioner. There is a limited awareness of Deaf culture and the fact that Irish Sign Language is the first language for some people which can make communicating in written English difficult. This is compounded by a lack of access to ISL interpreters and awareness of ISL amongst health care staff. Deaf and hearing impaired people are often embarrassed to say that they don't understand what the doctor or nurse is saying to them and difficulties in communication can result in misdiagnosis, resulting in some cases in serious long term illness. In some cases children or other family members have had to interpret for a Deaf person, resulting in problems of privacy and confidentiality. There are many positive experiences of healthcare staff taking the time to communicate with and understand the needs of Deaf and hearing impaired people. Specific issues were raised about the communication requirements of Deaf women

in maternity services. The following examples were given from service users about specific accessibility problems encountered:

- A Deaf man who visited his GP was asked by the GP 'have you tried to commit suicide?' The man was not sure what it meant so he said no. He then went to the IDS to ask what it meant. If GP would rephrase the words such as "have you tried to kill yourself" the Deaf person would have understood better.
- Medical information and health promotion not translated to Irish Sign Language means that Deaf people often miss out on it. An example of this is when a Deaf man went into his GP and he told him he had high cholesterol and should eat his five portions of fruits and vegetables a day. The Deaf client did not know what cholesterol was and had never heard of your "five a day". A very useful way of explaining something like cholesterol to a Deaf person maybe by drawing it where this is possible. This also show the importance of translating basic information into ISL so that Deaf people can have equal access to information like their hearing peers.
- Service users not knowing when they are called for a service: According to one Deaf service user: "I sat in outpatients for ages, and I could see everyone who arrived after me going in ahead of me. I realised that people were called by name, but I couldn't hear so I missed the nurse calling my name. If they knew in advance that I was deaf they would be able to come and tap me on the shoulder. Or it would be much better if my name came up on the screen so I could read when it was time to go in."
- Communications problems: A Deaf man broke his finger and was admitted to hospital for minor surgery. He was taken to have an anaesthetic, which made him feel sleepy. The nurse shaved his chest. He said 'I didn't know why but I let him do it. Then I began to feel sleepy and was brought to the hallway before the theatre room. Two doctors came over to me with their mouths covered by masks, I told him that I was Deaf and one of the doctor asked me questions and I did not understand him but I said 'yes' as I was very drowsy'. It turned out that there had been a mistake and he had been assumed to be a patient for triple by-pass surgery. If the doctors had removed their masks it might have been possible for him to lip-read. Most importantly if there had been an ISL interpreter available the man would have been able to answer the doctor's questions and avoid the mistake.
- A Deaf woman from the west of Ireland was diagnosed with breast cancer when she was in her mid-thirties. She had received treatment and was given the all clear a few months later. A few years after this, she was very ill and was told she was on final stages of breast cancer - she was shocked as she did not realise that she was supposed to have a check up once or twice a year. This was as a result of a communication breakdown between the woman and her doctor because she had a low literacy level.



## **Enable Ireland**

Enable Ireland's Service User Consultation Report documented the views of children, adult services users, parents of children, carers of adult service user and staff. As part of the consultation process for the guidelines, Enable Ireland drew up a separate report to inform the guidelines, using the data collated. This covered recommendations on the need for a partnership approach between service users and healthcare staff, the role of key workers in supporting people with disabilities in accessing healthcare, the need for accessible and transparent information and communications covering the need, the inclusion of people with disabilities in programmes that support their independence and the involvement of people with disabilities in the development of services. Additional service user feedback was also provided in the Enable Ireland Action Week on Disability 2009 Survey on Social and leisure activities.

## **Spinal Injuries Ireland**

Consultations and research with people with Spinal Cord Injuries (Spinal Injuries Ireland 2004 and 2009) show that assistive living is the service most frequently needed. This includes support of a personal assistant, home help or public health nurse. Lack of access to physiotherapy in the community is a key issue that many people with SCI highlight in consultations. Spinal Injuries Ireland found that 60% of people with SCI do not receive the physiotherapy services they require. Spinal Injuries Ireland research shows low levels of satisfaction with occupational therapy, physiotherapy and public health nursing services. The research found a lack of support and understanding of the community health needs of people with a SCI. Other services required include improved access to equipment for mobility, the need for counselling services and access to support groups. Health issues faced by people with SCI are complex. Significant health problems include spasm, pain, bladder and bowel problems, sexual dysfunction, skin problems and pressure sores, and depression. Overall, bladder and bowel problems have a severe impact on quality of life and independence. Examples of problems experienced by service users during a hospital stay or if there is a long wait for an appointment include a build up of pressure sores. During a hospital stay appropriate bowel care is also necessary to prevent other long-term health consequences.

Ataxia Society Ireland highlighted the importance of accessible GP and dental practices, accessible communications and raised awareness to counter the assumptions that people with disabilities do not get sick or require screening services. Consultations with people with disabilities are important also in progressing the guidelines and their implementation. Feedback from service users to the Society found that GPs have limited awareness of Friedreichs Ataxia and that the main barriers experienced by service users are having access to physiotherapy and hydrotherapy. A key issue is that service providers do not listen to the needs of service users and their service requirements to enable them to have independent living, health and well-being.

People with Disabilities in Ireland stated that accessible transport is vital to enable people with disabilities to attend healthcare appointments and that there is a need for healthcare staff to take time to listen to the requirements of people with disabilities and to take account of multiple disabilities. Key issues were highlighted from a questionnaire distributed to service users, with responses from 39 service users. The most commonly reported problem was physical access to GP surgeries, with examples given of consultations taking place in the car park and in corridors, inadequate disability car parking, inadequate space in disabled toilets and waiting areas to accommodate motorized wheelchairs, no accessible toilet on a hospital ward, absence of lifting hoists and height adjustable beds, absence of audio calling systems for people with impaired vision and transport for people with disabilities when discharged from hospital. The following suggestions were made to improve accessibility:

- Enhanced physical accessibility, particularly for motorized chairs, and better awareness amongst staff of how to accommodate the accessibility requirements of people with physical disabilities.
- Disability audits in hospitals
- Provision of larger signage and coloured walkways.
- Better systems for calling patients for an appointment, for example, so that receptionists inform doctors that a person with a disability requires assistance in getting in and out of an examination room.
- Assistance with toileting and other services when waiting on a trolley.
- Accessible information in large print, for example, on notice boards and on medicine bottles.
- Accessible information about the services available from a GP or Primary Care Team, including information disseminated widely in public libraries, other public places and on web sites.
- Better staff awareness, the possibility to see a GP at short notice and longer consultation times, for GPs to arrange home visits and/or appointments at a time that suits the service user.
- Respectful communications 'stop treating us like children' and direct questions at people with disabilities, not their carers or support persons.
- Discharge procedures from hospital to be coordinated so that a person who has a stroke can have follow up services in the community.
- Support for hospital inpatients with hydration and feeding at meal times.
- Better support from healthcare staff to enable a person with mental health difficulties to access employment.
- Disability awareness training, including training on hidden disabilities.

- Involvement and consultation with people with disabilities in service developments to improve accessibility
- More accessible complaints procedures.

Shine provided insights from the experiences of service users with mental health difficulties arising from consultations carried out by Shine. One of the most important issues raised is that service users are not listened to and that their opinions and views are not always respected. Many difficulties with non-compliance could be resolved through discussion and when the patient is involved in his/her care that there is more likely to be compliance with treatment, medication or health advice. Accessible information, including information in an Easy-to-Read format, is very important for people with mental health difficulties as their levels of stress, fear and anxiety may be heightened in a healthcare setting. Awareness of how healthcare staff can build in a 'recovery model' into their services is seen as one way that all healthcare staff can provide a supportive environment for people with mental health difficulties. There needs to be more awareness by staff of the reasons why a person may not respond, and in using simple techniques of listening and reassurance. An important issue for healthcare staff is to recognize and act upon the signs of suicide and greater awareness of how to address suicide.

Headway Ireland highlighted the low levels of awareness of mainstream healthcare providers of acquired brain injury (ABI). This is particularly important because ABI is a hidden disability. There can be a gap in services before a person with a brain injury is able access rehabilitation hospital care. It is at this stage that community services and Primary Care Team services have a key role to play. There is also a gap in support for carers in an acute hospital setting and in relation to providing sensitive communications after a family member has acquired a brain injury following an accident.

Acquired Brain Injury Ireland stated that the low level of awareness and knowledge amongst healthcare staff of neurological disabilities resulted in poor understanding of the physical, emotional, sensory and other disabilities experienced by people with ABI. In some cases it is difficult for people with ABI to retain information and in others an overload of information can often lead to distress and anxiety. An example was given of a service user who, as a result of a fall, was taken to A&E. The fall resulted in him having poor tolerance, difficulties in understanding information and in making decisions, and aggressive behaviour; the hospital staff responded by calling security. The learning from this was that if healthcare staff had better awareness of the impact of a fall on a person with ABI they would have responded more sensitively in communicating, in providing information and listening to his concerns. Acquired Brain Injury Ireland recommended that healthcare staff need to give more attention to understanding the changes in life circumstances of people with ABI and for a shift from a medical to a social focus on the person, rather than the disability.

National Rehabilitation Hospital highlighted the importance of improving coordination between hospital and community services, accessible information, awareness raising and training for families, carers and friends on brain injury. Improving access to general healthcare for people with an acquired brain injury, people with spinal cord injury and people with cognitive impairments was highlighted as being crucial for promoting general health and well-being of patients. In particular, Primary Care Teams need awareness and better understanding of the needs of service users with complex disabilities and cognitive impairments.

Inclusion Ireland highlighted the barriers faced by people with intellectual disabilities in accessing general health services. Anecdotal evidence cited by Inclusion Ireland is that the quality of mainstream healthcare services range from good to poor. Barriers include a lack of supports and a reliance on family members and carers to provide support and care when a person with an intellectual disability is a hospital inpatient, poor access to preventative health care and screening, and poor knowledge of communication aids and techniques. Poor communication can result in misdiagnosis and health conditions not being detected. There also needs to be greater awareness amongst healthcare staff of how advocacy can be used in a healthcare setting. There are also significant difficulties faced by people with intellectual disabilities in accessing mental health services.

Feedback from Cheshire Ireland's service managers in Cork, Carlow, Dublin/Wicklow and Waterford highlighted significant barriers experienced by service users in accessing health services. The most common problems encountered included inadequate disabled parking, lack of physical access into a hospital, narrow doors that cannot accommodate the width of a motorised wheelchair and no lifting hoists. A significant number of GP surgeries are not physically accessible, requiring GPs to make home visits. In some cases consulting rooms are too small to be accessed by a large motorised wheelchair. A lack of lifting hoists was particularly highlighted in GP surgeries and Dental surgeries. People with mobility disabilities may not be turned regularly enough when in hospital and consequently develop pressure sores.

People with disabilities were not consulted about a procedure, resulting in inappropriate or the wrong procedures being used. In many cases carers/support persons had to stay with a person with a communication difficulty during a hospital stay as hospital staff made little or no effort to communicate in accessible ways. People who are PEG fed were not always attended to when the tube becomes lodged. Sometimes food got cold because there was no one to assist a person with feeding. Poor consideration was also given to the scheduling of appointments with little understanding that people with disabilities will usually take longer to get going in the morning or they may have to travel further or have difficulties with transport.

Specific examples include a service user who was unable to have a scan owing to no overhead hoist being available and had no option to access the scan in a private clinic in Dublin, which also did not have an overhead hoist. After many phone calls an alternative procedure using a different method was put in place. With forward planning and listening to the service user, these problems and the distress caused to the service user could have been avoided. Another service user with no upper body control and pressure sores had to be pulled over in her wheelchair to have abscesses lanced from her wheelchair as there was no lifting hoist.

Muscular Dystrophy Ireland stated that physical barriers experienced by people with muscular dystrophy created major problems for service users, including no lifting hoists available to facilitate medical examinations and lack of accessible bathrooms. In some cases there have been difficulties in allowing a service user's personal assistant to provide support for the person during a hospital stay. Healthcare staff also need to be aware of the support needs of family members and carers, particularly when a child is diagnosed with muscular dystrophy. Providing more time to communicate and give information is seen as one important way to improve the accessibility of healthcare services.

### **4.3 Consultations and feedback on draft guidelines**

Consultations were held with disability organisations and healthcare service providers/practitioners on the draft guidelines (see Appendix 2 for details of the organisations/individuals that provided feedback).

These consultations informed the content and structure of the final guidelines. Feedback also included some very practical suggestions arising from the experiences of people with disabilities of accessibility in a healthcare setting.

#### **Specific examples within a universal approach to accessibility**

Adopting a universal approach to accessibility was viewed as an important way to enhance accessibility for all people with disabilities. At the same time the need for more concrete examples integrated into the guidelines on people with specific disabilities was recommended. This included people with complex or multiple disabilities and people without the capacity to give consent. A number of organisations recommended including more concrete examples of specific adaptations to services for people with specific disabilities. A large number of very concrete and practical suggestions were made for inclusion in the guidelines, including the need to define more clearly definitions of accessibility.

#### **Target audience of the guidelines**

There was a consistent view from disability organisations that the guidelines should be directed to all healthcare staff, from clinical staff through to porters and catering and housekeeping staff. In this regard it was recommended that the guidelines

should be approached from a social model of disability or bio-psycho-social approach, rather than one based on a medical model.

### **Capacity to give consent**

More information on capacity to consent and informed consent, including need to familiarise a person with the healthcare environment to aid their capacity to consent and understanding abstract concepts etc. It was also suggested that reference be made to the Mental Capacity Bill and to the HSE's forthcoming policy and guidelines on capacity to consent.

### **How healthcare staff can accommodate the accessibility requirements of people with disabilities**

Some of the common issues highlighted included the need for healthcare staff to give more time to accommodating the needs of people with disabilities. Examples include the scheduling of appointments, addressing waiting times for appointments and enabling a person with a disability to visit a healthcare facility in advance of an appointment or a hospital inpatient stay. Best practice can be found in a partnership between DeafHear and Limerick Regional Hospital resulting in protocols to provide an accessible service for Deaf or hard of hearing patients. Practical outcomes resulted in:

- A sticker being included on a service user's file, with the permission of the service user, so that healthcare staff are informed about a person's accessibility needs.
- Displaying good communications tips at the patient's bedside.
- Introduction of portable loops in the hospital.

### **Information and communications**

Feedback on communicating with people with disabilities included the need to provide more time for communicating with people with specific communication requirements, more specific examples of communication around medical procedures, to have better awareness of people's communication requirements, and to understand how to communicate and respond to and reduce stress, disorientation or challenging behaviour in an unfamiliar environment. Particular recommendations were made to enhance the guidelines on the different ways in communicating with people who are Deaf (through ISL interpreters) and people who are hard of hearing, people with vision impairments, people with cognitive and intellectual disabilities and people with speech disabilities.

Asking people how they would like to communicate requires awareness of multiple ways in which communication takes place. For example, DeafHear stressed the importance of always asking people who are Deaf or hard of hearing as they may prefer to write, lip-read, use a listening device or hearing loop system or communicate through a sign language interpreter. DeafHear's consultations with

approximately 50 older people who are Deaf or hard of hearing, as part of a broader consultation about the guidelines, found that a large number preferred to communicate with a health professional in writing as communicating through an interpreter could reduce the person's independence.

Specific issues were also raised about the need for information to be provided in a wide range of formats, including through apps with pictures for smart phones, video clips and DVD, and communication supports such total communication, communication passports, non-speech methods, and augmentative and alternative communication. Particular relevant information was provided in the Make it Easy Guidelines, drawn up by speech and language therapists in the HSE.

### **Physical accessibility**

A large number of comments were made regarding physical accessibility of healthcare facilities and the need for adaptations to be made in line with legislative requirements and with regards to common sense and practical ways that healthcare staff can approach accessibility.

The Irish Wheelchair Association, for example, provided a wide range of practical suggestions of issues to include in the guidelines and recommended that the guidelines on physical accessibility should separate out specific minimum and best practice access provisions required from practical guidance on disability awareness. Specific reference was made to the need to refer to the Irish Wheelchair Association's IWA Best Practice Access Guidelines – Designing Accessible Environments, NDA guidance on disability access, including Buildings for Everyone, the building regulations and legislative provisions (Equal Status Acts and the Disability Act).

### **Role of family members, carers and support persons**

Family members, carers and support persons play vitally important roles in caring for and supporting people with disabilities. Their involvement can improve patient outcomes and they can play an important role in helping to plan admission to hospital or discharge from hospital and in helping a person with a disability to manage a health problem in the community.

Recommendations were made by a number of organisations about the role that families, carers and support persons play in facilitating accessibility, particularly for people with severe or complex disabilities. Specific areas include the involvement and value of families, carers and support persons in planning for a person's accessibility, managing the person's care, navigating the healthcare system, understanding a person's drug regime, supporting a person with a disability to attend an appointment or during a hospital stay and support with communications. Specific issues were also highlighted in relation to receiving a bad news diagnosis.

The Carer's Association, for example, stated in their feedback that there are ethical challenges facing health professionals in protecting the patient-doctor relationship, however, "more can be done to develop mutually beneficial patient-doctor-carer relationships while protecting patient confidentiality". This would take place on the basis of communication with the person with a disability in the first instance and for a person with disabilities to be asked for their consent in sharing information or involving their family member, carer or support person. The specific needs of family carers was also highlighted in relation to family carers experiencing distress, the financial burden of paying for transport and parking when attending repeated hospital visits, and the need to have greater flexibility to enable family carers to support people with disabilities with feeding or bathing during a hospital stay.

### **Policy issues**

Recommendations were made by disability organisations, HSE managers and healthcare professionals about the broader policy issues that need to underpin the guidelines. These can be summarised as follows:

- Making an assessment of how accessibility could be planned for on an incremental basis and also with regards to establishing an access improvement plan.
- Organisation-wide guidelines in carrying out an access audit, building universal design into procurement policy and engaging in the longer-term planning and funding for accessibility.
- The importance of the role of Access Officers in promoting accessibility.
- The broader context of HSE work on planning for accessibility through business planning, the role of quality and safety policies, clinical strategies and programmes and emerging standards of care.
- Training of healthcare staff was a consistent theme running through all of the feedback in order to raise awareness of staff. Recommendations were also made for training in discrete areas, such as dementia training.



## **Section 5: Policy issues and recommendations**

A number of broader policy issues have emerged from the guidelines that are relevant to the implementation of the guidelines in hospital, primary and community based health services. These have a focus on changing policies, procedures and practices; the provision of aids and services to ensure, for example, so that people with disabilities can avail of relevant communication aids; and ensuring that physical, information and communication barriers to a healthcare facility are removed.

### **Senior and corporate leadership**

- A strategic approach and corporate leadership should take place in parallel to the implementation of the guidelines. Senior level commitment and leadership are essential if accessibility is to be built into all aspects of service delivery, planning and evaluation.
- In the HSE this requires the development of key performance indicators on accessibility and staff awareness in the HSE's annual service plans and in the HSE Corporate Plan, and integrating accessibility into the business planning in each HSE service. This should include policy development, resource allocation, planning, implementation and monitoring of actions. As part of the planning cycle, it will be important to ensure that the HSE sets goals and clear priorities for meeting legal requirements and to further enhance accessibility.
- The appointment of Access Officers should be supported through training. The creation of a network of disability specialists and Access Officers across the HSE would support learning across all services.

### **HSE Universal Access Steering group**

The HSE Universal Access Steering Group has established four sub-groups with a view to drawing up policies on Irish Sign Language interpretation; accessible information; the role of Access Officers in the HSE; and consent issues. Progressing these policies will be important to filling gaps in knowledge and to giving further guidance to healthcare staff.

### **Training and awareness raising of healthcare staff**

- Meeting the accessibility requirements of people with disabilities means that all healthcare staff, including managers, health professionals, front-line service providers, primary care teams, community mental health teams and health promotion teams, are trained in disability awareness and the skills to meet the accessibility requirements of people with disabilities.
- It is the responsibility of all clinicians, health care staff and managers to promote equality and disability access as part of their core business and service. This

needs to be promoted at all levels of the organisation, from the senior decision-makers to the front-line service providers. This is crucial for staff awareness on accessibility and to ensuring that all healthcare staff take ownership of accessibility in their work.

- Raising awareness about accessibility should be promoted through a learning organisation approach. Training on disability awareness and accessibility should be integral to staff development, including in-service training, professional development and induction.
- There should be an HSE-wide approach to integrating disability awareness into all education and training programmes.

### **Patient information systems**

- The development of patient information systems will be important to ensuring that accessibility requirements of service users can follow through their patient journey across different health services.

### **Information about accessibility**

- All healthcare facilities should draw up an accessibility policy that sets out all aspects of the accessibility of the service as well as complaints procedures. Accessible information about accessibility should be included in the patient information booklet and information provided on the web site of the relevant healthcare facility.

### **Consultation with people with disabilities**

- Consultation and involvement of people with disabilities should be promoted, and where relevant the involvement of carers and support persons and representative organisations. This should be seen as a core element of the goals on service user involvement set out in the 2008 Department of Health /HSE Service Users Strategy.

### **The role of professional bodies**

- Professional bodies should be encouraged to promote best practice approaches and specific guidelines. There is a role for professional regulatory and accreditation bodies such as the Medical Council and An Bord Altranais (Nursing Board); and for professional bodies such as the Irish Society of Chartered Physiotherapists, Irish College of General Practitioners, Irish Association of Speech and Language Therapists, Psychiatric Nurses Association, Irish Nurses and Midwives Organisation and Irish Medical Organisation. This should be integrated into initial education, professional training and development.

## **Development of policies and protocols to promote accessibility**

- All service providers should be encouraged to develop policies and protocols on disability accessibility. These should cover, for example, policies on the involvement of people with disabilities and their carers/support person in the planning and evaluation of services, procedures for identifying a person's accessibility requirements, and policies to ensure coordination of care across primary and hospital care services.
- In primary care centres and health care centres policies and protocols should be put in place for information sharing, coordination of care across different service providers and ensuring that people with disabilities have access to the full range of healthcare services, including health promotion, preventative and screening services.
- In hospital services, procedures should be put in place to build accessibility into pre-admission planning, in-patient care and discharge planning.
- Protocols and agreements, as part of pre-admission planning, should be developed to enable carers, support persons and personal assistants to provide support to people with disabilities during a hospital stay. This should also include specific policies on the value, role and involvement of carers and support persons in care planning, with the consent of people with disabilities.
- Protocols and policies for pre-admission planning should cover the relevant accessibility and communication resources and physical aids and support such as lifting and feeding requirements, personal care requirements and procedures for determining informed consent.
- Protocols and policies are required on discharge planning, particularly on information sharing on accessibility requirements with relevant health professionals in the community, carers, support persons, personal assistants, home helps and other disability support staff. This should also cover specific protocols on meeting mobility and transport requirements and assessment of how accessibility and care needs can be met following discharge. Specific account needs to be taken of the accessibility needs of people with disabilities who live in supported accommodation and residential care facilities.
- Protocols and policy on patient consent and substitute decision-making are another key element.

## Appendix I: List of individuals and organisations who participated in the consultations to inform the draft guidelines

<b>Disability organisations</b>	<b>Person interviewed</b>
Acquired Brain Injury Ireland	Declan O'Donnovan / Lucia Power
Alzheimer Society of Ireland	Annie Dillon
Aware - Helping to Defeat Depression	Domonic Layden
Care Alliance Ireland	Colum Conway
Carers Association	Clare Duffy
Cheshire Ireland	Mark Blake Knox
Disability Federation of Ireland	John Dolan / Jacqueline Grogan
Dyspraxia Association of Ireland	Catriona Cahill
Enable Ireland	John O'Sullivan
Ataxia Society (formerly Friedreich's Ataxia Society Ireland)	Barbara Flynn / Annette Kelly
Headway Ireland	Kieran Loughran
Inclusion Ireland	Deirdre Carroll
Irish Deaf Society	Elaine Grehan
Irish Wheelchair Association	Kathleen McLoughlin
Mental Health Ireland	Brian Howard
Muscular Dystrophy Ireland	Joseph T. Mooney
National Council for the Blind of Ireland (NCBI)	Desmond P. Kenny / Oona Walls
National Federation of Voluntary Bodies	Brian O'Donnell (and outreach team)
People with Disabilities in Ireland (PWDI)	Morgan McKnight
Shine	John Saunders
<b>Other</b>	
National Rehabilitation Hospital	Aine Carroll / Lisa Held

## Appendix 2: List of individuals and organisations who gave feedback on the draft guidelines

Disability organisations	Feedback from
Alzheimer Society of Ireland	Annie Dillon, Avril Dooley
Aware - Helping to Defeat Depression	Sandra Hogan
Carers Association	Clare Duffy
Cheshire Ireland	Mark Blake Knox
Disability Federation of Ireland	Jacqueline Grogan
Enable Ireland	John O'Sullivan
Headway Ireland	Kieran Loughran
Irish Deaf Society	Elaine Grehan
DeafHear	Brendon Lennon
Irish Wheelchair Association	Delores Kavanagh
Mental Health Ireland	Brian Howard
National Council for the Blind of Ireland	Desmond Kenny
Shine	John Saunders
Individual	Maura Buckley, Service User
Individual	Kerry Cuskelly, IASW member
<b>Other</b>	
Citizens Information Board	Mairide Woods
Sign Language Interpretation Service	Elfrieda Carroll
National Rehabilitation Hospital	Lisa Held
National Disability Authority	NDA staff and senior managers
HIQA	Meiread Ashe, Corporate Services
University of Galway	Professor Anne McFarlane
Federation of Catholic Voluntary Nursing Homes	Rosemarie Nolan, Chairperson
HSE	Caoimhe Gleeson, National Specialist in Accessibility, Quality and Patient Safety Directorate
HSE	Sara Cronin, Speech and Language Therapist, HSE Accessible Information Working Group
HSE	Jenny Ford, Speech and Language Therapist, HSE Accessible Information Working Group

HSE	Grainne Tinney, Speech and Language Therapist, HSE Accessible Information Working Group
HSE	Sheila Kissane, Principal Psychology Manager, St Senans Hospital, Enniscorthy
HSE	Olwyn Hanley, Physiotherapist, Galway PCCC
HSE	John Kenny, Programme Manager, HSE Quality and Patient Safety Directorate
HSE	Dr Joe Devlin, Quality and Patient Safety Directorate
St Vincent's University Hospital	Siobhán Reynolds, Quality Manager, St. Vincent's University Hospital,

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