

# **The Experience of People with Disabilities in Accessing Health Services in Ireland: Do inequalities exist?**

Report to the National Disability Authority

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People with Disabilities in Ireland

Rehab Care

## **Terminology**

References made to deaf people and those hard of hearing were phrased following consultation with the National Association of Deaf People.

# CONTENT

<b>EXECUTIVE SUMMARY .....</b>	<b>1</b>
<b>1. LITERATURE REVIEW.....</b>	<b>11</b>
1.1. HEALTH INEQUALITIES .....	11
1.2. EQUITY .....	13
1.3. ACCESS.....	13
1.4. DISABILITY .....	14
1.5. MODELS OF DISABILITY.....	15
1.6. INTERNATIONAL LEGISLATION .....	17
1.7. EUROPEAN LEGISLATION.....	19
1.8. EQUALITY, EQUITY AND ACCESS FOR PEOPLE WITH DISABILITIES.	28
1.9. PRIMARY SERVICE PROVISION.....	32
1.10. HEALTH EDUCATION AND HEALTH PROMOTION.....	33
1.11. HEALTH INFORMATION .....	34
1.12. HEALTH SCREENING.....	35
1.13. GENERAL PRACTITIONERS.....	38
1.14. DENTAL SERVICES .....	41
1.15. REPRODUCTIVE HEALTH AND FAMILY PLANNING .....	43
1.16. SECONDARY SERVICE PROVISION.....	45
1.17. ACCIDENT AND EMERGENCY DEPARTMENTS.....	46
1.18. OUTPATIENTS .....	47
1.19. MENTAL HEALTH SERVICES.....	47
1.20. TERTIARY SERVICE PROVISION.....	49
<b>2. BACKGROUND, STUDY DESIGN &amp; PARTICIPANT PROFILE .....</b>	<b>55</b>
<b>3. INTERVIEWS .....</b>	<b>63</b>
3.2. SPECIFIC SERVICES ON THE CONTINUUM OF HEALTH SERVICES ...	64
3.2.1. <i>Primary Health Care</i> .....	64
3.2.2. <i>Accident and Emergency Department</i> .....	72
3.2.3. <i>Secondary Health Services</i> .....	75
3.2.4. <i>In-patients</i> .....	79
3.2.5. <i>Mental Health Services</i> .....	83
3.3. EMERGING THEMES ACROSS SERVICES.....	85
3.3.1. <i>Participants' Perceptions of Equality</i> .....	85
3.3.2. <i>Layers of Inequality</i> .....	86
3.3.3. <i>Fragmentation of Services</i> .....	88
3.3.4. <i>Adaptation and 'fit'</i> .....	89

<b>4. DISCUSSION .....</b>	<b>91</b>
4.1. INTRODUCTION .....	91
4.2. OVERARCHING ISSUES.....	92
4.2.1. <i>The Nature of Inequality</i> .....	92
4.2.2. <i>Nature of Service Provision</i> .....	95
4.2.3. <i>Information Provision</i> .....	96
4.3. ACCESS.....	98
4.3.1. <i>Accessibility: Physical Barriers Relative to Location</i> .....	98
4.3.2. <i>Accommodation: Sensitivity to Individual Differences and Functioning</i> 100	
4.3.3. <i>Affordability: Financial, Time or Energy costs</i> .....	102
4.3.4. <i>Availability: The Type and Extent of Services</i> .....	102
<b>5. CONCLUSIONS .....</b>	<b>105</b>
<b>REFERENCES.....</b>	<b>111</b>



# **Executive Summary**

## **Research aims**

The overall aim of this study was to capture the experience of people with disabilities in Ireland in accessing mainstream health services, placing this experience within the context of an international literature review on the subject and making the results available to relevant parties to help them draw up recommendations in terms of practice, policy or further research. The findings are of particular relevance for people with disabilities, advocates, health professionals, professional associations, the National Disability Authority (NDA) and government departments.

A number of reports have documented baseline information on health service provision for people with disabilities and identified gaps including research by the NDA e.g. *Towards Best Practice in Provision of Health Services* (2003) and *Review of Access to Mental Health Services for People with Intellectual Disabilities* (2003). However, there is a lack of data on the lived experiences of people with disabilities. By researching the experiences of people with disabilities in accessing and using mainstream health services we can better address any gaps in the health system and identify areas in which there may be opportunities for more effective, efficient and equitable care delivery. The health service users perspective is essential in a process of health service reform that consciously promotes equality, inclusion and person-centeredness. Thus, this research has an appropriate contribution to make to the ongoing reform, development and re-orientation of Irish health services.

## **Methodology**

The study design was in two parts: firstly, a comprehensive international literature review on access and use of mainstream health services and secondly, individual interviews with adults with a disability on their experience of mainstream health services. Individual interviews were chosen as the most

appropriate method of data collection to capture service users experiences and to provide a person-focused approach (Priestley, 2000) and a framework within which respondents could express their understanding and experience in their own terms (Patton, 2002). Thirty-two interviews were carried out of which 27 were directly with people with a range of disabilities (15 men, 12 women; age range, 21 to 77 years, including persons with intellectual, physical and sensory disabilities, people who have suffered brain injury and people with physical who experience mental health difficulty). In addition to people with disabilities the mothers of two men with brain injury were interviewed, as were three advocates of people with moderate to profound levels of intellectual disability. Some of the participants had experienced their disability from birth while others had acquired a disability. Several persons experienced dual or multiple disabilities. Two thirds of the participants reported living in an urban area and more than half reported themselves to be employed although only four participants were in full time open employment with the others working in either part time (2) or in sheltered or supported employment or on training schemes. The majority of those interviewed had a medical card and a few had private health insurance while three persons had neither. The interviewees were identified through voluntary agencies that liased between the interviewee and research team to facilitate communication. All participants reside within one health board area although many had previously and some continued to access health services from other health board areas.

## **DISCUSSION**

### **Preamble**

In the main report, the findings section contains the results of the interviews while the discussion section in both the main report and, here, in the executive summary is based on the combined findings of the international literature review and the interviews. While the interviews were carried out only with people living in one part of the country, the findings support and echo closely the international literature, which lends support to the transferability of the findings. It can be

reasonably assumed that the experience of mainstream health services in one health service area in Ireland reflects, to a considerable extent, the situation in other parts of Ireland, given the central organisation and control of services. At the same time, there are some regional variations and, one might consider it both prudent and worthwhile to repeat this qualitative study on a countrywide basis and, also, to consider undertaking more in-depth qualitative work with particular sub-groups of people with disabilities, to corroborate and explore further the findings.

In the main report the discussion is divided into two parts: overarching issues (the nature of inequality, the nature of service provision and information provision) and access (accessibility, accommodation, affordability and availability). Here, in the executive summary the discussion is outlined under eight headings: health service inequalities; inequality of access to health services; health services that are fragmented and un-coordinated; preventative and screening services; specific groups are particularly disadvantaged; financial barriers to accessing services; health services and independent living; communication, attitudinal and physical barriers; and health service development.

### **Health Service Inequalities**

The fieldwork findings report positive experiences with the health services. The value of acceptance and reciprocity is demonstrated in the participants' experience of General Practitioners. Those actively sought out exemplified partnership approaches and inclusive practices. Unfortunately, this was not experienced across all areas of health service provision. The inequalities reported in the interviews are similar to the findings of the literature review and include inequalities in general medical services, dental medicine, mental health and preventive health programmes. Our research findings gave instances of inadequate public provision of certain services including speech therapy and physiotherapy. In some instances, while the availability of particular health

services is at a sub-optimal level for everyone, the consequences of the deficiency are greater for people with a disability where they are contending with additional disadvantage and, also, when the services are vital to their optimal functioning and participation in society.

### **Inequality of access to Health Services**

For many people with disabilities interviewed in this study the degree of fit between themselves and the health service is a poor one. To compensate for the poor fit a range of adaptations is brought into play. In this research it was found that the system is generally rendered accessible only with considerable support from friends and relatives and from the informal goodwill of individual health workers who try to personally compensate for the deficiencies, inefficiencies and injustices of the system. "Society" acts as a buffer to compensate for a health service that is too rigid to be person-centred. Iacono et al (2004) describes this reality as an "adapter" mechanism that disguises the underlying inadequacies and inequalities of the system. The inequalities experienced by those interviewed would be far greater if the 'adapters' were not compensating for and concealing them. The limitations of this 'propping up' of health service provision are best evidenced by its inability to compensate for or to conceal the inaccessibility of preventative and screening services for many people with disabilities.

### **Health Services that are fragmented and un-coordinated**

From the interviews in this study it would appear that the Irish health services are un-coordinated and too fragmented to support a person-centred approach. Fragmented services are insensitive to individual differences and needs and compromise the quality of service provision for everyone who seeks to access it. They impact inordinately on people with disabilities whose multiple service needs can be complex and who are often contending with educational, social and economic disadvantage. Fragmented services also place increased demands on

their physical support capacities in a way not experienced by people without disabilities.

A health service is not a coordinated, inclusive, person-centred service<sup>7</sup>, where health professionals will walk away from a person with communication difficulties rather than attempt to communicate with them; where no one has responsibility to ensure that an in-patient who is blind knows that their meals have arrived; where professionals demand that a person with an intellectual disability is accompanied at all times by a carer without regard to the person's individual need for support and without regard to the impact that tying up a support person may have on other people who share the same support resource. It is also a system that removes from health care professionals the obligation to become aware of the issues concerning both individuals with a disability and intellectual disability. These experiences challenge the stated government commitment to re-orientate health services towards a social model (Commission on the Status of People with Disabilities, 1996; Department of Health and Children, 2001). While theoretically the social model of disability has superseded the medical model, in practice, with the exception of some of the General Practitioner Service, fragmented health services prevail. The continued adherence to the medical model may explain why the health system has disregarded levels of adaptation that would render the health services fully accessible.

### **Preventative and screening services**

Preventative and screening services presented physical barriers to the few people in this study who accessed them and this was also found in the literature together with lower proportions of people with disabilities being screened in certain services (e.g. Iezzoni et al, 2000). It would appear, therefore, that such services often discriminate against people with disabilities. While this inequality is overt, other, subtler, inequalities may also exist in relation to preventative and

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<sup>7</sup> A person-centred approach is one when the unique makeup of an individual is acknowledged as well as his/her emotional needs, rights, his/her place in society and his/her value as a human being.

screening services. For example, people with disabilities may not be thought to require the same level of health screening as their peers without disabilities (Chan et al, 1999; Sullivan et al, 2003). Where screening was accessed it was not as part of population breast or cervical cancer screening programmes, as these are not nationally available. This may be an inequality in itself but one that results from geography rather than disability. As national population screening programmes are rolled out, people with disabilities and their advocates should be actively included in the developments and their rights upheld throughout the screening process.

### **Specific groups are particularly disadvantaged**

Specific groups that appear particularly disadvantaged in the use of health services include those with intellectual disabilities, people with disabilities who have mental health needs and people who are deaf, emphasising the heterogeneity of the needs of people with disabilities. People with a hearing impairment or who were deaf were identified as one of the groups of people with disabilities most likely to be subject to layers of different and compounding inequality. Mental health services offered a particularly inequitable service to people with disabilities who also have mental health needs. The paucity of services described in other Irish reports (NDA, 2003; Irish College of Psychiatrists, 2004) is evidenced in this study where the perceptions are that neither specialist nor mainstream services provide equal and adequate services to people with intellectual disabilities. The Irish College of Psychiatrists (2004) have proposed solutions with regards people with Intellectual Disabilities. However, it is suggested that in reviewing and developing mental health care, provision, recognition and active inclusion of the needs of all people with disability, not just those with intellectual disabilities, is required.

Participants reported that people with intellectual disabilities were denied access to in-patient hospital services unless they were accompanied twenty-four hours per day. As long as professionals will not interface with people with intellectual

disabilities without the presence of a third party, conditions do not exist to develop mutual acceptance, nor reciprocity. Research suggests that health service professionals feel unprepared and lacking in training when presented with patients with learning disabilities (McConkey & Truesdale, 2000), and while there is an absence of similar research on treating and caring for people with physical and sensory disabilities, it is likely that similar reservations will be held by some health service professionals.

### **Financial barriers to accessing services**

Participants raised the issue of finance in relation to therapy services, including physiotherapy, occupational therapy and chiropody. Discrepancies were perceived between those who paid for an adequate service and those who did not have the resources to do so. These societal inequalities compounded the negative experiences of people with disabilities in this study. Those eligible for a medical card were denied choice in accessing General Practitioners and could not easily, if at all, access support such as chiropody, counselling, speech therapy or physiotherapy. Many of those ineligible for a medical card also could not afford to access support services. In the main, only those who could afford to access support services received them. Occupational therapists within the public sector were perceived to only have a remit regarding aids, equipment and extensions.

### **Health Services and Independent Living**

The under-provision of other services that promote independence emerged as a theme from the interviews. The restrictions placed on these services may be partly a consequence of their being provided by the health services with its tradition of care and dependency. Limited availability of Home Help and Personal Assistant services can render individuals excessively dependent on family and informal support with an undermining of their autonomy. The experience of one participant of being told to ask her neighbours to do some housework when they

called to visit her, suggests a lack of understanding as to how the dynamics of relationships can be altered by dependency. The restrictions placed on Home Helps and Personal Assistants can also serve to compromise the independence of a person with a disability when they are precluded from administering medication or driving the person with a disability in their car. This highlights the urgency of a quantum leap to the social model, so that a health service is provided that formally supports independence and cultivates a partnership with the service users who have expertise in their own needs and lives.

### **Communication, attitudinal and physical barriers**

The barriers experienced by the participants of this study concur with previous research. Poor communication skills on the part of health service providers drive some people with disabilities into a state of dependency, which is unnecessary and serves to reduce their status as independent individuals. Communication barriers were reported most frequently by those with sensory disabilities who identified a lack of alternative forms of communication and information provision. For people who are hard of hearing, this situation would be ameliorated through the provision and use of information technology such as visual displays and text readers. Lack of information can be both dis-empowering and dangerous. Many of the participants were severely disadvantaged in their access to health information and health education, an issue that has been identified previously (MacDougall, 1998; Commission on the Status of People with Disabilities, 1996; National Rehabilitation Board, 1994).

With a single exception, no health service provider was reported as offering information in an alternative format or inquiring whether the supplied format was accessible. This creates an inequality of knowledge between people with disabilities and the general population and can endanger individuals who, for example, cannot read or understand information supplied with medication. When people with disabilities can access the same information that is available to the general public, a fundamental step towards equality in health care will have been

achieved. The right to information in a format suitable to individual needs and abilities must become a reality.

Frustration was experienced by participants when they encountered professionals within the health services, particularly doctors, who were both insensitive to the differences generated by a disability and also unwilling to be informed about them. Other studies have suggested that people with disabilities must often educate their physicians about health related issues associated with their disability (DeLong *et al.*, 2002).

An accessible built environment is a core element for the realisation of a society based on equal rights. The built environment experience of participants in this study was negative with regards the use of not just older buildings but also of buildings built or extended since the introduction of building control regulations under the Building Control Act (1990), which suggests that measures aimed at facilitating access for people with disabilities are not working.

### **Health Services Development**

The attitudinal barriers experienced by participants identify the need for mandatory training of all personnel in the health services, not just service providers, in specific areas of anti-discriminatory work practice, communication skills and on how to address diverse needs. This training is urgent and should be included in all health service induction programmes for any new staff as well as in the core curriculum of all health professional training and as a pre-requisite to professional registration. Such training should acknowledge that many people with disabilities and advocates of people with disabilities have knowledge of disability in general and of individuals' needs and emphasise that health service personnel should respect this reality.

Direct involvement of people with disabilities at all levels of the health services will ensure that addressing inequalities is prioritised. People with disabilities do

not have a positive visibility of the health services at the present time with a variety of barriers marginalising them by, for example, forcing a wheelchair user to sit in a corridor rather than in the waiting room. People with disabilities can work to raise their visibility and to ensure that all plans, policies and strategies are disability proofed before they are implemented. The identification and highlighting of models of best practice in the involvement of people with disabilities in service development is thus an important step.

The need for a synchronised and holistic health service is evident and integrating services in a person-centred way is an issue that needs to be addressed in the context of equity. A review of case management as a model for service provision for people with disabilities is timely given the Health Service Reforms, the lack of definition around service reorganisation and the openness to be informed by ongoing research and consultation. It is to be hoped that the reform of the health services will take the requirements of people with disabilities into account in a more formal and professional manner. What is required, according to one participant is, "*A quality service for quality people*" (Participant 2:9).

# 1. LITERATURE REVIEW

## 1.1. Health inequalities

Health inequalities are differences in health experiences and health outcomes between groups of people according to socio-economic status, geographical area, age, disability, gender, sexual orientation and ethnic group (Department of Health, 2003). These axes of social differentiation are linked yet represent separate dimensions of inequality (Graham & Kelly, 2004). The causes, risk factors and impact of health inequalities are therefore complex. Within the health system in Ireland, inequalities associated with the existence of a private and public health service frequently result in lengthy waiting lists and delays in receiving treatment in the public sector. Anecdotal evidence (e.g. from the St. Vincent De Paul Society) suggests that in some cases people waiting months or years to gain admission as a public patient have been offered much faster and sometimes immediate access to the same hospital when they have indicated that they will “go private”. This type of situation is viewed as one of the most inequitable in the Irish health system (The Institute of Public Health in Ireland, 2001). The extent of fee paying in Irish health care has led many to argue that personal circumstances, particularly income, may well determine the availability, extent and speed of treatment (Layte & Nolan, 2004). Thus, those who are more affluent have increased access to healthcare. It is also the case that this group experiences less illness and longer life expectancy than those less affluent (Marmot & Wilkinson, 1999; Davey Smith *et al.*, 2001). The reasons for this are again complex but a growing body of evidence exists which indicates that health is remarkably sensitive to the social environment and to the social determinants of health (Marmot & Wilkinson, 2003). It is now accepted that health policy is about more than the provision and funding of medical care and that many of the differences in health across individuals and groups are caused by social factors (Marmot & Wilkinson, 2003; Graham & Kelly, 2004). Marmot and Wilkinson, (2003) list the ten social determinants that have a lifelong impact on the health of individuals and populations. These are early life experiences, social support,

social exclusion, the social gradient, work, unemployment, stress, transport, food and addiction. Although the responsibility for many of the determinants lies outside the remit of the health services, the health services have a role to play in leading and supporting intersectoral collaboration and community actions to improve population health and well-being (Queensland Government, 2004). Health services also directly impact on health status through primary prevention and health promotion initiatives as well as through a range of primary, secondary and tertiary level health services.

To understand equality and inequality, Sen (1992) suggests that one must begin with an appreciation of the inherent heterogeneity of humanity, that all people are not created equal, as they are genetically and socially different. Any notion of equality should therefore accommodate these personal and circumstantial variations. Sen (1996) analysing equality as a political virtue points out that any conception of equality that respects ethical individualism must aim to make people equal, not in wellbeing judged from some collective viewpoint but in the resources each controls. This is also reflected in the view of Forbes and Wainright (2001), who question whether it is possible to bring everyone's health to the same common denominator and whether, instead, the aim should be to define an acceptable threshold, a social consensus which signals a minimum point for the health expectation which should be available to all. Thus, all individuals would ideally have the same opportunity to achieve their potential. Equity, therefore, does not imply equal health status for all, since individuals may differ in their health endowments (Culyer & Wagstaff, 1993), but the reduction and elimination of avoidable and unfair differences in opportunity. If conditions were equitable, where two individuals have equivalent health endowments, it would be expected that they would reach the same health level.

## 1.2. Equity

Equity, is concerned with fairness. Equity in health care is a desirable state, and is considered to be a right of all individuals (Sowney & Barr, 2004). Whitehead (1990 & 1992) states that equity in health implies that everyone should have a fair opportunity to attain their full health potential and that no-one should be disadvantaged from achieving this potential. The aim, therefore, is not to eliminate all health differences but rather to reduce or eradicate those differences that result from factors which are considered to be avoidable and unfair. In relation to health care Whitehead (1990) defines equity as:

- Equal access to available care for equal need
- Equal utilisation for equal need
- Equal quality of care for all.

Therefore equity is concerned with people having equal access to the service as well as receiving equal benefit from the service.

According to the World Health Organisation equity in health means that *'everyone should have a fair opportunity to realise his or her health potential and that no one should be prevented from achieving this potential'* (WHO, 1999a:5). To this end, it has also stated that *'societies should organise their resources for health equitably, so as to make them accessible to everyone'* (WHO, 1999:5). In relation to health inequalities, it is important to consider the availability of and access to health services.

## 1.3. Access

Access can be seen as a right to have or gain entry and/or the opportunity to avail of something (Sowney & Barr, 2004). Bommier and Stecklov (2001) propose that access to health resources is a basic right and that health access should be distributed equally in an ideal society. Accessibility to health care refers to the physical environment and to information and communication

services (United Nations, 2003), and not only to the service being easily available in terms of distance, but also in terms of time and ethos. In relation to time, accessibility to health care can be viewed as the time taken to reach a service and the actual waiting time after reaching the service (Sowney & Barr, 2004).

Research has identified the factors that contribute to an individual's ability to access health care services. These factors include social class, wealth, education, housing, ethnic background, sexual orientation, age and disability (Black *et al.*, 1982). Pechansky & Thomas (1981) define access as a concept representing the degree of "fit" between the clients and the system. In adapting this dimension of access, Simeonsson *et al.*, (1999) identified five characteristics of access to health care:

- Availability – the type and extent of services
- Accessibility – physical barriers relative to location
- Accommodation – sensitivity to individual differences or functioning
- Affordability – financial, time or energy costs
- Acceptability – mutual acceptance and reciprocity.

While many people do access and receive good health care, equity of access for some groups, particularly people with disabilities, can be problematic (Sowney & Barr, 2004) and this has been recognized by some service providers specifically in the area of physical and staff attitudinal barriers (Morgan, 2003).

#### **1.4. Disability**

In the past, disability was treated as an almost self-evident category into which people were placed by reference to problematic individual characteristics, usually defined by medical assessments (Brunel University, 2004). Disability was viewed as a pathway running from impairments (abnormalities of anatomy, physiology or psychology), to disability (restriction of ability to perform an activity

in a normal manner), to handicap (the disadvantage due to impairments or disabilities limiting role fulfilment).

In recent years, the concentration on the functional deficits and problems of the individual alone as a basis for understanding and managing disability has been systematically and robustly challenged. 'Disability' has evolved to become not simply a personal attribute but a complex collection of conditions, activities and relationships, many of which are created by the social environment. It is also viewed as a "process" emphasising the importance of the gap between individual capacity and environmental demands and the role of intra-individual factors such as personality, and extra-individual factors such as the built environment (Verbrugge & Jette, 1994).

## **1.5. Models of Disability**

Traditionally disability was regarded as a personal tragedy afflicting the individual with the response being via the charity, health and welfare systems. Disability was a medical issue and all efforts were directed towards cure and rehabilitation and the 'experts' on disability were the medical profession. The medical model of disability stemmed from a control model and influenced policy responses to disability until relatively recently. Such thinking resulted in segregated programmes, which perpetuated a cycle of social exclusion, low self-esteem and discrimination (Quinn, 2001).

The social model of disability focuses on issues other than individual functional problems and argues that disability should be defined primarily by the inadequacies of social, environmental, political and economic factors in the wider society which do not facilitate all people to achieve their full potential. In other words, it is not the individual's impairment which causes disability or which is the disability, but rather disability is predominantly caused as the result of social arrangements that act as barriers to restrict the activities of people with impairments (Thomas, 1999). This exclusion occurs because of a segregated

education system; inaccessible working environments; inadequate welfare benefits; discriminatory health and social support services; inaccessible transport, housing and public buildings; lack of recognition of alternative forms of communication, and negative media portrayals (Clark, 2002). Thus the social model draws on the factors identified as the social determinants of health. The social model holds that the medical model of disability has the effect of “*blaming the victim*” for their problems. Terzi (2004) concludes that the social model of disability acts as a powerful remedial to our understanding of disability and to the oppressive nature of some social arrangements.

The disability rights movement aims to develop inclusive societies where everyone is entitled to the right to participate regardless of difference. A rights-based perspective on disability asserts that everyone is born equal and has inalienable rights (Quinn, 2001) and that difference is a social construct used to separate those who do not conform to the average. In order to incorporate the social model of disability into a legally binding international human rights instrument, and to support equality for people with disabilities, Brown (2003) argues that a taxonomy relating human rights to disability is necessary. He goes on to offer three potential domains to be considered in the taxonomy – (1) the environment, (2) accessibility domains between individuals and their environment and (3) legal expressions of human rights.

Quinn (2001) distinguishes an equal opportunities model from the formal equality model. He asserts that the equal opportunities model demands that all persons are treated on their individual merits and that the role of law and policy is to open up opportunities to all on an equal basis. Such a model tracks the typical lifecycle of an individual and focuses on preparing people with disabilities for participation, guaranteeing access to the life-world, breaking down doors through anti-discrimination law, mainstreaming disability in the policy process and re-styling welfare and social supports to achieve the goals of independence and participation. He further asserts that the development of disability rights in the US

has provided a model for the rest of the world and that the Americans with Disabilities Act '*is the near perfect embodiment of the equal opportunities model in law*' (Quinn, 2001, p.6), having at its heart a legal obligation to 'reasonably accommodate' disability.

The Irish Government is committed to re-orient services for people with disabilities towards a social model of service provision (Commission on the Status of People with Disabilities, 1996; Department of Health and Children, 2001). The NDA's strategy is underpinned by a core belief in a rights based approach '*realised through the pro-active adoption of a civil and human rights perspective in the development of policy and practice for people with disabilities*' (Pillinger, 2003, p.35).

## **1.6. International Legislation**

The adoption by the UN General Assembly of the Standard Rules on the Equalisation of Opportunities in 1993 was a key step in the development of rights based disability legislation. There are 22 rules covering all aspects of life for people with disabilities naming preconditions and target areas for equal participation as well as implementation and monitoring measures. Although not legally binding they act as a policy-making tool, representing a moral and political commitment by governments to take action for the equalisation of opportunities for people with disabilities. Many governments have taken them as their explicit frame of reference. Finland, for example, was the first country to adopt the Rules in its legislation in 1993 and in 1998 the Greek Government incorporated them into their national law.

There are various instruments dealing with the right of people with disabilities to access health services. Although not specifically mentioning health services, Rule 5 of the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities considers "accessibility" with reference both to the physical environment and to information and communications services. In 1997

the General Assembly identified accessibility as a priority in promoting the equalisation of opportunities for people with disabilities. It suggests that a focus on accessibility is an effective approach to reversing exclusion and enhancing equalisation of opportunities in a positive and sustainable way.

Article 12.1 of the UN International Covenant on Economic, Social and Cultural Rights (1966) includes the right to timely and appropriate health care, stating that health facilities, goods and services have to be accessible to everyone without discrimination. This comprises physical accessibility, economic accessibility, information accessibility and non-discrimination – where health facilities, goods and services are available to all but especially to those who are vulnerable or marginalised.

Article 12.2 (d) deals with the right to *‘provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education’*. Articles 2.2 and 3 of the Covenant also prohibit discrimination in access to health care on a number of grounds including physical or mental disability and health status.

In December 2001 the United Nations took a landmark step towards the advancement of the human rights of people with disabilities (Brown, 2004) when it established an Ad Hoc Committee to *‘consider proposals for a comprehensive and integral convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination...’* (UN General Assembly, 2002). The U.N. Convention on the Rights of People with disabilities has held a number of sessions in New York. A convention such as the one being considered would, for the first time, offer an enforceable mechanism under international law to protect human rights related to disability (Brown, 2004). Ireland, however, may still have some way to go towards establishing a, human rights taxonomy with respect to disability. The United Nations Committee on

Economic, Social and Cultural Rights (2002) recommended that Ireland “*revisit the recently published National Health Strategy with a view to embracing a human rights framework in that strategy, in line with principles of non-discrimination and equal access to health facilities and services*”. Notwithstanding the UN recommendation, disability policy in Ireland has undergone significant change in the past decade.

## **1.7. European Legislation**

Disability is a major public policy issue in Europe and there is a growing acceptance of a need to protect the rights and freedom of people with disabilities, securing their full inclusion within society and a right to equality of opportunity.

In 1996, the EU Commission set out a new Community Disability Strategy supporting the international move towards a rights-based approach in the disability policy field. This approach is based on the notion of rights rather than charity and an accommodation of difference rather than adjustment to an artificial norm.

The Council of Europe, with 41 member countries, has played a vital role in establishing a range of civil, political, social and economic rights in Europe. The implementation of human rights legislation has impacted directly on the lives of people with disabilities where in the UK, for example, people can take legal action against the withdrawal or restriction of medical services (Daw, 2000).

This move towards a human rights approach has been endorsed by the Council's Resolution on Equality of Opportunity for People with Disabilities (1996) which stressed the need for a new approach which focuses on the identification and removal of the various barriers preventing people with disabilities from achieving equality of opportunity and full participation in all aspects of life. Part of the European Community Action Plan (2001-2006), which includes the European Strategy on Social Inclusion, has led to the development of National Action Plans

on Social Inclusion in each member state, establishing, amongst others, a rights-based approach to access to quality health care services. While a large number of countries have outlawed discrimination against people with disabilities at work, the rights to health and social care services are more limited.

European countries that are considered at the forefront of best practice in terms of provision of disability and health services and using a rights based approach are Finland, Denmark, the Netherlands, France and the UK. Finland for example, has amended its Constitution to include the rights of people using Sign Language and the need for interpretation and translation services. In the UK the Disability Discrimination Act (1995) was recently extended to cover accessibility of services, for example the right to accessible information and physical access to buildings and services. The report by Dr Jane Pillinger *'Towards Best Practice in the Provision of Health Services for People with Disabilities in Ireland'* (2003) contains an in-depth and comprehensive description of each country's provision of disability services along with the relevant legislation.

However, it must be borne in mind that anti-discrimination legislation does not provide a generalised right to a particular health or support service or standard of service for people with disabilities. In countries such as Sweden and Finland there is a right to named services including personal assistance and support but in the case of Sweden the reality is that the services available differ substantially from area to area (Nolan, 2003). German legislation, introduced in 2002, (Behindertengleichstellungsgesetz, BGG) regarding equality of treatment for people with disabilities has as one of its objectives the elimination of barriers and provision of Sign Language. However, this is unenforceable at an individual level as the legislation only provides organisations of people with disabilities the right to legal action.

## **1.8. Ireland: legislation and policy**

In addition to International and European legislation and recommendations, many identify as one of the catalysts for the change of policy in Ireland the publication of the Report of the Commission on the Status of People with Disabilities, A Strategy for Equality, in 1996. This report was the outcome of a major consultative process involving people with disabilities. It outlines the needs and rights of people with disabilities and highlights a range of issues, amongst them the inaccessibility and quality of health services. On the basis of recommendations in this report the government introduced the National Disability Authority Act, (1999) which led to the establishment of the National Disability Authority (NDA) - an independent statutory body whose role is to co-ordinate and develop policy for people with disabilities. The NDA is responsible for the development of standards and codes of practice for services for people with disabilities, monitoring the implementation of these standards and with a statutory remit to carry out research in the area. In addition, the NDA also has a key role in ensuring that the rights and entitlements of people with disabilities are protected and promoted.

Equality legislation has an essential part to play in the accessing of mainstream health services for people with disabilities. The Equal Status Act (2000) obliges anyone providing a service to accommodate the needs of people with disabilities provided, however, that the cost does not amount to more than a 'nominal cost'. Government services including Government Departments, health boards and local authorities are covered under the Act although certain exemptions apply. The Act covers disability access and requires an employer, a person providing goods or services, accommodation, educational institutions and clubs to do all that is reasonable to accommodate the needs of an employee or a person with a disability by providing special facilities or treatment. The Act is also relevant to the provision of assistive technology as it prohibits educational establishments from directly or indirectly discriminating in relation to access and participation. Under the Act positive action to promote equality of opportunity for people with

disabilities is facilitated. However, although the Equal Status Act has important implications for the delivery of public services in non-discriminatory ways, it does not place a statutory duty or requirement on Government Departments to outlaw discrimination and promote equality for people with disabilities.

The Equality Act 2004 transposed three European Directives on Race, Gender and Employment into Irish Law and made a number of mainly procedural changes to the Employment Equality Act 1998, the Equal Status Act 2000 and the Pensions Acts 1990-2004. The Act changed the definitions of some core concepts such as direct or indirect discrimination, harassment, victimisation and reasonable accommodation and made a number of changes to what is covered by equality law. Under the provisions of the transposed European Employment Directive all people with disabilities in Europe are guaranteed equal treatment in employment.

Other specific disability policy initiatives can be found in commitments made under the Social Partnership Agreements of 2000 and 2003. The Programme for Prosperity and Fairness (PPF) includes measures to improve the quality of services and disability access. The PPF Framework III on social inclusion states that public services will be accessible by the year 2006:

*“...each Government Department will ensure that reasonable steps are taken to make its services and those of agencies under its remit, accessible to people with disabilities. To facilitate effective action and acceptable standards in this regard the NDA will issue guidelines in accordance with international norms and will award an accessibility symbol to compliant public offices”* (PPF, page 100).

The current social partnership agreement – Sustaining Progress – covers the period from 2003 to 2005. The government’s commitments under this agreement include that:

- It will carry out a strategic review of existing service provision, in consultation with relevant interests, with a view to enhancing health and personal social services to meet the needs of people with disabilities and
- It will, within six months, complete a review of the waiting lists for residential care for people with disabilities.

The Agreement included a consensus that the “Draft National Standards for Disability Services” drawn up by the NDA and the Department of Health and Children will be completed and implemented on a pilot basis as soon as possible. The Agreement further undertook to implement three European Employment Related Equality Directives and to publish a Disability Bill in 2003.

The National Disability Strategy (Department of Justice, Equality and Law Reform, 2004) contains four elements that propose to strengthen the participation of people with disabilities in Ireland. One of these is the Disability Bill (2004), which provides a statutory basis for accessible public buildings and services, as well as an individual right to an independent assessment of health and education needs. The Bill has been widely criticised for not containing positive rights for people with disabilities and that the services offered are dependent on available resources.

Arising from the Disability Bill (2004), six Government Ministers will be required to prepare sectoral plans for their Departments, setting out the services to be provided for people with disabilities. Each Minister must consult with representatives of people with disabilities before drawing up the plan and must provide for co-operation with other departments in the development and co-ordination of services. The Departments implicated are Health and Children, Social and Family Affairs, Transport, Environment, Heritage and Local Government, Communications, Marine and Natural Resources and Enterprise, Trade and Employment.

Other elements of the Strategy include the Comhairle (Amendment) Bill (2004), which will provide personal advocacy services for people with disabilities to help those who have difficulty in accessing services. The emphasis of the Bill is on individual services through a Personal Advocacy Service and ‘advocacy services are seen as supporting an application for an assessment of need, a health service and, *‘any other service from a statutory or voluntary body...’* (Goodbody, Economic Consultants, 2004).

The Mental Health Act (2001) effectively changed the legal rights of people experiencing mental health difficulties, allowing an independent review process for all involuntary detentions as well as new regulations for the admission and detention of people in mental health facilities. The most significant advance was the establishment of a Mental Health Commission – an independent statutory body to protect the interests of people with a mental health disability and to ensure best practice in the delivery of mental health services. The Act also created the role of Inspector of Mental Health Services whose role it is to report on the standard of care provided in Irish mental health facilities. However, the majority of people with intellectual disabilities who receive mental health services do so within specialist disability services and these services are not covered by the protective legislation (NDA, 2003).

### ***Legislation for the built environment***

Access was characterised by one commentator as being across the three main dimensions of physical, sensory and communication (Darcy, 1998). Efforts to address the restricting effect of an inaccessible environment have taken place at both a national and an international level. The UN Standard Rules on the Equalisation of Opportunity for people with disabilities (1993) requires countries to introduce programmes to make the physical environment accessible and to undertake measures to provide access to information and communication. The Barcelona Declaration of 1995 has been adopted by a number of cities and towns from Europe and Israel who have committed themselves, inter alia, to 17

actions to ensure inclusive environmental design. Other international initiatives include; 'Towards a Barrier Free Europe for People with Disabilities (2000)', 'Resolution ResAP (2001) on the introduction of the principles of universal design into the curricula of all occupations working on the built environment', 'the CEN/CENELEC Guide 6 – Guidelines for standard developers to address the needs of older persons and people with disabilities', and the ISO Standards. European expert and working groups have also been established and in 2001 the Toegankelijkheidsbureau v.z.w Hasselt and LIVING Research and Development s.p.r.l published an overview of the accessibility of the built environment in European countries and of the policies and legislation that govern such accessibility. It also considered any anti-discrimination legislation enforced by the individual countries.

The Building Regulations 1997-2000 controls accessibility to the built environment in Ireland. The Regulations are set out as a series of requirements each addressing an aspect of design, construction or building alterations. Part M of the Regulations focuses on access for people with disabilities. Separate Technical Guidance Documents give detailed guidance on how to comply with each of the requirements.

The aim of the Part M regulation is to ensure '*that as far as is reasonable and practicable, buildings should be usable by people with disabilities*' (O'Herlihy 2004; NDA 2004). Under the Regulations all new public buildings and major extensions to old ones must have, among other requirements wheelchair accessible paths, ramps and public entrances, a suitable passenger lift in buildings above a certain size, suitable communication aids for people who are deaf, in places such as theatres, places of worship, meeting and conference centres, large print and Braille signage to aid people with visual impairments, space for wheelchairs in places such as cinemas and theatres and adequate safety features in case of emergencies. Originally the regulations did not apply to private housing but the Building Regulations (2000), introduced by the

Department of the Environment and Local Government brought in the concept of "visitability" standards for new houses. This requires that '*access and adequate provision shall be made to enable people with disabilities to safely and independently access and use a building*'. However, the regulations constitute a "minimum standard" and designers and developers are merely "encouraged" to go further. The 'Buildings for Everyone' (NDA, 2002) guidelines recommended by the NDA are designed to encompass all forms of disability, not just physical disability but so far have not been incorporated into the Building Regulations and are, therefore, not legally enforceable.

Architects, designers, builders and property owners have the primary responsibility to implement the Building Regulations while the local building control authority is charged with monitoring and enforcing the building control system. Access officers, building control officers and disability liaison officers are employed by Local Authorities to ensure that the regulations are complied with and local authorities can order changes to buildings in order to ensure such compliance.

The Social Partnership Agreements of 2000 and 2003 addressed issues of accessible environments. The Programme for Prosperity and Fairness committed the Departments of Government and its agencies to implement all reasonable measures to make all public services accessible by 2005. In furtherance of this commitment, the NDA was charged with drawing up guidelines and monitoring and auditing progress towards its achievement. The NDA was also authorised to introduce an award scheme in the categories of the Built Environment, Information and Communication Technology, Transport and Quality Customer Service. The Sustaining Progress Social Partnership Agreement was concluded to cover the period up to 2005 and impacts on the built environment in that it deals with housing, access to quality public services and equality (O'Herlihy, 2004).

Other Acts including the Employment Equality Act 1998, the Health and Safety at Work Act 1989 and the Heritage Act 1995 also have some relevance to the accessibility of the built environment. A comprehensive overview of all policy and legislation relating to the accessibility of the built environment is detailed in the NDA document: '*Overview on the governance of Public Policy and legislation with regard to accessibility of the built environment*' (2004).

In addition to the above, health policy in Ireland has been shaped by a number of key policy documents. These include the 1994 National Health Strategy – *Shaping a Healthier Future* (Department of Health, 1994) which had equity and accessibility of services for people with disabilities as one of its underlying principles. The current Health Strategy – *Quality and Fairness* (Department of Health and Children, 2001), continues this theme outlining a number of principles aimed at tackling health inequalities including fair access to health services. One of its goals is a person centred health system, ensuring a health service that responds to the needs of the individuals it serves. However, although the overall action plan is comprehensive, there are no clear provisions contained within the Strategy to address the inequalities in access and outcomes in health service provision which have been identified by disability organisations. In 2001 the Primary Health Care Strategy (Department of Health and Children, 2001) emphasised the need for a broader, more inclusive model of primary care which would meet the needs of its clients by ensuring a team based approach between primary and secondary health services. It also states disability awareness training for health services staff as one of its objectives, as well as accessibility of primary health care centres for people with disabilities and an action plan for rehabilitation services.

Health Promotion strategies in Ireland have consistently identified the combined need to promote health in relation to key settings and priority population groups as well as specific topic areas. The 1995 Health Promotion Strategy (Department of Health, 1995) while identifying the need to promote mental health as a key

topic area did not specifically identify people with disabilities as a priority population group, although reference was made to promoting health with 'vulnerable groups'. The succeeding strategy published in 2000 continues with the combination of topic, population group and settings approaches. However, within population groups a so-called 'catchall' phrasing is used with reference to 'other groups within the population'. These 'other' groups are stated as travellers, people from ethnic minorities as well as people with intellectual, physical and sensory disabilities (Department of Health and Children, 2000, p.45). Those with mental health difficulties are not referred to in relation to the population group of people with disabilities, although the promotion of positive mental health is identified as a specific topic area. A number of determinants of health are referred to in the document including access to health services. Access to health services is recognised as an area of disadvantage for those living in rural areas and older people, but no reference is made to people with disabilities. The strategy as a whole advocates a multi-sectoral approach using health proofing as a tool to develop healthy public policy. A review of the Health Promotion Strategy carried out in 2004 (McKenna et al, 2005) identifies limited development of health promotion programmes for those with disability and recognises the need for further action in this regard. A number of strategies have been developed for specific disease areas, notably the Cancer Strategy (Department of Health, 1996) and Cardiovascular Health Strategy (Department of Health & Children 1999). The Cancer Strategy refers to lifestyle approaches to cancer prevention and the introduction of screening for early detection. The Cardiovascular Strategy promotes a settings approach with reference to specific topic areas. Neither makes reference to people with disabilities and their specific needs in relation to accessing services.

## **1.8. Equality, Equity and Access for People with Disabilities**

Many people with disabilities live in their own homes in the community. They live either independently or with the support of health and social care services, family and friends and disability organisations, rather than in hospitals or in residential

accommodation. One in five people with a long lasting health problem or disability who lived in private households in 2002, lived on their own and this proportion rose to one in three for those aged over 65.

Like everyone, people with disabilities use facilities such as G.P. surgeries, dentists and opticians, Accident and Emergency Departments, in-patient and outpatient hospital services. However, some people with disabilities are more susceptible than the general population to secondary health conditions (Kinne *et al.*, 2004; Lennox *et al.*, 2003; DeJong *et al.*, 2002) such as urinary and respiratory tract infections, and are more at risk of, for example, cardiovascular disease and stroke (Marge, 1993). As a result, people with disabilities may have greater health care needs than the general population.

According to the Combat Poverty Agency (1995), people with disabilities come across multiple layers of discrimination, exclusion and poverty. The impact disability can have on an individual's health includes a reduced income due to exclusion from the labour force (Jenkins & Rigg, 2004), greater demands on that income due to the extra costs of being disabled, increased incidence of other disabling conditions and illnesses, and lack of access to acute and rehabilitative services (The Institute of Public Health in Ireland, 2001). In an American study, two-thirds of disabled participants reported a financial barrier as the main reason for not going to see the doctor. The results suggest that low-income people with disabilities were more likely to experience financial barriers to care (Rosenbach, 1995). This is supported by a national study of 800 people with physical disabilities in the US by Beatty *et al.*, (2003) which found that those reporting the poorest health and the lowest incomes were least likely to receive a comprehensive array of health services. In a UK study, people with disabilities in employment who use community health services such as physiotherapy, occupational therapy and chiropody commented that it was impossible to get an appointment out of office hours (Clark, 2002).

While financial barriers, geographical barriers and organisational barriers within the health care system can affect other people in the general population in accessing care, people with disabilities may experience additional disadvantages in their health and well-being (Iezzoni, 2003).

Access to health care services can present particularly potent challenges for people with disabilities (Lawthers *et al.*, 2003). Physical accessibility is the first and most obvious potential barrier for people with disabilities. In health care, the physical environment often impedes access to health care services, particularly for people with physical disabilities, for example doors that are too narrow for wheelchairs. Some physicians' offices and other health care facilities are not easily accessible (DeJong *et al.*, 2002) and even typical physician office equipment, such as the examining table, present a major barrier to the receipt of services for the physically disabled (Lawthers *et al.*, 2003; Scheer *et al.*, 2003). One woman was advised to “*go round looking at surgeries*” until she found an accessible one. Since some practices have specific catchment areas, it is possible that a person's local practice will not be an accessible one (Clark, 2002). Furthermore, health care staff are often not trained to correctly and safely transfer a patient from a wheelchair onto an examining table.

A recurring access problem for people with physical disabilities is transport (Scheer *et al.*, 2003). Making the clinics accessible is of little use if you cannot travel to them. People with disabilities may have reduced mobility and their relatively poor financial circumstances restrict their ability to own and run a car. As a result, they are often reliant on friends, family, public transport and taxis to travel. Whilst other populations, particularly in rural areas, might similarly be excluded from health care services due to poor public transport, this is exacerbated for people with disabilities where public transport is not physically or financially accessible to them (Anderson & Kitchin, 2000; DeJong *et al.*, 2002).

Social barriers are subtler. For example, the presence of significant communication barriers between health care providers and people with disabilities, such as a lack of proficiency in Sign Language on the part of care providers, often results in the health care needs of such individuals being unmet (Witte & Kuzel, 2000; Lawthers *et al.*, 2003; Lennox *et al.*, 2004). Informational barriers, such as inadequate knowledge among health care providers in relation to treating people with disabilities, has been widely reported as a barrier to obtaining needed health care services (Scheer *et al.*, 2003; Schopp *et al.*, 2002). In fact, people with disabilities must often educate their physicians about the health-related issues associated with their disability (DeJong *et al.*, 2002). Providers may also tend to view the disability as overriding all other health concerns, and as a result health screening and preventive services are often overlooked (Lawthers *et al.*, 2003).

Attitudinal barriers can have a devastating impact on the quality of health care (Schopp *et al.*, 2003) particularly in relation to people with learning and mental health disabilities, who have a long history of misunderstanding, fear and stigma (Morgan *et al.*, 2002; Lawthers *et al.*, 2003).

In order to address the effects of these barriers to health access faced by people with disabilities, some studies have compared levels of satisfaction with access to health care between people with and without disabilities. In a study involving a large US sample, Iezzoni *et al.* (2002), showed that, in general, people with physical and sensory disabilities were satisfied with their care. As the extent of disability increased, however, so did the percentage of persons who were dissatisfied. This finding is supported by previous research (Fouts *et al.*, 2000). The aspect of care generating the highest levels of dissatisfaction varied somewhat across disabilities and age ranges. For example, younger persons were most dissatisfied with the availability of medical services and specialists, while among older people the highest level of dissatisfaction involved follow-up care and the ease of getting to the doctor.

In a review of the current health services' literature related to quality of care for persons with disabilities, Lawthers *et al.*, (2003) reported that co-ordination linking all areas of care for a person with a disability needed to be significantly improved, because multiple medical and social providers are typically involved in the care of individuals with disabilities. Co-ordination can permit the smooth interaction between different providers of care and reduce fragmentation and barriers to care. This is particularly relevant in Ireland, where a fragmented health system does not encourage care co-ordination. Few important outcomes can be achieved by the health service providers working in isolation (Smith, 2000). Services that are decentralised, co-ordinated and provided to people in their local communities are particularly important for people with disabilities in order to overcome access barriers and to ensure service inclusion (Pillinger, 2004).

The following sections of the literature review will discuss evidence of the specific barriers that have been experienced by people with disabilities at all levels of health service provision through the core continuum of – primary, secondary and tertiary service.

### **1.9. Primary service provision**

Primary care is the first point of contact that the majority of people have with the health services. This service is part curative and part preventive as it can include health education, immunisation (e.g. influenza and pneumonia vaccinations) and screening programmes (e.g. cholesterol screening, hypertension, cervical cancer). Primary care is routinely provided at local level to people living in the community and encompasses a wide range of health services delivered by a variety of professions. It includes the range of services that are currently provided by General Practitioners (G.P.s), Public Health Nurses, Social Workers, Dieticians, Dentists, Community Welfare Officers, Physiotherapists, Occupational Therapists, Home Helps, Health Care Assistants, Chiropodists, Community

Pharmacists, Psychologists and others. The primary care system is delivered by these various disciplines, very often working in isolation from each other, either as private practitioners or as direct employees of the public health system (Department of Health & Children, 2001).

During the consultation process for the National Health Strategy, one of the main strengths of primary care services identified in Ireland was the satisfaction expressed with G.P. services (Department of Health & Children, 2001). The element of choice that people have and control over selecting their own G.P. may, in part, explain this (Pillinger, 2004). The consultation process, however, also identified a number of inadequacies, which must be addressed. Firstly, the primary health care service is fragmented from the user perspective and is difficult to access out-of-hours. A scarcity of many key professionals was also identified, which results in secondary care having to provide a number of services that are more appropriate to primary care, e.g. occupational therapy and physiotherapy (Department of Health & Children, 2001).

### **1.10. Health Education and Health Promotion**

Although people with disabilities tend to have greater health care needs than the general population (Lennox *et al.*, 2003), research has demonstrated that people with disabilities tend to consume less primary health care services (Fouts *et al.*, 2000). Health promotion services for the prevention of further disability and the promotion of health in general, are important in determining the quality of life and health status of those with disabilities (Lennox *et al.*, 2004). According to Rimmer (1999) effective health promotion programmes for people with disabilities should be community based and aim to:

- ❑ Reduce secondary conditions (e.g. obesity)
- ❑ Maintain financial independence
- ❑ Provide opportunity for leisure and enjoyment
- ❑ Enhance overall quality of life

- Reduce environmental barriers to good health.

This is a more comprehensive vision of health promotion for people with disabilities than that suggested by Lennox *et al.*, (2004).

Health promotion has a particular pertinence within the area of infectious diseases including sexually transmitted diseases such as HIV/AIDS, as health promotion interventions can impact on the incidence of the condition (Ellis et al, 2003: CDC, US, 2001). Yet little attention has been given to the risk of sexually transmitted disease for people with disabilities, although a growing body of research has indicated increased risk factors for disabled populations. For example, individuals with a disability are more likely to be victims of sexual abuse and rape due to their increased physical vulnerability (Groce, 2003). Practitioners must be aware that traditional methods of educating about sexually transmitted disease including HIV may not be effective with the deaf community (Crowe, 2003). Crowe used focus groups to assess the needs of 31 people who are Deaf or hard-of-hearing, in relation to education about HIV issues. Many participants had misinformation or partial information about HIV. Social barriers such as inaccessibility of services and materials, and difficulty obtaining Sign Language interpreters, often prevented participants from becoming educated. This study also addressed design aspects of prevention materials (a poster and a condom card) about which study participants strongly encouraged the use of visual images and real photographs of people who are deaf signing to each other. Robertson *et al.*, (1991) argue that AIDS education campaigns may not benefit people with intellectual disabilities due to limitations in their understanding or poor reading skills, and as a result may be at increased risk of contracting HIV infection.

### **1.11. Health Information**

Clark (2002) reports the findings of a one-year project on the accessibility to people with disabilities of information provided by the National Health Service

(NHS) in Liverpool. One hundred and thirty people with disabilities were consulted about certain NHS health information leaflets and asked for their comments. The main criticism of the leaflets from people who were Deaf or hard-of-hearing was that none of the information was of any use to people who do not read. In Ireland, Sign Language, rather than English, is the first language of many people who are deaf, although it is often assumed by health professionals that people who are deaf read English fluently. Therefore videos made by people who are deaf using Sign Language are needed. People who are Deaf or hard-of-hearing cited access to Sign Language interpreters and the lack of health service staff who can sign as a huge barrier to their accessing information. Approximately 50 people with a visual impairment were interviewed. They preferred a number of different formats including large clear print, Braille, audiotape, spoken announcements, computer disc, accessible websites and telephone services. Most of the people with a visual impairment that were interviewed were unable to access any of the leaflets, as the size of the font used was too small. Many cited other types of health information that are inaccessible to them because of the size of the writing, such as appointment letters, hospital signs, prescriptions, labels on medication bottles and literature that comes with medication.

In relation to people with intellectual disabilities, one leaflet in particular was criticised for using real photographs in the standard edition and “childish cartoons” in the version for people with intellectual disabilities (Clark, 2002).

### **1.12. Health screening**

The association of disability with substantial disparities in common conditions indicates a need for increased access to general and targeted prevention interventions to improve health (Kinne *et al.*, 2004). Primary care for people with disabilities often concentrates on underlying debilitating disorders to the exclusion of preventive health concerns. Recent studies have compared receipt of preventive health services between those with and without disabilities. In a US

study exploring the use of screening and preventive services in adults with mobility problems, multivariable logistic regressions predicted service use on the basis of mobility level, demographic characteristics and indicators of health care access. Results demonstrated that people with mobility problems were as likely as others to receive pneumonia and influenza immunisations but were less likely to receive other services such as the Papanicolaou (smear test for cervical cancer screening) and mammography screening. Even when controlled for demographic characteristics and health care access it was found that 81% of women who had no mobility problems had received a smear test within the previous three years compared with 63.3% of those with major mobility problems (Iezzoni *et al.*, 2000).

Similarly, Chan *et al.*, (1999) reported that people with higher levels of disability were less likely to report receiving a mammogram or a smear test but for immunisations the results were less clear. People with higher levels of disability were more likely to report receiving an influenza vaccination but no trend, however, was found between level of disability and pneumococcal vaccination. Sixty percent of the total sample (over 15,000 Medicare patients) reported never having had a pneumococcal immunisation, indicating that missed vaccinations may be frequent regardless of disability. The most vulnerable population appeared to be those living in long-term care facilities, as rates for smears, mammograms, and pneumococcal vaccinations were lowest for this group (Chan *et al.*, 1999).

Diab & Johnston (2004), using data from a nationwide telephone survey conducted in the US, also examined the relationship between level of disability and receipt of preventive health services such as cervical and breast cancer screening, and influenza and pneumococcal vaccination. Similar to the findings of Iezzoni *et al.*, (2002), pneumonia vaccinations were more frequently received by persons with mild and moderate disabilities than people without disabilities or those that with severe disabilities. It was also reported that women with severe

disability were somewhat less likely to receive clinical breast examinations and a smear test. The results indicate that, although people with disabilities may have received certain preventive services somewhat less frequently, they received other services, such as influenza vaccinations, more frequently than other groups. However, it must be acknowledged that the use of a telephone survey for this type of study poses a great limitation. For example, it undersamples those with limited telephone coverage and/or usage such as those who are hard-of-hearing or have a speech impairment. Also, the definition of disability used for purposes of data collection (“limitations in ordinary activities”) does not allow for sensitive measurement of those with mental health difficulties and intellectual disabilities.

Physical accessibility of clinics has been shown to have a significant effect on the uptake of mammography screening by women with disabilities (Schopp *et al.*, 2002). In an American national survey, 40-45% of women with disabilities over the age of 35 reported that they had never had mammography, 23% of women with spinal cord injury reported that mammography equipment was impossible to position for them, and 11% reported that no examination room was available for mammograms (Nosek *et al.*, 1996). A recent Australian study reported that the uptake of breast cancer screening among women with intellectual disabilities was 20% lower than that for the general population and that failure to use screening services was positively associated with severity of intellectual disability, presence of physical disabilities and urban residence (Sullivan *et al.*, 2003).

In the UK, Bland *et al.*, (2003), in a questionnaire survey, found that in general, care staff for older people with disabilities were satisfied with the access and quality of health care. However, access to some areas of health screening was poor. For example, only 17% of women had received a breast examination and only 26% of individuals had received a hearing test. This may suggest that G.P.s are reluctant to undertake health screening for people with intellectual disabilities (McConkey *et al.*, 2002). It has been suggested that both care staff and health

providers ought to be more aware of the need for health screening (Bland *et al.*, 2003).

### **1.13. General Practitioners**

In order to determine to what extent offices of primary care physicians (e.g. G.P.'s and family practitioners) are usable for people with disabilities, Grabois *et al.*, (1999) conducted a cross-sectional survey, which also aimed to determine if primary care physicians were in compliance with the American with Disabilities Act of 1990 (ADA). The ADA requires that places of public accommodation be readily accessible. In general, many respondents reported high rates of compliance based on architectural features in their offices, indicating that primary care physicians are making their offices physically accessible to people with disabilities. However, when asked why they were unable to serve a patient with chronic impairments, the main reasons given by respondents were (1) the patient was difficult to treat or handle and (2) they felt more comfortable referring these patients to other physicians, although they generally treat non-disabled patients with the conditions requiring medical treatment. It was also found that some physicians (8%) reported scheduling appointments for patients with disabilities at certain times of the day, for example at the end of the day, indicating a lack of flexibility in seeing patients with disabilities at a time that is mutually agreeable.

In a Canadian study, Veltman *et al.*, (2001) explored the extent of access to and perceived quality of primary care for people with physical disabilities living in the metropolitan area of Toronto. This was achieved using a postal self-report questionnaire, which, not surprisingly, resulted in a low response rate (20%). Despite the fact that a significant number experienced some barriers to access, 82% reported being somewhat to very satisfied with the services provided by their family doctor. However, 19% felt they were receiving inadequate primary healthcare and 22% felt their disability prevented them from receiving appropriate care. Another important result from this study is that many respondents felt their family doctor lacked knowledge and education about disabilities and this should

be covered more extensively within the medical school curriculum. The limitations of this study, however, relate mainly to the recruitment of participants. Firstly, the respondents were from a large urban area with a relatively good transport system. Secondly, all participants belonged to a disability group and as a result, may perceive their access differently to those not affiliated to any group. Also it could be argued that people who experience more difficulties may have been more likely to respond to the survey.

Clark (2002) reported that many primary care providers often have great difficulty with letting people with disabilities, especially those with sensory impairments, know when it is their turn to be seen. One person with a visual impairment spoke of being “*forgotten*” and having “*to wait in the waiting room for one and a half hours to see the doctor*”. Other people spoke of often missing their names when they were called out. Various systems for alerting people when their appointment is due were suggested, including announcements on a speaker, a flashing light and audible alarm, name and room number being called out or printed on a screen.

Everybody interviewed thought that the attitudes of health care staff towards people with disabilities were a major barrier to accessing information, which resulted in not being given choices about managing their health. Also most people with disabilities saw receptionists as “guard-dogs” or “gatekeepers”, who created a barrier to them accessing that service. This was attributed to their poor attitudes towards people with disabilities.

People who were Deaf said they thought receptionists should be able to use Sign Language, and that very often they cannot see the receptionists’ faces in order to lip-read. Factors such as the counter being too high or glass between the receptionist and the person can also cause communication problems for people with disabilities. People with mental health needs spoke of receptionists talking slowly to them and having “*no respect for confidentiality*”. They also described

sitting and waiting for an appointment as being “intimidating” and preferred the doctor to come out and escort the patient to their room. The majority of the comments about doctors concerned their “*authoritarian*” attitudes towards people with disabilities. Participants said that their doctor tended to focus on their disability instead of the ailment that they presented with. Some comments on the attitudes of doctors include: “*The doctor just talks down to you like you’re a child, and wants to get you out as quickly as possible*”. Many spoke of the problem of doctors only talking to the person accompanying them and not to them, “*The doctor talks to my carer and not to me. He patronises me*” (Clark, 2002).

A recent UK study reported that people with intellectual disabilities consulted their G.P.s more frequently than other patients (Cassidy *et al.*, 2002). A survey consisting of quantitative and qualitative questions was administered to 49 people with intellectual disabilities, and the results showed broad satisfaction with primary care services and that health care professionals were very helpful (Lennox *et al.*, 2003). Bollard (2003), however, used focus groups with people with Down’s syndrome who had mild intellectual disabilities, and found more negative experiences in relation to going to the doctor than Lennox and colleagues. One of the main themes elicited from Bollard’s study was an unravelling of the role of the carer and the G.P. during the consultation process. One of the responses “*I would never go on my own*” demonstrates how people with intellectual disabilities can be dependent on others to access primary care and how daunting going to see the doctor can be. Participants were asked to reflect upon how they felt during their last doctor’s appointment, which drew out comments such as “*I’d like the doctor to talk to me more*” and “*He always explains to my mum and dad first*”. These comments highlight that people with learning disabilities can sometimes be excluded by their G.P. from the consultation process (Bollard, 2003).

Powrie (2003) conducted a survey of primary health care professionals in one Scottish region and identified certain barriers that prevent access to health care

services. For example, practice nurses described complex issues such as ethical dilemmas and communication barriers that arise when working with people with learning disabilities. One nurse stated that there is fear and difficulty when working with someone who has a learning disability (Powrie, 2003). Muir & Ogden (2001) used semi-structured interviews to examine G.P.'s explanations for their attitudes and behaviours towards people with congenital disabilities. At times, the patient's appearance was described as influencing their attitudes and behaviours and issues of communication were cited as influencing the quality of the consultation. The behaviour of the patients and their carers was also seen as important. In particular, the G.P.s described the importance of their own previous experiences of people with congenital disabilities, as more experience tends to result in positive perceptions and can enhance the doctor's ability to act professionally (Muir & Ogden, 2001).

An Australian study, concerning people with developmental disabilities living in rural areas, described both positive and negative experiences with G.P.s. Negative experiences related to having to wait for appointments and the perceived insensitivity to people with developmental disabilities or those who care for them. Descriptions of positive experiences related to fitting in people for appointments, handling difficult patients and assisting a support person. One of the strongest themes to emerge from this study was the heavy reliance of G.P.s on support workers or family members, particularly in relation to patients with communication problems (Iacono *et al.*, 2004).

#### **1.14. Dental Services**

An Irish study in 2003 (Taylor-Dillon *et al.*, 2003) reported major concerns about dental service provision among parents and carers of people with disabilities. Parents and carers felt themselves to be lacking in information and support about promoting optimum oral health and they were, largely, lacking in confidence about their ability to access dental services on behalf of children or clients with special needs. They identified barriers that could be classified as organisational,

environmental and attitudinal. Organisational barriers included a perceived inequality of waiting time between appointments and lack of sensitivity to the additional stress that long waiting times in waiting rooms may cause to people with disabilities. Environmental barriers within dental premises were cited as a more serious barrier than was physical access to dental surgeries and no participant spoke of a hoist being available to assist in the transfer of mobility impaired individuals. Parents and carers described experiences of both positive and negative attitudes on the part of dental professionals. Negative attitudes were largely ascribed to lack of experience in treating people with special needs and dentists were characterised as not listening, not taking issues on board and lacking in understanding. Parents and carers consistently called for more training and education in this area for dental staff. Likewise, those parents and carers that reported positive experiences ascribed these to the personal or professional experience the individual dental professional had of people with disabilities. Overall, parents and carers considered that their children or clients were valued less by dental professionals because of their disabilities. These findings stand in contrast to a U.K. study, which found that dentists rated favourably for relating well and directly to people with intellectual disabilities, and also providing education to carers on how to deal with people who do not like having their teeth brushed (Lennox *et al.*, 2003). However, Waldman & Perlman (2002) argue that the provision of dental care for people with intellectual disabilities is still being neglected, mainly due to a lack of basic knowledge and experience on how to treat these patients. In a UK study Cumella *et al.*, (2000) interviewed 60 patients and/or their carers to assess the unmet oral care needs of people with intellectual disabilities. The results found higher levels of untreated dental caries and gingival problems in the sample than in the general population. The oral health of many people with an intellectual disability was found to depend largely on their carer yet few carers had received any training in oral health, suggesting an unmet need. Participants expressed the importance of a good relationship with the dental provider, one that was friendly, able to

communicate with and familiar with the needs of people with an intellectual disability (Cumella *et al.*, 2000).

### **1.15. Reproductive Health and Family Planning**

Issues surrounding sexuality and sexual activity are important aspects of health care for all people, but some health care providers may not address these issues thoroughly, or at all, with people with disabilities (Schopp *et al.*, 2002). For example, in relation to women with disabilities not accessing cervical screening services, health service workers in the UK offered the following reasons:

- *“Assumptions are made about disabled people not having sex”*
- *“Parents speak on their behalf”*
- *“Physical issues”*
- *“Disabled people are not considered a priority” and*
- *“Unable to assume an appropriate physical position” (Clark, 2002).*

Despite the common stereotyping that people with disabilities are sexually inactive, people with disabilities are sexual beings (Nosek *et al.*, 1996) and therefore need access to services that provide advice and health care relating to sexual issues.

Through in-depth interviews with 31 women and a national survey of over 500 women with a variety of physical disabilities in the U.S.A, Nosek *et al.*, (1996) reported that 37% of women believed that their physicians were not well informed about the effect of their disability on reproductive health. Many women also reported that their physicians regarded them as asexual and did not acknowledge their need for reproductive health care. Becker *et al.*, (1997) interviewed a small group of women with physical disabilities in order to explore their experiences of reproductive health care. Analysis of the data revealed that structural barriers such as inaccessible offices or equipment were a problem. The most difficult barrier faced by the women, however, concerned interactions with health care providers. Providers were described as insensitive to their needs and reserved when it came to discussing issues such as family planning

or sexually transmitted diseases. One woman stated that they were treated as asexual beings and another stated that the health care provider seemed shocked that she wanted to use contraception. It must be noted, however, that some of the women interviewed also reported positive experiences. For example, one woman commented positively on a provider who asked about her partner: *“He assumed I had one”*. Another positive attitude related to having someone in the physician’s office to help with her wheelchair. In general, positive views were held towards providers who ask questions, are willing to learn, and respect the woman as being able to make decisions about her health. Women also spoke of the importance of providers, who in treating the patient consider the whole person and not just the disability, *“He really sees the big picture”*. Physically accessible offices and equipment also increased satisfaction; for example, one woman described a chair that converts into an examination table, making it easy to transfer from the wheelchair. This study’s generalisability, however, is limited by the fact that the sample included only well-educated women in one geographic area, all of whom worked or attended school, most had access to private health care providers and many of them were able to drive, and therefore ,were not reliant on public transport (Becker *et al.*, 1997).

Broughton & Thomson (2000) report on the views and experiences of women with intellectual disabilities (and their carers) regarding the cervical smear test. Over half the women interviewed had never had a cervical smear test. Those that did, often experienced pain and difficulty with the procedure. The majority of women with learning disabilities did not understand the purpose of the cervical smear test, this included women who had and who had not previously undergone a test. Carers interviewed in the study emphasised the need for and importance of careful preparation, effective communication and providing an explanation and information about the test to women with learning disabilities.

In order to analyse the levels of access for people with disabilities to information on family planning, sex education and sexual health in Northern Ireland,

Anderson & Kitchin (2000) conducted a short questionnaire survey of all family planning clinics in the Province. 29 of the 34 clinics that responded considered their premises to be physically accessible to people with disabilities. However, it should be noted that staff completed the questionnaire, and what a non-disabled assessor determines to be accessible and what people with disabilities themselves find to be accessible, may greatly differ. Family planning services were particularly poor for those with sensory or intellectual disabilities. Only one clinic indicated that it provided family planning and sexual health information that was specifically targeted towards people with disabilities. Indeed in over 70% of cases, information services were inadequate and even where there was information, it was not available immediately and had to be ordered.

These time delays have significant implications for those seeking services such as the morning-after pill. Overall, the results of the study found that no one clinic met the requirements to be fully accessible to all people with disabilities, and therefore not one clinic was found to be fully accessible (Anderson & Kitchin, 2000).

### **1.16. Secondary Service Provision**

Secondary health care is usually dispersed from hospital-based clinics to patients who normally live in the community, e.g. outpatient clinics, rehabilitation services, and accident and emergency services. Access to specialists is particularly important to people with disabilities, especially those with relatively rare conditions that may not be well understood by general practitioners (DeJong *et al.*, 2002). Entry to secondary care is usually through G.P. referral but also, in some cases, through Accident and Emergency Departments. Self-referral is also possible. The G.P. referral practice may be perceived as being physically and psychologically draining for persons with already compromised resources (such as a lack of transport) and the necessity of seeing a G.P. before a referral to a specialist is a potential barrier to appropriate secondary health care (Scheer *et al.*, 2003). For example, in a qualitative study of 30 individuals with disabilities,

Scheer and colleagues reported that some participants were refused referral to occupational therapists by their G.P, on the grounds that he or she could work. The total level of resources, the availability of particular health specialists, the location of services, the costs of services, and waiting times influence the level and pattern of use of secondary service provision. While several research studies have evaluated primary health care for people with disabilities, less attention has been paid to their experiences in relation to secondary health care.

### **1.17. Accident and Emergency Departments**

Long (2002), in a telephone survey measured access and use of health care services among over 800 Medicare disabled adults in New York City. Frequency of use of health care services was higher than national rates, particularly in Accident and Emergency services. Indeed, more than half of the individuals who reported a visit to Accident and Emergency Departments also reported multiple Accident and Emergency Department visits in the year prior to the study. In an exploratory study carried out by Cumella & Martin (2004), it was found that there were limited skills among hospital staff in communicating with people with intellectual disabilities, and reluctance on the part of staff to talk directly to the person or to determine the extent of their comprehension. Even though they had little experience or ability in using public transport, some participants were told by Accident and Emergency Department staff to find their own way home after being discharged, indicating a basic lack of awareness of people with intellectual disabilities' needs. Family carers said that hospitals could be more responsive to their needs. For example, one individual with an intellectual disability found it difficult to be kept waiting; and a refusal by a receptionist to move them to the front of the queue led to a violent and destructive incident in a hospital waiting-room (Cumella & Martin, 2004). Iacono & Davis (2003) reported a similar problem with a lack of understanding by staff in Accident and Emergency Departments in relation to the long waiting times being poorly tolerated by people with intellectual disabilities.

## **1.18. Outpatients**

Mulley (1995) investigated the experiences of people who are hard of hearing in relation to secondary care and found that they often had problems when attending clinics. Most had communication difficulties with staff – for example, staff were not aware of their hearing impairment, talked too fast or did not face the person while speaking. Other problems related to getting lost in the hospital due to inadequate or unclear signage, and the absence of visual display boards in waiting areas, which resulted in patients missing their turn. Witte & Kuzel (2000) conducted focus groups of older people who are Deaf also experienced similar barriers to health care, including difficulty in communicating with providers and scheduling appointments.

## **1.19. Mental health services**

Traditionally, health care systems have relied heavily on inpatient and institutional care for those experiencing mental health difficulties. While there is now more of an emphasis on community-based mental health care, the lack of services has made getting care more difficult (Long, 2002). People with intellectual disabilities, and probably those with a dual diagnosis, may be particularly disadvantaged with respect to mental health care. The NDA's Review of Access to Mental Health Services for People with Intellectual Disabilities (2003) outlined serious deficiencies in service provision, attributable both to policy confusion in the sector and to funding issues between the services. People with intellectual disabilities who are registered with an intellectual disability service provider were said to find it difficult or impossible to access appropriate mental health services and may suffer adverse health consequences.

In 2004 the Irish College of Psychiatrists acknowledged that the mental health services for people with intellectual disabilities are under resourced and grossly underdeveloped in many Health Board areas, with some counties having no

mental health services for people with intellectual disabilities. They asserted the right of people with intellectual disabilities to the same type of mental health service as people without disabilities, taking into account their specific needs. The College made twenty recommendations to improve the service including the immediate commencement of a significant reform of the mental health services for the intellectual disability population. It recommended that consultant psychiatrists in intellectual disability should, in the future, be appointed to catchment area-based multidisciplinary mental health of intellectual disability teams. These teams would work in close liaison with Health Board consultant psychiatrists in other specialties thereby integrating '*the psychiatry of intellectual disability with mainstream psychiatry and would involve partnership with the voluntary bodies*'. The College also recommended that funding for the necessary reforms should be prioritised and ring-fenced, and that the Mental Health Commission and the National Disability Authority should oversee the implementation of the reforms and monitor the quality of the mental health services that are provided to people with intellectual disabilities.

Deficiencies in mental health services to people with intellectual disabilities have also been reported in other countries. As part of a large cohort study in the UK, McCarthy & Boyd (2002) interviewed eighty young adults with intellectual disabilities in order to establish whether those with mental/behavioural disabilities were in receipt of mental health services and if users were satisfied with this service. Participants were interviewed in childhood and early adulthood in order to assess for mental health difficulties and behaviour disorders. A questionnaire with a parent or other primary carer was used to assess service use. Although all were in contact with the primary health care services, the results found that the majority of those with severe behaviour disorder persisting into adult life had no contact with a mental health professional such as a psychologist or psychiatrist. Another key finding was that the majority of carers were more concerned with the lack of specialist health professionals appropriately trained to

deal with people with mental health disabilities, rather than dissatisfaction with the services received (McCarthy & Boyd, 2002).

Care providers' attitudes to people with disabilities were explored in a study in the U.S.A. A postal survey of 481 psychologists, who were American Psychological Association members, ascertained psychologists' perceptions of access barriers and support needs in providing services to clients with disabilities. The study found that barriers to service provision include funding, accessibility, lack of provider knowledge, limited training in disability issues and services, and lack of sensitivity. It was concluded that additional training for psychologists in disability issues and disability resources is needed, and that psychologists with disabilities may be an important resource (Leigh *et al.*, 2004a, 2004b). The need for training (of Australian trainee psychiatrists) in the area of dual diagnosis was identified in a similar but earlier study by Lennox & Chaplin. (1995)

Inequality of access to and treatment within the mental health services is an issue for people with other disabilities. Leigh *et al.*, (1996) identify the need for psychologists to develop awareness of the needs of people who are Deaf in order to deliver appropriate services in an ethical manner. As early as 1985, the environmental barriers to mental health services for people with severe physical disabilities were identified (Pelletier *et al.*, 1985) and a UK report in 2004 reported that these and other barriers still mitigate against people with physical disabilities receiving equal and appropriate treatment (Morris, 2004). The study by Morris documented the perceptions of people with physical disabilities and mental health difficulties as negative attitudes, lack of understanding, fragmented services and inaccessible physical environments.

## **1.20. Tertiary Service Provision**

The tertiary health care service refers to the provision of care to people in hospitals. Access issues in relation to tertiary services can be particularly severe

in remote geographical areas, where the nearest hospital may be several miles away (Lawthers *et al.*, 2003).

In relation to barriers experienced by people with physical disabilities, a US national survey of over 500 women with physical disabilities found that 26 women with spinal cord injury had children after their injury, but that more than 50% of these women reported their hospital could not accommodate them during childbirth due to architectural barriers (Nosek *et al.*, 1996).

Effective communication with patients is critical for effective care. Hemsley *et al.*, (2001) suggest a need for training nurses in the use of alternative modes of communication. Their study provides information about the experiences of 20 nurses who cared for patients with severe communication difficulties. The results suggest that nurse-patient communication is difficult when the patient has severe communication impairment, particularly when many patients lack an effective mode of communication. However, even when a patient had an alternative mode of communication, nurses were often still unable to communicate effectively with the patient due to being unfamiliar or uncomfortable with using that method. On a more positive note, many nurses reported the use of logical strategies that assisted them in communicating with patients with severe communication difficulties such as looking at the patient during communication, learning to recognize the patient's non-verbal cues and using an agreed "yes" and "no" indication system.

Iacono & Davis (2003) determined whether the needs of people with developmental disabilities were met during stays in hospitals. Most of the 119 respondents reported general satisfaction with the care received, in terms of getting the right medication, getting sufficient nutrition, and being able to move from the hospital bed when needed. However, significant associations were found between getting enough to drink and being able to move from the bed when needed, and the presence of a support person staying with the patient.

These results suggest a great reliance on support people during hospitalisation. This “theme” of reliance on support people such as carers, family members or friends, was also identified in a later study by Iacono *et al.*, (2004). Health providers depended on these support people to stay with a patient in hospital to assist with eating and other care requirements, and particularly to assist with communication between the patient and provider. Comments about the attitudes towards and lack of knowledge among health care providers about people with intellectual disabilities were also common in both studies (Iacono & Davis, 2003; Iacono *et al.*, 2004).

Cumella & Martin (2004) reported on the experiences of people with intellectual disabilities in hospitals. When participants were asked about their stay in hospital, they recalled being fearful, being ignored by staff, and not understanding why tests were being performed. Several reported being presented with a written menu for meals and receiving no assistance in making a choice. Carers also expressed their concerns; in particular hospital staff often expected them to be present throughout the stay of a patient with an intellectual disability.

In Northern Ireland, McConkey & Truesdale (2000) investigated the reactions of nurses and therapists, who worked in a variety of acute hospital and community settings, to their contact with people with intellectual disabilities. The results found that both nurses and therapists were significantly less confident working with a patient who had intellectual difficulties as opposed to one with physical disabilities. The fact that nurses and therapists reported feeling less confident and not knowing what to say suggests a lack of communication skills among staff. Both groups also felt unprepared and were more inclined to seek advice on patients who had intellectual disabilities, again suggesting the need for further education and training (McConkey & Truesdale, 2000).

Fox & Wilson (1999) in a small qualitative study in the UK, interviewed parents about their experiences of general hospital inpatient care for their adult sons and daughters with intellectual disabilities. Parents reported inappropriate sedation of patients, failure to provide particular dietary requirements, failure to provide pads for a patient with incontinence, and a general reliance on family members to care for the patient. Although no staff were thought to be hostile or impolite, some parents expressed concerns that staff showed little understanding of the nature of their relatives' disabilities. During longer admission, however, these misunderstandings diminished, indicating that the initial problems are those of unfamiliarity with people with intellectual disabilities.

In summary, in relation to people with disabilities, deficiencies across all levels of health care services are common themes in much of the research literature. The most common theme that emerged from this review was the lack of knowledge among health care providers about the needs of people with disabilities. This could be explained, in part, by the lack of training and education they seem to receive in this area. Not surprisingly, this lack of knowledge appeared to manifest itself in communication and attitudinal barriers between health care providers and service users, such as difficulties relating to people with disabilities and providers being insensitive to their needs.

Across all levels of health care service provision, experiences that generated negative reactions from people with disabilities included the tendency of the provider to focus on the underlying disability rather than the illness needing treatment and their reluctance to talk to the person directly, resulting in the service user being excluded from the consultation process. In general, positive views were held towards physically accessible offices and equipment, and towards providers who considered the whole person and not just the disability. The importance of a provider who was able and willing to communicate directly with people with disabilities was also commonly expressed. There was some evidence in the literature that both people with disabilities and health care

providers relied largely on family members and carers to “fill the gaps” present within health care services. There appears to be a lack of coordination and integration between the primary, secondary and tertiary services whose tendency to operate independently hinders the effective provision of care for everyone, but particularly for those with disabilities.

Care providers' attitudes to people with disabilities were explored in a study in the U.S.A. A postal survey of 481 psychologists, who were American Psychological Association members, ascertained psychologists' perceptions of access barriers and support needs in providing services to clients with disabilities. The study found that barriers to service provision include funding, accessibility, lack of provider knowledge, limited training in disability issues and services, and lack of sensitivity. It was concluded that additional training for psychologists in disability issues and disability resources is needed, and that psychologists with disabilities may be an important resource (Leigh *et al.*, 2004a, 2004b). The need for training (of Australian trainee psychiatrists) in the area of dual diagnosis was identified in a similar but earlier study by Lennox & Chaplin. (1995)

Inequality of access to and treatment within the mental health services is an issue for people with other disabilities. Leigh *et al.*, (1996) identify the need for psychologists to develop awareness of the needs of people who are Deaf in order to deliver appropriate services in an ethical manner. As early as 1985, the environmental barriers to mental health services for people with severe physical disabilities were identified (Pelletier *et al.*, 1985) and a UK report in 2004 reported that these and other barriers still mitigate against people with physical disabilities receiving equal and appropriate treatment (Morris, 2004). The study by Morris documented the perceptions of people with physical disabilities and

mental health difficulties as negative attitudes, lack of understanding, fragmented services and inaccessible physical environments.

## **2. BACKGROUND, STUDY DESIGN & PARTICIPANT PROFILE**

### **BACKGROUND**

Almost 324,000 persons, representing 8.3% of the total population, have a long lasting health problem or disability according to the 2002 national census. Approximately 188,000 or 51% of these persons had more than one disability (Central Statistics Office, 2004). The incidence of disability was higher among women than men (8.7% compared to 7.8%) and two thirds of people reporting disabilities were aged 50 years or over. Thirty eight percent of men with a disability in the 15 - 64 age range are in the labour force compared with 78.2% in general. Twenty four percent of women with a disability in the relevant age group are in the labour force compared with 55.4% of the general female population. Labour force is defined as people who are at work plus those who are unemployed or looking for their first regular job. Only 13% of men with a disability and 6% of women with a disability who are not working describe themselves as unemployed. The “unskilled” socio-economic group had the highest incidence of disability at 11.4% while the lowest incidence was among the higher professional classification with 3.7%.

In relation to the epidemiology of disability, DeJong *et al.*, (2002) report that as a result of advances in medicine that improve the survival rates of premature infants, and accident and spinal cord injury victims, coupled with those with a disability living into old age (Walsh *et al.*, 2003), the incidence and prevalence of disability is growing. Disabling conditions are diverse in their causes, nature, timing, pace and societal implications (Iezzoni, 2003). Disability is a highly complex concept with varying definitions. The term disability can include people who:

- ❑ Are Deaf or hard of hearing
- ❑ Are blind or have visual impairments
- ❑ Have mental health issues

- Have learning difficulties
- Have speech impairments
- Have physical impairments (Clark, 2002).

For the purposes of this research, the National Disability Authority Act's (1999) definition of disability will be adopted. This is that:

*“Disability, in relation to a person, means a substantial restriction in the capacity of a person to participate in economic, social or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment”.*

In 2000 the United Nations Committee on Economic, Social and Cultural Rights re-affirmed that *‘health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity’*. The determinants of health are broad and include biological, environmental, social, psychological and behavioural factors. In this study we examine access to and use of the health care services.

Inequalities are experienced by people with disabilities in access to and use of mainstream health services through segregation, attitudinal barriers, physical barriers and unmet need for advocacy and outreach programmes (Pillinger, 2004). People with disabilities have experienced these barriers at all levels of health service provision, primary (Clark, 2002), secondary (Wittle & Kuzea & Martin, 2004) and tertiary (Cumella & Martin, 2004). To facilitate the development and re-orientation of services appropriately and cognisant of impending changes to health service organization this is an apposite time to actively seek the service user's perspective which can inform and influence service development to promote equality and inclusion. Such information is best elicited through a qualitative approach to data collection, based on a social model which looks

beyond the individual's impairment to the causes of their exclusion from and disadvantages in social and civic life (Brown, 2000). Such research with service users will capture their lived experience and provide a person focused approach and an insight into the disabling environment of the health services (Priestley, 2000).

The aim of this research is firstly to assess the literature in the context of policy initiatives in relation to people with disabilities accessing mainstream health services and secondly to make explicit their experiences of mainstream health services in relation to access and inequality. This report presents the review of literature together with the methods used to elicit the views of people with disabilities, the findings of this data collected and a discussion of the issues raised. Finally, conclusions are drawn.

## **Study Design: Literature Search Strategy**

A number of methods were used to identify the relevant literature;

- Database searches on Medline, Swetwise, Science Direct, Cinhal, Omni;
- The library of NUI, Galway was hand searched for relevant books, reports and general articles;
- Web based searches on disability and health inequalities, e.g. Websites, The World Health Organisation, The Irish Government, The United Nations, The European Commission, The British Government, The Australian Government;
- Web searches were carried out using, Hotbot, Google, Metacrawler.

Key words used: Disabil\*, inequality, barriers, access, health services, equity.

## **Study Design: Qualitative Study - individual interviews**

The assertion that perceptions of health services and their use are embedded in the context of society suggests that more qualitative methods are appropriate to explore the issues of access to mainstream health services by people with disabilities, specifically in an Irish context. Such research with service users aims to capture their lived experience, provide a person focused approach and give insight into the potentially disabling environment across the continuum of health services from primary through to tertiary service provision (Priestley, 2000).

## **Study Design: Sample**

In qualitative research the fundamental process of sampling is dependent on the selection of information rich cases (Patton, 2002), individuals that can act as so called '*expert witnesses*' (Polit & Hungler, 1995). Within this study data were gathered from purposefully selected adult individuals who experience the range of enduring physical, sensory, mental, emotional and learning disabilities as identified in the NDA Act definition of Disability (1999). Notwithstanding the

limitations of classification, (where the individual experience may be mild, moderate or profound or where a person may experience concurrent impairments), the NDA Act definition of disability was used to identify the broad spectrum of disability exhibited within the categories of physical, sensory, mental health, learning and emotional impairment. Where appropriate within a category, representation was sought from participants experiencing mild, moderate and profound disability. In some situations an advocate was sought to represent the views of the participant.

### **Study Design: Sample size**

It is difficult to specify the sample size in qualitative studies prior to data collection (Robson 2002). Sample size is largely a function of the purpose of the enquiry, the quality of the participants and the sampling strategy used (Polit and Hungler, 1999). Morse (1994) suggests that from 30 – 50 interviews should be carried out. A focused and inclusive sampling structure designed to meet the informational needs of the project and a tight time constraint determined the total planned sample of 30 participants across the disability spectrum identified by the NDA to be interviewed. The sample meets the criteria of informational adequacy and appropriateness and reflects other similar studies (Morris, 2004; Scheer *et al.*, 2003).

### **Study Design: Access to sample**

The Centre for Health Promotion Studies has a well-established network with a number of organisations working within the disability sector, particularly those involved in voluntary service provision. Through ongoing working relationships and strategic partnerships these organisations were invited to contribute to the study through the identification of participants. In this instance due to ethical considerations the initial participant was asked to provide contact details to potential participants and it was then up to that person to contact the research team. The organizations advised the research team in relation to facilitating individuals' communication needs in this regard.

## **Study Design: Data collection**

Focus groups as a method of data collection were initially identified. However, the use of interviews as opposed to focus groups as the form of data collection was proposed for both methodological and pragmatic reasons. People with disabilities are not a homogenous group and their experiences vary accordingly. The focus group may place greater emphasis on the homogeneity of disability as a construct whereas the semi-structured interview captures the individual experience valued within qualitative approaches. The basic principle of interviewing is to provide a framework within which respondents can express their own understandings in their own terms (Patton, 2002). The semi-structured interview as the method of data collection was used to explore participants' experience of primary, secondary and tertiary health service provision and the interview schedule was developed to this end. The initial schedule proposed was reviewed and discussed with organisations representing a range of people with disabilities, and changes made. Further pilot testing was carried out with individuals with disability and again changes made prior to field use.

A short questionnaire was administered prior to the interview to ascertain socio-demographic information for each participant. Interviews were carried out at a time and in a place convenient to the participant, with the proviso that the place identified was private. Therefore, interviews took place in participants' workplaces, participants' own homes, and in offices of organisations representing people with disabilities.

## **Study Design: Data analysis**

The basis of the process of data analysis for this study draws predominantly but not exclusively on work by Miles and Huberman (1994). The aim of analysis in qualitative research is, according to Burnard (1991), to establish a detailed and systematic recording of themes and link them together in a category system. All interviews were tape recorded and transcribed verbatim with the permission of

the participant and entered into the qualitative research software package *Nvivo* (Richards, 1999). Initially the data was fractured or split into discrete parts (Straus & Corbin, 1990; Miles & Huberman, 1994); these parts were then labelled or coded. The data gathered under the code is referred to as a category. In this instance a priori codes were developed prior to data collection through the specified aim of the research to explore the experiences of a range of services. Therefore, questions in the interview schedule followed the continuum of care through health education/promotion, primary, secondary and tertiary care. These areas were used as a so-called 'start list' (Miles & Huberman, 1994) rather than strict differentiations in the analysis process. A further level of analysis is referred to as pattern coding (Miles & Huberman, 1994). At this stage the categories are brought together or clustered into groups. Patterns of relationships between groups of categories develop providing a coherent, conceptual, structured order, which can be presented as a matrix or table (Miles & Huberman, 1994).

### **Study Design: Ethical considerations**

Ethical considerations in research are paramount and the lack of a national ethical committee to review research in this area is an issue for concern. However, this study was guided not only by the ethical principles inherent in any research study but by those principles set out by the NDA in their ethical guidelines. Information required for informed consent of participants was provided in an appropriate manner taking each individual's needs for accessible information into account.

### **Participant profile**

Thirty-two interviews were carried out of which 27 were directly with people with a range of disabilities (15 men, 12 women; age range, 21 to 77 years, including persons with intellectual, physical and sensory disabilities, people who have suffered brain injury and people with physical who experience mental health difficulty). The mothers of two men with brain injury were also interviewed, as

were three advocates of people with moderate to profound levels of intellectual disability.

Two thirds of the participants reported living in an urban area with the remainder considering themselves rural dwellers. All participants reside within one health board area although many had previously and some continue to access health services from other health board areas. More than half reported themselves to be employed. Four of these participants were in full time open employment and the others were either part time (2) or in sheltered or supported employment or on training schemes. The majority of those interviewed had a medical card and a few had private health insurance, however 3 had neither.

The nature of disability experienced by participants varied and included those with sensory impairments and deaf and blind people, people with intellectual disability and their advocates and those who have suffered brain injury and their advocates, people with physical disability and those who experience mental health difficulty. Some participants had experienced their disability from birth others had acquired disability. Several of the participants experience dual or multiple disabilities.

In the short questionnaire administered prior to the interview to ascertain basic socio-demographic data participants were also asked to rate their health. The majority of participants reported their health as very good or good. This was reflected in the interview data where many participants considered themselves to be healthy and therefore having limited need and experience of health services generally. However, there was a minority of participants who found themselves accessing the health service on a very regular basis. Participants referred to the health services in two ways, one in relation to their disability and the other in relation to health needs more generally. Some considered that their disability had no relevance to the health services,

*“I am blind, not sick..... I mean they cannot fix me so why would I go back to them? There is no reason for me to access the medical service” (Participant 2:7).*

In relation to general use of health services people with disabilities interviewed did not identify themselves as disabled people accessing the health services but rather as people accessing the health services who also have a disability that may need to be accommodated. These two experiences of the health service are inextricably linked in the experiences drawn on and reported by the participants.

### **Limitations in the study design**

Some of the limitations of this study are that participants are sampled from one area of the country only and constitute primarily an urban sample (two thirds of sample). Most of the participants reported good health and, given the research question of exploring mainstream health services, it would have been advantageous to access participants who relied heavily on secondary and tertiary health services. Further studies could usefully look more closely at the experiences and needs of particular sub-groups who appear, in this study, to be particularly disadvantaged within mainstream health services in order to replicate and explore these findings.

### **3. INTERVIEWS**

This section presents the results of the analysis undertaken on the data gathered. The experiences of the participants of each level of the health services, from primary to tertiary, will be presented and where specific issues were raised for specific groups, these will be highlighted. Direct quotes from participants are used to illustrate issues raised. Finally, over-riding issues that emerged throughout participants' reported experiences of health service access are presented.

## **3.2. Specific Services on the Continuum of Health Services**

### **3.2.1. Primary Health Care**

#### **3.2.1.1. General Practice**

All participants spoke about experiences of the service provided by General Practitioners (G.P's). The large amount of data generated by consideration of this service was categorised into attitudinal barriers, communication barriers and environmental barriers.

#### **3.2.1.2. Participants' relationship with the general practitioner**

Participants' relationships with their General Practitioners (G.P.) varied and while some perceived their relationship to be positive, others reported theirs to be poor. The characteristics of positive relationships equated to G.P's attitudes and approaches that facilitated service use. The characteristics of poor relationships denoted negative attitudes that acted as a barrier to service use.

#### **3.2.1.3. Attitude as facilitator**

Most participants reported an extremely positive relationship with their G.P.s who were described as '*marvellous*', '*nice man*', '*lovely*', and '*on the ball*' among other things. Doctors characterised as those who listened and those who had time for their patients were particularly valued. Many participants had long-standing relationships with their G.P's, which was also important,

*"I am so long going to him, he is used to me and I am used to him"* (Participant 1:4).

In several cases the relationship pre-dated the disability and was not diminished by the diagnosis. However, the length of time an individual had been registered with a G.P, appeared less of an indicator of a satisfactory positive relationship

than the extent to which the doctor was freely chosen by the individual. Characteristics of G.P.s that were actively sought by participants included being treated as an individual in a holistic manner,

*“I wouldn’t use a G.P. that wouldn’t have that kind of an approach, you know, I would be very aware of that myself, to be talking to a man that’s looking at me as a whole”* (Participant 3:0).

Another positive characteristic of G.P.s identified by participants was their reported approach to their level of knowledge about disability. It was acknowledged by several participants that G.P.s could not have an expertise in all conditions but those that recognised the limitations of their knowledge and accepted information or suggestions from others were valued,

*“My doctor would be very open in that she’s never had any training in the area of brain injury and I have given her information myself through booklets that have been written on the subject and informed her as best I can because she’s quite upfront, she’s not defensive. I have in the past been up against G.P.s who have been quite defensive in me trying to educate them”* (Participant 2:6).

The relationship between people with disabilities and their G.P.s can be complicated by the involvement of advocates, carers and family members. G.P.s with the ability to work in the context of these relationships were highly regarded. One mother, son and G.P. were reported as working as a ‘team’ concerning the 21 year old’s health needs. Another G.P. was perceived to be sensitive to the balance required when interacting with a person recovering from a disabling event and the person’s partner,

*“For someone to understand that J. understands everything but sometimes stuff might need to be repeated to me, like a change in medication or something like*

*that, to absorb the information, to accept J. as an individual and still get me to back up something, that is a fine art” (Participant 2:5).*

This way of working coupled with the acceptance and sharing of information demonstrates a partnership approach by some G.P.s in their relationship with people with disabilities and their advocates, which was perceived as positive for the participants reporting this type of experience.

#### 3.2.1.4. Attitude as barrier

The participants who were least satisfied with the services from their General Practitioner were those who perceived themselves or were perceived not to have any choice regarding which G.P. they attended. This lack of choice was reported to be due to the disability itself coupled with restrictions imposed from having a medical card,

*“I have actually gone to other doctors and asked them... and some of them wouldn’t take me because I was Dr. X.’s patient and because I have an illness... And then there are other ones that don’t do Medical Cards.....” (Participant 6).*

In contrast to participants reporting a positive relationship with their G.P. those who perceived the services provided as relatively poor reported these doctors as failing to acknowledge the limits of their knowledge and the expertise of others. This particularly emerged from interviews with advocates of people with significant levels of intellectual disability, who considered that G.P.s not only had limited knowledge of intellectual disability but also failed to take their own professionalism into account,

*“...and you kind of go and tell all the things and then he has been known to give out to the staff and say what are you telling me for, God I know I’m the doctor and I know this and that and I’m sure I know what to do” (Participant 3).*

Two participants who did not have any choice in their doctor considered their G.P.s did not have sufficient knowledge to give them the care that they required. The lack of a proactive approach to care provided by the G.P. was also identified as a negative characteristic of G.P.s for people with an intellectual disability,

*“In all my time I have never, and I have brought hundreds of clients in all my years working with people with learning disabilities,.....I have never actually gone into a doctor’s that they would have proactively given them a health check”* (Participant 3).

#### 3.2.1.5. Environmental barriers

Transport to G.P.s’ surgeries was cited as a potential barrier to access by some participants, while others experienced barriers at the surgery premises itself. Although many of the G.P.s were said to have flat or ramped access to their surgeries, some participants did encounter physical or environmental barriers,

*“It’s kind of hard, there’s a step going in the door and it’s a bit tight in....he has to lift the wheelchair up and kind of manoeuvre it, there’s not enough room that if I do push it, use my hands to push the wheelchair itself, basically it gets caught in the jambs’ and ‘it’s a worse idea trying to get a wheelchair in, even though he did get a ramp done it’s not great”.* (Participant 2).

The size of the waiting room was cited as a cause of difficulty for some participants. It was an issue not just for those using a wheelchair or walking aid but also for those who need to bring, “an 80 pound Labrador” with them.

A high number of the participants saw their G.P. at home. In a few instances this was because the General Practitioner recognised that their premises were not accessible, or to ameliorate the need for the participant to organise transport but in other cases it was primarily for the convenience of the patient.

### 3.2.1.6. Communication barriers

Effective communication was an issue for some of the participants in the study, specifically for those who experience hearing loss or are deaf and for those with difficulty remembering information. It was reported by participants who are hard-of-hearing that difficulties arise in communication through the whole process of accessing a G.P.. From trying to make an appointment in the first instance, to being unable to hear when your name is called in the waiting room and finally difficulty in the interaction with the G.P. A lack of awareness was cited as the cause of the communication difficulties, which was further compromised by a lack of suitable technological supports for effective communication such as availability of fax machines and e-mail access either on the part of the G.P. or the service user. For those with memory impairment, strategies to overcome the difficulty, such as having key points written down by the G.P., were reported as useful. For those who were hard-of-hearing a number of strategies were used including raising the awareness of the G.P. and taking along an interpreter.

Several participants stated that health information in the form of leaflets was available in the waiting room of G.P.s they attended. Participants identified that this information was not accessible to those with limited literacy, sight difficulties or cognitive impairment.

### 3.2.1.7. Reception staff in General Practice

The participants who responded to a prompt to discuss their contact with other people in the primary care setting, usually talked about their experiences with the practice receptionist and this discussion focused on the receptionist's lack of disability awareness. One felt the onus was on him to put the receptionist at ease,

*"I find her pretty unaware, pretty unaware. I would have to take all the initiatives nearly myself"* (Participant 3:0).

### 3.2.1.8. Public Health Nurses

The nature of the service experienced by participants of the Public Health Nurse varied. For many the only point of contact is when they need to order equipment or supplies. Three participants had accessed and experienced the PHN service intensively at a specific point in their lives but no longer had this level of contact. However, two participants have daily contact with the nurse. The PHN service was characterised positively although two participants would like increased and more regular contact.

### 3.2.1.9. Home Help and Personal Assistant services

A few participants are in receipt of a Home Help service. Among the issues identified participants referred to the adequacy of this level of provision as well as the quality. Two participants considered their access to Home Help service provision inadequate, one having had her Home Help hours cut by one third without any change in her situation and without explanation from service providers. Five other participants not in receipt of the Home Help service consider that they would benefit from it. Two have not applied because they do not think that they would get the help and one made the point that at the time of diagnosis of a disabling condition, a person should become entitled to any services which they require rather than having to 'beg'. Two participants who had applied for Home Help services perceived the assessment to include the expectation that alternative support from friends, family and neighbours would provide an adequate alternative. One participant was told when being assessed for Home Help services, that when neighbours call to her house,

*"You say to them "well do you know what, next time you come, don't bring anything but you might do a little bit of housework for me, like a little bit of ironing or a bit of hoovering." That is what she said. Now wouldn't you look sweet with somebody coming to visit you and you say 'keep your biscuits but you might take out the hoover there now and run around the place" (Participant 1:4).*

While level of service provision was of concern, negative aspects of the service were also reported. Concern was expressed about the reliability of some Home Helps and the tendency of some to discuss one client with another. Restrictions in the nature of the service were also identified. It was reported that Home Helps and Personal Assistants are not insured to carry their clients in their cars or to administer certain medications. These restrictions may limit people's access to independent living and specifically access to other health services.

Four participants employed Personal Assistants to facilitate independent living. The value of this service was described by one participant thus,

*"..without that help, I wouldn't be able to live the life I'm living" (Participant 3:1).*

#### 3.2.1.10. Dentists

Most of the people who participated in the interviews have had positive relationships with their dentists, some of whom were described as being 'respectful', 'interested', 'nice and 'very, very, very thorough'.' However, some people with Medical Cards experienced difficulties, which mainly resulted from the limited choice available to them, similar to that reported in relation to access and use of G.P. services. One participant found that the dentist most convenient to his home only treats private patients; another is thwarted by the fact that all the dentists in her home town who will accept her Medical Card work from premises that are wheelchair inaccessible. Environmental barriers to access for those with physical disabilities were identified in relation to initial access to premises as well as within the surgery itself, such as transferring from a wheelchair to the dental chair. Attitudinal barriers to dental service provision were identified by advocates of people with intellectual disabilities. The dental service offered to people with intellectual disabilities was considered compromised as it was reported that they were not invited to attend their dentists on a regular basis for check-ups, but only attended when they were in pain.

#### 3.2.1.11. Pharmacists

While only a few individuals commented on pharmacists, those that did were overwhelmingly positive. Pharmacists were reported to check for contraindications of medications and ensure that the individual understood how to take the medication. Three were said to go out of their way to give assistance including collecting prescriptions from doctors and delivering the medication to people's homes.

#### 3.2.1.12. Dieticians, Opticians, Chiropodists

Only a minority of the interviewees had used the services of a dietician, an optician or a chiropodist. The few that had were generally positive. In relation to service access the barrier identified was that of finance in that some participants perceived themselves or their clients in need of chiropody services but unable to access it due to cost.

#### 3.2.1.13. Physiotherapy, Occupational Therapy and Speech Therapy

In relation to physio, occupational and speech therapies the issue for participants was the very limited availability of the services in any capacity. Contact that participants had was considered to be inadequate for their needs and/or the result of waiting for protracted periods of time. Access was facilitated by paying privately for services for those who could afford it, although that still does not guarantee receipt of a service for people with an intellectual disability according to an advocate,

*"It could be two years time before you got that [physiotherapy] so we were trying to get the private one at the time and it was very difficult. But the private ones won't, they only do sports physio"* (Participant 3).

For those few in receipt of some level of physiotherapy the service was widely perceived as overstretched and uncaring. One participant suggested that the physiotherapy service sets its own standard of success too low and is satisfied with what should be intermediary goals. Only one participant had received speech therapy and this was accessed privately. While others perceived a need, notably for those with intellectual disabilities, no speech therapy service was available. Those participants that had accessed the occupational therapy service had done so for reasons of equipment ordering or maintenance. Most of the participants considered that the occupational therapists were knowledgeable about the equipment and a few considered them to be accessible to them for that purpose. However, long waiting times for assessment for occupational therapy were identified and some participants resorted to paying privately.

The potential benefit of access to these therapeutic services was identified by all participants. The result of restricted or denied service access was perceived as profoundly limiting for people with disabilities in relation to their independence and quality of life. One mother considered that her son's life would be '*indescribably*' better if the health services had given him the physiotherapy, occupational therapy and speech therapy that he needed, when he needed it.

### **3.2.2. Accident and Emergency Department**

Most of the reports about the Accident and Emergency service relate to the same department, although some participants had experience of other facilities. Barriers identified to access fell into the five sub categories of: waiting, gatekeeping, environmental, attitudinal and communication. These will be described in turn.

#### **3.2.2.1. Waiting**

Although a few participants spoke of attending the Accident and Emergency department and being treated promptly and appropriately, many spoke of

enduring long delays with one characterising the service as, *'slow beyond all belief!'*. People with intellectual disabilities were reported to find the experience of waiting for protracted periods of time difficult and distressing and it was said to be so stressful for people in a mental health crisis that it may serve to exacerbate their condition. It was pointed out by several participants that people with disabilities may be required to attend Accident and Emergency for procedures that they consider could be more swiftly and appropriately carried out elsewhere such as through direct access to a specialist ward or by a G.P.

*'she has MS and she has a catheter and that goes wrong nearly every 6 or 8 weeks... and she has to go to casualty every time, that is disgraceful. The ambulance has to pick her up because she has to be brought by ambulance, she is landed into casualty and ... she could be sitting there from 3 o'clock in the day to 12 o'clock at night... She has to go through that instead of being brought up to the urology ward and it being done there. What she has done, doesn't take 5 minutes'*.

#### 3.2.2.2. Environmental accessibility

The Accident and Emergency department consistently used by participants was generally considered to have a good level of accessibility within the department. However, the absence of a hoist to facilitate a transfer would have compromised one participant's treatment if he had not been accompanied by an able-bodied person,

*"..... but my carer at the time like was with me all the time so, and my brother came in as well, now if I was up there on me own I don't know, I don't know like, I had to go up on a trolley like or whatever bed where I had to be examined and everything like that. Sure if I didn't have the help with me I don't know what would have happened, I probably would have come back home again like"*  
(Participant 3:1).

### 3.2.2.3. Attitudinal barriers

Many of the personnel were considered to be unaware of issues raised by disability. Some participants considered that they had been treated well by everyone while others felt that they have been treated roughly or without consideration. And whereas the experience of several participants was that the staff within the Accident and Emergency Department had little knowledge about or concern for people experiencing mental health difficulties, another spoke of the kindness of individual nurses when she presented in a state of crisis. One participant found the experience of bringing her brain injured son to the department highly stressful due to the doctors' lack of knowledge about the implications of such an injury. Her stress was compounded by a doctor's assumption regarding her motives towards her son,

*"The doctor that was dealing with him was under the assumption that I wanted rid of [X] and I wanted him just put in hospital because I needed a break"* (Participant 2:6).

### 3.2.2.4. Communication barriers

In the whole process of access and use of Accident and Emergency departments, people with sensory disabilities experienced barriers due to communication difficulties. According to participants who were hard-of-hearing the first barrier is the reception desk,

*".....and the receptionist is inside a glass panel ok, and that stops it and her speech reaching me. And the holes and the slots in it, they are fine for her, but the other way out it does not suit"* (Participant 2:4).

The waiting area can create further difficulties as participants reported those who are hard-of-hearing cannot hear their names called and those with visual impairments cannot orientate themselves to their surroundings and see where, for example, toilets are situated. Participants with sensory disabilities

experienced a sense of isolation in waiting in the Accident and Emergency Department.

Factors identified by participants to facilitate their access and use of Accident and Emergency departments focused on the need to provide personnel working in this environment with training and education so that they can develop skills to accommodate people with disabilities.

#### 3.2.2.5. Accident and Emergency as gatekeeper

Participants expressed the opinion that the Accident and Emergency department functions as a gatekeeper to restrict and control access to hospital services for people with disabilities. This was specifically cited in relation to those experiencing mental health difficulties and those with intellectual disabilities.

### 3.2.3. Secondary Health Services

#### 3.2.3.1. Screening Processes and Procedures

People with disabilities, specifically those with intellectual disabilities and people with limited mobility, are perceived by some participants to be excluded from some screening processes and procedures. This was at two levels, the first in relation to the perception that people particularly with intellectual disabilities were not in need of specific screening, for example for cervical cancer. As an advocate said,

*“.....you never, presume that Q would be getting cervical cancer or would need a breast check, for some reason you just do not think along those lines,”*  
*(Participant 2:8).*

For those who did access the screening process the barriers reported were due to a lack of awareness of the personnel carrying out the procedure in the case of

those with intellectual disabilities and environmental barriers for those with physical disabilities. Two advocates for people with intellectual disabilities described tests being abandoned when the patient found it difficult to co-operate with the required procedure. This was said to be because the time was not taken to fully inform and reassure them prior to and during the test.

For those with a physical disability the mammogram procedure was one that was identified as being particularly difficult as it was reported that it requires the patient to be in a standing position. Equal difficulty was experienced when a test or examination requires the person to be lying on a bed or couch and a hoist is not available to transfer the person from a wheelchair. One participant was unable to transfer into the chair in front of the test equipment for an eye examination as the chair was in a fixed position and she has limited mobility.

#### 3.2.3.2. Getting to secondary services

Lack of appropriate transport was cited as a barrier to accessing secondary health care services. One woman described how, in the absence of a single ambulance in the Health Board area able to transport an electric wheelchair, the Health Board hires a 26-seater bus to transport her to and from outpatients appointments. The bus and its regular driver wait for the duration of the visit and then return the person to their home. This participant had experienced a similar difficulty in accessing a hospital in another health board area, which also lacked appropriately equipped ambulances. Other participants reported being dependent on friends and family for transport, and overly long waiting times left them feeling guilty and anxious about being a burden.

#### 3.2.3.3. Waiting lists and waiting times

Waiting times caused difficulties beyond that of transport needs. Most participants reported that they had to wait protracted periods for services because they were Medical Card holders rather than because of a disability per

se. However, an advocate for people with intellectual disabilities believes that he has witnessed discrimination against his clients while in waiting rooms,

*“I find as well that I have sat in waiting rooms and because we are, have a handicap that we are left sitting longer you know”* (Participant 3).

For some people with intellectual disabilities waiting long periods in surroundings exhausted their patience and tolerance and rendered them uncooperative when they eventually saw a doctor. The consequence of the wait was perceived to impact particularly on the lives of people with disabilities. Most agreed that waiting times acted as a barrier to services and that the experience was akin to being, *‘in a cattle mart’*. Some participants made the point that they were treated the same as everybody else and were not *‘singled out as disabled’* to get any special treatment. Two participants with diabetes described the wait as being *‘dangerous’* unless they have access to food.

#### 3.2.3.4. Environmental barriers

Opinions varied as to the physical and sensory accessibility of the environs of the outpatient facility. Newly built and recently renovated parts of the hospital were said to be appropriately colour contrasted for people with visual impairments while a revolving door was characterised as too *‘dangerous’* and *‘scary’* for people with disabilities to use. Wheelchair accessible toilets were said not to be widely available and some toilets that are designated for people with disabilities are not big enough to accommodate wheelchairs,

*“There’s a wheelchair toilet there and you can’t even fit in it, you’ve got to keep the door open”* (Participant 2).

Most of the wheelchair users involved in this project do not manage to access the waiting room at all,

*“When you come in you’re left in the hallway area, have to park yourself in the hallway, this is what I find more infuriating than anything else, is that your just blocking parts of the hall, doctors trying to get around you” (Participant 2:9).*

Participants with sensory disabilities also reported experiencing great difficulties within the waiting rooms due to cramped conditions.

### **3.2.3.5. Communication barriers**

As in participants’ experiences of General Practice and Accident and Emergency departments, those who were hard-of-hearing reported barriers caused by being unable to hear when their name is called in the outpatient environment. Participants with a visual impairment described how, without visual information, they were unable to judge where they are in the queue or how it is progressing. Participants identified factors which would facilitate service provision and access including: education and training of all staff to raise awareness of issues and promote skills development as well as the use of technology such as visual displays.

### **3.2.3.6. Attitudinal barriers**

Many participants did not consider that the receptionists in outpatients’ clinics were aware of or responsive to issues relating to disability. Receptionists were reported as failing to greet or talk to people with learning disabilities. One participant, a wheelchair user, characterised their manner as *‘brutal’*; he now always approaches the reception desk on his own because in his experience if someone is with him, the receptionist will only talk to that person. He believes,

*“People behind counters, they kind of think you’re dumb you know, if you’re in a wheelchair” (Participant 2).*

In considering doctors and nurses in outpatients many participants drew distinctions. Some identified certain clinics as providing positive outpatient

experiences with respectful care and conditions and ‘great’ people. Some singled out nurses for particular praise though a few also had bad experiences with nurses. One participant distinguished between junior doctors who she considered to be ‘*holistic and caring*’ and consultants who were, in her opinion, ‘*arrogant, disrespectful and rude*’. This attitude of senior staff was reiterated by participants who were hard-of-hearing who recounted incidences when consultants refused to talk to them in the absence of a hearing person supplied by the deaf person, refused to write things down and made no effort to communicate with them and made them feel extremely uncomfortable.

All the participants that commented on the issue agreed that there was an enormous lack of disability awareness among all levels of personnel with whom they dealt in outpatients. This is demonstrated by an experience recounted by one participant in an attempt by a nurse to overcome an environmental barrier, “*She came over to me several times and she asked me would I be able to come into the next room. Would I be able to walk into the next room and I said not really, I said I’m paralysed, I thought that would be good enough for her you know but she came back twice more and asked me would I not be able to come a little bit, even if she helped me could I come, I said I’d love to be able to but I said I’ve tried for 38 years and it didn’t work, so I don’t think it’s going to work for me now*” (Participant 2:9). The solution was unanimously and emphatically given as ‘*training, training, training*’.

### **3.2.4. In-patients**

#### **3.2.4.1. Maternity Services**

Four participants experienced the Maternity services as women with disabilities. Two women did not consider that their disability impacted on their experience of the maternity services, one as she did not inform them of her situation. The experiences of the other two women stand in marked contrast to each other. A woman with a physical disability had an extremely positive experience, which she attributes in part to her disability having a ‘novelty’ status,

*“They were so busy minding me ..... I was a whole new different wonder to them”*  
(Participant 4).

Conversely, a deaf woman describes her experience of the Maternity services as a lonely and distressing time. While some nurses were pleasant to her she felt that others were irritated by her inability to communicate and by her distress; and these nurses treated her abruptly and shouted at her. This participant described the staff, as a whole, as,

*“In fact in the maternity they were awful. Very bad”* (Participant 7).

#### 3.2.4.2. Hospital admission

Advocates for people with intellectual disabilities spoke of their experiences of being required to provide twenty-four hour care to their clients as a condition of their admission to hospital whether the admission was for routine procedures or through the Accident and Emergency department. It was stated that without this commitment from family, and/or carers, a person with an intellectual disability would be denied hospital admission irrespective of their actual support needs.

#### 3.2.4.3. Attitudinal barriers

Some participants praised nurses in the hospital setting highly and referred to their compassion and caring capacity as positive attributes. One participant said that the nurses are,

*“Very clearly the best [of the health professionals] in that they are caring and they have, seem to have more room for understanding..... they always have that bit of extra room just to be compassionate”* (Participant 2:3).

While experiences of nurses were generally positive, participants, particularly those with limited mobility, described negative experiences of care that were ascribed to nurses' lack of time. As a consequence one man described how he was left on a commode for an hour. This perceived lack of time resulted in one participant and her family staying with the person with a disability, who had high support needs, while he was an inpatient in hospital,

*"He needs a lot of care and the nurses do not have the time to do it"* (Participant 2:3).

However, one participant with mental health difficulties who was admitted to the general hospital did not attribute his negative experience to a lack of time by staff he stated,

*"Nurses and doctors are people, they should have more consideration for people who are sick and who are in hospital and need more consideration, they should look after them, that's what they're getting paid for, that's their job"* (Participant 1:6).

This range of experiences with nurses and other hospital staff was explained by one participant as,

*"You will get individual people who are excellent and then you'll get the one who's hopeless and so you're at the, it's just if, you know, it's hit and miss"* (Participant 3:0)

This variability was reported by participants to be the result of a lack of disability training and awareness so that only those with personal experience of disability are perceived as equipped to deliver the level of care required,

*“I once asked a nurse like how are you able to deal with me and she said her brother was in a wheelchair so that answered that question, you know”*  
(Participant 3:1).

The consequences of inadequate awareness by hospital staff of people with disabilities' needs were highlighted by many participants and can be illustrated with reference to the experience of a participant with a visual impairment. He spoke of the difficulty in eating when, if you are blind you are not told when food is put in front of you, or what the food is, or where it is on the plate. Some participants referred not only to lack of awareness but also lack of skills. Participants requiring assistance in transferring from, for example, a wheelchair to a bed reported the staff as being inadequately trained.

#### 3.4.2.4. Environmental barriers

The environment within the wards created difficulties for some of the participants. People who were wheelchair users reported being forced to use commodes when toilets proved inaccessible. Participants with visual impairments identified the need to keep the general environment as clear from obstacles as possible to facilitate independence.

#### 3.4.2.5. Communication barriers

Participants consistently reported that hospital staff did not take account of specific communication requirements of people with disabilities. Doctors in particular were reported to be insensitive to the need to introduce themselves, and anyone that is accompanying them, verbally to people with visual impairments each time they approached. A participant who has difficulty remembering was given information verbally, unsupported by written material

and, while written material is inappropriate for others, no alternative is offered. A participant with visual impairment stated believes that everyone should be asked,

*“How are you going to access this information? Do you require it on tape or in Braille or large print? and if this can't be provided how will you, they should be asking, ..... - how are you going to access this when you go home?”*  
(Participant 3:0).

### **3.2.5. Mental Health Services**

#### **3.2.5.1. Community Mental Health Services**

While three reported contact with community mental health services only one participant elaborated on his experience. This involved a psychiatrist visiting his home, an experience he referred to as *‘brilliant’*.

#### **3.2.5.2. Gaining admission**

According to a number of participants access to in-patient mental health services was denied. Advocates for people with intellectual disabilities stated that it is health board policy to actively exclude this client group from mainstream mental health services, particularly in-patient services. Another participant whose son has an acquired brain injury who was refused admission, reported the psychiatrist’s explanation for not admitting the young man,

*“He said the psychiatric unit would be a very, a totally inappropriate place to place somebody with an acquired brain injury, in a psychotic state or no”*  
(Participant 2.6).

This participant went on to explain that ironically, when informal care is no longer available for a brain-injured person, the only provision available from the health board is a mental health hospital.

### 3.2.5.3. Communication barriers

Eight participants experienced being an in-patient in a mental health unit and those that did found the experience isolating. A man who is Deaf described his time as an in-patient as a period without human contact. While a few patients made the effort to try and communicate with him, the doctors and nurses were 'very poor' in this regard. A participant with impaired mobility found the experience equally lonely and was unable to initiate contact with either other patients or the staff.

### 3.2.5.4. Attitudinal barriers

Participants' reference to their experience of nursing staff was very varied. Some participants considered nurses as caring and helpful, others uncommunicative and insufficiently qualified. Participants consistently reported their experience of medical staff as poor.

### 3.2.5.5. Counselling services

While participants spoke about their experiences of services many also spoke about their unmet need for access to counselling services. Not to offer counselling was considered to result from a lack of awareness by service providers that a person who is diagnosed with a disability undergoes a process of grieving. Counselling should be available, it was suggested, not at any particular point in time but whenever the person experiencing the disability is ready to enter into it. Participants from the Deaf and hard of hearing community reported experiencing extra disadvantages when seeking counselling. There are no counsellors in Ireland who are fluent in Sign Language and, therefore, all consultations must take place in writing or involve a third party as an interpreter. Both act as barriers, as one participant explained,

*“Once I did go and see a counsellor and I ended up trying to write back and forth but in my experience that wasn’t working, we needed an interpreter” (Participant 7).*

### **3.3. Emerging Themes Across Services**

#### **3.3.1. Participants’ Perceptions of Equality**

Participants were asked explicitly if they considered that the health services treat people with disabilities the same way as they treat people without disabilities. Responses fell into three categories: those that believed that they were ‘treated better’, those that felt they were ‘treated the same’ and those who considered their experience ‘worse’ than that of people who are not disabled.

##### **3.3.1.1. Treated better**

Many participants with a positive relationship with their G.P. considered that they received a better service than did the G.P.’s patients who do not have a disability. Outside this aspect of the health services, only a few participants considered that they were treated better than people without disabilities and this was in relation to, for example, being moved to the top of the queue in the outpatients department. Participants discussed their perception of the motivation for this concession, which was consistently negative. For example, one participant believes that the readiness of personnel to put people with disabilities to the top of a queue is based on their own fear of the disability rather than concern for the person with the disability. Thus, while the outcome of waiting less time may be perceived as positive, the motivating factors may in fact be negative.

##### **3.3.1.2. Treated the same**

Four participants considered that people with disabilities are treated the same as people without disabilities. In two instances this answer was unequivocal but a

third participant restricted his answer to people who have the power of speech. The fourth participant believes that she is treated the same as everyone else because she is assertive but that other people with disabilities are not treated the same.

### 3.3.1.3. Treated Worse

The majority of participants expressed the opinion that, apart from General Practice, people with disabilities had less access to and experienced poorer quality health services than non-disabled people. The advocates for people with intellectual disabilities were emphatic people with intellectual disabilities are not treated the same as people without disabilities by the health services: they have less access to services and those services they do access are of poorer quality. The inequality was perceived to permeate through all aspects of the health services and to be rooted in the attitude to and value placed on people with intellectual disabilities,

*“It’s all about how much a person values you...It’s that if you see them as a person, you’ll go do the actions. If you don’t actually see them as a person, then they are nobody you know. ...because they’ve a disability, it means they’re less of a person” (Participant 2:8).*

### 3.3.2. Layers of Inequality

The inequalities experienced by people with disabilities across the continuum of the health services appear to be compounded by other layers of inequality experienced more generally. While some may face one additional layer others come up against multiple strata of inequality. Concomitant areas of disadvantage experienced by participants included, education, economic, language, gender and age.

### **3.3.2.1. Education**

One participant alluded to her difficulty in reading and writing,

*“When you’re a bit upset or a bit hyper, trying to write something down and then I wouldn’t be that confident with my English as well and if I had to explain myself, or had to read somebody else’s communication”* (Participant 7).

Limited literacy skills compound communication difficulties with service providers as it restricts alternative forms of communication, such as written material.

### **3.3.2.2. Economic**

As can be seen throughout the findings reported for each service area, financial issues impact on individual participant’s access to services. This is reflected at various levels. Financially able participants were in a position to exercise choice, which was clearly seen in relation to G.P. services and was beneficial in promoting positive service experiences. This group was able to subsidise service provision if they felt it inadequate to meet their needs such as accessing additional physiotherapy. Participants’ access to some services such as speech therapy, only happened because they were able to pay for it. As well as access to receipt of services directly, financial issues were reported to impact on the promotion and maintenance of participants’ independence, as is demonstrated by transport barriers reported by participants who are able to drive but cannot afford to buy and run a car.

### **3.3.2.3. Language**

None of the participants in this project were native Irish language speakers or non-nationals; however reference was made to the extra layer of inequality experienced by such individuals when they also have a disability. The language issue was reported to be of importance to Deaf people whose first language is often Sign Language. No participant who was hard-of-hearing had ever met a

medical professional with any level of fluency in Sign Language. Availability of interpreters for Sign Language was reported as severely limited.

#### 3.3.2.4. Gender

A Deaf woman thought that men with disabilities tended to be better educated than women with disabilities but that this did not lead to better treatment by the medical profession and a woman with a physical disability considered that men found the experience of disability more traumatic,

*“It’s an awful shock to a man’s ego you see. A lot of women are being put down already and it was just one more straw on her back. But a lot of men also think of themselves in terms of physical strength”* (Participant 1:0).

#### 3.3.2.5. Age

Participants expressed the opinion that as older people use the health services more than younger people, older people with disabilities are likely to have more encounters with the services; therefore any barrier faced by a younger person will be faced more frequently by the an older person.

### 3.3.3. Fragmentation of Services

The lack of co-ordination of services was reported to be a barrier to care at various stages of access to the continuum of health services. One participant spoke of attending three outpatient clinics on three different days in one week. Several participants called for consideration to be given to the synchronising of appointments; one patient had asked the hospital to try to arrange that she would attend two clinics on the same day but was told that this was not possible. This organisation of service provision was reported to act as a barrier to people with disabilities.

Some of the participants were under the care of several consultants and almost all expressed unease about the lack of communication between the various specialists. Doctors were said not to network or interact with other specialities. One participant depicted a body of doctors working away in their own fields with her as their only 'common denominator'. The fragmentation of care was reported to result in inconsistent information provision,

*"The doctors are a grand job, they're only doing their job but one fella says one thing and another fella says something else and another fella says something else"* (Participant 2).

The lack of information and co-ordination at the time of discharge was also reported by another participant to be a barrier.

### **3.3.4. Adaptation and 'fit'**

It became evident from the data that while participants did experience explicit barriers to accessing health services, often these barriers were reduced or ameliorated. However, this was not through any accommodation by the system to the needs and requirements of the individual but by the interception, negotiation and action of others, usually informal carers. At times specific health personnel accommodated the participant in their interaction with the service. The result of this adaption process is that the participant receives the service in some form, in instances where no accommodation or adaption is made then services are not received. This can be seen through the continuum of health service provision and is presented in tabular format for clarity

### Adaption and the Health Services: some forms and effects.

Level/Type of Service	The need for interaction with Service	Reported barrier or difficulty	The adaptation	The Result	Implications
Health Information	Participant with visual impairment needs information about health or medication.	Information not available in large font size, in audio form or in Braille.	Individual' s spouse conveys the necessary information to him.	Individual is informed about his health and can take any medication in a safe and informed manner	Time cost for spouse  Lack of independence and confidentiality
Primary Care: General Practice	Participant who is Deaf makes an appointment to see G.P.	Doctor does not have text-reading equipment or person does not have access to fax.	A hearing person makes the appointment	Person who is Deaf gets appointment.	Lack of independence and confidentiality Cost of communicator
Dental community care service	Participant requires a dental x ray	Door to x-ray room too narrow for wheelchair.	Staff and P.A. lift person onto a swivel chair and push into x-ray room while supporting the balance of the participant.	Person with impaired mobility has dental x-ray.	Width of doorway not addressed. Health & Safety issues
Secondary Care: Outpatients attendance	Participant who uses electric wheelchair requires to attend hospital outpatients department	No car due to grant restrictions No appropriately equipped ambulance in Health Board area	Health Board commissions local private bus. Driver assists to manoeuvre powered wheelchair up and down ramp. Driver waits for duration of appointment	Individual attends outpatients appointments.	Loss of independence. Health & Safety of driver Resource of driver and bus misused
Outpatients attendance	Participant who is Deaf has consultation with specialist	Specialist refuses to communicate with participant without an interpreter	No interpreter available	Distressed participant sent home without consultation	Loss of confidence for person who is Deaf. Inability to interface with health professional causes difficulties
Tertiary Care	Advocate of person with intellectual disability attends accident and emergency department with client	Hospital services refuse admission without 24 hour carer.	Care workers provide the cover.	Individual receives treatment as an inpatient.	Other clients with whom care workers work get reduced service

## 4. DISCUSSION

### 4.1. Introduction

Literature over the last two decades and beyond indicates that certain health care needs of people with disabilities may be neglected; yet there are still gaps in our knowledge, particularly in relation to secondary and tertiary care. Disability studies in Ireland have tended, until recently, to follow a predominantly medical agenda with a concentration on quantitative methodologies. From the NDA's review of disability research in Ireland (2001), it is clear that there is a lack of qualitative data on how people with disabilities conceptualise their health and a lack of research into the delivery of Government policy on mainstreaming. Few studies have addressed health inequalities for people with disabilities in an Irish context. By broadening our knowledge of the disabled population in Ireland, we can better address the gaps in the current health system, including identifying areas in which there may be opportunities for more effective delivery of care.

The findings of the literature review are supported and illuminated by the lived experiences of those interviewed whose testimonies concur with previous research (MIND, 1996; Disability Rights Commission, 2004). This study demonstrates that inequalities in access to health services in Ireland continue and are similar to those experienced by people with disabilities in other countries.

To frame a discussion of the issues emerging from this study – from both the comprehensive literature review and from the interviews – we considered the issues by reference to Simeonsson *et al.*'s (1999) five characteristics of access to health care:

- ❑ accessibility, which relates to physical barriers to access
- ❑ availability, which refers to the type and extent of services
- ❑ accommodation, which refers to the sensitivity to individual differences
- ❑ affordability, which equates to financial, time or energy costs

- acceptability, which includes mutual acceptance and reciprocity.

However, a number of important overarching issues span and are common to each of these five areas, and are discussed initially. They are the nature of inequality experienced, the nature of service provision and health information.

## **4.2. Overarching Issues**

### **4.2.1. The Nature of Inequality**

The testimony of people with disabilities in this study demonstrates the multiplicity and complexity of layers of disadvantage experienced by some of them in their access of health services. This complexity and layering reflects constructs of inequality (Graham & Kelly, 2004). The experiences of the participants can be divided into those where they receive the services that they need and those where they do not receive required services.

Where services are received, equality of access to those services may be judged by looking at the 'degree of fit' between the person or client and the system (Pechansky & Thomas, 1981). It is clear that, for many, this fit is a poor one. To compensate for a poor fit, a range of accommodations or adaptations is brought into play to facilitate and enable access. The person with a disability may rely on formal or, more usually, informal support systems and occasionally individual health service providers function as the adaptor. In facilitating an accommodation the adapter renders an inaccessible service accessible but in doing so s/he also serves to disguise the underlying inadequacies and inequalities in the system (Iacono *et al.*, 2004). Thus the inequalities experienced by those interviewed may be far greater than would initially appear if they were not masked by the intercession of 'adapters'.

Adapters played a significant role in ameliorating the barriers imposed by the environment but environmental barriers also indicate the extent to which the

success of adapters can be a double-edged sword. The use of adapters can serve to ease access to some aspects of service provision while limiting access to others and undermining the equality of individuals. Thus, the accommodation and flexibility of General Practitioners to make home visits to mobility impaired participants may render it less likely that G.P.'s will consider making their primary care premises fully accessible. Visiting patients at home also results in the avoidance of further environmental barriers such as limited waiting room space and the difficulty in the use of examination couches, a barrier identified in previous research (Scheer *et al.*, 2003). While participants valued their G.P. visiting their home, the range of services that will increasingly be available from primary care units (Department of Health and Children, 2001) will not be accessible on this 'adapted' basis.

Adaptation in the out-patients environment may be achieved by fast-tracking the person with disability through the system. So, if a wheelchair user is forced to block corridors because the waiting room is not comfortably accessible to them or other patients, an adapter may speed an individual through the queue and thereby minimise the visibility of the inequality of environmental access. One participant characterised his response to such actions as one of ambiguity - his pleasure at reducing his waiting time by several hours tempered by his acknowledgement that this preferential treatment was, in effect, both the result of an inequality and constituted an inequality. Adaption within the outpatients system is a good exemplifier of the negative effects that can result if the inaccessibility of the waiting area is not addressed: the mobility impaired individual suffers the embarrassment of being an obstacle in an inaccessible area, albeit for a reduced time and the consequence is a reduction of equality of access.

Even with the support of 'adapters', some participants were clearly still unable to access the health services that they need. In some instances, they were falling foul of the same inadequacies that a person with the same requirement but

without a disability would encounter, but in others they were clearly being discriminated against as a consequence of their disability. Those with the weakest voices - those with an intellectual disability and those with a mental health difficulty - were most excluded. The fact that these groups are often the most stigmatised serves to compound the inequality (Morgan *et al.*, 2002; Lawthers *et al.*, 2003).

The Deaf community, as portrayed in this study, did not perceive themselves as enjoying any level of acceptance or reciprocity with the health service personnel with whom they dealt. People with a hearing impairment and particularly individuals who are Deaf were identified as being among the group most likely to be subject to layers of different and compounding inequalities. For many people who are Deaf, sign language is their first language and one that few health professionals can use and that many health professionals know nothing about. Because spoken English is not their first language and because of deficiencies in the educational system experienced by deaf people they may have low levels of literacy and a combination of these factors make it probable that a person who is Deaf will also suffer the economic disadvantage of unemployment. The cumulative effects of encountering negative attitudes served to demoralise one participant who is Deaf to the extent that she no longer has the confidence to access the health system without support. In Ireland, no data exists to quantify how widespread is this reluctance to interface with health professionals but research from England suggests that many deaf people actively avoid seeking medical advice when ill (Sense, 2001). The experience of deaf people demonstrates the inequalities of access compounded by the health services being embedded within a society that already discriminates against people with disabilities in a multitude of ways (Combat Poverty Agency, 1995; Jenkins & Rigg, 2004). It also illustrates the need for specific training and education around the requirements of individuals with particular disabilities.

It would appear that, while people with disabilities experience inequality in access to health services as compared to the general population, within the community of people with disabilities, inequality is also experienced differently between those with different functional impairments. There is evidence from the research literature that this pattern of inequality is further complicated by the experiences of women with disabilities and ethnic minority groups with disabilities who are further disadvantaged within society (Pierce, 2003; Disability Rights Commission and Centre for Education in Racial Equality in Scotland, 2004). The picture of inequality experienced is therefore complex (Graham & Kelly, 2004) and demands a response that is both individual and holistic and one that does not assume that 'the disabled' are a homogeneous group. However, most of the health services are still highly medicalised and fragmented, and therefore, not working within a paradigm that supports such a person-centered approach.

#### **4.2.2. Nature of Service Provision**

Much of the health services as portrayed in the data from this study are oriented to the delivery of medical care and are delivered within the framework of a medical model. With the exception of much of the General Practitioner service, the social model of disability has not permeated the health services as experienced by many of the participants, even those services providing social care. This experience challenges the stated government commitment to re-orientate health services towards a social model (Commission on the Status of People with Disabilities, 1996; Department of Health and Children, 2001). A similar finding has been documented in an English report (Clark, 2003). It may be due to the continued adherence to the medical model that the system disregards levels of adaptation that would render services fully accessible. The time and energy costs required in compensating for the deficiencies in health service provision impact not only on the person with the disability but also on those who provide support. The provision of such support may impose considerable stress on those providing it (Iacono *et al.*, 2004) and the impact of

caring on informal carers, including the 149,000 family carers (Census, 2002) is documented (Care Alliance Ireland, 2004). However, it is clear that receiving such care may also impact on the recipients. Many participants in this study expressed serious frustration that the health services appeared to increase their dependency on carers rather than strive to maximise their independence.

Participants reported their experience of health services as fragmented. It has been recognised previously that primary care services work in isolation from each other (The Institute of Public Health in Ireland, 2002), but the fragmentation of care experienced was not just within one level of care provision but across and through the whole continuum of health care services. Services are not perceived to be integrated in a patient-centred way (The Institute of Public Health in Ireland, 2001) and this is an issue that needs to be addressed in the context of equity. This lack of service integration is regrettable as person centred services is one of the goals of the current Health Strategy as a means of ensuring that the health service is responsive to the needs of the individuals that it serves (Department of Health and Children, 2001). Fragmented services are fundamentally insensitive to individual differences and this fractured care compromises the quality of service provision for people with a disability whose multiple service needs can be complex (Lawthers *et al.*, 2003; Smith, 2000). Some participants in this study were clearly concerned that they were made very vulnerable by the fragmented nature of a health service wherein different doctors of the same patient do not confer on the compatibility of their treatments. Other studies (Smith, 2000) have addressed the benefits of a “case management” system as a way of co-ordinating all the various services that an individual may require.

#### **4.2.3. Information Provision**

Many of the participants in this study were severely disadvantaged in their access to health information and health education, an issue which has been identified previously (MacDougall, 1998; Commission on the Status of People with Disabilities, 1996; National Rehabilitation Board, 1994). This creates an

inequality of knowledge between people with disabilities and the general population and can also endanger individuals who cannot read or understand information supplied with medication. With a single exception, no health service provider was reported as ever offering information in an alternative format or inquiring whether the supplied format was accessible. An informed public produces a more efficient use of health services, improved compliance with treatment regimes and greater patient satisfaction (McDougall, 1998). Consumer health information is the strongest growing area in health information. Lack of access to this information on the part of some people with disabilities may result in increasing rather than decreasing marginalisation.

Lack of information was identified as a deficit in service provision leaving many participants unclear and unaware of any rights, which they may have vis-à-vis the health services. Some spoke of entitlements to specific levels of various services but did not specify wherein these rights lay. Others spoke of not knowing whether or not they had any rights, to the extent that a deaf participant sought information during the interview about her entitlement to an interpreter when accessing the health services. The rights of people with disability are embedded throughout numerous pieces of legislation and policy documents and it may be that this information itself is inaccessible to people with a disability. Advocacy can support people to access information and health services themselves, and can bring considerable empowerment to people who are vulnerable or marginalised. Advocacy services for people with disabilities in Ireland have heretofore been very underdeveloped (Goodbody Economic Consultants, 2004), a position that may change with the implementation of the Comhairle (Amendment) Bill (2004).

## **4.3. Access**

### **4.3.1. Accessibility: Physical Barriers Relative to Location**

Extensive environmental barriers were experienced by participants in this study in all aspects of the health services from primary care through to tertiary care. The public built environment experienced by participants excludes or severely restricts access to health services at all levels. This was a feature of not only older buildings but also those built or extended since the introduction of Building Control Regulations in the 1990s.

The principal aim of building regulations is to provide for the health, safety and welfare of people in and around buildings. Part M of the Irish Building Regulations (1997 – 2000), requires that all buildings be constructed to minimum standards to facilitate access for people with disabilities. Based on the principle of universal accessibility, Part M was revised in 2000 and an amended regulation came into effect in 2001. Part M now requires that access to new non-residential buildings by people with disabilities should be ‘adequately’ provided.

However, the effectiveness of Part M at improving access to buildings has been strongly criticised by people with disabilities and the wider disability community. In response to these concerns, the National Disability Authority (NDA) has recently commissioned independent research into the effectiveness of Part M. Preliminary findings from this research suggest that the monitoring and enforcement mechanisms for Part M lack the rigour required to be fully effective. The findings also suggest that for many people with disabilities, Part M has not improved access to the built environment (NDA forthcoming).

The physical environment impedes access to services in a number of ways not just the entry to premises in the first instance as has been found previously (DeJong *et al.*, 2002). Impediments also occur in negotiating corridors and

waiting rooms, accessing basic facilities such as toilets and transferring from chair to bed or examination couch.

Access to Accident and Emergency Departments would have been restricted had participants not been accompanied. While participants gained access to the department, they experienced difficulty in transferring from chair to couch. While this can be facilitated by the use of a hoist, participants reported a lack of this basic equipment. A lack of staff training was also reported in relation to transferring participants, an issue which has been identified previously (Clark, 2002).

Dentistry provides interesting illustrations as to the limits to which adapters can fill the gaps. As long as manpower can be mobilised to lift a person with physical disabilities into an x-ray room, the barrier of a narrow door need never be addressed. Many dental surgeries were inaccessible to people with mobility impairments and this was cited as a real impediment to dental treatment for individuals whose medical card status made 'shopping around' difficult.

The physical environment may prove to be having its most serious consequences in respect of preventative and screening services. Adapters may plug the gaps adequately for immediate and emergency care, but an inaccessible physical environment may render screening and preventative tests impossible (Nosek *et al.*, 1996). Thus, while physical assistance may be available to transfer an individual from a wheelchair to a examination or x-ray bed in the event of a crisis, it might be less easily or appropriately accessed for a routine smear or mammography screening. While the Department of Health and Children in Ireland espouse the importance of screening (National Cancer Strategy, 1996) there is a lack of national population based screening. However, even if such screening was more widely available the findings of this study support other indications that health screening and preventative services to people with disabilities may be inaccessible or restricted (Sullivan *et al.*, 2003; Lawthers *et*

*al.*, 2003). The extent of the inequality in screening and assessment experienced by people with disabilities in Ireland is not quantifiable due to lack of research and data in this area. In the absence of such data, it may be reasonable to assume that Irish people with disabilities experience the same level of premature and often preventable death as documented in other countries (Hollins, 1998; Harris & Barraclough, 1998). However, it must be recognised that both the breast ([www.breastcheck.ie](http://www.breastcheck.ie)) and cervical cancer screening ([www.icsp.ie](http://www.icsp.ie)) programmes refer to the need to accommodate women with disabilities. BreastCheck through its Charter refers to facilitating those with 'special needs'. The cervical screening programme, with reference to Women's Rights Ireland, acknowledges the right of all women to effective communication, to be treated with respect, the right to dignity and independence and the right to freedom from discrimination – among other rights. Neither programme is available on a national basis.

#### **4.3.2. Accommodation: Sensitivity to Individual Differences and Functioning**

Huge frustration was experienced by individuals when they encountered professionals within the health services, particularly doctors, who were both insensitive to the differences generated by a disability and also unwilling to be informed about them. Other studies have suggested that people with disabilities must often educate their physicians about health related issues associated with their disability (DeLong *et al.*, 2002). Doctors who are perceived to be open to being informed about aspects of a disability were particularly valued while those who did not undermine confidence in the health care provided.

The finding in this study, that the highest level of satisfaction is with General Practitioners, is consistent with those of previous studies (Department of Health and Children, 2001). This may, in part, be explained by the level of choice that people in Ireland have in selecting their G.P. (Pillinger 2004). In exercising their choice, participants actively sought out G.P.s that met their own requirements. It

is clear that the only participants in this study who were unhappy with their General Practitioner also perceived themselves not to be in a position to exercise the choice to change doctors due to the fact that they had Medical Cards. Until such time as all G.P.s are equally sensitive to the individual differences of disability, it may be that some people with disabilities should be supported to register with a G.P. with whom they feel confident and comfortable rather than with the most proximate G.P. Allowing people this level of choice would acknowledge the importance that people with disabilities attach to a positive and respectful relationship with a General Practitioner (Morris, 2004).

Notwithstanding some individuals, the system as portrayed by the participants in this study is not sensitive to individual difference or functioning and has not moved to accommodate difference. This is the case even where what are required are relatively minor and/or inexpensive accommodations. Thus, previous studies and reports have identified the same findings as this study, namely that visual display units would equalise the experience of people with hearing impairments experience in waiting rooms (Clark, 2002), that hospitals and surgeries need a hoist if they are to transfer individuals with mobility impairments from a wheelchair to a bed or couch (Scheer *et al.*, 2003) and that blind people require to be kept informed orally and oriented (Clark, 2002). However, the extent to which the health service has taken any of this knowledge on board is disappointing.

People with mental illness and advocates of people with intellectual disabilities reported attitudinal barriers, which are demonstrated by their being deliberately overlooked and ignored in waiting rooms, an obvious example of active exclusion.

Sensitivity to individual differences and functioning requires health professionals to respect the rights and abilities of the individual with a disability. Many participants experience negative attitudes from health service providers ranging

from refusing to deal with individuals in the absence of a third party to treating them in an offhand or dismissive manner. Several interviewees felt they had to make the point that their physical or sensory disability did not mean that they had lost any of their cognitive or intellectual facilities. These attitudinal barriers have previously been found to impact devastatingly on the quality of health care provision (Schopp *et al.*, 2003).

#### **4.3.3. Affordability: Financial, Time or Energy costs**

Whereas other studies have found that the cost of health care was a major barrier to access for low-income people with disabilities in the US, (Rosenbach, 1995), few participants in this study raised it as a general issue. This may be due to the difference in the organisation and financing of care provision between the U.S. and Ireland. However, it was raised as a significant issue in relation to the therapy services where great discrepancies were perceived between those who paid for an adequate service and those who did not have the resources to do so. Several participants accessed physiotherapy and/or speech therapy privately in order to obtain the level of rehabilitation that they or their supporters considered necessary to reach their potential following a disabling event. Most participants who require access to these services on a regular basis also perceive them to be inadequately provided for in the public system. The impact of such deficient provision may have wide reverberations in the life of an individual with a disability preventing them from staying in or returning to work and from participating in family life to their fullest potential (Disability Rights Commission, 2004).

#### **4.3.4. Availability: The Type and Extent of Services**

In considering the type and extent of health services inequalities reported by the participants in this study, the multiple layers of discrimination described by the Combat Poverty Agency (1995) become apparent. In some instances the availability of health services is at a sub-optimal level for all or much of the

population but the consequences of the deficiency may be greater for people with a disability as they may also be forced to contend with educational, communication, transport and attitudinal disadvantage.

The mental health services were perceived to offer a particularly inequitable service to people with disabilities and the capacity of the service to provide adequately for people with disabilities must be questioned. The extent to which mental health services for people with intellectual disabilities in the U.K are specialised is subject to criticism (Linsey, 2002), but there may be some consensus that a quality service is provided to many of the 10 – 39% of adults with intellectual disabilities who also have mental health difficulties. The paucity of services described in other Irish reports (NDA, 2003; Irish College of Psychiatrists, 2004) is evidenced in this study where the perceptions are that neither the specialist nor the mainstream services are providing equal and adequate services to people with intellectual disabilities in Ireland today. The concerns of some advocates of people with intellectual disability that lack of services may have serious health and social consequences is one that is well supported by other reports (NDA, 2003). The experiences of people with physical and sensory disabilities with the mental health services in Ireland are not as well researched or documented as those of people with intellectual disabilities. However, the data from this study would suggest that while people with physical or sensory disabilities may find it easier to access the service, their treatment may be so insensitive and uncaring that their disability isolates them within it.

The unmet need created by the lack of availability of specific services such as physiotherapy, speech therapy and counselling and the limited availability of Home Help and Personal Assistants, prevent people with disabilities reaching their full potential and living independent lives.

#### **4.3.5. Acceptability: mutual acceptance and reciprocity**

The recognition of the value of acceptance and reciprocity is demonstrated in the participants' experience of General Practitioners. Those doctors who were actively sought and chosen were exemplified by partnership approaches and inclusive practices. Unfortunately this was not experienced in other areas of health service provision. Many people with disabilities clearly do not have a relationship with the health services that is based upon mutual acceptability and reciprocity. A system within which health professionals will walk away from a person with communication difficulties rather than attempt to communicate with them or where no one has responsibility to ensure that an inpatient who is blind knows when their meals have arrived is not an accepting one. A system that demands that a person with an intellectual disability is accompanied at all times by a carer, without regard to that person's individual need for support, pays no regard to the impact that tying up one support person has on the other people with intellectual disabilities who share the same support resource. It also serves to remove from the medical professionals the obligation that they become aware of both the issues concerning intellectual disability and individuals with a disability. While a recent study demonstrated that people with learning disabilities can be excluded by their G.P. from the consultation process (Bollard, 2003), the advocates in this study perceived that professionals in all sectors of the health services exclude people with learning or intellectual disabilities. As long as professionals will not interface with people with intellectual disabilities without the presence of a third party, the conditions do not exist to develop mutual acceptance, nor reciprocity. Research suggests that health service professionals feel unprepared and lacking in training when presented with patients with learning disabilities (McConkey & Truesdale, 2000), and in the absence of similar research about attitudes to treating and caring for people with physical and sensory disabilities it may be assumed that many of the same reservations pertain.

## 5. CONCLUSIONS

Key issues highlighted in this study includes the need for synchronised, person-centred health services that incorporate, in practice as well as in theory, the social model of disability; the exclusion of people with disabilities from services such as preventative services; inadequate public provision of certain services including speech therapy and physiotherapy; the inequitable service offered by the mental health services to people with disabilities; and the physical, communication and attitudinal barriers that continue to exist for people with disabilities.

- **The need for a Synchronised and Person-Centred Health Service based on a social model of disability**

Based on this study the need for a synchronised and holistic service is evident. The Irish Health Services continue to be medicalised and fragmented and are therefore not working within a paradigm that facilitates and supports a person-centred approach. Some participants expressed concerns that as a result of the fragmented services their care was compromised. They perceived that it was difficult that specialties, working without reference to each other, could ensure that treatments provided were synergistic and complementary. Fragmented services place increased demands on the physical support capacities of people with disabilities in a way not experienced by people without disabilities. They are fundamentally insensitive to individual differences and compromise the quality of service provision for everyone who seeks to access it. However, the consequences of fragmentation impact inordinately on people with disabilities whose multiple service needs can be complex and who are often forced to contend with additional disadvantages including educational, social and economic disadvantage.

The social model of disability has not permeated the health services with the exception of some of the General Practitioner Service. Thus, while theoretically the social model of disability has superseded the medical model, in practice, fragmented health services continue to “pathologise” people with disabilities into conglomerates of medical conditions. The continued adherence to the medical model may explain why the health system has disregarded levels of adaptation that would render the health services fully accessible. The recognition of the value of acceptance and reciprocity is demonstrated in the participants’ experiences of some General Practitioners who were actively sought out and who exemplified partnership approaches and inclusive practices. Unfortunately this was not experienced in other areas of the health services.

A review of case management as a model of service provision is required to assess its appropriateness to facilitate appropriate service provision for people with disabilities. Such an initiative may be timely given the Health Service Reforms, the lack of definition around service reorganisation and the openness to be informed by ongoing research and consultation.

- **Access to Health Services**

For many people with disabilities, the health services are rendered accessible only by an intricate system of supports and compromises. Thus, society acts as a buffer to decrease the effects of a health service that is too rigid to be truly person or client-centred. The limitations of this ‘propping up’ of health service provision are best evidenced by its inability to conceal the inaccessibility of preventative and screening services to many people with disabilities. The health services were perceived to assume these supports and compromises and not acknowledge either the deficits that they conceal or the effect they have on either the supporter or the individual who receives this support. In some instances the availability of particular services is at a sub-optimal level for everyone but the consequences of the deficiency is often greater for people with disabilities when

they are contending with additional disadvantage and when these services are vital to their optimal functioning and participation in society.

Preventative and screening services presented physical barriers to those few people in this study who had accessed them and it would seem that such services discriminate against people with disabilities. While this inequality is overt other, subtler, inequalities were also perceived to exist in relation to preventative and screening services. For example, people with disabilities may not be thought to require the same level of health screening as their peers without disabilities.

While screening was accessed it was not as part of population breast or cervical cancer screening programmes, as these are not nationally available. This may be an inequality in itself but one that results from geography rather than from disability. As national population screening programmes are rolled out people with disabilities and their advocates should be actively included in the developments and their rights upheld throughout the screening process.

- **Independent Living**

An under-provision of other services that can promote or maximise independence emerged as a theme from the interviews. Limited availability of Home Help and Personal Assistant services forces individuals into dependency on family and informal support that may undermine their autonomy. The experience of one participant of being told to ask her neighbours to do some housework when they called to visit her, suggests a lack of understanding as to how the dynamics of relationships can be altered by dependency. The restrictions placed on Home Helps and Personal Assistants can also serve to compromise the independence of a person with a disability when they are precluded from administering medication or driving the person with a disability in their car. Perhaps the restrictions placed on these services are, in part, a consequence of their being provided by the health services with its tradition of care and dependency. It highlights the urgency of a quantum leap to the social

model with a health service that formally supports independence and cultivates a partnership with the service users who have expertise in their own needs and lives.

- **Financial barriers to accessing services**

Societal inequalities, particularly in relation to finance and education compounded the negative experiences of the people with disabilities in this study. Those eligible for a medical card were denied choice in access to General Practitioners and could not easily, if at all, access support such as chiropody, counselling, speech therapy or physiotherapy. Many of those ineligible for a medical card also could not afford to access support services. In the main, only those who could afford to access these support services received them. Occupational therapists within the public sector were perceived to only have a remit regarding aids, equipment and extensions.

- **Communication, Attitudinal and Physical Barriers**

All of the barriers experienced by the participants of the study concur with previous research. Communication barriers were reported by those with sensory disabilities predominantly but not exclusively with a lack of alternative forms of communication and information provision identified. For the hearing impaired this situation would be ameliorated through the provision and use of information technology such as visual displays and text readers. Lack of information can be both disempowering and dangerous. When people with disabilities can access the same information that is available to the general public, a fundamental step towards equality in health care will have been achieved. For this to happen, the right to information in a format suitable to individual needs and abilities must become as enshrined as the right to information in either of the two official National languages.

Attitudinal barriers experienced by participants identify the need for mandatory training of all personnel in the health services, not just service providers, in specific areas of anti-discriminatory work practice and communication skills. Such training should acknowledge that many people with disabilities and advocates of people with disabilities have knowledge of disability in general and of individuals' needs and emphasise that health service personnel should respect this reality. This training should be included in all health service induction programmes for any new staff as well as in the core curriculum of all health professional training and as a pre-requisite to professional registration.

People with disabilities may not be 'visible' in the health services. Physical and environmental barriers may marginalise them by, for example, forcing a wheelchair user to sit in a corridor rather than in the waiting room. Poor communication skills on the part of health service providers drive some people with disabilities into a state of dependency, which is unnecessary and serves to reduce their status as independent individuals. Greater involvement of people with disabilities in the health services can work to raise their visibility and to ensure that all plans, policies and strategies are disability proofed before they are implemented. Direct involvement of people with disabilities at all levels of the health services will ensure that inequalities are prioritised. The identification and highlighting of models of best practice in the involvement of people with disabilities will be the necessary first step.

Although all participants in this research experienced barriers to their use of the health services, specific groups appear particularly disadvantaged such as those with learning disability and people who are deaf, emphasising the heterogeneity of the needs of people with disabilities. The deaf community, as portrayed in this study, did not perceive themselves to enjoy any level of acceptance or reciprocity with the health service personnel with whom they dealt. People with hearing impairments or who were deaf were identified as one of the groups of people with

disabilities most likely to be subject to layers of different and compounding inequality.

Specific areas, notably that of mental health care provision, are also identified as exclusionary to people with disabilities. This has been recognised by the Irish College of Psychiatrists in relation to people with intellectual disabilities. The College has proposed solutions to the situation, which may or may not be appropriate (Irish College of Psychiatrists, 2004). However, it is suggested that in reviewing and developing mental health care provision, recognition and active inclusion of the needs of all people with disabilities, not just those with intellectual disabilities is required.

In summary, it was a disappointing finding that the experiences of so many of the participants in this study concurred with those reported in the literature. So much is already known about the inequalities that people with disabilities encounter and so much policy and legislation is already in existence to tackle many of the deficiencies of communication and the built environment. Many participants considered a key solution to be education, training and awareness raising for all those who work in the health sector. In the short term a resolution or charter to enforce the rights that people with disabilities have in receiving health services would be a determined start.

People with disabilities in Ireland continue to experience inequalities in their access to health services. While some positive experiences with the health services were reported, there were more negative than positive interactions. As it stands, there is at best a 'poor fit' between the system and many people with disabilities. The system is generally only 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. It is to be hoped that the imminent development and reform of the health services will take the requirements of

people with disabilities into account in a more formal and professional manner. What is required, according to one participant is, "A *quality service for quality people*" (Participant 2:9).

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## **Legislation**

Disability Bill 2004

Equal Status Act 1999

Mental Health Act 2001

National Disability Authority Act 1999

## **National, European and International provisions.**

Barcelona Declaration 1995 adopted at the Euro-Mediterranean Conference on 27-28 November 1995

Building Control Act and Building Regulations 1999

Council of Europe Social Charter Article 15 1996

E.U. Resolution on Equality of Opportunity for Persons with Disability 1996

Programme for Prosperity and Fairness 2000

United Nations International Covenant on Economic, Social and Cultural Rights 1966

United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, 1993.