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The Everyday Lives of Physically Disabled Young People in Oman: Barriers to Social Inclusion

Yahya Badr Al-Mawali

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Submitted for the degree of Ph.D.

University of Durham

Centre for Applied Social and Community Studies

Department of Sociology and Social Policy

2004

2 0 APR 2005

Abstract

This thesis investigates factors that might lead to the limited inclusion of disabled young people in Omani society. The key assumption which underlies this study is that there is a need to ensure the full citizenship of these young people. Realising the concept of citizenship requires practical steps from society to ensure equality of opportunity. Moreover, it proposes the need to move the perception of disability and the suggested solutions away from the traditional individualistic approaches towards those founded in a social model. The proposed change is closely related to a shift in disability research paradigms and methods; in other words, a move from quantifying the numbers of impaired people to qualitative research which seeks to comprehend the perceptions and experiences of disabled young people and their families.

Semi-structured individual interviews were carried out with 26 physically disabled young people. These explored their everyday lives in their families, their experiences in the wider community, the quality of services they are provided with, their relationships with the public and professionals, and their own views of themselves. Four focus groups, composed of eight to twelve mothers in each, were purposefully selected from four administrative regions in Oman. These groups explored the mothers' perceptions of their disabled children's daily lives and the barriers to their inclusion. Twelve professionals working in health, social services and education were interviewed to gain their views.

The disabled young people experienced considerable difficulties in their daily lives. A key finding was that the disabled young people attributed their disabilities to factors related to society rather than to their impairments. They were deeply concerned about the inaccessibility of physical and social environments that restricted their opportunities for education and relationships outside their families. They considered the current social security system as poor and, as most of their families had low incomes, they felt that their personal needs were disregarded. Public attitudes, especially in rural areas, were such that they were viewed with pity rather than as citizens.

The disabled young were very satisfied with their family relationship, especially with their mothers. They also valued the role of their siblings. They thought they should not be regarded either as different to them or their peers, and their needs should be equally met.

The mothers agreed with their children's views, particularly about inadequate service provision, the inaccessibility of houses and local communities and the discriminatory attitudes of society.

In both the statutory and the voluntary sectors, professionals lacked experience, training and understanding of the barriers that prevented disabled youngsters from being fully included as citizens. They perceived disability within the framework of the medical model and lacked information about the social model of disability.

The study concludes with some recommendations for policymakers and professionals. These include more service provision, public education, training for professionals and greater accessibility to community facilities. This might help to ensure a greater inclusion of the disabled young people and enable their participation as full citizens in Omani society.

Dedication

This piece of work is dedicated to my dearly loved mother and father who lie in my heart. Also, to those who I love very much: my beloved wife, children, brothers and sisters; all of them have supported me tirelessly and inspired me.

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First, I must express my enduring gratefulness to almighty Allah (SWT). My thanks should also go to Sultan Qaboos University for providing me with a full scholarship, which enabled me to carry out my work.

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DECLARATION

The material contained in this thesis is the work of the author alone and no part of it has previously been submitted for a degree at any university.

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Introduction

1.1 Introduction

The aim of this study is to examine the lives of young physically disabled people and their families, in Oman, and to identify opportunities and obstacles to their inclusion in their social world. The study uses the accounts of young disabled people themselves and those of their families, exploring their perceptions of service provision, public attitudes to disability and the accessibility of their society and communities. Young disabled people's perspectives and voices are therefore central to this research. Concepts such as equality, citizenship, the social model of disability were drawn on and informed the design of the research and the critique of the adequacy and appropriateness of service provision presented. This study of the experiences and perceptions of disabled young people in Oman, is therefore also informed by the literature on disability issues and the analysis of social policy in the wider international context.

The Omani Basic Statue (1996), in its Social Principles Article 12, declares that one of the main pillars of the society is equality of opportunities:

> *"Justice, equality, and equality of opportunities for Omnis are the pillars of the society and are guaranteed by the state".* (p.7)

The study, therefore, examines whether or not disabled young people are provided with equal opportunities as promised in the above statement. Alcock and colleagues (1998) define equal opportunity policies as polices aimed to give individuals an equal starting point in an unequal society. The role of the state is to provide equal opportunities for all people, with no exclusion of disabled people. According to the UN (1986), the equalisation of opportunities for disabled people means:

> *"The process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social*

> *life, including sports and recreational facilities, are made accessible to all".* (p.6)

If the society recognises disabled young people's rights as citizens in principle, it must consider how and if their rights are realised in practice. Oliver (1996) claimed that the notion of citizenship has become a shorthand device for talking about the relationship between individuals and their societies. However, while politicians, policy makers and professionals have rediscovered the notion of citizenship, disabled people have begun to redefine disability, not as personal tragedy requiring therapy, but as collective oppression requiring political action. Oliver also suggested that the idea of citizenship has been used, not simply to consider the social integration of the majority into society, but also as a standard to evaluate the context and measure the extent to which certain groups are not socially integrated. Sometimes, disabled people may be seen as minorities and lesser citizens. Lister (1991) pointed out that while the world is entering the twenty-first century there is a danger of a growing number of people, including disabled people, being excluded from the full enjoyment of their rights as equal citizens. She went further by saying:

> "*it is time to go on the offensive and restate the case for effective citizenship rights for all, regardless of class, race, gender, age, disability or employment status*".(Lister, 1991, p.2)

The Joseph Rowntree Foundation (1999) pointed out that there are several obstacles that prevent families of disabled young people, in the UK, from having adequate care. Examples of these are poverty, diminished employment opportunities and inadequate service provision including social, educational and health services. In developing countries such as Oman, as we will see in chapter three, disabled young people are likely to be given poorer services than they need. The deficiencies in service provision may prevent them from enjoying full inclusion in their society. Full inclusion in the ordinary life of the community, for disabled young people, is impossible unless they are

recognised as a part of the whole society, their demands are equally respected and the support they need to lead ordinary lives is secured.

Overall, this study will give disabled young people an opportunity to express their views about all these issues including the accessibility and availability of the needed services and the attitudes of society.

The chapter begins with some background information on Oman.

1.2 Background of Oman

1.2.1 The Geography and its Impact on the Development Process

The importance of the geography of any country can be explored in terms of its impact on its population's life. Oman is located in the south-eastern corner of the Arabian Peninsula, with, according to the Ministry of Information (1998), a total area of over 300,000 square kilometres and a 2, 700 kilometres coastline. Oman is divided into four regions. First, there is a long coastline with the historic ports of Muscat, Sohar, Qulhat, Sur, and Salalah. The people here live by trading, fishing and farming. The second is an area in the interior with mountains running from Mosandam, in the northern part of the country, towards the east. A large number of villages have been built there over the centuries, depending on the *Aflag* system of water channels, which was founded around the fourth century BC. Most people live by farming and trading. Third, the southern region consists of about one-third of the country. Its grazing land helps people to have a large number of cattle and camels, and they live by fishing and farming. The fourth is a large area of desert, composed of the Empty Quarter to the west and the *Wahiba* Sands to the south, with a total area of 117 square kilometres.

This geographical variation, the extensive desert areas and a large number of high mountains, have diversified the cultural, social, and economic aspects of the life of society in Oman. This has impacted negatively on the development process. The difficult geographical nature in Oman may have

prevented the acceleration of the development process and increased the costs of service development.

Oman is classified by the World Bank as one of the developing countries (World Bank, 2004). It is classified with countries such as Algeria, Albania, Yemen, Georgia and Latvia. However, unlike Algeria and the Yemen, for example, it is also classified along with Malaysia, Chile, Poland and Mexico as an upper-middle income economy. In other words, although its current state of development is low, its available resources are quite high and it therefore has relatively good potential for development.

1.2.2 The Political and Administrative Organisation

Oman is an independent sultanate under the leadership of His Majesty Sultan Qaboos bin Said Al-Said, who authorizes all laws and decrees. The administrative system of government under the Sultan consists of the Ministry of the *Diwan* of the Royal Court, The Council of Ministers, the Secretariat to the Council of Ministers, the Governor of the Capital (Muscat), the State Advisory Council (*Majlas a-Dawalh*), the Consultative Council (*Majlas Al-Shura*), and specialized councils for development, including financial affairs, education and training, and the civil services. The highest executive authority is the Council of Ministers, which is responsible to the Sultan.

Majlas Al-Shura (The Consultative Council) is composed of one or more representatives from each of the 59 *willayats* (states), who are elected by people of each *willayat*. Women have a right to represent their *willayat*. The role of the council is to discuss government programmes and laws, recommend amendments to laws, suggest measures to deal with socio-economic issues, and offer opinions on any other issues which the Sultan may refer to the Council of Ministers. The council questions ministers in televised public meetings and submits a report to the Sultan after every session. The council experience is relevant to several committees and activities, such as maternal and child involvement in decision-making at the national and regional level. This trend is likely to have increasingly important implications in the future for

community empowerment strategies at the regional, *wilayat*, and local levels, particularly in terms of people taking more responsibility for decisions that affect their lives. The latest National Development Action Plan (2000-2005) asserts the vital role of the community and voluntary work, as a partner sector with the governmental efforts.

The country is divided administratively into eight regions and governorates, which are further subdivided into 59 *wilayats*, each *wilayat* headed by an appointed *wali*. The *walis* fall under the authority of the Ministry of Interior. The *wilayat* system seeks to provide a mechanism through which administrative, legal and executive decisions that are carried out at the national level can be implemented throughout the country. As Oman's social and economic development gives priority to regional issues, the *walis* will continue to play an increasingly important role in national development. Decentralisation is by now established in strategic policies in almost every government ministry, and thus the administrative efficiency of the regional-and *willayat*-level systems will become ever more crucial to the country's ability to maintain and increase the well-being of its people, especially its women and children (Ministry of Development and UNICEF Muscat, 1995).

1.2.3 Social Organisation

Traditionally, Omani society is patriarchal, with men making most decisions and dominating political, economic, and social life. Women play a minor role in public life. However due to the recent development of universal education and social change, Oman is in the midst of significant changes in this respect, and women are beginning to play an increasingly visible and substantial role in public life. There are other socio-demographic trends, such as later age at marriage, lower fertility rates for women, and a rising percentage of working women supporting these changes (Ministry of Development and UNICEF Muscat, 1995).

Traditionally, women play a vital role in family and home life, in both urban and rural areas. Along with assuming virtually total responsibility for running the household and for child-rearing, women are also active in their current micro-economy. Women are no longer restricted to occupations only in farming and keeping livestock; they play a considerable part in the current development activities.

According to the Ministry of Development and UNICEF (1995), the benefits of the strong social and family structure of Oman are partly negated by a general lack of knowledge among families of proper techniques in such areas as water conservation, environmental sanitation, and early childhood stimulation. Subjects such as these are becoming more important, and in some areas are even critical to the quality of life of the next several generations of Omanis who will find themselves in a situation of deep social transition. This is particularly relevant to children's lives in a context of rapid social and economic transformation. The Ministry of Development and UNICEF (1995) reported that the strength and support of the family-based social structure would become increasingly important, as Omanis are challenged to work together and with the government at the local level, to assure their basic needs are met and to achieve further improvements in their quality of life.

1.2.4 Demography of Oman

The total size of the Omani population in 2002 was 1,869,580. More than the half, 57, 7% of them were under 19 years old. Two thirds lived in areas classified as semi-urban, and over half were found in just two of the eight regions, namely Muscat and Al-Batnah, which occupy only around 5% of the total land mass (Ministry of National Economy, 2000). The 1993 census showed that Omani women, on average, marry at an earlier age than men. The mean age at marriage for Omani women is 20.7, compared to 24.7 for Omani men. However, the data indicates that very early marriage is less common

among women of the younger generation and among those with higher educational levels.

The average household size is relatively large, at around 8 members. Rural households are on average somewhat smaller than urban ones, and significant regional variations are found. Categories of household membership vary by gender and marital status. While the vast majority of Omani household heads are male (87.5%), a surprisingly high percentage (12.5%) are female, with gendered variations by region, household size, and age of household age. Striking differences are found in the marital status and activity status of male and female household heads. Female heads are more likely than male heads to be widowed or divorced, but much less likely to be classified as economically active.

The data on the educational status of the adult Omani population reveals that, as a group, Omani women aged fifteen and over are less highly educated than Omani men of the same age. Illiteracy amongst women is greater than men; the proportion of women (35.9%) as men (28.9%) are illiterate, while over three times the proportion of men (2.3%) as women (0.7%) have university-level degrees or above, with significant regional variations in relative proportions. At the same time, however, overall educational levels have been rising over time, with tremendous improvements in the educational status of women. This is particularly evident among women up to the age of 29 who were the first to benefit from the stress put on education in Oman since 1970, when the first social development began under the leadership of His Majesty, Sultan Qaboos. However virtually all Omanis (96.7%) aged fifty years or over are illiterate.

Current school enrolment rates at primary level is relatively high at (86.6%) for children aged 6-11, with a significant number of additional pupils drawn from older age groups. A comparison of enrolments of boys and girls has demonstrated continued progress in reducing the gender gap, with only slight differences in the net enrolment ratios among boys (87.7%) and girls (85.5%). Governmental reports claim that there is significant attention being paid to further increasing enrolments, improving the quality and efficiency of the

educational system, and giving more consideration to disabled students (Ministry of Development and UNICEF, 1995). However, the issue of giving disabled students full inclusion in the education system in Oman is a matter worthy of examination.

The findings of both the Public Census of the population in 1993 and the Comprehensive Survey of Disabled People in 1995 provide figures showing the classification and distribution of disability in Oman. The estimated number of disabled people was 37, 239, which represents (2.3%) of the total population. More than a quarter of them, 9656 (26%) are physically disabled people; deaf people constitute 19%, learning disability is 13%, multiple impairments, including psychosocial and epilepsy, affect 12%. Blind people are the largest group, 14.606 (39%), but according to the Ministry of Social Development, (2000) the majority (93%) of those registered blind are over 40 years old, which is attributed to the absence of health services and environmental problems before 1970. Official documents suggest that a national prevention programme has since been able to deliver the objectives of improving and maintaining health of the society (Krafting, 1999; Ministry of National Economy, 2000).

However, factors like ambiguity in the definition of disability and uncertainty about the qualifications and understanding of the workers, who took part in such surveys, means that the apparent accuracy of the reported figures is questionable. There is also evidence that some families have hidden their child/children with impairment to avoid the social stigma resulting from the negative attitudes of society (AL-Mawali, 1998, Al-Barwani and Al-Beely, 1994). Consequently, the actual number of disabled people is likely to have been underestimated in official statistics.

1.3 Perspectives on Disability

Although the term “disability” has been defined by a great number of authors around the world and by international organisations such as the World Health Organisation (WHO, 1980), there is still a great deal of controversy amongst the users of the definition. This lack of agreement might be due to the models

used in the field of disability and/or to the different views of professionals who work in the relevant agencies such as, the social, health and education services.

The transition, from the dominance of the medical / individual approach to disability, to the emergence of the social approach, has led to the concept of disability being redefined, increasingly, in terms of the disabling impact of social and environmental factors on disabled people. Nevertheless, in chapter four, both the medical and the social approach to impairment and disability will be discussed in more detail. Over time, new experiences and new ideas may lead to new definitions. For example, in the UK as Oliver (1983) said, disabled people can be understood on the basis of a new understanding of disability known as the social model. Thorboun (1992) suggested that functional definitions still locate the causes of disability at the level of the individual, whereas the cause of disability often lies within society, which frequently puts disabled people at a disadvantage. The definition that focuses on the pathological conditions or describes people as objects of charity or pity (for example, 'they need our help') really denies the social nature of that disadvantage. According to Robinson and Stalker (1999), the social approach defines disability as the social restriction placed on disabled people by society. They also added that people are disabled by discrimination and prejudice, not by their bodies.

The social model therefore addresses society's failure to meet disabled people's needs. Robinson and Stalker (1999) interpreted the meaning of the social model thus:

> "*The social model argues that rather than investing time and effort in medical or psychological efforts to correct the impaired body, it is more appropriate to remove the barriers in society which cause problems for people with impairments: these may be inaccessible physical environments, discriminatory employment or welfare policies, segregated education or transport, negative stereotypes or prejudiced attitudes*". (p.14)

The manual on the equalisation of opportunities for disabled people (United Nations, 1986) reported that the problem occurs when disabled people encounter cultural, physical or social barriers which prevent their access to the various systems of society that are available to other citizens. However, in contrast to these changing attitudes in the West, Akhdar, (1994) in her study of childhood disability in Saudi Arabia, concluded that the meaning of disability in the developing countries is associated with such terms as, 'incurably ill' and 'inferior'. Regarding disability from this perspective may mean that disabled people are not included in the everyday life of society. Akhbar did not talk about issues, like social stigma and the environmental barriers in society, which may increase disabled people's exclusion. The term "disability", therefore, should be addressed with the notion that disabled young people should be enabled to interact with other people and that their needs should be met by their society.

1.4 Previous Studies

Chapters two and three present examples of important studies in both developed and developing countries that have contributed to our current knowledge and understanding of the situation of disabled people. However, a comprehensive study, to examine the social problems surrounding disabled people, has never been conducted in Oman. Disabled people' voices, what they have to say about service provision and their individual daily lives, have not been heard. Most research, into disability in Oman, has been based on the medical approach and used quantitative methods only.

Number, gender, types of impairments and geographical distribution, have been explored through the National Census in 1993 and in 2003 (Ministry of National Economy, 2003) and the Disability Survey in 1995 (Ministry of Social Development, 2000). In addition, partial surveys, with a medical focus, have also been conducted in some regions in Oman. Sulaiman and colleagues (1995), in their survey of Oman Family Health, linked the concept of disability and longstanding illness. They say:

> "*A person was considered as having a longstanding illness and disability if he/she was reported to have had any of the following doctor-diagnosed conditions: high blood pressure, heart disease, diabetes, stroke, asthma, joint disease, peptic disease, renal disease, liver disease, nervous disease cancer, or any longstanding condition which prevents or limits his/her participation in activities normal for a person of his/her age*". (p.12)

This definition is based on the medical model of disability that attributes all the responsibility on the individual's body limitations. This model, as the discussion in chapter three reveals, is dominant in the developing countries. There were other studies that were conducted in Oman, such as the Oman Child Health survey between 1988-1989 (UNICEF, 1989), Disabled Children in Fanja (College of Medicine and UNICEF, 1990) and the Ibri Survey of Disabled People in 1994 (Department of Social Affairs in Ibri, 1994). There was only one qualitative study, which was conducted by Al-Barwani and Al-Beely (1994), who examined the education and care of disabled people in Oman. However, this study did not interview any of the disabled people themselves; it sought only professionals' views about service provision such as health, social and educational services. In Chapter three, Al-Barwani and Al-Beely's (1994) study will be discussed in more detail, along with more studies conducted in Oman and other developing countries.

1.5 Incidence of Impairment in Oman

Krafting (1999), in her report about childhood disability services in Oman, estimated that in Oman there were more than 23,250 disabled young people under 19 years old and the number is increasing by 1,500 to 3,700 each year. The availability of good health services has resulted in the survival of some babies with impairments, who in the past would have died. Krafting's estimates were supported by a report of the Health Services of South Al-Batnah Region (2000). This showed that, as a result of the improvements in health services,

the infant mortality rate per 1000 Live Births decreased from 10.4% in 1992 to 5.7% in 2000. However, this figure was less than the World Bank estimations.

Duckworth and Winyyard's report (1996), to the Ministry of Social Affairs, concluded that the number of disabled people in Oman increases with age, as a result of increased exposure to accidents and illness. The (2000) Annual reports of both Ministry of Health and Oman Royal Police, show that a significant number of youths have been severely injured as a result of traffic accidents. Most of them become permanently impaired.

Although the definition of impairment is not clearly stated, most studies and official reports in Oman record that the incidence of impairment is increasing. The Disability Survey (1995) showed that among young disabled people, physical disabled has the highest incidence. There are a variety of factors behind the incidence of impairment of physical, mental or sensory functioning. They include illnesses, accidents, and a significant number of infants born with low weight. Figures also show that consanguinity is common in Omani society. However, the national immunisation programme is significantly reducing the incidence of impairment caused by diseases such as polio. According to Al-Barwani and Al-Beely (1994) and UNECEF (1989), the success of immunisation programmes, improvements in the care of families and preventative intervention in childhood, have clearly improved the health conditions of the community. However, Duckworth and Winyyard (1996) suggest that surveys underestimate the true numbers of disabled people. This may be because some people are not registered, because of their own embarrassment or fear of substandard services, should they identify themselves as being disabled.

1.6 Examples of the Societal Attitudes to Disabled People in Oman

Al-Barwani and Al-Beely (1994) in their study suggest that disabled young people were hidden away from the public eye and that they were treated as objects of pity. Al-Riyami, as a former director of the Association of Disabled Children in Muscat, reported that families of disabled young people seek help

from the government only when the care of their child becomes a burden that they can no longer cope with, as a result of deteriorating health conditions.

On the occasion of the International Day of Disabled People (1999) in Oman, a young physically disabled man highlighted, in his speech, all the activities and efforts of the Omani Association of the Disabled in their efforts to secure an accessible environment and to improve public attitudes towards disabled people. He added, "*We have been struggling to present ourselves as not different and moreover as capable participants in mainstream society; but we need a chance*". In the last ten years, the voluntary associations of disabled people, in Oman, started to voice their requirements and to raise issues of concern to them, in order to increase public awareness of their needs and situation. Significantly, they have used international and national occasions and high-profile events, in order to ensure that their voices are heard. This may result in educating the general public about their rights as equal citizens.

In his speech in the International Labour Conference, Al-Hosni (2001) as the Minster of Social Development in Oman, talked about the need for adequate service provision and the recognition of children's rights. However, it was not clear whether he was including disabled young people.

There is evidence that one of the obstacles that may prevent disabled young people and their families, having full inclusion in their own society is the negative attitude of non-disabled people. According to Al-Mawali, (1998), in the Omani society, it is not uncommon for people to stare at a young child in his/her wheelchair. Overall, most studies in this area show that family and public attitudes may exacerbate disabled people's exclusion from their own society. However, an examination of disabled young people's own views about the issue of full-inclusion is vital to a full understanding of their situation.

1.7 Service Provision

Contemporary values and modern thinking suggest that every individual should have the support he or she needs, not just to survive, but to be included as a citizen in a fair and just society (UN, 1986). The sentiments of legislation and

policy statements, like the Disability Discrimination Act, the Valuing People White Paper and the Human Rights Act in the United Kingdom, are echoed elsewhere. The Omani Basic Statute (1996), in its Social Principles Article 12 (discussed above), stressed equality for a disabled person; this implies the right to be provided with services he/she needs. However, the literature, to be discussed in chapters two and three, revealed that disabled people experience difficulties in obtaining adequate service provision. As mentioned earlier, there are obstacles that prevent them from enjoying the equality of opportunities that non-disabled people have at their disposal. The literature identifies the obstacles presented by inaccessible buildings and transport systems, social and cultural beliefs and low family income (Zarb, 1999; Glesson, 1999; Connors and Stalker, 2003; Fazil *et al.* 2002).

An unpublished study, conducted by the Economic and Social Committee in the Omani Consultative Council (Majlas Al-Shura, 1997), claimed that a number of obstacles prevent full integration for disabled young people in ordinary schools. These obstacles include lack of training for teachers and a shortage of other professionals, such as social workers, the inaccessibility of school buildings and transport. Majlas Al-Shura's study will be presented in detail in chapter three.

Morris (1997) listed the main needs of disabled people and her list included the need to be heard and to be valued. Disabled people in the UK have the right to ask for a comprehensive assessment of their needs, (under the 1986 Disabled Persons Act and the NHS and Community Care Act 1990). The role of health services is to provide care for disabled young people, which involves input from general and specialist medical, nursing, and other professions allied to health services and may include the supply of specialist medical equipment. Social care for disabled young people could involve the provision of a range of resources including transport, education, housing modification, help with personal and domestic care, financial support and respite care.

Barton (1999) suggested that service provision for young physically disabled people should not be regarded as charity and should not be allocated

as extraordinary services. Their services must be provided systematically within ordinary service provision, and mainstream social organisations and facilities should be adapted to be fully accessible to disabled young people. Inclusive policy and practice needs to be part of a whole national policy. Eiser (1993) expressed the view that disabled young people in the UK should be cared for at home by their families, wherever possible, and institutional care should be provided only when it is impossible to provide appropriate care in a community setting.

These examples revealed the most important services that are needed by disabled people. Society should meet their support and service needs in order to improve their everyday lives. My research explores whether or not disabled young people encounter difficulties in having their daily needs met.

1.8 Access to the Services

In developing countries, there is evidence that the majority of disabled people have inadequate access to the services they need, including social, health and education services (Thomas, 2000). In 1980, a report of International Children's Centre estimated that 98% of disabled people, in developing countries, have no access to any services in their lifetime. The report added that most disabled people lived in villages where no daily services are available. Although, that report was published twenty years ago, the situation of disabled people, including disabled young people in Oman, is still not much better. Krafting (1999), in her report about service provision for disabled young people in Oman, reported that, using a generous approximation, the relevant services and programmes covered only about 5% of disabled young people. She added that the number of disabled young people is increasing and the majority of them live far from the Capital and the main cities, where the required services are concentrated.

A review of reports about health, social and education services (Krafting, 1999, Majlas Al-Shura, 1997) showed only a modest increasing in service provision for disabled people, with the addition of some physiotherapy

departments in regional hospitals and several day care centres run by the voluntary sector.

These reports show that disabled young people in Oman possibly not only face inaccessible services, but many of them may not be able to get any services they need. Krafting (1999) suggested that, while a number of new initiatives to meet the needs of disabled young people and their families have taken place in the past five years, there are neither comprehensive policy documents nor accepted strategies in place. Krafting's (1999) report will be presented in detail in the third chapter. Chapter three will also include other studies conducted in Oman and other developing countries, in the field of disability.

1.9 The National Workforce

There is a crucial need for skilled and well-trained professionals and ancillary workers, to work with disabled people in the developing countries. Continuing training programmes for workers, such as social workers, community workers, medical workers and teachers are necessary. The annual statistics of the Social Services Department (2000) showed that fewer than 5% of the workers in the Special Care Sections and the Centre of Care and Rehabilitation for Disabled People, are well-qualified and trained. Those who are un-paid volunteers are not well trained and experienced either. Schools are provided with just one social worker, in each school, to serve hundreds of students. In chapter three, I will offer more information on the issue of the shortage of skilled practitioners in the health and social care fields. These figures indicate that there are only a small number of experienced and qualified workers in the disability field.

1.10 Legislation

Legislation can play a significant role in ensuring adequate service provision for disabled people. In Oman, as will be discussed in chapter three, there is no national legislation that organises service provision or considers the rights of

young disabled people. However, it would be useful to highlight some aspects of national government policies, relevant to disabled people, around the world. Hurst (1999) gave an example of disability discrimination laws in the United States, Australia and Canada. A significant comment, was cited in Hurst's introduction, by an American legal activist called Timothy Cook. Cook talked about how early attitudes to disabled people were reflected in state laws across the USA. He said:

> *"Individuals with disabilities were deemed unfit for citizenship under Mississippi Law; children with disabilities were deemed unfit for companionship with other children under Washington Law; individuals with severe impairments were considered to be anti-social beings as well as a defect which wounds our citizenry a thousand times more than any plague. They were denied the right to serve on juries, to hold public office, to marry, to work in certain occupations, to attend public school or even to be seen in the street". (Hurst, 1999, P. 89/90)*

Cook's comments illustrate that there has been segregation, hostile public attitudes and negative policies towards disabled people in the societies of the western world. However, writing from the perspective of UK legislation, Oliver (1999) asserted that legislation is only the starting point, and, in many respects, it is the process of implementation that is the most important. At the practical level, for legislation to achieve its objective, the recognition of disabled people's rights to be included by the society is requires.

1.11 Poverty and Disability

Poverty could be seen as one of the main difficulties that disabled people and their families experience. In her survey of over 1000 parents looking after a severely impaired child in the UK, Beresford (1994) explored the needs and circumstances of these families, comparing them with similar research from the 1970s General Household Survey. Her study showed the difficult circumstances in which families were struggling to live ordinary lives. In addition to housing, health, social, and other disadvantages, the families experience financial problems. Most parents reported insufficient financial resources to care for their

disabled children adequately (Dobson and Middleton, 1998; Beresford, 1994). Beresford asserted that the average annual cost for raising a severely impaired child was likely to be £7,355, at least twice as much as the amount required to bring up a non-disabled child. This would mean, as Beresford suggested, an increase in benefits of by 20-50 per cent, if the additional costs of disability were to be adequately reflected through the social security system, depending on the child's age and impairment. Having a low income, for a family with a disabled child, is a source of anxiety for parents and it also hinders them in gaining access to local work. According to Dowling and Dolan (2001) (their study of the quality of family life, will be presented in detail in the second chapter), mothers with disabled young people are much less likely to be in employment than their peers. Parents of a disabled child, therefore, need to be financially supported.

A summary of the findings of the research in the UK, funded by the Joseph Rowntree Foundation JRF (1999), showed that parents of disabled young people face three times the costs for parents rearing a non-disabled. The problem is greater when families of disabled people do not receive even the minimum standard of financial support. Hurst (1999) argued that the prime motivation for most disabled people in the developing world 'is to eat and stay alive'; and throughout the world, they are effectively segregated and humiliated.

In Oman, some disabled people benefit from the Social Security Act (SSA) of 1984. However, it is possible that such a benefit does not meet even their basic everyday personal needs. The total amount of the monthly benefit is only 30 Rials per person, which equals £50. Relative to the ordinary cost of living, this financial support is insufficient to meet the daily needs for a disabled person. The situation is even worse if that person has a complex impairment. Moreover, as will be discussed in chapter three, the social security system does not cover disabled people who are under eighteen. Their families have to be responsible for them. However, in Oman, and possibly in the developing countries, there is an alternative belief that the responsibility of taking care of and supporting disabled young people and needy people, should not only be taken over by the government but that the community should contribute.

Poverty may make families with a disabled child struggle just to survive in their daily lives. Article 27 of the UN Convention on the Rights of the Child talks about *"the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social well being".* The reality might be, however, that disabled young people are offered a standard of living below that necessary to satisfy this right.

1.12 Housing Problems

The housing situation, of a family or disabled person, is significant. It can be linked with issues like well-being, privacy and inclusion. Inadequate and inaccessible housing may increase disabled young people's exclusion and may make them feel different, simply because they cannot move freely in an inaccessible house. Beresford's (1994) study found that, for over four out of ten families with disabled child/children, their housing was unsuitable for caring for a disabled child. Beresford described how three out of four families reported one or more ways in which their housing was unsuitable, which led to the need for extra care and support services for their disabled children. They gave evidence that the unsuitability of a house may restrict a physically or visually impaired child's movement inside their home. It may also prevent them from enjoying normal childhood experiences and from taking part in their siblings' activities. They may even need help to enter the bathroom and kitchen, if their house is inaccessible.

A survey of Omani family health (Sulaiman and colleagues 1995), showed an average of around 1.9 persons per room and around 3.5 persons per bedroom. It also showed that urban households appear to be less crowded than rural households. While the average number of persons per bedroom is 3.3 in urban areas, it is 3.9 in rural areas. This survey showed that most people live in houses in poor condition. Yet, it did not adequately explain the housing situation; and it did not address the issue of the suitability of houses for physically disabled people's mobility. However, the Omani Association of the Disabled (Challenge, 2003) reported that a significant number of disabled

young people, who live in the interior areas, live in houses with poor facilities and in poor condition. Most of these houses were inaccessible and unsuitable for them, which resulted in their having no chance to move or to take part in various activities.

1.13 Community Based Care

In the last century, particularly in the west, there was a widespread practice of developing institutions for disabled people that separated them from the mainstream society (Krafting 1993; Thomas, 2000, Oswin, 1999). It was thought that this approach was the best for them. However, it led to many disabled people being segregated from their own society (Ieff, 1997). They had to be in special schools and special training programmes. However, nowadays, most societies recognise that the institutionally based care approach is insufficient to serve the needs of disabled people. Krafting (1993) suggested that though Oman has few services for disabled young people, it seems that it is trying to avoid making the mistakes of the developed nations, by avoiding establishing institutional services as the normal pattern of provision. Such services have been found to be expensive to develop and deliver, to serve only a small number of disabled people who live in large urban areas, and increase the dependency rather than the independence of disabled people.

In the 1990s social and health services, in Oman, attempted to adopt the community-based rehabilitation programme which is called CBR. The World Health Organisation (WHO) launched the notion of CBR in 1976. According to Hartley (2002), the fundamental principle of CBR is to provide primary care and rehabilitation assistance for disabled people, by using the human and other resources already available in their communities. They added that the CBR programme offers services for disabled people within their local community, in order that their quality of life may be improved. According to Vanneste (2000), the aim of CBR programmes is to improve, facilitate, stimulate and provide services for disabled people and their families and caretakers, within their own localities. The provision of CBR could be through local, full-time or part-time,

paid or volunteer, community rehabilitation workers, but, they should be well-trained.

However, it seems that the notion of CBR in Oman was not widely adopted because, when I carried out my research, I did not see any sign of its implementation at ground level. The president of the Omani Association of the Disabled suggests that the CBR programme is significant, but it requires a financial allocation by the government. His comment shows that the programme has not been officially implemented yet. Akhdar (1994), in her study of childhood disability in Saudi Arabia, said that the CBR programme provides support in the form of medical care, rehabilitation, help with daily living, as well as financial, social and emotional support. Yet, she did not mention whether or not the CBR programme had been implemented in Saudi Arabia. Thomas (2000) showed that volunteer organisations in India are interested in using the CBR strategy, especially in the rural areas. It enables them to serve a great number of disabled people and their families. The CBR programme aims to reach disabled people, and their families, in their own local community. Its objective is to enable them to be involved in activities with non-disabled people, by using the existing resources in their social environment.

Taken overall, this chapter has indicated that there are only a few studies in developing countries, including Oman, which have investigated disabled people's and their families' viewpoints and identified the problems and negative factors that impinge on their ordinary lives. Therefore, it is very important that disabled people and their families are given the chance to introduce and raise the issues they identify as important, and to describe their own daily needs and difficulties. There is evidence that disabled people know better than anybody else about what they experience and what they need. It is also their right to be listened to and to be offered equal opportunities. Mitchell and Sloper (2001), in the introduction to their study of quality in services for disabled young people and their families, suggested that there was a belief that children are perceived as having little 'wisdom' because they do not have enough experience. This view has significant consequences, with respect to the extent to which children's voices are devalued, when examining service users'

perceptions of 'quality'. However, Franklin (1995) argued that children have competence for rational thought and they are able to make informed choices.

It is also true that in the developing countries, including Oman, only few studies have examined the perceptions of parents and workers or professionals who work with disabled young people. Moreover, very little work has been done in developing countries based on the social approach to disability. In Oman specifically, as discussed above and further in chapter three, all previous studies were based on the medical approach. A comparison between the medical model and the social model will be discussed in detail in chapter four.

It is worth mentioning, here, that my interest in conducting this study has come also from my personal experience, as the father of a 17-year old daughter with Spina Bifida, as a worker in the Social Services from 1980 to 1999, and my recent appointment as a lecturer in the Sociology and Social Work Studies Department in the Sultan Qaboos University. All these factors pushed me to conduct this study which, as I said earlier, aimed to examine the experiences of disabled young people and their families of their social world. However, my motivation, and the study design, will be explained in greater detail in chapter five (methodology chapter).

1.14 The Organisation of the Thesis

The thesis consists of eleven chapters, including the introduction:

The first Chapter: The Introduction:

Chapter one introduces the thesis, and outlines how it examines the experiences of young physically disabled people and their families, with respect to their everyday lives, service provision and social and local environment accessibility. Here the argument is first made that a full exploration of these issues must seek and give full consideration to the voices of disabled young people themselves.

This chapter also gives an outline of the chapters which follow.

The second chapter: Disabled Children in the Developed Countries:

This chapter reviews the studies conducted in some developed countries, so as to examine the experiences of disabled young people and their families' daily lives in different societies.

The third chapter: Disabled Children in the Developing Countries, Especially in Oman:

Chapter three includes an analysis of the implications of the Omani national development processes and their impact on disabled young people and their families' lives. This chapter then presents studies that have examined the situation and issues facing disabled people, especially disabled young people and their families. The literature is discussed, with particular reference to what the studies reveal about the inclusion of disabled young people in the life of their society and the service provision they need. This chapter includes a discussion about research carried out in other developing countries and its relevance to the main focus of my own study.

The fourth: chapter: Disability, Children Rights and Citizenship:

Chapter four presents the theoretical grounds for the study. This chapter explains and discusses the implications of the social model of disability, for the way in which the individual's experience of 'disability' is understood. In the social model, 'disability' is defined in terms of the 'disabling' impact of social and environmental barriers on the lives of disabled people. The concept of citizenship is also addressed in this chapter. The implications of the concept of citizenship are relevant to and provide a context in which to consider the experiences of the subjects of my own study.

The fifth chapter: Methodology:

This chapter presents the research methods employed in this study. The procedures of the research, including the difficulties I experienced in obtaining

access to the participants, the credibility and confidentiality of the research will also be explained. The approach to qualitative data analysis will be described. The methodology chapter details how three categories of respondents took part and elaborates on why alternative approaches to data collection were used with each group. In-depth-interviews were employed to examine the perceptions of disabled young people. Focus groups were used to examine mothers' perspectives. Semi-structured interviews were used to investigate professionals' views.

The sixth chapter: Disabled Young People in their Families:

This chapter presents disabled young people's views about their relationship with their parents, siblings and extended families. They also give their opinions about the accessibility of their houses.

The seventh chapter: Disabled Young People in the Wider Community:

In this chapter, disabled young people raise various important issues about their experiences of the wider community. For example, they talk about service provision, public attitudes and accessibility.

The eighth chapter: Disabled Young People in their Schools:

Disabled young people talk about their experiences of educational services, accessibility of buildings and school transportation, and their relationship with school staff and with their peers.

The ninth chapter: Disabled Young People's View of themselves:

This chapter explores the feelings, views, interests and visions of disabled young people.

The tenth chapter: Mothers' Perceptions:

This chapter introduces the issues that were raised by the mothers of disabled children, including their accounts of the everyday social lives and service provision of their children.

The eleventh chapter: Professionals' Perceptions:

This chapter reports the perceptions of concerned professionals about the issues affecting disabled young people, including service provision and attitudes towards them.

The twelfth chapter: Conclusion, Towards More Inclusion for Disabled Young People:

This chapter concludes the study by drawing together the research questions, previous work discussed in the literature review and the theories tested in practice in this study, namely, the social model of disability and the concept of citizenship. It highlights the main contribution of the study.

Disabled Young People and their Families in Developed Countries

2.1 Introduction

The purpose of this chapter is to examine the literature on disabled young people in the developed countries, specifically the UK. In the last chapter, I examined some examples with references to Australia, Canada and the USA. . Childhood studies, particularly in the developed countries, reveal a growing interest in disabled young people's experiences of their everyday lives. The literature has started to address that concern from the perspective of the social model of disability. This model is explained in chapter four.

Today, there is evidence of a mounting concern, internationally, to secure disabled children's rights to a decent life, in conditions which ensure their dignity, promote their independence and facilitate their active participation in the community (Article 23: United Nation's Convention of the Rights of the Child). According to some commentators, however, the large sums of money invested in services for disabled young people and the recruitment and training of professionals, have not resulted in the achievement of those rights. McConkey and O'Toole (1995) explained that a large number of institutions, including special schools and sheltered workshops, have not created full and fulfilling lives for disabled people. This realisation has compelled developed countries to think about a new approach (community care), to fulfil these aspirations. The community care approach, simply, aims to re-accommodate disabled people and elderly people within ordinary society. McConkey and O'Toole suggested that this new thinking has created a whole new role for services, to disabled people and professionals engaged with them. The professionals' role is now to develop disabled people's abilities including cognitive, physical, social and emotional abilities, and to create opportunities for disabled people, that is to 'open doors' for them.

The perceptions of disabled young people were previously largely ignored by researchers, who relied on parents', adult siblings' and

professionals' views (Baldwin and Carlisle, 1994; Beresford, 1997). As will be demonstrated later, children, including disabled children, are able to express their opinions on important matters, if they are given a proper chance to take part in discussions. Service provision, relationships with professionals, their families and public attitudes towards them, are issues that have been examined more recently by researchers both in developed and developing countries. However, particular techniques, requiring the skills and sensitivity of appropriately trained and qualified researchers, are required to explore the perceptions of disabled young people.

2.2 Disabled Children's Lives

Connors and Stalker (2003), in their introduction to their Scottish study (discussed below), claimed that a very limited number of studies have examined a wider view of children's lives and aspirations, investigated to what extent and in what ways they could manage disability, or explored what helps them and obstructs them in that process. Even amongst those studies that have discussed children's psychological experience of their impairment, not many have adopted a 'social model' perspective, exploring disabled young people's views on the barriers facing them in everyday life. Again, the opinions of disabled children's families, including those of mothers, fathers, brothers and sisters about the effects on them of having a disabled member, have not been widely examined.

In Scotland, Connors and Stalker (2003) conducted a qualitative study to examine the views and experiences of disabled children and their siblings. The aims of the study were: to explore disabled children's understanding of impairment and disability; to examine their perceptions of their relationships with professionals and their knowledge and views of service provision; to explore these children's aspirations for the future and their views on the type of support that might help them; to examine siblings' perceptions of the effects on their lives of having a disabled brother or sister; and to identify and draw out

the implications for social work and health services. The examination of disabled young people's own perceptions is a major contribution of their study.

Connors and Stalker recruited 26 disabled children, 24 siblings and 38 parents for their study. The children used a wide range of communication methods, and data collection techniques were adapted where necessary. The children took part in guided conversations, on a one-to-one basis, on between one to three occasions. Brothers and sisters were interviewed once, as were their parents. The sample of disabled young people comprised 15 boys and 11 girls, aged from seven to fifteen, living in both urban and rural areas across southern Scotland. The children had a variety of impairments. Twelve were being educated at special schools, nine in mainstream schools and five in integrated units.

The disabled young people reported that they were happy, had friends and felt that they had, for the most part, enough say about what happened in their lives. Most children were close to their parents and siblings; there was a degree of conflict between disabled young people and their siblings-as there would be among most siblings. Some parents encouraged independence in their disabled children. Many disabled young people had ordinary contact with their extended family. Most children experienced good relationships in their schools and were positive about their teachers. Some of them enjoyed being at school more than being at home, because there was more to do. Children in special schools, or schools which were not in their neighbourhood, experienced less contact with friends or had fewer friends out of school, than those attending local schools. The attitudes of parents had a significant role to play in children's friendships.

However, some children reported that they had been bullied in school, at home or in their local community. Some of them made an effort to address this and once dealt with, bullying did not re-occur. Disabled young people had different interests; many of the boys named football as their main interest. Opportunities for developing this interest in football were mainly inside their school, especially for those boys who had a physical impairment.

The results of Connors and Stalker's Scottish study suggested that if disabled children are offered adequate services to meet their needs, an accessible local environment, and if their families and extended families have positive attitudes and are aware of their needs, they are very likely to be satisfied.

Connors and Stalker (2003) provided significant information about the extent of user-satisfaction with service provision, from the point of view of disabled children and their families. Their findings are summarised as follows:

1. Disabled children and their parents identified similar services and professionals in their accounts.
2. Disabled children were mostly positive about the professionals they encountered; they were however, vague about the differences between some of them, for example General Practitioners and consultants.
3. Parents were more qualified in their opinions about professionals. They were very positive about the support they received from voluntary organisations, less positive about some health professionals; they felt they had to battle with some education professionals and most of them had no contact with social work professionals.
4. Half of disabled children had short breaks away from their families. These took a variety of forms, including time with an extended family and stays in hospital. However, parents and disabled children were rarely satisfied with the short breaks offered to them, believing them to be too infrequent, irregular and not suited to the children's needs.
5. Most disabled children were positive about their future.

The experiences and understanding of disability that were similar in the accounts of disabled young people, their siblings and parents were summarised as follows:

1. Disabled children and their siblings had similar experiences of disability. They experienced it in terms of impairment, difference, people's reactions and physical barriers.
2. Neither group had a "tragic" view of impairment.

3. Impairment was usually seen in terms of a medical condition.
4. Some parents had already thought about an 'ideal' scenario for their disabled child's future.
5. A small number of parents had a very bleak view of the future, seeing themselves as caring for their disabled children for life.
6. Siblings did not, for the most part, see their future as tied up in helping their disabled sibling.

These findings challenge the assumption that disabled young people have negative images about their everyday lives. Most disabled young people were optimistic and hopeful. Their families valued their inclusion and independence. The findings of Connors and Stalker's study raised issues that were relevant to the application of the 'social model' of disability These include, the ordinariness of children's lives, their perceptions of impairment, their understanding of difference, the communication within families, disabled young people's friendships, and the lack of effectiveness of some services for families.

In another recent study, Mitchell and Sloper (2001) examined the quality of services provided for disabled young people and their families. They explored the concept of 'quality' in these services. Their analysis was based on a review of theoretical models, considered in relation to key policy guidelines and empirical data, drawing upon parents and disabled young people's experiences of services.

They identified five key themes interwoven within the concept of 'quality services':

1. Staff, particularly staff attitudes, knowledge and training; Information which is accessible, relevant and up-to-date;
2. Flexibly designed services, especially in terms of meeting each individual child's and their family's needs;
3. Relationships underpinned by respect and dignity;
4. Personal and familial development, whether social, emotional or material;
5. Promoting community links and working towards greater community inclusion.

Mitchell and Sloper discussed the ideas and experiences shared in seven focus groups, which included children and young people, parents and carers, and practitioners and managers. In the focus groups, parents and their children were asked to think of any services they had received which were really good and what made them good, and any services that they did not find helpful and what made them unhelpful.

The focus groups of children and young people in Mitchell and Sloper's research regarded the attitude and approach of staff as a key criterion of quality. They highlighted how staff perceived and treated them. They suggested that staff making them feel welcome and part of the service was important. It was stressed that quality services should not only listen to children and their families, but also act upon their ideas and experiences. However, in reality, parents, especially mothers, complained that professionals adopted a patronising manner, in which they felt dismissed as overanxious mothers rather than respected or valued.

All the groups valued services that facilitated and encouraged choice. Opportunities for personal self-development were enjoyed. However, they were unlikely to be perceived as such by children and young people. For instance, many viewed helping in clubs, tuckshops or kitchen as fun rather than as a means to develop social and particular skills for independence.

Participation in sport and social activities was enjoyed by many children. However, they said that it was more enjoyable and worthwhile to go to out into the community and join in popular leisure activities, such as 'playing out' or 'eating out' Nevertheless, it is important to recognise that participation in leisure activities does not necessarily always mean community inclusion, especially accommodation and acceptance within non-disabled society.

Managers and practitioners, who took part in Mitchell and Sloper's study, asserted that service providers should, as far as possible, seek to meet each child's individual needs, whilst recognising and respecting the holistic needs of the wider family.

In the conclusion of their study, Mitchell and Sloper highlighted four significant characteristics of quality service provisions. First, well trained staff who listen to and, as far as possible, act upon each family's ideas and wishes. Second, use of understandable and accessible language. Third, flexibility to meet each family's needs, especially flexibility about 'how' and 'when' a service is provided. Finally, multi-agency collaboration was crucial. Mitchell and Sloper also stressed the importance of listening to disabled children's ideas and feelings. This is an imperative, as they not only experience services differently, but also have different expectations of, and priorities for, 'quality' services, compared with those of parents and carers.

Barnes and his colleagues (1999) also explored disabled young people's experiences, and perceptions of impairment, of services and their social relationships with family, peers and professionals. They wanted to establish if there were similarities and differences in experiences between urban and rural locations or among different ethnic groups; to compare families in which one or both parents is disabled, and families where neither parent is disabled; to contrast the experiences of disabled young people who attend segregated schools and to compare them with those who attend mainstream schools and those of children who live with their families and those who live in residential institutions.

To have an overview of the lives of disabled young people in different settings, Barnes and his colleagues, first used participant observation in a number of different segregated and inclusive schools, voluntary agencies and leisure schemes. In the second phase, the researchers used serial semi-structured qualitative interviews, combined with other verbal and nonverbal techniques, such as written accounts and diaries kept by the children themselves. Four main themes were highlighted in their study. These are: adult surveillance; the creation of a disability category; peer relationships; and identity.

First, the study has shown a high level of "surveillance" of disabled young people by adults. Disabled young people, most of the time, were engaged in the company of adults and in social activities where adults were actively

present. In addition to professionals, including teachers and others, disabled young people came into contact with other adults, such as the drivers of taxis and other transport, therapists and volunteers, which meant that almost their entire day was in the presence of adults. Many of the disabled young people had few contacts outside the family, and these often comprised contacts with specific adults, such as volunteers, respite carers or professionals with an interest in disabled young people, rather than other young people. There was a high adult ratio in both segregated and inclusive schools. Disabled young people in schools were under closer surveillance than non-disabled children. The clearest issue in children's accounts of school concerned their relationships with specific adult support staff. For instance, many of the disabled young people in mainstream schools had regular help from Special Needs Assistants (SNAs). This support had the effect of increasing surveillance and control, and some disabled young people felt that it excluded them from their peer group. The presence of SNAs in a mainstream classroom created resentment against disabled young people, by non-disabled children, and meant that teachers could ignore the disabled young people. For many disabled young people, the schools environment was adult oriented. There was little or no privacy for the children to talk and teachers commonly talked about the children as if disabled young people were not there. Teachers openly discussed the children's medical conditions or what they understood about their home life, in front of other children. However, not all adults treated disabled young people in the same way, and each setting contained some contrasting practices within this overall picture.

Secondly, Barnes and his colleagues found that social settings and adult behaviour have contributed to the creation of disability as a distinct category. This was examined through the way in which adults discussed disabled young people, the way in which social activity was organised, and the way in which other differences were minimised. The study showed that adults labelled disabled young people as distinct from other children. They were seen as different because it was thought that they did not understand things in the way other children could, and were dependent on adults. This account revealed

practices and policies that were used to justify any institutionalisation of difference and the establishment of language that could be used by adults within schools and other settings. These processes operated within both segregated and mainstream schools. For example, disabled young people were exempt from many normal requirements within mainstream settings, such as punctuality and from completing work assignments. Non-disabled children were very aware of this privilege, and it tended to cause resentment. Another aspect of these practices was that disabled young people were constantly reminded that they were essentially different from their non-disabled peers, but were compelled to adopt the behaviour, the ways of speaking, the ways of walking which most closely approximated that of non-disabled children.

Disabled young people often did not attend their local school, either because they went to segregated schools some distance from their homes, or because the only accessible mainstream school also involved transportation. This meant that most disabled young people had few friends at home, and these tended to be confined to family members. Some disabled young people complained that it was difficult to maintain friendships with non-disabled children, when they were unable to access areas like some fast-food outlets and other child-centred spaces. They did not feel that they could ask their friends to push their wheelchairs around all the time. Often non-disabled children were unwilling to associate with disabled young people, or would only do so in certain contexts. Sometimes, this was associated with gender differences: disabled girls reported that non-disabled girls were less likely to be discriminatory than non-disabled boys. Sometimes, peer relationships with non-disabled children were dominated by assumption of need and care; the non-disabled children behaved not as equals, but as guides or helpers. All disabled children reported that they were aware of physical, emotional and verbal bullying; for instance, being called names as 'spastic', being excluded from peer groups, or being kicked and hit, and the researchers observed all these processes. Even those who had not actually experienced bullying personally, were aware of the possibility, and it therefore shaped their sense of self and their social relationships.

Barnes and his colleagues found that disabled young people who were well integrated with their peer groups, had many friends and experienced positive social relationships, yet this was not an option open to many disabled children. Connors and Stalker (2003) found that those children who are in special schools experienced less contact with friends or had fewer friends than those in local schools. These different studies provided evidence that segregated settings prevent disabled young people from having free social communication.

Children identified with disability in different ways. Sometimes, they saw themselves as the same as others with their impairment. Sometimes, they saw disability as something which marked their difference from non-disabled children. Barnes and his colleagues received a variety of answers about what 'disability' meant to disabled young people, including how they encountered disabling barriers in the social world, mainly access and attitudes. For non-disabled children, being 'disabled' meant having a visible physical, sensory or cognitive impairment. However, the researchers commented that this definition of disability meant that some children with a hidden impairment could exclude themselves from the category.

Identity and notions of difference were not attributed to impairment, structure or culture, but resulted from the interaction of these and other factors as disabled young people negotiated their life-world. The data from these studies challenged a common concept of 'the disabled child'. The diversity of the disabled young people's definitions and descriptions of disability, gave a different notion of 'a disabled child'. Barnes and his colleagues claimed that previous writings, on disabled childhood, have tended to homogenise these different lives, creating a singular disabled child. This tendency was recognised by the disabled young people who took part in Barnes and his colleague's (1999) study and also those who took part in Hussain and his colleagues' (2002) study.

Hussain and his colleagues (2002) explored the views of South Asian young disabled people about their everyday lives and experiences in the UK. The main purposes of their study were: to explore ideas about impairment and

disability among young South Asian disabled people; what they and their families thought of the formal and informal support that they received; how factors like gender, age, and friendships affect the experience of impairment. Young disabled people, in addition to their families, were asked to express their own views. Twenty nine young disabled people took part in this study.

With regard to the opinions of young disabled people on identity (religion-culture-and ethnicity), Hussain and his colleagues (2002) reported just a slight effect of impairment on their religious and cultural knowledge. It did not seem as important as the value placed on these things by the rest of their families. On the whole, if parents stressed the importance of religion, so did the young disabled people and their brothers and sisters. In general, it was reported that impairment is only one aspect of young disabled person's identity. Other social factors, including culture and religion, influenced their experiences of disability and impairments. Young disabled people who took part in this study felt that their parents were more protective of their daughters than their sons and worried about their daughter's reputation.

Hussain and his colleagues reported that disability and impairment were interpreted within the family in negative terms. There was often tension within families as a result of having a disabled person. However, this did not stop young disabled people from valuing the good relationships that they shared with their families. The disabled young people were more worried than their siblings about having difficulty finding a marriage partner. Disabled young people experienced discrimination that stopped them doing what they wanted to do. Negative views of disability affected how disabled young people saw themselves. They also experienced racism at work and in the outside world generally. Some of them felt discriminated against, even at home because of disability. Most young disabled people felt that once they had left school, they were forgotten about. Some of them relied on their families for support and encouragement.

Some families of young disabled people felt that they should receive help for their disabled young people and criticised other people's poor expectations of what they could do. Some families were less encouraging. They themselves

had negative views about impairment, as some of them had low expectations of their disabled children, perceiving them as able to do nothing. According to Hussain and his colleagues (2002), one of the key things that young disabled people mentioned was how they dealt with such issues, as their needs changed with age. They had to deal with 'growing up', just as their siblings did, leaving school and finding work, as well as learning to use social and health services. In this regard, Hussain and his colleagues found that in education, health and social services, young disabled people's experiences were not always positive. There were racist and disabilist barriers within the welfare services. Limited opportunities were offered because of the inability of services to recognise and respond to their needs. Young disabled people and their families had to be assertive to have their needs attended to.

The findings of these studies showed that young disabled people and their families encounter inadequate service provision. They need to be provided with services that are accessible. Their daily needs should be met too, and wrong attitudes towards them should be addressed, regardless of ethnicity differences or being a minority in a wide white society.

2.3 Families' Experiences

A study by Dowling and Dolan (2001) illustrated that it is not only disabled children, but also their whole family, that suffer from unequal opportunities and the outcomes of inequality. This study was also grounded in the social model of disability and showed that the lives of these families are often characterised by financial hardship, stress and anxiety, as a result of social barriers, prejudices and poorly considered service provision. Some studies reported the way in which society disabled, not just the family member who has an impairment, but the whole family unit (Oliver, 1998).

In her study, Beresford (1994) reported that three quarters of parents of disabled young people said that they did not have enough money to care for them. Families with a disabled child had significantly lower incomes than other similar families. Mothers of disabled young people were much less likely to be in

employment than their peers. There was also a strong relationship between disability and household income. Areas of the country with higher indicators of poverty would be expected to register higher numbers of disabled young people than areas with lower poverty indicators.

Dowling and Dolan (2001) concluded their study by identifying several significant issues. First, many interviewees reported that the process of obtaining social services, was often long, slow, time consuming, complicated and the source of intense frustration. The frustration was compounded because funding for many services is reassessed on a regular basis, so the whole procedure has to be repeated over and over again. Whilst funding does not have to be arranged in a similar way for health services, lack of funding often results in long waiting lists, so parents end up battling to access health services as well. This causes particular anxiety to parents, who are aware that valuable time is being lost, waiting, for instance, for a physiotherapist. The energy that has to be invested in this struggle for resources and support, influences family life detrimentally. The conclusion here was not that the disabled child causes stress and negatively impacts on the quality of family life; it is the complexity of service systems and bureaucratic procedures that families face that have damaging consequences. Parents asked that such processes should be less complicated and more family friendly.

The second finding of Dowling and Dolan's research related to the way services were provided. Parents of a disabled child experienced a constant stream of appointments with service providers that they have to attend, unlike families with non-disabled children. Despite the importance of these appointments to the child's health and well-being, these schedules can be very punishing for children and parents, who often have to travel considerable distances with the child and possibly siblings. The researchers wondered why service users did not expect service providers, especially health care professionals, to travel to them, at home or school. Service delivery, they argued, needs to be re-conceptualised, to take account of the tiring nature of these visits and focus on what is best for the child and parents, rather than what is most practical for the professionals.

Dowling and Dolan's third finding related to the reaction of the parents to these experiences. It was usually mothers, who reported crying, depression and in some cases 'nervous breakdown'. However, sometimes these problems were not always inherent in the impairment, they were social in nature. The fourth finding, of Dowling and Dolan's study, was associated with missed experiences. They found that families with disabled children can miss out on experiences that others take for granted. Respondents reported that due to having a disabled child, it was difficult sometimes for the family to go to the cinema or to visit other nice places, because of the lack of respite care. Clearly, it is not just the child's impairment that is responsible for this unpleasant experience, but responsibility lies with the whole society and in particular the lack of appropriate support services. Dowling and Dolan made reference to the findings of another study, by Oppenheim and Harker, (1996), that impairment can involve extra costs for items and services such as transport, heating, laundry, clothing and special diets This means that families of disabled children are likely to experience both the difficulty of lower incomes combined with greater living expenses. Dowling and Dolan recommended improvements for services for disabled young people, including extra funding for these services as required. Concerned professionals have to do their best for individual disabled young people and their families, but the inclusion of service users in planning service provision is important too. Service planning and provision should aim to remove barriers and recognise difference, to allow families with disabled children to participate in society more equitably. More extensive use of the social model of disability, rather than the medical model, by professionals, government and voluntary organisations, in the application of welfare policies, is required.

2.4 Conclusion

The literature discussed here has highlighted some significant points. All the debates in these studies are engaged in with a common theme, which is 'the social model of disability'. They also showed that it is inappropriate to consider

disabled young people as unable to express themselves and their views. These studies illustrated how much disabled young people can express themselves and describe their social world, when they are given a chance to do so and proper techniques are used. In the literature discussed, their opinions and accounts of their everyday lives, the standard of service provision they experienced and attitudes towards impairment, were significant. The children in Connors and Stalker's (2003) Scottish study, for example, reflected positively on friendships with their families and the local community. They were delighted to have the chance to represent themselves and to express their views. They described enjoyable experiences, in their ordinary schools, and positive relationships with their teachers. However, segregated schools or institutions reduced their social contacts. Mitchell and Sloper's (2001) study, suggested that friendships are important for disabled children. Hussain et al., (2002) concluded that impairments did not stop disabled people from valuing the good relationships which they share with their families.

In contrast, Barnes and his colleagues' (1999) study reported that disabled young people were restricted, even in their schools, and in their opportunities to play and interact with others. Moreover, their relationships were mainly with specific adult support staff. They also showed that outside school, due to the inaccessibility of public facilities, disabled young people experienced limited opportunities to develop relationships with non-disabled children.

In general, the level of service provision for disabled young people and their families varies. Connors and Stalker's study showed that most disabled young people and their families had positive comments to make about the professionals they encountered and the support they received. However, although parents were positive about the support received from voluntary organisations, they were less positive about some health professionals; they felt they had to battle with some education professionals and most of them said they had no contact with social workers. In Mitchell and Sloper's (2001) study all the participants valued services that facilitated and encouraged choice. King and his colleagues (2000) asserted that health based services and community care were received by a high proportion of disabled young people. However, the

participants, in Dowling and Dolan's (2001) study, reported several difficulties in obtaining needed services. South Asian disabled young people and their families who lived in the UK, according to Hussain and his colleagues (2002), experienced limited opportunities to have the services they needed. This was because of the inability of the services providers to recognise and deal with their needs.

The concept of disability had different meanings. Connors and Stalker' (2003) study showed that disabled children experienced disability in a number of ways, particularly through restrictions on their 'doing' and their 'being'. They linked disability with their impairment and the effects of the medical and health problems on their lives. However, some of the disabled young people saw disability in terms of physical barriers. Barnes and his colleagues (1999) reported that disabled children identified with other children with the same impairment, and some of them saw impairment as something which marked their difference from non-disabled children. Hussain and his colleagues' (2002) study showed that disability is only one part of young disabled people's identity. Other social factors, including culture and religion, influenced their experience of disability.

Despite the fact that government policy in developed countries aims to have high standards of service provision, a lot of work remains to be done to ensure full inclusion for disabled people in mainstream society. A considerable amount of money has been allocated by governments in recent years, which may help improve service provision and may increase the number of professionals and trained workers. However, if disabled people experience restrictions imposed on them by their societies, it means that social policy has more to do in order to remove both physical and social barriers that may prevent the full inclusion of disabled people, in their social world.

Of course, the literature on the evolution of policies on disability in the developed countries shows progress. However, some of this progress and recognition were achieved through the individual and collective struggles, of disabled people themselves and their advocates. To complete the account of the reality of the lives of disabled people and their families, the next chapter will

explore several pieces of research conducted in the developing countries, especially in Oman.

Disabled Young People and their Families in Developing Countries, Especially in Oman

3.1 Introduction

In this chapter, I explore the experiences of disabled young people and their families, in the developing countries, with particular reference to Oman. Studies are discussed that address the issues of how disabled children are served, if they have the chance to be fully included and participate fully in their societies, and whether or not their own voices are heard. There are limitations to the knowledge and insights offered by the literature presented in this chapter, in that there have been only a few studies of disabled young people' experiences in the developing countries, and most of this research was based on the medical model of disability.

In the context of research that draws on the social model, consideration is given to the influence of public attitudes on disabled people, lack of resources and service provision, and obstacles to their full inclusion within mainstream services. These considerations are mainly explored on the basis of disabled people's own views. In the developing countries, there is research evidence to suggest that disabled people are treated as a burden on society and family, including that carried out by Japan's International Cooperation Agency (2002). For example, a disabled person, speaking for the National Forum of Organisations working with the disabled people (NFOWD), claimed that 90% of the disabled population of Bangladesh falls within the 80% of the total population who live below the poverty line. He also suggested that physically disabled people were being treated as a burden and curse on society, because they were not able to voice their demands, and did not receive proper education or opportunities for personal development. Moreover, if they were children or women then they become "doubly disabled".

This chapter examines several studies conducted in developing countries, particularly in Oman. The interests of the researchers, the objectives of the studies, how they address disability issues and how they present the future for

disabled people and their families, are discussed. From these studies and reports, I introduce a picture of the lives of disabled young people and their families, in the developing countries.

The chapter begins with some background information on service provision for disabled people in Oman.

3.2. Services for Disabled Children and their Families

3.2.1 The Need for Services

Despite continued improvements in health care services and primary prevention programmes, the number of disabled young people, as mentioned in the first chapter, will continue to increase. While new cases due to some diseases have been eradicated, the survival of low birth weight children and children born with multiple impairments presents new problems for long-term care and creates more demand for services, (Krafting, 1999, Al-Barwani and Al-Beely, 1994).

One of the major problems faced by disabled people and their families in developing countries, is lack of information and poor accessibility in mainstream society (Thomas, 1997), Oman, moreover, experiences two issues that contribute to the incidence of preventable disability, which have been identified as challenges for the future, namely consanguinity and traffic accidents. Consanguinity is common in Oman. The 1995 Oman Family Health Survey reported that 54% of women had a blood relationship with their husbands, and, of these, 34% were first cousins. Marriage between blood relatives is perceived as increasing the risk of the transmission of genetic conditions, leading to impaired health and function. Disability resulting from traffic accidents has and will continue to increase, as those now under 15 years old reach the age when they are eligible to drive at age 18. While the Royal Omani Police have introduced many strategies to increase road safety, medical experts have noted that the injuries received in accidents are more severe and disabling than those associated with consanguinity (Al-Majali, 1998). This will increase the need for medical and social services in the future.

3.2.1.1 Health Services

There are around 85 government hospitals in Oman, seven national hospitals (all with rehabilitation departments), nine regional hospitals (only some with partially staffed rehabilitation departments), 29 local hospitals, and five *wilayat* hospitals and about 120 health centres (Ministry of national Economy, 2000). Outside the Muscat area, disabled young people are seen in all of these facilities for regular childhood diseases but there is limited expertise in helping disabled young people, particularly those who live away from main cities and those with multiple impairments.

There are deficiencies in some aspects of the health services. According to Krafting (1999), while physiotherapists represent an important source of professional services for disabled young people, currently there are fewer than 120 in the whole of Oman. There are no physiotherapy assistants. There are only six occupational therapists, including only one Omani national, at the Armed Forces Hospital. Only one occupational therapist, an expatriate, is working at *Khola* Hospital (Krafting, 1999). Krafting adds that seven regional hospitals, outside the capital area, have physiotherapy departments. Most treat up to 60 patients a day and focus on acute care. The high demand for services for acute care patients, means that *Sohar* Hospital, for example, is only able to provide a service to physically disabled children once a month. In several regional hospitals exceptionally well-equipped departments have never been opened due to lack of trained staff. Although the number of therapists outside the capital area has greatly improved, they cannot meet all the needs of disabled young people, nor are they trained to work with all kinds of disability, including visual and hearing impairments and learning disabilities.

These figures show a significant shortage of national professionals and expert workers. They also reveal that most specialised services, such as physiotherapy and occupation therapy departments, are located in the capital and the major cities only. This indicates that disabled young people and their families, who do not live in the cities, must have to pay for transport and may spend a whole day travelling in order to use such services. As the literature discussed in the last chapter revealed, even in developed countries, where all

the facilities were accessible, most families with disabled children struggled and experienced hardship, if they were obliged to travel to hospital appointments, to consult specialists or for therapy.

3.2.1.2 Social Services and Social Care Provision

Social services are mainly provided through the Ministry of Social Development. The responsibility of this Ministry is to cover social, vocational, and recreational rehabilitation for disabled people, as well as to provide equipment and income subsidies or income replacement benefits /pensions to poor families of disabled children. The ministry also maintains a register of disabled people. In addition to the central staff, there are Special Care Departments in each region who, in only a few cases, have a background in social sciences, but no advanced training in dealing with disability matters (Krafting, 1999).

In his proposal to the committee of Community Care for Disabled and Elderly people, Al-Mawali (2001) pointed out that the Social Security Act (1984) does not cover disabled young people who are under 18 years. This means that their everyday needs are not taken into account, and their families might need financial support to meet their ordinary needs, including their basic needs for clothing, food and so on. Adult disabled people who benefit from social security, according to the Ministry of Social Development (2001), amount to 7,616 cases. This figure represents only 20.4% of the total number registered by the National Census (1993) and the Comprehensive Survey of Disabled People (1995). This figure also gives more evidence of the lack of social services provision, because it shows that more than two thirds of disabled people might have a need for assistance and that they are poorly served.

One of the responsibilities of the Ministry of Social Development is to provide care and vocational training services for disabled people, including children. The only governmental centre that provides this service is *Al-Khoudh* Rehabilitation Centre. It is located in the Capital region. In this centre, there is also a section that provides social and health based rehabilitation services for severely impaired children. According to 1999 data, there are more than 35

severely impaired children in residence. Around 50 mildly physically impaired children, and those with learning disability, attend five days a week. Of these, only a few were integrated into the regular school system after leaving (Krafting, 1999).

The Ministry of Social Development operates 18 voluntary day care centres called (*Al-Wafa* Centres), which are considered as focal points for service provision, information and local awareness raising activities. These centres are operated by more than 250 volunteers, and have served approximately 800 disabled young people since opening (Ministry of Social Development, 2000). Currently, there are more than 600 disabled young people registered in the centres. Disabled young people aged from 3-14 years are accepted in the centres, however, the majority are six years and older. A small number of older youths continue to attend, because they have no other alternative. Most centres have focused on learning disabled children (43% of total) and hearing disabled children (23%) and a minority of the children served (only 7%) have been physically disabled.

Krafting has described these centres as examples of using community mobilization, resource utilization and dedication, which began with no experience and still operate with limited expertise and few resources. The female volunteers have developed the only day-care services for disabled young people outside the Muscat area. Although, these volunteers have no professional background and minimal technical support, they are major contributors to the national service delivery system. However, as mentioned earlier, it is not clear on what basis the types of impairments were classified. As will be discussed later, the high percentage of deaf children and those with a learning disability in these centres, is a significant indication of the lack of educational services. However, those who live away from these centres may receive nothing.

3.2.1.3 Education Services

The approximate number of disabled young people in Oman who receive educational services is less than 900. Krafting (1999) and Al-Barwami and Al-Beely, (1994) reported that only mildly impaired children receive education through government schools, including the *Tarbia Al-Fikruya* School for children with a learning disability and *Al-Amal* School for deaf children, both of which are in the Capital; and voluntary organisations, including *Al-Wafa* Centres and the Disabled Children's Association. There are no standardised special education curricula for the schools, the Ministry of Education (MOE) curricula are adopted and revised periodically to meet the needs of the students.

An un-published report, of the National Committee of Disabled People Services (NCDPS), showed that inclusive education is now becoming a priority issue in discussions between concerned bodies within the context of education reform. Physically disabled children are offered the opportunity to enrol in ordinary schools. However, the total numbers of physically disabled children, and the obstacles they face within their ordinary schools, are matters of investigation and discussion (Majlas Al-Shura, 1997, Krafting, 1999, and Al-Mawali, 1998). The Ministry of Education, within its education reform plan, might give more consideration to the inclusion of disabled students within ordinary schools. Statistical data showed that, in 2002, 92 physically disabled students were registered in ordinary schools run by the Educational Services of South Al-Batna Region (Ministry of Education, 2002).

Despite the fact that a considerable number of physically disabled children are placed in ordinary schools in Oman, there are questions about their satisfaction, the quality of facilities they are offered and their relationships with their peers in these schools. A further question can be raised here, how far and how well do the educational services serve all physically disabled people, especially those who live in the rural communities?

3.2.2 Non Government Organisations

There are four voluntary organisations working in the field of disability (Ministry of Social Development, 2000). The Omani Association of the Disabled focuses on advocacy, especially for access to services and overcoming environmental barriers, awareness raising, sports and social support. The Association for the Welfare of Disabled Children provides services for approximately 200 school-aged disabled young people, mainly those who have hearing impairments and learning disabilities. The *Al-Noor* Association for the Blind focuses on issues related to visually disabled people. The fourth voluntary group, called the Group for Early Intervention, promotes early detection and intervention systems for disabled young people under 6 years old. This group plans to provide specialist care and to develop as a training and resource centre for other organisations.

However, although these associations make a considerable contribution through providing voluntary services for disabled people, they mainly serve the capital area. It is not clear whether or not these associations are aware of the full range of everyday problems of disabled people; and if they will succeed in their efforts to improve the lives and experiences of disabled people and their families. These associations currently focus their activities in the Capital and, it might be argued, neglect *wilayats* and rural communities, where the majority of disabled people live. A partnership between all responsible bodies, including non-governmental organisations, may achieve more in developing more services for disabled people.

3.2.3 Accessibility

It is difficult to judge the level of awareness and to generalise about the nature of attitudes towards disability, in a society made up of diverse communities, in terms of their economic, geographic socio-demographic characteristics and access to support services, provided in both the government and voluntary sectors. However, there are visible indicators of significant efforts to recognise

the needs of disabled people. For instance, reserved parking spaces for disabled people and ramps in buildings have become familiar in most main cities around the country. Other signs of progress include the active involvement for community members in some Day Care Centres, increased financial contribution by the community, and better media coverage of the national education programme about disability matters. The Ministry of Social Development leads an effort to assert the rights of children, including disabled children. The ministry does this by reference to documents such as Article 23 of the Convention of the Rights of the Child (CRC), stimulating and supporting the trend to avoid institutional-based services, especially, for disabled young people; asserting the importance of inclusive education services and childhood health services, and supporting efforts that remove physical and social obstacles faced by disabled young people in their everyday lives (Krafting, 1999).

Avoiding institutional-based services is a policy objective that has been adopted, at least in theory, by many countries in the modern world. The alternative approach, however, requires empowerment and an investment, with economic or social and cultural implications. As the literature discussed earlier demonstrated, the developed countries spend billions on services to support disabled young people and their families. Accommodating disabled young people within their families/communities requires allocating a lot of money, removing physical obstacles and challenging prejudice and negative social attitudes.

The government-UNICEF Master Plan of Operation (MPO) 1997-2000, identifies two major impact objectives for childhood disability: the reduction of preventable impairments and increased access for disabled young people to community based care. However, the meaning of the term disability is still a matter of debate; there is no overall agreement on what constitutes a “disabled child”. As mentioned earlier, national surveys, including the 1995 Survey, used a diversity of definitions, which resulted in wide variation in the estimates of the extent of disability. For example, mild and invisible impairments were not accounted for. When officials, professionals, and sometimes-disabled people

themselves and their families, define disability, they usually focus on lack of physical ability or loss of function. Disabling social and environmental barriers are not recognised. Another challenge to policies, with the objective of improving disabled people's lives, is a lack of co-ordination between the various organisations involved (Krafting, 1999). This might be considered as wasteful of resources and time, and consuming financial resources unnecessarily through the duplication and fragmentation of effort.

3.3 Research on Disabled People in Oman and Developing Countries

Very little has been written about disabled people in Oman. Disabled children's views about their everyday lives have not been taken into account. The studies, which have been conducted, have been largely based on the medical model; that is, an approach to disability that focuses on the individual's loss of ability or function rather than the disabling nature of environmental barriers, service limitations and negative social attitudes. The social model of disability is not well known in Oman or widely used by researchers.

Al-Barwani and Al-Beely (1994) conducted a study of education and care services for disabled people in Oman. The purpose of their study was to evaluate several services provided for disabled people, including educational, training and rehabilitation services. They also aimed to explore different issues and challenges, which prevent improvements in the quality of these services. Al-Barwani and Al-Beely, in their study, concentrated on the education and care of disabled people in the light of the contributions made by both the governmental organisations, such as the Ministry of Social Development, the Ministry of Education and the Ministry of Health, and the non-governmental organisations such as, the Omani Woman's Association, UNICEF and the Association for the Care of Disabled Children. They used a range of research methods. The tools that they used were: document review, analysis of existing information, official records and reports, and interviews with a small number of professionals working in education, health, and social service departments, and also volunteers from the disability field. However, this study did not aim to

examine the opinions and experiences of disabled people, or to include disabled children's perspectives. Even families with disabled children were not given a chance to express their views.

The researchers revealed some aspects of service provision and touched on the issue of public attitudes to disability. For example, based on several interviews with volunteers in the Disabled Children Care Association, Al-Barwani and Al-Beely, reported that disabled children were treated with sympathy but they were mainly hidden away from the public eye. They added that families would normally seek help from the government, only when their disabled child became too great a burden for them to cope without help, as a result of the presence of a newly born baby, who required a lot of attention, or as a result of the deteriorating health conditions of the disabled child.

The problem of disabled people being hidden was not examined from the families' perspective. However, there is evidence in the literature that suggests that this problem, as a social problem, has historical roots. For instance, Oswin (1999) suggested that attitudes towards disabled young people were based on the need for a society to survive, so those who were considered weak were thrown aside in case they depleted the strength of the group. Al-Mahi (1994) asserted that disabled young people had no chance of survival within hunting groups. In his historical study of the Ancient Nile River Societies, he said that disabled young people and vulnerable people were often killed, because they prevented such societies being superior.

Al-Barwani and Al-Beely (1994) reviewed several quantitative studies that were conducted within the last twenty years in Oman. Although most of these studies were not comprehensive, they indicated that there is a high prevalence of disability in Oman. The researchers suggested that in order to provide services for all disabled people, unified efforts among all concerned bodies and organisations, are crucial. In fact, they did not assess the range of the current service provision including services provided by Health, Social Development and Education Ministries. They mainly presented in detail the written roles and rules of each organisation and its responsibilities for service provision for disabled people. Whether or not disabled people and their families were

satisfied with the support they received, and whether or not their needs were met, were not examined.

Al-Barwani and Al-Belly reported a slow improvement in the quality and quantity of service provisions for disabled people in Oman. However, while the government was seeking to provide good quality basic services for all, including health, education and social services, a modest number of disabled people were benefiting from these services. As Krafting (1999) reported, not more than 5% of disabled people benefited from the services currently provided in Oman. However, a comparison with earlier reports, showed that only 2% of disabled people were benefiting from provided services in 1993, which reveals a slight an improvement in service provision. However, to develop or to improve the available services would require more effort and investment, to cover more than 90% of disabled people who are still not well covered. The core of the issue seems to be that it is not enough to theorise about what should be provided for disabled people within mainstream society, rather it is also vital to adopt a practical plan of action, with more consideration for the views of disabled people.

Despite the increase and improvements in service provision for disabled young people in recent years, there are still many challenges to be addressed. According to Al-Barwani and Al-Beely (1994), the governmental and non-governmental bodies must coordinate their efforts and must jointly develop and implement strategies, to achieve identified worthwhile goals with regards to the rights of disabled people, their care, education, employment, and the provision of social facilities. More importantly, agencies must educate the general public to raise their awareness of the needs and rights of disabled people. For example, the Ministry of Health has led a great effort in the prevention of impairments. This has mainly taken the form of educating the community regarding causes of impairments, the importance of nutrition, immunisation and so on. These efforts have mainly been based on the medical approach.

As mentioned in the introductory chapter, the Ministry of Social Development has adopted the principles of Community Based Rehabilitation (CBR). CBR is similar to the Community Care model used in the UK. The

philosophy of CBR is to help disabled people within their own community, making the best use of local resources, thereby helping local communities to become aware of their responsibility towards disabled people. Krafting (1999) suggests that in the CBR programme, it is not only that disabled people are listened to, but they are fully involved in all the stages of service design and implementation. According to Al-Barwani and Al-Beely (1994), services for disabled people should reach them in their own communities and they should be seen, not just as recipients of service but also, as contributors to community welfare. In this approach, disabled people are encouraged to do the maximum for themselves and where disability matters are concerned, they should play a leadership role.

In developing countries, there are massive problems, including poverty and ignorance, that may prevent the full improvement of the service provision. Although Oman is not categorised as one of the poorest countries, Krafting (1999) says only 5% of disabled people benefit from educational, care, social and training services, and public attitudes still have to be given more attention to be improved. This shows a wide gap, between the availability of public services and what should be offered to disabled young people and their families in developing countries. For this gap to be bridged, Al-Barwani and Al-Beely (1994), suggest that accessible mainstream services for disabled people, which Oman is trying to achieve, can be maintained by the CBR programme. This programme, according to Krafting (1993), serves a larger number of disabled people than institutional based services. The government, in this regard also, stimulates and encourages voluntary work and private sector contributions, in order to develop and improve the services for disabled young people. However, the CBR programme requires practical steps, including allocation of money and training for community workers.

Institutionally based services cannot meet all the needs of disabled people. In their comments on the *Al-kohd* Centre of Care and Rehabilitation for Disabled People, as the only government centre located in Muscat, Al-Barwani and Al-Beely (1994) summarised some important points that should be addressed. An example, of the issues identified, was a lack of facilities to

accommodate the large number of applicants with different kinds of impairments. It should be understood that most disabled people have no chance to benefit from the Centre's services, especially those who live away from the Capital. Another issue is the limited number of qualified Omanis to manage the Centre and run and provide services. The implication of the work of Al-Barwani and Al-Beely (1994), Krafting (1999) and the Majlas Al-Shura Report (1997) is the need to develop an intensive national training plan. Omani people should receive training as social, health and community workers. They should be enabled and equipped to manage and run the educational, care, social, and rehabilitation programmes. Although, non-Omani professionals make an important contribution, in the longer term, if the government seeks to develop and extend its services for all disabled people, the number of trained national workers should be increased.

Al-Barwani and Al-Beely (1994) highlighted some aspects of the public's attitude towards disabled young people. They recommend more effort by all responsible bodies to support the families of the disabled children, since their needs have not yet been fully recognised; and more work to decrease the social stigma that is still evident in Omani society. Some families abandon their disabled children in hospitals. While hospitals are doing their utmost to care for these abandoned disabled children, their condition does not improve since these institutions are not equipped to deal with such cases. Al-Barwani and Al-Beely stressed the need for a greater consideration to be given to the difficulties for these disabled young people, in being ignored by their own families. These examples provide evidence of the dominant negative attitudes towards disabled young people, even sometimes by their own families. This problem is constantly reported by most disability studies as one of the key problems in society.

Al-Barwani and Al-Beely (1994) reported that the availability of services is highly inadequate. If one takes the actual or possible number of impairments in the country, and if one considers the actual or possible number of cases that require special education, training or rehabilitation, it is perfectly obvious that

the few facilities available in the country cater for a very small percentage of the group in need. They recommended that:

> *"In order to mainstream the disabled, the schools will need to be built or modified, so that students with disabilities can be safe in them and special education teachers, psychologists, social workers, and counsellors, will need to be employed in schools". (Al-Barwani and Al-Beely, 1994, p.52)*

In their study, Al-Barwani and Al-Beely, recommended a greater effort by society to encourage further community participation and involvement, either in the form of giving donations, doing volunteering work or contributing to the education of the general public. Although, Al-Barwani and Al-Beely have touched on significant issues, there are inherent dangers if the responsibility for service provision for disabled people is shifted from the role of government to that of the community only. In order to improve service provision, a partnership between all the relevant agencies, including governmental and non-governmental organisations is crucial.

An un-published study conducted by the Social Committee of the Majlas Al-Shura (1997), about disabled people's services within governmental plans, raised important questions. The aim of the study was to make recommendations to the Ministerial Council, in order to improve the service provision for disabled people. The study was based on contributions made by education, health and social service departments, volunteers, and meetings with officers, including the Under-secretary of Social Services Sector, and selected local people. To collect the data, several tools were used, including questionnaires posted to the concerned departments, interviews with volunteers from Day Care Centres, and secondary data analysis, including analysis of the statistical data.

One of the shortcomings of the Majlas –Al-Shura's study was that it did not touch on discriminatory public attitudes towards disability, and also it did not take into its account the views of disabled people and/or their families about service provision. Nevertheless, it raised several important issues. For example, as was mentioned earlier, there was ambiguity in the definition of disability used in earlier work. The study criticised the governmental published

statistical data about the total number of disabled people, types of disability classification and geographical distribution. It said that the published figures were not accurate and assumed that the real number of disabled people was larger. This inaccuracy was criticised as misleading the plans for service provision. Another example of the issues raised was that the definition of disability was not clear, especially to those who took part in the surveys and who work in the disability field. Therefore, Oman, based on its social and cultural structure, must adopt and adapt a clearer definition of disability.

The Majlas Al-Shura's study stated several problems that prevent improvements in service provision. It emphasised that disabled people are not different. Their rights to live equally and to the rights that non-disabled people enjoy within their ordinary lives, have to be secured. For instance, the study argued that youth activities organisations, including Youth Clubs and Women's Associations, in the country, should be open to disabled people. It also reported that they do not need different public services and exceptional care; at the same time, any neglect of their needs may lead to greater exclusion of disabled people from the mainstream of society.

As all the studies reported, the Majlas Al-Shura's study showed that the education services have not covered the needs of all disabled people. For instance, those who have learning and hearing disabilities have no opportunities to join ordinary schools. As mentioned earlier, there are just two special schools in the capital Muscat. Lack of native workers in schools, deficiencies in the transport arrangements for students and the inaccessibility of school facilities, are problems that should be resolved. Problems, like negative public attitudes and the increasing incidence of disability, should be confronted by increasing public education, prevention and early detection programmes.

Oman has neither a comprehensive plan nor has made systematic efforts to provide a sufficient service to meet disabled people's needs. However, while each Department, including Education, Health, and Social Services, attempts to provide inclusive services for disabled people, more concern about the quality of services is required. For instance, the provisions of the Social Security Act (1984) are only enough to cover the minimum of disabled people's everyday

needs. The Voluntary Associations are there to serve a large number of disabled people and their families; the role of the Government is to give greater support to these organisations.

The study, discussed above, recommended improving service provision for disabled people. More encouragement could be given to the role of the local community, through support from government for the voluntary centres and to develop vocational rehabilitation and care centres in all regions. National training programmes for workers and volunteers in the field of disability require more attention. A national strategic plan and greater financial support are required in order to ensure that service provision is improved.

Krafting (1999) who was sponsored by the Ministry of Social Affairs, Labour and Vocational Training and UNICEF Office in Oman, reviewed the services offered for disabled young people in Oman. Krafting, in her report, started by offering justifications for the importance of service provision for disabled young people. She claimed that the number of disabled young people under 15 years was between 23,250 and 62,000, and that the number was increasing by 1,500 to 3,700 children each year. She added that between 2,300 and 6,200 of the total number of disabled young people have severe lifelong impairments. She also revealed that the number is increasing because of improved medical care, consanguinity and traffic accidents.

The evaluation tools that Krafting used were; document review and analysis of the existing information, interviews with governmental and non-governmental workers in the field of disability, observational field trips to three randomly selected Voluntary Day Care Centres (Al-Wafa Centres), and focus groups with volunteers in these centres. However, disabled people were not involved or given the opportunity to express their views.

As mentioned earlier, Krafting also reported that there was only a modest increase in services for disabled young people throughout the nineties. She showed that less than 5% of disabled young people, who need services, receive assistance. The majority of services for disabled young people are located in larger urban communities, particularly the Capital region and the main cities. These facts show that disabled young people and their families who live outside

the capital and main cities have less chance to receive or access the services they need.

It is worth noting that these three studies conducted in Oman (Al-Barwani and Al-Beely 1994; Majlas Al-Shura, 1997; Krafting 1999), emphasised the importance of developing coherent national policies based on giving disabled young people and their families more attention. There is a consensus in their recommendations that there should be more concentration on a number of important problems. The issues identified were the development and maintenance of training programmes for national professionals and local volunteers, an investigation of the possibility for providing respite care for families of severely impaired children around the country, the activation of community support groups to spread disability prevention messages, and continued advocacy for the inclusion of as many disabled young people as possible into the mainstream education system. These studies also recommended more research into areas such as education, social and health services, and into the everyday circumstances of disabled people and their families, to identify the potential for improvement in both service provision and the quality of people's lives.

The conclusions and recommendations of these studies recognise that the availability of services for disabled young people and their families is not satisfactory and that attitudes towards disability may need improvement. However, a major weakness of the research already conducted was that it has not sought or given consideration to the opinions of disabled people, particularly disabled children.

3.4 Studies from other Developing Countries

As was the case with Oman, a search of the literature in other developing countries, found just a few studies that introduced the social model of disability and qualitative methods. One qualitative study, (Turmusani 1999) that was similar to my own, with respect to some of its objectives and design, was conducted in Jordan. Turmusani focused on the economic needs and priorities

of disabled people. It is exceptional in the literature, both because it was a qualitative study and because it drew on the social model of disability. However, the participants were adult disabled people, not children.

Turmusani's study had two main objectives. The first was to gain an insight into the perceived economic needs of disabled people and the impact of unmet needs on their lives. The second was to highlight the disabled people's perceptions of the existing services and legislation on employment and welfare support in Jordan. However, his study did not involve disabled young people, and the emphasis was merely on the economic aspects of disabled people's lives. Nevertheless, in common, with the focus of my research, Turmusani used the social model of disability. He also gave disabled people themselves a chance to explore and express their viewpoints.

Turmusani's study revealed that the economic provision for disabled people in Jordan is not sufficient or adequate to meet their needs. However, Tumusani talked about one government official who was critical of the situation of disabled people in Jordan. This man commented that disabled people in Jordan are lucky, and that they should be grateful to the whole community, who care for their needs within a relatively poor economy. My own comparative study of experiments in service provision for disabled people in several developing countries, including Jordan, the Gulf countries, and Indonesia, suggested that the society in Jordan gives disabled people's issues a clear focus and supports volunteer based services.

Turmusani's study reported that only a small number of disabled people were consulted about the nature of the work they were given to carry out ,or the training they received, and a few were involved only in social activities. Turmusani pointed out that disabled people were not included in decision-making about the services they received, or about those aspects of their lives that affected their economic participation. How they were represented when decisions were made, showed the practical limitations in regard to their involvement. All the respondents in his study were diagnosed by medical professionals and in only a few cases had their families participated in the process of diagnosis. Generally, the power of medical professionals can be

clearly seen in the disability field, especially when it comes to defining the causes of impairments and the suggested intervention needed (Turmusani, 1999; Coleridge, 1993).

Despite the fact that physically disabled people were not represented in great numbers in Turmusani's study, they revealed that they experienced a limited number of contacts outside their home and families, and therefore suffered a degree of social isolation. When respondents were asked to describe the kind of contacts they had been able to develop, only a few of them said they had access to professional contacts, while only a third had access to social activities, and more than a half had no contacts at all. This provided evidence that the society sometimes prevented disabled people from communicating with, and developing relationships with, people in their social world.

Disabled people expressed a high level of dissatisfaction with current service provision in Jordan. Turmusani (1999) highlighted several issues in this regard, including the lack or absence of income, limited job opportunities and the financial and personal insecurity disabled people experienced. Issues like segregation and dependency were noted too. Most disabled people, including adults, had no income and depended on their families. This forced dependency had two implications. First, if the income of their families was low, it meant that their everyday needs would be poorly met and more hardship could be expected. Second, governments were not informed of their dependency and this lack of awareness in policy terms exacerbated their segregation. Walker and Walker (1991) argued that the only way to break the link between poverty and disability would be by having financial schemes to meet disabled people's living costs.

Institutional services were preferred by some disabled people in Jordan, just because of the general attitudes towards them. However, Turmusani claimed that this style of service located disabled people in a segregated environment. The experience of his research respondents was that they were denied effective and equal benefits from integrated education and training. However, the respondents linked their disability to their lack of inclusion in the

everyday life of society. Some disabled people viewed their disability as limiting their ability to be fully involved in the economic life of their community. Disability in the participants' opinion, not only limited their activities or their studies, but moreover, it prevented them from being able to secure a source of income, which was needed to facilitate their integration into society. Disability was also regarded as restricting their daily life activities, those who suffered severe disablement especially, found difficulty in performing daily life activities independently. More than a third of those interviewed regarded their impairments as limiting their studies and their plans for further studies. The majority of respondents seemed to view their condition from a medical perspective. They regarded disability as a personal problem and they blamed their inability to participate socially, economically and educationally on their own functional limitations.

Disabled people's perceptions about their disability and the attitudes of others towards them were also explored in Turmusani's study. Disabled people became aware of their incapacities through the comments they received from family and friends. Yet, they valued the assistance of their families and friends in helping them to cope with their impairments. It appeared that families and friends were a source of both information and support. The respondents were conscious of their disability as a problem when their family and friends treated them differently. They also reported that they came to see their disability as a problem in relation to mobility, their ability to engage in independent activities in school, and success in making friends.

The role of the family in shaping disabled people's perception of their situation was emphasised. This usually starts from early childhood and continues throughout their upbringing. Most disabled people in Turmusani's study reported having supportive families, who understood the problems associated with disability, and how they had dealt with it positively.

The disabled people in Turmusani's study were asked about how they wanted their needs to be addressed. Nearly half wanted their needs to be given the same importance as non-disabled people's needs, of this number, a fifth wanted their needs to be considered as a matter of rights not charity.

Regarding who should assess their needs, nearly half preferred government departments to do so, and only a few suggested that they would prefer them to be assessed by disabled people. More than half thought that a combination of government professionals and disabled people's NGO's [voluntary organisations] might perform best in assessing needs.

Turmusani (1999) concluded his study by stressing the imperative need for a change in attitudes towards disabled people and their abilities, on the part of the general public, including teachers and other professionals. He argued that even disabled people themselves should change their attitudes towards an affirmation of their rights and needs. Discrimination was a key problem dominating the lives of disabled people, which pushed them to the margins of their societies. He suggested that more awareness and dissemination of information were among the solutions to the problems of ignorance that create discrimination. If the rights of disabled people and the responsibilities of society are recognised, this will ultimately affect policy instruments for fighting social discrimination against them.

In Jamaica, a study was conducted by Thorburn (2000), to determine the extent of the provision of services for disabled young people and the progress made in the period between 1988 and 1997. A questionnaire was sent to 23 agencies, of which 22 responded. However, while disabled young people themselves were not asked their views about service provision, the study produced important findings. The results of Thorburn's study showed that the coverage of services varied considerably and that there was an inequitable distribution of services for adults, in comparison with those for children. The majority of disabled young people were in rural areas and the school-age group were the main beneficiaries of services. The estimated number of disabled children in Jamaica receiving services was less than 5% of the total number. This shows a similarity between Oman and Jamaica, in the gap between current service provision and the real need that has to be bridged. While many agencies in Jamaica, especially the Ministry of Education, have recognised the need for the expansion of inclusive education and have carried out in-service

teacher training programmes, the practical support for the developments advocated by government has not yet materialised.

Funding was another aspect of the inadequacy of services in Jamaica. In fact, there was very poor financial support delivered to disabled young people and their families, which meant that society gave their needs less attention than other policy priorities. However, the Government of Jamaica had recently increased the allocation of financial support to NGOs providing services, which were originally supported by local charitable donations or funding from overseas donors.

Thorburn (2000) concluded his study with a number of recommendations. He suggested that community based services have to be expanded to include as large a number of disabled young people as possible. He argued that training for professionals, including health workers and teachers, should be taken into account. An increase in the availability of services needed by disabled people, including equipment, inclusive schools for mildly impaired children and special schools for more severely impaired children, were required. Finally, Thorburn built on previous studies, reporting that there was a determined need for further changes in society's attitudes towards disabled young people and their families.

3.5 Conclusion

The studies from developing countries, discussed above, portray the general situation of disabled young people and their families in their own societies. This chapter concludes with a summary of the common themes and issues identified by these studies:

1. In Oman, there is no strategic plan agreed between the responsible government bodies and voluntary and community organisations concerned with the needs of disabled people, including children. Each organisation has its own approach, according to its priorities and budget. To address the problems of uncoordinated services and fragmentation in

provision, all previous studies recommended adopting a national action plan based on a coherent practical strategy and objectives shared by all responsible bodies.

2. All previous studies reported gaps in service provision, including education, health and social services which were inadequate and concentrated in major towns.
3. These studies recommended avoiding the development of institutionally based services, to address unmet need, and instead proposed that local community based services should be supported by government.
4. To overcome the negative attitudes of the general public towards disability, the previous studies advocated an education programme, especially in the rural communities.
5. All studies reported a lack of native workers and professionals, including social workers, community workers, therapists, teachers and others. To address these problems, it was suggested that more investment should be made in training programmes.
6. While efforts were being made to remove physical obstacles and to make public facilities accessible to disabled people in the major cities, this was not the case in the rural communities and many urban communities. These studies recognised that a greater effort to remove obstacles and make the environment more accessible was required.
7. A high prevalence and increasing incidence of disability was reported, and these trends imply that public education programmes, prevention and early detection systems are needed.
8. The studies revealed that there is little money for developing or improving the services needed by disabled people.
9. The public misunderstanding of disability influenced the everyday lives of disabled young people and their families. This impacted on their personal identity and self image and meant that disabled people were labelled as special cases by others and that they saw themselves as different.

With the exception of Turmussani's (1999) study, none of those reviewed have explored these issues from the disabled people's point of view. The studies did not give enough consideration to the perceptions and everyday experiences of disabled peopled and their families. That these people were given no chance to express their opinions, on issues that are important to them, is in itself an indication of the prevailing negative attitudes to and perceptions of the disabled, as both disadvantaged and unable to take part. Disabled young people' views were probably never taken into account in any of the studies conducted in the developing countries.

Most studies in developing countries approached disability as a personal tragedy. The social and external factors were usually given no consideration and not related to the exclusion and isolation of disabled people from their own societies. Familial issues and environmental problems influenced' everyday lives. Surprisingly, these studies were dominated by the medical approach to disability and devoted most attention to the health and physical functioning of disabled people, which meant that their condition was presented primarily as a personal tragedy rather than as a social problem.

The review of the literature in this chapter identified significant gaps in the research previously carried out in developing countries, in that the studies discussed neglected both the social dimension of disability and the accounts, opinions and everyday life experiences of disabled young people. My own study is an attempt to bridge these gaps.

The next chapter will discuss the meaning of the social model of disability and the concept of citizenship in the context of disabled young people's rights.

Disability and Citizenship

4.1 Introduction

This chapter aims to examine what the concepts of citizenship and the social model of disability mean for disabled people, and what implications they might have for the provision of state welfare. The purpose is to give a general understanding of these concepts and to build up a framework to be used as a structure for all further discussions in this study. These two concepts are fundamental to the notion of equality and the inclusion of disabled people as equal members, with the same rights as non-disabled people in their own societies. Whether or not disabled people have been given full citizenship in a political and legal sense, I will attempt to identify what prevents them exercising their rights and what the obstacles are to their full inclusion and participation in their own social world.

4.2 Citizenship

The notion of citizenship simply refers to full membership in a politico-legal community (Roche, 1992). Marshall and Bottomore (1992) defined it as:

> *"Citizenship is a status bestowed on those who are full members of a community. All who possess this status are equal with respect to the rights and duties with which the status is endowed". (p.18)*

'Full membership' of society and 'civilised living' were the key features of Marshall's writings. Citizenship concerns the relationship between individuals and their societies. Historically, citizenship was the concept used by many philosophers and social theorists to describe the political integration of people into their societies. According to Marshall (1952), the history of citizenship can be seen as the achievement of certain rights, which he divided into political,

social, and civil rights. Citizenship is closely connected to human beings' equal rights in society. Marshall (1964) described three elements of the citizenship concept. The first, civil citizenship, is based on the idea that each human being is equal before the law. It comprises personal integrity, freedom of speech, religious autonomy, freedom of thought and the right to property. The second, political citizenship, includes the right to vote in general elections and the eligibility to stand for election. The third, social citizenship, covers the principle of welfare for all, which means each person's rights to a secure economic situation and the right to education, social services and health. This resonates with Roche's (1992) definition of social citizenship, which adds duties to rights and refers to:

> *"Those rights and duties of citizenship concerned with the welfare of people as citizens, taking 'welfare' in a broad sense to include such things as work, education, health and quality of life". (p.3)*

The most significant event in the evolution of social citizenship, especially in the Western World including the UK, was the introduction of the welfare state, which combined the idea of 'full citizenship' with 'social rights'. The right to receive benefits, not simply 'social security' benefits or income replacement benefits, but the benefits of receiving all kinds of services, including education, health, social care and housing, deemed necessary to a full and dignified life consistent with the standards of the particular society. Marshall claimed that the welfare state would address issues such as poverty and inadequate health care, and would give people the right to a decent standard of living, or at least a fair chance to participate fully in society.

In the UK, citizenship means equal access to the law, political rights and equal access to the benefits offered by the welfare state (Campbell, 1992). However, during the 1990s, the meaning and implications of the citizenship concept became more widely and overtly discussed and more recently became part of even the primary school curriculum (Hine *et al.*, 2004). The debates surrounding citizenship inclusively addressed the notion of social citizenship (Dwyer, 2004).

The 'new right' perspective challenged the notion of social citizenship (Institute of Economic Affairs (IEA), 1990). Nevertheless, the debate about the meaning of social citizenship was not exclusive to commentators of the New Right. Discussion about the definition was increasingly dominant on most political agendas. As McCormick (1997) argues:

> *"New Labour's orthodoxy holds that extending social justice is a requirement for economic efficiency. The 'Intelligent Welfare State' proposed by the commission on social justice is rooted in improving opportunities to earn. Social justice is not just about cash transfers". (p.109)*

Marshall did not believe that the state should take over all the duties of families and communities, (Roche, 1996, Halsey, 1996), and indeed the welfare state was always supposed to be based on a mixed economy of welfare, with state assistance overlapping with voluntary and familial duty. The principle of 'Community Care' (Community Care Act, 1990) would not have been so far removed from Marshall's notion of achieving social citizenship within a framework of assistance from the state and from community-based sources.

Hutton (1995) argued that social cohesion was deteriorating year by year. If his analysis was correct, it raises the question of how can a community's ability to look after those requiring care and assistance be maintained and how can it achieve full inclusion for those who are socially excluded? Perhaps the welfare state had exceeded Marshall's expectations, and social citizenship, rather than being based on just mutual rights and obligations, has come to signify a pure relationship between the individual and the state. Therefore, this raises the further questions of what does being a citizen entail, and what should a citizen expect? It appears that the issue of what the individual should expect from the state is more complex, as the world has changed so much since Marshall was writing in the early years of the establishment of the state in the United Kingdom. Today, in a changing world where economic, social and health problems are becoming more complex, the question of how far it is possible for governments, especially in the developing countries, to secure a decent life for all their population, is discussed in the literature (Turmusani, 1999; Thomas, 2000; Thorburn, 2000).

The concept of citizenship also implies membership of a community. The notion of community here needs to be seen in the context of inclusion and exclusion issues. According to Dwyer (2004, p. 16), rules about who has a lawful claim to welfare rights and who does not, and the reasons why certain claims are viewed as valid while others are dismissed, are of more than theoretical interest. He added that to enjoy social rights, individuals need to have their right to membership recognised by others within a community. However, Drake (2001) pointed out that simple membership is not enough; participation within a society is also a requirement of full citizenship. Dwyer (2004) claims that if certain individuals or groups lack significant rights to welfare, and they are unable to take part in society in meaningful ways, then that means the very idea of citizenship, of a shared common status, begins to be lost.

4.2.1 Citizenship and Disability

According to IN Unison (2000), as an institution of disability studies in Canada, the concept of citizenship is central to disability issues. Citizenship is the inclusion of disabled people in all aspects of society. Full citizenship depends on equality, inclusion rights and responsibilities, empowerment and participation. People choose to participate in society in various ways, including economic activity, involvement with community activities and organisations, political participation. These choices should also be available to disabled people.

In recent decades, there has been an aspiration around the world, especially in Western countries, to enable disabled people to fully realise their citizenship, in terms of equal opportunities to participate in their own societies. Citizenship was originally based upon individual rights defined in legislation, while more recent analyses relate it to individual 'freedoms' not in law. According to Taylor and Bishop (1991):

> *"The new development of the Left is a definition of citizenship based upon need. This is informed by an appreciation of 'difference', and underlined by an understanding of societal power and how certain groups such as black people, people with disability, and women, have been marginalized". (p.5)*

Oliver (1996) claimed that the idea of citizenship has been used, not simply to consider the social integration of the majority into society, but also as a yardstick to measure the extent to which certain groups are not socially integrated. In fact, until the beginning of the 1980s, disabled people were generally invisible in most developing countries. They were usually regarded as having only a limited potential contribution to the development process. Even in the developed countries, policies and programmes concerning them focused on the provision of institutional care, medical rehabilitation and allowances. Those measures, although well intentioned, have tended to reinforce their exclusion from active participation in community life (Krafting, 1993; Thomas, 2000; Houten and Bellemakers, 2002).

During the last twenty years, the world has witnessed a transition towards ensuring a full citizenship for disabled people. To support developing full membership for disabled people in their societies, the United Nations (UN) has made declarations in several conventions, with which all countries in the world are asked to comply. Greater achievements ensued during the International Year of Disabled Persons (1981) and the United Nations Decade of Disabled Persons (1983-1992). For example, the declaration of the Asian and Pacific Decade of Disabled Persons (1993-2002) reinforced a growing trend towards equalization that has its roots in the progress made during the United Nations Decade. The goals of the Asian and Pacific Decade are "full participation and equality".

With the launching of the International Year of Disabled Persons and the United Nations Decade, perceptions concerning disabled people changed. For the first time, the global community agreed upon a set of definitions and proposed measures for action in the field of disability (WHO, 2001). The aim was to highlight the need for promotional measures to realize the goals of full

participation of disabled persons in social life and development, and of their equality. Such clarity concerning conceptual approaches towards disabled people had a significant effect on the development of legislation concerning this group throughout the world.

In the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (United Nations, 1993), the recognition of human rights for disabled people is stipulated. It is stated that disabled people should have equal rights and obligations, just like all other citizens. Underlined in the World Programme of Action is the principle of equal rights for disabled and non-disabled persons. The World Programme of Action states that resources must be employed in such a way as to ensure, for every individual, equal opportunity for participation. Furthermore, it refers to the equal obligations of disabled persons to take part in the building of society. For this, society must raise the level of expectation so that disabled persons have full citizenship and mobilize their full resources for social change.

Each state has an obligation to strengthen the citizenship of disabled people. This is through developing and/or changing polices that concern ensuring equality and inclusion. The Western world has taken action to secure full inclusion for disabled children and elderly people through legislation. However, it is not yet clear whether or not disabled people enjoy opportunities on equal terms with the rest of the population, with respect to participation in society. Different Acts have been introduced in the UK (Children Act, 1989; Carers and Disabled Children Act 2000 and others). However, these have not resulted in full inclusion for disabled young people. For example, a review of research concerning these children and their families, commissioned by Joseph Rowntree Foundation (1999), showed that the rights of disabled young people to be consulted are often not recognised in practice, particularly in the case of those who have high levels of support need. The Audit Commission (2004, p.48) found that disabled young people and their families are, in general, poorly served and remain at risk of social exclusion. There were different reasons cited for these deficiencies, including the fact that practitioners did not feel that disabled young people have the necessary skills or experience to communicate

with them; it was also because of the lack of support, flexibility in services, clear and appropriate information, housing provision and short breaks.

Houten and Bellemakers (2002) claimed that disabled people in the Netherlands were considered as second-class citizens. First-class citizens have jobs, enjoy health and normal everyday live, but this is not the case for many disabled people who, therefore, face problems on two fronts. Until some years ago, many welfare and care services were organised on a residential care basis and recent policy proposals aimed at 'reintegration' of service users into the community have been confronted with many problems. Social support networks, for example, have not been sufficiently developed. Community care is still an unrealised principle. Neighbourhoods either do not welcome disabled people or deal with them in unacceptable ways. More recently, Netherlands produced the 1999-2004 strategic policy plan of the *Gehandicaptenaad* that was entitled 'Full Citizenship'. The principle was that disabled people are no longer prepared to be treated as patients and demand to be accepted as citizens. The keywords of recent polices are 'empowerment' and 'full involvement'.

In Sweden, according to Kjellberg (2002), the aim of legislation (Support and Service for Persons with Certain Functional Impairments, SFS, 1993) is to ensure disabled people enjoy full citizenship. However, Kjellberg claimed that in Sweden today, disabled people are not viewed on equal terms with the non-disabled, with respect to participation in society. Results from Kjellberg's (2002) study showed several factors that hinder or facilitate disabled people enjoying full participation in decision-making. The significant factors included staff members' attitudes, the type of activities performed, and inaccessibility. It is not enough to produce good-quality regulations, but adequate implementation and recognition of disabled people's rights as citizens by the whole society, including regulators, decision-makers, practitioners and public people, are crucial.

According to Kempt (2002) in Australia a third of disabled people's community service needs are unmet. Kempt's study concluded that to gain the services they needed, service users need to submit to the "dominance" of service providers. This resonates with Oliver's (1996) comment:

"Above all else, assessment of need is an exercise in power, as even the language we use to talk about the exercise shows. The professional assesses the need of the client or the users, as they have now come to be called. And various studies over the years show that clients are very unhappy about the way professional assessments of all kind have distorted or denied their needs". (p.70)

Kempt's (2002) study showed that the provision of care and respite services was based on the medical model (the meaning of the medical model of disability will be presented later in this chapter), paramedical services were provided to those who could only be 'cured' and transport services served to 'segregate' disabled people. According to Yeatman (1996), while the key aims of the Commonwealth State Disability Agreement were to set up an initial framework for the rationalisation of the administration of disability services, and to build up integrated service to ensure that disabled people have access to suitable services that meet their individual needs, activity has been almost entirely focussed on developing the framework for administration.

Kempt's (2002) study suggested that, although governments and service providers were striving to achieve a sufficient and equitable production of quality services to meet the needs of disabled people, their efforts were being obstructed by the underlying philosophies of community service provision that have existed unchanged for decades, and service structures that strengthen disabling ideologies. To improve and expand the levels of services, he recommended harder work by service providers at recognising and transforming the philosophical and structural underpinnings of current service provision.

4.2.2 Political Rights of Disabled People

The issue of political rights is not the focus of this study; it is raised here to show how much disabled people are excluded, even from exercising political choice. Marshall's (1964) seminal work identified the granting of political rights as a stage in the development of citizenship that preceded the granting of social

rights. It was reported that disabled people, in the UK, do not enjoy political rights because they do not appear on the electoral register for a whole variety of reasons (Ward 1987; MIND 1990). Others, who do appear, are effectively denied the opportunity to exercise political choice because of access barriers (Spastics Society, 1992); access to polling stations, access to transport to take people there or to access information to make an informed choice (Fry, 1986; Barnes, 1991). However, the Disability Rights Commission Act (1999) promoted a "society" where all disabled people can participate fully as "equal citizens" (Disability Rights Commission, 2000).

In practical terms, there are number of ways in which disabled people find it difficult to participate in the political process, not solely concerned with voting. In the UK, for example, according to Oliver (1996), many local political parties hold their meetings in inaccessible places and hence joining a political party is often not without difficulty. Even if these difficulties are overcome, campaigning is difficult for any of them, because of the problems in the physical and communication environments. These trends have led to a situation in which very few disabled people are active in political parties. David Blunkett, the visually-impaired Home Secretary in the current Labour Government, provides an example of the potential contribution disabled people have to make to political life in the UK, if given the opportunity. However, disabled people having the opportunity to be full participants still seems to be the exception rather than the rule in public life.

According to Al-Mokani (2002), in eastern societies, politics are dominated by cultural values, and issues of race and kinship. However, as a result of the modern development process within the last thirty years, in the Gulf countries, the political trends have been changing. These developing nations have begun to show a determination to reformulate the concepts of 'minorities' and 'citizenship' , to challenge discriminatory attitudes and to ensure that the rights and status of membership are equally distributed to all people in society. However, efforts at the level of national governments may not be reflected in greater empowerment and political participation by disabled people. This is because of the important role that local communities play in the democratic

process, and awareness of the rights of minorities may not yet have been raised at that level. Al-Mokani added that in the Gulf countries, during the last three decades, the political agenda has been changing significantly and the relationship between different groups within society is only as important as the dynamics within each individual community. Al-Mokani suggests that:

> *"It is very important to keep in mind that minorities are not about size, it is rather about power". (p.10)*

Oman has begun to experiment with parliamentary democracy since 1984, but the representation in the Consultative Council (*Majlis Al-Shura)* is based on the population in each *Wilayat, where* disabled people have no power and are seen as minorities. The Basic Statue of the State (1996) ensures full participation in the political activities for all Omanis, but to be a member in the Majlis Al-Shura you have to be elected by the majority, who may still regard disabled people negatively.

4.2.3. Social Rights

The relationship between social rights and the development of citizenship has been defined by Marshall (1952):

> *"By the social element I mean the whole range from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilised being, according to the standards prevailing in the society". (p.11)*

Marshall's theory places social rights at the core of the welfare state, but he did not use the concept 'welfare state'. This may have been perhaps because he was more interested in society than in the state and in this sense, social rights are mainly instrumental in enabling people to lead a civilised existence. According to Marshall, every citizen, irrespective of their class position, shared a common 'equality of status' with others who were also

members of a shared (national) community. The status of the citizen implied not only rights but also certain duties and responsibilities.

Oliver (1996) interpreted Marshall's notion of social citizenship as that of the right not to be poor or live in fear of poverty to use social facilities in the same way as everyone else and to have a standard of living or lifestyle compatible with current social expectations. However, it can be argued that disabled people, especially in the developing world where the majority of them live, do not share the rights to social citizenship. The UN figures show that the majority of such people in the developing countries have incomes below the poverty line (Turmusani, 1999, Thomas, 2000). Even in the UK, the Government's own figures (Joseph Rowntree Foundation, 1999) showed that a substantial number of families with disabled children were reliant on social security benefits. Moreover, ethnic minorities do not receive their full benefit entitlements, as a result of a lack of information and miscommunication. In fact, the benefit system in the UK does not take into account the total costs of having more than one disabled child (Tozer, 1999). This may provide evidence of the inadequacy of the social security system, and also indicate that a significant number of disabled people and their families have low incomes. However, at the global level, there is an underestimation of these figures, and the nature and extent of poverty amongst disabled people is considerable (Thompson *et al.* 1990; Thomas, 2000). The indications are that so many disabled people live in poverty and that the full integration of these people into society is problematic.

Oliver (1996) suggested that social rights, that is, the use of the same facilities as everyone else, are not accorded to disabled people. Rights to move around the built-up environment, to travel on transport systems which claim to be public or to have access to public information of all kinds, because it is usually only produced in spoken or written form, are often denied in the developed world. However, more than fifty countries declared (Washington Declaration, 1999) their commitment to principles intended to ensure independent living for disabled people. One of the principles was:

> *"We recognise the importance of equal and inclusive education, employment opportunities and entrepreneurship,*

> *assistive technology, personal assistance, accessible transportation and a barrier free environment to promote independent living". (p.1- 2)*

As a response to these world trends (for example, the Washington Declaration, 1999, Government Reports on the UN Standard Rules, 1996), the developing countries attempted to take action through the formulation of policy and legislation, on issues of access and so on, to secure equal opportunities for disabled people as equal citizens. However, to translate these written objectives into practical achievements and outcomes for these people, more understanding of the real obstacles and barriers that prevent full inclusion for disabled people in their own societies is vital.

Canada provides another example of the development of policy to ensure the extension of social rights to all members of society, in its vision of full citizenship reflected in its strategy on disability. It has been claimed that Canadian Society is based on the values of equality, inclusion and independence in which disabled people are full participants. Policy statements have recognised that the realisation of the vision is a responsibly shared by all:

> *"Persons with disabilities participate as full citizens in all aspects of Canadian society. The full participation of persons with disabilities requires the commitment of all segments of society. The realization of the vision will allow persons with disabilities to maximize their independence and enhance their well-being through access to required supports and the elimination of barriers that prevent their full participation". (Province of Manitoba, 2002, p.1)*

4.2.4. Civil Rights

Marshall's theory of citizenship, went beyond a narrow conception of legal rights, and extended not only to private property rights and the right of contract, but also to rights in the public arena to freedom of thought and speech and equality before the law, which, by implication, means for disabled people, and the range of freedoms that non-disabled people have. In theory, disabled people are recognised and given these basic civil rights. However, in reality

they face social and environmental barriers to the exercise of those rights, through employment, buying or renting property, and access to goods and services, (Oliver, 1996, Disability Rights Annual Conference, 2002). Those disabled people living in rural communities or even residential centres located in urban communities, may also experience having their freedom curtailed by closed social environments that deny inclusion in the community, communication barriers and other restrictions on their everyday lives.

The UK Government, for example, is committed to securing comprehensive and enforceable civil rights for disabled people. A White Paper was published in 1998 to promote disabled people's rights, which made proposals for a Disability Rights Commission. Following legislation, (Disability Rights Commission Act, 1999), the Commission began work and declared its intention to ensure disabled people's participation as equal citizens. This offers evidence that the UK government is committed to improving the situation and everyday lives of disabled people. Governments must, nevertheless, give more consideration to the issue of how they can improve the attitudes of society towards disability. As Marshall (1952) argued more than fifty years ago the role society has to play in promoting full citizenship rights is vital. He suggests:

> *"Failing to achieve full citizenship rights may call into question the idea of citizenship as a means to the social integration of individuals into society in that is rooted in a conception of what it is to be a full member of a community and social rights that are necessary to protect and reinforce that membership". (p.11)*

This quotation refers to the fact that social inclusion is a condition of citizenship. Every member of society should have equal rights, including the rights to education and work (Swain *et al.*, 2003, p.113). However, social inclusion cannot be practically achieved unless society recognises all its members on equal terms. Thomas *et al.* (1998) suggested that, for example, to ensure accessible mainstream schools for disabled young people, as an imperative right for them, society must in principle underpin their right of education; with practical developments in the curriculum and teaching, the

organisation and management of schools, the physical environment, and the ethos and culture of the education community.

4.2.5. The Duties and Obligations of Citizenship

I have suggested that disabled people are not accorded the full range of rights that are granted to citizens. However, definitions of citizenship include the duties and obligations a society requires of its members. The concept of rights has been framed to mean basic human rights, including freedom of thought, belief and expression, freedom of association, freedom from discrimination on the grounds of race and sex and so on (NCC, 1990). Definitions of the duties and obligations of citizenship are also influenced by current political ideologies. The concept of political rights or freedom has tended to describe the idea of citizenship as the protection of the individual from the interference of the state. Currently, there is a connection between the idea of citizenship and the obligations of the state to its citizenry. There has therefore been a distinction drawn between individual and collective models of citizenship, reflected in the conceptualisation of the relationship between the citizen and the state and that between the citizen and society.

In Marshall's analysis, this distinction might be accounted for by the stages in the development of modern society, with a consequential progress from the recognition of the legal and political rights and status of individuals, preceding the acknowledgement of the collective duties of society to each of its members. More recently, commentators have suggested that the notion of the relationship between the citizen and the state in the UK has been re-conceptualised in individualistic terms. Oliver (1996) claimed that the duties and obligations of the citizen are seen as the contribution of the individual to the collective welfare of all. However, Dwyer's (2004) analysis offers an alternative slant; in the late 1990s the duties and obligations of the active citizen became that of contributing to their own individual welfare because, only in this way, can the welfare of all be maximised.

According to Taylor (1989), social policy programmes based on either collective or individualistic notions of welfare and citizenship have not been wholly successfully He suggested:

> *"Citizenship has not been realised for excluded groups either through the false collectivism of social democratic welfare or through the consumerist democracy of the market". (p.19)*

As mentioned earlier, the poverty experienced by disabled people, their restricted access to public transport, housing, employment and so on, can be regarded as evidence of the state's failure to provide equal opportunities for the disabled (Walmsley, 1991).

In the context of social relations based on citizenship, it can be observed that disabled people have been denied access to their full rights , as they have also been denied access on account of their impairment in the UK. According to Morris (1992) and Stuart (1992) there has been a reluctance to talk in any detail about the social relationships between groups who experience oppression that emerges in different ways, including "ageism, racism, disablism" and so on. In their study about ageing and disability, Zarb and Oliver (1993) suggested that:

> *"Although it is clear that older disabled people have no wish to demand any more than they need to maintain control over their own lives, the combination of ageism, disablism and other form of oppression, means that many are forced into a life of dependency and denied even the most basic rights of citizenship". (p, 131)*

The citizenship concept as expressed by Marshall, highlights the relationship between individuals and society, and most definitions of citizenship that came later, can be related to this. Turner (1986) says that:

> *"Citizenship may be defined in various ways (by reference to civil, legal, and social features) but citizenship rights are essentially concerned with the nature of the social participation of persons within the community as fully recognised legal members". (p.134)*

Social participation in the community, sometimes, depends on the customs and practices of the community itself and the implications of different types of impairment in alternative community environments illustrate the significance of the social model of disability. Subjective perceptions of disability, social expectations of the 'able' and the practical implications of disability that prevail in particular social and historical contexts are all relevant. For instance, blind people in Oman were traditionally not considered as disabled by, or in the context of their own communities, as were those who had physical and/or cognitive impairments. That was because most of them could learn religious teachings by heart, practice their everyday lives in a local agricultural community in a normal way; and constitute their own families as the others do. The disabling or enabling nature of the social environment was exemplified by Martha's Vineyard, an isolated community off the North American coast, where deaf people participated fully in their community because everyone there spoke sign language (Groce, 1985).

4.2.6. Citizenship and Children

I should point out here that there are certain problems when applying Marshall's concept of citizenship to children. In his analysis, the development of social citizenship is based on an evolutionary process, with the granting of social rights being based on a foundation of legal and political rights. As Alderson (2002) points out, modern concepts of rights are only 400 -800 years old. Paine (1790, 1792) also wrote of the "inalienable rights of man" (sic) in a history which denied rights to women, let alone children. The basic rights implied by equality before the law, granted in the United Kingdom in the 18th century, might be recognized today as fundamental and universal human rights and are reflected in the United Nations declaration and, therefore, it could be argued, apply to women as well as men, children as well as adults. Children were once seen as the property of their parents, but this concept has been changing since before the introduction of the welfare state in developed societies. Historically the

greater vulnerability of the child was acknowledged to some extent in the recognition of the need for protection, although it may seem that at times the law has treated the child as a possession or subhuman creature, entitled to protection from extremes of cruelty and neglect.

Equal political rights however, though achieved in the UK in the 19th and early 20th centuries, are reserved for and awarded to 'adults', as defined by the respective state and in keeping with the cultural norms of that society. So for Western democracies, including Britain, 'universal' suffrage, the right to vote and the status and power that that implies, was granted first to men, and the age at which a young person became an adult, in the sense of having 'the vote', has changed with society. However political rights are dependent on the individual attaining the recognized age of adulthood, and thus in so far as citizenship rights involve the right to vote and hold office, a child can not achieve citizenship in the sense defined by Marshall.

Furthermore, with respect to Marshall's concept of 'social rights', it must be argued that the British welfare state, which provided the context for his theorizing about social rights, was based on the 'male breadwinner model' of citizenship. Welfare rights to income subsidy and substitution were conditional upon contributions through the National Insurance system, so access of married women and children to benefits was indirect. Similarly, early access to publicly funded medical care was restricted to the contributing (usually male) adult worker.

Applying the concept of citizenship to children is problematic because it is based on ideas of exclusive membership and conditional upon contributions (originally military service) which children are unable to fulfill (although young people may today serve in the armed forces in many Western democracies before they are old enough to vote). The UN Convention on the Rights of the Child talks of rights founded on universal obligations to children, based on humanity rather than membership of a particular state, community or other association. In recent years there has been a re-emergence of the concept of conditional citizenship and rights contingent on contribution and an emphasis on

education as a preparation for citizenship. Childhood is not fixed but develops with society and varies between societies.

> '*In truth, definitions of children, as well as the varied childhoods which children experience, are social constructs shaped by a range of social, historical and cultural factors'.* (Franklin, 2002, p.17)

The modern concept of childhood, as a prolonged period of innocence and dependence, originated in the 16th century in Europe (Franklin, 2002). However, for the majority of 'children' in most societies denial of the rights of adult status, including personal autonomy and public participation, has not meant exemption from contribution to the lives and welfare of their families and societies, through various sorts of service. When Marshall wrote about the concept of welfare citizenship, young people could work from the age of 14. Therefore, because the British government's social programmes have emphasized the link between rights and responsibilities, the recent interest in the literature concerning conditional citizenship (as discussed earlier) is relevant to the situation of the child in modern society. The government's interest in children as potential and emerging citizens, can be discerned in childcare policy initiatives and the promotion of education for citizenship in schools (Hine *et al.*, 2004).

The idea of children as potential and emerging citizens has long been reflected in common law, statute and case law, for example, it is applied to decision-making about when a child can give consent to treatment in the United Kingdom (case law). The right to be consulted in decisions concerning welfare and accommodation, may be seen as statutory rights rather than responsibilities (Children Act, 1989). The age of criminal responsibility, at which a child can be tried in an adult court, varies between modern Western democracies, but is not set at the age of majority. Contract Law in Britain allows a young person at 16 years of age to accept the responsibilities of being party to a contract, or they may be even younger to contract for the 'necessaries'. Similarly the legal age at which a child can work or marry is below the age of majority. Therefore, rather than focus on the limitations of applying Marshall's model of citizenship to children, it might perhaps be more useful to recognize that the idea of the child

as a future, potential and emerging citizen, should apply to all and thus include disabled young people, if they are ever to realize their potential as full and equal citizens with their non-disabled peers.

As we saw earlier in this chapter, Marshall's work on citizenship focused on the key aspects of the relationship between the citizen and the state and the way that relationship had evolved in the development of the British welfare state. To Marshall, 'citizenship' concerned the relationship between individuals and their societies; and the gradual recognition of equality, through equal legal and political rights, to equal rights to a guaranteed standard of living and welfare. Marshall also talked about the role of the welfare state in addressing the issues of poverty and disadvantage, as obstacles to every individual's full participation in society. However, Marshall's concept of citizenship was applied to adults rather than children and in focusing, historically, on the principles of equality before the law and universal adult suffrage, did not concern itself with the development of the relationship between the state and the child.

Is the concept of citizenship relevant today to the situation of the child? What should the child citizen expect of his or her relationship with the state and civil society? It appears that the issue of what the individual should expect from the state is more complex than it was in the 1950s, as the world has changed so much since Marshall was writing in the early years of the world's first 'welfare state' in the United Kingdom. Today, in a changing world, where economic, social and health problems are becoming more complex, the question of how far it is possible for governments, especially in the developing countries, to secure a decent life for all their population, including children, is worthy of debate.

The latest literature on citizenship relates the concept of citizenship with the notion of community, which needs to be seen in the context of inclusion and exclusion issues. Dwyer (2004, p. 16) pointed out that rules about who has a lawful claim to welfare rights and who does not, and the reasons why certain claims are viewed as valid while others are dismissed, are of more than theoretical interest. He added that to enjoy social rights, individuals need to have their right to membership recognised by others within a community.

However, Drake (2001) suggested that simple membership is not enough; participation within society is also a requirement of full citizenship. Dwyer (2004) claimed that if certain individuals or groups lack rights to welfare, and they are unable to take part in society in meaningful ways, then the very idea of citizenship, of a shared common status, begins to lose its meaning for some members of society. The status of citizenship and participation in the life of the community depends on access to the expected standards of living of a citizen and the means to exercise rights and choices The status of children as future citizens requires the recognition of their rights to be treated equally as valued members of their communities, consistent their cultural norms and social expectations. This implies fair access to society and its resources and formal and informal means of socialisation and education, as a preparation for participation as adult citizens. For the disabled child, as for every other, denial of basic rights to evolve, to develop social and life skills and to learn about and participate in the cultural, economic and social life of their community, means denial of his or her potential as a future citizen.

In recent decades, there has been an aspiration shared by many policy makers and campaigners around the world, especially in the Western countries, to enable children to fully realise their citizenship, in terms of equal opportunities to participate in their own societies (Franklin, 2002). Citizenship was originally based upon individual rights defined in legislation, while more recent analyses relate it to individual 'freedoms' not set out in law.

During the last twenty years, the world has witnessed a transition towards ensuring full recognition of the implications of the rights of citizenship for children. To support the development of children and to facilitate their full membership and participation in their societies, the United Nations (UN) made a declaration in the Child Rights Convention, with which all countries in the world were asked to comply. The key goal of the Convention was "full participation and equality". Issues like the principle of the child's rights to full participation and equality became recognised across the world. Newell (2002) suggested that the recognition of child rights was globally stipulated. The World Programme of Action (UN, 1982) states that resources must be employed in

such a way as to ensure, for every individual, including children, equal opportunity for participation. For this, society must raise the level of expectation so that children have full citizenship, and mobilize their full resources for social change. Each state has an obligation to strengthen the position of children as full members of society and developing citizens. This is through introducing and/or supporting the implementation of polices concerned with ensuring equality and inclusion. However, it is not yet clear whether or not children enjoy opportunities on equal terms with the rest of the population, with respect to participation in society. The situation of the disabled child is, therefore, even more precarious with regard to their rights as both equal members of society and their opportunity to develop their potential to fulfil their responsibilities as citizens.

Legislation has been introduced in the UK (Children Act, 1989; Carers and Disabled Children Act 2000 and others) that have recognised the rights of every child, including those with impairments or otherwise 'in need', to minimum standards of living and opportunities to develop physically and socially. However, these have not resulted in the achieving of the full inclusion of disabled children, the fulfilment of rights to make informed choices or equality for all. For example, as we saw earlier, a review of research concerning these children and their families, commissioned by the Joseph Rowntree Foundation (1999), showed that the rights of children to be consulted are often not recognised in practice, particularly in the case of disabled young people who experience high levels of support need. Another example, found by the Audit Commission (2004, p.48), was that disabled young people and their families were, in general, poorly served and remained at risk of social exclusion. There were various reasons suggested for these deficiencies in service provision, including the fact that practitioners did not feel that children, whether disabled or not, had the necessary skills or experience to communicate with them; it might also have been because many people in society, including parents, public, professionals and decision-makers, lacked an understanding of children's rights, particularly their rights to choice, freedom and full participation in society. Jans (2004) suggested that many supporters of the children's rights movement

strive to achieve full membership for them in society. Such membership means that children cannot be separated from the rest of society and treated differently, as people without the right to develop and express opinions. Children should be considered as able to formulate their own opinions, based on their level of understanding and experience and to share in taking decisions, especially those about their own affairs (Flekkoy and Kaufman, 1997). The whole thrust of government policy in the United Kingdom is towards the involvement of children in the decision-making that affects their lives and the services they use, and the development of their skills and potential as future contributing, participating citizens.

The context in which consideration is given to the rights and status of children needs to be clarified. Decades ago, especially in developing countries including Oman, the concept of children's rights was not even part of the daily dialogue of society. Franklin (2002, 21) pointed out that children in different societies are denied some basic human rights, which as adults, they take for granted. The dominant belief was that adults were fully responsible for children's affairs and children were not able to take any kind of responsibility. Moreover, children were not capable of expressing their opinions, even about their own lives (Al-Koly, 2000). For instance, it was quite common for a young woman or young man to be married without his/her consent. Adults thus used to deny children the right of choice and expression, even in private issues like marriage. However, nowadays the issue of children's rights has greater prominence and the situation has improved. For example, in Omani society, parents are becoming accustomed to giving their children more opportunities to take decisions about their own activities and plans for the future, including their studies and marriage; parents no longer intervene, even in very private issues like marriage. However, it is still the dominant view that children cannot take their own decisions independently, without the advice and support of their families, and adults are still expected to act on their behalf in the public realm.

It has been pointed out that even in developed countries, Franklin (2002), that the denial of children's rights is evident in the public domain of children's involvement in education and the care arrangements of the state, as well as in

the private realm of the family. Children's exclusion from decision-making ranges from relatively unimportant matters, such as decisions about what to eat, which clothes to wear or what time to go to bed, to more significant concerns about the right to a voice in shaping the curriculum at school and the rights to vote (Jans, 2004; Franklin, 2002). Lack of acceptance of children's rights to participation, expression and choice may undermine their dignity as equal citizens. If society does not recognise a shared responsibility with regard to the rights and needs of all children, they may be deprived of a means of guaranteeing that their basic rights and needs are met, because they are vulnerable to the control, resources and ability of those deemed to have responsibility for them. Parents and guardians may not be well informed or motivated and may themselves be disadvantaged by poverty, lack of education, and have needs unmet, for example, for adequate healthcare and housing.

The revival of participatory discourse stands out in contrast to this bleak background; children have started to receive more and better opportunities in which to achieve and exercise rights and take more responsibilities (Jans, 2004). The UN Convention on the Rights of the Child (1989), which was approved by the vast majority of the world states, clarified in detail the entire concept of the Child's rights and responsibilities. This may make societies more aware about the issue of children's citizenship. Such a notion has been included in the curriculum of schools , which aims to teach all children what the concept of citizenship means to them, in preparation both for adult life and to gradually enable them to exercise the rights and responsibilities implied in being a good citizen (Hine *et al*., 2004). Nowadays, children in the west are encouraged to be the authors of their own life stories (Beck, 1997). There is evidence that they are able to fulfil these responsibilities and to present themselves as social actors with their own interests and rights (Wyness, 1996). Wyness (1996) pointed out that children have increasingly begun to grasp the opportunity to show themselves as individuals. Jans (2004) suggested that a recognition of the right of children to address their desires and means is on the increase. Moreover, Jans (2004) indicated that the difference between children and adults can no longer be indicated by a classic modern frame of concepts, in which

children are the ones who need to become qualified and adults are already fully qualified.

Jans (2004) pointed out that the meaning of citizenship as a whole, in a rights approach, includes full citizenship for children, only when they have the same rights as adults. However, children, whether in developed countries or/and developing countries, do not have the right to vote. The age of majority varies between societies and over time, and so is not determined by a chronological age or level of maturity. The level of actual participation by adult citizens in the world's best established democracies is often below half the population who have the right to vote. Nevertheless, this means children cannot be seen as full citizens, because they do not have the responsibility to take part in the democratic process or the power to hold political leaders to account. The children's rights movement has gone some way to addressing this distinction by attempting to secure recognition for their rights and autonomy for them through a say in the decision-making that affects their own individual lives and to enable them to contribute to civic processes, by being consulted on the public policies that affect them as a social group. According to Jans (2004) the participation and involvement approach offers an opportunity for the development of children's citizenship. Jans added that while, in former days, citizenship used to be a static given and the final destination of childhood, nowadays, citizenship presents itself as a dynamic and continuous learning process.

Stroobants *et al.* (2001) stated that adults and children are interdependent in the learning process by which they give a meaning and shape to their citizenship. If society recognises this mutual dependence, the social position of children is less problematic. Citizenship for children, therefore, should no longer be presented as an impossibility, but as a realisable aspiration that runs in parallel with the achievement of the international movement of child's rights. In the Child's Right Convention, Article (26) states the right to survival and includes the right to development. These rights include among others, the child's claim to 'the highest attainable standard of health' and to benefit from 'social insurance'. The right to education is also strongly expressed (Article 28 and 29). The concern about development is also reflected in Article

23, which provides for development rights for the disabled child. However, according to Middleton (1999, p.119) citizenship for disabled young people is more than improving the quality of existing services; participation as citizens means becoming part of the decision-making processes which determine the sort of society we live in, and hence what kind of services are desirable.

4.2.7. Citizenship and Welfare

Disabled people, like everybody else, might expect state welfare to provide security for all its members. Whether or not disabled people are accorded all the rights of citizenship is questionable. In his comments on this, Oliver, (1996) says:

> *"Not only has state welfare not ensured the citizenship rights of disabled people, but through some of its provisions and practices it has infringed and even taken away some of these rights". (p.52)*

For example, Oliver considered that segregated residential care provision denied some disabled people the right to live where they chose to live. The imposition of some assessment procedures deny some disabled people the right to privacy in that they have to reveal details of all their financial affairs in order to be supplied with aid for daily living.

The relationship between ensuring that daily needs are met to minimum standards and the provision of statutory entitlements is debatable on the grounds that, despite the establishment of a comprehensive legal framework for the provision of services to disabled people in the UK, for different reasons, including lack of information, inaccessibility and attitudes of professionals, these services may not be received by those who need them (Oliver and Barnes 1991, Oliver, 1996). More recently, as mentioned earlier, the Government in the UK, as in most of the developed countries, has decided to develop the way it provides care in the community. However, despite the public investment in services and all the achievements at the policy level, giving consideration to the issue of citizenship rights, we need to re-consider whether or not disabled

people and their families have been enabled, in their struggle to live independently, as others do.

4.3. Models of Disabilities

Social policies relating to disability can be understood with reference to different approaches including isolation, medical and social models of disability (Turmussani, 1999, Lang, 2000, Shakespeare and Watson, 1999). The first, the isolation model, looks negatively at disabled people and considers illogical explanations for the individual's problem. From this perspective, marginalisation from the community, with minimum intervention to keep the disabled person alive, is the best solution. Examples of the implications of such notions are the treatment of those people who have Leprosy or Aids; they are likely to be placed in isolated institutions. Societies, especially in the developing countries, believe that such people should be isolated.

The medical model recognises the need for caring and equal rights for disabled people, yet considers the problem as personal. From this perspective, disability is looked at as an individual problem that requires interventions for "cure or care". The social model recognises the disabling nature of the social and physical environment and is based on the principles of equal opportunities, adequate service provision and full inclusion for disabled people in their own societies (Turmusani, 1999). This model, like the citizenship concept, is concerned with ensuring equal rights and the removal of all kind of obstacles that prevent full participation and anti-discrimination legislation.

However, Lang (2000) suggests that medical and social models of disability provide incomplete explanations, with each partially reflecting the "reality" of disability. The following discussion, examines these models, defines and seeks to find a comprehensive understanding of the medical and social models of disability, in terms of their implications for service provision and enable disabled people to achieve full inclusion in their own societies. According to Lang, neither model can fully explain how disabled people can be enabled to recognise their potential to change their present situation, and to be full and active citizens in the contemporary societies in which they live. Both

models are based on philosophical assumptions about the understanding of human nature, the process of social change and development, and how individuals within their own society are able to function.

4.3.1 The Medical Model

The medical model is generally considered to focus attention on individual impairments and to suggest "care or cure" interventions to deal with disabled people. By locating and situating the problem of disability with the individual, impairment becomes an individual responsibility. Society's responsibility towards disabled people is thus minimised and the responsibility of professionals is maximised (Dalley, 1991). Having said that, it is equally important to note if the problem is located with an individual, then the solution may involve the individual being assisted and trained to cope better. In this sense, this model, though putting the burden on the individual, may imply the need for society to provide assistance.

In this account, the construction of disability is explained in relation to poor inclusion in the mainstream of societies. Disabled people are excluded from mainstream society due to their functional limitations and their inability to perform social activities. Thus, an individual who is unable to walk is seen as being disabled because he or she cannot walk. In fact, this narrow view may negatively impact on the identity of disabled people who have considered themselves to be ill, rather than impaired (Campbell and Oliver, 1996).

In this model, disability is defined primarily as a disease state and perceived as a deviation from normality. It looks on the disability from the point of view that disabled people face the loss of physical and/or cognitive impairments, as well as occupational ability. Hence, the medical model views disability as a problem, focusing upon the individual physical and /or mental impairments. This model also assumes that disabled people are biologically and psychologically inferior to those who are able-bodied, and by implication, often do not have the competence to make decisions for themselves (Imrie, 1997). In the context of the medical model, service providers continued to view disabled

people as a problem with the emphasis on what they could not do because of their disability (Dowling and Dolan, 2001). Thus, the medical model does not give enough consideration to those factors which may prevent disabled people from having adequate services and an accessible social environment. It is the individual, rather than society that has to adapt.

Disability, within the medical model, is seen as a personal tragedy, which occurs in individuals on a random basis, as it is a matter of misfortune (Oliver, 1990). Furthermore, the medical model of disability assumes that there is an objective state of 'normality', which gives professionals a dominant role. Finkelstein (1993) has argued that the aim of returning the individual to the state of normality is the critical foundation upon which the whole "rehabilitation machine" is constructed. Furthermore, Finklestien asserted that there is little scope for disabled people and their families to participate in any decision-making because of professional dominance.

4.3.2 Critique of the Medical Model of Disability

A comment by Oliver (1996) suggested that the problem of disability cannot be denied, but should be strongly located within society. It is not individual limitations, of whatever kind, which cause the problems, but society's failure to provide appropriate services and to adequately ensure that the needs of disabled people are fully taken into account in the social organisation. Those who seek to locate disability issues in the context of a socio-political-cultural perspective, do not perceive the medical model of disability as the best approach to addressing the problems of disabled people.

According to Lang (2000), the principle criticism of the medical model is that it fails to give consideration to the socio-cultural context in which impairments are placed, and that disability is essentially a social, not a biological construct. The emphasis placed upon impairments and physiological conditions maintains the notion that disabled people are weak and dependent, and that physical incapacity essentially defines the quality of life that a disabled person is able to live. Lang (2000) adds that:

> *"In criticising the model, one does not question the necessity and validity of offering high quality medical support, but rather one challenges the nature of the social conditions and relationships that are encountered when disabled people and the medical profession interrelate with each other over*". (p.2)

4.3.3 The Social Model of Disability

The social model of disability provides a socio-political conceptualisation of disability. This model has arisen in response to the critique of the medical model. While the medical model focuses on the deficits of the functional, physiological and cognitive abilities of the impaired individual, the social model is concerned with the oppressive structure of society, and the negative social attitudes encountered by disabled people throughout their lives (Hahn, 1986). Hahn claimed that disability stems from the failure of a structured social environment to adjust to the needs and aspirations of disabled people as citizens, rather than from the inability of disabled individuals to adapt to the demands of society.

The World Health Organisation (WHO) started centring the perspective of disabled people in its care policies, giving an account of society's essential role. Different voices of disabled people from the world countries were raised in the conference "Rethinking Care" organised by WHO in August (2001). Examples of these voices are as follows:

> *"Everything is restricted in such a way that people with a disability are entirely left out*" (A disabled student, Ghana). (p.6)

> *"Over the fifteen years of my disability, I have learned what it is like to be isolated, segregated, and discriminated against. I know this, not only because of my own experience, but because I have joined an organisation of*

others who have the same condition, and who have the same experiences" (A psychiatric system survivor, United States of America). (p.6)

"We (disabled people) have to gain control of our own lives, our own physical rehabilitation, our own personal assistance" (A disabled activist, Belgium). (p.6)

"*Disabled people have been the most destitute of Africans. Government planners have tended to emphasise the majority and thus they have ignored the needs of disabled people and their families. African society has already accorded women a lower status than man. Disabled women face discrimination because they are women and because they are disabled"* (A disabled Women, Zambia). (p.7)

"Today's challenge is the participation of disabled people as members of civil society; as leading characters in the diagnosis, elaboration and evaluation of public policies, so as to reach a better approach" (A disabled lawyer, Chile). (p.7)

"Society has to acknowledge that, until there is a coordination of effort between a range of medical, allied health, and developmental services, families (with disabled children) will go on facing stress and pain" (A professional working with families with disabled children). (p.7)

"All treatment should have the objective to improve human life, not just the body" (A representative of an international non-governmental organisation for disabled people). (p.7)

However, these statements were made by activists amongst disabled people, other disabled people, their parents and professionals around the world, may have evidence to offer of multiple deprivation experienced in economic, political and social terms. The deprivation experienced may be attributed mainly to the inadequacy of current service provision and their inaccessibility. More importantly, if this is the case in all countries, including the developed countries, in the developing countries, where resources are rather poor, ignorance of disability issues is quite common and the incidence of disabilities is greater, the situation suggests an urgent need for substantial and comprehensive improvements (WHO, 2001).

Alongside this new understanding of disability issues, there is a growing recognition that health and disability can no longer be understood in purely medical terms and that a more holistic approach is required. The significance of this approach, according to WHO, is to consider the wider society and to give more consideration to economic, political, cultural and social issues. This perspective means that disability is no longer seen as an isolated issue and disabled people as disadvantaged by their individual conditions and impairments; however, all barriers should be removed, if we seek full participation for them.

As a result of the growth of the disability movement, the Western world has developed a body of academic and policy literature based on the understanding of disability. For instance, in the UK researchers (Oliver, 1990; Oliver, 1996; Barnes, 1991; Morris, 1991; Morris, 2000), have provided analyses of disabling social relations, evidence of discrimination, in accounts of disabled people's lives. Recently, the literature has extended a social model approach into various areas of society and disability, and challenged individualist traditions of analysis (Shakespeare, 1996, Shakespeare and Watson, 2002).

There has also been an attempt to achieve a wider and clearer understanding and to produce an updated social model of disability that includes a positive statement about disabled people; recognises their diversity

and difference; recognises institutionalised discrimination; talks about choice; recognises that all the things that exclude disabled people are about society barriers; and talks about the source of these barriers including attitudes and access (Greater London Action on Disability (GLAD), 2000). Disability has in recent literature, therefore, been situated in the wider, external environment, and is not explicable as a consequence of an individual's physical and/or cognitive deficiencies. Thus, in focusing upon the manner in which disability is socially produced, the social model has shifted the debate regarding disability from a bio-medically dominated agenda to one which gives central importance to politics, empowerment, citizenship and choice (Lang, 2000). The disability, hence, is the result of society's failure to provide adequate and appropriate services, and because the needs of disabled people are not adequately accounted for, within the social organisation of society. Lang (2000) suggested that:

> *"A central tenet of the social model is that, irrespective of the political, economic and religious character of the society in which they live, disabled people are subject to oppression and negative social attitudes that inevitably undermine their person-hood and status of full citizenship. (p.3)*

Oliver (1996) suggested that, initially, some professionals, policymakers and staff from organisations for disabled people rejected the social model, because they had vested interests in maintaining the status quo that underpinned the medical model and questioned the experiential validity and explanatory reliability of the social model. However, we have seen a transition, to the extent that many professionals have now become supporters of the social model, in theory at least (Oliver, 1990; Oliver, 1996).

The social model sees disability from the angle of all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on (Morris, 2000, UPIAS, Union of Physically Impaired Against Segregation, 1976). According to UPIAS (1976), the disability has sometimes resulted from society's attitudes:

> *"In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society". (p.14)*

The social model argues that rather than just investing time and effort in medical or psychological interventions to correct the impaired body, it is also appropriate to remove the barriers in society which cause problems for disabled people. Examples of these problems, may be inaccessible physical environments, discriminatory employment, inadequate welfare polices, segregated transport, negative and prejudiced attitudes (Shakespeare and Watson, 1999, Morris, 2000).

Oliver (1996) suggests that disabled people demand to be accepted by society as they are, not as society thinks they should be. It is society that has to change, not individuals; and this change should not be through social policies and programmes delivered by politicians and policy-makers nor through individual treatments and interventions provided by the medical and care professions, but as part of a process of political empowerment of disabled people as equal citizens. Thus, Oliver asserted that the core of the social model and its message should not be confused by conceptual misunderstandings about meanings of terms like illness and disability.

Usually, disabled young people's views, in the context of the social model, have been taken into account only as a result of adults' experiences. Even when Shakespeare and Watson (1999) identified principles that they thought helpful in their research with disabled children, they claimed that though their ideas were based on adults' political practice, they might also be connected to the experience of disabled children. But more recently, Shakespeare and Watson (2002) in their research with disabled children (the "Life as a Disabled Child" project), funded by the UK Economic and Social Research Council, started with the idea of imposing the social model perspective on disabled children's lives. However, Shakespeare and Watson, because they were following the implications of the new sociology of childhood

and treating children as agents, were forced to rethink their adult-oriented social model assumptions. They suggested that children easily identified the social barriers that they experienced, and often complained about the treatment that they received. This meant that disabled young people were able to understand their own social world; it also meant that their disability is caused by their society rather than their impairment.

Shakespeare and Watson (1999) suggested three principles that they thought helpful in examining the experiences of disabled people. First, the principle of equality has different implications. The social model suggests that the social experience of disabled people, including children, can be understood in terms of disadvantage and restriction, not physical incapacity. The widespread poverty, unemployment and marginalisation of disabled people are not explained by individualistic differences, but in terms of social policies, economic priorities, and physical barriers. Removing such inequality between disabled people and non-disabled people, in terms of access to society, political and economic resources, will make a vital difference and will bridge the gap between them.

It is worth noting that the concept of equality has a wider meaning than just economics (Alcock *et al.*, 1998). Equality suggests that disabled people are entitled to full citizenship rights, and to equal treatment with non-disabled people (Dwyer, 2004). Many states have enacted anti-discrimination legislation. Some Arab Countries, including Kuwait, Jordan and Bahrain, have produced regulations to establish that disabled people have to be served equally. Oman has not yet developed such regulations or introduced legislation to implement these policy objectives. It seems that instead Oman currently uses the UN conventions in this regard, at least in theory. These regulations were produced as a result of pressure from disabled people and their advocates, as well as the UN organisations including UNICEF, ILO, and Human Rights (Thomas, 2000, Turmusani, 1999). However, due to these efforts and a growing understanding and awareness of disability issues, the situation of disabled people and their families may improve, in terms of obtaining more opportunities to voice their demands and in securing a place in mainstream society.

The second principle, identified in the work of Shakespeare and Watson (1999), is inclusion. This explains the ways in which environments and policies have developed which clearly exclude disabled people, or do not take in account their different needs as members of society. It has been argued that not only do disabled people have "special needs", but also everybody has needs that should be met. The difference is that the needs of disabled people are less likely to be fulfilled. Therefore, structures and systems need to be developed in which disabled people's needs are not ignored. A particular example of this is education, where disabled young people have been excluded historically and where they and their families are now demanding access. Inclusion is regarded as being a more appropriate notion than integration (Mason and Reiser 1994). While integration as a concept seems to imply that if society does not change, disabled people have to be normalised; the idea of inclusion means that all barriers should be removed and systems should be explicitly designed to make society accessible for all; inclusion also allows the recognition of difference whereas integration seems to play down its importance.

The third principle that has also emerged from the campaigning practice and political action of disabled people, is the idea of autonomy. It claims that disabled people are the experts on their lives. The principle of autonomy suggests that most professionals, bureaucrats, clinicians, therapists and others may actually become obstacles to the self-development and liberation of disabled people. Wherever possible, disabled people should be in positions of power.

Instead of acting on behalf of disabled people, service providers should give them a chance to make decisions for themselves. Providing them with what they want is so much more effective than giving them what professionals think they need. The principle of autonomy does not mean that experts and professionals should be disregarded. The technical knowledge they possess and the assistance of committed workers in education, health and social services is vital to disabled young people and their families and even organisations. However, the key for disabled people themselves is to be

involved individually and collectively, to state the priorities and to have a real voice in decision-making about their lives.

4.3.4. Criticisms the Social Model

A major criticism of the social model has been made by the disabled themselves. They have argued that this model does not connect with their experience of impairment. French (1993), for example, argued that her impairment 'blindness' imposed social restrictions that cannot be resolved by the application of the principles of the social model. As a blind person, she is unable to recognise people and read or emit non-verbal signs in social interaction. Other disabled people have criticised the social model for its assumed denial of the 'pain of impairment', both physical and psychological. Morris (1991) claimed that:

> *"There is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability - and do indeed disable us- to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying". (p.10)*

Addressing these criticisms, Crow (1992) argued that the way forward for the social model is to integrate fully the experience of impairment with the experience of disability. However, up to now and for very important reasons, adherents to the social model have insisted that there is no causal relationship between impairment and disability.

A significant criticism came from Finkelstien (1991). He has questioned the ability of the social model to fully explain the social position of disabled people in modern society, and suggested that there are at least two variants; "the social death model and the social barriers model". Greater London Action on Disability (GLAD) (2000) suggested that there is a vital need for an updated social model of disability that includes a positive statement about disabled

people, recognises their diversity and difference, acknowledges institutional discrimination, talks about choice, accepts that not all the things that exclude disabled people are about society's barriers, and talks about attitudes and access. The social model should be publicised to a wider audience than the disability movement, either through the Media or the Internet. The potential of more collective voices, in challenging the common negative portrayal of disabled people, is considerable.

The social model has brought a fundamental change in the way that the exclusion of disabled people has been perceived. However, some considerations were not accounted for adequately. For example, the social model did not consider the individual experience of disability. According to GLAD, for disabled people to have equal access in society there must be a recognition of their difference as individuals and their shared experience of discrimination. Some disabled people ask for wider understanding that the different requirements arising from their impairment need to be met on an individual basis.

Shakespeare and Watson (2002) argued that the very success of the social model is now its main weakness. Because it is such a powerful tool, and because it has been so central to the struggle of the disability movement, it became an ideology that could not easily be challenged. Part of its effectiveness came from its simplicity. It could be simplified to just a phrase: "disabled by society not by our bodies". Organisations and policies could be simply evaluated: did they use the (social model) term "disabled people" or did they use the (medical model) term "people with disabilities"? Did they focus on barrier removal, or did they focus on medical intervention and rehabilitation? The social model could be used to view the world in black and white; however, it was not the intention of those who initially framed it.

The problem sometimes is not in the social model but in those who use it. For example, impairment was never ignored but the activists who advocated the social model did not mention it explicitly. According to Shakespeare and Watson (2002), most activists admit that, behind closed doors, they talk about pains and urinary tract infections, even while they deny the relevance of the

body while they are out campaigning. This inconsistency is not just unacceptable but will lead to more problems and alienation of individuals whose experience of pain and impairment is denied; therefore, a re-examination of the language of the politics of disability needs more honesty. However, there are also political factors behind this denial.

Shakespeare and Watson suggested that the social model itself has become a problem, and that it cannot be reformed. This was because the British version of the social model has outlived its usefulness. The dangerous tendency of associating the social model with purity and orthodoxy in disability politics and disability studies has to be rejected. However, it is only in Britain that the social model has played this role. In other countries, including USA, civil rights, social change and the community based care approach have successfully emerged, in the absence of the dominance of the social model of disability. Of course, in Britain itself, there were other perspectives at the beginning of the disability rights movement. For instance, the Liberation Network of People with Disabilities (Crosby and Jackson, 2000) developed the concept of disabled people as an oppressed minority group without needing to define disability as social oppression.

The invalid distinction between impairment (bodily difference) and disability (social creation) can be revealed by asking, "where does impairment end and disability start?" Corker and French (1999) have argued that not only can sensory conditions include pain but pain itself is generated through the interplay of physiological, psychological and socio-cultural factors. Some impairments because they are invisible may not generate any disability but may have a functional impact and implications for personal identity and psychological well-being. In fact, some impairments cause constant pain, which it is impossible to alleviate just by making the social environment more accessible. For example, if someone has a significant intellectual limitation, we might ask how can society be adjusted to make this irrelevant to employment opportunities? (Abberley, 1996). Thus, there are people who, because of their impairment, cannot work.

Shakespeare and Watson (2002) argued that both the body and social barriers together could be the cause of disablement, and there is a middle ground between the medical and the social model. However, these authors suggested that any interpretation of disability would include all the aspects of disabled people's experiences: bodily, psychological, cultural, social, political, rather than claiming that disability is either medical or social. Shakespeare's and Watson's argument was founded on the idea that the British social model has been an excellent basis for a political movement, but is now an inadequate grounding for a social theory. For the world, now at the beginning of twenty-first century (the social model was born more than thirty years ago), it is possible to claim that a collective perspective with major implications for medical and social intervention is necessary.

4.3.5 The Social Model in Context

I accept the criticisms about the limitations of the social model as outlined by Shakespeare and Watson (2002), French (1993), Morris (1991) Finkelstien (1991) and others. Nevertheless, I also consider that the social model of disability remains applicable to the policy context and to an understanding of the experience of disabled people. Oliver (1996) suggested that the articulation of the social model was welcomed by disabled people themselves because it made an immediate connection to their own experiences. Consequently, I consider the social model to be the most appropriate approach to examine disabled young people's daily lives in the developing countries, where the medical model is dominant,. The social model is also relevant to the study of social inclusion, to an understanding of the citizenship concept and to identifying the societal barriers to participation.

The emphasis of the study, as will be revealed in the next chapter, is on understanding the disabling nature of the social and physical environment from the children's point of view. This, as we saw earlier, is based on the principles of equal opportunities, adequate service provision and full inclusion for disabled young people (Middleton, 1999; Flekkoy and Kaufman, 1997). Their voices and perspectives lie at the heart of the study. This study recognises that they have

the right to express their own views on their own affairs. Adults should start giving them the means to express their opinions and should listen to their voices and understand the significance of their opinions.

As we saw in chapter two, some researchers in the developed countries, particularly in the UK, have enabled disabled young people to raise significant issues that shape their social world and affect the way they experience their different rights. Whatever criticisms of the social model of disability may be, as we saw in the last section of this chapter, the studies in chapter two suggest that disabled people themselves still believe that their exclusion is due to society, which disadvantages physically disabled people. According to Oliver (1998, p.33), disabled people view their disability as something imposed on their other impairments, because of the way they are successfully isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. Their situation of in developing countries is still very backward. As we saw in the first chapter, there is plenty of evidence of the oppression of the disabled, including children; they are excluded from mainstream society, provided with poor services, their voices are ignored and they are discriminated against.

It seems to be the case that professionals and policymakers in developing countries, including Oman, do not see a distinction between disability and impairment. This might imply that the main barriers to disabled young people's inclusion remain hidden. This means that any strategy and/or action intended to develop services for disabled young people is based on the medical model, that is, the provision of services to manage the impairments. However, I consider it is more appropriate for developing countries to start viewing disability issues on the basis of the social approach, given the evidence from developed countries of the negative effects of ignoring the social barriers that disadvantage people, in the development of services. I believe that an understanding of the social model would not only lead to a better understanding of disability but, moreover, it might result in more inclusion for disabled people. This belief has motivated me to examine the experiences and views of disabled young people about their daily lives. Chapters six to eight will present all the

different issues raised and the discussion in these chapters and the later chapters will draw on those experiences and consider them in the light of the social approach.

4.4. Conclusion

In this chapter, we have seen factors, including social, cultural, economic and political ones, which may exclude disabled people from their own societies. Therefore, the responsibility of those societies, which claim to be modern and democratic, is to secure a decent life for disabled people as equal citizens. The theory of citizenship takes the view that all people have to be considered and treated equally by their own states. The examination of the concept of citizenship in this chapter explored the relationship between disabled people and their own societies as well as their responsibilities as equal citizens.

Ensuring full membership for disabled people in their own societies, and securing their social, civil and political rights, are matters that have been examined through a full understanding of the citizenship concept. As mentioned earlier, within the latest three decades, the world has witnessed the increasing expression of the intention to empower and enable disabled people to improve their daily lives. The issues of equality and adequacy of service provision lie at the heart of such efforts. There have been actions taken by world organisations and academic institutions as well as, in some countries, pressure from national movements, which have contributed to re-view the concept of citizenship in order to stimulate more accessibility and inclusion, as well as to ensure citizenship rights for disabled people.

The notion of citizenship and models of disability (medical and social model) will be essentially used as backdrops in analysing the findings of this study. Views of disabled young people, mothers and professionals, who took part in this study, are explored and discussed in the following chapters. The aim is to examine the extent of disabled young people's inclusion in their own society, so that they can exercise their rights and responsibilities as citizens. The conclusions of this study, clarify the extent to which disabled young people

experience difficulties and obstacles to their full inclusion in their own societies. In this regard, the role of impairment and societal barriers is also clarified. However, the final analysis reveals and discusses important details about disabled young people's experiences and perspectives of their inclusion in Omani society, placing their accounts in the context of the literature.

Methodology

5.1 Introduction

Clarke (2001) suggests that qualitative research within the interpretavist tradition is based on several philosophical assumptions concerning the nature of reality and the role of the researcher. According to the interpretavist framework, 'truth' is a very elusive concept. Individuals and groups make their own reality. In other words, the social world consists of multiple, subjective realities. Also, a key theme in the qualitative approach is the emphasis placed upon 'naturalism'. In its widest sense, naturalism maintains that social phenomena are distinct, as they cannot be understood simply by a quantitative approach to data collection and analysis and the use of instruments, like surveys and questionnaires. Consequently, the qualitative researcher uses methods like participant and non-participant observation and non-standardised interviews, as a way of getting close to the data and studying social interaction in its natural surroundings (Robson, 1999; Clarke, 2001). Clarke (2001) points out that the contribution of qualitative research for policy evaluation is increasingly being recognised.

My aim is to capture the experiences of the participants conveyed in their own words; and to use their viewpoints as the basis for discussion and analysis. Padgett (1998, p.8) suggests that when the researcher seeks understanding, the qualitative methods are the way to explain the respondents' position. Padgett adds that the ways in which respondents view their worlds and create meaning from their life experiences are countless and can best be explored by a qualitative approach. Williams and May (1996) suggest that the concern of qualitative research is primarily with qualities of given phenomena and less with quantities. Qualitative research encompasses a range of strategies that allow researchers to get close to the data. They are often described as being concerned with the daily actions of people and the meanings that they attach to their environments and relationships. Research approaches in the qualitative

tradition take various forms that include ethnography, case studies, biography and autobiography. In my research I used the case study approach and relied on in-depth and tape recorded interviews. This method was more appropriate to the subject matter and the focus of my interest than other qualitative methods, because I was concerned with examining disabled young people's understanding of their daily lives. It also enabled me to explore their feelings and reactions.

This chapter explains the methodology and methods used in my study. It has been argued that, to a large extent, the personal perspective of the researcher dictates the methods used in academic research (Wilkie, 1999). In my case, several factors motivated me to conduct this study and to use specific methods. First, I have a personal insight and interest in the topic of this study based on my own experience, as I have a 16 year old daughter who has Spina Bifida. Her experiences, as a disabled child, and mine as a parent, have been complex. I learned from personal involvement that my daughter's disability was not only a medical condition but had implications for her day-to-day relationship with her social environment. Second, I have worked, for more than eighteen years in the social services field in Oman. This professional familiarity taught me that disabled people face complex issues and barriers in their everyday lives and relationships that can only be understood from their specific vantage point. Third, recently I have been appointed as a lecturer in the Department of Social Work Studies in Sultan Qaboos University. My appointment motivated me to read about childhood and disability issues, to try and place my personal and professional experiences in a theoretical context. I realised that children, including disabled young people, have a wide range of firsthand experience of disability, of service philosophies and social policies in practice. They are able to express their opinions about issues in their everyday lives, and have the potential to contribute to the expansion of knowledge, with wider relevance to the development of social policy theory.

Carrying out a piece of social research requires design skills. In designing the study the researcher should specify its scope and objectives, the questions to be asked and how they will be addressed, the methods to be used

to collect the data and why they are appropriate, the sampling strategy and the number of interviewees, ethical considerations and so on. Specifically, I decided that this study would examine the experiences of disabled young people in their everyday lives. This required me to select the most suitable method to elicit information of significance to them, and to the objectives of the study. When I commenced my investigation, I found that in the world of social research, particularly in the childhood area, it had been the case that children were rarely given the opportunity to express their understanding about issues concerning themselves and about which they had firsthand knowledge and experience. The second, very recent development, has been in the publications of guidelines setting out ways to improve communication with disabled young people, including those with communication impairments (e.g. Morris, 1998; Thomas, 1999). However, as Stalker and Connors (2003) argue, it should be emphasised that talking to disabled young people is often no different from talking to any child; many have neither learning difficulties nor communication impairments. They assert:

> *"The most important 'rule' is probably to see the child as a child first and disabled second".* (p.27)

In recent years, the sociology of childhood has witnessed a significant transition, in which the opinions of children, including disabled children, about their everyday lives have been privileged (Middleton, 1999; Brannen and O'Brien, 1995; Connors and Stalker, 2003).

5.2. The Objectives of the Study

The study aimed to understand the social situation of disabled young people and their families in Oman. This included exploring the extent to which society was accessible to disabled youngsters, public attitudes to their disability and the quality of service provision they received, specifically the social, health and education services. Mainly, I aimed to provide an opportunity for disabled youth to explore their experiences and express their understanding of their everyday

lives. They talked about their experiences inside the family, in the wider community, in school and about their relationships with staff in the different organizations they use. The study sought to understand their expectations and concerns about their futures, how they perceived themselves and whether or not they were included in their own society. The study also attempted to understand the views of mothers on the lives and experiences of their disabled children. The accounts of professionals, who worked in health, education and social services, and their standpoint on the lives of the disabled young people, would be examined too.

The study, therefore, had the following objectives:

1. To understand disabled young people's experiences in their daily lives. To explore how they identify themselves in interaction with non-disabled people.
2. To examine disabled young people's experiences of education, health and social services. To explore the extent to which their needs are met and to identify barriers to meeting these needs.
3. To understand the perceptions of mothers about their experiences of their disabled children's daily lives.
4. To examine the perspectives of professionals working with disabled young people, including teachers, social workers and medical workers.

5.3. The Methods

Because of the objectives and questions of the study, I used qualitative methods. In his comparison between quantitative and qualitative methods, Silverman reported that for any researcher who is interested in exploring people's life histories or everyday behaviour, then qualitative methods might be ideal. Qualitative methods are understood simply as the analysis of words and images rather than numbers (Silverman 2000, p.8). Also they are preferred to research based on observation rather than experiment. Unstructured rather than structured interviews are used to explore the meanings actors give to their actions and experiences rather than just the behaviour itself and attempt to

document the world from the point of view of the people studied. Morris (1995) and Thomas (1999) suggested that qualitative approaches are being increasingly used in disability studies, as the details of disabled people and their families' lives are explored.

Therefore, the study was designed to answer its key questions and to fulfil its objectives. In-depth interviews were used to understand disabled youngsters' attitudes towards their everyday lives; their mothers' views, as both the closest carers to their children and the closest witnesses to their experiences, were explored using focus groups; and the views of concerned professionals were examined via semi-structured interviews.

5.3.1 In-Depth Interviews

The in-depth interview is a powerful tool for data collection in qualitative studies. It is important to know what qualitative data coincides with what the researcher is going to collect. The data from interviews are respondents' experiences, opinions, feelings and knowledge (Bryman and Burgess, 1999). The interview has been defined as a conversation with a purpose. It aims at shared understanding and meaningful interaction between the interviewer and the respondent. The researcher should bear in mind that his key role is to build a rapport with the respondents, in order to ensure a flow of relevant information. The researcher should ground an interaction in context, either during pre-visits or during the interview. However, this role requires him/her to have an understanding of both the respondents' circumstances and the larger society. In my case, I had the knowledge that enabled me, as the researcher, to choose and to conduct the interview in a way that encouraged the respondents to be responsive and to explore their experiences, views and feelings.

According to Bryman and Burgess (1999), the validity and reliability of qualitative data depends on the methodological skill, sensitivity, and integrity of the researcher. It means that skilful interviewing involves much more than just asking questions. They also commented that generating useful and credible

qualitative findings requires discipline, knowledge, training, creativity and hard work.

I believed that, through in-depth interviews, the views, experiences, feelings and knowledge of respondents might be fully understood. According to Patton (1990), language is the data of in-depth interviews, enabling the researcher to capture the individual's feelings, thoughts, and perceptions. It means that the respondents' words reveal their mental worlds and subjective experiences. A skilled researcher can link what respondents say with their personal life events. It is thought that in-depth interviews provide a flexibility in interaction, through which both interviewees and interviewers can come to understand each other.

According to Thyer (2001), social workers in most countries receive extensive training in interviewing techniques, as part of their education, and that includes the observational aspects of assessment. Therefore, they enter professional life with confidence in their interviewing skills, and this confidence improves through experience. However, in-depth interviews are much less standardized than other data collection methods because of interviewer variability and interactive effects between interviewers and respondents (Thyer, 2001).

I illustrated in chapter two how disabled young people, through selective methods, including in-depth interviews, might express their views. However, if these children take part in studies and are asked to reveal their perceptions and sensitive, subjective information, several considerations must be taken into account.

5.3.2 Disabled Children's Views

It is worth remembering that, until very recently, the dominant approach to collecting data about children and/or disabled children's worlds, relied on parents and/or professionals' perceptions. Ten years ago, Baldwin and Carlisle (1994) concluded, from their review of the literature, that the voices of disabled young people were largely absent from disabled childhood research:

> "*We found no studies focusing in detail on the disabled child's daily life and the way disability affects her*". (p.33)

And:

> "*We lack children's accounts of pain, discomfort, dependence on others for feeding, bathing and toileting. We do not know how they feel about the way doctors, social workers, therapists and other children treat them*". (p.35)

Since then, there has been, in the UK, an emergence of studies which have sought to understand disabled young people's points of view, although the number is still quite small (e.g. Beresford, 1997; Morris, 1998; Barnes *et al.*, 1999; Robinson and Stalker, 1999; Connors and Stalker, 2003; Connors *et al.*, 2004). Even so, Connors and Stalker (2003, p.11) suggested that it was difficult to find any work exploring the ways in which children 'cope' with disability and that little was known about their experience of being disabled.

Of course, in developing countries, the time has still to come for the development of studies based on understanding the disabled young people's world, and giving them a chance to express themselves in their own words. None of the studies presented in the literature review (Chapter three), about developing countries, including Oman, examined disabled young people's views; and all of them were based on quantitative data.

According to Barnes *et al.* (1999), close discussion with disabled young people to explore their perceptions and experiences, allowed a great deal of specification and helped to address the absence of their voices within childhood research. Punch (2002) suggested that childhood researchers need to consider children's varied social competencies and preferred ways of communicating with unfamiliar adults. Using a flexible range of techniques can be an effective way of managing their different abilities and preferences. However, if researchers choose to draw on a combination of tools, they need to be aware of

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the disadvantages and advantages of each technique and the subsequent implications for the data produced.

In this study, I decided to focus on physically impaired adolescents and so I did not anticipate the need for using special techniques to gain information from the respondents, because all of them were able to communicate verbally. I interviewed them individually, using a recorder, without an interpreter.

Collecting data from disabled young people raised ethical issues of consent, access, privacy and confidentiality (Mauthner, 1997). Although, these are not unique to disabled youngsters, they do present researchers with specific dilemmas to do with unequal relationships, mainly age related, that exist between adult researchers and children as respondents. The argument here is for a child-centred approach to data collection that views children as subjects rather than objects of research, in order to address this difficulty. In this study, I was aware that my relationship with the respondents presented two differences that implied inequality between the researcher and the subjects of the research. I am an adult and non-disabled researcher and the respondents were young and disabled.

The question of unequal power relationships between adult researchers and children (Brannen, 1994) has been posed on the basis of children's rights. This has become an area of growing concern which translates in the research realm to a focus on consent and an approach which takes the perspective and position of the child into account (Children Rights Development Unit, 1994). There are several ways of equalising 'power relations' between researcher and child. Researchers should emphasise the need for reflexivity, responsiveness and methods that allow children to set their own agendas and talk about their daily lives and views according to their own priorities (Farquhar, 1990).

Generally, it was assumed that respondents would prefer the individual interview, because it provides privacy and it is flexible. It allows the respondents more opportunity to say what they want to say comfortably. However, factors like the place where the interview is held, the interaction between the respondents and the researcher, and using a recorder, which might have made some young disabled people feel frightened, were considered.

To obtain consent for accessing disabled young people, whether at school, day-care centres or at home, I had to seek agreement from head teachers, social services departments in the regions, the children themselves and their parents. Accessing disabled young people at home was easier than at schools and centres. To approach them at school and centres, the researcher had to secure the agreement of both the administration of the organisations and parent/s. Sometimes, it involved following long procedures, which meant considerable time and effort. However, accessing disabled young people at home required the agreement of parent/s and sometimes these might act as gatekeepers (Wight and Barnard, 1993).

Another difficulty I faced once I had gained access to disabled young people was negotiating privacy, whether at school, home or in the hospital setting (Alderson, 1994). Obtaining a separate space away from the classroom or the main family room was a sensitive issue. Staff and parents, or adults in general, usually do not consider children's need for private space for an interview. They see themselves as 'protecting' children and they may feel that children do not have the right to privacy at all (Holland *et al.*, 1996). At school, there was a shortage of space. At home, siblings or parents could interrupt the interviews and problems of privacy arose, especially when families were living in cramped housing conditions (Daly, 1992).

Assurances about confidentiality and attention to its implications, is necessary to gain trust and elicit the revealing of information considered sensitive by the respondents. It has been suggested that different results can emerge when interviewing teenagers alone or with their parents (Brannen, 1994). Alone, young people might disclose matters, which, they do not usually reveal in the family. It can be even harder for researchers to obtain the views of disabled young people in the home context. Some parents, especially mothers, wanted to be present and to control, or exert influence over, their children's responses, particularly when trying to uphold a certain public image of their family life. However, as the findings presented later reveal, I managed to overcome such difficulties.

According to Mauthner, *et al.* (1993), eliciting children's accounts of their subjective experiences, requires adopting a flexible approach during the interview. This process can take three forms. First, the researcher can let the children have a greater say in setting the terms of the conversation. Children are likely to talk about a number of topics more easily in the wider setting of their lives, especially in the context of their social relationships. A second way for the researcher to draw out children's subjective experiences is to encourage them to describe events from their daily lives through storytelling. A third approach the researcher can also consider, is to explore children's experiences of the research process itself.

All these matters were considered through each stage of the individual interviews with disabled young people. Most of the interviews took place in both day-care centres and houses. A significant number of these young people were still going to the day-care centres. However, I found it easier to gain access to them in their homes, rather than in the centres. In the latter, it was more likely that other children would disrupt the proceedings; and the participants themselves felt happier to be interviewed in their own homes. Nevertheless, in all cases, I had to reach an agreement with the parent/s before the interviewees took part in the study. All the parent/s, whom I contacted or met, were helpful and, moreover, encouraged their disabled children to participate. However, I was careful to give every child the chance to decide personally whether to take part or not. Fortunately, all of them were delighted to be asked and did not hesitate to express their opinions and to share their experiences of their daily lives. In a few cases, I had to visit them twice. The first visit was to give a full explanation about the aims and implications of the study, for both disabled young people and their parents. The second visit was arranged for the interview. These initial visits were not only useful in terms of giving the youngsters and their families an explanation about the study, but also played a part in increasing the confidence of both parties (interviewees and interviewer).

To maintain privacy while the interview was in process, I attempted to ensure that it took place in a room away from any interruption. During the pilot study and pre-visits, I observed that parents, especially mothers, tended to be

there when their disabled children were talking. The significance and importance of privacy was explained to their family members, especially the parents, before the interviews started.

All the interviewees were informed in advance that the conversations would be taped, and they could either withdraw or take a break anytime they wished. However, the majority of the participants sustained their side of the interview to completion and they did not ask for a break in the middle. As for confidentiality, it was agreed with the participants that their names would be changed.

5.3.3 Mothers' Perspectives (focus groups)

There is evidence from the literature review, and consistent with the nature of social life in Oman, that mothers had a close relationship with their disabled children. They are regarded as more responsible for the care of their offspring than fathers. The majority of the fathers work outside their native cities or villages; they only met their families at weekends. The mothers may have played a key role in helping their children to receive services and to participate in the ordinary life of their communities. However, I could not find a single study that examined mothers' views about their disabled children in neighbouring countries, never mind in Oman. For these important reasons, I arranged four sessions of discussion groups with the mothers of disabled children to examine their perceptions.

Focus groups are discussion-based interviews that produce a particular type of qualitative data. As Milward (1995) said, these groups involve the simultaneous use of multiple respondents to generate data and are focused (that is, on an 'external stimulus') and relatively staged (that is, by a 'moderator'). Their aim was to get closer to the participants' understanding of attitudes towards certain issues.

This method was chosen as a suitable tool to communicate with the mothers with disabled children. In a previous study that I conducted, in Oman, using the focus group method, I found out that the participants were motivated

to disclose vital information, especially if the other participants shared similar conditions and circumstances. It was also more culturally acceptable, and therefore easier, to invite the mothers for group discussion rather than conduct individual interviews. In a conservative society, it is quite difficult for a man to have a (private) individual consultation with a woman. However, a possible disadvantage of the group method is that it might be embarrassing for some mothers to disclose sensitive experiences in the presence of others.

I made contact with the mothers of the disabled young people, who took part, before the focus groups, so that they were informed about the aims and the process of the session. I also obtained their individual consent for the discussion to be recorded. Millward (1995) says that contacting participants can be done in two ways. Firstly, the researcher could visit the respondents in person. This method has the advantage of explaining the process and objectives in face-to face interaction, especially useful for those who do not read or write, and for the moderator and respondents to become acquainted with each other. Secondly, the researcher could write to the individual respondents, and by liaising, by telephone, with a specific member of staff who will explain the process to the respondent. This method is cheaper and, having a member of staff involved, allows the respondents regular access for queries, rather than having to contact the researcher.

I preferred the first way simply because it was the most convenient for most mothers who would take part in the sessions. This way gave me a chance to have personal contact with potential participants, via their families, prior to the group sessions; this facilitated and contributed greatly to group rapport (Millward, 1995).

The number of respondents in each discussion group depends on the study's intended applications. Millward notes that the suggested size of the sample varies, with the size of the individual group being between 6 and 12. I decided to have four discussion groups, one in each region, with between 8 and 12 participants in each group. According to the information that I gained through each session, I did not require a further session for each group.

Each session had a 15-minutes break. Group participants were allowed to bring drinks (water, juice, coffee, tea) into the session with them. However, to create a more friendly and social atmosphere, I myself arranged soft drinks for each session.

According to Millward (1995), the most appropriate focus group style is "process facilitation", in which there is high moderator control over the process with low control over the content of the discussion. I preferred this way, simply because it ensures the generation of relevant data, and encourages participants to clarify their comments where necessary. I was aware that I would be able to elicit explanations of what the participants meant in their comments, and to explore what was implied in less explicit statements. I managed to keep the discussion flowing and focused on the topics, and handled the sessions even when some of the mothers wanted to explore certain issues further, if they were personally uncomfortable. My role was to ensure that all group members have an equal chance of putting forward their views. Of course, such techniques require tact and sensitivity.

Consent was required from each participant. This was obtained prior to the group sessions, when I visited the mothers individually in their families. Also, the group were reminded at the beginning of the sessions that they were allowed to leave the group at any time if they so wished.

Using a tape recorder in the sessions was on the basis of the participants' agreement. Millward suggested that there are several ways of recording the data that is generated by the focus groups, each has its own advantages and disadvantages. Using video recordings of the group in progress enables the research team to record both verbal transcripts and observations of group interaction (non-verbal communication). However many people may find the camera equipment obtrusive, and not be as open in their comments as a result.

Using audio equipment enables a transcript of the discussion to be made and is less obtrusive. However, the microphone needs to be positioned to pick up all of the conversations, which can be difficult if some group members speak

quietly. It may also be that some participants have speech difficulties and/or need an interpreter.

Both of the above methods of recording enable the group to be handled by one moderator. The recorded information can be supplemented by general notes, e.g. on flip charts. This also helps to remind the group of the main points which have been raised.

Using two moderators allows one person to concentrate solely on the discussion, while the other takes notes. However, Millward suggests that the presence of another facilitator can often have adverse effects on the group (similar to the presence of equipment), and not be conducive to an informal atmosphere.

In this study, I decided to use audio equipment and general notes. I thought that they would be adequate, as the aim was to generate the mothers' accounts and opinions on defined criteria, not to analyze how the group interacted. However, an assistant moderator for recording data would have been preferable, but no one was available.

5.3.4 Professionals' Perceptions

In order to discover the professionals' views, I recruited a sample, who worked in different settings, that dealt with disabled young people. These were chosen in the light of the data collected from the disabled young people who took part in this study. They represented the social, health and education services. The aim was to examine their points of view on the availability of services and other key issues, including social and environmental access and the attitudes of staff and society towards disabled young people. In this regard, I employed individual semi-structured interviews. According to Robson (1999), such interviews allow greater freedom in the sequencing of questions, in their exact wording, and in the amount of time and attention given to different topics. The interview schedule could be simpler than the one required for structured interviews. It would be likely to include the following:

1. Introductory comments (probably a verbatim script);

2. Topic headings and possibly key questions to ask under these headings;
3. Set of associated prompts; and
4. Closing comments". (p. 238)

Although the professionals agreed that using the young people's accounts was helpful, I had to contact them several times before I obtained their agreement to participate. Most of them were either busy or on holiday. As was the case when I arranged the interviews and focus groups with the disabled young people and their mothers to meet the professionals, I had, in some cases, to travel hundreds of kilometres; moreover, some of them required two visits. The professionals were given clear information about the objectives of the study. This gave them time to think about the issues raised and facilitated their understanding of the questions they were asked in the interview. Overall, they were helpful and their accounts provided significant information of relevance to the research questions (chapter eleven).

5.4 The Sampling Strategy

The aim of my sampling strategy was to generate purposive samples, which would enable me to make comparisons between the experiences of the participants. According to Silverman (2004, 104), purposive sampling allows us to choose the sample because it demonstrates some feature or process, which the researcher is interested in. However, Silverman suggested that such sampling demands that the researcher thinks critically about the limits of the studied population and chooses his/her sample carefully on this basis. The study aimed to identify respondents from four different regions with cultural, social, geographical, demographical and administrational variety. Rural and urban variation was taken into account too. This variation would allow me to compare experiences of the respondents from the four different environmental and social situations, and to take into account the possible differences that were related to the environment and situation of each group.

Silverman (2004, p.102) suggested that data in qualitative research are derived from a few cases and it is not common for these cases to be selected on a random basis. Very often a case is chosen simply because it is possible to access it. The number of participants required depends on the quality of the data gathered. One approach is to start with a small number of cases and keep adding to it until such time as no 'new' information is being derived from the analysis. At this point we can say that the data are "saturated". For example, a study was conducted in Scotland by Connors and Stalker (2003), they engaged 26 disabled young people as participants in their research and the sample provided sufficient data to generate significant findings. Another approach is purposive sampling, as used in this study. Here the researcher seeks to generate a sample which is likely to provide sufficient data about the different circumstances which were considered at the beginning to be important. As discussed above, I reasoned, at the outset, that children's experiences might be influenced by the region in which they lived. This was based on my local knowledge of the variations in the geographical, environmental and social features of the regions. I therefore aimed to recruit 20 to 30 participants, and to ensure that there were between two to six participants from each region.

In order to enlist a sample I contacted the regional departments of social services. The Ministry of Social Development is the department responsible for ensuring services for disabled people and therefore it has a statistical database. The regional department of social services might hold lists of disabled people, including children. This strategy was successful. Several contacts and explanations of my research to responsible people in these departments resulted in my being allowed full access to the lists of disabled young people in the targeted areas. However, from the lists, I had to choose only the physically-disabled people aged between 12 and 19. The demographic and gender distribution factors in each region were considered too. For practical reasons, I decided not to approach severely and multi-impaired young people or those who had major communication impairments. I did not have the appropriate communication equipment or skills to enable them to express their views, and time was also limited.

It is worth mentioning that in order to have access to both disabled young people and their mothers, who took part in this study; I had to make direct contact with the potential respondents and to use a verbal consent procedure. This approach to the issue of informed consent was appropriate as most of parents were illiterate and could not have read or understood any written material explaining my research, or a conventional consent. A verbal introduction to myself and my research was appropriate too because it gave me a chance to provide the participants with a detailed explanation and therefore meant that they could give their fully-informed consent. This strategy meant that I could give a full explanation about the requirements of the interviews, answering questions and addressing any concerns in person. It also encouraged both the disabled young people and their mothers to have more confidence in me and in the value of their contribution. Almost all the chosen participants were helpful and consented to take part in the study. The responses might have been positive because I made contact with them through trustworthy official agencies and/or because the parents themselves were willing and encouraged their disabled children to take part. Moreover, almost all the participants were pleased to have the chance to express their views about their daily lives (see chapters six to eight). However, as earlier mentioned, I had to make sure that the disabled young people did not feel obliged to take part; I gave them the choice to withdraw from the study if they so wished, after they had initially agreed to participate.

5.5 Ethical Considerations

Earlier in this chapter, I raised the issue of ethical considerations in the design of a research study. I would now like to examine them further. According to Gordon (1975), an ethical approach means being determined that the respondents' rights should be maintained. For example, it is their right to have a brief explanation of the purpose of the study in advance so that their choice to take part is an informed one. This should include, the objectives of the research, the type of questions to be asked, the intended use of the information and of

course how confidentiality will be protected. There could be a conflict between the task of maximising respondent cooperation and ethical considerations governing the lengths to which an interviewer may go in persuading people to give an interview (Gordon, 1975).

As I mentioned earlier in my study, access to disabled young people, including those who were in schools or care centres, depended upon a prior agreement by the parent/s. Sometimes, the young people themselves declined to take part if their parent/s were not informed. The process of gaining access to mothers also required giving a full explanation about the objectives of the study and, in Oman, the mothers usually needed to obtain their husbands' agreement, if they were to take part in the discussion groups. As noted above, it is quite uncommon in Omani society for a male researcher to have individual (private) interviews with women respondents. Using discussion groups rather than individual interviews encouraged women to take part in the study. Consequently, the discussions in the four groups were smoothly introduced. For the purpose of confidentiality, the names of all the participants in this study were changed.

5.6 Agreement to Participate

The respondents were all informed that their participation was entirely voluntary. They were all given information in advance about what the study was about, the identity of the researcher, and how the data would be used. The respondents were informed that they could decide not to take part, even while the interview was in progress. They were also aware that they could decline to answer any particular question that they found unacceptable. In addition, if the respondents had second thoughts after the interviewer had left, needed further information or even decided to withdraw from the study, they retained the right to do so. All the respondents were given information about how to contact me (interviewer). Williams (1993) said that rejection happens even after the interview has taken place, especially in research among special groups whose relatives may have misgivings about the legitimacy of the study, and particularly if it is of a sensitive

nature. However, all the participants were willing to take part and none of them withdrew their agreement either during the interview or afterwards. They were all apparently keen to help with the research.

5.7 Piloting

The pilot study is an essential step in developing studies (Williams, 1993). Interviewers should have the skill to record information and to ask respondents about their reactions to the study methods. For the interviewer, the procedures, the acceptability of the task required from the respondents and any other features of the study affecting cooperation, are vital issues. According to Williams (1993), it is preferable to have a debriefing session rather than simply continuing to knock on doors and starting interviews. He also adds that there may be differences of opinion between the interviewers as to what makes it easy or difficult to conduct any study. Piloting methods can lead to a discussion of the different approaches and provide a deeper understanding of the benefits and disadvantages of each.

For the purposes of this qualitative study, the checklist of questions was piloted with four disabled young people (these were among the main participating disabled young people). They were interviewed using a checklist of questions (see Appendix, checklist). The purpose of the pilot was to test these questions for ease of understanding, to ensure that there was no ambiguity of meaning in the language used, and to see if they elicited the required information. Also, it was to build a rapport between each of the participants and me. The purpose of the research was explained to those taking part. Having a clear picture about the research encouraged them to be helpful. The opportunity was taken to begin with an introductory conversation with them, which was considered as an 'ice-breaker' and consequently they seemed to develop more confidence in expressing their different experiences.

As a result of those interviews very few changes were made to the checklist of questions. Prior to each interview, the participants were given a clear idea about the study, and the questions that they would be asked. Issues

like privacy, flexibility and confidentiality were discussed with every participant in the pilot study. This explanation not only increased their confidence and encouraged them to talk freely, but, as a researcher, it gave me a chance to understand the way in which I would access and interact with the respondents.

I also had to meet six mothers in a pilot focus group, in order to test out the checklist questions and to find the most appropriate way of enabling them to talk about their own experiences and those of their disabled children. Considerations like confidentiality, freedom and privacy were taken into account too. No changes were made to the initial checklist of questions for mothers (see appendix). Two professionals were recruited in the pilot study. This resulted in some changes to the questions used. For example, a question about their original motivation in working with disabled young people was added after the pilot interviews; and the professionals' vision of the future of service provision was explored in more detail.

5.8 Transcription and Analyses of the Data

There are several ways to deal with qualitative data. Tesch (1990) distinguished a total of twenty-six different kinds of approach to qualitative research, which she reduced to three basic groupings, where the interest is in;

1- The characteristics of language;
2- The discovery of regularities;
3- The comprehension of the meaning of text or action, and reflection.

The major task of any study is to answer research questions. This has a major influence on the method of analysis required. Robson (1999) suggested that:

> *"to come up with trustworthy answers, the analysis has to treat the evidence fairly and without prejudice, and the conclusion must be compelling, not least in ruling out alternative interpretations".* (p.372)

The central requirement in qualitative analysis is clear thinking on the part of the analyst. As Fetterman (1989) put it, in the context of an ethnographic stance, the analysis is as much a test of the data. Robson (1999) believes that an analysis is a test of the ability to think, to process information in a meaningful and useful manner. Bromley (1986) recommended that throughout the analysis process, one should keep in mind four important questions:

1- What is at issue?
2- What other relevant evidence might there be?
3- How else might one make sense of the data? And
4- How were the data obtained? (p.100)

Robson (1999) presented basic rules for dealing with qualitative data:

1- Analysis of some form should start as soon as data is collected. Do not allow data to accumulate without preliminary analysis.
2- Make sure you keep tabs on what you have collected (literally-get indexed).
3- Generate themes, categories, codes, etc. as you go along. Start by including rather than excluding; you can combine and modify as you go on.
4- Dealing with the data should not be a routine or mechanical task; think, reflect! Use analytical notes to help to get from the data to a conceptual level.
5- Use some forms of filing system to sort your data. Be prepared to re-sort. Play with the data.
6- There is no one 'right' way of analysing this kind of data-which places even more emphasis on your being systematic, organised and preserving.
7- You are seeking to take apart your data in various ways and then trying to put them together again to form some consolidated whole. Your main tool is to make comparison. (p.377)

It is possible for the analysis to be based on two strategies (Yin, 1989). It could either be founded on a theoretical or descriptive approach to the data. My study was based on two theoretical propositions; the social model of disability and the citizenship concept (chapter three). I approached my data collection strategy with these theoretical concepts in mind and they provided me with a framework, a powerful aid in building the analysis, indicating where, and on what, attention should I focus.

The primary method of data analysis used in this study was a procedure of manual coding of all data sources. Although this is time consuming, I believe the benefits of this process compensated for the loss of the benefits of using computer software for qualitative research. The use of ATLAS or Nudist or NVIVO1/2; computer-aided coding would have required a lengthy period of transferring all taped and hand-written data for the core interviews into a computer database.

Coding is described by Miles and Huberman (1994) as:

> *"To review a set of field notes transcribed or synthesised, and to dissect them meaningfully, while keeping the relations between the parts intact, is the stuff of analysis".* (p.56)

My aim was to divide text meaningfully, which led me to read through sets of data to determine what would constitute a useful unit of analysis. I listened to the tapes on the way home from each interview to make sure the interviews were clear. I then took notes in Arabic from each tape as soon as possible afterwards, while the expressions and words used by the participants were still fresh in my mind, in the context of the flow of the discussion. There were always difficulties when trying to record, especially when taping the discussions of the groups of mothers, because of the limits of the technology (the microphone was not able to pick up all interactions clearly).

The initial analysis was content-based and identified responses to particular questions and the amount of consensus on an issue. I made notes of

the main subjects covered in the interviews, relating to each of the key areas of the participants' experiences. For example, when the disabled young people talked about their experiences at their school (see chapter eight), I noted that in most of the interviews the recurring themes were the accessibility of transport and buildings, their relationship with peers and teachers, and their exclusion from activities. There seemed to be a consensus among the accounts of most participants that these were the key issues. This enabled me to conclude, with some degree of certainty that these issues were among the factors that these youngsters encountered in their daily lives. However, I was careful about attempting to generalise from these findings, as there was, to some extent, disagreement amongst a few respondents on some issues such as, their relationships with their siblings or peers and their perceptions, especially of their future marriage prospects . Moreover, I felt I should assume that, (as discussed in chapter seven and ten), the physically disabled young people might have different experiences to those with other impairments, especially with regard to issues like accessibility and discriminatory attitudes.

All the interviews with the disabled young people, the mothers and the professionals were audio-taped. The average time of each interview was 90 minutes. To analyse the material, audio-taped interviews were transcribed in full. However, I found that this was a lengthy and difficult process, because transcripts had to be read carefully several times and analysed manually. Moreover, the interviews were in Arabic and I had to translate every single word into English. It was really tiring. Furthermore, I was worried that the translation would not give the precise meaning. This made me read the translated material carefully several times, and I had to frequently go back to the tapes to make sure that what I had translated was accurate. Sometimes, I asked for help from a friend of mine whose English was better than mine; in some cases I had to explain to him what I meant by certain words. This made the classification of the data clearer.

The data were classified into patterns, common themes, sub-themes, sub- sub-themes and key points (see appendix). Substantial major themes were

identified and these, together with additional notes were used to clarify the findings.

5.9 Conclusion

Taking time to ask the disabled young people about their opinions and experiences of their everyday lives was enlightening and challenging. They provided rich data that offered an insightful and deep understanding, which was unexpected and challenged my assumptions about their abilities. What my research approach demonstrated, as the findings presented in the following chapters reveal, is that these young people were able to express their views and to take part in the research that touched their lives, and that the careful choice of research methods was especially important. They were the key source of knowledge and information on their everyday lives and their expertise guided me in the development of my research strategy and in identifying further data sources.

The disabled young people advised me to ask their mothers to take part in this study. This was because of the close relationship they had with them and their mutual understanding of each other, even with regard to the most private and personal issues. They also, during the interviews, named particular professionals, including teachers, volunteers, doctors, nurses, physiotherapists and workers in the social services that played a part in their lives. I, therefore, grounded my selection of the professionals, who took part in this study, on the basis of the insights I gained from the disabled young people. The findings presented in the following chapters breach the boundaries surrounding those who are considered to have expertise and valuable knowledge to share, in research in the developing countries. Their contributions challenge any lingering belief that disabled young people are not able to express their points of view about their social world.

Disabled Young People in the Family

6.1. Introduction

The findings presented in this chapter are drawn from interviews with 26 children in Oman and explore disabled young people's experience of everyday life in their own family. The young people highlighted issues that were very important to them and the quality of their lives, such as their relationship with their siblings, parents, and extended families. Practical concerns, like the accessibility of their homes, were also significant. These matters were raised by the disabled young people themselves, as they were given a rare opportunity to express their views and to give an account of their experiences of family life.

6.2 Participants

Table (1) Demographic Characteristics and Distribution of Physically Disabled Young People[1]

Age	Gender		Total	Demographic Distribution (see Appendix- Areas Code- P.351)					
	Male	Female		CA	C1	C2	C3	C4	R3
12-14	5	2	7	1	1	2	1	1	1
15-17	7	8	15	1	3	3	3	3	-
18-19	3	1	4	-	-	-	2	1	1
Total	15	11	26	2	4	5	6	5	4

[1] See appendix

Twenty six young people and their families agreed to participate in the study. Their demographic characteristics are summarised in Table 1. As mentioned earlier, there were three different categories of respondent who took part in this study. Each category was represented by a number of interviewees. For the purpose of this study, the key category of respondents was the physically disabled young people whom I interviewed in depth.

6.3 Relationship with Parents

The disabled young people in this study all made it clear that their parents took full responsibility for meeting their needs. They were very positive when they described their parents, using words such as, 'nice', 'helpful', 'supportive', 'the most important persons', 'offering all things, understanding me and giving me full care'. Disabled young people's accounts reflected the dominant nature of the relationship between parents and their children in their society. In Oman, it is common to see close relationships between family members. However, slight changes in the nature of social relationship have started to be perceptible.

The great majority of disabled young people experienced close relationships with their mothers. Mothers have provided them with full care from birth; they stayed with them when they were admitted to hospital. Mothers usually spent most time at home, which meant disabled young people spend a lot of time with their mothers. The young people described how some mothers had the opportunity to work; however, they did not use it, as they wanted to be with their disabled child/children. One boy said approvingly:

> *"My mother now stays with me and I no longer depend on the housemaid".* (CA-male-11 years old)

The disabled girls thought that the person who understood them best was their mother. For example:

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The disabled girls thought that the person who understood them best was their mother. For example:

> *"Mother likes me and gives me full care. I also love her as I spend most of my time with her. She understands me even in my private things".* (C1-female-15 years old)

Another disabled girl valued the role of her mother, as she took her to school everyday and often took her when she went shopping, as she owned a car.

A disabled boy (15 years old) had a different experience with his mother. He has lost his father in a car accident when he was four and his mother was the only person responsible for him. According to her son, she treated him as though he was still a young child:

> *"When I come back from the Centre [Al-Wafa Centre], the only place I can go is to the shop here, my mother does not want me to go further".*(C1-male-15 years old)

She was apparently still reluctant to send him to school and she preferred to send him just to the Al-Wafa centre. However, while he was telling me his story, he did not show any resentment. He seemed quite content, however, he was quite concerned about how his mother's protectiveness might affect his opportunities for employment in the future.

However, the disabled young people knew about how they became impaired from their parents, the great majority of them knew from their mothers. The mothers told them the full story and gave the history in detail.

> *"My mother told me that I was born after only seven months of pregnancy. She told me how I was when I was born. It was trouble from day One of my life".* (C3-female-16 years old)

It was clear that both boys and girls were closer to their mothers because fathers usually spent less time at home.

The great majority of the respondents regarded their fathers as supportive; they described how they took financial responsibility for them, helped them in joining schools and making contact with hospitals. Fathers usually dealt with the outside world on behalf of their families. While mothers carried more of the responsibility for managing the household and meeting the family's needs within, the disabled young people valued their fathers' support and help. More than half of the children interviewed pointed out that their fathers financed alterations in their houses, to make them accessible for them in their wheelchairs. Six of the interviewees also explained that the equipment they needed, such as wheelchairs and crutches, were bought by their fathers' money. The majority of the young people who already went to school asserted that their fathers had played a significant part in enrolling them in school, whether through a direct contact with schools or through joint efforts with the Al-Wafa centres. A physically impaired boy gave an example of the support he received from his father:

> *"My father decided to move from there [a rural village] to this town and he bought this house. He made it accessible for me, as you see it is OK now".* (R3-male-17 years old)

A girl, who had a physical impairment, described an extraordinary relationship with her father. She viewed him as devoting himself to making her happy and improving her condition. He, moreover, asked her mother to give her more attention.

> *"Father offers all things I need, he asks my mother to give me more attention. He does his best to make me happy. He is keen to see me improved; he takes care of me and takes me to the hospital and physiotherapy".* (C4-female-13 years old)

However, it was not always the case that the contributions of fathers were appreciated in this way. Two disabled young people complained that their fathers did not send them to school. They believed that their fathers had not made enough effort to enrol them and they questioned why their siblings went to school but they did not. A disabled girl who was 16 years old commented:

> *"As you know, I am now 16 years old. I was not given a chance to go to school. My father did not send me to school. This makes me ask myself, 'why was I not sent to school but my sisters and brothers are going to school?' I wish I were given a chance".* (C4-female-16 years old)

This girl's account revealed a situation where disabled young people did not experience equal opportunities, even with their own siblings. This apparent discrimination within families might be attributed to the disabled children and their parents lacking information about the possible service provision available, including the opportunity to receive education. Earlier examples showed that the majority of the respondents were enrolled in their schools through the joint efforts of Al-Wafa centres and parents. They did not join normally as their siblings did, and the majority of them were late in commencing their studies.

6.4 Relationship with Siblings

The great majority of disabled young people gave positive accounts of their experiences and relationships with their siblings. To describe the nature of the relationship between them, disabled young people used terms such as , 'they are nice', 'helpful', 'supportive', 'they like me and I like them', 'doing different things together', and so on. However, the young people interviewed gave different accounts of their relationships with older and younger siblings. Most of their descriptions of their relationships with their older siblings, especially brothers, were very favourable. Almost all older brothers shared the responsibility for providing for them, with their fathers, and they assisted them

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in different ways, especially with financial matters. The majority of disabled youngsters described various ways in which their older brothers helped them. For instance, in providing opportunities for recreation and relaxation:

> *"As brothers, we like each other. My older brothers, take me to the park in Muscat, especially during the weekends. At home they even help me in my studies".* (C2-male-15 years old, 2)

A disabled girl expressed her gratitude to her older brother, because he buys all the things she needs, especially schools things.

> *"Nasir provides all the things I need. When school starts, he brings all the tools and books I need. I really like him".* (C2-female-16 years old)

Older brothers, therefore, played a vital role in improving the everyday circumstances of their younger disabled siblings. This of course, would help the whole family, especially their fathers who, according to the dominant social values, should take responsibility for the family, especially the financial responsibility as the traditional breadwinner.

One disabled boy reported that his older brothers helped him and offered to meet all his needs within the home. However, at the same time, they never took him to public places. He complained of being alone most of time after school:

> *"After coming back from the school or in holidays, I just stay in this room".* (R3-male-18 years old)

This disabled boy tolerated his brothers and accepted being restricted at home, as his father was an old man, and had no car. Actually, his brothers worked away from the village, which meant they only came back to the family home at weekends. They might have had limited time, as they needed to be

with their own children, or they might, as he claimed, have avoided being seen in public with their brother in his wheelchair.

The relationships of disabled young people with their younger siblings were also discussed. The great majority of disabled young people experienced a good relationship with their younger siblings also. They viewed them as 'helpful', 'nice', 'supportive' and said 'we like each other'. They provided help for them inside the house, outside the house and in school. Parents were sometimes overprotective of their disabled children, however, siblings did not show them any kind of resentment. Most disabled young people experienced having opportunities to take part in different activities with their siblings, including, studying, homework and playing easy games. If they wanted to take a break outside the house, their siblings would push them in their wheelchairs. Generally, the relationships were described as 'normal', as between all siblings in their society, irrespective of disability.

However, a small minority of viewed themselves as different to their siblings, because they were prevented from doing all the things their siblings could do and from going to places their siblings could go. They expressed some anger when they identified educational opportunities reserved for their siblings:

> *"My brothers and sisters started going to school when they were six, nobody thought to send me to the school when I became six, I just started when I was ten".* (C1-male-16 years old)

Two respondents reported negative attitudes on the part of their younger siblings. They thought that their siblings were not happy to have a disabled brother or sister. One disabled girl explained:

> *"I am not happy with my brothers as they sometimes say 'we do not want any more disabled sisters'. They repeat these negative words, but my mother shouts at*

them when she hears them saying so". (C2-female-12 years old)

Almost all the interviewees suggested that young disabled brothers have closer relationships with their brothers, and sisters have closer relationship with their sisters. However, that did not mean that the relationship between brothers and sisters was weak or not based on respect or affection. This is an aspect of the cultural traditions in Oman that might complicate the lives of disabled young people, who rely so much on relationships within the family for practical support and opportunities to socialise. It is expected that brothers and sisters should be separated when they become teenagers, to ensure more privacy for them and to avoid the risks of any undesirable contact. However, it means that their siblings of the opposite sex must transgress normal cultural boundaries to help them. A disabled young man gave an example:

"I, sometimes, ask my sister for a help; she pushes me to the toilet". (R3-male-18 years old, 2)

6.5 Extended Family

Disabled young people did not have much to say about their relationships with their extended family. Almost half of the children interviewed identified extended family members, such as aunts, uncles, grandparents, and children of aunts. They mentioned a range of visits exchanged yet, from their accounts, there was no evidence that the extended families provided more practical support or care for their disabled relatives or to their parents. One disabled child gave an example of the contact he experienced with his extended family:

"My uncles and aunts with their families and children visit us. They like me. When I was younger, my mother took me with her when she went visiting them.

> *They live not so far from here* [the village]. (C3-male-12 years old)

The great majority of disabled young people reported that most of their relatives lived in the same town. However, as mentioned earlier, only half the children were in contact with them and identified them as important people in their lives. The former were not particularly negative about them, but they described the discriminatory behaviour of some relatives, for example:

> *"Aunts and uncles often come to visit us. They seem to sympathize with me. It is something different when they talk to my brothers [siblings]. I feel their way of talking to me is not as the same as they do to my brothers". They use words like "Miskeen"* [feeble or deprived]. (R3-male-18 years old, 3)

This disabled boy was disappointed because he never visited his uncle, who lived a mere hundred metres away from his house, just because of access problems. I noticed, during my visits, that the local environment was inaccessible and that it would have been virtually impossible for a wheelchair to move about outside. This might have restricted the opportunities for the development of relationships and contact between disabled children and their extended families.

One eighteen year old disabled young man preferred spending his holidays with his grandmother, who lived in a rural village. He claimed that he enjoyed being with his nice grandmother; he also liked the village where he had grown up and all people there knew and liked him. He said, the only reason that he left the village was to enrol in a school.

> *"In the holidays I like to visit my grandmother and uncles. They really like me and I love to visit them. I enjoy spending my time with them".* (C3-male-16 years old)

This example shows that some disabled young people left their own rural communities where most of their relatives and friends lived, simply because they wanted to join school in towns. This could mean not only that they missed their relatives and friends, but that they faced difficulties in developing new friendships in towns.

One disabled child described the close relationship he enjoyed with his uncle [his mother's brother] who gave him a lot of attention. He suggested that his uncle, for him, was an important person because he made him feel happy by taking him to the park at the weekends and offered to help him with the things he needed for school.

> *"I like my uncle very much. He regularly, especially in the holidays, takes me in his car to the park and to see different places. He buys me pens and books* [stationery]". (C3-male-17 years old)

More than the half of the respondents had frequent opportunities to play with their aunts' children. They met each other, either because they lived in the same town or when they visited each other.

> *"My uncles and aunts like us very much; they often visit us. I most like my aunt's children because they often visit me and play with me".* (C2-male-13 years old)

6.6 Accessibility of Houses

Accessibility is one of the most important issues to be addressed, if disabled people are to enjoy social inclusion. Disabled young people regarded the issue of access as a crucial theme in their lives and experiences.

More than half the reported that they lived in inaccessible houses. They had no provision for independent access to their homes, which they were

obliged to ask for help to enter. They almost always shared a bedroom with their siblings and did not have adequate toilet facilities. Sometimes, the room was small which made them feel unhappy, especially, according to the level of disability, when they needed privacy because of their personal care needs. Nor were the shared rooms usually comfortable for studying and sleeping. A disabled young man gave an example that showed how many disabled young people feel that their dignity is not considered, just because they have mobility difficulties inside their houses:

> *"I stay in this room; for me it is so difficult to move even inside the house. It is not adapted for a wheelchair and even unsafe for crawling. When I need to use the toilet, I have to wait for a long time until somebody else comes to push me in; the toilet is behind the house, not inside. Sometimes after I have been pushed into the toilet, I would have to wait for a long time again, under the very hot sun, until somebody else comes to help. It is really terrible and difficult".* (R3-male-18 years old, 4)

This disabled boy lived among nineteen family members, in a rural village. His father was an old man and had an inadequate income and so depended on his three sons, which meant he could not afford to finance alterations for the house. His disabled son had been struggling as he did not have his own room and had difficulty getting to the toilet. He was determined to use his time in studying, as he was in the third secondary class (A-S level) at the time of the interview. To have a quiet space to study, he used the sitting room.

There was evidence that disabled young people, especially in rural areas, encountered substantial access problems inside their homes. Almost all the houses in rural areas are small, old, and not adaptable. They just consist of small rooms for sleeping, sometimes with no toilets. Some houses are located on mountains and hills.

> *"When I was in (Wadi Sahtan), always staying at home; I never got out. The house was very small, old and not comfortable. I did not have my own room; there was not even a toilet and no electricity. It was really difficult".* (R3-male-17 years old, 2)

Fewer than half of the disabled young people stated that their houses were fully accessible. Most of these lived in urban areas and they all reported that their fathers or older siblings had made the adaptations. Only two participants reported that they had their own private room and toilet. One teenage girl said:

> *"My house is fine. I have my own room and toilet which was installed by my father. There is also a ramp in front of the main door for the wheelchair".* (C4-female-13 years old, 2)

The respondents identified a strong link between accessibility inside their homes and dependency. They claimed that an accessible house helped them be independent and gave them more chance to move and to do different things for themselves, with no need for help. One disabled young man gave an example:

> *"If my wheelchair could go easily to the toilet, I would go with no need for help from my brothers".* (C4-male-17 years old)

The accessibility of the house also affected the involvement of disabled young people in various activities with their siblings. For instance, only two disabled girls reported that they took part with their sisters and mother in

domestic activities, including preparing meals, simply because their wheelchairs moved freely inside the house.

6.7 Discussion

One of the main objectives of this study was to understand disabled youngsters' experiences of their daily lives and to explore how they identified themselves in interaction with non-disabled people. Their accounts reflected the major role played by their parents in caring for them and providing for all their daily needs. They, moreover, gave evidence that they have a good understanding of their social world. The focus of this study has been on how disabled young people understood their relationships with their parents, siblings and relatives. They also viewed the issue of the accessibility of their own homes as crucial, and demonstrated how unsuitable accommodation disabled them by denying them the opportunity for self-care and independence within them.

Physical barriers, like the absence of wheelchair access ramps from their homes and those of their relatives, made participation and shared activities with siblings and other relatives more difficult. Disabling environments therefore had an impact on relationships within their homes and within their extended families. The young people's perceptions about the wider community and identity will be discussed in the next two chapters.

However, I should mention here that the sample was not representative of all disabled young people in the country. There were those living in the desert (Al-Wusta area), hundreds of kilometres away from the main cities. I assume, they faced difficulties in their daily lives such as inaccessibility, ignorance and absence of some key service provision. Because of the time limitation and the long-distance travel that would have been required to contact them or their families, I could not interview any of them. The 1999 data showed that the percentage of the population who live in Al-Wusta area was 0.9% of the total population. Nevertheless, the perspectives of disabled children, who live in the desert society, should be examined in the future. Those who live in wealthy families, of high social status, did not take part in this study; because I did not

consider them during the data collection time. While their numbers might not be great, their social world would be worthy of examination, especially their perceptions of service provision and the attitudes of professionals and society towards them, as they are probably attended to by servants.

In this study, access to the interviewees (disabled young people and mothers) was through the regional departments of social services; unfortunately, there were no children enjoying the relatively privileged circumstances I have described in the lists that I received.

Relationships with Parents

Thomas's (1999) study in the UK, about disabled women's childhood experiences, found that:

> *"A mother, father, or both were viewed as sources of support, caring, love and self-sacrifice". (p.89)*

In the current study, almost all the respondents, both girls and boys, talked about a close relationship with their mothers and helpful fathers. Mothers spent more time with them, as their fathers had limited time at home. Generally, according to the Omani social norms, mothers are responsible for caring for their children, including the disabled. Sometimes, mothers of disabled young people had to take the responsibility for their care outside the home. For instance, they frequently accompanied them when they were admitted to hospitals. Mothers were the source of the key information that their disabled children needed. The majority of disabled youngsters knew about their impairment through their mothers. Similarly, Connors and Stalker's (2003) reported close relationships between disabled young people and their parents. They described the role of parents in providing help and support, in spending time with their disabled children, in playing with them, in visiting places and doing things together. In this study, only two disabled young women suggested that their mothers took them in their own cars when they went shopping or visiting relatives or, sometimes, they gave them a lift to school. For the remaining young people, their mothers did not drive or their fathers were too

busy. Young disabled women, in particular, valued the close relationship with their mothers. They regarded them as confidantes, especially in personal matters. Mothers also tried to promote warm and caring relationships between their children.

The majority of disabled young people reported that they did not feel that they were restricted by the closeness of their relationships with their parents. Only one disabled young man complained that his mother did not let him go far from home, because she was worried about him. He felt restricted and he did not have many friends, yet, he understood that his mother did so because she loved him. However, the interviewees did not suggest that they had any problem with their parents' surveillance of them; they tried, moreover, to show that they were happy and their independence and involvement were not at risk because of their parents' attitudes. Parents were concerned to ensure their safety. This is in contrast to studies in the UK which showed that from the young people's point of view, parents' protectiveness had a direct effect on restricting their friendships, independence, and inclusion (Connors and Stalker, 2003, Shakespeare and Watson, 1999, and Bignal and Putt, 2000). South Asian disabled youngsters in the UK, had a chance to play with friends from other families known to them and living locally (Connors *et al.*, 2004, p. 63).

Disabled young people did not suggest that the way their parents treated them, their attentiveness and care, limited their opportunities to be fully included and independent. Compared to their brothers and sisters, they had fewer opportunities to play, whether inside the house or in the local community. However, the majority of them considered that the inaccessibility of houses and the local community and the attitudes of other people were barriers to their inclusion and independence. This study, and Connors and Stalker's (2003) Scottish study, found that there were major factors which prevented disabled young people from being fully included in the society, including inadequate services, public attitudes and lack of information. For example, a disabled young woman, whose mother had not agreed to send her to the blind institute, which was more than 350km from her home, had never blamed her mother. She was angry because she was not offered a chance to be educated in her

own local community. Another example, of the disabling aspect of mainstream society, was provided by those children who said they hesitated about appearing openly in public, because they believed negative public attitudes would hurt them and their families' feelings.

Yet, Middleton (1999) suggested that disabled children are treated differently; their sisters and brothers are allowed to take part in different activities outside the house and visit friends, while disabled children are kept at home. None of the respondents believed that their parents kept them at home. However, it does not mean that all disabled young people in the country did not face difficulties in this regard. One of the participants, as well as the Omani Association of Disabled People's (Challenge, 2003) report, gave an indication that there were families who still kept their disabled young people at home and they did not let them go out.

Disabled young people explained that the major role played by their fathers was that of providing financial support and searching for services. In Omani society, fathers are unlikely to provide daily care for their children, whether disabled or not, unless the mothers are not able to do so. Fathers played a complementary role to their spouses. Fathers are responsible for providing financially for the various everyday needs of the family, including those of their disabled children. However, some disabled young people gave evidence that their needs were greater than those of their siblings, which meant that their fathers had to spend more money in order to meet their personal daily needs and to help them to be less dependent. More than half of the participants reported that their fathers provided them with wheelchairs and house adaptations. This meant, as I will argue later, that such services were poorly provided by Omani society; because equipment and house adaptations should be provided for all disabled young people by the government rather than by families.

Society should recognise that families with disabled children need help to be able to raise them. In the UK, it has been estimated that such children cost their carers three times more to look after than non-disabled children (Parker, 2000; Dobson and Middleton, 1998). Generally, the disabled young people were

aware of the role of their fathers and they valued it to the extent that they hoped to help them in turn when they became adults.

However, there were factors preventing most of the parents from fulfilling the various needs of their disabled children. The majority of the respondents reported that they lived in families with low incomes; many had elderly and, sometimes, poorly educated, parents, and the size of their families was quite big. The majority of the respondents had fathers who worked far away from their homes and they came back only during the weekends and holidays. This meant the accounts of most of the disabled young people's daily lives in the family included few references to their fathers as direct carers or about their taking them to public places or playing with them.

These factors identified in their accounts, gave the impression that more than half of the disabled young people lived in uncomfortable conditions, especially if they did not have their own bedroom or enjoy privacy at home. They also had unmet daily needs, in circumstances where their parents were not able to meet even the basic demands of the family as a whole. Some reported that such difficulties, due to low income, were exacerbated when they and their parents had to fight to obtain access to education that was granted automatically to their siblings, and where they were denied entitlement to social security benefits that might have relieved some of burden of financial responsibilities carried by their fathers. The Omani Association of the Disabled (Challenge, 2003) pointed out that there were many parents whose income prevented them from providing for even the minimal basic needs of their disabled children.

Relationship with Siblings

The disabled young people distinguished between older and younger siblings, and between male and female siblings. The majority described their young brothers and sisters as kind. They shared activities and played with them mainly inside the house; outside the house, it was difficult because of the inaccessibility of the local environment. Most of them valued their siblings' help,

especially when they pushed them in their wheelchairs. Generally, feelings of resentment among brothers and sisters were not reported in this study. Such a positive picture of the relationships among children might be linked to the fact that more than half of participants were mildly impaired and they were not very different in terms of daily needs from their non-disabled siblings. It might also be that most parents (see chapter ten) played a role in making the relationships between their children harmonious, through treating them equally and balancing the attention they gave each child. Parents may have explained to their siblings that they should help their disabled brother or sister.

Disabled young people highly valued the support and attention they received from their older brothers. A significant number of the latter not only provided for personal daily needs and school requirements, they also made or paid for housing alterations to enhance their disabled siblings' mobility. In Omani society, it is common that older brothers take responsibility for their parents and siblings, especially if their fathers' income is low or their fathers are dead. Connors and Stalker (2003) found that the relationship between disabled young people and their siblings was also positive in the UK. Similarly, Connors's *et al*. (2004) study presented evidence that South Asian disabled young people who live in the UK, viewed their siblings as a constant source of help and support.

However, just a few of the respondents were not very happy with their younger brothers who wished to get rid of them, shouted at them and remained unresponsive to their feelings and needs. These negative attitudes of siblings could be attributed to several factors. It might be because parents did not treat their children equally, which led them to feel resentment. Siblings could be affected by the discriminatory attitudes of the public who, sometimes, look at disability as a social stigma. It also might have been because their parents did not educate them to respect their disabled siblings. However, only two interviewees reported this as an issue. None of the disabled young people, whether male or female, complained about their sisters. This might be because female siblings, in general, were expected to be helpful and caring to other

members of their family and were perceived as such by their disabled brothers and sisters.

Relationship with Extended Families

Disabled young people pointed out that extended families did not provide direct care for them. This might have been because they had their own familial responsibilities and they did not have any spare time to give them support as well. In some cases they also lived far away from the disabled child's family home. Those who lived close to them, were said not to have enough confidence or experience to take care of disabled children. However, the disabled young people did not indicate that their relationships with their extended families were negative. More than half of the disabled youngsters mentioned relatives' visits, especially those of uncles (brothers of mothers) and their children. The respondents enjoyed this contact; they felt their relatives liked them a lot, because they took them to public places and let their children play with them and, sometimes provided them with books and pens for school.

Although, disabled young people described their relatives as helpful and nice, they did not want their sympathy because it made them feel different from their siblings and other children. Similarly, Connors and Stalker (2003 p.44) suggested that regular contact with extended families did not make parents of disabled young people feel supported by them. Nonetheless, in a few cases, relatives provided short breaks for disabled young people from their parents. The explanation for this was that the extended family regarded disabled young people as different and that they were not sure about how to treat them.

The Accessibility of Housing

The Manual on the Equalization of Opportunities for Disabled People (1986), (para, 114), emphasises the importance of access for all, including disabled people, and the issue of the accessibility of houses. Joseph Rowntree

Foundation's survey (2002) reveals widespread housing problems among families of disabled young people in the UK. The survey reports:

> *"Having a disabled child can mean that a family has particular housing requirements. Whether these housing needs are met or not can make a major difference to the quality of children's and parents lives. It can also influence what other support is required". (P.1)*

Although, this statement was based on a study conducted in the UK, it probably embodies an experience of a large number of families with disabled children around the world. The survey also suggested that nine out of ten families with severely impaired children face at least one significant difficulty with their homes. I found that the vast majority of the respondents complained about the unsuitability and the inaccessibility of their houses. The Omani Association of the Disabled (Challenge, 2003) suggested that most disabled people in Oman live in inaccessible houses. These associated the inaccessibility of their houses with restrictions and dependency and having no privacy. The situation of those who lived in rural areas was even worse.

In the absence of a housing adaptation service in Oman, disabled young people experienced difficulties in moving about inside their houses. Because of this, they were not able to take part in various activities with their brothers and sisters. Inaccessible houses led to greater dependency on the help of others, which was not what they wanted, despite the good relationships they had with their family. Inaccessibility of housing might also restrict disabled young people from getting out often. As we saw earlier, most of the interviewees lived in families with a low income, who consequently could not afford to make alterations to their houses. This problem has negative consequences for the whole family, whether or not they have tried to address it. Either parents forced themselves to adapt their houses and the family endured financial hardship as a result, or their houses remained inaccessible, which obstructed their disabled children's mobility and increase their reliance on the physical assistance of parents and siblings.

Clearly, disabled young people regarded lack of privacy (and consequent loss of dignity), dependency and exclusion as outcomes related to the inaccessibility of their homes and the local environment. The national survey of housing problems among families of disabled young people in the UK (2002) suggested that lack of resources for housing adaptations may result in a poor quality of life for many children and undermine their human rights to privacy, to play, and to involvement in family life. Oldman and Beresford (1998), in a research project on the housing circumstances of disabled children, also make a link between the inaccessibility of houses and social exclusion. They recommended that these issues should be included and addressed in national and local initiatives to tackle social exclusion.

This chapter has focused on the daily lives of disabled young people in their own families. The next chapter will consider their experiences in the wider community.

Disabled young people in the Wider Community

7.1. Introduction

Children and young people, who have impairments, have a right to be involved in the life of their communities (UN, 1986, p.6). This chapter explores the young people's accounts of their involvement in their own communities; how they perceive their daily lives in the wider community, including their experiences of service provision, public attitudes and accessibility. Recent research has encouraged disabled children and young people to express their ideas and feelings (Beresford, 1997; Ward, 1997). However, in this chapter, I present evidence that disabled young people have encountered barriers to full social inclusion in their own community. They identified significant obstacles to their inclusion. Public attitudes, the inaccessibility of the environment and society, together with difficulties in obtaining adequate services to meet their various needs, are all discussed on the basis of disabled young people's perceptions. The discussion, as in the last chapter, is placed in the context of the concepts of citizenship, social inclusion and the social model of disability.

7.2. Public Attitudes

Almost all the disabled young people framed their discussion, about public attitudes, on the basis of the responses and behaviour towards them of people of different ages. They experienced negative attitudes from children in both the local community and in school. Adults and older people behaved in a more sympathetic and supportive way towards them.

The great majority of disabled young people complained about non-disabled children's attitudes. They gave examples of offensive language used by non-disabled children, as well as incidents that illustrated the nature of the problems they suffered in their relationships with them. They usually encountered such behaviour and responses in certain settings, such as the

playgrounds of the local communities and in schools. However, they did not complain about relatives' non-disabled children.

A blind disabled boy was disappointed with the children in his town, as they used to shout at him when he approached them, using words that stigmatised him because of his disability:

> *"When they see me, they say words that hurt. They say, Oh- Oh this person has white eyes, or he is blind. It's mainly the neighbor's young children who utter such words; adults are different, they do not do the same".* (C2-male-12 years old, 2)

This boy lives in an urban community, where most people are not related to each other. While he was telling me about these experiences, he complained of there being few children who would play with him. His feelings were illustrated by his comments, to the effect that he would like to ask those children how they would feel if somebody else hurt them and to put themselves in his position. As a reaction to such negative public attitudes and his wish to be accepted, he explained:

> *"I am thinking about putting in contact lenses, just to be seen as normal".* (C2-male-12 years old, 3)

Most respondents were bothered by the behaviour of those people who identified them solely by negative labels. Their accounts demonstrated how this treatment undermined their human dignity, individual identity and feelings of self worth. Disabled young people indicated that such comments might be one source of their exclusion from the mainstream of society. One disabled young man had a terrible experience in this respect:

> *"They do not see me as "A", they just look at my legs, and when they see me they say, "his legs are twisted". I have therefore become known as "the paralyzed". Even so*

> *many people do not know my real name".* (C3-male-16 years old, 2)

More than half of the disabled young people interviewed suggested that non-disabled children have no interest in spending any time with them. They often would not play or walk with them. A disabled boy complained about his relationship with non-disabled children, who were unwilling to involve him in their activities:

> *"Children in the town play together. They do not think of coming to chat with me, they prefer just to be together. They do not think about me. I wish they would spend some time with me".* (C3-male-16 year old, 3)

This suggests that some disabled young people have limited contact with others of their age and they might face difficulties in expanding their friendships with non-disabled children. They believed the others had their own activities and preferred to be friends with companions who were able to engage in the full range of activities with them, with no difficulty:

> *"I hate being disabled, because it is just so hard for me to make friends accept me for who I am, to like me and not to hurt me".* (CAP-female-16 years old)

Almost half of the disabled children, who took part in this study, said that they tried to ignore the negative attitudes of other non- disabled children. This did not mean that they did not find their behaviour hurtful, or that their dignity was not being attacked. They gave evidence that they found such attitudes very painful. However, they tried not to be preoccupied by them, as they hoped a change would occur in the near future. Most importantly, they reported, that they were determined to overcome such attitudes, to gain more involvement in the community and to have more chance to use service provision, especially education:

> *"Sometimes, young children use negative words against me. "Oh look, the one who limps has come!" I used to hear such words, however, [now] I ignore them; I am determined to go to school, I have no choice. However, older people's attitudes are better".* (C2-male-15 years old, 3)

Disabled children, generally, did not presume to understand or explain why non-disabled children have such negative attitudes towards them. However, it was a good sign that a significant number of them were resolute in the face of such negative attitudes. Their reactions, however, were filled with anger and disappointment, it seemed they realised those children's attitudes would change as they became adults. Just one interviewee made a link between negative attitudes and disabled young people themselves being excluded from different activities in mainstream society:

> *"People often view us differently and negatively. [It's] because they are not aware of our needs. It is also because we do not have a chance to show society that we are able to do so many things just like everyone else".* (C2-male-18 years old)

It can be assumed that non-disabled children have not yet gained enough information or awareness about the rights of disabled young people to be included in their own society. Three participants were reluctant to appear in their wheelchair or on crutches in public places, for example, one teenage girl explained:

> *"People ['s attitudes] make me reluctant to go to the park or shopping or to any public place. When my mother takes me shopping with her, I prefer to stay in the car".* (C3-female-16 years old, 2)

Almost a third of the participants believed strongly that their society had a negative image of disabled children. They believed that they would still be unable to lead their everyday lives independently, even when they became adults. They believed that negative public attitudes were not necessarily restricted to young children. They expressed the opinion that society was still discriminating against them in different ways. This was made clear by their words when they were talking about different worries they experienced, or their fears for the future. One disabled young man did not expect that public attitudes would improve in the future:

> *"I am sure, in the future, it will not be easy for disabled people like me to have a job or to get married or even to go to school. People in general still believe that we are different and so we don't need such things. I just ask those people, whether they do not think we all have the same rights?".* (C3-male-18 years old)

Half of the disabled young people considered that there were many like them, still effectively "imprisoned" in their families. They did not interpret this as being because families wanted to it to be so, but that they and the disabled young people themselves behaved in this way, just to avoid those negative public attitudes. One disabled girl described how she was shocked when she went with her mother to visit a family, because she met another disabled girl there and she had a chance to talk with her and hear about her life:

> *"I was really shocked when she told me that she never went outside her house. She told me that it was better for her to stay inside because she believed that people would look at her negatively, and she did not like that".* (C3-female-16 years old, 3)

The great majority of disabled young people suggested that adults and older people were most sympathetic to them. However, sympathy was not always what these disabled young people wanted. They looked on such attitudes as a form of discrimination, treating them differently because they were disabled, for example:

> *"When people speak to me, it's clear that they do it not because I am "R". They are "being nice" to me because they know I am disabled".* (C2-male-15 years old, 4)

This form of treatment provoked some disabled young people to believe that society denies their dignity:

> *"People think that we are just disabled and they do not think that we are similar to them".* (C2-male-15 years old, 5)

There were incidents recounted that showed that even when disabled young people go out to use services , for example, to the hospital with their mothers, they resented the way that other people often treated them as objects of pity. A disabled girl was aware that people talked with her mother using words of sympathy, rather than respect:

> *"Sometimes, when we [her mother and she] go to the hospital and sit waiting for to see the doctor, women talk with my mother or they say to me, "miskeenah ma'tistahal" [sadly, she is disabled, she should not be disabled]. They also say, "Allah will reward her".* (C1-female-15 years old)

7.3. Accessibility of Local Community

The inaccessibility of the local environment was one of the crucial barriers to their participation that was identified by disabled children. Almost all made it clear that they did not enjoy moving about in their own local community. They experienced different kinds of difficulties that meant they were unable to move freely, or to be independent in using their wheelchairs. Each disabled child, at least, used one of the following expressions, to illustrate the obstacles and difficulties they had encountered, in the physical environment of the local community.

'Hard'

'Inadequate facilities'

'Not adapted '

'Unsafe

'Stones and sand'

'Not friendly'

'Hills and holes'

'Wheelchair got stuck'

'Wheelchair got broken'

'Impossible to get out of the house with not help

'Struggling to move'

'Difficult to get involved in different activities in inaccessible environment'

'I cannot go walking and playing with them'

'Crutches are easier than a wheelchair'.

According to these accounts, disabled young people were able to make a coherent link between the barriers to access they faced and the implications for their involvement in everyday life. For example, the great majority of disabled young people experienced few opportunities to take part in their neighbours' activities:

> *"Although I have my own wheelchair, it is quite impossible to move around and to get involved in*

> *activities with neighbours. The wheelchair often gets stuck and would not move when it gets out of the house".* (C2-male-15 years old, 6)

Almost a third of disabled young people (8) considered that the inaccessibility of the local town might exacerbate negative attitudes towards them and reinforce their exclusion, through preventing people from expecting and accepting their presence and participation. They thought that the inaccessible environment prevented them from getting out and involving themselves in everyday activities. They suggested that the more often disabled young people appeared in public, in their wheelchairs, the better society's attitudes would become. As one disabled young man explained:

> *"I think, people do not know me because I do not often get out. You know, I can't get out and meet people because it is difficult for the wheelchair to move there.* (C3-male-17 year old)

He also said:

> *"I try to go to watch football games every afternoon; my brother and cousin push my wheelchair. Most people there have got to know me. I think if all places here were accessible, I would move freely and all people around would know me".* (C3-male-17 year old, 2)

More than half of the disabled young people blamed the inaccessibility of the local community for some of the difficulties they had in developing friendships. While they were talking about their experience of friendship, they revealed that they felt that most non-disabled children preferred to be with friends who could walk and move without difficulty. It was evident, from their accounts, that the mobility difficulties that prevented them from moving about with other children were not just because of the impairment itself, but also the inaccessible environment was a substantial disabling factor:

> *"It was difficult to go out in the wheelchair. Now that I am using crutches instead of the wheelchair, I am able to move and get involved with more girls in the town".* (C4-female-13 years old, 3)

The great majority of disabled young people experienced problems that meant they were unable to get out of their houses easily. They explained that they believed that it was quite dangerous to fall down in a place that was full of stones, and where there were hills and holes:

> *"Outside the house, the story is different; it is hard to push my wheelchair there. How can I push it on stones and on un-adapted paths? If I do so, the wheelchair might break and if I fall down, I might get injured. It is really unsafe".* (C4-male-16 years old)

Even in the cities, the children had problems in moving around outside their houses. These children's accounts thus illustrated how a society, by not providing adequate pavements, effectively disables some of its citizens. This inability to join in activities outside the house thereby contributes to their social exclusion.

Almost all disabled young people made a clear link between inaccessibility and dependence. They thought that it was impossible for them to move in their wheelchairs with no help. If they needed to get out, somebody else was required, to volunteer to push the wheelchair and to keep the disabled child safe from harm:

> *"It is impossible to go outside the house by myself, I need somebody else to push me and to help me avoid falling down".* (C1-male-15 years old)

Six interviewees suggested that their wheelchairs were damaged as a result of the inaccessible environment outside their homes. They pointed out that several times their wheelchairs were broken just because of the inaccessible paths and hostile environment. One disabled young man complained about obstacles in the physical environment that led to his wheelchair being broken several times. This was a major issue, because it took days for his wheelchair to be repaired:

> *"Stones, hills and holes, are not just preventing me from getting out, but my wheelchair has been broken three times up till now, because I use it there".* (C3-male-18 years old, 2)

Disabled young people in both urban and rural communities experienced access problems; but in rural areas, these problems were worse. In rural communities the mountainous landscapes and naturally hard and uneven surfaces, might make it be impossible for entrances and paths to be adapted or made accessible to people with mobility difficulties and wheelchair users. Three disabled young people expressed their good fortune, as they had had the opportunity to move to urban communities, where it was easier to use their wheelchairs. Before they moved from their rural villages, they did not think of having a wheelchair, or even of getting away from their homes:

> *"There, if you can't walk, there is no way to get out of the house unless you crawl. The only thing I could do was to crawl in front of the house and take a rest under a tree. I had no wheelchair because it was not only impossible to use it there but also dangerous [fall down]".* (R3-male-17 years old, 3)

7.4. Service Provision

7.4.1. Health Services

The majority of the disabled young people interviewed had, at least, one contact with hospitals. Almost all the disabled children, who were from urban communities, were born in hospitals. For a significant number of them, their impairment was identified at the time of birth. For those who had experienced frequent admissions to hospital wards, their impression of the treatment they received was that it was unhelpful:

> *"I stayed for a long time in the hospital, but what is the result! I gained nothing, as you see me now, I am still in my wheelchair".* (C3-male 18 years old, 3)

Most of the disabled young people judged the health service on the basis of how much they had improved. They believed that their treatment should have helped them to recover fully. Although their impressions of the intervention they experienced was that the results were contrary to those they would have wished for, the majority of the participants were satisfied with the doctors' attitudes and efforts. They used expressions like "they did their best and there was nothing more to do". However, a minority of disabled young people considered that the doctors were not realistic when they told their parents about the diagnosis and implications of their impairment. The doctors exaggerated when they provided information about the impact of the impairment. One disabled young women complained that:

> *"The doctors said nothing could be done for me. They said to my parents. 'Your daughter has complicated problems in her brain. She will be unable to walk, to speak, to see and she might even die".* (C3-female-16 years old, 4)

This girl was clearly disappointed with this and the way that the doctor conveyed very negative expectations to her parents. She explained that she wished that doctors would think carefully before delivering information to disabled young people or their parents. She suggested that doctors should calmly provide accurate information.

Nurses were not often mentioned, yet two disabled young people complained about the way that nurses had dealt with them. They experienced agony because nurses did not inject medication carefully or sensitively. A disabled girl reported that, when she was admitted to hospital with her mother, the nurses were not helpful and they often asked her mother to do everything including feeding and washing her. She, moreover, perceived negative attitudes and inappropriate behaviour from nurses:

> *"I don't know why nurses were laughing when they saw my mother carrying me in her arms, It was really unpleasant".* (C3-female-16 years old, 5)

Due to their families' determination or doctors' recommendation, five participants had been sent abroad, to have a chance of better treatment. Either the Health Department or parents took the responsibility for the treatment costs. However, three of the five reported that they experienced very little improvement:

> *"There were attempts to address my impairment. I was sent to Germany and Iran. However, none of them were successful. I was told, "There is no treatment for you".* (C2-male-12 years old, 4)

Only half of the interviewees experienced regular visits to hospitals. The purpose of the visits was an appointment with a doctor, physiotherapist or occupational therapist. Although they described positive relationships with these professionals, they complained about the ordeal of their difficult journeys

to hospitals and the lengthy waits in the reception halls. Most of them had to start their journey early in the morning, as they lived far from the hospital. Sometimes, they had to take more than one taxi to travel to the hospital. Disabled young people complained of missing lessons, as they could not go to school because, when they had appointments, the whole day was usually taken up. They described how they waited for a long time to see doctors, and this was boring. One disabled young man gave an example of how arduous his hospital appointments were for him and his family:

> *"When we have an appointment with the doctor, my parents and I have to start our journey from very early morning. We need to travel more than 130km by taxi, as my father has no car. It is not only difficult to travel such long distance and sometimes to transfer from a taxi to a taxi; it is also hard to wait for a whole day to see the doctor. On that day, I miss my school, which means I miss all lessons".* (C4-male-17 years old, 2)

The other half of the disabled young people interviewed did not have regular contact with hospitals. This might have been because they were dissatisfied with the treatment they had already had, and their condition was considered 'incurable', or they might have found it too difficult to get to hospital. As was indicated earlier, all these matters were relevant in the accounts the young people gave of their experiences and expectations of hospitals. The great majority of the participants who lived in rural areas experienced fewer opportunities to meet health professionals. A disabled boy, who was born in a rural village, asserted that when he was born in his parents' house, his family did not think to send him to the hospital until they moved to a town, when he was seven years old. He believed that there were disabled young people in rural communities whose need for health services were unrecognised:

> *"I did not think it is possible for me to get services. I was thinking, I would just have to stay at home. It was*

> *a good idea to move here. I know disabled children who are still there with no services".* (R3-male-17 years old, 4)

Interestingly, there are a significant number of disabled young people who were exposed to traditional forms of medicine or remedies. Traditional 'medicine' in Omani society means using religious or spiritual means by reciting spells or words of God; or the use of ancient treatments, including traditional physiotherapy, which uses local oil products, or involves burning the sick part of the body. The interviewees gave evidence that the traditional medicine is still used, however, they did not comment on whether or not they were interested in it or found it helpful:

> *"When I was four years old, I was walking and suddenly my legs became paralysed. My parents made attempts to treat me, they took me to hospitals and I also was burnt here and here [in his legs and his back], yet, none of them was useful, I did not get any better".* (C4-male-16 years old, 2)

7.4.2. Social Services

The participants had experience of several kinds of social services. They mentioned social security benefits, Day Care Centres (Al-Wafa Centres), Centres of Care and Rehabilitation for Disabled people, and the supply of equipment they needed.

The great majority of disabled young people were very disappointed with the social security provision. They strongly questioned its adequacy. They reported that disabled young people were not entitled to social security benefit, unless their fathers were eligible. The current regulations of the social security system did not offer any commitment to providing benefits for those who were

less than eighteen years old. One disabled child described the response to his application for the social security benefit as negative:

> *"If you think that the Social Service Department was concerned about us, it would take action to give disabled people, like me, a monthly income. The government should give us the financial support we need; but I ask myself, 'Why do disabled people, like me, who have no income and need different things not deserve social security?' We sent an application with all the documents they needed, but their response was negative. They said, 'you need to wait until you are 18 years old'. Do you think this was an acceptable response? Don't they know that we also need lots of things to buy?".* (C1-male-14 year old)

A few disabled young people did not think about the social security system, because their families provided all the things they needed. Some of them did not apply for benefits, just because they knew that they would be told as the others were told that they were not eligible.

Almost all the disabled young people identified an association between their everyday needs and the financial support they required. They specified particular needs that had to be met including clothes, food, sanitary pads, transport, equipment and the adaptation of houses. Even those who did not think about social security benefits, valued their families' support in providing for their needs in these ways:

> *"I do not think that the Department of Social Affairs is going to give me monthly financial assistance. However, everything I need, is provided by my father. My father made me forget about getting financial support from anyone else".* (C1-female-15 years old, 2)

Day Care Centres (Al-Wafa Centres) are provided by the voluntarily sector, but under the supervision of the Department of Social Development. The majority of the young participants in this study had an opportunity to benefit from these centres' services. They were highly pleased with the provision of these centres. As discussed earlier, these centres played a vital role in helping disabled young people to join ordinary schools and to have greater involvement in their society. They also helped them to get out of their houses, to practice different activities, to meet and play with friends and to learn useful skills. A significant number of disabled young people looked on these centres as schools, and on the volunteers as teachers. For example, one teenage boy explained:

> *"I like the school so much that I can't wait for the bus to pick me up every day! The bus picks us up early in the morning. I like my teachers. They teach me many things. They take me to the park, we play together and they teach me to play computer games. It is really nice"*. (C1-male-14 years old)

The disabled children, who still attended these centres, liked to compare themselves with their siblings who went out to school, as they left their houses early in the morning and returned in the afternoon. However, according to the regulations governing these centres, disabled young people from fifteen years old, do not have the right to benefit from the centres' services. Therefore, there were children who were excluded from the centres because of their age, but the centres could not help them to be included in the ordinary schools or special institutes. A disabled young man was not accepted in the ordinary school, because his right hand and leg were paralysed, and he had to leave the centre:

> *"When I became fifteen years old, I was told to stop going to the centre. Now I just stay at home, I have no thing to do. Children here still go to the centre or go to school"*. (R3-male-16 years old)

Six disabled young people valued the service provision of the Centre of Care and Rehabilitation for Disabled People. They looked on it as better then ordinary schools in terms of staff attitudes, friendships with peers, provision of facilities and involvement in activities.

> *"There is a big difference between the centre where I am now and the school where I was. The centre is different; I receive more attention. I have more friends and it is more accessible".* (C3-male-16 years old, 4)

Disabled young people suggested that staff behaved nicely to them, realised and understood their interests and encouraged them to become involved in different activities. It was extremely clear, from the accounts of these young people, that being with peers who had had similar experiences to them, made them happier. They suggested that they shared common perceptions that brought them closer to their peers.

> *"We are here as friends and we do different things together".* (R3-female-16 years old, 2)

However, one of the problematic issues that was raised by disabled young people, who were in the centre, was that of other service users who had different needs to them, including older people and deaf teenage boy students. The disabled young people recounted how they had experienced incidents of aggression and even, sometimes, physical abuse by other service users. However, they said that when they reported such incidents to the staff, the situation improved. A disabled young woman explained that she preferred to be in the centre because she wanted to learn an occupation, but she could not hide her anger about the bad behaviour of some deaf teenage boys, who attended at the same time and who were rather hyperactive. She regarded them as a problem in the centre:

"The problem we have there [in the centre] is that some deaf boys [teenage boys] behave badly. Our teachers are aware about this problem and they try to make sure that they behave politely". (C3-female-19 years old)

Two disabled children, however, could not join ordinary schools in their local community and they did not want to join the centre, because of the long distance between their homes and Muscat where the centre is located.

The participants mentioned different appliances and aids they used, including wheelchairs, crutches, glasses and walkers, yet the wheelchair was the most common. The government had a duty to provide these pieces of equipment, according to the regulations of the social services (Social Security Act, 1984). However, the accounts of a third of the interviewees revealed that their equipment was bought by their families. A few of the disabled young people received their wheelchairs from the Omani Association of the Disabled in Muscat. Although the Department of Social Development is officially committed to providing such equipment and mobility aids, some disabled young people complained of complicated procedures and long waiting list to get them. More than a half of the interviewees mentioned that they, or their fathers, had been asked many questions and that they had to wait months until they received the wheelchair they needed.

"*They asked me several questions, and I had to wait quite a long time to receive my wheelchair*". (C3-female-19 years old, 2)

However, some participants expressed satisfaction with the way that they acquired their wheelchairs. One disabled young woman was happy because her father had not faced problems in obtaining a wheelchair for her. She, moreover, said that she was given two wheelchairs, one to be used in the house and another one to be used in the school.

> "*My father was given two wheelchairs from the social services. I do not think it was difficult to come by them*". (C3-female-16 years old, 6)

The majority of disabled young people experienced terrible problems when their wheelchairs were broken; it was difficult for them to get a new one. The only workshop they knew of, able to repair wheelchairs, was in Muscat and they had to wait for them for days if not weeks until they were repaired.

> "*When it gets broken, I face a big problem until they repair it*". (C3-male-17 years old, 4)

7.5. Discussion

In this chapter, disabled young people raised various issues about their experiences of their wider community. They talked about public attitudes towards them and their families, the accessibility of the local environment and service provision. Their level of understanding about such issues was significant. Their accounts provide evidence that disabled young people are able to raise their voices and express their demands, if they are given a proper opportunity. However, in order for this to happen and to be effective, their society must recognise their rights, including the right to be heard.

The issue of public attitudes towards disabled people was important. However, it needs to be addressed from different angles. First, there are questions about the effect of such hurtful attitudes, on disabled young people's feelings and self-esteem, and if these stigmatising attitudes increased their exclusion. Secondly, the question should be asked about why the wider Omani society appears to perceive disabled young people in a negative way and what particular social factors made people view disabled young people differently.

Although, the respondents did not place much stress on their impairments, they did not deny the emotional and physical pain they endured. Middleton (1999) comments:

> *"Disabled children have an impairment, which, without any discrimination from society, may cause inconvenience, pain, discomfort, tiredness, sickness, ill health, or premature death. Most reasonable people would prefer that children were not impaired". (p.77)*

Hardly any of the young people talked much about their impairments, yet they believed that they faced obstacles to their full inclusion in their own society because of various social and environmental barriers, including discriminatory public attitudes. They preferred not to talk much about their impairment. They talked about offensive language, negative images and expectations, and "sympathy". These characteristics of society's response to disability might lead disabled young people to be isolated, dependent, disappointed and have fewer friends than non-disabled young people. The same experiences have been reported in the developed world. According to Connors and Stalker's (2003, p.11, 112) Scottish study, there was a concern among older disabled young people and their mothers, because of adults who stared at them when they appeared in their wheelchairs in public places. Parents, in Connors and Stalker's study, stressed the importance of better public education.

The disabled young people in Oman distinguished between the attitudes of older people and younger children. Generally, younger children were less positive and most adults were positive. It seemed that young children had less education and awareness about disabled young people and the way they should respond to them. It could also have been because the interviewees felt more sensitive about the attitudes and behaviour of people of their generation and this made them interpret young children's views in a negative way.

Disabled young people talked about how it was difficult for them to have real friends in their own local community, and this made them sometimes feel isolated. They each knew just a few children who were willing to play with them. However, relatives' children were more likely to play and let them join in their

activities. Although, these negative experiences were attributed, by the young people, to discriminatory attitudes, the inaccessibility of the local community and the deficiency of their equipment contributed to their difficulties in developing relationships with other children. It might have been because, as one of the interviewees said, non-disabled children preferred to play and to do activities with children who did not have mobility difficulties. This implied that more education was required in order to make people, including non-disabled children, aware that disabled young people are equal citizens and they have the right to be involved in different activities with their peers and siblings. Disabled young people also needed to be enabled to do so, by the removal of the barriers that prevented them from moving and by the provision of suitable wheelchairs.

Nevertheless, disabled young people believed that public attitudes had a direct negative effect on their friendships, as well as their feelings. Four disabled young people complained about the discriminatory language of children in their own local community. The direct effect was not only that disabled young people had fewer friends, but that it was painful to be portrayed as paralysed or blind. All these factors led to greater exclusion from their own societies. Most of the disabled young people questioned how they could gain full inclusion in a society that did not respect or protect their right to be fully involved. Again, this issue could be tackled by the development of a national education programme. This should be focused on challenging people's negative beliefs about disability and disabled young people, as well as enhancing the self-esteem of disabled young people themselves; their recognition as equal citizens and respect for their dignity should be maintained. Most importantly, society has to be sent a message that it has disabled young people and that it exacerbates the effect of their impairments, by failing to acknowledge their rights and to meet their needs on equal terms with non-disabled people. Young people's accounts revealed that, by identifying the negative impact of public attitudes, the inadequacy of services and equipment and the barriers in their physical environment, they recognised the relevance of the social model of disability to their situation. Eventually, negative attitudes restricted their opportunities for participation in ordinary activities with children

of their age. A significant number of disabled young people made it clear that they hesitated to get involved with people who regarded them as different. This meant Omani society should be aware of the way it perceives and portrays disabled young people.

The findings presented in this chapter have shown that the discriminatory attitudes could prevent disabled young people from enjoying full inclusion in their own local communities. They also limited their friendships and their opportunities to take part in the range of activities taken for granted by others. These issues should be considered by society, in order to secure greater inclusion and a brighter social life for disabled people, with its associated benefits for the individuals and their communities. Middleton (1999) argued that:

> *"Inclusion in each phase offers social encounters and the chance to make friends. The need for disabled children and young people to take part in leisure activities is therefore irrefutable. Leisure participation can act as a means of empowerment by the reduction of isolation, the promotion of positive self-image and the development of community contacts". (p.98)*

The commitment of a society to ensuring the full inclusion of disabled young people, however, requires a clear understanding of the different barriers that stand in the way of the achievement of such objectives, including discriminatory attitudes. Society should change the prevailing negative perceptions about disabled people and should raise awareness about their rights, including the rights of inclusion and equality. More attention to, and investment in, education and information may possibly improve social attitudes, may result in disabled young people having more friends and being less reluctant to appear in public. Greater presence in their communities may, of itself, be a step towards greater participation, as society comes to expect and accept the involvement of disabled people. According to Swain *et al.* (2003):

> *"In recent years disabled people have formed a vibrant international movement which has challenged the disabling physical and social environment in which they*

> *are compelled to live. A central aim of the disabled people's movement has been to change the definition of disability from one of helplessness and tragedy, brought about by impairment, to one of civil rights and equality where disabling barriers are believed to be the cause of disability". (p.68)*

In this study, the participants were convinced that the cause of their disability lies in the heart of society rather than in their impairment. We saw earlier the extent of the effect of public attitudes on disabled young people's inclusion. It was also true that the inaccessibility of the local environment was a great concern of the participants. It was, in their view, a source of restriction and exclusion. It prevented them from taking part in different activities and from moving independently in their own community. The several examples which were presented earlier, from the accounts of the disabled young people, demonstrated that physical obstacles prevented them from having adequate chances to use the facilities and services they needed in their everyday lives. For some young people, hostile environments meant that they were almost confined to their own homes, unable to leave safely. They did not talk about the inaccessibility of public transport, as they usually went out accompanied by their parents. Yet, as will be discussed in the next chapter, the participants complained about the inaccessibility of school buses.

Almost all the disabled young people interviewed used descriptive expressions to complain about the inaccessibility of their environment. It was a feature not only of rural areas but of urban areas too, but the former were much worse. Yet, the nature of the local environment in rural communities made it hard to adapt, as the terrain is full of stones and hills. To provide an adapted accessible environment for wheelchairs, users would require a joint-effort between society and the government. This issue should be considered, if there is an intention to give disabled young people the chance to move freely in their own local environment. Connors and Stalker's (2003, p.49) study found that disabled young people who lived in rural areas, because of inaccessibility, faced an obstacle to their involvement in different local activities.

The suitability of wheelchairs in a stony environment is a significant issue. Most of the participants complained of that their wheelchairs were

broken, often because of the harsh nature of the local environment. The existing wheelchairs provided are not suitable to be used in both the mountainous rural areas and the desert areas that are covered with sand. The unsuitability of wheelchairs might have a significant effect on their inclusion. The type of wheelchair should be suitable not only for the age and size of users, it is also important to be usable in different local communities. This might draw our attention to the quality of wheelchairs that are currently offered to disabled young people. The notion behind this is that they need to have suitable and comfortable equipment in order to be able to move freely, to be able to visit their friends or neighbours and to be able to take part in different activities inside and outside their homes. Motivation (2004), as an international organisation which is working with a range of organisations to implement projects that enhance the lives of physically disabled people, suggested that their project has helped a significant number of physically disabled people, especially in the developing countries, to have suitable wheelchairs. It has resulted in more inclusion for those who have already appropriate equipment.

Disabled young people presented several examples that showed that, because of the inaccessibility of their environment, they were excluded from the mainstream life of their society. Everybody interviewed had his/her experiences to relate, about how far the inaccessibility affected their full involvement. Of course, there were other factors which aggravated their exclusion, including public attitudes and lack of service provision. The United Nation (UN) (1986) asserted that:

> *"Disabled people have the right to move in their own societies without any obstacles as other citizens do. This should be considered in planning human settlements, including programmes in rural areas". (UN, 1986, paras. 112 and 113)*

Research, in the developed world, suggests that disabled young people are prevented from being more independent and moving into their wider community, simply because of physical restrictions (Middleton, 1999; Connors and Stalker, 2003). The barriers that disabled young people face might not only

lead to more exclusion, but also would deprive them of facilities that are granted for the rest of their peers and fellow citizens. Connors and Stalker's (2003, p. 115) study found that physical restrictions to access places such as shops, food outlets, leisure facilities and clubs, were matters of great concern for disabled children. Inaccessibility also increased their dependency. It made disabled young people unable to move without help. Being dependent on their sisters and brothers, or on other children in their local community, had an impact on their feelings and privacy. They did not hesitate to show their despair as a result of being always pushed by somebody else, even when they moved about close to their houses. Connors and Stalker (2003, p.115) showed that many disabled children, because of lack of physical access, could not move about, if they went to places like shops and parks, except in the company of adults.

It is worth noting that when disabled young people become older, especially those who live in rural areas, their everyday lives grow even more complex. The respondents were clear in expressing their understanding about the difficulty they would face in an inaccessible environment, especially beyond their childhood. They thought that it would be not only embarrassing to be pushed by others in public, but also it would be difficult for others to push them in bigger wheelchairs and in an inaccessible environment, as they became heavier. Almost half of the sample hoped that in future the local environment would be more accessible. There is evidence that, in both developed and developing societies, as disabled young people grow up, physical barriers become more apparent (Stark, 2001; Turmusani, 1999). Cavet (1998) suggested that disabled young people tend to move from the familial setting for leisure to wider contacts in the local community. However, such people would still face a great challenge if their own local community remained inaccessible, as is the case of most local communities in Oman. Therefore, such a problem should be tackled by promoting more understanding and awareness about their rights, including their right to be equal citizens and their right to have an accessible environment. However, this cannot be achieved unless society recognises their rights, as a means of opening the way to their achieving full inclusion. The Omani Association of the Disabled (Challenge, 2003) advocated that disabled people should be regarded as equal to non-disabled people. It

added that society has to take into account that the former should be given the adequate services and freedom of movement that are already ensured for non-disabled people.

Service Provision

Disabled young people broached important questions about service provision. They focused on three main services, namely health, social, and education services. Their experiences of school are discussed in the next chapter. The aim was to establish whether their needs for services were met, or not; and if they perceived any obstacles to receiving adequate services.

Only a few participants talked about health services. This was possibly because most thought that medication or therapy would not help them get better. It was also true that when they were young children, almost ten years ago, the specialist therapies were not provided with in regional hospitals. Krafting's (1999) report suggested that there was a shortage of physiotherapy and occupational therapy outside of Muscat. It was also possible that they lacked information about the importance of physiotherapy or occupational therapy, which meant that they and their families were not in contact with such therapists. It might have been because of the distance to hospitals, especially for those who lived in rural areas. Some disabled young people revealed that their families' income was low and their fathers did not have a car. Some of their fathers worked far away from their homes. These issues might have prevented them from going to hospital. Another possibility was that most disabled young people interviewed received therapies from Al-Wafa Centres (day-care centres), rather than through regional hospitals.

These various obstacles should be taken into account if there is a plan to encourage disabled people and their parents to use the existing health services. More information, education and greater health service provision in the local communities, including rural areas, should be considered in this regard. However, a few participants, who were in contact with hospitals, encountered several difficulties, including long distances, transport costs and long waiting times for doctors. The findings revealed that disabled young

people, and probably their families, struggled to obtain health services. This might be because most of the hospitals they had to use were located far away from their homes. This issue, in most cases, meant that not only did disabled young people struggle to use the health services, but also their parents and sometimes their siblings struggled too. On the day of the appointment sometimes most, if not all, family members had to travel to hospital. Their parents might have been obliged to pay for transport and for food during that journey (in the next chapter, mothers raise the same issue). This might increase the responsibility of their parent/s, which in turn, as disabled young people themselves reported, made them conscious that they cost their parents more than their non-disabled siblings. Some of them were concerned about this, to the extent that they planned that when they became adults and employed, they would help their fathers.

Similarly, Fazil *et al.* (2002, p. 247) found that some South Asian families, in the UK, reported missing hospital appointments for their child as a result of transport difficulties. They were unable to take their disabled young people by car and taxis; it costs them a lot of money. By contrast, Connors and Stalker's (2003, p.66) study found that most disabled young people and their mothers did not experience difficulties in attending regular appointments in hospitals. These two examples show that for families of disabled children in the UK, the difficulties in keeping hospital appointments were not because of distance from or the availability of hospitals, rather it was because of problems related to the circumstances of the families themselves, including low incomes.

Only three participants talked about the question of staff attitudes in hospitals. Mothers of disabled children, whose accounts are presented in chapter ten, raised more issues related to the health services, including the attitudes of medical staff. The three disabled young people, who talked about medical staff, believed that doctors were nice. It was possible that their impairment was mild and that they felt that doctors could help them to get better. Alternatively, doctors might have treated them with respect or given them a chance to speak for themselves about their impairment, rather than relying only on their parent/s. This might have been because these participants lived in the main cities, where major hospitals were located, and they did not

face difficulties in travelling to hospital. Yet, two participants complained about the way that doctors diagnosed their impairment and the language they used to inform their mothers. They believed that those doctors gave them incorrect information about their condition. As a small number of the participants raised this point, there was possibly a misunderstanding between the doctors and the disabled young people and their families. It seems that these incidents happened when those participants were younger, ten years earlier or more, when the vast majority of doctors were not Omanis and did not speak Arabic. It was also possible that those doctors did not give them enough chance to ask questions and to reach a full understanding about their impairments. Connors *et al.* (2004, p. 109) found that South Asian parents of disabled young people, in Britain, complained about the quality of information they had been given about their child's impairment; doctors seemed not to explain anything in detail.

In contrast to the views expressed about doctors, the young people's views about nurses were negative. They gave evidence that nurses, in wards, were not helpful and had discriminatory attitudes towards them. Although a few participants raised this point; their complaints indicated that some hospital staff lacked knowledge, about the significance of promoting the rights of disabled young people to be dealt with in a respectful manner. They should not have been let down by staff attitudes when they were in wards, especially at a time that they felt lonely because they were away from their own homes, siblings and peers. It was also possible that there were problems in communication with non-Arabic speaking nurses, which might have implied they were unable to understand the disabled young people's expressed needs. The nurses might not have realised that their roles were, not only to provide medication but also, to encourage the young people and to support them in using the existing health services without difficulties. Yet, almost all the professionals I met, as discussed in chapter eleven, were familiar with the medical approach to disability, rather than the social model, which the vast majority of them were unaware of. This leads me to highlight the importance of introducing the social model and explaining its implications to all professionals working in services for disabled people, especially children, in the future.

In contrast, Connors and Stalker's (2003, p.66) Scottish study found that doctors in hospitals explained things clearly, using age appropriate language, when they talked to disabled children. This showed that doctors and medical staff understood that it was their responsibility to make sure that disabled young people and their families were provided with clear information, using clear language. However, this could not have been achieved without those professionals having a full understanding of the rights of disabled young people, including their right to be listened to and to be served adequately.

The respondents in Oman talked about different issues when they discussed their experiences of social service provision. They were aware of the importance of financial support through the social security system. However, the majority of the young disabled people complained about the current social security system, which did not cover people who were under eighteen. Most of the respondents drew our attention to the fact that, because of the inadequacy of the current social security system, their families faced significant problems in meeting their daily needs; this was especially difficult for those families with low incomes. Disabled young people might think that, because of their impairment, they were more expensive to provide for than their non-disabled siblings, as they needed extra clothes, special diets, transport to hospital and so on.

Disabled young people indicated that not all their everyday needs were met, because their parents could not afford to provide everything. They might have also felt that they did not want to be a burden on their fathers. One disabled young man said it clearly: '*it is our right to be financially supported by the government*.' The Omani Association of the Disabled (Challenge, 2003) suggested that most families with disabled children are not able to provide for even a decent minimum standard of life for them. Similarly, in the UK, Parker (2000) showed that 55% of families with disabled children were living close to or on the margins of poverty. He indicated that most parents did not receive their full benefit entitlement; this was because of lack of information or problems in making applications, especially parents from ethnic communities.

In Oman, however, the problem was that disabled young people were not covered by the social security system. This suggested that policymakers were not fully aware of the imperative daily needs of disabled young people,

which were likely to be greater than non-disabled children's needs. Several studies in the UK showed that raising a disabled child costs parents almost three times as much as raising a non-disabled child (Beresford, 1994; Oldman and Beresford, 1999). The significance of social security benefits was identified by young people in Oman. They recognised that parents had difficulty in meeting their needs. They believed that their parents should receive support from the government. The young people argued that it was their right to be aided, so that they did not feel that they were a burden on their fathers' budget, as this made some of them feel unhappy. Service providers should realise that the absence of the financial support, for disabled young people, especially when it is compounded by the low income of' the family, would mean that it would be difficult for them to have their minimal daily needs met. Hardship, due to lack of recognition of the reality of the financial situation of families with disabled children, is another source of disadvantage that can be attributed to society, rather than the individual's impairment alone. However, this might exacerbate the feelings of being different to their peers that disabled young people experience, because their needs are more likely to be met. This feeling of being different might erode the individual's sense of self-worth, decrease their well-being and so, at a personal level, exaggerate the negative impact of their impairment.

Housing adaptations and equipment, to aid independence or personal care, were issues raised by most of the respondents who were dissatisfied with the inadequacy of this kind of provision. The accounts presented in the last chapter, revealed how much disabled young people complained about the inaccessibility of their houses. They made a link between such problems and important issues like dependency, restriction, isolation, risk and exclusion from different activities that their brothers and sisters could participate in. For those who lived in rural areas, the difficulties were greater. The absence of adaptation services provided by the government made the problem worse. Some disabled young people valued the adaptations which were made by their fathers or older brothers. However, to many families the major building work required on their homes was unaffordable, unless they were able to save money by having spare income.

The respondents, who used Al-Wafa Centres, were very satisfied with their services. Al-Wafa Centres are voluntary day-care centres and they provide basic education, therapy and leisure services. Yet, they are located only in the main cities in Oman; which means that thousands of disabled young people can not use them. According to the Al-Watan newspaper dated in 9-7-2004, there are only 1,680 disabled young people who are currently served by Al-Wafa Centres. Although most disabled young people considered Al-Wafa Centres as schools, these centres were not expected to provide professional services. The volunteers were inexperienced and not qualified, yet disabled young people were happy with the way they were dealt with by them. This was possibly because volunteers treated them with consideration and respect and gave them a chance to take part in different activities; some of the disabled young people reported that volunteers helped them to enrol in ordinary schools. Another possibility was that these centres were regarded positively by the young people because they provided leisure activities, and a suitable environment and atmosphere for them to develop friendships with children who had similar experiences. They also provided a break for parents. Disabled young people compared themselves to their sisters and brothers. These centres made them feel that they were not so different to their siblings, as all of them went out every morning and stayed out all day. They reported that it was an awful experience, when they had to stay at home for the whole day. According to Connor and Stalker (2003), voluntary organisations in the UK were also regarded positively by the young people who used them, as they afforded opportunities for them to have frequent contact with others, and provided leisure activities as well specialist therapeutic services, including counselling.

This chapter presented evidence that disabled young people in Oman experienced social exclusion and the responsibility for this lies with their society. The accounts of young people also demonstrated that they were able to identify and discuss significant issues arising in their own social world. They talked about inadequate service provision, inaccessible local environments, discriminatory attitudes, and were able to identify the links between these real and practical problems and their exclusion from their own society. In the next

chapter, disabled young people present accounts of their experiences of school.

Disabled Young People in School

8.1. Introduction

In this chapter, I present findings based on the disabled children's own accounts of their experiences of school. The children and young people posed questions of importance to them, including staff attitudes, their admission to school, the accessibility of transport and buildings, support services, their peers' attitudes and friendships. I was particularly concerned to see whether or not they experienced any difficulties that prevented them, from having an adequate chance to be included in the mainstream life of their schools, and to identify what kind of obstacles they encountered.

In her research about the Government's policies towards disabled young people and their families in the UK, Russell (2003) suggested that education plays a vital role in their lives. The Convention on the Rights of the Child mandated that states make primary education compulsory and free to all children. Price (2003) highlighted the importance for disabled young people of having access to and using educational facilities, in a manner that helps each child to achieve the fullest possible integration and individual development. However, as Price reported, the current situation in developing countries is not encouraging, and this does not exclude Oman. According to Jones (2001), statistics in developing countries show that a very small number of disabled young people receive an adequate education service.

In this chapter, I examine the situation in Oman, on the basis of disabled children's views. It is worth mentioning that my 26 participants had physical disabilities and they were able to communicate verbally, which meant that they had no need for specialised staff to assist with communication, and that they were able to express their views directly without any intermediary.

8.2. School Enrolment

Staff Attitudes

The great majority of the interviewees were positive in their perceptions of teachers' attitudes. They described them, using words like "nice, helpful, encouraging, supportive, and welcoming". A disabled girl, who is now in elementary school, remarked that her teachers were:

> *"Very good, thanks be to God. All the teachers like me, I have no problem with them, they are really helpful".* (C3-female-16 years old, 7)

It was not surprising to find out that the children viewed their teachers in this way. There are factors promoting and supporting teachers' positive attitudes. In general, teachers are seen as offering respected role models for people in society. Islamic culture puts teachers on a level with God's prophets. Teachers probably have more awareness than most people of disabled children's rights to education. They realise that most of them have no choice or access to education, unless they are included in ordinary schools. Special schools are not provided outside the capital (Muscat). Although, these children experienced a good relationship with their teachers, they did not mention receiving any kind of extra attention from them, which might have served to maintain a stable relationship with their peers. The children themselves showed a great interest in their studies. They felt that they worked harder than their peers, an attitude to learning which may have made their teachers more helpful towards them. The young people looked on study as very important in their lives. One said:

> *"I like my studies because I see my future in them. How can I have a good life without studying? How will I obtain employed with no qualifications? I will work very hard to complete my studies".* (C3-male-17 years old, 5)

A very small minority saw non-Omani teachers in a less positive manner. An incident was reported by one participant, a wheelchair user:

> *"There was a (E) teacher, whom I still remember. He asked me to stand up because he did not know that I was a disabled student. He looked at me and shouted loudly at me, why don't you stand up? It was difficult and hard".* (C3-male-18 years old, 5)

It cannot be assumed that non-Omani teachers consistently showed negative attitudes towards disabled children. This incident could be explained as due to a misunderstanding on the part of the teacher, rather than malice. It is not necessarily the case that each teacher knows all the students, including the physically disabled, in circumstances of overcrowded classes, especially if she/he has just started teaching.

Just one disabled child mentioned social workers in school.

> *"I asked the social worker to help me in adjusting my table which does not fit my wheelchair. But he did not take any action".* (C3-male-18 years old, 6)

This suggests that the majority of disabled young people communicated mainly with their teachers, and that only a few of them were in touch with social workers in school. Usually, there is only one social worker in each school and she/he has to take responsibility for the various problems of hundreds of students.

Admission to Ordinary Schools

Within the last ten years, there has been a significant increase in the number of disabled young people who have had the opportunity to join ordinary schools (Krafting, 1999). However, in being admitted to school, the respondents experienced different obstacles. Almost all faced a delay on commencing their education. This was due to numerous factors. A number of the interviewees did not know about the possibility of being accepted into ordinary schools. One disabled boy claimed:

> *"I did not know that it was possible to get into a school. Fortunately, through the Al-Wafa centre I learnt about such a possibility"*. (C2-male-15 years old, 7)

Although, this child lives in one of the main cities in Oman, where most key services are provided, he lacked information. The major question to be raised here is about the situation of those disabled young people who live away from the main cities or, moreover, about those who live in rural communities, where basic services are poorly provided. Are they aware of their rights to have the opportunity of an education?

One of the participants described his situation before his family had to move from a rural community to an urban community.

> *"Before my family moved to [the town] I did not think it was possible for me to get into school. I thought I would stay at home all my life. I know some disabled children who still live with no services. They just stay at home. I remember when I was there, all the children in the village went to school except me*". (C3-male-17 years old, 6)

This boy's account suggested that there are substantial numbers of disabled young people in Oman, who still have no opportunity to go to school. He thought that most families believed that disabled young people should not go to ordinary schools. In the urban communities, the situation is not much different. A girl from a city called "Sueq", who was 13 years old, still does not know it will be possible for her to go to ordinary school. She has not received any education yet.

> *"My father and I did not know that it was possible for me to go to school. I thought that I would have just to stay at home. Now I have been told by the Al-Wafa Centre that I can go to school, which all my brothers and sisters do".* (C4-female-13 years old, 4)

According to Krafting (1999), before the nineteen nineties, disabled young people were unlikely to be seen going to school. The trend was not to send them to ordinary schools, which meant that the great majority of them just stayed at home all day. The denial of opportunities to attend school might have contributed to greater exclusion for disabled children. However, in the last decade, with the development of more than 12 voluntarily day-care centres (Al-Wafa Centres), the picture began to change. The centres helped the children to gain more inclusion in ordinary schools. A participant expressed herself in the following words:

> *"The centre has made it easier to me to join the school. I remember my father and a volunteer from the centre took me several times to school until I was accepted".* (C2-female-12 years old, 1)

When disabled young people endure a delay before commencing school, they face two problems. First, if they are put in a lower class to their

age, they have to be with children younger than them, so that might have an interaction problem with their peers in class.

> *"They wanted me to be in a class where all the students were small. I did not feel happy with them".* (C3-male-18 years old, 7)

Second, if they are put in a higher class than their chronological peers, they might be at a disadvantage and have difficulty in catching up on lessons they had missed. As one young woman recalled:

> *"I had a chance to join school when I was just eleven. I was promptly put in Class Four where all the other students had started their studies from scratch. The school did not give any consideration to my level of knowledge. The result was that I failed twice in that class. But I was determined and I worked very hard, as I had no other choice. However, you can see me now in the secondary school".* (C4-female-18 years old, 1)

The disabled young people probably do not join ordinary schools through the normal channels, used by non-disabled children. The great majority of the participants required help to enrol. In collaboration with their fathers or older brothers, Al-Wafa Centres played an important part in helping them to be included in ordinary schools. The several quotations above show how very grateful these children were to these centres for the support they gave. However, such centres are only found in the main cities and they serve a small number of disabled young people in Oman (Krafting 1999).

A wheelchair user, who lives in a rural village, faced a barrier to joining the ordinary school in his village. The school would not accept him at first. He mentioned that he was helped by a social worker to join the school:

> *"I remember very well when my father and a social worker took me to the education department in the region. One officer asked me, "Are you sure that you want to go to school?" "Of course" I said. Then I was accepted* [in school] *because I brought a letter from the department"*. (C3-male 18 years old, 8)

It is worth mentioning that the majority of the respondents, who already go to ordinary schools, declared that the new school buildings are more accessible than the old ones. However, they complained about inaccessibility of the first floor and toilets.

8.3. Accessibility in School

Accessibility and environmental barriers, to inclusion in school, were the subjects most frequently mentioned by the disabled youngsters in this study. In their comments, they noted obstacles in the accessibility of transport (school buses), school buildings and various facilities inside schools, including doors, toilets, first floors, and sport areas. They made associations between access and their involvement in different activities in schools.

Transportation

Almost all the participants who already went to school complained of the inadequacies of the arrangements for transporting them there. They experienced difficulties getting to the bus station, where all the students wait for school buses. Sometimes the station was at some distance from their homes. Therefore, they needed to leave quite early, and sometimes they needed somebody else to push their wheelchair to station:

> *"My mother takes me to the bus station, she pushes my wheelchair, and sometimes carries me, as I am not overweight".* (C3-female-16 years old, 8)

Moreover, those who had no wheelchair or whose wheelchair was broken faced double trouble:

> *"Before I had a wheelchair, I had to crawl to the station which was so hard, I arrived there exhausted, and my clothes were dirty. However, I had no choice but to do so".* (C3-female-19 years old, 1)

Two interviewees lived in a village where school transport was not provided, which made their journey very difficult. One of them was still using his wheelchair to travel from his home to the school, and he had to cross two *Wadies* (wide dry streams for heavy rain that come from the high mountains):

> *"The distance from my house to the school is more than 1km. My brother [who studies in the same school] pushes my wheelchair there every day. The path is not really accessible. There are stones, hard climbs, and hills. I would really be in trouble if I always had to travel on this inaccessible route".* (C3-male-17 year old, 5)

Another participant, who lived in a rural village, faced obstacles to his mobility when he attended the primary school, which was not adapted, and transport was not provided. While he was recalling his experiences, he could not hold back his tears:

> *"In the beginning, I did not have a wheelchair and no bus came to take me. My father himself, who is an old man, carried me in his arms. Then, he and my older brother said, it is too difficult to carry you every day for more than*

1km. My father bought a gardening trolley (Wheelbarrow*). It was hard for me to be pushed on a trolley".* (R3-male-18 years old, 5)

The great majority of the interviewees, who used school buses, experienced various difficulties, including buses that were overcrowded, unsafe, inaccessible and uncomfortable. These buses were not adapted for wheelchair users and they did not provide minimal standards of safety for them. There is evidence that some disabled young people were reluctant to use them, as they wanted to avoid any risk of harm. If they had to use such buses, they were among more than 30 non-disabled students travelling in a vehicle with a capacity of just 25 students. A disabled boy pointed out:

"The school bus is not suitable for students like me. I need a safer and less crowded bus". (C2-male-15 years old, 8)

School Buildings

Most of the participants who already went to school pointed out that there were facilities in their schools, namely ramps and access doors, which made the buildings more accessible. However, they complained of inadequate toilet facilities, inaccessible sports' areas and the impossibility of going up to the first floor.

"I use my wheelchair inside the school; there are ramps and accessible classes. However, the toilet is not suitable and it difficult to get there in my wheelchair". (C2-male-15 years old, 9)

The inaccessibility of accommodation on the first floor and the sports' areas kept disabled young people away from others, and meant that they were excluded from participation in a range of activities in school. A third [7] of the participants raised this problem. One boy was delighted to be a

member in one of the school's groups. However, he was disappointed because some activities, including group meetings, were held in the first floor, which he could not access in his wheelchair:

> *"My teacher wanted me to take part in different activities. For example, I am a member of a daily education group. However, some activities and meetings are held on the first floor which I can't access"*. (C3-male-17 years old, 7)

A third of the respondents used crutches and some had visual impairments. Although they had fewer difficulties in gaining access to the school buildings, they confronted other general barriers that prevented full involvement for the disabled young people. They considered that the provision of accessible entrances and toilets were important matters. One boy, who used crutches, suggested that while he did not have difficulties gaining access to the school, he was very concerned about the inaccessibility of school accommodation and facilities for other disabled children:

> *"I use these crutches and I do not have a big problem to move inside the school. In my class, I have a friend who uses a wheelchair. He sometimes faces difficulty getting t into [the building] or when he goes to the toilet. He sometimes asks for help"*. (C2-male-16 years old, 3)

8.4. Peers' Attitudes

The great majority of the participants explored their peers' attitudes on the basis of their ages and class level. They regarded their young peers in the primary school as unfriendly and negative. By contrast, they found that their peers in the elementary and secondary schools were friendlier and had more positive attitudes towards them.

The respondents recalled negative behaviour in primary schools, evidenced by insensitive comments and questions, although reported

incidents of aggression and bullying were uncommon. Three participants experienced this sort of treatment:

> *"Once, my classmates asked me, when did you become disabled? They asked just for fun. When I was in classes 1 and 2, however I can't remember the exact words of my companions, but I can still imagine how bad their words were. Another mate asked me, Oh, are you still in your wheelchair till now?".* (C2-male-17 years old, 1)

One disabled girl reported similar experiences in primary school. She gave an example of bullying incidents:

> *"When I was in the first three years [primary school], one girl asked me a strange question, "Why are you disabled?", she said. Another one pushed me and I fell down on the floor which caused a lot of pain".* (C3-female-16 years old, 9)

Generally, the disabled young people experienced negative reactions from young children, not just in school but also in the local community, as discussed in chapter seven. It is possible that those children lacked information about disability and did not have the skills of communication, with members of society who were "different". The disabled young people were not helped to become involved in different activities and therefore were rarely seen in public places. Consequently, as one teenaged girl suggested.

> *"I believe they asked, "Why is this disabled girl accepted in our school?". For them it was strange to see a person like me in my wheelchair studying in their school. Because, it was not common for a disabled child to go to ordinary school, they thought we should stay at home".* (C4-female-16 years old, 10)

In contrast, disabled young people saw their peers in elementary and secondary school differently. They described them as friendly, mature, and helpful.

> *"They are helpful and more friendly".* (C2-male-15 years old, 10)

Interestingly, none of the interviewees made any negative comments about their peers in these schools. It is possible that older non-disabled children at these stages of schooling might have more understanding about the rights to education of disabled children. The more positive attitudes and behaviour, of older school children, might also be attributed to the presence of disabled young people becoming more familiar in the ordinary school environment. The disabled young people themselves became more able to develop relationships with their peers.

The respondents who were from rural areas had slightly different experiences. They suggested that most people in their rural villages were relatives. This meant that most of their fellow students there were either relatives or neighbours. The respondents did not show much concern about their classmates' attitudes. However, two interviewees said that they felt humiliated, because they were obliged to crawl into the class, in front of the other children. One young man reported:

> *"Before I was given a wheelchair, I crawled from the entrance of the school to my class. This was in front of all my companions, which was awful".* (R1-male-18 years old, 3)

8.5. Support Service

Almost all the respondents talked about the need for assistance, either before they get into the school or inside. They, sometimes, needed help to enter and leave school buses. A great number of the participants had their brothers and

sisters to help them. They also valued their friends' help in pushing their wheelchairs. However, they did not feel happy to be dependent on their companions. Moreover, some of them complained that these did not know how to help them properly. A disabled girl experienced difficulty in this way:

> *"I am really happy with them, and they are keen to help me. But they do not know how to hold me when they help me to move from the bus to the wheelchair, and that causes a pain in my shoulder"*. (C3-female-16 years old, 11)

In fact, officially there is still no special support service for disabled students in ordinary schools in Oman. This may influence a significant number of them, who need help in some aspects of their daily lives, to decide against going to school. Four participants experienced difficulty in coping without support. If disabled young people were heavily dependent on personal care from others and could not manage without assistance, they usually avoided going to ordinary schools, preferring instead to attend the Centre of Care and Rehabilitation for Disabled People in Muscat. A disabled youth made a comparison between his experiences in both school and the Centre:

> *"There is a big difference between the Centre where I am now and the school where I was. In the Centre it is much better, more accessible and [there is} more attention and people understand and help me"*. (C3-male 16 years old, 12)

This disabled boy explained that his father, who works in Muscat, helped him to join the Centre, which is also situated in Muscat. Although it is more than 160km from his home, he regarded it as better than the local school simply because of the support service and the accessibility of the environment. However, not all disabled young people in his condition would have had the

same chance, because the capacity of the centre is limited to fewer than fifty disabled people each year. For those who lived far away from the Centre, it was sometimes difficult for them to leave their families. One of these boys had an opportunity to join the Centre, but he found it difficult to leave his mother and stay there, as it is located far away more than 360Km.

> *"This year I was told to go to the Centre, but I did not want to go, it is so far away".* (C1-male-14 years old, 1)

8.6. Friendship in School

Friendship in school is one of the key problems highlighted by disabled children. There is evidence that they have more limited opportunities to make friends than non-disabled students of the same age. The great majority of the interviewees claimed that they had prior relationships with their friends at school, as relatives and neighbours.

> *"I have some friends at school whom I knew before I got there. Most of them are nice".* (C2-male-13 years old, 1)

In rural areas, there are close communities. All the local people know each other and most people are relatives, so it is more likely that disabled young people there have friends in school.

Sometimes, the disabled young people found it difficult to have close relationships with their fellow students. In ordinary schools, where almost all students are non-disabled, the disabled young people had trouble in developing friendships, as the majority preferred to be with classmates doing other activities. However, the disabled young people themselves might lack the ability to be involved in a friendship with their companions. They indicated that they find themselves reluctant to develop friendships, because they are prevented from moving freely and practicing different activities in school. They thought that most non-disabled students were not ready to form close relationships with

disabled students. One boy suggested that non-disabled students in his school, pursue their own interests together and he could not join in with them because of his mobility difficulties. Another disabled boy believed that his comrades had very limited expectations of him:

> *"They think, I am unable to do the same activities they do, because I have a wheelchair"*. (C3-male-16 years old, 5)

However, one boy had overcome the obstacles to developing friendship in school, through recognising that he had a part to play.

> *"In the beginning, I faced a problem when I could not adapt easily to students. Maybe that was because of me or maybe because they were not sufficiently familiar with [disabled] students like me. But now I have so many friends"*. (R3-male-17 years old)

This boy was one of the most approachable and gregarious children I have ever met. He appeared active and had communication skills. He was determined to widen his relationships inside the school and with children in the community.

8.7. Discussion

This chapter has presented a picture of disabled children's experiences in school. They talked about their admission, relationships with staff, including teachers and social workers, and their relationships with their colleagues. They also made links between their exclusion from school activities, the accessibility of the environment and staff attitudes.

According to Motawi (2002 p. 60), society should not disregard or ignore the significance of education for disabled people. It should not be provided for them as a charity; it is a right and should be granted to them, as it

is granted to all citizens. All disabled people should be offered the chance of an education. With the benefits of education, they will be able to contribute to their societies and themselves, rather than be excluded and humiliated. In a study about students' attitudes towards their disabled peers, in inclusive and special schools in Canada, Bunch and Valeo (2004) emphasised the importance of the introduction of the right of such students to be educated in the company of typical peers. Bunch and Valeo also argued that education, especially inclusive education, will lead to stronger social and academic achievements, advanced citizenship and the development of a better community.

Education, in the eyes of the majority of the respondents, was crucial, yet they had difficulties before gaining admission to school and after entry. Almost all the disabled young people enrolled in ordinary schools with the help, mainly, of the Al-Wafa Centres, with the cooperation of their parents. Yet, almost all of them delayed commencing their studies. There were a number of factors behind such experiences. Most of disabled youngsters and their parents lacked information about the possibility of entry into ordinary schools. However, for a significant number of them, the headmasters were not happy to accept students with wheelchairs in their schools. Some of them had to bring special letters from the Education Department. Similarly, as discussed in chapter ten, mothers confronted great difficulties to enable their disabled children to go to school, as they had to negotiate with staff in school until they could gain admission for them.

In the chapter eleven, the accounts of professionals who work in the Education Department are presented. They talked about oral (unwritten) orders from their Department about the possibility of admission of physically impaired children to ordinary schools. This indicated that the education services might not give enough consideration to the government offering the same guarantees, to disabled youngsters, as they offer to non-disabled young people. In general, the former showed dissatisfaction with the way they were placed in ordinary schools. In all cases, they compared themselves with their brothers and sisters or children in their own local community, who did not experience barriers to school admission. This is in contrast with the findings of Connors *et al.* (2004,

p. 64) who reported that South Asian children in the UK, who attended school or college fulltime, had high levels of satisfaction with their schools. Similarly, Connors and Stalker's (2003, p. 52) Scottish study found that disabled young people describe school as a positive experience; to them it was better than being at home.

The majority of the young people who participated in this study suggested that their teachers were "nice". However, it was not because they had regular contact with them, or because they gave them special help. The teachers in ordinary schools, as discussed in chapter eleven, admitted that they lacked experience, so they were not well qualified to deal with disabled students. They also had to deal with more than thirty non-disabled students in each class. Nevertheless, the disabled young people reported that the teachers dealt with them in a helpful way. They said that, in a few cases, they prevented non-disabled students from using hostile language about or against them. Yet, most of the disabled young people did not have the chance to be involved in activities with their peers, as their teachers did not make enough effort to support their participation. Only two disabled youngsters reported that they took part in certain extra-curricular activities, but they were disappointed because some meetings were held on the first floor, where they did not have access because they used wheelchairs. Only three young people reported having had contact with social workers: however, they did not mention any significant support that they received from them in school. The teachers had more contact with them and provided more help. The disabled young people thought that the social workers in school had to deal with hundreds of non-disabled students; they were also responsible for doing administrative work. These factors, they considered, might make it difficult for them to be as involved with disabled students as they might wish.

The disabled young people faced difficulties, because they were not provided with special assistance in ordinary schools. They reported feelings of anger, embarrassment and shame, as a result of their enforced dependency on their colleagues. They relied on their classmates who helped them in different ways, including pushing them in their wheelchairs. Yet, they had mixed feelings

about this. Although most of their comrades were willing to help them, they considered that it was not their role; some of the children thought that their companions pushed their wheelchair just for fun, which made them feel unhappy. The point that should be raised here is, why should these disabled youngsters experience such difficulties? Is it not their right to receive education without obstacles? Schools, it may be argued, should make sure that their needs are met, in order to gain more independence and to maintain their dignity. Yet, this requires policies that take into account their different needs, and qualified staff who should believe in their right to education.

The transport services were considered unsatisfactory. Almost all disabled who went to ordinary schools were very dissatisfied with the school buses. They regarded them as unsafe, overcrowded and inaccessible. They were not suitable to transport them and their wheelchairs. Those who were not provided with a transportation service had difficulty in travelling to school. This was because the environment was not accessible, or their families could not afford to meet their travel costs. Four of the respondents had to use their wheelchairs to go to school, but they needed somebody else to push them along difficult paths. It was painful for them to be pushed over terrain filled with stones and holes. This also frequently caused damage to their wheelchairs. Yet, they showed determination and patience, as if they realised that if they did not overcome such difficulties, they would not be offered any alternative, which means they would simply stay at home. This was further evidence that the barriers to disabled young people using the education services, were neglected by society, to the extent that if they and their families were not patient in the face of such difficulties, they would easily miss the limited opportunities offered.

Three disabled young people had a chance to be placed in segregated centres and schools in the capital. They were, to some extent, satisfied with the accessibility, involvement and assistance they enjoyed. Yet, these special schools were far away from their homes and did not have enough capacity to cater for all the disabled youngsters in the country. However, more research about the experiences of disabled students in special schools and their interaction and satisfaction, would be worthwhile in the future.

The disabled young talked about their relationship with their colleagues in ordinary school. They drew a distinction between the primary stage and the secondary stage of schooling. At the primary stage, their accounts of their experiences were negative. The opportunities to build friendships and to engage in different activities in primary school were limited. It might have been a matter of confidence, as they lacked the experience to prepare them for involvement among hundreds of non-disabled classmates. In most cases, they did not have disabled peers. They thought that the other students regarded them, in their wheelchairs, as different, as they were not able to move freely and faced difficulties in taking part in various activities. The teachers lacked experience, in creating an atmosphere that enabled non-disabled children to interact with their disabled peers. Teachers had to explain to the former that their disabled classmates have the right to be in the same school. Bunch and Valeo (2004) argued that non-disabled students learned their behaviour through their teachers, who led them to accept disabled students in inclusive schools. It is not necessary or possible to place the latter in special schools only, if these were the only option, most would be obliged to stay at home with no education. Baker and Donelly's (2001) Australian study, showed that the professionals in school had a role in increasing the opportunities for disabled students, to form friendships and engage in social interactions. For instance, teachers used social skills training in familiarising students with each other; this could be through games and activities requiring the children to name and help each other. However, such interventions require the skills of well-trained teachers who realise the significance of the inclusion of the disabled in their schools.

In the secondary school, almost all the disabled pupils talked about positive contact with their mates. Disabled youngsters themselves, when they entered secondary schools, had more confidence and experience and were therefore more able to be involved with their peers' activities. Most of them talked about good relationships with their schoolmates. Non-disabled students in secondary schools might consider that it is their duty to respect their disabled peers, as they become mature and have a greater understanding of the

education and rights of their disabled peers. Bunch and Valeo's (2004) study found that the higher the class that the disabled students reached, the more appropriate the relationship with their colleagues, they experienced. They attributed such trends to the fact that students in the higher classes had a greater awareness that they should not behave unacceptably towards their disabled peers.

The respondents, in this study in Oman, blamed the structure of the buildings for preventing them from taking part in different daily activities with their companions, including early morning activity, school radio and sport activities. Although, such obstacles made them feel disappointed, they remained calm and resilient in the face of such obstacles; because they did not have any choice, other than to use such schools. In their study about the social experience of disabled young people and the influence of the environment in Australia, Baker and Donelly (2001), found out that school design influenced disabled children's social involvement in them. For instance, they found that classroom seating arrangements, such as rows and squares of tables might help disabled students to have more chance to move and take part in their peers' activities. They also found that inaccessible schools or classes prevented many disabled children's enrolments, as their parents were concerned about enlisting them in inaccessible schools.

In Scotland however, Connors and Stalker's (2003, p.53) study found out that most of the disabled young people they interviewed were positive about their schools. The majority talked about positive relationships with their teachers and peers. Disabled young people perceived themselves, in school, as being helpful to other people, in the same way as they were helped, and as being good friends to others and active. These points seemed to be different to the perceptions of the disabled young people in Oman. This indicates that the latter faced more difficulties, than children in Scotland, in asserting their right to education. In their everyday journey to school, they faced different barriers, including inaccessible transportation and inaccessible buildings. In school they endured a lack of support for their involvement in activities, as well as busy and inexperienced staff. However, they showed determination in the face of all

these difficulties, simply because they wanted to take advantage of an education which, they perceived, would help them to achieve a better future. Again, if society claims that disabled young people have the right to adequate education services, which are already provided for the non-disabled, the question remains as to why they and their families still experience such annoying barriers.

The next chapter presents and explores, some important points raised by disabled youngsters about themselves and their individual experiences. The chapter includes their perceptions about their impairment, their feelings, and their interaction with their everyday social world.

Disabled Young People's View of themselves

9.1. Introduction

This chapter recalls data that was represented in the previous three chapters. However, the focus here is on disabled children's perceptions of themselves. They were not directly asked about their views of themselves, yet they made valuable comments when talking about their experiences in schools, in their families and in their local communities, that offered insights into their self-images. They were clear in their descriptions of their struggles in the face of the various barriers they faced, how these obstacles to their inclusion affected their feelings, self-perception, interests, friendships, aspirations and expectations. This chapter examines these issues, as they arose in the young people's own accounts.

It is worth mentioning that almost all the interviewees reported that they were not used to being asked about their own experiences. For them, this study was looked on as an opportunity to release the many words that they had been obliged to keep inside themselves. They did not show any reluctance, when I asked them to take part in this study, that is with the exception of one disabled child who, during the interview, asked me, "*why do you want me to tell you about myself*? However, he had been given, as all the respondents had, the full background and the objectives of the study, and agreed to take part. Nevertheless, the interview with him went smoothly.

It is important to remember that in developing countries, including Oman, studies attempting to understand the social world of disabled young people, and research that seeks such an understanding from the perspectives of these people themselves, are uncommon.

9.2. Feelings

The great majority of the respondents expressed some negative views about their everyday lives, and they did not hide their feelings. They gave clear accounts, which provided evidence that they realised precisely and understood the attitudes of the rest of society towards them and the impact of their impairment. The dominant feelings expressed in their accounts were, *'anger', 'sadness', 'shame', 'embarrassment', 'disappointment'* and *'being let down'*; each emotion was described from time to time. However, feelings of happiness and gladness were mentioned too.

The negative feelings were associated with, both their everyday interactions with their society and, their reactions to the impact of the impairment on their full inclusion. In the previous chapter, I described their experiences in school, how much they struggled to join ordinary schools, the extent to which they were deprived from participating in various activities, and the nature of their relationships with their peers, particularly in primary schools. In recalling their experiences, they expressed deep feelings of disappointment, especially when they compared their circumstances to those of non-disabled children, in their own age groups. They complained about the inadequacy of opportunities that they had and the injustice of the differential treatment they experienced.

> *"All children go to school, I, at the same time, ask my mother, when I will go to school? It is still not the time to go to school, 'my mother says. I do not know when I can go"*. (C1-female-15 years old, 3)

This disabled girl cried while talking about such experiences. She, as a blind person, felt sad when she knew that she would not have the chance to go to school in her local community, at least in the near future. A school for blind children had recently been opened in Muscat. However, some families were unwilling to send their children to a school hundreds of kilometres away from their homes.

Several participants considered that they were not entitled to a place in ordinary schools, merely because they and their parents believed that these schools would never accept them. They did not know that by making an effort to enrol a disabled child in an ordinary school, it was possible to secure a place. These families thought simply that it was unusual to see disabled young people involved in ordinary activities, including going to the local school.

> "*My father and I did not know that it was possible for me to go to school. I thought I have just to stay at home. Recently, I have been told, in Al-Wafa Centre, that I could go to the school where my siblings go".* (C4-female-13 years old, 5)

The great majority of the respondents, who already went to ordinary schools, were angry because they were not given the opportunity to take part in various school activities. Even those who struggled to take part, experienced difficulties in accessing the first floor and playground. The respondents also felt excluded, as they had to enter their classroom before their peers, who usually started their school day by doing exercises.

> "*I sometimes feel angry when I see all the students taking part in different activities and I can't, and they do exercises before entering the classes but I don't. They move freely but I need help*". (R3-male-17 years old, 6)

This example showed that physical obstacles prevented disabled young people from enjoying full involvement in ordinary school. It was not enough for them to be allowed to join such schools. These schools should have taken into account the need to remove all kinds of barriers to the access and mobility of disabled children, to ensure their inclusion. If the education service considered making ordinary schools accessible as a right for disabled children, schools would be obliged to remove all restrictions confronting them. Disabled young

people regarded such obstacles as a source of disappointment and frustration. One disabled student compared the opportunities that were offered to his peers, and what they did in the school, with the options available to him. Being prevented from moving about, by obstructions in the school environment, meant he had to ask for help which he found hard, because he felt embarrassed.

As was shown in the previous chapter, the vast majority of disabled young people were not happy with the provision of school buses. They complained about the way bus drivers dealt with them. They sometimes would not agree to stop near their houses, which meant they were forced to struggle to get to the bus stop. The school buses were not adapted for wheelchair users, and non-disabled students overcrowded them, which made disabled young people feel anxious, uncomfortable and sometimes fearful for their own safety.

> "*Frankly, the bus is never suitable. The bus is always crowded and unsafe; seats are not comfortable; but I have no choice*". (C3-female- 16 years old, 13)

Another example,

> "*I really have difficulty in using the school bus, it is overcrowded, and I find it difficult to use it with my crutches. However, I have no choice but to ask for help to get in the bus, which is terrible for me*". (C3-female-19 years old, 3)

The majority of the wheelchair users experienced difficulties in getting into or out of the buses, which caused them embarrassment, especially when they asked for help from their peers. They felt it was not only hard for them to ask others to help them, but it also, sometimes, made them feel inferior to the others. Some students pushed their wheelchairs just for fun. A number of disabled young people were not grateful for the help they received from their peers, because they believed that many of them did it for their own gratification.

> "*Although students, especially in the primary school, compete to push me in my wheelchair, I feel they do it just to enjoy themselves. It is fun for them while they push the wheelchair*". (C2-male-18 years old, 2)

A significant number of the interviewees felt ashamed and humiliated when they crawled in front of the other students, to the extent that they wished that they could rid themselves of the impairment. A disabled boy experienced terrible distress before he had a wheelchair, as he had to crawl to his class. He also felt miserable and embarrassed when his older brother pushed him to school on a gardening trolley.

> "*I really felt ashamed when my peers and neighbours saw me pushed to the school in that silly trolley*". (R3-male 18 years old, 4)

However, most of the respondents, including this disabled boy, did not go further in expressing their emotions. They were calm and resilient in the face of such distressing experiences. Moreover, they were determined to overcome social and physical obstacles, to gain more inclusion in their own society.

> "*I was patient and firm, just [wanting] to be a student like the others*". (C2-male-18 years old, 3)

Being in a wheelchair was not the issue; most of the children did not show any frustration simply because they used wheelchairs. The great majority of them were concerned about obstacles that prevented them from accessing different facilities, which increased their dependency. They were uncomfortable when they asked somebody else for help. They gave numerous examples of painful experiences, caused by the inaccessibility of the environment. In the previous three chapters, I reported how much disabled young people struggled when they encountered inaccessible surroundings, buildings and /or transport.

The feeling of frustration was worst when they could not move about in the local community. Almost all the respondents experienced difficulties in getting involved in the activities of their neighbours' children, which increased these negative feelings. How society looked at them, as wheelchair users, was also a reason for the reluctance to appear in the public places that some of them described.

> "*Actually, I don't want to appear with my wheelchair, because when people look at me, I feel that I am the only person in the town who has a disability. People make me reluctant to go to the park or shops or any public places. I prefer to stay in the car when my mother goes shopping or often I do not go with her*". (C3-female-16 years old, 14)

However, three of the children did not hide the pleasure, which came from the transition they made from using wheelchairs to crutches.

> "*Once I got rid of the wheelchair I felt better. When my brothers were pushing it in front of people, it was really something that made me appear at a disadvantage and I asked myself, why I am like this? Yes, I am still using the sticks, but I can walk around and inside the house with no help*". (C4-female-13 years old, 6)

This example was symptomatic of the association between the feelings of disabled young people and their experiences in their everyday lives. It was not the impairment itself which shaped their feelings, but the obstacles that prevented them from being independent.

The impact of negative attitudes was identified with deep feelings of sadness and anger. A great number of the participants were disappointed by

others' attitudes, especially during their early childhood. As we have seen, they experienced difficulties in becoming fully involved in the local community and having friends, which made them feel depressed. For instance, a disabled girl expressed her reaction towards such experiences when she said:

> "*OK, I am disabled, but why do the others look at me as if I am inferior to them; they do not like to be friends of mine; it is sad*". (C3-female-16 years old, 15)

The respondents were more concerned about the consequences of the impairment than the impairment itself. For instance, a twelve-year-old disabled girl was embarrassed because she was still using incontinence pads, which made her feel ashamed. She also felt disappointed because, sometimes, a horrible smell from a leak in the incontinence pads, which she felt, made others annoyed. She was embarrassed in talking about such sensitive matters; but she could not hold back her intense feelings and her tears were noticeable.

> "*I sometimes feel ashamed when I can't control the urine which causes a wetness and horrible smell*". (C2-female-12 years old, 3)

Most of the interviewees expressed their feelings with regard to what others thought about them. For instance, a disabled boy, whose arms had become deformed as a result of crawling when he was young, did not complain about the injury as such, but about the embarrassment he felt because other people saw him.

> "*My hands and legs became twisted because of the crawling on the* floor *for a long time in my early years. However, it was more embarrassing to crawl in front of other children and siblings*". (R3-male-18 years old, 5)

9.3. Self Perception

At the beginning of this section, I would like to discuss the way in which terms such as disability, impairment and handicap, are used in Omani society, even among professionals. These terms, referred to the limitations of body functions. Of course, each term has its meaning, but in Oman the term disability is used to mean inability or lack of ability. Terms like 'abnormal', 'with special needs', 'deprived' (*Miskeeen*) and 'sick' are used synonymously with disability. However, the significance of language and terminology will be explored further in the discussion section.

Almost all the respondents reported that they were informed about their impairment by their parents, usually by their mothers. A young disabled woman gave an example.

> "*My mother* told *me that I was born like that and the family attempted to treat me in the hospital and by traditional medicine, but there was no way*". (C3-female-19 years old, 4)

And another example,

> "*My mother told* me *that I was born after only seven months of pregnancy*". (C3-female-16 years old, 16)

The majority of the respondents did not show any reluctance to accept their impairment, instead they expressed a determination to adapt themselves to the reality of its implications. They, fortunately, realised that they had to make maximum use of the opportunities that were provided by society. The best example of this was in ordinary schools, where disabled young people experienced difficulties, but they overcame them. Nevertheless, five children were not so resigned.

> "*Frankly, when I knew about the disability, I really felt angry and sad*". (C4-female-13 years old, 7)

Three of these disabled young people had not been impaired at birth. They remembered when they were still young walking and taking part in ordinary activities, with their siblings and other children. These children were more disappointed because their conditions transformed their lives.

> "*My father told me and I remember too, the day when I was walking outside the house, I felt my legs starting to become weak* and *my movements to be abnormal. I realised that on that day my problem had started; It is quite hard to be unable to move*". (C4-male-16 years old, 3)

Impairment was regarded as a factor that prevented disabled young people being involved in activities with non-disabled children; it was also identified as a source of unpleasant feelings.

> "*How can you expect me to be happy when I can't even stand up? All friends of mine do what they would like to do. They do very well in their study and their life is going well but I am not*". (R5-male-16 years old, 8)

Young disabled people perceived various causes for their impairments. A significant number of them suggested that the disability had occurred because of a high fever they had in their childhood.

> "*My mother told me that when I was two years old, I developed a fever, and my family took me to the hospital, but I received nothing, my legs since then have become deformed*". (C4-male-16 years old, 4)

However, some of them did not recognise the cause of their disability. A small minority related it to demonic influences (Jinni), a belief which prevailed in traditional societies at the time of this study.

> "*Who knows, I was walking well and suddenly I started to be unable to walk. Do you think it is just like that, you know. I think, and my mother and father too, it is the work of* demons (Jinni)". (C4-male-16 year old, 5)

However, above all these causes, most of the interviewees referred everything in their life to Allah's will.

> "*What can I do, it is not my choice, but Allah* [the God] *wants it so*". (R3-male-18 yeas old, 6)

It is worth pointing that, as in other religions, in Islam everything is submitted to Allah's will. This helps people feel resilient and calm, in the face of different setbacks. However, this does not mean that disabled young people should face avoidable difficulties that prevent them from having a decent life. If people in society referred such things to Allah's will, they would accept their own share of the moral responsibility for the socially imposed disadvantages experienced by disabled people, simply because Allah does not accept any kind of social oppression. There is a need for more understanding of the religion's teachings, which, of course, are in opposition to inequality and discrimination. However, this issue will be explored further in the discussion chapter.

Almost all the children interviewed perceived themselves as different to others of their age. Each one had his/her personal experiences of incidents to recount that confirmed this difference. However, the majority were negative about their abilities, service provision, involvement in society and their future. They used expressions that symbolised their perceptions. A significant number of the interviewees looked at their impairment as a factor that prevented them from moving well which, in turn, made them feel different.

> "*I am disabled, I can't walk for long distances, I think that I am not like everybody else, however, I try to do things that others do".* (C1-male-14 year old, 4)

Their inability in performing different activities did not always make them feel different, but some of the interviewees thought that they were different because they used equipment that the others did not use.

> "*I use crutches which make me different to my siblings and friends*". (C2-male 15 year old, 11)

These two examples give another indication of the way disabled young people viewed themselves. They compared themselves with friends and siblings who, they thought, looked different to them. Alternatively, perhaps, they regarded themselves as different to others. I think, there is a link between the way society views disabled young people, and how they perceive themselves. The respondents expressed the opinion that they were different and disabled, and their representation and image of themselves corresponded with public attitudes towards them.

They were also anxious about the future, if they continued to need to use such equipment.

> "*If I continue using the wheelchair, I think the future will not be as pleasant as it should be*". (C3-female-19 year old, 5)

This young woman implicitly identified a crucial issue for disabled young people's feelings about themselves and their futures. Usually non-disabled young people view the arrival of adulthood as a stage of transition in their lives, but this is not necessarily the same for those who are disabled. Because of circumstances that mean that they are not provided with adequate education and training opportunities, or because public attitudes towards them obstruct

their participation and their environment remains inaccessible, becoming an adult does not promise greater independence or autonomy, or any major change in their lifestyles.

Almost all the interviewees compared themselves, regardless of the level of impairment and the equipment they used, with others in their age group, and their self perception or self image was based on how others saw them. This fact was obvious when the respondents talked about their everyday experiences. When discussing their inabilities, because of the impairment they had, they blamed the society that prevented them from taking part in the full range of activities that others enjoyed. It was clear that they were aware that they could have more opportunities to achieve greater inclusion in their own society, if the necessary adjustments were made to the environment.

> "*Disabled people have rights to move and take part in different life activities. Ramps, toilets, hospitals, parks and schools should be accessible for us".* (C3-male-16 year old, 17)

The young people also indirectly indicated that they felt that they should be dealt with as equals to non-disabled children. This was manifest in their comments about the inadequate education services they received, and the restricted opportunities they enjoyed for involvement in wider society.

A great number of them were more concerned about the equipment they used, than the impairment itself. Some of them, surprisingly, blamed the appliances as they prevented them from moving easily. It was obvious when they attempted to mention these devices instead of their disability.

> "When *I want to get out of the house or to go to see children playing, this wheelchair is small and I can't use it to go there*". (C4-female-13 year old, 8)

However, the relationship between disabled young people and their equipment or aids to mobility is quite complex and more understanding about it is essential.

Some of the interviewees named their impairment when they were complaining about others who labelled them negatively. They appeared to perceive themselves as disabled people, identified and defined by their impairment, as they were portrayed in this way by some people in their society. A disabled child revealed how people regarded him.

> "*They just look at my twisted feet*". (C1-male- 14 year old, 5)

A young man gave another example of the way that disabled young people felt defined by their impairment:

> "*I became known as the limper*". (C2-male-15 year old, 12)

These two examples show the damage to the feelings, self image and dignity of disabled children, caused by a society which treated them as inferior and failed to recognise their human rights and needs. Who knows how much they struggled to resist the impact of such negative views? The challenge for society was not to help disabled young people recover from their impairment and achieve greater functioning, but to ensure that they perceive themselves as equal and fully included. Society, in fact, should condition itself into regarding and responding to disabled people as equal citizens with their own dignity, and the impairment they have should not be seen as the major issue. Because of their painful experiences, a reaction common to more than half of the young people's accounts, was that they hoped to "get rid" of the impairment. In talking about their aspirations for the future, significantly, they did not hesitate to say.

> *"I hope I find myself without impairment"*

"I just hope to get rid of this impairment".

9.4. Interests

More than half of the disabled children, interviewed, said that their main interest was in watching television and fewer than half were interested in playing and biking. Those, who spent their time watching television, did so because they did not have anything else to do after school or during the holidays. They just stayed at home. They thought the inaccessibility of the local environment, and their inability to walk, were the reasons for their inactivity and isolation outside of school hours. However, they were not content with this situation:

> "*I do not know what I should do; I just stay in front of the* television *and I just watch it. It is really boring*". (C3-male-16 years old, 18)

Those who were interested in biking and playing outside had relatively mild impairments and they seemed to have good relationships with their friends, who were also relatives. These disabled children, therefore, showed more enthusiasm and experienced more involvement in society.

> *"I do not use a wheelchair or crutches. My impairment does not prevent me from going to the toilet. Most of my peers in the school know me as a neighbour. I have no problem with them. I use my bicycle and practice most of the activities they do*". (C2-male-15 year old, 14)

Two girls were interested in working in the kitchen with their mothers. They expressed satisfaction and pleasure that they had the ability to do so and their mothers encouraged them. However, they had the chance to take part in

such work just because, as they said, it was easy for them to move about in their wheelchairs inside their homes.

> "*My house is ok, I can move inside it. Sometimes, I go to the kitchen to help my mother and sisters. It is really a nice thing. I feel happy when I do something with them*".
> (C3-female-19 year old, 7)

This example draws our attention to three things that helped these girls to take part in the housework. First, they were interested in carrying out activities, which means that disabled young people should be enabled to do things they like. I think this is a significant starting point because only they know what they want to do. Second, fortunately, their families realised the importance of making the house accessible, and had the financial resources to do so. I think that there are many disabled young people who cannot do things, or move inside their homes, simply because of the inaccessibility of the accommodation. Third, they reported that they were encouraged by their families to participate, especially their mothers. The role of families, in enabling young disabled people to lead ordinary everyday lives, is essential. However, it may be that families who understand the concept of inclusion are more likely to play such a role. This concept will be discussed in detail in the final chapter.

9.5. The Future

The great majority of the respondents thought the impairment would continue beyond their childhood. Nevertheless, a great number of them expected an improvement in their situation in the future, in terms of the accessibility of the environment, improved service provision and more enlightened public attitudes. However, almost all the participants were anxious about particular issues they would expect to confront in the future, including problems for them associated with restricted opportunities for education, marriage, employment and independence. Moreover, the great majority of them, especially girls, expressed

considerable worries about how they would survive after the death of their parents.

> "*As I am a girl, I think about the future; how I will be in the future, especially after my parents are dead and when all my sisters and brothers have their own families. I am really worried and I think a lot about it*". (C4-female-13 year old, 9)

In traditional societies like Oman, families play a vital role in ensuring that individuals have the opportunities to interact in appropriate social activities within the society. Young people, particularly girls, derived their social status and value from their own families. These considerations have caused the respondents, especially the girls, to be worried about being alone after their parents' deaths. It is not just a matter of their need for care by their parents, but also about their social life in their own society, when they are without their families. It is worth mentioning, both mothers and professionals who took part in this study, talked about this issue, as we will see in the next two chapters.

Education and Employment

The interviewees had all thought about their futures and were aware of the crucial issues of concern to adults. Education was the top worry.

> "*The only thing I think about is to finish my study, it is my future*". (C2-male-12 years old, 5)

Education was a tool to secure the essential things they hoped to achieve in the future. They questioned whether or not they would have the opportunity to work without qualifications. Their aim was not only to land a job, but also to achieve an important change in their lives, which was to be independent. They did not like to contemplate just staying at home, but hoped to find an occupation.

> "*To have work is a vital thing in my life. Next year I will complete my course. Therefore, I hope not to go back and just stay at home doing nothing*". (C3-female-19 year old, 8)

Therefore, another point that was raised by almost all the disabled children, was that of employment. They regarded it from different angles. It was not just to ensure an adequate income, but also a means of raising their status and participating in their society. They did not hide their concerns that they might not have a chance to work in the future. For a number of them, having a job meant dignity and respect. However, the majority of the respondents regarded employment as a source of the income they needed, which would help them to be independent.

> "*Having a job means having your own income and being independent. If I get a job in the future, it means a better situation to me*". (C2-male- 15 years old, 15)

Half of the respondents not only asserted the importance of having their own income, but, in addition, they were responsive towards their families' need. More than a half of them wanted to help their families and they felt they should also be self- reliant.

> "*I hope to have a job in the future. I look forward to helping my father, I want to repay some of his attention and help*". (C4-male-16 years old, 6)

Marriage

Marriage is an important institution in the structure of Omani society. It means social stability and it ensures a secure life. The great majority of the

interviewees were conscious about its centrality to the organisation of their society. However, they did not expect to be married in the future. Most of them, both boys and girls, wished to marry but they did not believe others would accept them. They expected rejection, this was especially so for those who experienced great difficulties in becoming involved in the society.

> "*To get married for me is so important, but the question is, am I going to marry? Who will accept me in my wheelchair as a husband? This problem and many others are always in my mind, however, Allah is generous*". (C3-male-16 years old, 19)

The interviewees were not interested in talking about whether or not it would be possible to marry other disabled people. However, in Omani society, it is common that people with hearing impairment marry each other. It is acceptable that blind people marry non-disabled people. Nevertheless, wheelchair users probably faced obstacles to marriage, especially with non-disabled people, and with disabled people it is quite rare. In Omani society, it is quite common for parents to help their son's and daughters find a partner. However, the respondents did not talk about their parents' role in this regard. As we will see in the next chapter, mothers did not discuss the parents' responsibility to assist their physically impaired children to get married. This may have been because they would not expect anybody to want to marry their disabled child in the future.

Disabled young people associated marriage with the ideas they had about adulthood. They were concerned about their future, after their parents' death, and when their brothers and sisters had their own families. Disabled girls showed greater anxiety because it would be difficult for them to be alone. Usually in Omani society, it is quite unusual for girls to talk about sensitive topics like marriage, especially to strangers or men. However, some did not hesitate to express their worries about this matter in the interviews. One

disabled girl wondered about her future and she revealed uncertainty in her feelings about her life ahead.

> "*If I miss my parents and if my brothers and sisters get married, how will my life be? Do you think that somebody else will come to marry me? I am not sure. For me, it is a problem*". (C3-female-19 year old, 9)

However, a small minority of the respondents said that they never thought about marriage and they did not regard it as a big problem. These disabled young people might not like to talk openly about it. In a conservative society, marriage is usually a major concern and topic of discussion for adults, more than it is for children.

9.6. Discussion

This chapter has examined issues of considerable importance about how disabled young people identified themselves. Their views were based on their experiences of their everyday social world. They had mixed feelings and gave contrasting accounts of their experiences, yet most of them could recall unhappy incidents. The majority of the respondents were disappointed because of a variety of factors, including the way their society treated them, public attitudes, inaccessible environments and lack of service provision. Connors and Stalker (2003, p.118) suggested that disabled young people understood disability through their experience of being made to feel unequal, through physical restriction, institutional barriers and the reactions of others.

Feelings of anger, disappointment and being let down were mentioned on different occasions. Disabled young people were very disheartened when they talked about people who spoke or looked at them in an unacceptable way. This, to many of them, made them feel inhibited, which led them to think that it was better to stay at home, rather than to go out in public. For a blind young person, it was distressful to hear comments about 'deformed' eyes, or for a

paralysed one, it was harrowing to be called a 'limper'. These negative experiences generated painful feelings among disabled young people, to the extent that some of them hoped to rid themselves of their impairment. It did not matter whether young people used offensive terms or adults sympathised, the responses of other people had a psychological and emotional effect on them. They described how words of sympathy or insensitivity made them feel unequal, even if they believed that they deserved to be treated as well as their peers and siblings. In contrast, the children and young people, in Connor and Stalker's (2003, p.106) Scottish study, generally adopted pragmatic attitudes both towards their impairment and to the impairment's effects. Disabled young people in their study deported themselves in a practical and positive manner, as they focused on the 'sameness' of their lives with others, rather than on the differences (p.107).

Poor service provision was a major concern for these young people in Oman. Their anger increased when they compared themselves to non-disabled children, in their age group and living in the same areas. They believed that, while those children were granted education services and everything they needed, the time was still to come when they would be given equal opportunities. Even those who were placed in schools talked about several difficulties, such as inaccessible environments, exclusion from activities and lack of friendships. These issues affected their feelings too. The feeling of self worth of wheelchair users was undermined if they had to ask for help, as they felt dependent and would have preferred to be self reliant. Accepting help from others made them feel that their peers regarded them as inferior. The best example of this was when they talked about their experiences with their younger peers in school.

However, Connors and Stalker (2003, p.122) reported that disabled children, in their study, did not reveal many negative feelings. For example, feelings of sadness were linked to specific incidents rather than to on-going situations or facts. Their accounts of their lives were not different to the experience of children in general; the majority of disabled young people were happy for most of time. They had a sense of achievement related to school or

sport activities; all were involved in making some choices about their lives; they had chances to express their opinions about what was happening to them.

These contrasting accounts of Scottish and Omani disabled young people demonstrated how society plays a vital role in shaping their attitudes and regard for themselves and their lives. Society is able to make their social world seem either bright or dark. The Omani young people revealed that they would be happy if they were involved in their society, if their daily needs were met and if their voices were heard. On the other hand, they gave many examples of being unhappy, simply because of the barriers to their inclusion and participation, and to having their needs met adequately, that their society failed to address. This, as we saw, resulted in increasing their negative attitudes and reinforcing a poor self-image.

However, disabled young people expressed their feelings of being content on certain occasions. When they talked about their parents, the vast majority of them had pleasant memories to share and positive accounts of their family lives. This might have been because they felt supported by their parents who met their requirements, as far as they were able. Parents had a vital role in securing different services that their children needed. Close and loving relationships with parents, especially mothers, were a source of comfort and pleasure for most of the respondents. This might have been because this closeness gave disabled young people a sense of self worth and security, and their parents (unlike other people in society) treated them as equal to their brothers and sisters. All these matters made disabled young people feel happy. However, in contrast, for disabled young people in the UK, parents' surveillance was not seen as very helpful. As discussed earlier, most of them suggested that their parents, to some extent, prevented them from being fully involved in activities outside the home and in the mainstream life of their society (Connors and Stalker, 2003 p. 40).

Three disabled young people were happy because they were able to walk without help. Their accounts suggested that their independent mobility might make them think that they were not so different to their peers; being able

to walk meant that they were not confined to their homes in their wheelchairs, as a result of physical obstacles in the environment.

Different factors made the participants view themselves as different. The main influential factor on their perceptions of themselves was society's view of disability. Disabled young people reported that they were dominated by attitudes that defined them and shaped their self-images, as different and unequal. Expressions like 'deformed', 'deprived' (*Miskeen*), 'limper' and 'abnormal' were commonly used and became accepted as the usual terms for describing or labelling disabled people. Disabled young people suggested that these labels originated in a common belief that all disabled people were permanently impaired. In my experience, their society regarded disabled young people as needy and depicted the disability as an incurable disease. It might have been because Omani society failed to consider that such portrayals had a negative impact on disabled young people's feelings. Swain *et al.* (2003, p.11) argued that the names we are given or the names we give ourselves have a strong effect in shaping our understanding of who we are. They added that labels could evoke feelings of superiority or inferiority or be marks of inclusion or exclusion. According to Middleton (1999, p.22), disabled young people learn lessons about their place in the world, beyond their family and schools. They learn that they are seen by the majority as objects of pity, and can therefore be subjugated. This exploitation could be deeply embedded in a culture where credit goes to those seen to be helpful and charitable towards the less fortunate.

In all cases, disabled young people regularly compared themselves to non-disabled citizens of their age and in their locations. They did not talk so much about their impairment but rather about their social world, they assessed their abilities in relative terms. For instance, many of them reported that they felt different simply because they could not do what others did. They saw all the children playing freely, going to school everyday without difficulty and having friends, yet they did not have the same opportunities. They considered non-disabled children's needs were adequately met, but their's were not.

Unfortunately, these particular experiences made them regard themselves as different.

Nevertheless, the participants, in the face of such portrayals, were determined to remain strong, calm and resilient. The vast majority of them reported that they ignored negative perceptions, simply to be given a chance of greater inclusion. They did not offer any indication that their parents educated them to be aware of the potential impact of accepting the negative definitions of others, but the findings reported in chapter ten, detail how mothers testified that most of the families ignored the negative attitudes of society. Connors and Stalker (2003) found that disabled young people dealt effectively with situations that illustrated their difference from their peers. This was a result of the efforts of parents, who gave their children the message that their differences had nothing to do with being of lesser value and that it was possible to be equal but different (Connors and Stalker, 2003, p.107).

The participants linked statements they frequently used, like "*I am disabled*", with their inability to take part in different activities, their use of certain equipment, including wheelchairs, and the physical obstacles they faced. They thus considered that they were disabled because of these external factors, rather than because of their impairments. Similarly, Shakespeare and Watson (1999) reported that disabled young people identified 'disability' with the disabling barriers in their social world, especially access and public attitudes.

The participants in this study sent out a strong message when they expressed their determination to achieve maximum inclusion. The best example of this was their determination to enrol in schools, even though they were in most cases full of obstacles. A few of the disabled young people and their families adopted strategies to gain more access and service provision, as they moved from rural areas to towns. Some of them modified their houses to make them accessible. Some even battled with schools and education authorities to secure a place in school. Most of them tended to ignore negative attitudes and did not give them much consideration in making decisions, however hurtful the language and behaviour of other people were. Similarly, Shakespeare and Watson (1999) found that disabled young people attempted to resist the

dominant discourse about them; they resisted the label of being impaired. All these examples illustrated the fact that these people and their families struggled to obtain adequate service provision and to overcome the physical and moral barriers in their daily social world.

The disabled young people talked about having different interests. The majority of them watched television. It was not because they had a passion for doing so, but because they were prevented from having interests outside their homes, in their own local community. The availability of childhood-based activities in the interior areas was limited. Moreover, they found it difficult to play on poor terrain and with children who did not welcome them. This meant they had to spend their leisure time in front of the television just because of the environment, which was not accessible, or because they could not move without help. Therefore, they felt bored. Those who were from rural areas had no chance to talk about interests and activities, simply because the situation there was even worse. Girls were interested in doing some domestic work, yet just two of them had a chance to do so because only they lived in houses which were adapted for wheelchair movement. In Connors and Stalker's (2003 p. 47) study, disabled young people also had a variety of interests, including watching or playing football and taking part in different activities. However, some of them identified certain impediments to their participation, such as a lack of mobility. They linked such difficulties with the barriers they encountered in their everyday lives. They also talked about the difficulties for a few children who lived in rural areas, because of the unsuitability of clubs for children with their impairments or because their families did not have a car. All these examples meant that the majority of disabled young people experienced exclusion from most of the social and leisure activities which were available for the rest of children in their own communities.

Almost all the respondents talked about their future. They had a mixture of feelings about it. While they hoped that public attitudes and accessibility might improve in the future, they felt hopeless about more personal issues like educational qualifications, marriage and employment. The disabled young people's perceptions about the future mirrored their understanding of their

social world. They believed that there had been changes in terms of public attitudes and service provision. They recognised that since the 1990s, Al-Wafa Centres had developed and disabled young people had increasingly managed to enrol in ordinary schools. Al-Wafa Centres played a vital role in improving people's attitudes. The participants thought that the situation in the future would improve, as the positive messages promoted by the Al-Wafa centres, reinforced by the more visible presence of disabled young people in schools and communities, spread.

The participants were concerned about what would happen to them after their parents' deaths. For all of them, but especially the girls, it was a significant worry. They looked on their parents, especially their mothers, as primary caregivers. As described earlier, they thought that the family unit was a source of social stability and security. They expected that in their adult lives, they would not get married; this was especially a concern for the young women. Most of them believed that their non-disabled brothers and sisters would have their own independent families. However, other factors possibly increased their dependency on their parents. In the last three chapters, the participants gave examples of these determinants, such as lack of service provision, including training programmes, prejudiced attitudes towards their employment and the inadequacy of the social security system.

The disabled young people had a strong belief that both education and employment were crucial for their future wellbeing. They associated them with independence and inclusion. They sought to be independent of their parents or brothers when they become adults. They also thought that being educated and employed would give them the opportunity to be less excluded from their own society. Similarly, Connors and Stalker's (2003, p 124) Scottish study found that disabled young people thought about being employed in the future. They were pleased to work for qualifications at school to guarantee this. Connors's *et al.* (2004) study found that South Asian disabled young people in England were able to identify different careers, such as a teaching or nursing, which they hoped to follow in the future. All the disabled young people interviewed suggested no reason why they would be unable to work if they were trained and

educated. However, they did not talk about their society's attitudes towards disabled people's employment.

Those who talked about marriage, both girls and boys, were quite uncertain about it as part of their future life. They believed that their chances of getting married were very limited, because of their impairments. They thought that they would not be able to fulfil their duties as spouses; this was especially the case for those with complex impairments. Even those with mild impairments, did not expect that non-disabled people would marry them. They believed that it was because non-disabled people would not be interested in marrying a disabled spouse. They also thought that parents of non-disabled people would prevent them, because Omani society considers disabled people as ineligible for marriage. However, the Omani Association of the Disabled (2003) suggested that most of those who became impaired after marriage had stable family relationships. Disabled young people did not talk about getting married among themselves. Yet, from my experience, wheelchair users face difficulties if they hoped to get married in Oman. Blind people did not have problems marrying, whether to other blind people or, in a few cases, to sighted people. Similarly, deaf people were likely to get married to deaf spouses.

Cultural factors played a significant role in shaping beliefs and expectations about who should or could marry. Yet, in my opinion, most religions are against the discriminatory or oppressive treatment of disabled people and emphasise the value of each individual. Therefore, in societies where most people believe in Allah and practice a faith, as in Islamic societies, religious teachings could be employed in improving public attitudes. Thomas (2000) suggested that people in developing countries are likely to be influenced by the religions they adopt. She considered that negative attitudes towards disabled people might change, if community based programmes used religion in educating people. Similarly, Connors *et al.* (2004) found that South Asian disabled young women in England linked their profound impairment with the difficulties they were likely to face if they married in the future. They feared that they might face problems if they had children. However, these young Asians

had positive expectations about their getting married in the future. They expected that their parents would help them.

This chapter has reflected further on the issues that were raised by disabled young people and explored in the last three chapters. The discussion considered the impact of external and social factors on the individuals' feelings about themselves, their expectations of the future and their self images. The accounts, opinions and expectations of Omani young people were compared with those of disabled young people in other countries, particularly the UK, and similarities and differences highlighted.

The young people interviewed in Oman provided evidence that they had a clear understanding of their social world. They were also sure that the difficulties they faced in their daily lives were not only attributable to their impairments, and that society played a significant role in excluding them from the mainstream and in labelling and treating them as people who were not equal citizens.

In the next chapter, the accounts of the mothers of disabled young people are discussed and their views about the everyday lives of their disabled young people are explored.

Mothers' Perceptions

10.1 Introduction

This chapter presents and discusses mothers' perceptions of their disabled children's lives, their role and relationships with the family and community, their experience of service use and their own feelings about having a disabled child.

The data presented in this chapter was collected through individual interviews and focus group discussions. Four groups of mothers formed a geographically- based selection, from urban, semi-urban and rural communities. The average number of mothers in each session of the discussion groups was between eight and twelve. Disabled young people, in interview (see chapter six), suggested that the most important people in their lives were their mothers. Mothers spend most of their time with them and they took substantial responsibility in caring for them. They were therefore well placed to provide more data on the care needs and experiences of their own disabled children. The accounts provided by the mothers of disabled children showed that they were able to clearly express their understanding of their disabled children's experiences.

This chapter, therefore, explores several aspects of disabled children's lives from their mothers' perspectives, including disabled children's relationships with their siblings their parents and their siblings' feelings and responsibilities. Mothers talked of their feelings about having a disabled child/children, their perception about disability and their attitudes towards their disabled children. Mothers pointed out how they responded to the wider family, wider community, and service provision. The situation in rural communities, and these women's expectations and concerns about the future for their disabled children, were also explored in the discussions with mothers.

This chapter concludes with a discussion that places the data presented in an international context, by comparing accounts of the families of disabled children in Oman with those of families in the UK, and other countries in the

developing world. The similarities and differences between the experiences and viewpoints of Omani families, and those of families in the UK, are considered.

10.2 Disabled Children and their Siblings

10.2.1 Positive Attitudes of Siblings

The great majority of mothers talked about a positive relationship between their disabled children and their siblings. They described it as "normal", in the sense of being the same as other relationships between all siblings. Mothers asserted that disabled children feel happy when they play with their siblings, who in turn like to play with them. Mothers also gave examples of the assistance that the children gain from their younger siblings. Younger siblings, especially sisters, usually spend most of their time after school inside the house. They help each other in their studies and with homework and, for example, push their disabled brother or sister's wheelchair, either inside the house or when they want to go outside. One mother was delighted with the good relationship between her disabled daughter and her sisters, who make an effort to teach her the basic things she needs; as she is younger, they also help her in bathing and dressing.

> *"Frankly, she likes her sisters. Her sisters do their best to help her. They teach her everything; they like and help her. They teach her names and colours of things "this is a door, this is a scarf and so on, this is white, and this is green". Even when she needs the toilet, they help her. But she likes to choose the clothes she prefers".* (SUR)

Mothers raised different issues when talking of siblings' feelings about having a disabled brother or sister. Generally, non-disabled children have positive attitudes towards their disabled siblings. As disabled children themselves described different aspects of the positive interaction of younger and older siblings with them, so mothers also expressed the same positive

perception of the relationship between them. They outlined the relationship between disabled children and their siblings, using different expressions.

"They like each other"

"They help each other"

"They play together"

"They go out together"

"Older brothers offer different things for them"

The mothers said that the non-disabled children showed resentment, because of the public attitudes they felt were negative towards their disabled siblings. The majority of mothers suggested that siblings felt unhappy when they heard uncomplimentary words, or noticed adverse attitudes towards their disabled siblings. In three focus groups, mothers believed that people avoided reacting negatively in front of parents, however, they do not mind saying words like *crazy, mad, and violent* in the presence of siblings, which accordingly makes them feel unhappy.

> *"Sometimes, people say derogatory things s disabled children. Brothers and sisters feel angry and they tell us what they hear and frankly we feel unhappy too".* (RSQ)

Some mothers described non-disabled children as helpful to them. They alleviated their hurt feelings when they became depressed in particular situations. A mother of three blind children said:

> *"Sometimes, I feel sad when I think about them. I think about their future; how they will manage when they get older? How will they get the help they need? However, their older brothers, when they see me like that, they come to me and say "do not blame yourself so much; take it easy; otherwise you will make them worried; this is not our choice but Allah's". They really inspire me with their words".* (RSQ)

Mothers described the adult siblings of disabled children as "helpful". They provided substantial financial support for their siblings. As discussed earlier (in chapter six), disabled children expressed their gratitude to their older siblings, who provide the different things they needed. Mothers also valued the attention and support that their disabled children received from their older siblings. They provided the requirements for school, such as uniforms and stationery. They also provided for their personal everyday needs, including paying for clothes and food. The adult siblings also took responsibility for making adaptations and housing alterations. A mother of a physically disabled child gave an example:

> *"Currently, the house is suitable for the wheelchair. It was difficult for it to be used before the adaptation that was made by (S). The entrance and the corridor are OK and (M) was able to move about easily inside the house and to go to the toilet".* (NZW)

10.2.2 Siblings' Negative Attitudes

A quarter of the respondents talked about the negative attitudes of siblings, who felt embarrassed about going out with their disabled brothers or sisters. They hesitated to be seen with them, because they expected negative reactions from society when they pushed them in their wheelchairs. A mother of a disabled young man suggested that his siblings did not like accompanying him outside the house.

> *"He asks me, "why do my brothers go out and I do not go with them", he says. They ("siblings") do not like going with him or pushing him outside the house. They say, "It is not necessary for him to get out".* (MCT)

A few mothers talked about conflicts between disabled children and their siblings. However, this was generally seen as a normal aspect of the

relationship between all siblings. A mother gave an example about the relationship between her visually impaired child, who just likes to be close to the TV, and his siblings.

> *"His siblings are always angry with him because he cannot watch the TV unless he is close to it. This makes them shout at him and sometimes they hit him".* (MCT)

As discussed earlier, disabled children reported a number of incidents of negative behaviour by their younger siblings, some mothers also gave similar examples. The mothers suggested that some non-disabled children behaved negatively towards their disabled siblings and they used hostile language. Sometimes, they gave the impression that having a disabled sibling was not a very good experience. Here is an example of what the mothers reported in this matter:

> *"My daughter shouts very loud when her siblings say to her "you are disabled and we do not want you". She gets angry and she shouts at them. But I try to make them quiet".* (NZW)

The negative responses of siblings to a disabled brother or sister, possibly, might, at least to some extent, be attributed to the dominant public attitudes or those held by some people in the local community, which still stigmatise families having a disabled child. This would also explain why children feel embarrassed about being seen with a disabled sibling outside the home. On a more personal level, children might also feel that their disabled siblings take too much of their parents' attention, and they resent this.

10.3 Disabled Children and their Parents

10.3.1 No Rejection

Almost all the mothers who discussed the experience of having a disabled child did not describe their feelings in negative terms. However, they did acknowledge that it was a great shock when they, initially, knew that they had given birth to a disabled child. Mothers explained how they were worried about whether or not they could fulfil their responsibilities in caring for them and in meeting all their needs. Moreover, the majority of mothers did not hide their concerns about the future of their disabled children. However, the mothers in all cases referred to having a disabled child as being God's will. It was seen as a matter of a test from God. An example of how the mothers expressed this sentiment follows.

> *"We (mothers or parents) do not resent having a disabled child, but we have worries about him/her. It is not our choice but that of Allah who controls all things in the Universe, who creates everything in life. We can do nothing"*. (RSQ)

10.3.2 Worries

Mothers revealed that they were very worried about their disabled children not improving. They described how they became disappointed because they did not respond to the medication, or rehabilitation, and it seemed to them that they would stay permanently dependent. Most of the mothers suggested that always having to look after disabled children was a problem for them, and for all the family members.

> *"In fact, when we knew that we had a disabled child, we became sad. All the family was depressed. It is not a small responsibility to care for a severely disabled child. He stays sleeping for whole time; he does not move; he does not*

> *recognise us. It is awful to see your child like that; we do not know how he feels either".* (MCT)

Mothers did not hide their anxieties about their children, who have fewer abilities to be involved in different activities with their siblings. Most of them suggested that parents have to teach and guide their children to have more confidence to interact with each other. One mother was pleased because her children played and interacted normally with their disabled sister.

> *"They are really good. They play with her; they sometimes fight with each other; she in turn likes playing with them; their relationship is the same as between all the siblings".* (MCT)

While the mothers explained the closeness of their relationship with their disabled children, they described them as dependent and in need of permanent assistance. This made the mothers think about their relationship with their husbands and their duties towards non-disabled children.

> *"My daughter is severely disabled and I am so busy with her. Sometimes, I think about my duty towards our family. To be honest with you it really requires a lot of time and effort".* (NZW)

10.3.3 Responsibility of Parents

Mothers talked about different aspects of the responsibility that families accept. Most of the mothers suggested that families have a vital role to play in ensuring a normal relationship between the disabled children and their siblings. Parents have to treat them equally and guide the non-disabled children to respect their disabled siblings. The mothers agreed that families are able to create an

atmosphere that makes all siblings like each other, and normalises the everyday lives of disabled children among their siblings.

> *"Thanks be to God; my child has lived normally among his siblings, since he was a baby. We "the family" went on outings together to the park and everywhere. This is important to make all the children familiar with each other".* (MCT)

This mother raised various important points of principle and meaning, including those of normality and equality. She suggested that parents should enable the disabled child to have a good relationship with their siblings. Most of the mothers believed that if families dealt with all the children kindly, equally and identically, it would make them like and help each other. The mothers thought that being over protected by their families was not always the best way for them. This might lead to feelings of resentment. A mother, of a physically disabled boy, suggested that appearing to be 'over protective' might make for an uncomfortable relationship between the disabled children and their siblings.

> *"In fact, we "mothers" must be careful how we treat them. Over sympathy and overprotection are not always good for them; we must accustom them to having everything they need in a normal way. If we seek a normal relationship among them, we must treat them equally".* (MCT)

However, a small minority of mothers thought differently. They believed that if disabled children are to be encouraged and involved in different activities, with their siblings, they need more attention and greater protection. One mother, of a physically disabled boy, considered the intensive care and extra attention given to disabled children to be part of the treatment they need. She suggested that it helps them in improving and integrating normally, with their siblings, in activities in the local environment.

> *"My son "M" needs my attention. I always ask his siblings to mind him and to be kind to him. I think this is the best way to lighten his suffering and to enable him to be involved with his siblings' activities".* (MCT)

Almost all mothers claimed that the person who understands disabled children best is the mother. They spend most of the time with them and asserted that they understood their needs and their feelings. Mothers were generally positive when they talked about the relationship with their disabled child/children. However, they distinguished between mildly impaired children and severely impaired children. Mothers reported that the former require less effort compared with the latter. They responded readily to efforts made by parents and professionals.

> *"The mildly- disabled child does not need a lot of effort".* (RSQ)

In contrast, for severely disabled children, the mothers suggested that all the members of the family have to cooperate, in order to meet their various needs. A mother of a severely disabled boy explained:

> *"My son is dependent. He has a complicated problem. He does not know what he needs. I just do everything for him including feeding, dressing and bathing him. Sometimes, I ask his sisters and brothers to help me".* (RSQ)

Mothers of disabled children with conditions requiring regular admissions to hospitals, talked about the difficulty of balancing their responsibility towards their non-disabled children and housework. They displayed confused feelings because they were torn between giving their full attention to their disabled children, who were admitted to hospital for weeks, and meeting their responsibility towards their other children, husbands and homes.

> *"When he was admitted to hospital, I would be busy with my non-disabled children who were left at home with nobody to look after them. I did not know what to do; should I stay with him or stay at home? Sometimes, I have to spend a month with him at the hospital, it is really difficult".* (RSQ)

Mothers suggested that families assume joint responsibility for providing different things their disabled children need. Both parents share responsibility. On the one hand, mothers take most responsibilities for caring either inside the house or in hospital. They have a substantial role to play to enable their children to use the Al-Wafa centres service. On the other hand, mothers valued the role of the fathers, who ensured that different everyday needs were met for the disabled children, including extra clothes, food, equipment and housing adaptations. Mothers reported that fathers satisfactorily meet these needs and they, moreover, encouraged them to do their best for their disabled children. According to the participants, most of the fathers believe that "having a disabled child is a test from Allah".

> *"Her father does not respond negatively; he offers all the things she needs. He likes her very much. He takes her when he goes out. He always gives her his attention and he does not allow anybody to hurt her feelings".* (MCT)

10.3.4 Mothers' Views about their Disabled Children

Mothers' accounts of their perceptions and experiences can be broadly distinguished on the basis of the severity of the impairment and the level of dependence of the disabled child. There were some mothers who had mildly impaired children who were able to perform different activities. They described them, using words like *nice, helpful, not different, clever and quiet*. They suggested that disabled children have a tendency to help their parents in particular situations. For instance, disabled young women help their mothers in

everyday housework. This kind of help was highly valued by mothers, who said that their disabled young daughters and sons were even more helpful than are their siblings. A mother of a disabled girl gave an example:

> *"I have five other daughters, but I feel that I like her more than her sisters. She is really nice. When I want a glass of water, she quickly goes to bring it for me. If she knows that I have a headache, she tries to help me and asks me, "are you OK now?" Her sisters do not do the same".* (SUR)

Disabled young men were considered helpful too. Several examples were given, showing that they were active and helped their families. The best example of this was given about a young man (19 years old) who helped his elderly father to walk around the local community and in shopping.

> *"He is always sitting with his father and going to the market with him as well. He helps his father to cross the street. His father cannot get out of the house without his help. He has six siblings, but none of them does what (A) is doing".* (RSQ)

Mothers thought that their disabled children were more willing to help their parents, and showed them more concern and attention, than their non-disabled siblings. It may be that disabled young women and men, especially those who do not go to school or have no activity to do, feel bored. They, therefore, try to use their leisure time in helping their parents. In contrast, non-disabled young people are usually busy with their studies and engaged in different activities after school. In most societies, teenagers do not prefer to take part in different activities with, or to spend time helping, their parents.

A second group of mothers were those who had severely disabled children, or children whose abilities to take part in different activities were limited. They described them as *different, dependent and difficult*. Most of these

mothers regarded their disabled children as different to their siblings. This view was based on the type of needs and effort they required to be cared for. The mothers reported that the disabled children had to be provided with special services by society, and they needed more attention from their families. They distinguished between the needs of those who have mild and those with severe disabilities:

> *"The mother views her disabled child as different to his siblings and relatives. He/she has special needs and requires more attention".* (RSQ)

The mothers distinguished between them and their siblings on the basis of their abilities take part in different activities. The mother of a severely disabled boy gave an example:

> *"He does not understand what he should do. I only do everything for him because he does not know what he needs. He has limited consciousness, which makes him unable to be involved in different activities with his siblings".* (RSQ)

Some participants did not hide their emotions about having a severely disabled girl. They described such feelings as painful and hard.

> *"Despite the fact that we have faith that Allah controls everything, it is still difficult and painful on mothers who have a disabled child, especially if it is a daughter who has less chance to get out and become involved in different activities in the local community. A young disabled boy is able to use his wheelchair to move outside the house and go shopping".* (NZW)

However, the mothers suggested that their disabled children perceived themselves as different to their siblings. They thought that they

were different because they did not have the same ability to take part in different activities as their siblings did.

> *"He feels different because he can't walk. He does not play with the others".* (RSQ)

Another factor, behind this negative view, was that disabled children are provided with fewer opportunities to integrate within their own society. They are also provided with inadequate services. The mothers asked:

> *"Why are our disabled children deprived of the key services they need".* (MCT)

They reported that their disabled children felt angry and disappointed when they saw, for example, their siblings going to school and they stayed at home doing nothing.

10.4 Families' Attitudes

The mothers suggested that there are families who still do not like to acknowledge to society that they have disabled children. They even hide them from visitors they receive or, sometimes, they do not take them to public places, which means they deprive them of the basic services they should use. However, the mothers described these families as ignorant.

> *"We know families, of course they are not educated, that hide their disabled children and they are ashamed to say, "we have disabled children". They also do not take them when they go out. They even hide them when they have visitors because they do not want to show that they have a disabled child".* (NZW)

The mothers also talked about families who do not give their disabled children any attention, they neglect them. According to the participants, these families believe that disabled children do not respond to any kind of treatment, education or care programmes. They may also have had no information about the possibility of using services, including ordinary schools and Al-Wafa Centres. There were examples of this experience presented by disabled children themselves (in chapter seven).

> *"Some parents do not give enough care to their disabled children. They just leave them at home without giving them any attention. They believe they will stay disabled for their whole lives. They do not know that it is better for them to take them to the Al-Wafa Centre".* (NZW)

Although the disabled children did not talk about having any negative impressions of their fathers (in chapter six), a few mothers complained about fathers who are not helpful and behave uncooperatively.

> *"Some fathers are careless and they do not give any consideration to such circumstances. They are unhelpful. They do not assist the mothers in caring for their severely disabled children or help them in their house work".* (MCT)

10.4.1 Restriction

The mothers considered that they had fewer opportunities, to be involved in the everyday life of their society, than those who do not have disabled children. There were different factors obstructing them from leading full lives. Negative public attitudes, as discussed in chapter seven, made disabled children and their families reluctant to appear in public, or to receive and to visit other families, including relatives.

> *"It is true that others do not feel happy to be involved with us because we have a severely disabled child. This makes it impossible for us to go out much. Moreover, some people do not like us to visit them because they are worried that our son will do something wrong to their children. We ourselves feel ashamed if they comment negatively. Therefore, we do not often visit others. And we do not receive many people; it is shaming and embarrassing".* (RSQ)

Unhelpful public attitudes are a problem for disabled children too. As described in chapter seven, public attitudes were a significant factor that made them feel ashamed and unhappy in their own society. The mothers gave evidence that the children felt unhappy when others viewed them differently or talked about them negatively.

> *"When I go to the hospital or to the park with my daughter in her wheelchair, people ask me "why is your daughter like that? From when?" These questions are not wanted. They see her in her wheelchair, "what is the matter?" she feels ashamed when somebody talks about her. She even puts her head down and does not like to see people who talk about her. They ask such questions just for fun".* (MCT)

10.5 Extended Families

Most of the participants talked about their relatives who were in touch with them, namely uncles, aunts and grandparents. They described them as *helpful and nice.*

> *"Uncles and aunts are nice. They like her and they sometimes invite her to visit them and to play with their children".* (SUR)

Some participants' families had a traditional extended family structure. In Omani society, grandmothers and grandfathers usually stay within their sons' families. These mothers described a warm relationship between the disabled children and their grandparents, for example,

> "*He likes to stay with his grandmother who in turn likes him. He feels happy when, for example, she tells him stories*". (SUR)

However, there were some participants who did not project a positive image of the role of extended families. They described uncles and aunts as unhelpful. A mother described her experience of sometimes needing somebody else to help her, yet none of the wider family responded to her need.

> *"I ask for a help to look after my daughter when I need to do something else. I only need this once a week. However, all of them are busy with their own everyday work. They do not like to help me".* (NZW)

10.6 The Impact of Public Attitudes

Almost all the mothers talked about the impact of public attitudes towards disabled children and their families. Although disabled children, as discussed in chapter seven, were angry with children more than adults, the mothers did not state whether it was the young people or the adults who showed such outlooks. Despite the fact that public attitudes have a big impact on disabled children and their families, mothers believed that they should not prevent them from being involved in society.

> *"We do not need to give any consideration to the public point of view. They say lots, but we have to ignore them".* (RSQ)

In fact, negative public tendencies caused feelings of shame, embarrassment and anger among members of families. This, sometimes, led the families of disabled children to hide them or at least feel uncomfortable when they appeared in public. However, a great number of mothers were determined to ignore such views, and to feel that it was natural to be with their disabled children in public.

> *"Families should not feel ashamed because they have a disabled child. They do not need to hide their children but to appear with them in public. The natural thing is to be normal and it is not honest to conduct themselves in a negative way".* (RSQ)

The mothers considered that those families, who do not have disabled children, tend to have more negative viewpoints than families who have disabled children. In addition, families, who do not have disabled children, viewed the latter as abnormal and different. They even showed an inhospitable or hostile demeanour, if they were obliged to receive a family with a disabled child.

> *"Nobody feels what we feel. Those families who do not have disabled children do not feel happy to receive us. They even make their children avoid playing with our disabled children".* (RSQ)

10.7 Service Provision

10.7.1 Social Services

The mothers expressed their need for regular financial support for their disabled children. They suggested that most disabled children need different things to the non-disabled, including extra clothes and food. If they are to go to hospital,

transportation costs a lot for their families. Their houses, in most cases, require adaptation for wheelchair users. The mothers broached these subjects, and they complained about the social security system, which does not take into account the cost implications of the extra and different needs of disabled children.

> *"They usually need more things. For example, they use more clothes; sometimes, they need extra items. If the income of the family is low, of course disabled children must be given financial support that will help the families to meet their everyday needs".* (RSQ)

10.7.1.1 Al-Wafa Centres

Almost all the mothers valued the role that the Al-Wafa Centres play. They showed their gratitude to these centres, and to the volunteers who work there, because they felt their children's conditions improved as a result of this service.

> *"Our children, have improved ever since they started going to the Centre. Now they are more independent; they go to the toilet by themselves; they walk better; they do different things without any help. When they are in the Centre, we are able to do other work".* (RSQ)

Interestingly, the mothers were aware that a partnership between such centres and families is beneficial for their children.

> *"Centres and families have to help each other".* (RSQ)

However, all the participants showed great concern about the regulations and eligibility criteria of these centres, which exclude disabled children over 14 years. The mothers asked why their children should have to stay at home without any kind of activity.

> *"The Centre is a very good place where my daughter received beneficial services. However, next year she will be excluded because she will be 15 years old".* (SUR)

Another example given was:

> *"It is a problem for us and for him. Why is it that at a time that he needs most help, when he is starting to become more involved in society, he is to be excluded and imprisoned at home".* (MCT)

And as another mother said:

> *"There is no alternative; no school accepts her, nothing else. Her siblings go to school and she sees them going every morning, which makes her feel angry and me too".* (RSQ)

10.7.1.2 Special Care

In Oman there is only one centre called a Special Care Unit. This centre is located in Muscat and provides care for severely disabled children. It offers residential services and respite care services. The mothers, in two focus groups, explained that they were not happy with the service provided by this centre. They complained about the staff's attitudes and the quality of service afforded by the centre. They expressed their experiences of this centre thus:

> *"He spent a year in the Centre, and I was taking him back at the weekends. Later they told me, "He does not need to come here anymore".*
> *"When he was there, the staff did not allow me to go inside to see what his room was like. All the visitors had to wait in the reception".*

"Once I insisted on entering. I was shocked when I saw the room. It was not clean and no attention was given; all the children were crying. I wished that I had not placed him in the Centre".

"I visited my son and I found him in dirty clothes. And moreover, they were not his clothes, they were his peer's cloths. There was shocking negligence. I got the impression that the Unit was not a good place". (MCT)

Despite the fact that the respite care service is important for families with severely impaired children, it needs to be well equipped and organised. The previous example showed the inadequacies of the services provided by this particular Centre. It was not clear whether it provided residential care or respite care. The accounts generally, given by the mothers, revealed that most of the workers in the Centre were not helpful and did not give enough attention to the disabled children, which means they might not have been properly trained or qualified. Yet, contemporary policy and practice internationally supports the view that residential care is not appropriate for disabled children, because. It excludes them from mainstream society. However, as revealed in chapter seven, the disabled children were not delighted with the respite care on offer. The same feelings expressed by the young people (chapter seven) were echoed by most mothers, who were given a chance to put their severely impaired children in the only Special Care Unit. Their impression of this Unit was negative, not only because of the staff attitudes and quality of service, but also, because the mothers preferred to look after their disabled children at home.

"Since he started going to the Disabled Care Unit, I became depressed and his feelings sank too. I missed him and he of course missed us. (All mothers) it is not a good idea. We do not want it". (MCT)

10.7.1.3 Equipment

Most of the mothers were happy with the way they received wheelchairs for their children. However, a few complained about the complicated procedures they had to follow to obtain one, which impelled some of them to buy them from United Arab Emirates, where such equipment is cheaper than in Oman.

> *"Even his wheelchair was bought by his father from the UAE where it is cheaper than in Oman".* (NZW)

10.7.2 Health Services

The majority of mothers did not enjoy very good experiences of the health services. Mainly, they talked about the negative attitudes of the doctors who, they believed, did not make enough effort in diagnosing their children when they were born. The mothers suggested that, in most cases, the families themselves detected their children's disabilities. When they reported them to the doctors, their response was not helpful. Mothers described their relationship with the doctors as "unreasonable".

> *"The doctors did not diagnose him well. We told them our child has a problem with his legs, but they did nothing. All the staff told us that he was fine and he had no problem. When he grew up, the doctors realised that our son has a problem, but they said, "we can do nothing for him". Frankly, there is not enough attention given to disabled children".* (MCT)

Those mothers, with disabled children requiring regular admission to hospital, were not happy with the way nurses and doctors dealt with them.

> *"My son is regularly admitted into the hospital. When I take him there, the doctors and nurses do not make me feel*

welcome. I feel as though they are fed up with my son. I feel that they do not want me to bring him to the hospital any more. They do not treat us nicely. They often ask me "Don't you want to leave?" I say "of course I want to go back to look after my children I left at home". (RSQ)

However, the picture is not always dark, there were mothers who perceived the health services and professionals' attitudes as helpful. They described them by using words like nice, good and helpful.

"Hospital is OK; people there are nice and do their best to help us". (MCT)

10.7.3 Education Services

The mothers' accounts, of their experiences of the education services, were not very different to those of their disabled children. The former faced negative attitudes from some staff in schools. They described them as unhelpful and unwelcoming. They talked about difficulties experienced, when some families wanted to place their disabled children in ordinary schools.

"When my son was six years old we took him to the school, just like his siblings, but the school did not accept him. They said, "we have to be sure that he is able to study here". They examined him three times and finally they accepted him. However, they were not helpful because they did not deal with him nicely and equally as they do with non-disabled children. Because he limps, they refused to take any responsibility for him. In any case, they asked us to declare and sign that it was our responsibility if something happened. Because you are insisting on placing him here, you have to provide transport for him. Actually, we accepted their conditions, and now he is doing well in

the third elementary class. I wonder why the school was negative like that. Why are disabled children dealt with differently, why did the school not encourage him and us to place him there? It is their right to be provided with education services, is not it?". (NZW)

However, a significant number of mothers suggested that ordinary schools are getting better.

"We think schools have changed. It is not the same as before, many disabled children are accepted in ordinary schools". (RSQ)

One of the difficulties that was mentioned by the mothers was transport. The disabled children also reported this problem (see chapter eight). The mothers suggested that their disabled children were at risk if they were to use the buses provided, which are not adapted for wheelchair users, and take more students than their capacity allows.

"The school bus does not come to the house. It stops away from it. This requires pushing him in his wheelchair to it. The bus is not safe because there are so many students to take. We do not know how to ensure that our child uses such buses safely". (NZW)

The mothers, in the same way as the disabled children, talked about peers' attitudes. A significant number of mothers suggested that their disabled children were not happy because of the negative attitudes of some of their peers.

"My son has a problem at the school because of his fellow students' negative attitudes. They call him "limper". He feels embarrassed when he hears such words. He

> *complains to me but I try to alleviate his feelings. They stigmatise him because he has a disability".* (RSQ)

10.8 Rural Areas

According to the mothers who were from rural communities, "rural areas are not provided even with the basic services". They were angry that their disabled children were deprived of services, such as day care, education, social and health services. As discussed earlier, the children themselves reported that they received no services, which forced some of their families to move to towns where such services were provided. Mothers also stated that some families from rural areas move during the weekdays to live in the town, just to use the service of the Al-Wafa centres. This may affect the family's stability and makes them spend more for the rent, travel costs and so on.

> *"We live in a village where nothing is provided; no physiotherapy, no school, no centre. My daughter now is 10 years old and she receives nothing. To place her in the Al-Wafa Centre, we had to rent a house in the town during the week. She is getting better, since she started going to the centre. What can we do? We had to do it".* (RSQ)

All the mothers, from towns and from rural areas, suggested that there were obstacles in the local environment, which needed to be removed. Most places they might visit were not adapted for wheelchairs, including shopping places and roads. This issue was described as one of the factors that prevented disabled children from getting out and engaging in children's activities. The same point was highlighted by the children earlier.

> *"Sometimes, we want to give him a break from the house. His sibling can't push his wheelchair outside the house because the environment is not accessible. There are hills, holes and stones. It is really difficult for a wheelchair to move there".* (NZW)

10.9 The Future

The mothers expressed great concern about the future of their disabled children. Almost all of those who participated in the research, were worried about the future of their disabled children, when they would be unable to continue to provide care and after their older siblings had their own families. The disabled children themselves, as discussed earlier, voiced the same concern. The severely disabled children, especially the girls, were seen as frail and they needed somebody to look after them, even when they became adults. The girls, according to the prevailing culture of their society, were seen as more vulnerable and could not live alone. This perception not only applied to disabled girls, but to all girls. However, the parents of the disabled young people dreaded the future, when they would no longer be there to provide a home and care.

> *"We don't know what the future holds. We, as parents, think about the future. Who will take on the responsibility for our disabled children after us and after their siblings have their own families? We don't know".* (RSQ)

Another example of how a mother expressed this concern:

> *"I have a disabled girl who still needs my care. I am really worried about her after her father and me have gone. I don't know how she will be in the future".* (SUR)

The mothers hoped that the services needed by their disabled children would improve. As the children themselves asserted the importance of education, health and social services, the mothers also expressed the opinion that such services should be developed in the wider society, for the use of disabled people.

> *"It is so important that our disabled children are offered all the key services they need including schools, university, physiotherapy, and financial support. They need such things because these are only offered for non-disabled children. We need schools similar to the special schools in the Capital"*. (RSQ)

Mothers regarded such services and equipment, for disabled children, as key tools leading to independence. They wished to see their disabled children improve, with greater independence and more social inclusion in future. The children themselves strongly expressed their hopes to be less dependent and to do most personal things without help. The mothers, for instance, asked the social services departments to provide services and equipment for the same purpose.

> *"Our disabled children have to be provided with all the services and equipment they need. We would like to see them walking and doing different things"*. (RSQ)

10.10 Discussion

In this chapter, I have presented the views held and opinions expressed by mothers of disabled children. Although these mothers were from different locations and their children had different impairments, they posed almost identical questions and described similar experiences.

I should, however, acknowledge that the participants (mothers) did not represent all mothers with disabled children in the country. There were mothers who did not want to take part in the research, because either they did not wish to acknowledge having disabled children or they were not interested in talking about their experiences. Some had conservative attitudes; the researcher to them, as a man, was a stranger; therefore, they preferred not to take part. It was difficult to me to contact those mothers who live in the desert (*Badw*), hundreds of kilometres away from where the interviews took place. There were

mothers who were of wealthy social status, that the researcher expected would not be interested in taking part; because they probably do not need direct full-time care for their children, including their disabled children. They usually rely on servants who take the responsibility for the care of children and housework. However, I recommend that in future efforts should be made to include mothers who did not take part in this study, so that theirs and their disabled young children's views may be examined.

The participants talked about their relationship with their disabled children and the family relationships in general. On the level of the wider community, they discussed difficulties that their disabled children faced, including the attitudes of society. They had also views about service provision for disabled children and concerns for their children's futures.

Like their children, the mothers gave a bright and positive picture of the relationship between disabled children and their parents. Both mothers and children described their relationship as close, and they were delighted with their husbands and fathers, for the role they played in providing for the various everyday needs for their disabled children. However, the burden of the responsibility was more likely to be on mothers. These described the typical parents' role in the Omani families. Whether the family has a disabled child or not, the mother's role is to provide full-time care for their children, including disabled children. Even if the mothers had a job, their responsibility towards their children was not diminished. Yet, as I will discuss later, most mothers with disabled children found it difficult to work outside of their homes. They did not talk about the role of the fathers in providing full-time care for their disabled children, because a father's key duty, primarily as a breadwinner and provider according to the social norms, was to ensure the daily needs of the family members, including the disabled children, were met. Most of the examples cited earlier, showed the significance of the role of mothers in doing most of the things their disabled children needed. Although they acknowledged that it was their duty to serve their disabled children, they did not hide how difficult it was to give full-time care to a child with complex needs.

In the UK, a national survey, of 1100 families with a disabled child, showed that in 69 per cent of the families sampled, the mothers were identified

as responsible for providing most of the care (Beresford, 1995). More recently, a study in England, conducted by Connors *et al.* (2004) examined the perceptions of severely disabled Pakistani and Bangladeshi children and their families. This study showed that many Pakistani women did not expect support from their husbands; in South Asian families, adult daughters made a considerable contribution to the support needed. Similarly, some participating mothers reported that their adult daughters helped them with housework and in caring for their young children.

Three of the mothers reported that they had preferred to leave their jobs, just in order to assume responsibility towards their disabled children; they felt strongly that they had to be permanent caregivers for them. The vast majority of the mothers were not employed. Being unemployed was not just because of having disabled children, but it was also because most of them were not well educated and qualified to work, or they were not interested in working outside the home. However, almost all of them had a belief that they had to fulfil their responsibilities towards their disabled children, whether that meant giving them primary care at home or to taking them to the hospital, as some of them have regular appointments. It is also true that in the UK, the opportunities for mothers with disabled children to work and to have a job are considerably reduced. Research, published in the mid 1990s, indicated that their position had deteriorated over the previous 20 years (Baldwin and Carlisle, 1994; Beresford, 1995). Dowling and Dolan (2001), in their study of the respite care needs of disabled children and the quality of family life in the UK, found that mothers of disabled children had difficulties finding a job. This was because of the restrictions on the time they were available, and because their disabled children often had to attend hospital frequently.

The mothers were generally not keen to work, yet they stressed the problem of financial hardship. Some of them talked about the difficulties fathers experienced in trying to meet all the everyday needs of their families, as their income was low. Those mothers with severely impaired children talked about their daily expenses and requirements, which were higher than for non-disabled children. This made them place emphasis on the need for social security benefits, as we will see later. Connor's *et al.* (2004) reviewed different studies

about the employment of South Asian parents who live in the UK, and concluded that families had lower income than White families; unemployment among fathers, but especially among mothers, was high; this made for the difficult financial circumstances in which families found themselves. According to Family Fund Trust (2003), 84% of mothers with disabled children, in the UK, were not working, while this applied to only 39% of mothers without disabled children.

The mothers in this study did not show a great deal of frustration at having a disabled child. However, almost all of them talked about experiencing a shock, when they initially identified that they had a disabled child. They attributed this shock, not to feelings of anger, but to worries about him or her and concerns about whether he/she would be provided with help to meet their different daily needs. The mothers also were not sure whether they could fulfil their responsibilities, towards their disabled children, and meet their extra and complex needs. The participants described how they were not given enough information about their baby's condition before their delivery, which increased their trauma. Most of them had no expectation that they would have an impaired child. According to Beresford (1995), a mother of a disabled child becomes stressed, if she has to learn quickly how to take responsibilities for her child, which may be quite outside her experience.

Some mothers had more than one disabled child. They felt more stress as a result of having a greater responsibility and because they did not know why this had happened. These mothers acknowledged that afterwards they were told it was because of genetic factors, and they were asked to be careful about having more children in the future. Krafting's (1999) report showed that consanguinity is common in Oman. However, recently a national education programme has been introduced, especially for mothers, giving them a clear message about the significance of diagnosis before and during their pregnancy. This programme should make people more aware of the causes of disability, consequently its incidence may decline, or at least people would be pre-informed and so prepared; consequently, if they had a disabled child, they might not be so shocked. Apart from such experiences at the time of birth or diagnosis, the mothers talked about the greater difficulties they met when they

had to face greater involvement for their disabled children in society. The evidence, presented in the mothers' accounts, shows the need for an education programme that identifies disability as a social issue, rather than just a health problem.

The participants did not hide their worries about their disabled children and they had many concerns about their children's futures, as we will see later. They also showed great concern about their offspring when they did not respond to medication and to different therapies. All these worries can be linked with the fact that most disabled children, especially those with complex needs, need permanent care and help. The UK literature has suggested that while some children's needs for care and assistance are reduced as they grow up, for large numbers this is not the case. Beresford (1995) found that four out of five of the young people studied still needed help with self-care even when they were adults. It meant that the physical demands on many mothers became endless. One of the mothers, in Connor's *et al.* (2004) study, expressed her fears about the future and the prognosis for her disabled children's condition. She considered that mothers might face difficulties caring for bigger children. Mothers moreover liked to have information about what services their disabled children would need in the future, in order that they could be planned for in advance.

Almost all the mothers believed that their having a disabled child was the will of Allah. They believed, it was a test from God. This belief, I think, is quite common among the public in Oman. The mothers, accordingly, frequently said 'it is Allah's will, we just have to do our duty'; 'it is not our choice'. Almost all the mothers showed a greater anger towards the society that provided inadequate services for their disabled children, and to the negative public attitudes, which undermined them and their disabled children, than about their having a disabled child.

The role of parents in 'normalising' the everyday lives of their disabled children was significant. The 'normal' concept meant here that parents should meet their children's personal needs; encourage disabled children to participate in activities with their brothers and sisters. The mothers emphasised that parents should treat their children equally; they should not overprotect or unduly

favour their disabled children, because it would produce a feeling of resentment among the non-disabled children. However, a few mothers believed that the more they take care of their disabled children, the more they become involved in different activities with their siblings. Some professionals, who took part in this study, as we will see in the next chapter, used the term 'normal person' to mean non-disabled people, in contrast to the term 'abnormal' to mean the disabled. They used the 'abnormal' term to point out that disabled people are different, because their impairment prevents them performing what the others could do. They viewed disabled people on the basis of their physical inabilities. Society has not yet recognised that disabled people are disabled by their society, which isolates them from ordinary daily lives and the opportunities other people expect and enjoy. Watson (2002, p.521) suggested that the struggle to achieve 'normality', and to eliminate the existence of impairment, adds further to the oppression of disabled people. According to Abberley (2003, p.9), abnormality has been traditionally used in the context of medical definitions, to segregate disabled people.

The mothers distinguished between severely and mildly impaired children. They believed that those with a severely impaired child, have a greater responsibility. They considered that the frequent admissions to hospitals, and the intensive care inside the house for severely impaired children, might affect the extent to which they could fulfil their duties towards their non-disabled children, their homes and their husbands. They also thought that severely impaired children prevented them from having regular contacts with outsiders. In the UK, Dowling and Dolan's (2001) study found that having a disabled child meant that a family could rarely go out together.

Severely impaired young people were described, by the mothers who participated, as different, dependent and difficult. They suggested that mothers might feel that they had to play the primary carer role, in which their incapacitated children needed assistance with various personal aspects of daily living, including feeding, toileting and bathing. There were various factors that could make the responsibilities of mothers for their disabled children onerous and complex. First was the unavailability of support services; those mothers who have more than one disabled child face a greater difficulty. In Omani

society, as mentioned earlier, adult daughters help their mothers, however, if these do not have adult daughter/s and their family was large, the difficulties experienced by the mothers would be very great. Beresford's (1995) UK survey also revealed the significant everyday duties of mothers towards their disabled children, who might have frequent needs for bathing, washing, eating, toileting, mobility and other support.

Compared to their siblings, disabled children required more effort and regular care, the mothers suggested. This led them to believe that society should accept responsibility and enable families to meet the everyday needs of their disabled children. They meant that adequate health, social and education services should be provided. Almost half of the mothers found that the services, their disabled children needed, were unavailable or inaccessible. This was exemplified when they talked about the difficulties they encountered trying to enrol their disabled children in ordinary schools; they also faced hardship and problems in securing financial support. Those who lived in rural areas faced even greater difficulties obtaining the help they needed to care for and provide for their disabled children.

The mothers gave the impression that they did not even realise that it was their right to voice their demands. They lacked information about the existing services that their disabled children might need, or benefit from. All the mothers, whether living in urban or rural areas, had similar experiences. Some of the parents did not even know if it was possible for their physically disabled children to be placed in ordinary schools. According to one of the professionals I interviewed, the current legislation does not oblige the education services to place disabled children in mainstream schools. The chairperson of the Omani Association of Disabled People was disappointed that the law, which should support the general rights of disabled people and their families, has not yet been promulgated.

On the other hand, in the UK, the literature showed the investment of significant resources in services and legislation that sought to ensure the provision of adequate services for disabled young people and their families (Audit Commission, 2003; Roberts and Lawton, 1998; Dowling and Dolan, 2001). However, research found out that some mothers of disabled children in

the UK were still talking about unmet needs for basic services. Research in the UK also revealed that there was dissatisfaction with many aspects of the services that existed, including the way they are delivered and the contact between families and service providers (Read, 2000; Beresford, 1995; Audit Commission, 2003). In the 1990s, social policy recognised that disabled children's rights were not fulfilled. Disabled children and adults were categorized less as patients or needy people and more as disenfranchised citizens, denied the civil, social and legal rights which were granted to others (Barnes, 1991; Bynoe, *et al*, 1991). Oliver (1996), for example, argued that disabled people were prevented from leading full lives according to the prevailing standards enjoyed by non-disabled people. More recently, Connor's *et al.* (2004) study suggested that South Asian mothers with disabled children experienced various unmet needs. Yet, it was not because the services were unavailable, but because of other factors, such as lack of information and misunderstanding about services, miscommunication, insensitivity to cultural considerations and lack of flexibility.

The mothers discussed the relationship between disabled children and their brothers and sisters. The majority of them considered that these relationships were positive. They gave examples of the assistance and help that were provided by siblings for their disabled sisters and brothers, including pushing them in wheelchairs and keeping them company. The mothers, like the disabled young people themselves, valued the roles of older brothers describing them as "helpful". They often provided financial support for their disabled siblings to meet their different everyday needs, including school requirements and clothes and even the cost of housing adaptations. According to the nature of the family structure in Oman, elder brothers (the older sons in families) are responsible for providing financial support for their parents, brothers and sisters, especially if their fathers have died or their father's income is low. Living away from the family, does not exempt them from such responsibility. Connors' *et al.* (2004) study talked about the significant support of siblings for their disabled brothers and sisters. Adult daughters, in the South Asian families who live in the UK, played an important part in helping their mothers who had disabled children.

A few mothers talked about the negative attitudes of siblings towards their disabled brothers and sisters. The mothers did not talk about the resentment of the siblings for having a disabled brother or sister. This might be because the parents educated their children to be helpful to each other. Connors and Stalker (2003) reported that the siblings, of disabled young people in Scotland, did not indicate that there had been a significant negative impact on their own lives through having disabled sisters or brothers. However, some of them reported restrictions in different everyday activities, such as getting out. However, when the mothers, in my study, talked about the necessity of a balanced treatment, and giving equal attention to their disabled and non-disabled children, in order to make them feel happy with each other, I felt that they feared provoking some kind of resentment if they were not careful in treating them equally. The disabled young people themselves, as we saw earlier, talked about the negative views of some of their younger siblings. A significant number of mothers in Read's (2000) study, in the UK, had a strong sense of the importance of increasing the awareness and understanding of siblings in order to avoid resentment and jealousy.

Parents should educate their siblings and give them explanations about the discriminatory attitudes of society and about the importance of the inclusion of disabled children. The whole family has a role to play in helping disabled children to have full involvement in their own communities. However, most of the mothers talked about their siblings hesitating to appear in public with their disabled sisters and brothers. Mothers thought that their non-disabled children felt ashamed to be with a wheelchair user, because people would stare at them. It was also true that mothers themselves did not like people looking at them, when they went out with their disabled children in their wheelchairs. As discussed earlier, the disabled young people themselves described the same experiences and feelings. Similarly, the mothers in Read's study also talked about the siblings' uncomfortable feelings, about being with their disabled brothers and sisters, as a result of discriminatory attitudes.

The mothers related how, on some occasions, the siblings got angry. For instance, disabled children with visual impairments sit close to the television, which sometimes irritated their siblings. However, the mothers reported such

negative attitudes among young children. As we saw earlier, older brothers and sisters were more positive in their outlook and behaviour towards their disabled siblings. However, such issues should be seen in the context of the ordinary relationship between all children in society. Connors and Stalker's (2003, P.101) Scottish study reported that most of the parents described their children's relationships with each other in very ordinary terms; they described it as 'normal'. It might be that the young children lacked an awareness about how should they be understanding and patient with their disabled siblings. As we saw earlier, the mothers interviewed in Read's study suggested that siblings should be given clarification when they come across difficult situations, whether inside or outside the family. The special demands of disabled children may also cause, on occasion, feelings of resentment in their siblings. In the UK, studies with the siblings of disabled children reported such phenomena without disregarding the positive aspects of their experience (Glendinning, 1983; Meltzer *et al.* 1989; Atkinson and Crawforth, 1995).

Another issue that was mentioned by the mothers, was that some parents of disabled children behaved in ways that might have reinforced negative social attitudes. They talked about families who hid their disabled children. They considered that these families either felt stigmatised by society, for having a disabled child, or lacked faith in Allah who controls all our lives. Similarly in the UK, five mothers in Read's (2000) study, talked about families, who had little experience of disabled people, and who received reactions from people, who regarded disability as a stigma and felt that disabled children should be hidden away. The effect of this would be the further exclusion of disabled young people. They would face additional impediments in their everyday lives, such as problems with appearing in public and being involved in social activities, as well as difficulties in gaining access to adequate services, such as therapy and education.

Initially, I had a high expectation about the supportive role of extended families in Omani society. My understanding was that apart from the capital, extended families are very helpful; people there probably know each other in their communities; in most cases, they are related. Accordingly, most people are likely to marry their relatives, which increased consanguinity in Oman

(Krafting, 1999). However, the majority of mothers did not reveal that they received significant support from their relatives. They, moreover, showed feelings of dissatisfaction because the latter did not offer them help, or did not give them short breaks and support in caring for the disabled child. The participating mothers, especially those with severely impaired children, thought that it was difficult for their relatives to care for their impaired children. They also thought that their relatives were busy doing their housework or taking care of their own children. It might have also been that their mothers, sisters or married daughters did not live in the same area. Only one mother reported that her sister, who lived close to her, provided her with help, as she still had no children of her own. This was evidence that mothers face additional difficulties in caring for their disabled children, especially in circumstances where they have a large number of children or more than one impaired child, the unavailability of short break services or family based support services and lack of extended family support. However, the mothers described uncles (brothers of mothers) as helpful, as they, sometimes, took their disabled children to the parks. In Scotland, (Connors and Stalker, 2003, p.44) a number of parents felt unsupported by their extended families. Their justifications were that extended family members thought disabled children were 'different', and they considered that they did not have enough experience and confidence to care of them.

However, Read's (2000) study suggested that the mothers of disabled young people, regarded the relationship with extended families as important, and they should maintain it. Fazil *et al.* (2002) in their study of Pakistani and Bangladeshi parents of disabled children in the UK, considered that for parents from minority groups, their extended families are likely to provide care for their disabled children. Fazil *et al.* described this kind of care as informal; yet, it is sometimes seen as a cause of the absence of formal care. Connor's *et al.* (2004) study showed that a number of Bangladeshi and Pakistani mothers placed a reliance on their own mothers and sisters. Yet, Pakistani mothers experienced less supportive families than Bangladeshi, especially families living a distance away.

The mothers talked about a lack of social, health and education service provision. There was a belief among them that disabled children were not

regarded as equal to non-disabled children. This was embodied in several aspects of their accounts, including the inadequacy of services, inaccessibility of agencies and the attitudes of workers they dealt with. Such a belief is supported by Krafting's (1999) report, which estimated that only 2% of disabled children in Oman, were covered by the different services they needed. More recently, the Omani Association of the Disabled (Challenge, 2003) reported that the families of disabled children were poorly supported and their disabled children suffered from inaccessible environments and services and restrictions on their lives, as they just stayed at home without having any activities. The mothers' concerns were that their disabled children would remain excluded from the different services that were granted for non-disabled children. As mothers, they were also worried, especially because of the absence of such services, that they would not be able to do a good job raising their disabled children.

The mothers talked about the right of disabled children to be given equal opportunities as citizens in their own society. They regularly compared them to non-disabled children and contrasted the way they were treated by society. For example, ordinary schools were designed for non-disabled children and these were not designed to be fully accessible for the disabled. Even those children who were placed in such schools, complained about access barriers and their exclusion from participating in different activities with their peers.

The mothers were disappointed with the social security system, which did not cover children who were under eighteen. This increased the responsibility of fathers, and sometimes the older brothers of disabled children, in providing for their different and extra daily needs. According to the Omani Association of Disabled People (Challenge, 2003), a great number of families with disabled children, especially those with low incomes, face difficulties in meeting the different daily needs of their children. The participants talked about the responsibility they felt that the government should accept to provide financial support for disabled children and their families, in order to enable them to satisfy their regular needs. Yet, this could only be achieved by a dramatic change in the laws in order to ensure adequate services for such children.

Kemp (2002), in his study about the unmet needs of disabled people in Australia, suggests that unfulfilled needs require more than just increased levels

of service provision. Moreover, service providers must recognise the factors behind the inadequacy of current service provision. Kemp's study reported that families in Australia do not lack the services they need; yet, he attributed unmet needs mainly to the attitudes of professionals, who should have asserted the rights of users to receive adequate services. Similarly, several studies in the in the UK, (Connors and Stalker, 2003; Connors *el at.* 2004, Audit Commission, 2003) attested that some parents of disabled children had to make an effort with certain professionals. in order to get their children's needs recognised and answered. Yet, there might be factors behind this unsatisfactory provision, such us miscommunication or misunderstanding between parents and professionals, it was not because of the unavailability of service provision. However, in the developing countries, including Oman, as was clear earlier, parents experienced further difficulties which prevented them from meeting their disabled children's needs. There were factors behind the mothers' dissatisfaction, including the inadequacy and unavailability of service provision, inaccessibility of facilities, discriminatory public attitudes towards disability and, more importantly, the professionals' attitudes.

The mothers complained about the way doctors behaved towards them. They believed that the latter did not make enough effort, even in diagnosing their disabled children. They gave examples showing that often parents, rather than doctors, detected the impairment of the disabled children. They claimed that doctors did not listen to them. As we will see in the next chapter, most professionals who took part in this study subscribed to the medical approach. They did not have an understanding about the social model of disability. It might also be possible that such misunderstandings between doctors and parents, referred to earlier, reflected the fact that the vast majority of the former were not Omanis and they did not speak Arabic. This was especially the case as recently as five years ago. The doctors could not express their ideas to parents and *vice versa*. In August 2002, I had a chance to discuss significant health issues with a doctor working at Rustaq Hospital; he suggested that the medical staff including doctors had large workloads, in which they had to meet tens of patients each day. This could have put them under pressure and that might have prevented them from having time to listen to the mothers and from

diagnosing their disabled children properly. Connors' *et al.* (2004) study found that South Asian parents were not given clear information at the time of their child's diagnosis. However, they reported that those parents who do not speak English could not understand the doctors. As Ahmad (2000) pointed out, shared language is not just a means of communication, for families, it is also the means to secure information about their child's impairment and about the services they need to access.

It is highly significant that professionals, whether doctors or others, have a role to play in promoting the rights of disabled children and their families and in enabling them to express their point of views. It is their right to be heard. Professionals should maintain a good relationship with disabled children and their families; they should respect their views. Mitchell and Sloper (2001), in their research on children's and parents' views about the quality of services in the UK, showed that a significant number of mothers stressed how some professionals adopted a patronising manner; they felt dismissed as over anxious mothers rather than respected.

In Oman, there was a critical lack of legislation to ensure that disabled children and their families received adequate services. There were also, as we will see in the next chapter, professionals who still believed in the medical model and regarded disability as a physical limitation, rather than recognising that the disablism is caused by society. Read (2000), in her review of legislation in the UK, suggested that during the past two decades significant legislative and policy changes have been witnessed, in relation to service provision for disabled children and their families. Yet, she reported that services remained inconsistent and difficult to find, which made children and their families often rely on their own personal coping resources to meet their needs. The problem of service provision in the UK, I assume, reflects a gap between the intention of the policies and their implementation outcomes, which should be bridged if policy objectives are to be realised. An inspection, by the Audit Commission (2003), concluded that sometimes families of disabled children felt that new services were set up to ease resource problems or because of the availability of special funds, rather than to meet their needs.

Like their disabled children, the mothers in Oman were happy with the services provided by the Al-Wafa Centres. Al-Wafa Centres, as mentioned earlier, provided voluntary day-care services for disabled children under fifteen, supervised by the Social Development Department. Connor and Stalker (2003) reported that disabled children and their mothers were keen on the support received from voluntary organisations. There were different factors behind the mothers' satisfaction of the Al-Wafa Centres. They were pleased to see their disabled children freed from their restrictions at home and having the chance to take part in activities with other children. They also believed that their children benefited from the therapy and education programme.

Most of the participants expressed the idea that these centres made disabled children feel just like their non-disabled brothers and sisters, who go to school everyday. These centres helped and encouraged parents to place their disabled children in ordinary schools. They also valued the way the volunteers dealt with their children. However, these centres were scattered around the country and only located in a few main cities. This meant that there were thousands of disabled children who did not receive such a service. A study, conducted in the UK by Petrie and Poland (1998), examined mothers' satisfaction with services provided for their disabled children and revealed striking similarities between the views of mothers in Oman and the U.K. It suggested that they were pleased with the benefits of the day care service; they were happy because their children enjoyed greater freedom, friendship with other children and varied activities. They liked the way the staff dealt with their children.

Short break (respite care) services, are important for families with severely impaired children and for those with more than one disabled child. In Oman, this kind of service was poorly provided and was just for children with complex health needs. In the entire country, there was just one centre that provided these services and it was located in Muscat. This meant that only a few families could avail themselves of the service. Some mothers felt that they needed to have more time for their non-disabled children and for housework. They believed that if they placed their disabled children in the centre in Muscat, they might get better and they have a chance to receive special care. However,

those mothers who did so, were very unhappy with the way their children were dealt with. They claimed that they were neglected and even denied choice in clothing, to the extent that one mother reported that her child was dressed in his companion's clothing. As a result, they would not consider sending their children back any more. The deficiency of such services may increase the pressure on mothers in caring for their severely impaired children without a break. Those with mildly impaired children were not keen to place them in a distant institution. It was not just because of the unavailability of such services in the interior areas, but also because they did not like to leave their children living far away. South Asian parents in the UK, were not happy about having their children staying away from home overnight. This was because of various factors, including the parents' uncertainty about the quality of care their children were receiving (Connor *et al*. 2004; Fazil, *et al*., 2002; Ahmad, 2000).

Robinson *et al*. (2001), in a review of UK studies, found dissatisfaction with services among a significant number of the families. The availability of services in the UK, compared to Oman, is incomparable. However, according to Robinson and colleagues some of the families in the UK had difficulties finding any form of short-break care that they thought suited their child's needs. They suggested, also, that most of the families were concerned about the lack of appropriate care for their children; sometimes, parents had concerns about the quality of the care that could be provided by people who were not qualified and were inexperienced.

Like their disabled children, the mothers in Oman complained about the long journey they faced when they had an appointment at the hospital. They looked at the appointment day as tiring; this was especially so for those who lived far away from the central hospitals and those who lived in rural areas. Some mothers complained about the money they had to spend on transport to hospital appointments. Some did not consider such regular visits to hospital as valuable; they were just for ordinary medical tests. They did not offer any sense of improvement in their children. Similarly, Dowling and Dolan (2001) in the UK, suggested that although parents valued clinical appointments, they described them as tiring. They looked on them as very gruelling for disabled children and

parents who often have to travel a long distance, with the child and possibly siblings.

There was a great awareness about the importance of education. In Oman, both disabled children and their mothers had the same views about the education service. Most of the mothers had very negative impressions of both ordinary and special schools. They described the staff in ordinary schools, especially the headmasters, as unresponsive; the parents had to negotiate with them until they accepted their disabled children. This gave a signal that the staff were not mindful of the rights of disabled young people to be included in the mainstream schools. Professionals, whose accounts will be discussed in the next chapter, revealed that the admission of disabled children into ordinary schools was not yet regulated by law. An interview published in the Challenge Journal (2003) with Fawzyah Al-Farsi, the former Undersecretary of the Ministry of Education, suggested that the Ministry was aware that there are many disabled children who were still not able to use the existing education services adequately. She added that the Ministry was planning to make all ordinary schools accessible for all disabled children, but progress in implementing these plans would depend on the availability of financial resources. Her Excellency's statement that education for disabled children was conditional on the availability of funding indicated that the Ministry does not fully take into account the inclusion of disabled children in ordinary schools. Her message revealed that disabled children are still not given equal consideration to their non-disabled peers in government policy. While education was granted to non-disabled children as a right upheld in law, disabled young people and their parents had to fight in order to obtain it. A significant number of the mothers only found out about the possibility of their disabled children's enrolment in ordinary schools through the Al-Wafa Centres. This meant that a great number of the families did not have enough information about their disabled children's rights and the opportunities that were available. In Scotland, Connors and Stalker's (2003, p.70) study reported that most parents had to fight in order to place their disabled children in inclusive schools; some headmasters were not supportive. In England, Connor's *et al.* (2004) study showed satisfaction among South Asian parents with the education service provided for their children. However,

miscommunication with staff in schools was the only difficulty that the parents interviewed experienced; this was a problem mainly for those parents who did not speak English.

Krafting (1999), in her report about service provision for disabled children in Oman, said that only three special schools were located in Muscat and they did not cover all the disabled children who were scattered around the country. It is quite hard for the families to send their disabled children far away from home. Some mothers were told that they would have to wait a long time for a place for their child, because there were many other disabled children before them who were still waiting. There was also a lack of residential accommodation, which was required for students who were from outside Muscat. The mothers did not talk about the accessibility of special schools and their relationship with its staff.

Negative public attitudes increased the concerns of the mothers and their disabled children. The former stated that many people still looked or stared at their disabled children and made them feel uncomfortable. It is possible that these people, when they saw the disabled children in their wheelchairs, sympathised with them and with their families, which was also contrary to the disabled young people's wishes. As the accounts in chapter seven revealed, they did not want to be objects of sympathy or pity. However, there was a positive signal when a few mothers indicated that they hoped that public attitudes might improve in the future. They believed that the voluntary organisations, such as the Al-Wafa Centres, played a role in raising awareness and making people's views change towards disabled children. Similarly, Read's (2002) UK study reported that the majority of women considered that public demeanour towards disabled people had improved. However, the participating mothers said that, while they were with their disabled children in hospital, they became used to being asked about the condition of their children by others, especially women. The mothers thought that such questions were not asked maliciously, but rather there was a trend of increasing sympathy towards disabled children, which encouraged people to raise such questions. However, in all cases, the mothers resented any interference in their children's affairs and so did not welcome this attention. This might result in decreasing the

appearance in public of disabled children, who did not like to be seen by others as different people.

Some Omani mothers reported that the siblings were annoyed by public attitudes. This meant that a whole family could be affected. A report about disability in Saudi Arabia by the Japan International Cooperation Agency (March-2002), highlighted a lack of public awareness and suggested that public attitudes based on sympathy and social pity had increased the exclusion of disabled people from the mainstream society. Connor's *et al.* (2004) study reported that, among South Asian people in England, there were negative views about disability; this resulted from a misunderstanding of its nature. These authors recommended educating families and communities about the condition.

The mothers in Oman, just like their disabled children, complained about the inadequacy of service provision in rural areas. These views were supported by Krafting's (1999) report, which showed that, as a consequence, a number of parents moved their families from their home villages to towns, where they thought such services would be better provided. The mothers also talked about physical obstacles that prevented wheelchairs from moving around rural areas; they described the rural local environment as hostile. This might have increased the pressure and responsibilities of parents and restricted the movement of disabled children. The mothers talked about dual responsibilities, in which they had to care both for their disabled children and to face obstacles with their children that prevented them from having a decent life, which is almost taken for granted for non-disabled children.

Almost all the mothers were concerned about the future of their disabled children. They were not sure whether the services would be improved or not. They thought that if the situation remained the same, without any improvements in service provision, their disabled children, especially when they became adults, would face greater problems, as their daily needs would increase. They talked about their anxieties, about the situation of their disabled children after their own deaths. They worried about how their children would cope with a situation that might be one both of the absence of informal caregivers and poor service provision. Their concern about their disabled daughters was greater, as discussed earlier. In Read's (2000) study, the majority of the mothers were quite

worried about their disabled young children's future. While some had confidence that they would be able to live normally and to have a secure life, others thought their needs would be met inadequately when their parents, especially their mothers, were no longer with them. Some Asian families in Connor's *et al*. (2004) study expressed the same worries.

These major concerns reflected problems experienced by the disabled children and mothers in everyday lives. The mothers did not hesitate in identifying the changes that would help improve service provision for their disabled children. They talked about their rights to be provided with adequate services. They sought more inclusion, independence and involvement for their children. Public attitudes, according to the mothers, should be changed and they considered that only an intensive and collective effort would make them more appropriate.

As we have seen, the issues that were raised in this chapter and in the previous chapters, placed a strong emphasis on the social implications of disability. The accounts of the mothers and young people themselves revealed how disability is strongly associated with the structure of society. The concept and significance of disability is, therefore, impossible to understand outside of the context of the everyday interaction between disabled young people, their families and their own communities; and its implications go far beyond the impairment itself. The following chapter discusses the views of professionals on the social world of disabled young people and their families.

Professionals' Perceptions

11.1 Introduction

This chapter examines the perceptions of twelve professionals who work with disabled young people in Oman. The purpose was not to gain information from them on behalf of disabled youngsters. It was to examine their views about the experiences of disabled young people and about the services provided to meet their needs, from their vantage point as witnesses to, and participants in, day-to-day service delivery. The professionals' sample was a convenience sample. Twelve individual local workers from the social, medical and education services were asked to discuss their views on the key issues, including service provision and public attitudes towards disabled young people. One tribal chief also took part to express his feelings about these issues. The selection of professionals was based on the data provided by the disabled young people. They named particular professionals who had dealt with them, including teachers, volunteers, doctors, nurses and workers in the social services.

The professionals in both the voluntary and government sectors, including those who work in education, health and social services, raised issues of relevance to the everyday lives of disabled young people. Interestingly, almost all the professionals were delighted to take part in this study.

11.2 Background and Motivation of the Professionals

The professionals interviewed for this study can be divided into two categories. The first is that of untrained staff, who work in settings run either by voluntary associations, like The Associations of Disabled Children Care, or by the Social Services Department like The Day-Care Centres (Al-Wafa Centres). The vast majority of volunteers, who work with disabled young people, are women. The volunteers suggested that they were motivated to work with disabled young people for a variety of reasons. They wanted to help others who, in their view,

needed help. They had a deep belief that disabled youngsters and their families needed support; they also thought that the work with the disabled was interesting. The volunteers regarded such work as the most valuable way to spend their leisure time. Almost all of them stated that such work would earn them a reward from Allah. A volunteer suggested:

> *"By nature, I like voluntary work. I have a sense of how others struggle. I know there are many disabled people who need assistance and help. These factors pushed me to become a volunteer. The Association of Women encouraged me to do this kind of activity. This is the best way to use my time in a valuable way. Of course, such work satisfies God and he might reward me".* (P1-volunteer-female)

However, in April 2004, I had a chance to meet 24 volunteers who took part in a workshop about 'the role of volunteers'. They worked in the day-care centres in the Al-Batnah region. These volunteers identified several reasons for working there. Their motivations were listed as follows:

1- I enjoy working with disabled young people because they need our help.
2- It is interesting work because I feel that I am doing something useful.
3- I feel happy because all the volunteers with whom I work are women.
4- My friend does the same job and she encouraged me to be a volunteer.
5- The best way to use leisure time.
6- One of my relatives is disabled. This increased my desire to help disabled young people. I also want to learn how to help him.
7- It is charity work. I may receive a reward from Allah.
8- I could not find another job and I want to have a monthly income.

These statements showed that voluntary services were predominantly provided by staff who were drawn to the work by personal motives and experiences, rather than by professional training and knowledge. Almost all the

workers, in the voluntary sector, were non-specialists and they did not even have a Bachelor's level degree. The majority of them had only been educated to secondary level and the rest had only elementary and primary level education. Moreover, most of these unskilled workers reported that the training programmes were not satisfactory. The majority talked about feeling a vocation to work with disabled young people. However, some of them said that they only wanted to have a monthly salary, rather than to help the disabled young people and their families. One respondent, who had worked with disabled youngsters for more than twelve years, expressed her concerns about this. She said that her Association has a list of hundreds of applications from women who say that they would like to work in these services, on a voluntary basis. However, in her experience, there were some who left after a while because the Association delayed paying them. This demonstrated that they did this work only in order to earn money.

> *"The problem is that some volunteers, once they begin t working in the centre, t start asking to be paid; sometimes, we [the Association] do not have a large enough allocation to pay all of them. Some volunteers, therefore, leave us".* (P1-volunteer-female)

However, I met a fair number of volunteers who were interested in helping disabled youngsters and their families. They reported that they do such work without asking for payment, simply because they feel pleased to help in this way.

Most volunteers said that they were not happy with the training they received. They suggested that they merely learned from the experience they acquired from their work with disabled young people. The workshops that were held, from time to time, in Muscat were useful. However, only some volunteers attended them.

> *"Actually, we need more workshops and seminars that update our experience. We just rely on our everyday experience. We feel that we can not give them more. The workshops that are held in Muscat are useful. But not all of us attend them".* (P1-volunteer-female)

However, some volunteers, who had been working for a long time, regarded these training programmes from a positive angle.

> *"For more than 10 years, I have been working with disabled children. This experience gave me knowledge as to how to organise activities for them in the Centre [day-care centre] and gave me skills to communicate with their families.*

But, she also said:

> *"In fact, I am not a specialist and I have no degree. However, from time to time there are conferences and workshops I attend, which is useful and gives me more information about disability issues".* (P1-volunteer-female)

Some officers who work in the Ministry of Social Development (MSD) considered that volunteers, who are not well trained, would not be able to provide satisfactory services for disabled young people.

> *"However, the Al-Wafa centres and voluntary associations provide services for disabled children and their families; they rely on volunteers who are not specialists. It is really an issue that should be considered. These volunteers should be trained and the centres should be supported by professionals who should work beside the volunteers".* (P6-social service-male)

The second category of people who worked with disabled young people were professionals, who were employed in different government departments, including health, education and social departments. Almost all the professionals, who took part in this study, said that they did not originally intend to work with disabled youngsters. One respondent explained.

> *"I did not think that I would work with disabled children. However, I was expecting to work as a social* worker *in the social service".* (P10-social service-male)

Only one respondent had a degree, from Jordan. He had an opportunity to take a placement with disabled people.

> *"I wanted to get a degree in psychology. During my study, one of the modules was to take a placement in the centres that work with disabled people. From that time on, I liked to work with disabled people".* (P8-education service-social worker-female)

None of the specialists, including doctors, teachers, physiotherapists and social workers, suggested that they had studied models of disability or courses that touched on the issue of the inclusion of disabled young people. One doctor said,

> *"It was not my intention to study disabled children. But, in the course [medicine degree], we were given an idea about the types and causes of disability, but we did not study it in detail".* (P11-doctor-male)

Moreover, all the respondents, who worked in the government departments, suggested that there was a shortage of professionals to work

with disabled young people. Besides, almost all the Omanis, who provide social services for disabled people, were not well qualified.

> *"You know, none of my colleagues in this department are specialist social workers. I know, in all the regions, all the workers rely on their everyday experience, which is not enough. They are called social workers but the majority of them do not have even a degree in social work"*. (P7-social service-male)

In ordinary schools, where physically disabled children are placed, almost all the teachers had a degree in education, but none of them had any knowledge about disability issues.

> *"I gained my degree as a teacher. I did not take any course about disability, and I do not think any teacher has any idea about disabilities and the everyday problems of disabled people. However, it does not mean that we can't treat them nicely. We have a small number of wheelchair user students. We do our best to make them feel happy at school"*. (P3-education service-male)

Most of the respondents did not view the work with disabled young people as the main priority or focus of their everyday work. They, moreover, expressed the opinion that they had to deal with them "nicely", which means that disabled youngsters were regarded as different from their peers. The professionals thought that they had wider responsibilities towards other people, rather than only to disabled people. For instance, physiotherapists in big hospitals, where such services are provided, are responsible for treating tens of patients everyday. Teachers in ordinary schools are responsible for teaching tens of non-disabled students. Social workers in ordinary schools have to take responsibility for hundreds of non-disabled students.

> *"We have only one social worker at this school, who is extremely busy and he has to do many jobs. He has to take care of all the students. However, he does his best to help the disabled ones".* (P3-education service-male)

These examples highlight some important points. Most of the respondents did not have any prior intention to work with disabled young people. They had wider responsibilities and their work with them was only a small part of their overall job. None of them had studied or trained as a professional, to work with disabled youngsters, and the training they were given was not enough. Generally, they agreed that there was a shortage of Omani professionals working in this field.

11.3 Understanding Disability

It was quite evident from the interviewees that the medical model of disability is dominant in Oman. All the respondents, whether working in the voluntary or in the government sector, defined disability as physical limitation or inability. They used several definitions; however, all of them could be placed under the umbrella of the medical model. The professionals did not distinguish between the concepts of disability, handicap and impairment. They switched between these different concepts in their accounts, which showed that they had a limited and confused understanding of disability. It also meant that they were dominated, in their thinking, by the implications of the medical model. While they were defining disability, even those who worked in the social and education services as well as those in clinical settings, started to describe the types, level and causes of disabilities.

> *"Disability means, a disabled child has a problem in his body or in his senses. For example, cerebral polio or*

> *deformation. All these problems come from damage to the brain".* (P5-social service-female)

Some of the respondents defined disability differently. They preferred not to use definitions like "a disabled person" or "a person with disability". They thought such definitions made disabled people feel inferior. "With special needs", in their view, was better. They thought that all people have different special needs. For example, those who use glasses have a special need.

A female volunteer defined disability thus:

> *"I think every person has a limitation and every person needs some kind of service. We do not need to look at disabled children as just unable to do things. They are able to be active if they are given a good service. I prefer to use the definition "people with special needs" because it is better, and it makes them feel they are not different".* (P1-volunteer-female)

This example demonstrates that she sought to avoid stigmatising disabled people, by indicating that everyone has special needs. However, her preferred definition overlooked the barriers to the inclusion in society of disabled youngsters.

Some of the respondents linked the inability to use the existing services used by mainstream society with disability:

> *"I think the disabled person means someone who is unable to use the facilities provided, because of his /her bodily or mental limitations".* (P2-tribal chief-male)

A few of the respondents were not sure about the exact definition of disability. A headmaster in an ordinary school stated:

> *"In my understanding, it could be a physical or a mental disability. Physical disability means a person who cannot move. I do not have a specific definition because I have never attended a course about or studied disability".* (P3-education service-male)

Professionals also distinguished between types and levels of disability.

> *"In my opinion, a disabled person is one who is fully impaired and has an inability to do things; it is a limitation in the body or the senses. For example, a disabled child can't walk, but he/she is able to do something else".* (P4-social services-male)

This extract exemplifies the fact that the disability is understood in the context of the medical model. Professionals focus on impairment, which, from this perspective, prevents disabled young people from engaging in activities.

Some respondents defined disabled youngsters by using the words "not normal". They repeated the words "normal people" to mean non-disabled people, which, implicitly meant that disabled young people were "not normal". This expression was widely used even among specialists as well as by the general public. They use the term "normal" to specify the difference between disabled and non-disabled people, in terms of physical ability in performing activities in their everyday lives.

> *"Sometimes, they can't go to school and do different things that normal people can do. The difference between normal people and them is that normal people are given more services and do whatever they would like to do".* (P3-education service-male)

This extract associated the meaning of disability with two significant points, namely, lack of service provision and inequality. This meant that there was a sense, among some professionals, that disabled youths have to be provided with adequate services that are assured for the non-disabled.

Almost half of the professionals drew attention to significant social problems such as lack of services, inaccessibility, public attitudes and the low income of families. They suggested that these issues should be considered by society. A volunteer argued that the state should provide early support for disabled young people and their families:

> *"Of course, to decrease the consequences of the disability, we, as a society, have to provide all the necessary services. Because the more we delay in providing such services the more disabled the children will become. This will have an effect on all disabled children, their families and the government. Because if it delays in providing key services for them, they will need intensive care, as it will be more difficult for their conditions to improve. The burden, therefore, will be heavier"*. (P1-volunteer-female)

Another example puts the responsibility of disability on society:

> *"Sometimes, society plays a role in making disabled children unable to participate in different activities. If they are humiliated and neglected, their disability will increase. I think, they have to be included in all social activities"*. (P10-social service-male)

These two examples provide evidence that some professionals, especially those who work in the social services, were aware that society might incapacitate and exclude disabled people. They also believed that it was the

responsibility of society to ensure full inclusion for disabled people to be active citizens.

11.4 The Families' Role

Generally, the professionals had different views about parents of disabled youngsters. Those parents who gave a lot of attention to their disabled young people were described as "helpful" and "responsive". They suggested that there were parents who sought to gain services for their disabled children. For instance, they accompanied them to schools or centres, to make sure that they did well and they were happy. The parents also helped their disabled children with their homework studies and physiotherapy exercises.

> *"Actually, his father is helpful. From time to time, he comes to school asking about his son".* (P3-education service-male)

However, these professionals recognised that, sometimes, parents were not able to support their disabled young people, in this way, and ensure that all their needs were met. For example, some of them had difficulty in getting transport to take their disabled kids to school or hospital; some of them worked far away from their homes and they were with their disabled sons or daughters only at the weekends or during the holidays.

> *"Families have to provide all the things their disabled children need. But, sometimes, they encounter problems which prevent them from coming to the physiotherapy units. Sometimes, families might have transportation problems or fathers can't leave their work".* (P4-health service-male)

Another reason for limited family involvement was said to be the lack of information:

> *"There is a considerable problem when those families who are uneducated have no information about how to use the services their disabled child needs. They do not know to where they should take their disabled child. There are many children who arrive here very late"*. (P1-volunteers-female)

Family income was seen by the professionals as one of the most significant factors affecting the family's roles in their disabled children's lives.

> *"There are many families who, due to their low income, can't help their disabled children, [provide basic needs for them]"*. (P5-social service-female)

Some professionals thought the age and educational level of the parents influenced their ability to take care of their disabled youngsters.

> *"Those families, who are young and well educated, are helpful and doing their best in helping their disabled children and in using the existing services"*. (P7-social service-male)

Some professionals suggested that, a significant number of, parents believe that their having disabled young people is a test from Allah. The disabled young people themselves and their mothers also raised this point, as we saw earlier.

> *"There are parents who view disability as a test from Allah. These families do their best in helping their disabled*

> *children, even sometimes they send them abroad in order to receive better treatment".* (P5-social service-female)

Families from rural areas sometimes moved to towns, just to enjoy a better service for their disabled young people. Disabled youngsters and their mothers also suggested this.

> *"There are families, who think about their disabled child and have moved to the town. They moved just to get a better service here. However, not all families are able to move. It is a problem".* (P3-education service-male)

There was a general belief that the attitudes of families are improving and they were generally much better then they were a few years ago. As one social worker explained:

> *"In the past 10 years, families were looking at their disabled children as a burden. They influenced their social, economic and whole life. Currently, most families are better educated and consider their disabled children as being on a par with their siblings. I know families who have made adaptations [to their homes] for the wheelchair. This means that their outlook has improved. This is my experience of many families".* (P10-social service-male)

The professionals talked about an improvement in families' awareness, which has resulted from the education programme. However, they pointed to the fact that it was those families, whose disabled young people used the existing services, such as the Al-Wafa centres, who benefited from this programme. This meant that it still did not reach the majority of families. A report was published in the Al-Watan newspaper, dated 30th October 2003, which showed that the total number of disabled youths in the eighteen Al-Wafa centres was only 1,370 out of a certain estimated total. Krafting (1999)

suggested that this estimated number of Omani disabled young people , under 15 years of age, was between 32,250 and 62,000. This means that a large number, of disabled young people and their families, still needed education.

The professionals interviewed believed that there were families that were not able to give enough care to their disabled young people. They suggested several reasons for this, including unstable relationships between parents, low income and wrong attitudes.

> *"There are parents who have an unstable relationship. Some families have a low income. The disabled children under such circumstances become victims. None of the parents, in this case, would give them enough attention. All these factors, sometimes, make such families reject a disabled child. From my experience, these factors could damage the feelings and health condition of disabled minors"*. (P1-volunteer-female)

As presented in chapters six, seven and nine, some families hid their disabled young people simply because of public attitudes; they felt ashamed to show society that they had a disabled child. Similarly, the professionals believed that there were families who still hid their disabled youngsters:

> *"I am sure, there are families hiding their disabled children. The total number of disabled people in Oman is larger than the published one. This is because many disabled kids are not registered. Families feel ashamed to say, "I have a disabled child". When they hide their disabled children, they deprive them of the key services they need, from education, training, rehabilitation, treatment, social security and equipment. It is not good for the families and of course for the disabled children themselves either. It does not help*

the government to allocate the various services they need". (P2-tribal chief-male)

Another said:

"Families should play a vital role in including disabled children in society. What happens now is that some hide their disabled kids n at home; they do not allow them to go t out at all. Moreover, some do not show that they have disabled offspring who become known only when they become adolescents. These families are embarrassed because of society's attitude .They believe that having a disabled child is a scandal. This gives an indication that they are lacking in education and faith in Allah. This is not only in the rural areas but in urban areas too". (P4-physiotherapist-male)

The previous two extracts showed that families of disabled young people might be influenced by various factors, including public attitudes, service provision and the awareness of the parents. These could play a significant role in shaping how families dealt with disabled youths. As we saw in chapter four, society plays an important part in the disabled young people's inclusion.

Another issue that was raised by the respondents was "overprotection". Some mothers, as seen in the previous chapter, thought that they should take great care to protect their disabled young people. However, all the professionals considered this approach had negative implications for the wellbeing of the child. They associated "overprotection" with isolation:

"Families play a vital role in including disabled children in their own societies. What happens now, is that many families behave wrongly. Some of them overprotect their

> *disabled children, to the extent that they isolate them from their siblings. Of course, this trend segregates the disabled even inside their families".* (P5-social service-female)

Another example showed that some parents overprotected their disabled offspring and this led them to receive inadequate services. The professionals thought that the parents did not like to leave their disabled kids out of their sight. This made some parents decide not to send them to special schools or centres.

> *"There are parents who treat their disabled children with overprotection, to the extent that they even do not send them to schools or centres. They just leave them at home and do not try to use the available services. I think these families need to be educated in order to be more positive with their children".* (P6-social service-male)

Another example relates the overprotection of parents to dependency in disabled young people:

> *"Some parents treat their disabled children with overprotection. Of course, this way is wrong. It does not help them to be independent. For example, in the centre [blind school] there are some blind students who, before they were placed there, relied on their parents for everything, they even fed them. Their parents did not teach them how to look after themselves. This way is wrong; parents should teach their disabled children to look after themselves*". (P3- education service-female)

These three examples showed that the wrong attitudes of the families might increase their disabled children's exclusion. The parents should be

aware that their children have a right to be provided with adequate services, just as much as their siblings and peers. The professionals considered that parents should help their impaired children to meet their own needs.

In traditional societies, it is quite common for people to link disability with the work of "jinni or sorcery". The professionals suggested that some Omani people still had this belief. Some parents, therefore, did not think to seek treatment for their impaired children, as they thought that they might not benefit from the health services.

> *"Some families believe that the impairment of their disabled children came about by sorcery. Such a belief prevents them from seeking treatment and care for their disabled children"*. (P6-social service-male)

The professionals suggested that almost all the parents with disabled children face at least one kind of difficulty. Most parents were worried about their disabled young people's futures. Those who have severely impaired children struggle more than those with mildly impaired children. Some parents lacked the information they needed to help their disabled young people.

> *"Having a disabled child is a source of worry and pressure for families. (Abnormal) children need more attention especially if their disability is severe. Families do not always know how to meet their needs"*. (P2-tribal chief)

Most of the professionals considered that, in the absence of early intervention and delays in receiving health and social services, the condition of severely disabled minors became worse; they became more dependent. The respondents suggested that the parents, especially the mothers, are more worried if they have a severely disabled boy rather than a girl. In conservative societies, like Oman, it is quite embarrassing for a mother to give personal assistance to a boy over 15 years old. The professionals thought that such difficulties might increase the parents' anxieties:

> *"Imagine a mother who has a severely disabled young son, not a daughter, and he receives no services, how can she handle all his personal requirements including bathing and feeding. It is really hard".* (P6-social services)

The professionals thought that families feel uncertain about the future of their disabled youngsters:

> *"I am sure that most parents are worried about the future of their disabled children. They are not sure how they will cope e in the future, what facilities they need. After their death, who will look after them? Actually, families are always worried about these complex problems".* (P2-tribal chief-male)

These statements gave a clear picture of how some professionals regarded the daily lives of disabled young people in their families. They showed that they recognised that parents experienced difficulties in raising their disabled young people , under social and economic pressure, as well as because of inadequate service provision.

11.5 Service Provision

Service provision was a common theme among disabled young people, mothers and professionals. All of them agreed that there was a lack of key services including education, health and social services.

> *"We think that there is a huge shortage of the key services disabled children need. What we do for them is just voluntary work to alleviate some problems they face in their everyday lives. Our abilities are not enough. They need*

> *special services and professionals who know how to meet their real needs".* (P1-volunteer-female)

In this example, the volunteers themselves suggested that the services provided by voluntary centres did not meet all the disabled youngsters' needs. According to the volunteers themselves, most of them were not well qualified. The voluntary services, which were provided through the Al-Wafa centres, served only a small number of disabled young people. This was because these centres were only located in the main cities and they did not serve disabled youths who were over 14 years old.

> *"These centres play an important role in helping disabled children and their families. However, they are located only in the main cities. There are thousands of disabled children who live away from these centres, just staying at home. Generally, disabled children' rights are not met. Those who are over 14 are not entitled to use such centres. So, where should they go? Probably, they have to stay at home".* (P1-volunteer-female)

A tribal chief suggested that, if disabled youngsters were not provided with enough services, it would affect the whole of society.

> *"If disabled children are not provided with adequate opportunities, they will stay "disabled" and in turn, they will be "a trouble" for their families and for society. In fact, disabled people are not well provided with the key services they need, including education, training and equipment".* (P2-tribal chief)

11.5.1 Education Services

Education was perceived as a vital necessity for disabled boys and girls and their families. Almost all the professionals put the education service at the top of the list of services that should be provided. However, the majority of them suggested that there were obstacles preventing disabled young people from making sufficient use of education services. Those who were placed in ordinary schools faced physical obstacles. Even the new school buildings were still not fully accessible.

> *"There are different obstacles, even in the new schools. Yes, there is an entrance and a toilet, but there are obstacles preventing them from taking part. They can't take part with other students in the daily morning exercise and activity or go to buy from the cafeteria. It is difficult for them to climb stairs to the first floor. Of course, the old schools are [even] more inaccessible".* (P3-education service-male)

One of the professionals summarised most obstacles that prevented disabled youngsters from having an adequate education service:

> "*Until now, if you wanted to place a disabled child in an ordinary school, you would face lengthy procedures. Even inside the school, not all the teachers are aware of the importance of the education for disabled children. These children also face difficulties on school buses, how to get in, and how to get out. Nobody is nominated to help them in these matters. They are not given a chance to take part in different activities in schools. All these difficulties make them feel unhappy*". (P4-physiotherapist-male)

The inaccessibility of schools was a problem witnessed even in Muscat. A significant number of the respondents complained about the way the headmasters responded to disabled young people's requests for enrolment.

> *"Many of the ordinary schools in Muscat are not accessible. Some headmasters of schools are still not willing to place disabled children in their schools".* (P5-social service-female)

Or as another respondent explained:

> *"Even in Muscat, physically disabled children still face problems in being placed in ordinary schools. I have experience in this matter:*
> *"Three physically disabled children wanted to join a school. It took months before the headmaster accepted them. They had to bring a letter from the Ministry".* (P1-volunteer-female)

Almost all the respondents reported that all the special schools were located in Muscat:

> *"I think the education service covers a small number of disabled children who need to go to school. If we view the overall situation, we will see only three special schools in Muscat, what about disabled youngsters who live outside Muscat? They face problems to be placed in ordinary schools*". (P6-social service-male)

The only three special schools, which were located in Muscat, lacked Omani specialist teachers. The majority of the interviewees suggested

that there was a need for a national training programme, to produce more specialist workers, especially teachers.

> *"Teachers in the special schools are not well trained and qualified. We need a programme that trains Omani teachers, males and females, to enable them to teach and help our disabled children"*. (P1-volunteer-female)

Surprisingly, one of the respondents, who worked in the education services, expressed his disappointment because physically disabled children might not be placed in ordinary schools any more. This new trend came with a comprehensive reform of the education system in Oman [Basic Education], which would exclude all students who experience health problems, including impaired students.

> *"Nowadays, the most recent vogue , within the framework of the education reform, is that all students should have a medical test in order to be sure that they are healthy and with no disability. I think this trend is incorrect, because physically disabled students are able to overcome difficulties in ordinary schools, where they should be placed"*. (P3-education service-male)

This extract showed that physically disabled young people's exclusion may increase in the future. Ordinary schools, according to this statement, would be inaccessible to physically disabled youngsters. At the same time, there is no sign that they would be offered special schools, or special classes, in their own local communities

11.5.2 Social Services

The majority of the professionals were not happy with the existing social services provided for disabled young people and their families. Social security (financial support) was the main issue in this regard. Almost all the professionals believed that the disabled require more support than their non-disabled colleagues. They also suggested that most disabled youngsters' families have low incomes. This meant that they considered that the government should allocate financial assistance to help them.

> *"Having a disabled child, means a higher cost compared to non-disabled children. In my experience, most of the children I knew are from low income families. It means, the government should help these families financially"*, (P2-tribal chief-male)

Another respondent supported this:

> *"It is terribly difficult for disabled children to receive social security benefit. There are complex procedures. However, no disabled children under 18 are entitled to social security benefit. Of course, they need daily things and their families have to pay for all these needs, even those families with low incomes. Actually, they need financial support"*. (P6-social service-male)

Equipment, including wheelchairs, were seen as important. Most of the professionals suggested that it is easy for the disabled youth to acquire a wheelchair. However, a few professionals still believed that there were disabled youngsters facing difficulties in obtaining equipment.

> *"Some families are not provided with wheelchairs. I know a disabled child who has injuries because he does not have a wheelchair and his environment is stony. It is hard for him to get better just by physiotherapy, he needs a wheelchair too".* (P4-physiotherapist-male)

Housing adaptation was one of the responsibilities of the social services. Most of the interviewees maintained that the homes of disabled young people should be adapted. It would make it easier for them to move about inside the house without help. However, most of the respondents believed that the vast majority of houses, of the physically disabled, were either adapted by their families or remained unchanged; the social services do not give enough priority to this issue.

> *"Before we talk about society, we need to make sure that the homes of disabled children are modified and suitable for them. I know many such children, with whom I deal, whose houses are completely inaccessible, and they need financial help because their income is low".* (P4-physiotherapist-male)

However, one of the workers believed that the adaptation service, whether in the local community or in the homes, was a shared responsibility of society and the families. He seemed to imply that the government should not provide such services.

> *"Making the local environment more accessible is very important; however, the families and everyone else must assume their responsibilities to make it so. They know that disabled children need to move and to take part in different activities with other children. Anyway, the families have*

> *started carrying out the required modifications in their homes".* (P10-social service-male)

If the Ministry of Social Development (MSD) believes that the adaptation service and the basic needs provision should be provided by the families, it means that many disabled boys and girls will be restricted because, the majority of the families cannot cope with making the adaptations, for financial or other practical reasons. Consequently, the disabled youngsters may face obstacles to being involved in activities with their peers and siblings. This example also shows that the Social Services do not allocate an adequate budget to provide modifications for physically disabled people's houses. One of the officers in the social services asserted:

> *"The Ministry makes strenuous efforts to provide social services for all disabled people, including children. However, what prevents this happening is the lack of allocation, the budget is not enough. Therefore, a greater allocation of funds is important in order to provide a better social service and to train more professionals".* (P6-social service-male)

This statement was supported by Al-Barwani and Al-Beely's (1994) study, which interpreted the lack of social service provision for disabled people to a shortfall in the budgetary allocation of the Social Services.

11.5.3 Health Services

Health services were seen as a key need that should be provided in early childhood. The professionals believed that there were many cases where the child's condition worsened, simply because of the lateness of diagnosis and detection. Of course, it was not in all cases because of a lack of health services, sometimes, as was revealed in the last chapter, it was because of the

families' lack of awareness. Some families did not take their new babies to hospital.

> *"I think the health problem is the biggest difficulty disabled children have. Because it continues forever, especially if no treatment is provided for them in the early stages. This problem may prevent them from being able to experience normal daily lives as "normal" people do".* (P2-tribal chief-male)

Specialist health services, such as physiotherapy and occupational therapy were poorly allocated; there were just a few units that provided such services and all of them were located in the main cities. The number of Omani professionals in these units was generally considered to be insufficient.

> *"I am talking about physiotherapy. For example, in this region, there are six states (Walayat) and the population is more than 200,000, however, the only physiotherapy unit is this one and it is not enough. We are the only three physiotherapists. Imagine a disabled child who lives in a mountainous village, how could he/she come regularly. Of course, it is hard to come every week. Expanding the physiotherapy service is a crucial matter".* (P4-physiotherapist-male)

This meant that many physically disabled young people could not receive this kind of important service.

The professionals, who worked in the health services, viewed disabled youngsters on the basis of the medical model. The social implications of disability seemed not to be fully taken into account. This was perhaps because the doctors and other workers had not learnt about disability issues, and they did not have enough knowledge about the social model of disability.

"I think we, as workers in the health services, including doctors, still view disabled children as patients. Their social issues and other difficulties are not noticed very much". (P4-physiotherapist-male)

11.6 The Feelings of Disabled Young People

The professionals talked about factors that influenced the disabled children's feelings. They gave evidence that the lack of services, and the unhelpful attitudes of the professionals, might increase the negative feelings of these youngsters, especially when they compared themselves to non-disabled children.

"Disabled children feel disappointed, when they compare themselves to their siblings and other children. They see their siblings are offered all the services they need including schools, playgrounds. Imagine a disabled child, seeing his brothers and sisters going to schools in the morning, while he stays at home. This, of course, makes him feel unhappy and affects his psychological and health' condition". (P1-volunteer-female)

Or, as another professional put it:

"Disabled children are not provided even with the key services they need. This makes them angry. Disabled children compare themselves to non-disabled children who play and move normally". (P4-physiotherapist-male)

The following example associated the dearth of services with disabled youngsters' exclusion. This showed that some people in their society were aware of the importance of the principle of equality.

> *"Disabled people are deprived of having a full interaction with others and of using the different services in their own societies. This is bound to lead them to see themselves as different to "normal" people".* (P2-tribal chief)

Inside the ordinary schools, the professionals thought that the disabled students felt embarrassed when they asked for help from their peers. This confirmed what disabled youths mentioned (in chapter eight.)

> *"There is a feeling of embarrassment when disabled students ask for help from their peers. They are worried about being rejected if they ask for help".* (P3-education service-male)

Staff's attitude in schools was a sensitive issue. They had to be careful how they treated the disabled young people. They should not be either neglected or sympathised with. Both approaches are contrary to the wishes of the young people themselves. The professionals believed that a great number of disabled students, especially in ordinary schools, were treated with sympathy.

> *"There is a problem in ordinary schools; we need to give it our consideration. Some teachers look at disabled students as "Miskeen" (deprived); they sympathise with them; they overprotect them. It is, of course, a wrong view. Through this approach they make them feel inferior".* (P7-social service-male)

Unfortunately, sympathy and overprotection were common even among the professionals including the teachers, when they dealt with disabled people. Although they might have considered that these approaches were helpful, the young people themselves regarded them as negative. However, I will return to this issue later in the discussion part of this chapter.

11.7 The Local Environment

Some professionals talked about the inaccessible aspects of society. They suggested that there were obstacles preventing disabled youngsters from moving freely in their own local community. They linked inaccessibility with social exclusion.

> *"The environment around them is inaccessible. The facilities in society, including local clubs, buildings and neighbours' houses are inaccessible. There is a problem for disabled children to leave their homes; this applies to both urban and rural areas. You can see no pavements, and no ramps. Their houses are not modified for the wheelchair. In this case disabled children face a problem getting out of their houses".* (P1-volunteer-female)

Another said:

> *"Undoubtedly, there are many obstacles. Disabled people need facilities and services. For example, the pavements are not adapted and this prevents them from moving about. These kinds of facilities would help disabled people enjoy greater inclusion in society".* (P2-tribal chief-male)

The professionals also talked about the inaccessibility of the rural areas. They believed that, in rural areas, where facilities and services are inadequate, the situation was more difficult than in towns.

> *"The rural community is filled with obstacles. Wheelchair users can't survive there. There is no way to move about in the local area there. Schools there are not adapted. Imagine that even towns prove quite inaccessible; of course the situation in the rural areas is much worse".* (P3-education service-male)

In contrast, there was a belief that society was becoming more accessible than before. In the main cities, there were places, like shopping centres and governmental buildings, that were adapted for wheelchair users. Three professionals indicated that there was evidence of an improvement in the accessibility of society. However, they talked only about a small number of major cities, where a few public buildings were adapted to be accessible for wheelchair users. They did not talk much about the negative public attitudes towards disabled youngsters, which, I believe, are important, if society is determined to include them.

> *"The situation is getting better. For example, all public buildings and parks are provided with ramps and toilets. Even some public MAJALIS (Community Halls), are provided with ramps. This gives an indication that people have started to change their attitudes".* (P10-social service-male)

However, this interviewee believed that the inaccessibility of local communities prevented disabled boys and girls from having a chance to move around and to take part in different activities. He himself suggested:

> *"Yes, there is some difficulty for wheelchair users to move about in their local community. Pavements are not adapted; the houses of neighbours are inaccessible. How can they move around there? These obstacles prevent disabled children from getting involved in different activities with non-disabled children".* (P10-social service-male)

11.8 The Future

The professionals raised important points that should be taken into account in future planning. They talked about the need for a comprehensive study in order to state the exact number and types of impairments. However, two surveys conducted in the 1990s, gave statistics about Omani disabled people and their characteristics (Ministry of National Economy, 1994; Ministry of Social Development, 2000). Almost all of the respondents stressed the importance of a national training programme, to provide more specialists in education, health and the social services. They also hoped that public attitudes would improve, yet this would also require a sustained national education programme. Financial support for disabled youths and their families was also one of the themes, which the professionals talked about. The accessibility of society and adequate service provision were emphasised too.

These various issues were summarised in one quote:

> *"A comprehensive study should be conducted to state the different needs of disabled children and their families.*
> In order to improve public understanding of disability, a national education programme should be introduced *It is not necessary to place disabled children in special institutions; however, they have to be included in their own society. This means that all the facilities in that society should be accessible.*

> *There is a need for a national training programme to train people that are able to help disabled children and their families, including teachers, medical workers and social workers.*
> *Families should be financially supported.*
> *Voluntary work has to be improved and encouraged".* (P1-volunteer-female)

However, surprisingly, there were two professionals who thought that there was a need to develop a large centre, to provide a range of services for disabled youngsters.

> *"I wish that the government would start to develop a large centre h covering all types of disabilities and would take all disabled children who wanted to be placed in such a centre".* (P5-social worker-education service-female)

This example shows what a negative vision some professionals have. At a time when everyone was seeking to achieve more inclusion for disabled youth in their own society, they were thinking about more exclusion.

11.9 Discussion

The professionals in this study raised a number of useful points. They talked about their motivation to work with disabled youngsters. They stated that disability was still viewed in the context of the medical model; this was clear in their understanding of the disability concept. The professionals also talked about service provision, public attitudes and the disabled children's futures. All these issues will be discussed here.

The professionals had different reasons for deciding to work with disabled young people. The majority of the volunteers were more interested in providing services for them and their families than the professionals, including

social workers, doctors and teachers. In fact, I could not find any study that addressed the professionals' motives in working with disabled youth in Oman. However, the volunteers themselves reported that they lacked training and qualifications. They, interestingly, admitted that they gained the relevant experience only when they started to work in the day-care centres. They did not take any relevant special course before they started to do this work. This highlights the fact that all the day-care centres in the country were run by inexperienced and untrained workers. This may have negatively affected the way that they carried out their work with the disabled and their families, especially in terms of enabling them to enjoy greater inclusion and of educating them against the discriminatory attitudes of society. The volunteers themselves talked about their need for more training, so as to be more capable of doing their jobs with, and of behalf of, the disabled youngsters and their families.

However, as we saw in chapter seven, disabled young people were happier with the provision of the day-care centres (Al-Wafa Centres), and with the service they received from these untrained volunteers, than from the professionals, including nurses and social workers. Yet, the explanation the children gave was that these centres gave them a chance to be involved in different activities with their peers and the volunteers were nice with them. The Audit Commission (2003, p.40) found that disabled young people in the UK liked the staff and named them because they made a difference to them, to the extent that certain staff members were popular. However, the children and their mothers did not talk about the proficiency of the volunteers.

An unpublished report (Bamyah, 1996), handed to the Ministry of Education, about service provision for disabled young people in Oman, revealed that the volunteers who were working with disabled young people lacked the knowledge and skills about how to provide adequate support. Overall, it was clear that while non-disabled children's services increasingly improved, and that the professionals who dealt with them are likely to be highly qualified, the disabled not only lacked adequate service provision, but were also still provided with inadequate daily services by inexperienced workers. Do

they not deserve to be helped by highly trained workers too? Similarly, in the UK, the Audit Commission's (2003, p.42) study found that with some services, there was a shortage of practical and technical knowledge and skills among the professionals working with disabled young people. The staff were often not being able to handle the range of needs, including medical ones and communication. This problem existed in both the statutory and voluntary sectors.

Unfortunately, the vast majority of qualified professionals, including teachers and social workers, reported that they did not originally plan to work directly with disabled young people. Even social workers, who were now working in the social services, reported that they did not intend to work with disabled people before they became employed. Those who worked in ordinary schools and in social security talked about the various responsibilities they had in their daily work, but their role with disabled people was not a priority for them. Moreover, those who worked in Special Care Sections (social services), which dealt directly with the disabled people themselves, reported that they did not have any knowledge related to social work studies or disability studies. Moreover, a significant number of them did not have a degree at all.

Another difficulty was that all the doctors who took part in this study viewed disability issues from the point of view of the medical model; they even admitted that they had never heard about the social model of disability, and had little appreciation of the barriers to inclusion experienced by disabled youth. This indicated that the professionals lacked understanding about the physical and social obstacles which prevent the disabled from sharing full involvement in different activities in their own society. These important points revealed that most of the professionals lacked training, qualifications and knowledge in the social issues of disability. This fact was supported by the Social Committee study (Majlas Al-Shura, 1997), which indicated that none of the Education College courses included any modules about disability issues. This Social Committee study reported an imperative need for a training programme, to increase the number of workers and to promote their skills, to provide quality services for disabled people.

Jahnukainen and Korhonen's (2003) study, which was about the integration of students with severe impairments into the comprehensive school system in Finland, suggested that teachers' education and experience might affect their willingness to accept the full-time integration of students with severe impairment. In their conclusion, they suggested that the rapid development of teacher education programmes and in-services training, in the spirit of inclusive education, was necessary. However, I will argue later that training programmes should give consideration to the context of the social model rather than focus on the individual or medical model. Professionals should be aware that their role extends beyond a concern with the impairments of service users; they should consider that it is the disabled child's right to be fully included in their own society. Professionals should be fully aware that the daily needs of disabled youngsters should be met; they also should have an awareness of those obstacles that confront the disabled young people in their social world. These barriers should be removed. Campbell (2002) reported that full inclusion for disabled people should be achieved through various means, including ensuring that professionals and experts who seek to help must be committed to promoting this objective.

The Omani professionals' definitions of disability were based on the medical or individual perspective. The vast majority of the respondents thought that impairment was the main factor in a disabled person's exclusion. Although the professionals talked about issues, like public attitudes and inadequate service provision, they gave no hint that they were aware that such issues might prevent disabled youngsters from being fully included in society. As we saw in chapter three, most studies that were conducted in the developing countries, including Oman (Al-Barawani and Al-Beely, 1994; Al-mawali, 1998, Majals Al-Shura, 1997; Akhdar, 1994), related the disabled child's exclusion to their impairment. These studies did not give a clear sign that the structure and characteristics of society could lead to more exclusion for disabled youngsters. For instance, a survey that was conducted by the College of Medicine (1994), Sultan Qaboos University, in Muscat, reported that the majority of disabled

people had trouble in their daily lives mainly because of their impairment. This survey did not identify social issues.

Although the professionals' understanding of disability was in the context of the medical model, they posed important questions that directly concerned the exclusion of disabled boys and girls. Some professionals gave an alarming signal about the deficiency of service provision for disabled young people. Krafting (1999), in her report, also mentioned unmet basic needs for disabled young people. She estimated that no more than 5% benefited from the existing services. Another problem, in this regard, was that most key services are located in Muscat; the availability of frontline services, especially in the interior and rural areas was poor or non-existent. Similarly, it was reported that in Saudi Arabia almost all the services and programmes were concentrated in the metropolitan areas (Japan International Cooperation Agency, 2002). This urban-rural distinction has even been reported in developed countries. For example, Kemp (2002) reported that for 39% of the disabled people in Australia their needs were unmet; one of the key factors of which was geographical inequity.

The professionals believed that disabled young people' needs should not be denied, otherwise they would experience multifaceted difficulties. A respondent suggested that they should be provided with services from their early childhood otherwise any delay would magnify their impairment, which, in turn, would increase their parents' responsibilities. Generally, most of the professionals acknowledged that service provision was unsatisfactory. This might also indicate the insufficiency of frontline services, especially those for the early detection of impairment and for pre-school services.

The professionals viewed the education services being as poorly provided, whether through ordinary or special schools. Like the mothers of disabled young people , the professionals talked about inaccessible ordinary schools and about a shortage of special schools. They also thought that there was a lack of specialist teachers and social workers in schools. This fact was supported by Al-Barwani and Al-Beely's (1994) study, which showed that the total number of Omani teachers, in the three special schools, was eight,

compared with fifty-eight non-Omanis, which represented less than 5%. Bamyah's (1996) report also suggested that teachers in the special schools needed training programmes that developed their abilities, to ensure more participation by disabled students in their classes.

The professionals attributed the difficulties that are faced by the disabled in schools to two factors. First, some of head teachers of ordinary schools had discriminatory attitudes towards their enrolment. It might be because the majority of the school staff had not undertaken any training related to disability problems; these staff possibly did not have any idea about the rights of the disabled youngsters to be included in the education system. They may have thought that ordinary schools were not the proper place for disabled young people. It could also be because of the absence of a clear policy that obliged staff in ordinary schools to facilitate their enrolment, as one of the respondents suggested. The professionals also posed questions about the inaccessibility of most school buildings and the unsuitability of school buses. Yet, they did not confirm that they, as professionals, were fully aware of the direct effect of the inaccessibility on the dependency and exclusion of the disabled. However, the disabled youngsters themselves and their mothers, (chapter eight and ten), were deeply concerned about these barriers that prevented them from having full inclusion in ordinary schools.

Although, Al-Barwani and Al-Beely's (1994) study was about the quality of education and care provision for disabled people; it did not identify the range of difficulties that were faced by the physically disabled and their families in ordinary or special schools. Their study, moreover, concluded that the education service for disabled young people was adequate. Probably, this was because the researchers did not ask the service users' about the services they received, including education. The major source of their data was the officers in different departments, who possibly wanted to improve the image of the service provision of their departments. It might also have been because their study's focus was on the capital, which was where most of the education services were located. However, as we saw in chapter eight, the young people

themselves described the education service as inadequate. They lacked opportunities in schools, especially in the interior areas.

The concern about the deficiencies in the quantity, quality and availability of educational provision, highlighted by the children, mothers and professionals earlier, led me to recommend in my conclusion, not only more accessible schools that would include all impaired young people, but also a reform of the existing special education service to make sure that impaired youngsters were fully included. The views of disabled young people, mothers and professionals should be taken into account. Middleton (1999, p.50) suggested that any attempt to reform any educational system should take the children's views into consideration, as well as the perceptions of parents and teachers.

The professionals talked about the importance of the social services. The issues they raised were similar to those put forward by the disabled young people (discussed in chapter seven), and their mothers, (discussed in chapter ten). They emphasised the need for an adequate social security system for people like themselves and their families. The professionals believed that the current social security system did not meet the daily needs of the disabled young people and their families. Even the respondents who worked in the social services admitted that the parents, who depend on social security benefits, struggled to provide for the most basic needs of their families, and they were probably not able to meet the daily needs of their disabled young people . Majlas Al-Shura's (1997) study found that the social security benefits were inadequate and recommended more consideration for daily living costs.

The professionals were also not happy with the adaptation service. They believed that the social services should allocate a budget for this service. Interestingly, they were aware that the accessibility of the home might enable wheelchair users to move around freely. However, a few of them believed that some families had started to adapt their houses for their disabled young people, which, to these professionals, was a sign of an improvement in awareness. Moreover, some of them thought that the modification work should be funded by the families, rather than the government. Unfortunately, this

belief was predominant among those participants who worked in social services. Regardless of the factors that shaped their thoughts in this matter, their expressed opinions raised significant points. These officers might have lacked knowledge about the fact that the majority of families of disabled young people in Oman were poor, as was reported by the disabled young people themselves and confirmed by their mothers in the earlier chapters. It is possible also that their understanding of the daily needs of disabled young people was incomplete. Adaptation is one of those important needs. Studies, in the UK, found that raising a disabled child costs three times more than a non-disabled child (Dobson and Middleton, 1998).

Moreover, the professionals might think that housing adaptation means "a ramp in the entrance of the house" and not that major internal alterations may be necessary, for the accommodation to be fully accessible, as I noticed when I visited the participants' homes. This problem was not only because of the poor design of the houses, which were not adaptable, but also because of the poverty of the families who could not afford the full adaptation of their homes, as the mothers reported in chapter ten. Society has to pay if it is to ensure a decent life for disabled citizens. Therefore, the adaptation service should be seen from the point of view of making the daily movement of disabled youngsters easier, to ensure they can take part in activities with their siblings and increase their independence. The National survey (2002), of housing problems among families of disabled young people, concluded that the adaptation services had a significant effect on disabled people's daily lives. It found that:

> *"Minor adaptations, such as grab rails and handrails, almost always produced lasting, positive results. Some 62 per cent of recipients said they felt safer from risk of accident and 77 per cent said their health had improved following the provision of the adaptations. Often, more than one person benefited, and there were no harmful side effects.*

> *Major adaptations, such as walk-in showers, building extensions and lifts, had literally transformed lives. Disabled people who described themselves as 'prisoners' 'degraded' and 'afraid' before the work was carried out, frequently used terms like 'independent' 'useful' and 'confident' afterwards".* (p.1)

The professionals saw the health services as a prime service. Interestingly, the participants who worked there expressed critical opinions in their accounts. They talked about the lack of physiotherapists and occupational therapists, especially in the interior regions. A physiotherapist was worried because his section could not provide an adequate service for his patients. This was because of a shortage of specialists and the large number of the service users. He also talked about a significant number of families, especially those who lived in rural areas, who could not bring their disabled young people to meet the physiotherapists regularly. This either might have been because of transport difficulties and living long distances from the facilities, because of low-income, because fathers might have been busy with work, or because the parents of disabled young people lacked information about the importance of physiotherapy. Similarly, Krafting (1999) reported that there was a dearth of health workers in the interior regions, including physiotherapists and occupational therapists. In Australia, disabled people experienced the same problem. Kemp (2002) reported that two thirds of all unmet needs were for physiotherapy services; because it was more likely to be offered to people who had greater functional abilities. However, none of the professionals, including the doctors, physiotherapists and nurses, talked about the rights of the disabled young to be listened to, or to be given a chance to take decisions about their own treatment plan. Moreover, three participants regarded disabled young people as patients, which meant that there was little consideration given to their social circumstances or their rights to be heard. The only focus of these professionals was on the impairment.

Four of the professionals thought that the health service played a vital role in decreasing the incidence of impairments, especially among children. They thought that the immunisation service covered all the new babies and believed that this had resulted in dramatic decreases in some kinds of childhood diseases, such as polio. However, Krafting (1999) suggested that the number of disabled young people had increased because of improved medical care and an increase in traffic accidents, associated with greater use of motor vehicles. Consequently, the government should expect a greater demand for services and an increased burden on parents, which in turn would increase the need for skilled professionals and for adequate support schemes, including income support.

Almost half of the professionals interviewed described the local communities as inaccessible. However, their views on accessibility were often superficial. They thought that services, like parking spaces and ramps in public buildings in some cities, were signs of great progress in the inclusion of disabled young people. Their vision of inclusion was quite narrow. Moreover, a few of the professionals interviewed even believed that adaptations of the local environment should be funded by public donations and the families of the disabled people, rather than by the government. Their justification was that society and the families of disabled people have to share the responsibility, and they also knew what adaptations should be made. This justification itself might increase the burden on families and it might exempt the government from taking responsibility for disabled children's inclusion. It also demonstrated that a government budget allocation for adaptations did not exist. In conclusion, most professionals did not talk about the range of difficulties that resulted from an inaccessible environment. They did not apparently appreciate the fact that disabled people were prevented from taking part in different activities, with their peers, because of the inaccessibility of society.

Half of the professionals interviewed talked about what should be done for the disabled young people and their families in the future. Their focus was on factors that would make service provision better. The main strategy they advocated in this included training programmes to meet the need for

national specialists to work with disabled youngsters and their families. They also strongly recommended more financial support, more accessible communities and adequate service provision for disabled young people and their families, Interestingly, these suggestions were similar to recommendations of the different studies and reports, which were presented in chapter three (Al-Barwani and Al-Beely, 1994; Majlas Al-Shura, 1997; Krafting, 1999). However, these arguments were mainly proposed by those who worked in the voluntary sector, rather than by the professionals from the statutory agencies. This might have been because those volunteers, who worked in the day-care centres, were closer to the reality of the daily lives of disabled children and their families than the second group. It might also have been because even the modest training programmes the volunteers attended, gave them a basic knowledge of the social world of disabled young people and their families.

One professional, from the statutory sector, even suggested that all disabled people should be placed in a big institution to be provided with all the services they needed. He believed it would be easier for the government to meet their different needs and it would be a good chance for the disabled people themselves to be together. This type of thought, although it was not commonly expressed, exemplified the discriminatory attitudes that disabled young people themselves experienced, as we saw in chapter seven. Al-Rwahi (2003), in his paper written for a conference about service provision for disabled people in Oman, suggested a need for a special centre providing a range of services for different needs, including care, rehabilitation, training, and education for all the disabled people in the country. These two proposals reminded me of a statement that was made in a meeting held in Qatar, in March 1994, about service provision for disabled people in the Gulf countries. One of the participants suggested, "We, as Gulf countries, have to develop a huge centre to accommodate all the disabled people in it; this will enable us to provide adequate services for them". However, the vast majority of the participants in that meeting strongly disagreed with his idea. Nevertheless, the drift of these ideas showed that there were people who still think negatively

about the inclusion of disabled people. They do not consider their right to be fully incorporated within their own society.

In the next chapter, I will highlight and discuss the most important findings of this study, relating them to the key conceptual themes of citizenship and the full inclusion of disabled youngsters.

Conclusion

Towards More Inclusion and Full Citizenship for Disabled Young People in Oman

12.1 Setting of the Issue

Is this study able to conclude that disabled young people are excluded from mainstream society? The answer could be both yes and no.

I have identified three reasons whereby the reliability and validity of my conclusions could be challenged, on the basis of my approach to the research and the methods used. In this chapter, I address each one in turn, before going on to detail and discuss the major issues highlighted by this study and my conclusions. Finally, I present a series of recommendations for disabled children and their families, for service providers and policy makers, for local communities and for Omani society as a whole.

The first reason my study could be challenged is because it did not follow the usual conventions of research into disability issues in developing countries. This study is the first and only one of its kind in Oman. It has attempted to examine the social world of disabled young people, and most importantly to listen to their voices. The dominant orientation in developing countries, in the field of disability and childhood, is that disabled children and children in general are not given a chance to express their understanding of issues in the world around them. I could not find even one study that was based on the children's views in either Oman or in the neighbouring countries. Moreover, I could find no study that was based on mothers' perceptions and professionals' experiences of the everyday lives of disabled youngsters. Even in the developed countries, including the UK, it has only been in the last ten years, or so, that disabled children have been given the opportunity to talk about their own everyday lives and to have their accounts used in the literature. In the developing countries, including Oman, most of the studies in the disability

field are concerned to enumerate classifications of different types and causes of disabilities.

It is worth remembering, as was discussed in chapter three, that the orientation of the studies in the developing countries, including Oman, has been based on the medical model of disability. The focus is on impairment and they begin with the premise that impairment is the factor responsible for all disablism.

The narrow focus of the literature from the developing countries, and the lack of attention to the accounts of disabled children and their families, made me unsure about the possibility of offering explanations of questions posed by the young people and their mothers, in my study, and drawing conclusions from them. Yet, studies, like Connors and Stalker (2003), Connors *et al.* (2004) and the Audit Commission (2003) in the UK, as well as Al-Barawani and Al-Beely (1994) and different reports in Oman, have all raised important points, that have supported my argument.

The second potential challenge, I wish to address, is that my sample was of particular physically disabled young people. They might have had dissimilar experiences to others who have different disabilities, such as cognitive and learning disabilities. This means that I cannot generalise all my findings to the wider group of 'disabled' children, especially those related to attitudes and access. For instance, children with learning disabilities in the developing countries are likely to be portrayed as "stupid" and "mad" (Al-Mawali 1998; Turmusani, 1999; Sally and Osman, 2003; Akhdar, 1994). My sample's experiences, in this regard, could be either similar or different.

Third, because of the geographical and social differences between people living in different areas of Oman (as described in the Introduction and chapter three), the sample might not be representative of all disabled young people in the country. There are some living in the desert and in mountainous areas who did not figure in my sample. Because of the great distances and time limitations, it was difficult for me to give them a chance to take part in this study. The disabled young people in those areas may have different experiences, especially experiences related to access to the environment, service provision

and social attitudes. Also, those who are from high-ranking, or privileged, families did not take part in this study. Although there are not likely to be many such children in that situation, they may have different experiences too and alternatives views to offer, especially in terms of service provision and the role of parents. The afflicted children of these parents are likely to be cared for by servants. All these considerations suggest areas requiring further research in the future.

On the other hand, the answer to the question I asked at the beginning of this chapter could be 'yes'. It is fair to draw the conclusion from this study that disabled youngsters experience barriers to their full inclusion in their own society. Their participation in this study gives it credibility. This research did not rely on data provided by the mothers, as primary carers, and the professionals only. However, the findings revealed that the three groups of participants had similar views, formulated from different standpoints, on the key issues in the lives of the disabled children, especially in terms of service provision and public attitudes. There was also a great degree of agreement with the findings of similar studies, although they were conducted in the UK (Connors and Stalker, 2003; Connors *et al.*, 2004; Audit Commission, 2003). Yet, there are considerable differences between the UK and Oman in terms of key issues such as policy and legislation and availability of basic services, which should be recognised.

The disabled children and their families in the developed countries experienced practical problems related to ineffective policy implementation, miscommunication, and lack of information (see chapter two). In contrast, most developing countries lack the requisite legislation which should guide and mandate service providers to ensure that these children and their families are adequately served. Moreover, the availability of frontline services is a controversial issue in developing countries. According to some reports, modest services are provided in metropolitan districts and poor ones in rural areas (Turmusani, 1999, Thomas, 2000, Akhdar, 1994) (see chapter three). This could be attributed to the fact that developing countries, due to their limited financial resources, give priority to capitals and the cities that are major centres

of population. Rural areas, where people are dispersed into smaller communities and locations, are likely to be low on the list of priorities for the allocation of limited resources. This must affect service provision for disabled young people (Akhdar, 1994).

12.2 An Overall Picture

The findings of this study highlighted three major problems. First, the disabled youngsters had valuable opinions to express on their social world, as their accounts in chapters six to nine demonstrated. These points will be discussed further later. Second, there was agreement among them, their mothers and professionals about the key matters that they raised. All of them reported that society failed to ensure full citizenship for them. Third, both services and research studies in the developing countries, including Oman, have been dominated by the medical approach. However, all the participants asserted that many of the effects of 'disability' can be better explained by its social model.

Impairment, undeniably, has medical implications, yet the social face of disability is the cornerstone of most recent studies. However, I found that, in addition to the implications of the medical and the social approach, environmental barriers had to be challenged by many of the participants. Stark (2001, p.37) suggested that the environment is a significant factor in the construction of disability; a better understanding of environmental barriers might greatly improve opportunities for improving the quality of life and performance of the disabled. For instance, paths, which are filled with stones, sand and holes in mountainous areas, are not only inadaptable for the use of wheelchairs, but also endanger the safety of young people with mobility problems and other impairments. In these environments, these people found themselves severely restricted. The issues which were highlighted in this study, supported, to a large extent, the new understanding of disability in the UK. The updated social model of disability, (Turmusani, 1999; Swain *et al.*, 2003, Lang, 2000, Oliver, 1996; Greater London Action on Disability (GLAD),

2000), includes a positive statement about disabled people; It recognises their diversity and difference; recognises institutionalised discrimination; talks about choice; acknowledges that all the things that exclude disabled people are barriers erected by society; and identifies the sources of these barriers including negative attitudes and inaccessible buildings and environments.

12.3 Disabled Young People in their Families

The disabled young people talked about their daily experiences with their families. They valued the role of their parents in caring for them and in seeking to provide for all their daily needs. They also reported a close relationship with their mothers. These findings concurred with Connors and Stalker's (2003) Scottish study. However, the vast majority of the young people, interviewed in Oman, did not indicate that their parents' attitudes prevented them from having friendships and from going outside the house. Studies in the UK (Connors and Stalker, 2003; Shakespeare and Watson, 1999; Bignal and Putt, 2000; Thomas 1998) have reported that parents might restrict the chances of their disabled children having friends. Yet, there were external factors too. While the distance from school and the attitudes of teachers restricted the opportunities for friendships for disabled children in the UK (Connors and Stalker, 2003), in Oman, their problems in this regard were attributed to factors like inaccessibility and negative attitudes towards them.

Generally, they expressed positive feelings about their siblings. There was little indication of resentment among the young siblings of the disabled children. However, where resentment was evident, its source was not in the disability of their brother or sister, but could be attributed to negative attitudes in their society, which stigmatise disability. The effects of stigma account for the negative reactions of some siblings. Fazil *et al.* (2002) and Ahmad (2000a) suggested that parents and siblings of disabled people are also subject to stigma. However, disabled youngsters were delighted with the physical and financial support older siblings, especially brothers, provided. The mothers (in

chapter ten) reported in the same way, the contribution of their older sons to meeting the needs of their disabled children.

The findings showed that the role and crucial contribution of parents was undermined, rather than supported, by factors such as income, a dearth of information, public attitudes and a lack of service provision. For example, disabled children were annoyed that their parents, especially those with low incomes, had to meet their various daily needs without receiving financial support from the government (see chapter seven). They also provided evidence that their parents lacked information about the possibility of their placement in ordinary schools. This led to the majority of them experiencing a delay in commencing their education.

The government did not offer adaptation services. The cost of adapting or extending the family home, to meet the needs of a disabled child, was an additional responsibility, which many parents could not afford to meet. Where the limitations on the ability of parents, to provide all their ailing child's needs, were allied with the unavailability of frontline services, the latter experienced difficulties in becoming full citizens in their own societies. The participants identified an association between the problems of access and funding adaptations to their homes and issues like independence and privacy. They thought that their needs could only be met in accessible housing (See Stark, 2001). The Omani Association of the Disabled reported that disabled children in Oman are profoundly excluded, as a result of the inability of parents to meet all their needs as well as lack of services (Challenge, 2003). Both the mothers and the professionals, in chapters ten and eleven, offered similar views.

Studies in the UK, reported that disabled children experienced similar day-to-day difficulties in their families. For example, Parker (2000) and Middleton (1999) noted the higher cost of raising a disabled child compared to a non-disabled one. Connors *et al.* (2004) found that lack of information might affect the ability of parents to obtain adequate services for their disabled children.

The disabled young people had both positive and negative experiences to share about their relationships and contact with their relatives (extended

families). They liked their cousins who, sometimes, played with them, and valued their uncles (brothers of mothers) who, sometimes, picked them up and took them to public places and bought some things they needed for school. However, they and their mothers claimed that extended families were not supportive in practical ways, especially in helping to care for the disabled children or giving mothers a break. In contrast, in the UK, South Asian families with disabled children valued the support that was offered by their extended families (Connors, *et al*. 2004, Ahmad, 2000a).

These key issues demonstrated that the disabled youngsters were able to identify and express their concerns about vital matters in their daily lives and those of their families.

These issues could be highlighted as follows:

1. Their parents are helpful and play a vital role in caring for them.
2. There are factors preventing their parents from fully meeting their daily needs, particularly low income, poor service provision, negative attitudes and the inaccessibility of the external environment.
3. In general, siblings were helpful and kind, especially older siblings.
4. Extended families were not as supportive as might have been expected.
5. Inaccessibility was the greatest difficulty they faced in their own homes.

Later in this chapter, I will link these important findings with their implications for theories of citizenship and the social model of disability.

12.4 Disabled Young People in their Wider Community

Disabled young people, as we saw in chapter seven, raised important questions about their lives within the wider community. They identified what they wanted for themselves; to be included and listened to, to be involved in activities and to have friends. They also talked about painful experiences in

their real, day-to-day lives, how they were disappointed by being excluded from different activities with their peers in the local community, with attitudes towards them and service provision (especially education) that they had to fight for, which others take for granted.

The main message from their words was that they received inadequate services and faced barriers to inclusion. Both the mothers and the professionals expressed the same opinions. Social and environmental barriers reinforced their exclusion from their own society. Inadequate services included education, health and social services. However, some of them and their parents did the best they could to use existing services, and their own accounts showed that they struggled to get some of their needs met.

Nevertheless, the study found that the existing services available to disabled youngsters in Oman were offered too little and too late. Surprisingly, in the UK, their needs for services are not fully met either (Audit Commission, 2003). In the rural areas and places away from metropolitan areas, the disabled children experienced greater difficulties, as a result of the inaccessibility and unavailability of the frontline services they needed. To some extent, Connors and Stalker's (2003) study found that some disabled children, who lived in the countryside, talked about the inaccessibility of services too. These problems had a detrimental effect on their daily lives and their personal feelings. The dominant feelings of the young people, explored in chapter nine, were relatively negative. All those interviewed, compared themselves to their non-disabled siblings and peers. The more they were deprived the services they needed and the opportunities they wanted, the more they felt frustrated and disappointed by the comparison.

Although, the accounts of disabled children in the UK, including the South Asian ones and their families, showed that they experienced, inadequate services and had unmet needs, it was not because of unavailability of services. Both Connors *et al.* (2004) and Fazil *et al.* (2002) found that it was because families lacked information and had poor communication with professionals, rather than because services were not available.

My study also found that the vast majority of respondents were negative about their experiences of key services, including health, social assistance and education. The provision in these settings was not satisfactory. For instance, all the special schools were located in the capital; ordinary schools were not fully accessible; teachers in both special schools and ordinary schools lacked training and they lacked knowledge of disability issues (see Krafting, 1999; Majlas Al-Shura, 1997; Bamyah, 1996).

Significantly, this study showed that daily support, for disabled children, was only provided by the day-care centres (Al-W\afa Centres), which were largely situated in the main cities. These centres were seen by the young people and their mothers as the ultimate their society could offer for disabled children and their families. The participants in this study, stated that these centres provided important services for disabled children, yet they depended heavily on charities, and the volunteers who work in these centres were not specially trained. This reliance on voluntary and charitable efforts demonstrated that disabled children and their families were poorly provided for by daily services, unlike their non-disabled peers who were entitled to public education.

It is worth noting that disabled people, in developing countries, were likely to be excluded from the priorities of the national development programmes or low down the list (Turmusani, 1999; Sally and Osman, 2003). For instance, daily-based services for these people, including children, rely on either international organisations' funds, such as ILO and UNICEF, or national non-government organisations and charities (Akhdar, 1994). This could indicate that governments in the developing countries consider disabled young people as second-class citizens. Why are they left to be served by non-government organisations, unlike their non-disabled siblings and peers?

However, the disabled youngsters and their mothers were delighted with the voluntary based services. Although, the volunteers themselves, as we saw in chapter eleven, admitted that they lacked knowledge and training, they did their best to make the disabled children, whom they dealt with, happy.

This was confirmed by the accounts of the young people themselves and their mothers.

Lack of qualified, skilled and experienced professionals was a significant complaint. This study showed that the professionals, who work in both the statutory and voluntary sections, were not able to provide adequate services. This was because of lack of knowledge, lack of training and the heavy burden of work they carried. Almost all the previous reports and studies identified the same problem (Krafting, 1999; Bamyah, 1996; Majlas-Al-Shura, 1997). Almost all the professionals interviewed demonstrated that their understanding of disability was based on the medical model.

Virtually all the participants talked about the inaccessibility of society. The disabled faced a number of barriers in their local community. Physical restrictions in the environment were the major factors disabling them. These were not only in the public domain, including a lack of accessible transport or places of leisure, but also within their own houses. They were restricted from taking part in different activities with their siblings outside of their homes. It is worth mentioning again, the accessibility was not only because of a lack of adaptable places and buildings, but rather because of the hostile terrain; hard, stony, hilly and sandy ground would require a lot of work and investment to be accessible and safe for wheelchair users. In Scotland too, disabled children experienced the difficulty of obstructed access, which limited their opportunities to use transport to events, leisure facilities and so on (Connors and Stalker, 2003, p.124). The effect of these barriers on the feelings of disabled youngsters was great. They expressed their hurt and disappointment that they were not able to participate in community based activities. They gave the impression that their exclusion affected their social well-being.

The findings of my study showed that negative attitudes had a direct effect on disabled young people's chances of inclusion in Omani society. Despite their complaints about the discriminatory language of young children, on certain occasions, the disabled youngsters were annoyed that they were generally regarded as objects of pity by their society. They did not like to be

portrayed with words like 'deprived' and 'not normal'. Unfortunately, their society did not realise that such terms harmed their feelings and stigmatised them. This language further set them apart in terms of the public consciousness as well as physically and defined them as different. Moreover, such portrayals led to their being seen as unequal to the rest of the people in their society. It meant that their absence from the places in which other young people were seen, like schools and community facilities, was generally not questioned. Moreover, their accounts suggested that the way that society viewed them had a damaging affect on their own self-image. The collective outcome of such negative influences and experiences was that they did not enjoy enough opportunities to join in activities with the non-disabled or to appear in public comfortably. Turmusani (1999), Akhdar (1994) and Thomas (2000) stated that discriminatory attitudes are barriers keeping disabled people on the margins of mainstream society.

The major conclusions that might be drawn from this are as follows:

1. The disabled youngsters were provided with inadequate, untimely and poor services. For those who lived in rural areas their situation was worse.
2. The families of disabled children were likely to be unable to meet their daily needs. This was because of low income, lack of information, lack of services and access issues.
3. The professionals lacked training, knowledge and qualifications in disability issues. There was also a shortage of them especially social workers, physiotherapists and occupational therapists. This meant that those there were faced overwhelming demand for their intervention and were unable to provide an adequate service for disabled children.
4. The inaccessible environment, both inside and outside houses, was a significant factor in the exclusion of the disabled. This was, in addition to the medical and social implications of their impairments, an undeniable aspect of the experience of the individuals affected, which

must be recognised in any attempt to reach an understanding of the meaning and reality of their lives.

5. Public attitudes, both disparaging and sympathetic, contributed to their feelings and experience of exclusion.

12.5 Participants' Understanding of Disability

Taken as a whole, the disabled boys and girls did not talk much about their impairments. They tended to talk about the social situation and circumstances that, they believed, resulted in their exclusion from their own mainstream society. They indicated that their pain was because of barriers they faced to taking part in activities with other people of their age, the inadequate provision of services, and public attitudes that defined them as unequal and different. They all compared themselves to non-disabled youth. Similarly, Connors and Stalker's (2003, p.120) study found that disabled children in the UK understood disability in the context of their being made to feel different through physical restrictions, institutional barriers and the reactions of others.

The disabled youngsters' accounts included the notions of both 'impairment and 'disability'. They frequently said *'I am disabled'*, yet, they regularly followed it by saying *'I can't walk'*, '*my wheelchair is stuck'*, and 'I *need help'*. This meant that they regarded their impairment as a limitation to their engaging in mainstream society. Turmusani (1999, p.239) found that disabled people in Jordan linked their impairment with being restricted from taking part in economic activity. However, disabled children in Scotland used the term 'impairment' or referred to 'disability' in terms of a functional limitation because of impairment: not being able to walk, not being able to see. It seemed they saw impairment from a medical perspective (Connors and Stalker, 2003, p. 121).

The most striking finding in this regard was that all the participants (the disabled young people, the mothers and the professionals) understood impairment as Allah's will. Such explanations and representations are quite

common in Omani society. This belief played a vital role in encouraging them to accept their condition with less resentment (.Al-Orami, 2001, p. 61). Connors and Stalker (2003, p.121) found that some parents of disabled children, in the UK, explained impairment from the religious angle to encourage their child to see it as part of God's plan.

The literature, discussed in chapter four, linked the medical model of disability and the notions of physical limitation and personal tragedy (Turmussani, 1999; Lang, 2000; Shakespeare and Watson, 1999). However, in this study the participants, although they talked about impairment, conveyed no sense of personal tragedy. They expressed great concern about being deprived of frontline services that were ensured for non-disabled people, about being restricted from moving freely in and outside their houses and being viewed differently by others in society. They were also greatly concerned because of an inaccessible and unsafe environment that they thought exacerbated their restriction, dependency and exclusion. Their accounts resonate with the notion that disability is an outcome of the failure of society to fully include disabled people in the mainstream (see Oliver, 1996).

However, the vast majority of the professionals identified the impairment itself as the key factor in the disabled youngsters' exclusion. They defined disability as the inability of the body to function fully. Moreover, they used negative expressions to describe disabled people, including 'they are *Masakeen'* 'deprived' and they are 'abnormal'. These expressions demonstrated that disability was seen as disease; and disabled people were seen as patients and a legitimate focus for charitable endeavours. Their accounts showed that professionals need to have their awareness raised about the disabling consequences of the way that society defines disabled people, and in so doing legitimises their exclusion. This study has shown that for young people in Oman disability is caused by social processes rather than from individual impairment alone.

12.6 The Future

The disabled young people looked towards their future with concern. They were worried that they would reach adulthood without any improvement in their circumstances. They expressed three key hopes for their future, namely employment, education and marriage. Such hopes were underpinned by both motivations and concerns. As we saw in chapter nine, these young people looked at these issues as relevant to their dignity, inclusion and independence. To ensure that they could gain employment, they were content to work for qualifications at school or on training programmes. Most of them attempted to overcome the barriers to their enrolment to schools. Similarly, disabled young people in Scotland believed that they would be employed and they worked in order to obtain qualifications at school to ensure this (Connors and Stalker, 2003, p.124).

Almost all the disabled youngsters looked at education as a target and as crucial for their welfare. They believed that it was an imperative and a right; and through it, their daily lives would improve. They did not hide their resentment that their peers and siblings were assured of such rights, while they had to struggle to acquire them. To some extent, they thought that poor education provision was indicative of their experience of inequality. Price (2003, p.4) suggested that the developing countries have to increase the enrolment of young disabled people in school, to close the gap between their current level of enrolment and the net enrolment rate of non-disabled people. He added that lack of access to education, remains the key risk factor for poverty and exclusion of all disabled children. In developing countries, there is evidence that deprivation of education leads to direct exclusion from opportunities for further personal development and social independence as well as exclusion from employment, income generation and business development (Price, 2003).

The disabled young people were worried about their social status in the future. As mentioned in chapter nine, the family provides social value and security for its members. Not being a member of a family implies a significant

loss in social terms (Al-koly, 2000). Disabled young people's concern came from a fact that their society assumed that disability meant they would not be entitled to social independence. They were portrayed as permanently 'needy'. Public attitudes that defined them as dependent made most of them believe they would not to be able get married in the future.

The disabled young women were more worried about remaining unmarried and the social implications of their single status for them after their parents' deaths. According to Kozue (2003), Arab disabled women are denied the most basic human rights, including the right to marriage. She added that the society in general fails to recognise the marriage of disabled women and discourages attempts to find spouses. This issue is a sign of the extent to which young people experience difficulties. It is not only during their childhood, but also in the future they would expect further obstacles to their full inclusion in their own society, unless public attitudes and service provision improve significantly. Recently, because of advances in medicine and health service improvements, people have started to think about disabled people's marriages in even more negative terms. There is uncertainty about the implications of 'genetics', which many people are coming to believe, cause diseases (Kozue, 2003). Rather than accepting impairment as the 'will of Allah', there is concern that disabled people will reproduce more children with physical defects. This may decrease the opportunities for disabled people, both male and female, to marry and have their own families, which in turn will increase their isolation and disappointment.

The mothers raised the same concern about their disabled daughters' future. They believed that these would encounter difficulties in living by themselves, if they did not have relatives to live with and if the current situation of negative public attitudes and poor service provision continued. They were profoundly uncertain about the possibility of their disabled daughters' marrying in the future. In contrast, for South Asian disabled young women who lived in the UK, an expectation of marriage was an essential part of their lives; yet, they linked their marriage prospects with the level of their impairment. Disabled young South Asian men were more optimistic about

their prospects for marriage in the future than were young women (Connors *et al*. 2004).

The professionals, as we saw in the last chapter, talked about the future of disabled young people. They paid great attention to the significance of the improvements required in service provision and to the need for training programmes for professionals who work with disabled people in both the statutory and voluntary sectors. This issue was also strongly underlined by studies and reports that were presented in chapter three (Majalas Al-Shura 1997; Bamyah, 1996; Al-Barwani and Al-Beely, 1994; Krafting, 1999). However, the professionals did not talk much about issues related to the employment, training and marriage of disabled young people - all these were matters of great concern to the young people themselves.

12.7 Key Issues

This study has identified significant problems. Too many disabled young people's daily lives were bounded with difficulties. They were provided with services that were too little and too late. These young people, despite being irritated about negative public attitudes, were more annoyed about the inappropriate sympathy or pity that was common among adults, including some professionals. Although, society believed that the disabled youngsters appreciated this, they themselves reported that it was contrary to their wishes. They even considered it as a source of harm. They felt that being perceived as objects of pity defined them as different. Sympathy was based on an acceptance of the individual nature of their disability; it reinforced expectations that they would be excluded from the mainstream lives of their communities and the opportunities enjoyed by others of their age.

The service providers need to clear the dust from their eyes to see how far disabled young people are deprived of frontline services. The findings of my study showed that lack of services leads to greater exclusion from mainstream society; less chance to take part in social activities, confinement

within the home, and to their being regarded as unequal citizens, essentially different to their siblings and peers. Yet, the key challenge is to gain recognition of the priority that should be given to their needs and to tackle these issues in practical and sustainable ways.

Despite the attempts of the various responsible departments, including health, education and social services, to meet these needs, this study revealed a gloomy picture. The disabled youngsters and their families were inadequately provided for and remained at risk of social exclusion. The two main challenges in this regard for policy makers and government departments now are; first, to develop rules that identify and organise the key rights of disabled youth to be fully included as citizens in their mainstream society; second, to reveal the reality of their services and make change happen. These changes should be addressed at the national level, as stated in the Basic Statue of the State (1996), which considers all Omanis are equal with no exception, in addition to the UN policies in this regard (UN,1986).

12.8 Disabled Young People and the Social Model of Disability

The disabled young people's voices lie at the heart of this study. The notion of disability, used here, was based on the social model rather than on the medical one. Recently, studies have tended to view disability on the basis of the social approach (Oliver, 1996; Robinson and Stalker, 1999; Swain *et al*, 2003; Middleton, 1999). The literature has interpreted the effects of disability in terms of society's failure to provide appropriate services, to meet the significant needs of disabled people and to including them in their own social organisations.

The disabled young people in this study showed that their parents have to struggle to meet their needs in the absence of key services. Their parents, moreover, lacked information about the existing services, which further increased their difficulties.

Being perceived by others as different and disadvantaged, made the participants view themselves as different too. With little exception, the dominant view towards disabled children was negative. This trend had widened the gap between disabled youngsters and the other people in their own social world. For example, their accounts revealed how some young people hesitated even to appear in public, as they did not like to be defined as different and discriminated against by others.

These issues, which were raised by the disabled young people, indicated the way that they viewed their social world and their understanding of their disability. It was clear that they believed that their "society" contributed to their disability, in restricting their daily lives. Although they usually painted a bright picture of their relationships inside their families, they experienced physical barriers that prevented their wheelchairs from moving about inside their homes. Such problems occurred under circumstances in which the state does not provide an adaptation service. This absence of help from the state led to other problems. Where families fund housing adaptations themselves, this causes financial hardship. However, if they cannot afford to pay for housing modifications, the, disabled youngsters are largely confined to their houses, without mobility within them.

These young people talked little about their impairment; however, they linked it with issues like inaccessibility, public attitudes and the inadequate provision of services. They were more frustrated by such problems than the impairment itself. They hoped to 'get rid of' their impairment mainly because they wished to survive in a society that failed to ensure their daily needs were met adequately and to avoid people regarding them negatively. This meant that the participants' complaints were less about the impairment, more about the structure and processes of society. They did not place much stress in their accounts on the medical implications of disability or give credence to the notion of personal tragedy (Shakespeare and Watson, 1999). The words of the disabled youth highlighted that the tragedy was the failure of the society to allow them to lead normal lives. Their mothers, as we saw in chapter ten, had the same experience and understanding.

The participants expressed feelings of sadness, anger and frustration. However, their accounts suggested that they did not let negative feelings dominate their daily lives, and they were not merely because of having impairment. They felt sad, angry or frustrated when either the people or facilities around them disappointed or failed them. For instance, they could not take part in many activities in the local community or in ordinary schools. This was because of the inaccessibility of the environment and the unsuitability of equipment or because the people around them were not interested in their participation. Accordingly, the reaction of these young people was negative. They thought obstacles to their participation and their physical exclusion from environments where other children interacted with each other, were the reasons they had problems in developing and sustaining friendships, which in turn reinforced their negative feelings about their lives. They did not regard their parents as preventing their friendships. This was in contrast to the, findings of research in the UK (Connors and Stalker, 2003; Thomas, 1999; Campbell and Oliver, 1996) that parents might prevent their disabled children from having friends, in their efforts to 'protect' them.

The disabled young people were not very interested in talking about their relationships with professionals. They mentioned teachers in ordinary schools, and doctors and nurses. However, they did not described close or significant relationships with them. Yet, they did not indicate that they valued the contribution of nurses and doctors particularly. The role of social workers seemed to be marginal to their lives. Only one disabled young man reported that he was helped by a social worker to enrol in an ordinary school. It seemed that social workers did not play a key role in helping disabled young people to achieve greater inclusion in their own society. However, the volunteers were important figures to disabled youngsters because they played a vital role in their lives and in supporting their struggle for inclusion in mainstream society.

12.9 Citizenship and Disabled Young People

It is worth to remembering that the state of Oman in its constitutional principles has assured the equality of all citizens without discrimination.

> *"Justice, equality and equality of opportunities for Omanis are the pillars of the society and are guaranteed by the state". (The Basic Statue of the State, 1996)*

I have witnessed a dramatic change in the development of Omani society since 1970. Before 1970, all aspects of deprivation, ignorance, poverty and diseases were widespread. This was the experience of the majority of my generation in Oman. However, currently the situation is improving dramatically. Thousands of schools, hospitals, and all kinds of public services and civil infrastructures, including transport systems, social services, electricity and water supplies have developed in the last thirty years. Yet, in the context of a society characterised by economic and social revolution, did disabled young people believe that their rights of citizenship were fulfilled?

The citizenship concept, as discussed in chapter four, has different implications, including civil, political, welfare and social citizenship. In this study, the focus is on the concept of social citizenship.

> *"'Social citizenship' refers to those rights and duties of citizenship encountered with the welfare of people citizens, taking 'welfare' is a broad sense to include such things as work, education, health and quality of life". (Roche, 1992, P.3)*

The main outcome of this study was to demonstrate how disabled youth faced barriers to their full inclusion in their own society. The participants frequently talked about the difference between them and other people of their age. They were highly frustrated when they found themselves confronting obstacles that prevented them from using facilities that were used by non-

disabled people, without any impediment. The best examples of this were the delays in them commencing their education and the inaccessibility of the local community, Both of these factors prevented them from being fully involved in ordinary activities with other children and by making this 'normal' seemed to legitimate their absence from society, and the denial of their place amongst other citizens .

The absence of support services in ordinary schools increased their dependence on their peers there, which made them feel inferior to non-disabled students. They also maintained that ordinary schools were designed for those who represent the majority in society, thus excluding disabled young people. Disabled youngsters were not taken into account when most of these schools were built. They had to face the inaccessibility of toilets and activity areas, and the impossibility of moving with their wheelchairs to lessons on the first floor. They also encountered a big problem when transported in inaccessible, unsafe and overcrowded school buses. The result was that most of them had to avoid this form of transport, which in turn gave their families (parents) an additional responsibility to get them to school.

Social security benefits have a potential role in meeting disabled young people's daily needs. The literature showed how finance is important for them and for their families, and how much more such children cost their families to provide for than non-disabled children. The interviewees reported that social security benefits were poorly provided. This problem made the majority of the disabled angry. As most of their families were on low incomes, they wanted to have financial assistance from the state rather than to be a burden their families. One of the participants explained it clearly: "*If the government claims that we* 'disabled young people' *are citizens and deserve support, why do they* (the government) not *give us monthly help, namely* 'social security benefit'".

Of course, this is just one example of the poor service provision that disabled young people experienced. Although, the trend in Oman is not to develop segregated institutions, it is not clear whether the policymakers took into account the full range and additional daily needs of disabled youngsters

living in the community with their families. It is moreover not clear whether the government is aware of the rights and needs of such people to be provided with the range of services they need. The existing data showed that only a few disabled young people in Oman, benefit from the provision of a variety of services, including ordinary and segregated schools, health services and social services (Krafting, 1999). However, additional factors to poor service provision were reported, including a lack of information and the negative attitudes of society. The question must be repeated here, what about those disabled young people who were unable to use the existing services, or who were poorly served, especially those who lived away from the centres of population where services are concentrated, or live in rural areas where the situation of the disabled is even worse.

The accounts of the young people in this study reflect the experiences of most disabled people around the world, not just in Oman. The literature showed the extent of deprivation and exclusion of disabled children in the wider world. Even in the developed world, there is evidence of the failure of governments to ensure decent standards of living for these people (Oliver, 1996). Different studies showed the extent of unemployment amongst them (Martin and Meltzer, 1989). Researchers also suggested that they are 'last on the list' of the policymakers (Beardshow, 1988). It was also suggested that services to enable disabled people to live in the community are poor (Blaxter 1980; Borsay, 1986). The disabled in developed countries criticised health and social services because they failed to provide them with a satisfactory quality of life (Oliver *et al.* 1988; Morris, 1989).

12.10 Developing Policy for Disabled Young People in Oman

It is worth noting that the accounts of the young people in this study reflect the experiences of most disabled people around the world, not just in Oman. The literature showed the extent of deprivation and exclusion of disabled children in the wider world. Even in the developed world, there is evidence of the failure of governments to ensure decent standards of living for these people

(Oliver, 1996). Different studies showed the extent of unemployment amongst disabled people (Martin *et al.*, 1989). Researchers also suggested that they are 'last on the list' of the policymakers (Beardshaw, 1988). It was also suggested that the services needed to enable disabled people to live in the community are poor (Blaxter, 1980; Borsay 1986). Disabled people in developed countries criticised health and social services, because they failed to provide them with a satisfactory quality of life (Oliver *et al.* 1988; Morris, 1989).

This study identified significant aspects of disabled young people's everyday lives. Their own accounts raised substantial issues and provided evidence that their society had failed to ensure their full inclusion, as a result of lack service provision, discriminatory attitudes, inaccessibility, a lack of information and a dearth of qualified professionals, including social workers. In other words, the disabled young people suggested that they were regarded as different from and not equal in importance to non-disabled children: they were provided with minimal opportunities, including those of education and participation in daily activities. All these issues were fully detailed in the last five chapters. The key contribution of this study is to provide a clear and comprehensive picture of the current situation of disabled young people and their families. Its principal aim is to influence and stimulate national policymakers to strive for equal opportunities and adequate service provision for disabled young people. The starting point should be with the frontline strategic planners and decision-makers, including Ministers and Under-Secretaries of Health as well as Social Development and Education Departments. The possible contribution of other members of society, including professionals, parents, voluntary agencies and public people, should be also considered.

According to Clarke (2001, p.35), research can offer an alternative way of viewing a problem and stimulate thinking about possible policy solutions. Thus, research findings can help shape policy debates, if not directly determine the actual policy choices that are made. Clarke (2001, p.34) asserts that social research can influence decision-making. He adds that

there are four main models of social research operation, namely, *'the knowledge-driven model, the decision-driven model or problem-solving model, the political model and the enlightenment model'* (see Gilbert, 2001, chapter three). Although, it may be the case that no single model of research utilisation is adequate, the enlightenment model can introduce policy-makers to alternative possibilities and influence how they conceptualise policy problem. This can be through social research, which helps to set the agenda in policy debate by raising the awareness and concern of key policy actors.

It is worth mentioning that, in recent years in Oman, there has been an expansion of service provision for disabled people, including children; various concerned departments, (including social, education and health) have emerged to include the needs of disabled people within their remit of responsibility and attention. The slogan has been 'to make society accessible to this category of people'. This trend appeared in parallel with, possibly as a result of, the influence of the international movement on disability issues. The pressure of UN agencies, including UNICEF, WHO, UNESCO and ILO, can no longer be ignored, especially when the debate on disability issues is moving in the direction of political positions (UNESCO, 1991). However, in principle, the aim should be not just to draw the attention and support of politicians. It is essential that a recognition of the basic rights of the disabled young is followed by action and the implementation of policies that ensure their full inclusion. Therefore, it is also crucial that the gap between the strategic level and the operational level is bridged by the realisation of strategies for inclusion and the fulfilment of the rights of citizenship.

According to the Basic Statue of the State, elements such as justice, equality and equality of opportunities for Omanis, are 'the pillars of the society and are guaranteed by the state" (The Basic Statue of the State, 1996). The Basic Statue does not exclude disabled people, yet it asserts that all citizens should be treated equally and provided with equal opportunities by the state. According to the main implications of the UN Convention of the Rights of the Child (UNCRC) and the Human Rights Act, disabled children and their families need clear information on the full range of services provided, in a way

that is easy to understand. However, in my study, the majority of the participating disabled young gave evidence that they lacked information about their rights to education, and this delayed the commencement of their studies. Campbell (2002, p.202) suggests that all children lack information about education, and disabled children are especially disadvantaged in this respect. This example shows that society, especially people at the decision-making level, must take decisive steps to ensure adequate service provision and equal opportunities for young disabled people. This study, as we have seen in the last five chapters, has highlighted important issues and given voice to the appeals of disabled children and their families for better service provision, greater accessibility and positive public attitudes.

All the issues pointed up by my study should be taken into account by policy-makers if their expressed values and goals for a just and equal society are to be realised and all citizens to be included. Therefore, the findings of this research are useful in identifying these issues and formulating a policy agenda for future planning, and for targeting the full inclusion of the disabled young. The discussion throughout previous chapters was based on two main approaches, namely, the social model of disability and citizenship (see chapter four). This model puts responsibility on the society that disadvantages disabled youth and denies them full inclusion. The concept of citizenship regards all members of society as equal and requires that they be ensured equal rights and opportunities. Therefore, the policy agenda suggested in this context is one that is based on the principle that disabled children have the same rights as other members of society and should not be discriminated against because of their impairment. This approach, based on rights, affirms the fact that the disabled young are equal citizens and should be regarded and respected in the same way as their siblings and peers. It also rejects the common view that disabled people should, in any way, be the object of charity. The proposed agenda and its implementation should be incorporated into macro-socio-economic planning processes, with more consideration being given to the notion that all people should have the opportunity to benefit equally from the fruits of national development, regardless of their disability.

The key findings of the study, which represent the voices and demands of the disabled and their families, should be clearly presented to all parties in society, especially the policy-makers. Fortunately, in Oman it is not that difficult to meet even the decision-makers, such as Ministers and Undersecretaries. I am able to arrange individual interviews with any of them, especially those who are responsible for frontline services. I may also send messages, through the media, that emphasise the role of society in securing the inclusion of disabled young people. Providentially, the vital contribution of the Sultan Qaboos University towards the development and advancement of Omani society, is highly appreciated, especially by the Government. This is where I currently work. My employment in this university will enable me to disseminate the findings and recommendations of my research and may help me to enlighten and raise the awareness of key decision-makers of social policies, and secure their commitment to what should be achieved through both long- and short-term planning. However, it should be borne in mind that policy developments and legislation cannot achieve their goals unless the wider society becomes aware of the rights of disabled young people to inclusion and its own role in ensuring that such right are realised.

As a starting point, I would suggest some practical recommendations that might bridge the current gap between the ideal and the real situation. The significance of the recommendations, which will be spelled out below, is that, as mentioned earlier, they are based on the views of disabled youngsters themselves. This study gave them a chance to put forward their points of view about their daily lives. They proved that they were able to express their ideas, as well as indicate that they were aware of the obstacles preventing their full inclusion in their own society. The mothers of the disabled youngsters and the professionals, in both the voluntary and statutory sectors, raised important questions in this regard too, and reinforced the validity of the analysis provided by the disabled children.

12.10.1 Recommendations for Social Policy Makers

1- Government departments, especially of health, education and social development, should assess the services they provide for disabled youngsters and their families. The aim is to improve these services which were seen, with few exceptions, as poor, inaccessible, limited and inadequate.
2- Standards should be set for appropriate schemes and programmes for the improvement of existing services.
3- In planning services, policy-makers could learn from the experience of the developed world. Research in the UK has shown that high investment in provision over many years, has not ensured that the needs of disabled children and their families are met, because service design has not always been based on the principles of inclusion and rights, and has sometimes reinforced social barriers.
4- Rules of eligibility for the social security system should be extended to take into account the extra costs of meeting the daily needs of disabled youngsters within their families.
5- Funding and standards should be developed for housing and adaptations for disabled people, and should identify unmet needs.
6- Resources should also be allocated to the development of equipment services that suit local environments and terrain, including the mountainous and desert areas where significant numbers of disabled people live in Oman.
7- The needs of rural areas should be taken into account in any strategy for the development of services.

12.10.2 Recommendations for Service Providers

1- Professionals in both the statutory and voluntary sectors should recognise the right of the disabled young to be included. Services should recognise the damaging effects of physical and social

exclusion. They should play a significant role in enabling disabled youngsters to use the existing services and in removing obstacles that stand in the way of their full inclusion. This includes supporting young people in identifying and challenging disabling attitudes, policies and environmental barriers and raising the aspirations of society, as well as young people and their families, to expect and demand the full inclusion of all citizens.

2- Professionals should be highly-trained and skilled, so as to be able to provide adequate services for disabled children and their families, to enable them to address the restricting aspects of their individual impairments and be as independent as possible. This means ensuring that specialist therapies are available, to promote physical functioning, and suitable equipment provided to support independence, particularly in personal care and mobility.

3- Professional training should include education about the social model of disability, to change their understanding of it from a narrow focus on the individual aspects of impairment to a wider focus on the disabling features of both the environment and society. They should be taught that disability lies in the heart of society rather than in impairment.

4- Providers should ensure that the people who need their services are well informed about what is available (eligibility criteria et cetera) and that service users (including disabled children) have a say in future service developments.

12.10.3 Recommendations for Parents:

1. Parent/s should be aware that having disabled daughter/s or son/s may mean that they carry the responsibility for ensuring that their needs are met, and that they have a central role to play in promoting their health and wellbeing. However, parents must also be aware that they must balance the attention they devote to the disabled youngster with the needs of the rest of the family. The disabled person may need

more care but does not benefit from being treated in an essentially different way to the non-disabled siblings. Parents should know that any imbalance in this regard might lead to resentment among their children. This would be detrimental to the disabled child, as most of those in this study benefited from the attention and support of their siblings.

2. Parents who neglect their disabled children should be educated and helped to understand that their role is not to oppress them but to ensure them a decent life.
3. Parent/s should be provided with information about the existing services that might be important for their disabled daughter/s and son/s to use.
4. Parents should resist those discriminatory attitudes that stigmatise them for having a disabled child. Moreover, they should play a crucial role in helping their children to challenge discrimination and to achieve more inclusion.
5. Parents, especially those with low incomes, should seek support from the state, in order to meet their disabled daughter/s and son/s requirements.

12.10.4 Recommendations for Disabled Young People

5- Disabled people, including disabled youth, should play a vital role in leading a national education movement in order to ensure that essential changes in society happen. Through such a movement, they could express their rights; raise awareness of their experiences of service provision and public attitudes towards them; they could also state what should be provided for them and their families. The significance of social citizenship and the social model of disability should be taken into account in any action recommended by the disability movement in Oman.

12.10.5 Recommendations for Local Communities

1- The local community should be free of physical obstacles and should be adapted to help wheelchair users' mobility.
2- Public attitudes should be improved by developing a national education programme. People should realise that they, by their discriminatory attitudes, might prevent disabled young people from enjoying full inclusion in their own society and achieving their full potential for independence.

Finally, I would like to conclude this thesis with the following words of a participant in this study. They embody his own impressions and those of most other disabled youngsters (cited in chapter seven):

> *"I am sure, in the future, it will not be easy for disabled people like me to have a job, or to get married, or even to attend school. People, in general, still believe that we are different and so we don't need such things. I just ask those people, whether or not they think we all have the same rights*?". (R1-male-18 years old)

It is society that must, in a practical way, aspire to the full inclusion of disabled youth and to recognise their rights as equal citizens.

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Appendices

Appendix (1)

Areas Codes

CA: The Capital (Muscat)

C1: Al-Sharqiah region

C2: Al-Dakhliah region

C3: Al-Batnah region (South)

C4: Al-Batnah region (North)

R3: Rural areas

Appendix (2)

Disabled Young People Talking About

1. Disabled young people in the family
    - 1.1. Relationship with siblings
        - 1.1.1. Helpful siblings (especially older brothers)
        - 1.1.2. Unhelpful younger brothers
        - 1.1.3. Few siblings feel ashamed for having a disabled brother or sister (mainly because of discriminatory public attitudes)
    - 1.2. Relationship with parents
        - 1.2.1. Positive
            - 1.2.1.1. Mother
                - 1.2.1.1.1. Close, nice, caring, helpful and loving
                - 1.2.1.1.2. A confidant and approachable (especially disabled young women)
            - 1.2.1.2. Father
                - 1.2.1.2.1. Offers all things
                    - 1.2.1.2.1.1. Adaptation

1.2.1.2.1.2. Equipment

1.2.1.2.1.3. Personal daily needs

1.2.1.2.1.4. Helpful (helps in finding services)

1.2.1.3. Parents viewing all their children as being equal

1.2.2. Negative

1.2.2.1. Some disabled young people are imprisoned at home

1.2.2.1.1. Mainly because of parents' ignorance

1.2.2.1.2. Public attitudes

1.2.2.1.3. Inaccessibility to facilities

1.2.2.2. Busy fathers

1.3. Extended family

1.3.1. Positive

1.3.1.1. Exchanged visits

1.3.1.1.1. Uncles, aunts, cousins,

1.3.1.2. Playing together with aunt's children

1.3.1.3. Kind grandparents

1.3.2. Negative

1.3.2.1. Dislike for relatives' sympathy

1.4. Accessibility of house

1.4.1. Accessible house (adaptation)

1.4.1.1. Fathers' responsibility

1.4.1.2. Older brothers' help

1.4.2. More participation

1.4.3. Less dependency

1.4.4. Happiness

1.5. Inaccessible house

1.5.1. Inadaptable house (especially in rural areas)

1.5.2. Unaffordable by parent/s

1.5.3. Dependency

1.5.4. Exclusion

1.5.5. Restriction

1.5.6. Disappointment

1.5.7. Lack of privacy

2. Disabled young people in the community

2.1. Public attitudes

2.1.1. Negative attitudes

2.1.1.1. Of young people (bad language)

2.1.1.2. Of the public (staring- sympathy)

2.1.2. Positive attitudes of older people

2.1.2.1. Neighbours

2.1.2.2. Relatives

2.1.3. Negative attitudes of neighbours and relatives

2.1.3.1. Sympathy

2.2. Service provision

2.2.1. Health service

2.2.1.1. Diagnosis

2.2.1.1.1. Inaccurate

2.2.1.1.2. Lack of information

2.2.1.2. Regular appointment

2.2.1.2.1. Tiring journey to hospital

2.2.1.2.2. Costs money for taxis and food

2.2.1.2.3. Unhelpful medication

2.2.1.2.4. Classes missing

2.2.1.3. Health staff attitudes

2.2.1.3.1. Positive

2.2.1.3.1.1. Nice and helpful doctors

2.2.1.3.2. Negative

2.2.1.3.2.1. Unhelpful nurses in the wards

2.2.2. Social service

2.2.2.1. Social security

2.2.2.1.1. Significant

2.2.2.1.2. Poorly provided

2.2.2.2. Day Care Centres (Al-Wafa)

2.2.2.2.1. Helpful

2.2.2.2.1.1. Different skills and activities

2.2.2.2.1.2. Leisure time

2.2.2.2.1.3. Medication

2.2.2.2.1.4. Participation

2.2.2.2.1.5. Better than staying at home

2.2.2.2.1.6. Friends

2.2.2.2.2. Volunteers

2.2.2.2.2.1. Nice and helpful

2.2.2.3. Centre of Care and Rehabilitation for Disabled People in Muscat (according to few participants)

2.2.2.3.1. Better than ordinary schools

2.2.2.3.1.1. Helpful staff

2.2.2.3.1.2. Friendly peers

2.2.2.3.1.3. More facilities

2.2.2.3.1.4. More activities

2.2.2.3.2. Negative

2.2.2.3.2.1. Away from families

2.2.2.4. Equipment (especially wheelchair)

2.2.2.4.1. Positive

2.2.2.4.1.1. Easy to get

2.2.2.4.1.2. Helpful

2.2.2.4.2. Negative

2.2.2.4.2.1. Insufficient and unsuitable wheelchair

2.2.2.4.2.2. Long waiting

2.2.2.4.2.3. Procedures

2.3. Accessibility

2.3.1. Inaccessible local environment

2.3.1.1. Restriction

2.3.1.2. Exclusion

2.3.1.3. Less participation

2.3.1.4. Dependency

2.3.1.5. Disappointment

2.3.2. Rural community more inaccessible

2.3.2.1. Hills

2.3.2.2. Stones

2.3.2.3. Holes

2.3.2.4. difficult for wheelchair movement

3 Disabled young people in school

3.1 School enrolment

3.1.1 Staff attitudes

3.1.1.1 Kind teachers

3.1.1.2 Unhelpful headmasters

3.1.1.3 Busy social workers

3.1.1.3.1 Almost absent in participants' mind

3.1.2 Enrolment

3.1.2.1 Lack of information

3.1.2.2 Almost all delayed in commencing their school

3.1.2.3 Unhelpful headmasters

3.1.2.4 Most of them enrolled by joined help of

3.1.2.4.1 The Day Care Centres (Al-Wafa Centres)

3.1.2.4.2 parents

3.1.2. Less educational opportunities in rural areas.

3.2. Accessibility

3.2.2. Transportation

3.2.2.1. Overcrowded busses

3.2.2.2. Unsafe

3.2.2.3. Inaccessible

3.2.2.4. Not comfortable

3.2.2.5. No bus available (just two participant)

3.2.3. Buildings

3.2.3.1. Accessible

3.2.3.1.1. Ramps

3.2.3.1.2. Wide doors

3.2.3.2. Inaccessible

3.2.3.2.1. Toilets

3.2.3.2.2. First floor

3.2.3.2.3. Sports area

3.2.3.3. No ramp in entrances

3.3. Peers attitudes

3.3.2. Primary school

3.3.2.1. Negative attitudes

3.3.2.1.1. Unfriendly

3.3.2.1.2. Bad language

3.3.2.1.3. Incidences of aggression (bullying)

3.3.2.1.4. View as strange and different

3.3.3. Secondary school

3.3.3.1. Positive attitudes of peers

3.3.3.1.1. More friendly

3.3.3.1.2. Mature

3.3.3.1.3. Helpful

3.4. Support service

3.4.2. No support service system in ordinary schools

3.4.3. Voluntary

3.4.3.1. Peers

3.4.3.2. Siblings

3.5. Friendship

3.5.2. Less likely to have friends in school

3.5.3. Most friends are relatives and neighbours

4. Disabled young people view of self

4.1. Feelings (in school, house and community)

4.1.2. Negative

4.1.2.1. Anger

4.1.2.2. Sadness

4.1.2.3. Shame

4.1.2.4. Embarrassment

4.1.2.5. Disappointment

4.1.2.6. Pain

4.1.3. Positive

4.1.3.1. Happiness

4.2. Self perception

4.2.2. because of factors like public attitudes, inaccessibility and lack of service provision they perceive themselves as:

4.2.2.1. Being different

4.2.2.2. Lacking abilities

4.2.2.3. Being isolated (activities taking part)

4.2.2.4. Being seen as disadvantaged

4.2.2.5. Being restricted

4.2.2.6. Being valueless

4.2.2.7. Being dependent

4.2.3. Being independent (sometimes)

4.2.3.1. No need for special support

4.3. Interests

4.3.2. TV watching

4.3.3. Biking

4.4. Friendship

4.4.2. Few friends

4.4.2.1. neighbours

4.4.2.2. relatives

4.4.3. No friends

4.4.4. More friends in day care centres than in school

4.5. Future

4.5.2. Education means

4.5.2.1. A better future

4.5.2.2. Everything in life

4.5.2.3. Being successful

4.5.2.4. A way to university level

4.5.3. Marriage

4.5.3.1. Negative expectation

4.5.3.2. Worried about it

4.5.3.3. Never thought about

4.5.4. Employment means

4.5.4.1. Independency

4.5.4.2. Earning own income

4.5.4.3. Helping family

4.5.4.4. Dignity

4.5.5. Get rid of disability

4.5.6. Better services

4.5.7. Better public attitudes

4.5.8. Fear of

4.5.8.1. Failure in studies

4.5.8.2. Being alone after their parents pass away

4.5.8.3. Being always dependent

Appendix (3)

Mothers Talking About

1. Disabled children
    1.1. Relation with siblings
        1.1.1. Positive
            1.1.1.1. Play together
            1.1.1.2. Like each other
    1.2. Relation with parents
        1.2.1. Equal treatment
        1.2.2. Offer all everyday needs
        1.2.3. Responsibility for care
        1.2.4. Special attention
        1.2.5. Mothers are closer
2. Siblings
    2.1. Feelings
        2.1.1. Positive
            2.1.1.1. Siblings feel angry because of public attitudes

2.1.2. Negative

2.1.2.1. Some siblings feel ashamed

2.1.2.2. Visually impaired child needs to be close to TV which makes siblings angry

2.2. Responsibility of siblings

2.2.1. Older siblings provide financial help

2.2.2. Share in parents responsibility

3. Mothers' feelings

3.1. The impact of having disabled child

3.1.1. First reaction of knowing about disability

3.1.1.1. Shock

3.1.1.2. Frustration

3.1.1.3. Worry

3.1.1.4. Anger

3.1.2. Regular feelings

3.1.2.1. Negative

3.1.2.1.1. Worry

3.1.2.2. Positive

3.1.2.2.1. Determination

3.1.2.2.2. Patience

3.1.2.2.3. Courage

3.1.2.2.4. Everything is referred to Allah

3.1.2.3. Number of disabled children (if more than one):

3.1.2.3.1. Increases negative feelings

3.1.2.3.2. Enlarges responsibility

3.1.2.3.3. Affects the way parents raise their children up.

3.2. Mothers' perception of disability

3.2.1. Disability affects disabled young people's:

3.2.1.1. Independency

3.2.1.2. Communication

3.2.1.2.1. Friendship

3.2.1.3. Mobility

3.2.2. Sensitivity of mothers towards disabled children

3.2.2.1. They give disabled children more attention than other siblings (a few of them)

3.2.3. All mothers attributed their having disabled children to Allah (it is a test of Allah)

3.3. Mothers' view

3.3.1.1. Girls

3.3.1.1.1. Socially more sensitive

3.3.1.1.2. Need more attention

3.3.1.1.3. Closer to their mothers

3.3.1.2. Boys easier to be independent in adulthood

4. The family's responsibility
    4.1. More financial needs for:
        4.1.1. Adaptation
        4.1.2. Equipments
        4.1.3. Transportation
        4.1.4. Clothes and food
    4.2. Mothers are less likely to have a job
    4.3. Social relationship
        4.3.1. Less outing (in case of severe disability or unavailability of wheelchair)
        4.3.2. Few visitors (especially in case of hyperactive disabled child)
        4.3.3. Avoid getting out because of public attitudes
        4.3.4. Good interaction with neighbours
        4.3.5. Extended family
            4.3.5.1. Negative
                4.3.5.1.1. No support provided
            4.3.5.2. Positive
                4.3.5.2.1. exchange visits with aunts and uncles
                4.3.5.2.2. Play with cousins
5. Wider community

5.1. Public attitudes

5.1.1. Negative

5.1.1.1. Discriminatory language

5.1.1.2. Perceptions

5.1.1.3. Attitudes

5.1.1.3.1. Some people prevent their children from playing with disabled children

5.1.2. Consequences of public attitudes

5.1.2.1. Families hide their disabled children

5.1.2.2. Few visitors

5.1.2.3. Few outings

5.1.3. Accessibility

5.1.3.1. Inaccessible environment

6. Services

6.1. Poor service provision

6.1.1.1. Makes disabled children confined to the home

6.1.1.2. Increases feelings of sadness and anger

6.1.1.3. Makes disabled children feel unequal to siblings

6.1.2. Health service

6.1.2.1. Attitudes of staff

6.1.2.1.1. Positive

6.1.2.1.1.1. Welcoming

6.1.2.1.1.2. Helpful

6.1.2.1.2. Negative

6.1.2.1.2.1. Not welcoming

6.1.2.1.2.2. Unhelpful

6.1.2.1.2.3. Inaccurate information

6.1.2.2. Absence of early detection

6.1.2.3. Admission at hospitals

6.1.2.3.1.1. Long time

6.1.2.3.1.2. Frequent

6.1.2.3.2. Long journey

6.1.2.3.2.1. Difficult

6.1.2.3.2.2. Costs money

6.1.3. Social service

6.1.3.1. Equipment

6.1.3.1.1. Takes long to receive

6.1.3.1.2. Unsuitable

6.1.3.2. Social security

6.1.3.2.1. Poor

6.1.3.3. Al-Wafa Centres (day care centres)

6.1.3.3.1. Staff

6.1.3.3.1.1. Helpful

6.1.3.3.2. Service

6.1.3.3.2.1. Positive

6.1.3.3.2.1.1. Important

6.1.3.3.2.1.2. Gives break

6.1.3.3.2.1.3. Improves children's skills

6.1.3.3.2.2. Negative

6.1.3.3.2.2.1. Those over 14 years are excluded from these centres

6.1.3.3.3. Respite care centre

6.1.3.3.3.1. negative

6.1.3.3.3.1.1. Unhelpful and careless staff

6.1.3.3.3.1.2. Negligence and unsatisfactory service

6.1.4. Education service

6.1.4.1. Mild physically disabled children are able to go to ordinary schools

6.1.4.2. Severely disabled children are not provided education

6.1.4.3. For deaf and mentally retarded children only two schools are located in Muscat (the capital)

6.1.4.4. Staff attitudes in ordinary schools

6.1.4.4.1. Some are not welcoming

6.1.4.4.2. Reluctant to accept wheelchair users

6.1.4.4.3. Do not offer transportation

6.1.4.5. Unsuitability of transportation

6.1.4.5.1. Unsafe

6.1.4.5.2. Overcrowded

6.1.4.6. Peers attitudes

6.1.4.6.1. Negative attitudes especially in primary schools

7. Rural areas

7.1. Lack of basic services

7.1.1. Day care centres

7.1.2. Schools

7.1.3. Health service

7.2. Push some families to move to urban areas

7.3. Lack of awareness

7.3.1. Hiding disabled children

7.3.2. More negligence

8. Future

8.1. Worries about the event of parents' death

8.1.1. Especially of those severely impaired children

8.1.2. More worries about girls

8.1.2.1. Social life in adulthood

8.2. More accessible service

8.3. Better public attitudes

8.4. More independence

8.5. Ask for more financial support instead.

Appendix (4)

Professionals Talking About

1. Background and motivations of professionals
    - 1.1 Voluntary sector workers
        - 1.1.1 Tendency to help others
        - 1.1.2 Belief in helping the disabled children and their families
        - 1.1.3 Encouraging work
        - 1.1.4 Best way for the use of leisure time
        - 1.1.5 Allah's reward
    - 1.2 Government workers
        - 1.2.1 No original intention to work with disabled children
        - 1.2.2 Part of entire work
        - 1.2.3 Find work interesting
2 Training
    - 2.1 Voluntary workers
        - 2.1.1 Low qualifications
        - 2.1.2 Lack of special training
        - 2.1.3 A few workshops

- 2.2 Government workers
  - 2.2.1 Higher qualification
  - 2.2.2 Lack of relevant training
  - 2.2.3 Lack of specialists
- 3 Definition of disability
  - 3.1 Lack or loss of body part(s) or sense(s)
  - 3.2 Restriction due to impairment
  - 3.3 The disabled person is (abnormal)!
  - 3.4 Persons with special needs
  - 3.5 Have no idea about the social model
- 4 Professionals' view of families
  - 4.1 Cooperation
    - 4.1.1 Positive
      - 4.1.1.1 Helpful
      - 4.1.1.2 Responsive
    - 4.1.2 Negative
      - 4.1.2.1 Hide their disabled children
      - 4.1.2.2 Feel ashamed
  - 4.2 Worries
    - 4.2.1 About the future especially after parents' death

- 4.2.2 Lack of service provision
- 4.3 Siblings
  - 4.3.1 Helpful

5 Service provision

- 5.1 Education service
  - 5.1.1 Special schools
    - 5.1.1.1 Located in Muscat
    - 5.1.1.2 Long waiting list
    - 5.1.1.3 Lack of Omani professionals
  - 5.1.2 Ordinary schools
    - 5.1.2.1 Negative attitudes of staff
      - 5.1.2.1.1 Unhelpful
      - 5.1.2.1.2 Not welcoming
    - 5.1.2.2 Complex procedures
    - 5.1.2.3 Positive attitudes of staff
      - 5.1.2.3.1 Helpful
      - 5.1.2.3.2 Informed
    - 5.1.2.4 Inaccessibility of schools
      - 5.1.2.4.1 Old buildings are inaccessible
      - 5.1.2.4.2 First floor is inaccessible

5.1.2.4.3 Playground is inaccessible

5.1.2.5 Relationship with peers

5.1.2.5.1 Difficulty in having close relationship with peers (majority)

5.1.2.5.2 Peers are helpful

5.1.2.6 Feelings of embarrassment

5.1.2.6.1 Reluctant in asking for assistance

5.1.2.7 Lack of professionals

5.1.2.7.1 Teachers in ordinary schools have no idea about the disability

5.2 Social service

5.2.1 Payment (social security)

5.2.1.1 No provision made for disabled children

5.2.2 Equipment

5.2.2.1 Are easily offered

5.2.2.2 Complex procedures

5.2.3 Al-Wafa Centres

5.2.3.1 Positive

5.2.3.1.1 Helpful

5.2.3.1.2 A break for families

5.2.3.2 Negative

5.2.3.2.1 Based on voluntary and non- specialist workers

5.2.3.2.2 Lack of professionals

5.2.3.2.3 Exclusion of children over 14

5.2.4 House adaptation

5.2.4.1 Inaccessible houses

5.2.4.2 Responsibility of their families

5.2.4.3 Only few families are funded

5.3 Health services

5.3.1 Disabled children are seen as ordinary patients

5.3.2 Lack of physiotherapists

5.3.3 Units of physiotherapy are not covering all cases

5.3.4 Some cases come late

6 Local environment (rural and urban areas)

6.1 Inaccessibility

6.1.1 No pavements

6.1.2 Obstacles

6.1.3 Stones, holes and hills

6.1.4 Wheelchairs not fit for such environments

6.1.4.1 less involvement in the local activities

6.1.5 Inaccessible transportation

6.2 Accessibility

- 6.2.1 Some public places are provided with
  - 6.2.1.1 Ramps
  - 6.2.1.2 parking

7 Public attitudes

- 7.1 Negative attitudes
  - 7.1.1 Stigma
  - 7.1.2 Shamefulness
  - 7.1.3 Embarrassment
  - 7.1.4 Hiding
  - 7.1.5 Sympathy
- 7.2 Positive attitudes
  - 7.2.1 Belief in Allah's will
  - 7.2.2 Respectful

8 Future-professionals recommend:

- 8.1 A comprehensive survey
- 8.2 Training programme to have more Omani professionals
- 8.3 Information provision and awareness programmes for the public
- 8.4 Family support
- 8.5 Full inclusion for disabled children
  - 8.5.1 Accessible society

8.5.2 Accessible schools

8.5.3 More accessible public facilities

8.6 More services especially education

Appendix (5)

Guideline of the Interviews and Focus Groups with Physically Disabled Young People (12-19 years old), Mothers and Professionals

The focus of the research is to examine the perspectives of disabled children themselves, and their mothers and professionals who work with them. The study will include urban and rural communities, both sexes and age variety that will hopefully provide a contrasts and variable factors within this subject area.

Introductory visit of families

The purpose

1. To give disabled young people and their families a comprehensive idea about the topic of the research.
2. To start to build up some rapport.
3. To find out their willingness to part take in this study.
4. To set up a suitable time for the interviews.

Topics to cover

1. Purpose of the research.
2. The key topics that will be covered.
3. How long the visit might take.
4. Freedom in presenting their own views.
5. Further explanations about the study.
6. The opportunity to take a break during interviews.
7. To find out from both the disabled young people and their mothers, whether they would like to be interviewed together or separately.

Discuss confidentiality

1. Ask permission to tape record and make sure that the recording would be used privately.
2. Explain what will be done with the results, and assure them of anonymity.
3. Ask if they require further explanation.
4. Confirm whether they have agreed to take part in the research.

Semi-structured Interviews with physically disabled young people:

Before the interview is started the interviewees should be reminded about what was discussed during the first meeting. Their views should be freely expressed. The researcher is interested in exploring their experiences. Confidentiality and permission to tape record interviews should be raised again.

Checklist of topics to cover during the visit:

1. Pre-school age or early childhood (his/her images about it).
2. [Have they an idea about how they got the disability? Their experience with the medication-how they look at that stage- how their lives were before starting school- was it easy to get to school? Who helped them? Any difficulties/obstacles].
3. A typical day in your life. [What time do you usually wake up, and who wakes you up? What do you start your day with? How do you go to school? How is your school day? - Is it welcoming, easy or difficult? - What do you do in the afternoon and at night? What do you basically dislike? Do you have break time and if you do how do you spend it?
4. Treatment by family members (including parents) Positive or Negative? Different as compared with non-disabled siblings?
5. People close to you (how they look at disability, their notions about causes of disability).
6. Going to school [was that easy/difficult, any barriers- how the school staff deal with you-accessibility of building-transport].

7. Home [is it comfortable and/or friendly- do you have your own room- is it adapted for wheelchair movement- is the toilet suitable for your need- who made it suitable- if not/who is supposed to provide housing services].
8. Local community [is it friendly for physically disabled people/ wheelchair users- how do neighbours treat you/ how they look at disability- do you have friends- do you play/participate in local ordinary activities-shopping].
9. Public attitudes [is it easy to interact with public people-how do you think, they view disability/or look at disabled children- do you feel happy to access the mainstream society including school, shopping, parks, local community, mosque, community youth club/or other public organisations].
10. Equipment you need (who provides them? is it easy to get them?).
11. Financial support (who provides this? is it enough?).
12. Suitability of the transport you need.
13. Do you choose what you like?
14. Professionals who help you (Social Workers, Doctors, Health Workers, Teachers), how do they relate to you?
15. Who else would like to help you?
16. Any worries or concerns.
17. Do you think your family needs a break or do you need a break?
18. The Future (how do you see the future? And how to be improved?

Semi-structured interviews or focus groups with mothers

Topics to be covered:

1. Their understanding of the disability (is it a normal phenomenon, cultural link, religion view, social perception).
2. Typical ordinary life (dependency, schooling, leisure, siblings' relationship).
3. Attitudes (positive, negative) of family members, extended family, local and public.
4. Accessibility to the services such as social, health and education (helpful or unhelpful, professional's attitudes, building structure, and barriers to

communication) do these services need to be improved. If they do not use these services then why do they not?

5. Families' experiences (positive or negative) of how they get services their children need (easy, difficult, efficient, inefficient, accessible and inaccessible).
6. Do they select what their children need (who decides, parents, children, professionals).
7. Worries and concerns.
8. The future.

Semi-structured Interviews with professionals

Topics to be covered:

1. How did you come to be in this job? Or how did you choose to work with disabled young people?
2. What do you think are the main issues facing the disabled young people in their families or local community?
3. Your understanding of disability (medical perception, social view).
4. Services of disabled children (using public services, special institutes, accessibility of buildings, legislations).
5. Qualifications (did they learn about disability issues, degree, workshops, conferences, seminars, reading of journals and so on).
6. Their experiences about disabled children's needs (are they met, barriers to be met, what are the most important needs that should be met).
7. Inclusion of physically disabled young people (attitudes of agencies, are they opened/closed), attitudes of professionals, public people and families (negative/positive).
8. Do they choose what disabled young people need/ or do they give them the chance to decide what they need? (listening to children).
9. Are the families of disabled young people helpful in enabling workers to help their children?
10. Do professionals ask parents about their needs?
11. What are the most significant barriers that prevent disabled young people from full inclusion (culture, social, economic, planning, attitudes)?

12. Are they happy about the existing service provision?
13. The future (vision of professionals of how their work could be if they have enough money).

The researcher is indebted to the help of all of the interviewees and hopes that the findings of the research will improve the quality of life of disabled young people and their families.