3. MOBILITY IMPAIRMENT

Friendship with a man is friendship with his virtue, and does not admit assumptions of superiority. Menicus

3.1 INTRODUCTION

In chapter one I referred to the problem of identity because of a changed body-image. People who are mobility disadvantaged are given a "disabled identity" that is fixed in perceptions of an imperfect body-image. Public perceptions about disability direct attitudes and behaviours that can imply that people who are mobility impaired do not belong to society in general.

This chapter is devoted to describing various dimensions of disability. The two main questions considered are: What is disability? What is mobility impairment? The difficulty of defining disability is therefore considered. A general understanding of the notion of disability (3.2) is followed by a description of mobility impairment (3.3). Against this background different models of disability are discussed. The two main competing models, namely the biomedical (3.4) and the social (3.5) model will be discussed first. This will be followed by a discussion of an alternative model, namely the developmental process of a psychosocial model (3.6). The chapter ends with a short conclusion (3.7).

3.2 WHAT DISABILITY IS ABOUT

Simplistically disability can be considered as a way of categorising someone who has a physical, psychological or mental impairment. Physical impairment usually refers to some defect of the body, while mental impairment usually refers to some mental retardation. Psychological

impairment usually refers to a psychiatric disorder that causes emotional disturbances in the person. However, these are simplistic and inadequate descriptions of disability. Defining what disability is, is far more complex. Parmenter (1988:10) reflects this complexity when he points out that "the way in which people determine their definitions depends upon a variety of factors including personal and community attitudes toward people who appear different".

In addition, Barbara Fawcett (2000:63) regards disability as a contested area and this author maintains that how "normality" and "abnormality" are understood, influences both the macro and micro levels of cultural, social, physical and historical environments. Defining what disability is has therefore had a profound effect upon the lives of people with disabilities. Thus, disability has epitomised a socially accepted form of oppression towards disabled people that is culturally ingrained, although the last ten years have produced some meaningful attempts to deinstitutionalise people with disabilities, according to Macfarlane (1996:6). My concern is that despite these attempts to deinstitutionalise people with disabilities, confusion about disability remains. One point of confusion that has compounded the difficulty of defining disability, Macfarlane (1996:7) points out, is misunderstanding of the distinction between illness and impairment.

In addition Shapiro (1999:49) points out that the number of people who are disabled is increasing and this results in numerous different kinds of disabilities. This author writes:

> In fact, identifying disabled persons and determining their number can be difficult because associations, state laws, branches of government, and persons with disabilities themselves use different definitions.

However, despite the knowledge that there are different types of disabilities, sometimes disability is described as if there is only one type. A person, for example, who is impaired in sight is categorised as disabled in the same way as a person who is hearing impaired or bodily impaired. This means that numerous different kinds of disabilities are treated as one kind, which can result in generalisations being made about disability (Corker 1999:635, Crisp 2000:356, Priestley 1999:66). The increase in the incidence of disability and the multiplicity of the types of disabilities make a common description of disability very difficult.

In addition, Finkelstein (1993:9-10) suggests that what makes ascribing terminology to disability even more difficult is that words used to describe disability have connotations that affect the way people who are disabled identify themselves and the way they are identified by society. Descriptions of disability have triggered behaviours and attitudes, such as discrimination against people who are disabled. Numerous words have, therefore, been associated with disability in attempts to aid description. It is due to these complex issues about disability that Oliver (1993b:61) points out that disability has gone through many processes of definition. Words such as handicapped, disabled, impaired and challenged are used to describe people who are disabled. Impairment referred to a defective physical part of the body, disability occurred owing to the lack of function because of the defective body part and handicap referred to the limitations resulting from disability (Barnes 1994:204).

Despite attempts to define disability in a language based on medically correct terms, it remains a problem. The biomedical terminology adds connotations of incompleteness and non-functionality to the notion of disability. Roger Slee (1996:107) gives the example of medical language which was used in special education services that only served to marginalise so-called "special students". Later vocabulary was introduced by the equity and disability rights movements in an attempt to describe

disability, but Slee (1996:108) argues that it is only cosmetic because it still maintains powerlessness for disabled students. It fails to address the substructures beneath the experience of students who are disabled.

Having reflected on the above discussion and arguments about the effect of language, I will argue that language which describes disability still remains largely in the realm of biomedical language. Terminology such as illness, incurable, rehabilitation and chronic is still used regularly when addressing people who are disabled. I therefore envisage a new language to address people who are disabled that gives meaning to the lived reality of people who are disabled. This will be discussed in more detail later in this chapter.

I suggest that consideration of national and international organisations can shed light on disability because these organisations have struggled and attempted to come to terms with the difficulties of language, terminology and people's experience with the reality of living with disability.

3.2.1 National and international views on disability

Britain was one national country that attempted to address the problem of describing disability. Organisations were formed that accessed the policy-making of the European Union and the United Nations. It resulted in impairment and disability being described as "impairment" as a physical defect and "disability" as a social problem (Priestley 1999:223; Riddell and Watson 2003:2,3).

However, such a definition creates the problem that disability is described in a way that confines impairment only to the physical dimension of life and disability only to the social dimension of life. Sally French (1993a:17) conveys an interesting point when contemplating the difficulties that arise when the social dimension of life is designated the sole prominence in

terms of disablement. The above author points out the dangers of arguing disability from an "either/or position". This means that disability is described as either a social environmental problem or a physical impairment problem. French (1993a:18) continues to reason that disability is about a "both/and" position: it has both physical and social dimensions.

However, at least endeavours were made through collective organisations to give understanding to the notion of disability. Sally French (1993a:22), therefore, lauds the collective process of organisations in Britain that joined hands to bring clarity to a social definition of disability. In the 1980s the British Council of the Organisation of Disabled People was formed.

Despite these advances economic values and bureaucratic politics still had an influence on policy-making, which was to the disadvantage of disability movements. However, on the positive side these advances opened the way for counter-cultures of resistance, which challenged negative social interactions about disability throughout the world (Priestley 1999:224).
The Disabled People's International (DPI) committee played a prominent role as an international voice and from 1985 began to work with the WHO, through a process over time, of defining terminology to describe disability (Driedger 1989:97-99).

Over time the result of different countries and organisations working together was that the International Classification of Functioning, Disability and Health (ICF) was formed as a core member of the WHO's health-related classifications. The ICF intended to be a multipurpose classification that would be introduced in phases. It recognised two components of disability in the beginning and later three dimension of disability were defined (Australian Collaborating Centre [AIHW] UN Conference 2001:1-3).

Thus, disability as a multi-dimensional and complex concept is defined by the WHO (2001) in terms of body structures and functions/impairments, activity, activity limitation, and participation or participation restrictions. Disability is described as "the presence and nature of one, some or all of these dimensions associated with current or previous health conditions, disease or injury" (AIHW 2001:16). It is noteworthy that these three dimensions focus on the functioning of the person and disability relevant to the body, the individual person and in society. Measurements for classification of activities and participation are according to two constructs. The two constructs are capacity and performance, which are used to classify the domains of activities and participation. These domains are coded through qualifiers, such as none, mild, moderate, severe, complete. The AIHW (2001:2) document refers to the key definitions of activities and participation as: *Activity* is the execution of a task or action by an individual; *Participation* is involvement in a life situation; *Activity limitations* are difficulties an individual may have in executing activities; *Participation restrictions* are problems an individual may experience in involvement in life situations.

Thus, the ICF classifications of disability include the dimensions of impairment and individual uniqueness and the social context. Thus, disability is understood: "...not only as a problem of a minority group nor just of people with a visible impairment or in a wheelchair" (WHO 2001). The WHO (2001) released a publication about decisions taken for the ICF. It was accepted by 191 countries as the international standard to describe disability.

I think that the point to be made is that the WHO and the new phases of the implementation of the ICF address the problem of disability more comprehensively, because they include the various perspectives of living with a disability. They seem to be attempting to provide a both/and position

to defining disability. Thus, in terms of a definition of disability, in this study I take into consideration the ICF's perspective of disability. The ICF's classification allows for the multiplicity of disabilities and understanding disability in terms of functions, limits and ability of participation. The WHO (2001) clarifies this by the statement, "For example, a person living with HIV/AIDS could be disabled in terms of his/her ability to participate actively in a profession".

3.2.2 A definition of disability

Following the ICF's way of describing disability I, therefore, define disability as a uniquely individual experience because of restrictive bodily impairment accompanied by social oppression by sections of society that discriminate and oppress through collective beliefs, values and meanings, which can present restricted participation for the person who is disabled. It means that the person who is disabled is seen to have her/his personal story about living with disability. There are bodily impairments that may or may not cause certain difficulties and restrictions for the person. Also, the environment, attitudes and behaviour from the social context may cause problems of coping for the person. All these dimensions are seen to be part of being disabled. Any one or a combination of two or all of these dimensions can describe disability in terms of the person experiencing the disability.

3.3 MOBILITY IMPAIRMENT

I will discuss the question: What is mobility impairment? Mobility impairment is discussed because it is an extension to the discussion on disability in general. What applies to disability will also apply to mobility impairment, which is the thrust of this study.

3.3.1 A definition of mobility impairment

The task of defining mobility impairment remains. In this regard Napolitano (1996:30) refers to impairment as some limitation in body or mental capacity and mobility impairment as, "…usually referring to limitations that the individual has in physical functions like walking, running, climbing and standing". Hence, for this study, I define mobility impairment as some limitations that the individual has in physical functions like walking, running, climbing and standing. However, this remains a confining definition of mobility impairment in comparison to the classifications of disability decided upon by the ICF.

The problem is that it is confined within bodily function. I choose to express mobility-disabled as anything that limits or restricts activities and participation in society for the person who is mobility impaired. It means that bodily impairment may limit activity and participation, but so can environmental barriers, cultural oppressive attitudes and behaviours. The people, therefore, that this study considers as mobility disadvantaged are people who live with chronic illnesses and congenital disabilities which restrict mobility, people who are elderly and frail and people who live with mobility restrictions because of congenital or acquired permanent damage due to injury.

This means that mobility impairment is considered a complex entanglement of bodily impairment, material, environmental, economic and culturally oriented problems that enhance restrictions in mobility. Mobility impairment will, therefore, be discussed from the perspectives of material and economic oppression, socio-cultural oppression and bodily restrictions. The reason for considering these perspectives is that in the next chapter I will consider the empirical research from the above two perspectives of oppression, as well as bodily impairment. In addition, the above three perspectives of mobility disadvantages will be considered in more detail in the section that discusses the two dominant models of disability (see 3.4 and 3.5).

3.3.2 Acquired and congenital mobility impairment

We have considered that the notion of disability is multidimensional. It has been concluded that there are different types of disabilities with different types of problems. However, whether there is a difference between congenital and acquired mobility impairment has to be considered. Differences in these two types of mobility impairment can result in very different, yet also similar experiences for the individual, family and significant others.

Evidence from available literature and clinical material indicate, according to Wilson (2003:28), that usually people who are born with a disability perceive their bodies as whole. The experience of challenges to this perception may come only later in life. What difference does this make to the individual who is mobility impaired, the family and others?

An example of living with a congenital disability may be found in the narrative of Diane DeVries, who was born with disabilities. She was born without arms and legs, yet she perceived her body as different, but not as defective. Diane tells of the event of her birth:

> The doctor, when I was delivered, the doctor fainted....But, uh, Dad believed and I do, too, that it was just something that happened. Because that's the only thing that's wrong with me, is just that I don't have no arms and legs.
>
> (Eiesland 1994a:33)

What was for the doctor a horrific event, was perceived by DeVries as just something that happened. Eiesland (1994a:33) explains that DeVries portrayed herself as a child born into a working class family who was expected and wanted.

However, while the individual who is disabled may experience the body as whole, this may not be the response of the whole family. Because of their previous exposure to cultural, religious and social beliefs about disability, the family members may experience feelings of guilt, shame and anger. The identity of the whole family unit may become threatened and perceptions of self-value may be destabilised. Their perception of what their social peer group thinks about them may reflect negatively on themselves. A sense of losing control of what should have been the predictable expectation of conceiving a normal child, may overwhelm parents. For example, a mother who gives birth to a child who is disabled may feel judged as a incompetent mother. A sibling may feel ashamed and fear condemnation from his/her peer group and resort to secrecy about a sibling who is disabled.

Thus, cultural beliefs and meanings can influence a society's expectations about disability. An example is illustrated in the story of Diane DeVries. Her parents moved away after her birth to remove her from her grandmother who rejected her as her grandchild. The grandmother accused DeVries's mother of fornicating with the devil and called her the devil's daughter (Eiesland 1994a:33-34).

Despite the rejection from her grandmother, as DeVries grew up, she rejected her grandmother's interpretation of her body without limbs. DeVries rejected defining her birth as a tragedy and rejected the perceptions about disability based on expectations of normality. She experienced ridicule and nastiness from some people who perceived her as a freak. Despite this, her evaluation of her body as unique and whole was established prior to the realisation of being stereotyped and stigmatised and helped her maintain a body-image as healthy although different (Eiesland 1994a:35). Although she had to endure numerous humiliating and discriminatory events throughout life, Eiesland (1994a:36) states that "DeVries has sustained her self-definition as different and ordinary."

However, disability in mobility that is acquired may have a different scenario. People who acquire a disability later in life may find that their altered body-shape leaves them desperately trying to piece their lives together. They move from a familiar world of able-bodied to that of feeling like aliens in a foreign country (Wilson 2003:31).

In comparison to DeVries's account, the story of Nancy Mairs (Eiesland 1994a:43) substantiates the struggle of an altered body when she became progressively disabled at the age of 25 years. She felt that her body had betrayed her and that there was no longer space for her in her home. She left her husband and children to find accommodation in a small room where she attempted suicide. After a lengthy time of depression she eventually came to terms with what her body was becoming. She began to take on a new meaning for her body. Mairs referred to her body as "a body in trouble" with the significant meaning that her body incorporated the acquired mechanical walking aids. Mairs says: "Slowly, slowly MS will teach me to live as a body" (Eiesland 1994a:43). Mairs wrote in her autobiography:

> The brace makes my MS concrete and forces me to wear it on the outside. As soon as I strapped the brace on, I climbed into trousers and stayed there (though not the same trousers of course). The idea of going around with my bare brace hanging out seemed almost as indecent as exposing my breasts. Not until 1984 soon after I won the Western States Book Award for poetry, did I put on a skirt short enough to reveal my plasticized leg. The connection between winning a writing award is not merely fortuitous; being affirmed as a writer really did embolden me.
>
> (Eisland 1994a:43,44)

In the beginning Mairs displayed denial of body changes due to multiple sclerosis. Denial is the way the person tries to preserve continuity and cohesion of life by removing the traumatic event from the conscious mind

(Wilson 2003:30). Slowly Nancy Mairs realised that her body was not going to go away and she became aware of a body she had not had before.

Mairs deconstructed the idea of an admirable conquering body by replacing these perceptions with a realistic experience in relation to the metaphor of a body in trouble. It enabled her to relate to life as a body that was emerging as she went along. Nancy Mairs first experienced the changes in her body as breaking down her value of herself. Later, when she acknowledged her body as only part of her personhood, rather than the body as her whole identity, she could see her body more positively. She could give herself space in daily living with others. She found that she could contribute through writing and so did belong in society.

In comparison with the story of DeVries it would seem that DeVries was comfortable with the only body she knew from birth. For her it was something that just happened. Mairs, however, experienced a struggle with her changed body acquired through her illness. She experienced the struggle between preconceived perceptions of a body-image and an altered body state that gave her a sense of discontinuity.

Bodily trauma, with permanent damage and altered body-shape can therefore damage the sense of continuity that humans experience with history. Confusion results because of the split between the good time as non-disabled of the past and the sordid disabled present and fearful future. An example substantiating this is that before Nancy Mairs contracted multiple sclerosis, she lived a life that found continuity of personhood in events of being a wife and mother. This was "who she was", wife and mother, and from which she gained her sense of belonging in her community. After being diagnosed with multiple sclerosis she experienced a break in this continuity as a person that sent her reeling into confusion about "who she was becoming". She could no longer find a sense of belonging in her family and community because she perceived the historical

continuity, that of being a wife and mother, as having been destroyed by her altered body. It was only later through her poetry that she re-established acceptance of her changed body-image (Eiesland 1994a:43-45).

The experience of discontinuity creates a link between physical and internal emotional reactions that require expression, because it affects the individual (Wilson 2003:24). Zola points out that avenues of expression that vent anger, such as running, hitting a punching bag, dancing about the boxing ring or slamming a little rubber ball against a wall are not usually available for people who are disabled. Often people who have retinopathy are warned by the physician not to exert themselves, or people with ongoing neurological deficits are warned not to do too much or to limit physical stress, emotional stress and to do things more quietly. In other words they are not to feel intensely, and there is no outlet for anger. It becomes suppressed. Zola (1982:222) writes about this:

> Thus, with virtually no acceptable avenue for expression, those with chronic disability are forced either to turn their anger in on themselves or to blunt it. To the degree that we succeed in the latter we become increasingly unfeeling, and often so distanced from ourselves that virtually nothing can touch us.

From the illustrations referred to above, it appears that an acquired disability has a greater influence on the body-image and adjustment to it. This study will focus more on disabilities which have been acquired because I want to emphasise that an acquired mobility impairment will present problems with identity and belonging for people who are mobility disadvantaged. The main argument for this is that the pre-morbid state (before disability) body-image and cultural beliefs that were formed will make the post-morbid (after becoming disabled) experience more difficult to manage.

3.3.3 The effects of mobility impairment

In this section I consider only a few effects of mobility impairment, because other details about mobility impairment are made later in this chapter (3.4 and 3.5). Problems of access, the difficulty of environmental terrain, the chasms between perception and understanding and preoccupation with aesthetics are given consideration. Literature about mobility impairment, from a point of view of research projects or the personal experiences of authors, such as Eiesland (1994, Kaufman-Scarborough (2001), Napolitano (1996), and Wilson (2003), are considered.

Most of life is about moving about and usually short distances are covered by walking or running. Longer distances are covered with the aid of different kinds of vehicles, from skateboards to jumbo jets. Public transport is a large part of moving about. Buses, trains, ocean-liners and air-flights are important to life. Walking in this day and age of technology is confined mainly to short distances. This is why Napolitano (1996:31) points out that in actual fact little walking is done in today's society. Modes of mobility are mostly vehicles with wheels. Walking usually consists of "nipping" into the shop, stopping to collect the post and "popping" in to visit a friend. A car, bus, taxi, bicycle or a motorcycle is the means of covering distance.

However, for some people moving about is limited because of age, frailty, loss of limbs and paralysis of limbs. Walking, running and standing may be limited or impossible. Napolitano (1996:30), makes the point that the solution seems easy because society needs only to design and build a way out of mobility restrictiveness. Napolitano (1996:30) uses a woman's liberation phrase and writes, "To borrow a phrase from the Woman's Liberation Movement, at last we can see that biology is not destiny." This means that removing environmental barriers is the answer.

Despite this simple solution to mobility restrictions, public transport is designed as though people who are mobility disabled should not travel in public. The mind-set of the public remains embedded in the belief that mobility impairment leads to immobilisation (Napolitano 1996:31). Accordingly, wheelchairs and walking aids produce their own problems, since public transport is not made to accommodate walking aids and wheelchairs.

Napolitano (1996:31) points out that barriers are not only a transport problem, because vehicles with wheels are only a part of what mobility is about. Access to facilities is a problem. A motor vehicle may get one from one building to another, but cannot get the individual about the building. Architectural structures may be either an asset or a barrier to people who are mobility disabled. A ramp may give easy access to a building while a stairway makes it inaccessible for these people. Uphill entries or multiple ramps make travel extremely difficult for people who are using a manual wheelchair.

Napolitano (1996:31) holds that removing barriers for people with mobility impairment is about effective transportation, accessible effective architectural structures and effective mechanical aids like wheelchairs, crutches and walking frames. However, the above author maintains that there is a chasm between perception and understanding that creates problems. The fact that a ramp has been built does not mean that barriers have been removed. If a ramp has a heavy door to open at the end of it to get into the building the problem for the person who is disabled cannot be perceived as being solved by the ramp. Entry into the building is still blocked by the heavy door for the person who is disadvantaged in mobility. Despite removing material structural barriers, the person who is mobility impaired may not find certain facilities available to them.

However, inadequate management of restructuring barriers is also a

problem. Removing barriers also means adequate management of the barriers or accessibility (Kaufman-Scarborough 2001:434). A ramp, for example, to a building, with automatic doors at the entrance are great steps to removing barriers, but if a wheelchair user's toilet is kept locked and personnel must be hounded down in order to access the toilet, it defeats the purpose of accessibility to the building.

Another problem is that aesthetics in creating an environment become a priority when planning architectural structures. Napolitano (1996:33) maintains that conservationists and disabled activists have spent enough time glaring at one another across conference room tables to contemplate that structures to enable mobility need not ruin the aesthetics of the environment or architecture. Aesthetics in creating an environment that is accessible to mobility impaired people is appreciated by these people as much as any environmental beauty or art is appreciated by people who are not disabled (Napolitano 1996:34). Notwithstanding this, when aesthetics are given priority over making the environment accessible to all, it sends messages of non-acceptance or non-belonging. Napolitano (1996:35) writes:

> Mobility impaired people want to get everywhere; with the technology and design know-how at the command of twentieth-century western society there is no reason why this desire should not become a reality. But being able to use the environment is about more than being able to 'get about'. At a deeper level it is about a sense of belonging.

However, until the environment enables people who are mobility disadvantaged to participate with dignity and pride, belonging will continue to evade them. Messages are continually sent to people who are disadvantaged in mobility, that barriers exist to exclude them. Environmental barriers are discussed in detail in the section on the social

model. However, the environmental barriers may cause emotional distress for people who are disadvantaged in mobility.

Lack of environmental support may expose the person to unnecessary stress, but immense frustration is experienced when barriers prevent the person from enjoying belonging and being wanted. Kaufman-Scarborough (2001:446) maintains that mobility impairment affects how a person is valued as a human being. A research project of one group of student researchers who were not disabled and a group of researchers who were disabled was studied in the consumer market. The student researchers who were disabled reported incidents of being depersonalised. Both groups experienced retail personnel addressing those accompanying them instead of themselves. It did have an influence on their social acceptance and formation of identity (Kaufman-Scarborough 2001:454). Attitudes and behaviours of people who are not disabled, therefore, may have an effect on how people who are mobility disadvantaged experience acceptance and a sense of belonging.

Professor Zola (1982), for instance, who is mobility disabled because of polio, was conducting a research project with people who were mobility disadvantaged living in a place called the Village. Zola (1982:221) substantiates the effect of perceptions of others, when he narrates that he was alarmed to find that he was immediately identified as a typical Villager. He writes that such experiences "concretized a truth conveyed by the residents during my first few days - how the outside world chose to think of me." They implied that all handicapped people look alike (Zola 1982:199).

It implies that recognising no difference between people who are mobility impaired can relegate them to insignificance and non-personhood. Often people who are mobility disabled try to "fit in" into society by trying to please others and concentrate on doing things the way other people think

they should. Zola (1982:226) speaks about how often he made himself do things that were destructive to his body. He forced himself to do it because he felt guilty about not doing something that he could do, but should not do because of the risk of furthering limitations of his body. He did it because of what others thought. After doing the task, his body suffered. Zola (1982: 226) writes, "But more disquieting was how tenuous I felt my identity was in the eyes of others". The effects of disability will be described in detail when discussing the next section.

In the next section models constructed over the past twenty years about disability, are discussed. A model represents a part of a whole. All the issues concerning disability are complex, but each model reflects only a part of that complexity (Wilson 2003:19). The dominant models identified to be discussed in this study are the medical model and the social model. The reason for the focus on these two models is that both have a major influence on any other model of disability in that other models base their perception of disability on either the biomedical or social model. An account will be given of each model of disability to show the different ways in which disability is conceptualised by people who are not disabled and people who are disabled.

3.4 THE BIOMEDICAL MODEL

A brief history about how the notion of disability came to be seen as a medical problem is discussed. Next, a discussion follows on the issues that resulted from the introduction of the biomedical model of disability taken from different literature accounts (Barnes 1996; Barnes 1994; Driedger 1996; Eiesland 1994a; Finkelstein 1993; Oliver 1993; Priestley 1999; Rolland 1989; Wilson 2003).

In America the first federal legislation to address disability was prompted

by the number of war veterans who returned home disabled in 1918. Despite such legislation as the Smith-Sears Veteran Rehabilitation Act of 1918 with the intention to assist veterans who were disabled, inefficiencies prevailed. To add to the dilemma, Eiesland (1994a:50-51) points out that in the years of the "baby boom", alongside birth deformities because of the drug thalidomide and the polio epidemic, the population of children with disabilities increased. These were factors that increased public awareness and responses to disability, but the response was to describe disability from a rehabilitation and health-care perspective.

There were two trends in rehabilitation modes. The one was the aim of rehabilitating for employment and getting the person back to work and to the best possible independence. The other mode was medical rehabilitation of people who were disabled. Finkelstein (1993:11-12) makes the point that there was a problem with rehabilitation for employment because of the difficulty in operating machinery for production. Large-scale manufacturing operations began to dominate the social era, which resulted in people living with disabilities being marginalised from employment and productive life (Oliver 1993a:51-52).

Eiesland (1994a:53) also notes that, despite the aims of rehabilitating for employment, no solution to the problem of employment was reached because of attitudinal and architectural barriers that denied access to opportunities of employment. It eventually led to interpreting disability in medical terms because people who were disabled were interpreted as being unemployable and equal to the rest of the unemployed (Eiesland 1994a:53, Finkelstein 1993:11).

It resulted in the rehabilitation model conveying disability mainly as a medical problem dependent on medical diagnosis and treatment (Driedger 1996:11; Eiesland 1994a:54; Finkelstein 1993:12-13). It meant that the medical and paramedical services of care dominated when it came to

attending to the needs of people who were disabled. Welfare support and medical boarding according to the classification of disability decided their ability to remain employed or not.

This brings us to the main issues that characterise the biomedical model of disability. I will first discuss the medical, health and welfare services and the different characteristics of the biomedical model embraced by them. The effect that power plays on the notion of dependence and the consequences that the biomedical model activates are discussed. The discussion is in relation to the dimension of the power to influence the public and those who are disabled .

3.4.1 Characteristics of the biomedical model

The biomedical approach to disability resulted in certain set characteristics such as emphasis on normal versus abnormal, functional versus dysfunctional and curable versus incurable. The characteristics took shape because the biomedical model proponents based their knowledge about disability on pathological considerations.

There are many points to be made when discussing the notion of power and dependence in relation to the biomedical model about disability. I will, however, focus on three points that I want to make.

1) The expectations attached to the idea of incurable versus curable and how the biomedical model interprets incurable. The point to be made is that this term is associated with the shifting of persons who are disabled into a role of dependence.

2) How the biomedical model influences services of care and bureaucracy and what effect it has on people who are disabled. The point to be made is that services of care are often associated with power-wielding actions and

are influential in creating dependence.

3) The biomedical model's influence on ways of marginalising people who are disabled and its impact on the way public perceptions about difference are formed. The point here is that these perceptions are frequently intimidating and invalidating.

The way in which I will discuss the above three points, is to consider the focus of each and to substantiate this from authors such as Atkin and Hussain (2003); Finkelstein (1993); French (1993); Oliver (1993); Priestley (1999); Riddell and Watson (2003); Shapiro (1999); Wilson (2003 and Zola (1982). A discussion will be entered into that considers the weaknesses and strengths of the biomedical model. I will also discuss it in relation to the new classifications of disability by the ICF in affiliation with the WHO (2001).

3.4.1.1 The control and influence of the health-care institution

Unfortunately attempts to manage disability medically means that the focus is on physical functionality and the person is encouraged to be as normal as possible through rehabilitation. However, in order to rehabilitate people who are disabled, classifying disability so as to enable interpretation of disabilities in medical terms was the primary concern (Finkelstein 1993:13). Despite the aim to rehabilitate people who are disabled for independence, it backfired, because the health-care services increasingly determined how disability was to be interpreted and perceived. Health-care professionals took the *role of managers of care*, which eventually presented the problem of power abuse.

Finkelstein (1993:13), therefore, points out that it was not long before

different agencies of care-givers classified people with disabilities according to the biomedical diagnostic categories. Physiotherapists, occupational therapists and psychologists, for example, employed the medical interpretation of disability in their management of disability. It means that the need for diagnosis, aided by classifying disability and the benefit of specialised services, paved the way for medical experts to be gatekeepers of disability (Finkelstein 1993:15; O'Day, Dautal & Scheer 2002:42).

Accordingly a distinction was made between impairment, disability and handicap, but these terms were described according to pathology that fitted into the *biomedical classification system* of disability. Impairment referred to the lack of all or part of a body or having a defective body part. Disability meant the loss or reduction of a functional ability. Handicap was the restriction of activity that was caused by disability (Oliver 1993b:62). Crisp (2000:355) points out that the emphasis remains on bodily dysfunction that is explained pathologically and is individualising.

In criticism of the biomedical model, Oliver (1993b:61) suggests that the WHO's description of disability was not widely accepted because the major criticism is that it has been based on able-bodied perceptions of disability, which are not agreeable to the personal realities of living with disability. It means that disability is *objectivised* as something to be managed, but it leaves the individual tied to the health-care institution, because body dysfunction is of the medical domain. Of course there is no way in which the person who is disabled can afford to be severed from the medical and health-care institution. I say this for a number of reasons. Although people who are disabled are usually healthy despite having to use mechanical aids to get about, there are times when they do need medical care. There is usually contact with the health-care institution for follow-up procedures, for progress checks and records. However, there may also be periods of care needs because of issues related to disability, such as bedsores, chest

infections and urinary tract infection. It means that their needs for health-care services are greater when they experience these related conditions (O'Day, Dautel & Scheer 2002:42).

Consequently, the objectivising of disability that the health-care institution exercises in care management of disability can be a *source of oppression* to people who are mobility disadvantaged. Young (1990:129), when discussing oppression in relation to people who are considered different, addresses the shift that takes place between normal and abnormal, which becomes linked to the idea of good and bad; in other words *normal* is good and *abnormal* is bad. The relevance of what Young (1990:129) says is that these connotations become linked to forming and describing perceptions about disability. Also, abnormal has become associated with deviance and to be disabled is to be described as deviant from what is considered normal. Thus, the biomedical model paved the way for a mind-set of social values to be collectively accepted on what is considered normal. The biomedical model, therefore, goes a long way in promoting connotations that guide perceptions about disability.

It means that the emphasis that medical science has placed on the term "*curable*" has largely resulted in acceptance of it as normal value for society. Medical advances have been such, that they have given priority and status to the curability of a disease or a condition. It has resulted in ingrained perceptions of success linked to the term "curable". On the one hand, advance and success have given credibility to the medical profession, while on the other, that which is perceived as *"incurable"* is usually understood as failure.

Despite medical advances, there are diseases and conditions that are incurable and, therefore, the only thing to do has been to relegate the "incurable" to the arena of care-giving. The end result is that anything permanently threatening bodily health is considered "incurable" and this has

relegated disabled individuals to care management by the health-care and welfare services, which can lead to dependence on the medical and paramedical professions (Durand 1994:7-8; Fichter 1981:34-36; Finkelstein 1993:15; Shapiro 1999:91).

It is ironic that it was probably the preoccupation with care management that increased the idea of disability as a *personal tragedy*. It reinforced the association between disability and tragedy that was personal because of what had happened to the individual. The primary concern was to organise who should give care, what care was to be given and at whom the care was targeted and how the individual should be cared for. In other words, disability was perceived as a personal tragedy that had occurred because it had caused a physical malfunction in the individual that resulted in dependence (Finkelstein 1993:13, Oliver 1993b:61-62).

It appears that little attention was paid to critically exploring other causes of dependence. It is almost ridiculous to think that the biomedical model was not more open to critically examining its own care management of disability with the outcome of dependence. The end result was that little was done to challenge other social structures of dependence in association with disability. Eiesland (1994a:53) points out that medical rehabilitation is of the utmost importance for people who are disabled, but its weakness is that it does not address the social aspects of disability.

The point that I want to make at this stage of the discussion, is the perception of disability as a personal tragedy facilitating dependence instead of independence. Ironically, making the person living with a disability independent was the original aim of the biomedical sciences. However, the setting up of the personal tragedy image naturally led to the idea of compensation and charity exercises for people who are disabled. Thus, voluntary organisations still reinforce charity and dependency.

Shapiro (1999:133) refers to the perception of the disabled person portrayed as a *"charity case"* when advertisements for charity campaigns display disabled children as helpless and pathetic to encourage donations to their cause. He draws attention to the fact that, despite the campaign being for adults who are disabled, pitiful portrayals of children are often used to manipulate the public. Unfortunately the activities of charity organisations can submit people who are disabled to being passive recipients of charity (Oliver 1993a:56). Watson (2003:44) refers to an account given by a participant during a semi-structured interview in a study of disability. The person described waiting for a taxi while tourists filed past and slipped money into his hat, which was on his lap. Despite his objections that he did not want their money they continued to press him to take the money. He was perceived as a charity case because he was in a wheelchair.

Another side to the "*charity image*" is that any kind of actions of care are assumed to be part of charity. Medical care and helping services meeting the needs of people who are disabled are seen as actions of charity for which the individual should be grateful. Zola (1982:221) expresses that charitable assistance creates the expectancy that people who are disabled must be passive recipients. Any refusal or show of embarrassment is perceived as insufficient gratefulness, yet the authors of such perceptions ignore the humiliating and invalidating affect it has on the individual who is disabled. Zola (1982:221) writes about this:

> Everything that could be done was being done, everyone was busy and overworked, and, besides, 'Weren't we grateful?' This gratitude has been our curse.

Another perspective of disability that was conveyed through the medical profession's preoccupation with care for the incurable, is that it sometimes enforces acceptance of the *sick role*. It creates the picture of unwellness that assumes that all people who are disabled are sick. Assumptions about

disability based on a distorted image of incurable disease, create the impression of being abnormal, dysfunctional and non-productive. People who are disabled are automatically assumed to be sick. For example, a person who uses a wheelchair is associated with sickness even when the reason for using the wheelchair has nothing to do with being sick. Shapiro (1999:88) aptly points out that despite a paraplegic being radiantly healthy he or she is assumed to be sickly because disability is usually seen as a health-related problem.

Dorothee Wilhelm (1994:106), for example, tells of feeling dehumanised and manipulated by a medical doctor who referred to her as someone to be pitied. When she retaliated by referring to her state of well-being, the response from the doctor was that she dealt admirably with her disability. She replied that he could not assume to know how she lived. Wilhelm (1994:106) writes:

> In this situation I was first made a thing, because I could be identified only by my hospital papers. I was made a thing once more, because the doctor fixed me with his fantasies and fears, which he believed to be validated by his empathetically imagining what it must be like to be like me.

The doctor in Wilhelm's story assumed that because she was disabled she was a pitifully sick person. When she maintained that she was healthy, he assumed her spunky reply was an admirable way of handling her dysfunctional body.

The image of a sick role of people who are disabled haunts even the educational system. Oliver (1993a:55) discussed a study that was undertaken of a small group of young students who were disabled and transferring from special education to a college. The students appeared to be conditioned to accept being relegated a sick role. However, it is not

surprising because the medical needs of students living with disabilities take dominance over educational needs. The schedules of the health-care institution took priority over education. The end result of this predominance led to the students passively accepting the sick role. Added to this problem is that the intrusion of the medical field into the educational field created dependence. It means that these students were probably socialised into accepting disability as a personal tragedy that had happened to them.

In what has been discussed thus far, we have taken into consideration that the notion of incurable, in relation to the biomedical model, often leads to dependence, despite the aim being to enable independence. It was also discussed that connotations attached to the perception of incurable "snowballed" into different consequences for people who are disabled. This is because of a preoccupation with the notion of cure versus incurable and control of care management for people who are disabled. The other points that create dependence are considered next.

3.4.1.2 Services and bureaucracy

One of the strengths of the biomedical model is that irrespective of its faults it does provide vital specialised care. However, the argument is not that human help is needed, which is provided through services of care, but how the services of care are provided. The question to be asked is: how to provide services of care that are not dominated by one model's mind-set of disability; how to manage care in a way that enables self-choice and as much mutual respect and cooperation as possible and not a one-sided structure of power. The answer to the question seems simply to note that there has been intense criticism of the biomedical model, but mutual cooperation between people who are mobility disadvantaged and the medical institution has not yet been achieved (Oliver 1993b:56-58; O'Day, Dautel & Scheer 2002:45; Wilson 2003:19-20).

The problem with *mutual cooperation* between healthcare and people who are disabled is that the health-care institution is a huge establishment to run. Sometimes the organisational skills can become a nightmare of trying to manipulate operation facilities between emergency intervention and the usual cold operation cases. Timing becomes a vital factor that often does not leave much choice for the medical staff, let alone for the people receiving the medical attention. Shortage of staff and the ratio of medical staff to patients add to the dilemma. Organisational factors in the health-care institution also control time factors and activities of medical and paramedical staff. Mutual cooperation, therefore, is not an easy task and lack thereof can result in the strength of the medical model turning into its weaknesses (Durand 1994:8-9; Tunks, Bellssimo & Roy 1990:33-34).

Oliver (1993a:55-56) draws attention to the lack of mutual cooperation between medical needs and educational needs. He points out, for example, that school children still have surgery performed during school time. Surgery is scheduled according to the health-care institution's programme with little consideration for the educational programme. Thus, medical and healthcare that centres only on individualistic care predominates over other needs of people who are mobility disadvantaged. It gives the impression that the medical institution is superior to any other needs. In a sense it makes the individual dependent on the health-care institution. Resignation to the various forms of management of control may seem to be the only alternative for many people.

Oliver (1993a:50-51) refers to two dimensions of the term "dependence". One dimension is the way in which welfare care has subjected some categories of people to dependence on the state. The second dimension mentioned is the inability of individuals to provide care for themselves because of physical limitations. The power of the health-care and welfare services, therefore, lies in the control of deciding how these services of care will be managed. *Wielding of power and dependence* go hand in hand

in reflecting the consequences that the biomedical model has for perceiving disability.

Morris (1993a:22) suggests the necessity to redefine the word "independent". Usually, independence is used to convey being self-reliant and self-supportive. The above author suggests that, because the term "independence" is often misunderstood in relation to disability, health-care institutions presume controlling measures of care are needed. Accordingly, Oliver (1993a:54) argues that there are multiple ways in which professional services *create dependence that hinges on power and control.* The problem is often created through institutionalised regimes that mould individuals who are disabled into routine and controlled ways of giving care.

Despite efforts to relax institutionally derived patterns of care services, unfortunately, control in the name of "service" still remains in the hands of professionals. Macfarlane (1996:7) makes the point, for example, that a lot of expert opinion has been given on what disability is about and describing and understanding disability have taken on many forms in the name of "service to the disabled". It results in people who are disabled being caught up in a dilemma as to whether their needs are of the domain of healthcare or social services. This causes the lifestyles of people who are disabled to be divided into compartments of problems or care according to the services provided, such as nursing, medical, domestic or social. The dilemma is more complicated when it is important to decide which service must finance which needs. For example, it is an issue to decide whether it is medical or social service provision when a disabled person requires help to bath or shower.

It means that despite being provided with a service, people who are disabled still have the making of their own decisions taken away from them by care-givers. People who are disabled have *not always experienced inclusion* in some form of consultation about what provisions they need to enable

them to operate at optimum level in society within the parameters of their disabilities. It results in inappropriate forms of service provision even in the year 2005. Bureaucracy rolls on determinedly even in community service. In Britain, for example, the provision of home care, although an immediate priority for people who are disabled, is addressed on the basis of a rota system, according to Macfarlane (1996:7).

The point is: bureaucratic regimes control when and how services of care are provided. Persons who are awaiting the service usually have very little say about their own care needs. Often administrative and office clerks are the decisive factor in the time lapse between the need and the provision of the service. It seems ludicrous that administrative personnel have the greater control over the decision on timing the provision of needs simply because of bureaucratic protocol. Such bureaucracy raises a remark from Macfarlane (1996:7), who writes that for the disabled person it becomes wasted time. The above author states, "In other words the system is designed around the staff and not a disabled person." Nonetheless, it is understandable that the medical and paramedical professionals need to manage disability in a way that suits their professional understanding of disability, in order to give specialised medical service to people who are disabled. However, because bureaucracy is part of huge institutions, such as the health-care conglomerate, it can *deprive* people who are disabled of *choice*.

The consequences are that dependence created through bureaucratic regimes can create *loss of dignity*, which goes a long way to *dehumanise* people. Authors such as Macfarlane (1996) and Wilson (2003) describe the indignity of being dependent. Some people who are disabled, for example, have to depend on others in order to function. Caregivers, such as doctors, nurses, therapists and family members, have to attend to their intimate and private bodily functions. Moreover, medical terminology, such as "the bowel and bladder routine", to describe these intimate care needs, can

objectivise the person being referred to as a body part. It can be a source of pain and humiliation for the person who is disabled. It can leave people who are disabled feeling that they have lost control of their own bodies (Macfarlane 1996:13; Wilson 2003:3). How these care-givers manage and describe care given is important for the person's validation as an independent member of society.

It is the consistent assumption of dependence and lack of their own choices and having to fit into the health-care institutions' ways of operating that can lead to being relegated to the margins of society for people who are disabled. Cooperating with the health-care services' demands can come at a cost. The health-care institution's demands are sometimes time-consuming and social interaction with others can suffer. Continued interaction with healthcare services can convey the message of unwellness, sickness, needing care and, combined with time-consuming management of care, can result in isolation from public interaction. The combination also conveys a message of the different other.

3.4.1.3 Difference and marginalisation

In this section of the discussion of the biomedical model, I will consider only briefly the influence that the notion of difference has on the public. The notion of difference will be discussed fully when considering what the social model perceives about disability. This is because the notion of "the different other" is also greatly influenced by social interaction, attitudes and perceptions of the public.

Driedger (1996:11) reminds one that medical classification of disability associated with being sick, renders people with disabilities unfit to participate in all aspects of life. The consequence of such perceptions is that it may relegate people to the *margins of their societies*. At the same time, it is a possible cause of *exclusion* because some people are *not*

recognised as citizens with rights (Tisdall 2003:25-26).

Furthermore, one of the complexities of social interaction is that where there are *acquired identities* in addition to the usual socially accepted identities, these are regarded as the "identity of the different other". "Othering", as referred to by Tisdall (2003:26), based on dependence, relegates people to exclusion from rightful citizenship. In other words, because people who are disabled are identified as different, they are assumed to be incapable of being independent.

Unfortunately, as already mentioned the connotations derived from language that is used to describe the notion of being dependent, result in the assumption that the recipient of care is inferior and those in control are superior (Morris 1993a:23; Oliver 1993a:50). It is possible, therefore, to argue that through language, perceived images and social interaction with others, people are made aware of "difference". The relevance is that past discourses shape perceptions about disability and influence how the public perceives disability. Thus, the influence on public opinion about disability can be negative through the language and images concerning the biomedical model of disability.

People with physical impairments are categorised in a way that can dehumanise the individual. They are perceived within the frame of reference of abnormal. These perceptions are developed collectively through shared expectations, which classify people for the purpose of identifying them. Anything, therefore, threatening the beliefs, values and meanings of a society's classification systems categorises the person as the "different other" (Eiesland 1994a:59-60; Watson 2003:36-37).

It means that the individual who is mobility disadvantaged is perceived as having only bodily attributes that are abnormal. In contrast, Ricoeur points out in *Oneself as Another* (1992:118), that the ascription of universal

"self" eliminates dual reference to consciousness and body. For example, the person in a changed body-image of post-quadriplegia is the same person as the pre-quadriplegic one. Thus, ascribed predicates of body (identifying reference) and ascribed mental predicates are responsible for "selfhood" and "sameness". They possess both designation as universal "self" as same as another person, or identification in an objective manner, and human agents who are accountable for their actions in a subjective manner.

In other words, the identifying reference of personhood is not only contained in body, but also a person capable of being an acting and suffering individual. Hence, the human agent is connected to human action, which means that, although quadriplegic in body, the person remains the human agent that has the capacity to speak, promise and act (Kaplan 2003:88-89). However, the biomedical language used to describe disability does not give support to the individual who is disabled being perceived holistically as a multifaceted person.

Thus, it must be noted that dependence, care, subordination and control are common words used to describe the biomedical model in reference to disability. The result is relegation of people who are disabled to being identified as the "other". In view of these connotations, independence needs to be considered as a basic right to have control over daily living tasks. In other words, as Morris (1993a:24) expresses, people who are disabled should have the right of control over the help that they need. However, rarely is such independence experienced within the frame reference of the *individualist approach* because it usually conveys difference. The consequence is that often the term difference is not understood in a multidimensional frame reference of disability.

To sum up this section on the biomedical model it is noted that the strength of the biomedical model is the provision of specialised medical and paramedical care and the facilitation of a rehabilitation period. The

weaknesses, however, are the lack of mutual cooperation between the health-care institution, the individual and significant internal structures such as the family and attached social structures, such as education, employment and other factors important to the person who is mobility disadvantaged. It also contributes to a fixed identity for people who are mobility disadvantaged, because of the medical language used to describe disability. Thus, I will argue that another language needs to be found that expresses disability within the context of daily living and diversity.

3.5 THE SOCIAL MODEL

The social model emerged in reaction to the narrower mind-set of the biomedical model. In contrast to the medical perspective the social model proposes that disability is a problem faced by people who are disabled that is not primarily caused by an impairment, but rather by the way society is organised to meet the needs of non-disabled people (Fawcett 2000:64).

3.5.1 Background to the social model

The reaction to the individualistic approach of the biomedical model resulted in numerous perspectives being considered. These perspectives were generated from several social movements of disability. Driedger (1989:119) is of the opinion that:

> A significant social movement becomes possible when there is a revision in the manner in which a substantial group of people, looking at some misfortune, sees it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable to society.

A movement takes shape when a group of people begins demanding amelioration of conditions as a right. Priestley (1999:58) considers the

emergence of disability movements from two main schools of thought on how and why social movements emerge. The first can be referred to as breakdown models that propose that social disintegration and discontent mobilise a movement to raise objections. Another school of thought, which Priestley (1999:59) refers to, is solidarity models, which stress consciousness, ideology and social struggle. They represent an identity-oriented approach to collective action.

The point is that accounts of movements of disabled people give recognition to concepts of either model. The history of disability movements reveals traces of discontent and the shaping of values that give cohesion, which often coincides with the establishment of solidarity in collective action that has developed positive identities (Priestley 1999:59; Riddell & Watson 2003:6). Movements may progress to the status of organisation where organised changes occur and disciplined strategies and goals are formulated.

The relevance of the above explanations is that institutional organisations identify social problems, usually through exposing beliefs and values in society that fall short of the expectations of certain interest groups. The point to be made is that during social interaction certain beliefs, values and meanings gain consensual status as to what is considered as the social reality of that society (Riddell&Watson 2003:7-8).

Examples of beliefs, values and meanings gaining consensual status can be seen in the biomedical model where professional knowledge of disability aided in persuading public acceptance of a superior knowledge as social reality (Driedger 1989:121). Despite the stranglehold of the dominant culture of individualisation for people who are disabled, counter-cultures emerged against the claims to superior knowledge. Alternative making-of-meaning can, therefore, reframe misinterpreted identity and form new identities for people who are disabled (Goodley 2003:106).

The development of counter-cultures resulted in disability movements beginning to refute the notion of unification in relation to disability and starting to seek inclusion instead of exclusion for their members (Eiesland 1994a:53; Priestley 1999:57-58). Three branches of social organisations have arisen since the 1970s throughout the world, namely the movement for independent living, consumer organisations and self-help groups. In the struggle for equality the Discrimination Act was passed in America in 1973 and in 1995 in the United Kingdom (Tisdall 2003:27-28).

Movements such as the DPI eventually gained consultation with the United Nations and liaison with the WHO, which ignited the forming of legislation throughout the world (Driedger 1989:36-40,94,103; Eiesland 1994a:54; Priestley 1999:60). Thus, despite being labelled and excluded from mainstream culture, disability organisations found expression in the social model as a counter-culture of resistance, which resisted individualised values and meanings about disability (Goodley 2003:108). Following the background discussed above, I will identify the main points that characterise the social model.

3.5.2 Characteristics of the social model

Certain characteristics have been engendered by supporters of the social model. The main problems targeted by social theorists and possible solutions will be discussed. The main problems considered by social theorists will be listed and a discussion of these points will follow.

A discussion of the points identified from the characteristics of the social model will be considered in two sections:

1) reconstruction of environment, material and economic factors, and

2) shift to a social, political and cultural understanding of disability.

Examples of explanations in relation to the discussion of the section referring to either of the two main points will be interwoven into each section. Arguments that support or oppose the discussion applicable to the point being made, are considered. The next step is to consider arguments that suggest possible solutions to the problems highlighted by proponents of the social model. A critical review is given of problems associated with the social model and how the ICF classification of disability fits in. The main characteristics are listed first.

1) *Material* and *economic oppression* and concern about *reconstruction of the social environment* are the focus of some social theorists.

2) Some social theorists stress that a shift in emphasis is required when considering disability. Longmore (1995), for example, refers to a working definition that reframes disability with its focus shifted away from care management to *social, political and cultural oppression*.

3) *Equal rights of citizenship* in the same way as everyone else should be the aim of every society. Deprivation of equal citizen rights paves the way for discriminatory behaviour. People who are disabled are considered a *minority group*. The minority group perspective, embraced by disability activists, suggests that people who are disabled should be analysed in relation to a majority group of people who are able-bodied. It means that people who are disabled are perceived as a minority group (Eiesland 1994a:62; Wilson 2003:31).

I will discuss the characteristics of the social model considered in two sections, namely reconstruction of the societal environment, material and economic oppression and a shift to the social, political and cultural dimensions of life. Equal rights, stigmas and minority groups are discussed in these sections. Examples will be presented to support theorisation of these points and the strengths and weaknesses of the theories will be

argued.

3.5.2.1 Reconstruction of societal environment, material and economic factors

Some proponents of the social model maintain that *disability is created by environmental factors*. The centre of the problem is the disabling world because society is built for people who are not disabled and those with impairments become disabled. They are unnecessarily excluded by the environment that makes places inaccessible because they are unable to get into buildings and suitable transport is not provided to get them to places. For example, a stairway into a facility is the disabling factor for a quadriplegic and not the loss of the use of his or her limbs.

Some disability rights movements therefore believe that the cure for the problem of disability lies in reconstruction of the societal environment (Eiesland 1994a:28, 47; Shapiro 1993:24-31). The environmental barriers are seen not only to present barriers for people who are disabled, but also to discriminate against them. Thus, this perspective of the social model is concerned with removing disabling barriers and increasing the autonomy and choice of people who are disabled (Wilson 2003:21). Thus, those who champion the social model articulate that intervention should not aim to bring about normalisation of the individual who is disabled, but should aim to remove barriers that prevent equal rights to citizenship (Oliver 1993b:61; Philpott and McLaren 1997).

An example of barriers these social proponents refer to, is described by Kaufman-Scarborough (2001:449), who refers to student researchers in a study project where observation, field notes, pictures and videos were used to record the experiences of the teams. The report of the research project revealed that a trip to the mall could turn into an exhausting nightmare even when retail locations provided reasonable access (Kaufman-Scarborough

2001:439).

The students related how a popular fast-food chain provided parking space and a ramp leading to the main door to provide accessibility for people who are disabled. Ironically the ramp was a steep uphill leading to a door that opened outward. This meant that the door had to be opened and would sweep into the path of the wheelchair. Perched in a wheelchair, with one's back towards a steep incline and performing a balancing act of negotiating oneself around the door was a frightening experience for the research students.

Furthermore, O'Day, Dautel and Scheer (2002:43) took a focus group of participants who were interviewed to explore aspects such as physical barriers, access to the doctor's office and access to medication and durable medical equipment. The above authors concluded that the physical environment was filled with narrow doorways and lack of ramp entrances and it was usually difficult to manoeuvre in the small consulting rooms. The participants remarked that getting from the taxi onto the pavement was difficult and maddeningly frustrating. Some found the examination table in doctor's offices too high to transfer from the wheelchair. X-ray rooms were found to be inaccessible and difficult to manoeuvre around. Getting to the doctors rooms was an issue and getting to and from therapy was difficult and sometimes so frustrating that they stopped going (O'Day, Dautel & Scheer 2002:43-44).

The proponents of this social perspective emphasise not only the physical environment, but also the materialistic aspects of life. The *financial barriers* that encumber people who are disabled are considered. The above-mentioned study also revealed that issues of economic problems were prominent for people who are disabled. Finding a doctor with knowledge about disability, for example, was a costly accomplishment. Finding a knowledgeable doctor was an important issue for the participants, but

access to a specialist was problematic because it was an expensive financial transaction. In the same way durable medical equipment was a problem because the healthcare plan covered only wheelchairs of the lower economic level, but these were not always suitable for the person who is disabled. Repairs and equipment for independent living, such as wheelchair lifts on the car, shower chairs and mechanical walking aids, were not always covered by the healthcare plan and the individual had to bear the cost (O'Day, Dautel & Scheer 2002:45).

Fanning and others (1991:8) point out that people with disabilities who have no financial burdens can afford to employ help and acquire specially built homes to make things easier. However, most people who are disabled do not find employment easily and are not usually financially viable for even the most basic requirements of independent living.

Although the social model's main aim is to remove disabling economic and environmental barriers and to increase the individual's autonomy and independence, there is a question that comes to mind. Is disability only about environmental barriers and economic viability or is there bodily impairment which can be a barrier? I will argue that the social model's preoccupation with restructuring the environment can result in exclusion for people who experience mobility impairment.

People living with quadriplegia at high cervical level, for example, require far more than environmental changes and disability will not disappear if environmental barriers vanish. It can become frustrating for people who are disabled when the social model attempts to justify removing barriers as the only solution for disability. I am of the opinion that it makes something too simplistic that is far more complex and results in excluding people who are severely disabled in mobility. *Impairment and environmental, material and economic barriers for these people are inseparable, like two sides of the same coin.*

The above argument can be supported by what Sally French (1993a:17) recounts about her attempts to find social solutions to some of the problems of being partially visually impaired. French (1993a:18) states:

> The difficulty I have described is not entirely due to my impairment, for it involves other people's responses, but neither is it easily modified by social or environmental manipulation; it occupies a middle ground.

In contrast, Sally French (1993a:18) describes an occasion when the situation was not entirely due to visual impairment because it did involve social interaction, but neither was it due to any social oppression. It was a *combination of visual impairment, social interaction and environmental factors*. However, she explains that it was not something she could not cope with. Her solution was found in her ability to cope with the combination of factors that complicated lecturing to a group of students. She chose to find a way of coping with these problems, which visual impairment created within a social setting. French tells how people fixed in a definition of disability as only "socially imposed restrictions" compartmentalised her experience and judged her choice of a solution unworthy of consideration. French (1993a:19) writes:

> This gives rise to feelings of estrangement and alienation. Morris (1991) states: 'We can insist that society disables us by its prejudice and by its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our oppression.'

Although Sally French (1993a:17) agrees with the basic claims that disability is socially imposed, she points out that certain people experience profound problems with impairments that are not possible to solve by social manipulation.

It means that, for French (1993a:17), impairment of a body part may be as restrictive as social barriers are and it is not a matter that *either* impairment *or* social barriers are disabling, but that *both* impairment of a body part *and* social barriers are disabling. It means that a middle ground must be found between the biomedical model and the social model(s). The point to be made here is that it is not a choice between removal of social barriers or medical services of care that is needed, but it is *both* medical care *and* removal of social barriers that are required. It means that both social and physical considerations must be given attention.

Steep hills, blocked doorways and short steep ramps are dangerous or impossible to use for the wheelchair user, but also *physically fatiguing*. Zola (1982:54-58) expresses this difficulty when he writes about his experience with polio. He had to cover considerable distances and he had to use a wheelchair instead of his usual walking aids. Added to the unfriendly terrain is the aspect of physical exertion. Zola writes of body fatigue when trying to propel himself around the Village, a place for people who are restricted in mobility. Describing a journey to the supermarket, Zola (1982:54) writes:

> The supermarket was a considerable distance from here, on the top of a hill, the highest point in the Village. Off we went, with Pieter leading the way and I trailing behind. Up one hill, then another. My arms ached and I was winded.

Professor Zola (1982:55) then proceeds to write of the frightening return that was downhill in the wheelchair. This illustration described in Professor Zola's story reveals that there are a variety of needs that must be addressed for, and by, people who are differently-abled in mobility. This implies that using a wheelchair means expending physical effort to get about. Using legs to walk has considerable power, whereas the use of arms to manoeuvre a wheelchair, with the weight of a human being, requires more

energy and physical exertion. Consequently, environments with difficult terrain to manoeuvre by wheelchair make life very difficult for people disabled in mobility, because material structures and the physical body continually form barriers.

The relevance of this point is that personal experience, referred to as the individual experience of disability, cannot be denied. Eiesland (1994a:54) is also supportive of such an argument. Despite favouring the minority-group mind-set that emphasises social discrimination, she does not exclude the individual uniqueness of persons with a disability. The relevance for this study is what Sally French (1993a) suggests about a middle ground between the various mind-sets about disability that must be found to combine solutions where possible. These are perspectives that cannot be ignored. The point to be made is that removing environmental barriers is correct, but the physical impairment remains, which can be as disabling. Obliterating problems of environmental barriers can be extremely liberating, but the disability may not vanish.

Thus, disability is multidimensional and is characterised by diversities. We have already noted that this is supported by the new ICF's classification of disability, which uses the criteria of participation, activity, limits and restriction to define disability. If a person is, for example, restricted in activity or limited in participating in society because of high level cervical quadriplegia, the likelihood is that impairment is the primary dictator of the capacity of participation in society and secondary to social systems that enlarge the problem.

The problem, I argue, is that a model of disability that builds its solutions based on a perspective of disability as separate from impairment, lacks insight into the wholeness or totality of the concept of disability. It reverts to the old classification of the WHO, where impairment, disability and handicapped are regarded as three distinctions. Thus the emphasis on

reconstruction of the environmental perspective is in danger of providing only half a solution to the problems of participation by people who are disabled in society.

Another perspective of disability that is a problems are cultural forces of oppression that form bias against people with disabilities (Barnes 1996:56). This perspective is discussed below.

3.5.2.2 The politics of social, political and cultural shift

Cultural forces sometimes oppress groups; an example of this is the way women have been treated in the past (Barnes 1996:57-59). What then is meant by culture?

a) The power of culture

Emphasis was placed on culture as a system which signifies something through set signs, symbols and beliefs (Riddell & Watson 2003:5). Accordingly, it is the system which produces and communicates a social order, which people in society accept as values and meanings of their social experience. Consequently a dominant group forms from acceptance of a produced social order. This has certain consequences for how disability is perceived publicly.

Riddell and Watson (2003:1) point out that, firstly, the dominant culture in a society paves the way for how disability is perceived. Secondly, that people who are disabled share a culture of resistance. In other words, through acts of resistance to preconceived ideas about disability, people who are disabled take ownership of their shared culture. It means that culture can be a form of both oppression and liberation. In relation to disability it is connected to the experience of power, inequality and human interdependence (Riddell & Watson 2003:6).

However, cultural oppression was not given the recognition it should have. In contrast, earlier writings focussed on economic and material oppression. Only recently has attention been given to the cultural perspective and accordingly, importance to the political dimension (Riddell & Watson 2003:2).

In support of the argument for the need for the social, political and cultural dimensions to be recognised with regard to disability Jakubowicz and Meekosha (2003:180) point out that although cultural studies have addressed cultural diversities of racial and ethnic dimensions, the diversities of disability have not been recognised. Hence, the above authors suggest that proponents who consider the environmental and economic factors of oppression, and those who consider the cultural oppressive factors of disability, must support one another in their concern about disability instead of denying one or the other. It means that agreement needs to be found with French's (1993a) idea of "both/and" perspective to disability and "both/and" approach to personhood.

To increase understanding of disability we need to consider the question: What impact can cultural beliefs and meaning have on people in relation to disability? In response to the question, we note that people's reactions and responses to disability are prompted by their personal history, experiences and their relationship with the tradition and values to which they hold. A family with a member who is disabled, is influenced by their cultural, political and social group experiences and belief systems. These are intertwined with their own beliefs and values, which give them meaning for existence in their social context. It influences how they are perceived by their social peer group and how they perceive themselves (Macfarlane 1996:3; Wilson 2003:4).

The influence of a social group on somebody who is disabled is illustrated through an example of religious beliefs experienced in the story told by

Adele McCollum (1994:123), who grew up in a family through which she absorbed certain attitudes toward body and ability. When she presented herself in a way that warranted approval, her grandmother would say, "Handsome is as handsome does". When McCollum was sitting around doing nothing, her grandmother would say, "Idle hands are the devil's workshop". If she accomplished some physical feat that pleased her, her grandmother's remark was, "Pride goeth before a fall". McCollum's grandmother interpreted disability in the frame reference of Calvinistic providence in which the calamity of disability was probably a deserved punishment. If not punishment, then God had a lesson to teach the person. When McCollum later got polio, these cultural and religious beliefs and the values of her upbringing created problems for her in accepting her bodily changes. Adele McCollum (1994:124) writes:

> If I were to summarize the remnants of this mixed background, I would say that I was taught that health is both earned and deserved. It can be taken away by God if you are naughty. If you work hard and do as you're supposed to do you will avoid sickness and disability or at least overcome them, just as being good allows you to overcome death. Those 'afflicted' are probably lazy, secretly sinful, or being used by God to educate the rest of the world.

McCollum's religious setting set the tone for how she experienced her own disability, which she had acquired. It seemed that her later unpredictable, acquired body difference was pre-set with accusations, condemnation and judgement because she veered from the path of predictability. She perceived her changed body as a flawed body.

It is almost inevitable that the person who is disabled and the family will experience exclusion from society because their physical disablement is in the realm of the unpredictable. Unpredictable means abnormal in contrast to a predictable world perceived as one of so-called normality. The

presence of a congenitally disabled baby or an acquired disability, for instance, may give a sense of helplessness. Anxiety because of loss of control of what should be predictable normality, brings a sense of failed predictability (Wilson 2003:5). The tragedy of disability threatens what is perceived as normal and predictable (Clapton 1997:423).

In Adele McCollum's (1994:126) experience, the message she received from her religious background was that those with flawed bodies are sinful. Prejudice is, therefore, drawn into the drama of perfect/imperfect bodies, because of the notion of difference from a society's expectations.

b) The notion of difference

It is not difficult to conclude that cultural oppression is part of a disabled person's life. We have through the discussion above gained insight into the influence of culture that strongly suggests that most people are shaped by a shared image of the human body that is perceived as wholeness. Any difference from the perceived image of wholeness is laden with guilt and failure. Parents, for example, who conceive a child who is congenitally disabled often feel that they have failed in the expectancy of producing a normal child. Self-condemnation, grief and guilt may become part of their lives (Wilson 2003:28). *Differentiation and stigmas* are closely associated in relation to disability. The stigma of giving birth to a disabled child can penalise people because of the body image and expectations of a society.

Eiesland (1994a:58) refers to the proponents of the micro-societal interactionist's analysis of disability, which is presented in the theory of stigmatisation. These proponents maintain that stigmas are socially constructed and usually within relationships and interactions. Through social interaction, people who are disabled are 'marked' and excluded because of certain characteristics that they possess. It results in stigmatised identities which emerge through interpersonal interaction and

is a socially oriented problem (Eiesland 1994a:59-60).`

Shapiro (1999:100), in support, maintains society is saturated by oppressive attitudes and behaviour that stereotype people who are disabled. An example of stereotyping is illustrated when chronic pain is generalised and people who suffer from chronic pain have experienced being labelled as malingerers and economic burdens (Jacobs 1996:21). Accordingly, frail elderly people and people who are disabled have experienced economic policy-making that has allocated social benefits that fall short of enabling a viable existence in the market of present contemporary living. Thus, *prejudice, stereotyping and discrimination* are often related to disability. Because of the prominent interplay of these three forms of stigmatisation I shall deal with the three notions referred to by some proponents of the social model.

1) Shapiro (1999:100) points out that prejudice is derived from the word pre-judged. Prejudice may be defined as "A grossly simplified belief about the characteristics of some groups of people, which is uncritically generalised to all members of that group" (Shapiro 1999:100). Shapiro (1999:101) suggests that prejudice is basically an attitudinal and verbal problem. People often show their attitude and their beliefs about disableism in words and by body language.

An example is illustrated by Elly Elshout (1994:97) who felt bewildered, humiliated and angered when she was sitting in her wheelchair in church and the bishop suddenly came up to her and made the sign of the cross on her forehead on his way out of the church. The bishop had assumed that she needed this touch simply because she was in a wheelchair. Needless to say she felt violated and refers to the incident as a "clerical assault".

However, the question that comes to my mind is: Why? Why are prejudices formed? Sometimes insight into why certain behaviours and attitudes occur

can help to dissect demeaning, degrading actions. Young (1990:130) points out that people considered to be able-bodied have problems with identifying with the embodiment of people who are disabled. This is because encounters with different "others" cause people of the so-called superior group to feel insecure and to react by bodily responses of their own. Examples are ageism or disableism which confronts the individual with anxiety and fear that, but for good luck, the disabled body or aged body may be his/her body. Boylan (1991:1) remarks that "No one is immune from becoming disabled..." Wilhelm (1994:107,108) aptly expresses the cause of prejudice when she says: "Your images of normalcy or of my suffering actually cloud your vision. What you see when you meet me are *your fears* and *your hurts*". However, those who manifest such behavioural responses are seldom conscious of their actions or how the "different other" feels.

Some proponents of the social model therefore argue that people who are disabled are viewed as different and sidelined by society because of how their bodies are prejudged. However, prejudging people based on generalisations about them usually results in stereotyping them (Eiesland 1994; French 1993; Watson 2003).

2) Another way of stigmatising is that of stereotyping people. Stereotyping occurs when prejudice takes on the form of a specific belief regarding a particular group (Shapiro 1999:103). It means that continued wariness and prejudging of people eventually lead to a fixed belief about some people, which stereotypes them. Stereotypes are basically generalisations about a group that distinguishes them from others. Stereotyping may be seen as a categorising process, as well as creating a fixed idea to accompany the category.

The category of a blind person, for example, can be a factual thing, but when it is associated with judgments of persons who are blind and a picture is painted of people who are clumsy, with a "sixth sense", or are pale

because they never get into the sun, then it is stereotyping the person. Stereotyping causes people who are disabled to be perceived as different from others in a way that goes beyond the facts of the disabilities (Shapiro 1999:104). It means that the person who is physically disabled is perceived as a disabled person with fixed notions of non-value, instead of a person who has some form of disability that restricts some physical dimensions of life (Stiteler 1994:118). The problem with forming fixed ideas about people is that it exposes them to discrimination.

3) Discrimination has to do with unjustified behaviour toward people that casts a negative reflection about them. Prejudice that causes a stereotype creates discrimination. Prejudice is a thought while discrimination is an act. The one is a negative attitude and the other is negative behaviour (Shapiro 1999:120).

Discrimination, therefore, denies people equality in treatment. This is verified by the government of South Africa in that *The Equity and Employment Act* (1996) reveals that statistics show that the employment of people who are disabled is minimal. Also that public transport is inaccessible to most people who are disabled and the buildings where employment opportunities occur are usually inaccessible to wheelchairs.

It means that discrimination can be a process of obstructing people from being offered equal opportunities. These fixed prejudgements can result in discriminatory practices that exclude some people from public participation. Thus, the reason they are prejudged and stereotyped seems to be simply that they are different in embodiment. Hence, such *stigmas are closely linked to the notion of difference and identity.*

It may be argued, for instance, that as a group, people who are disabled gain a collective identity through categorisation as a group of people. However, it must be remembered that a "disabled identity" is not through

choice, rather it is what has been imposed on people by groups that are dominant in society. It must also be noted that even within a group of disabled people there are differences. People who are disabled fall into many small groups. There are multiple differences between the various types of disabilities, yet frequently all are lumped into one category. This means that people who are disabled cannot easily claim a collective identity.

However, to label and stigmatise people is to dehumanise and insinuate they are inferior. The result is that as a group these people are collectively relegated to being the different other. Parents of a disabled child, for example, may experience rejection, because they are treated as different by society. Sometimes the disabled child may become the unwanted child. Denying the humanity of the disabled child may result in breaking the link with the child. Dehumanising a person is a way in which people can *separate the unwanted into "us" and "them"* (Wilson 2003:8).

Denying the humanness of an individual provides excuses for action taken in an unpredictable and non-purposeful situation. Thus, separating us and them is often induced because people are labelled as "the different other." For people who are mobility disadvantaged, their bodily and social reality is "being different in body". Systems of power, however, manipulate their bodily difference and relegate them to the margins of society.

Young (1990:55), thus considers that *marginalisation* occurs when people are not considered to be fully human. Letty Russell (1993:23) seems to agree with Young (1990) when she suggests that some feminist understanding of persons who are marginal, is that they are perceived as less than human.

On the other hand, Volf (1996:16) considers marginalisation as the means of excluding groups or an individual mainly because they identify differently

with the community's formed beliefs, meanings and expectations. This means that collective enforcement of dominant traditional beliefs and values can exert power to exclude some people (Young 1990:129). In other words, through cultural expressions, the collective constructs the "different other" in a society (Fichter 1981:25-26; Jacobs 1996:25-26; Parmenter 1988:14; Young 1990:58).

In criticism of the construction of the "different other" by society, Volf (1996:17-18) argues that the themes of identity and "otherness" must not be suppressed when considering people who are pushed to the margins. The above author points out that the identity of a person is attached to particularities of a social setting in which the person is born. Identity is formed in interaction with significant others, a particular human language, religious beliefs and meaning systems. In other words, identity is shaped partly by the recognition received from the community in which people live. Volf (1996:19) proposes that "...nonrecognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being."

The relevance of what Volf (1996) implies is important for this study because criticism about exclusionary acts are mostly argued from the point of view of human rights. It means that important themes, such as identity and difference, also closely associated with exclusionary actions, are sacrificed. Human rights may be an important aspect of giving voice to the cause of disability, but it is equally important how relegation to being the different other reflects on the identities of people who are disabled. Stereotyping people in a way that identifies them with connotations of being inferior, being less valuable and being denied opportunities to belong in societies, subjects them to discrimination and exclusion from society.

Valerie Stiteler (1994:117) illustrates being excluded as a fellow human being when she tells of an experience when going to feminist gatherings

expecting to be treated with warmth by feminists who were able-bodied. However, she often experienced feelings of fear and guilt from these fellow women. Her experiences of their reactions ranged from being infantalised because of assumptions that she needed them as caregivers, to that of hostility and rejection. Stiteler felt violated and invalidated by such responses to her disability. These feminists understood womenhood to mean fit able women and thus reflected perceiving that women with disabilities embody all that they do not want to be. It meant that negative attitudes and behaviours were generated toward disabled women. Accordingly, the reclaiming of power for women in general only resulted in relegating people with disabilities to difference and disempowerment.

Moreover, the proponents of the cultural oppression perspective argue two main dimensions of the notion of difference in association with disability. On the one hand, there is the argument, such as held by the disabled minority movement, that commonality, universality and collectivity will give people who are disabled empowerment and a sense of belonging. On the other hand, there is the argument that diversity of disabilities must be recognised and receive attention.

With the rising of disabled people's movements, emphasis was placed on the commonality of oppression experienced by people who are disabled. The importance of this emphasis was that its strength is seen to be the way in which such commonality will empower disability movements to have a voice in policy-making and legislative systems about disability (Priestley 1999:219). However, there are problems that occur when basing our argument on the commonality of disability.

The point Riddell and Watson (2003:7) make is relevant in criticism of ideas about commonality. These authors argue that the assumption of commonality of disability produces a fixed identity for people who are disabled because of the image of the impaired body. The objection is that

this is the way culture can act as a structure of power to present a popular consciousness that enables manipulation of groups of people by groups who obtain dominant status through these structures of power. The result, however, is that the formation of normality is an exercise of power. What is relevant is that the dominant social expectations influence how we think and how we react to people. Conforming to dominant expectations of a society is rewarded, whereas failure to conform is relegated to the realm of deviancy (Drake 1996:148)

However, it was through the challenge to these structures of power represented by popular consciousness that some proponents of the social model took the perspective that the struggles of power can result in inequalities. But because of these inequalities, sub-cultures can arise to challenge what is understood as dominant cultural power struggles. It is possible, for instance, to identify several sub-cultures of resistance that have arisen over twenty years to resist the notion of health as an important symbolic realm for creating identity (Oliver 1996:28-29; Riddell & Watson 2003:8). The relevance of this is the importance of a culture of disability resistance that can challenge these symbolic creations and recreations of personal identity.

Hence the need for the emergence of the culture of disability movements in resistance to fixed beliefs and values about disability. The power of resistance is that it challenges dominant mind-sets and raises political consciousness to counter-act the limited ideologies, which have instigated distorted images of people who are disabled. The power of challenging the distorted ideologies that result in a fixed "disabled identity", is that these people who are disabled can develop a more positive identity (Riddell & Watson 2003:9).

Ricoeur's (1992:43) notion of narrative identity (see chapter two) is relevant to the influence of counter-resistance to the major perceptions

about disability. The power of narrative mediation is that it can bring difference and identity into a unifying structure through narrative plot that structure different temporal experiences of the human story into a complete story. It is, therefore, a means of being critical in reflecting on ideologies of oppression and the actions of configuration and refiguration that challenge such ideologies. It makes it possible for people who are given an identity fixed in a body-image, of being "what" or an object, to be identifiable in a world through imagination and be identified as "who", in other words, to be perceived as a whole person with physical and mental capacities (Ricoeur 1992:44, 133).

The importance of what has been discussed above is the thought that transformation needs to take place through social, economic and political actions that acknowledge the construction of a culture that accepts difference instead of oppressing people who are different (Barnes 1996:56). French (1993b:74) points out that when people deny our disability they deny who we are. This means that when difference is denied or not acknowledged, this not only denies personhood, but forces the individual to act in the way society wants. Thus, seeing people who are disabled as not different results in denial of the unique needs that each individual experiences. It is the difference between disabilities that changes how people experience their disabilities (French 1993b:75-76; Morris 1993b:103; Morris 1993a:42-43).

Morris (1993b:106) states an appropriate finish to voicing what has been discussed above:

> Physical disability and illness are an important part of human experience. The non-disabled world may wish to try to ignore this and to react to physical difference by treating us as if we are not quite human, but we must recognise that our difference is both an essential part of human experience, and, given the chance, can

create important and different ways of looking at things.

In conclusion the relevance for this study is that two main forms of oppression are identified through the social model, namely environmental, material, economic oppression and socio-cultural oppression. It will be argued that anything other than exploring disability from a physical, material, economic, political and socio-cultural perspective is not exploring disability from a holistic viewpoint. The point is to attempt to solve the social problems identified from all the above perspectives. A multidimensional understanding is important because I am of the opinion that material environmental barriers, cultural codes and beliefs and the uniqueness of the person all contribute to understanding disability. Thus, a broader understanding of disability that includes all these factors referred to is required. This is the topic of the next section.

3.6 DEVELOPMENT OF A PSYCHOSOCIAL MODEL

During this discussion on the biomedical and social models' perspective of disability, attention was drawn to the suggestion that a new language was required to describe disability in a way that enables it to be understood by all and not only from a specific professional level.

The new classifications instituted by the ICF do address some shift in thinking that articulates disability differently. I have already pointed out that the old classification of disability made by the WHO referred to three distinctions in terms of disability that reinforced the individualistic mode of the biomedical model of disability (see 3.2.1). However, the new classifications of the ICF have changed the emphasis to a broader yet more specific understanding of disability. Disability is conceived as interaction between health-related conditions, environmental and personal factors

(AIHW 2001). Although the emphasis remains located in health and disease and therefore leads to a health-related classification, disability can be described as one or all of the above. The key features are the two domains of activity and participation that are means of measurement for the classification of disability.

An argument addressed through some proponents of the social model was that a balance needs to be kept between the individual and collective dimensions of disability (3.5). Accordingly, the ICF's classification reported by the WHO (2001) provides the vision for a new language to describe disability holistically instead of individualistically.

I continue this argument in a discussion of the interaction between biological, psychological and social aspects in relation to the typology of chronic disease of Rolland's (1989, 1993, 1994) and related emotional and social demands on the life of the family (see 3.6.1). It will form the basis for the suggestion of an unfolding narrative model for people who are mobility impaired (see 3.6.2). A short conclusion is given (3.7).

3.6.1 Rolland's psychosocial model of chronic disease

Rolland (1989:433) draws attention to the fact that in chronic disease the focus has been on criteria set by biomedical systems. However, the interaction of the disease process, the individual, family and the different bio-psychosocial systems is needed. In other words the family unit, medical and paramedical professionals are involved in the disease course of a person with a chronic illness, but this should expand to address the development of the chronic illness experience in relation to all of life. The above author points out that it is important to understand what he calls the evolutionary thread that intertwines in the phases of chronic disease in relation to the individual and family life.

By the way Rolland (1994:6-7,10) makes the noteworthy point that the need for a psychosocial dimension of addressing chronic disease arises because in the past psychosomatic processes have been expressed in pathological terms that have derogative connotations for people who are chronically ill. Unfortunately, normative bio-psychosocial processes are also defined as psychosomatic, which results in the tendency for the individual and family members to be labelled as dysfunctional. Rolland (1994:10-11) therefore suggests that treating psychosomatic processes from a normative perspective provides for psychosocial factors to be important in the healing process.

Atwood and Weinstein (2004) take up Rolland's (1989, 1993) reference to psychosomatic processes and point out that chronic disease is considered as largely determined by a conflict of life-style behaviours that has to do with extended or decreased recovery time of the disease. I, however, am wary of the term psychosomatic, because irrespective of the medical reasons for the new use of the term, a negative connotation remains. It still reflects the idea that the person and family are dysfunctional and responsible for the disease process. Rolland (1989), Atwood and Weinstein (2004) write specifically from the point of view of the medical practitioner's involvement in dealing with chronic disease. In my opinion it still retains some of the medical influence of control.

Urdang and Swallow (1983:74) in *Mosby's Medical and Nursing Dictionary* refer to psychosomatic as: " of or pertaining to psychosomatic medicine. 2. relating to, characterized by, or resulting from the interaction of the mind or psyche and the body 3. the expression of an emotional conflict through physical symptoms. A psychosomatic approach: the interdisciplinary or holistic study of physical and mental disease from a biological psychosocial and sociocultural point of view".

I am of the opinion that the explanation of a psychosomatic approach, by

Urdang and Swallow (1983), gives a better understanding of the development of a chronic disease in relation to the emotional and socio-cultural demands that the disease course puts on the family unit. Thus, I prefer to refer to the unfolding of the disease course that results in interaction with psychological, physical and social demands on the individual and different family members and significant others. In addition, it has a broader influence on all significant related environments, such as economic, political and religious structures that all influence the coping ability of the individual and different family members with the illness. I will, therefore, focus on the above perspective when discussing the chronic disease relationship in the individual and family unit.

Returning to Rolland's (1994:102-103) consideration of chronic illnesses, he considers chronic illness in relation to family systems theory and certain key concepts of the family system's notion of life cycle. Key life cycle concepts, such as life structures, developmental tasks, periods of transition and centripetal and centrifugal periods are the means of providing the foundation for a discussion of illness and disability. It provides a means of gaining insight in what practical and emotional demands occur when an illness invades an individual's and family's life at a specific point of the life cycle.

Life structures are described as patterns of a person's and family's life at any specific point in the life cycle. Some examples of life structures are marriage, relationships, roles in relation to self and others and occupation. Developmental tasks are marked by periods or phases of different tasks in relation to the development occurring at a specific period of the life cycle (Rolland 1994:104-105). Thus, it is an important point in relation to the invasion of a chronic disease. Another key concept of life cycle is that the generational family systems move between periods of high family cohesion (centripetal period) and lower family cohesion (centrifugal period).

The above key concepts are the prime consideration in integrating chronic illnesses into the family life cycle that provides for a psychosocial language to describe and understand the emotional and practical demands of chronic disease on the individual and family unit.

Rolland (1989:434, 1993:446) therefore proposes a typology of chronic illnesses that is based on key concepts that uphold distinctions of different patterns of the phases of the disease process. The phases are: 1) *onset*, with the distinction of *sudden versus gradual*; 2) *course*, which have the distinctions of *progressive versus constant, constant versus relapsing/episodic*; 3) *outcome* which consists of *fatal versus shortened lifespan, shortened life-span versus nonfatal*; 4) *degree of incapacitation* with the distinction made between being *present or absent*. In addition, there are three key time phases, which are: 1) *crisis*; 2) *chronic*; 3) *terminal*.

Atwood and Weinstein (2004) refer to a life event which broadly describes important events of the individual's and family unit's experiences that introduce significant changes to the patterns formed in the life cycle of an individual. The above authors explain becoming chronically ill as a life event. Generally life events are categorised in three ways; normative age graded events, such as marriage; having children or mid-life changes; normative history graded events, such as wars, economic catastrophe; and non-normative events, such as unemployment, illness or disability. Rolland (1994:127) refers to the importance of the cultural and religious belief systems on the life of people, however, this will be discussed more broadly in chapter five. The relevance at this point is that belief systems impacts on the life structures or life events.

Rolland (1994:57) introduces the metaphor of illness as a member of the individual and family life cycle. It means therefore that the disease development course phases and the disease time phases intrude into the life

of the individual and family with different impact on the family's structures and functionality, depending on what period is invaded by the disease process.
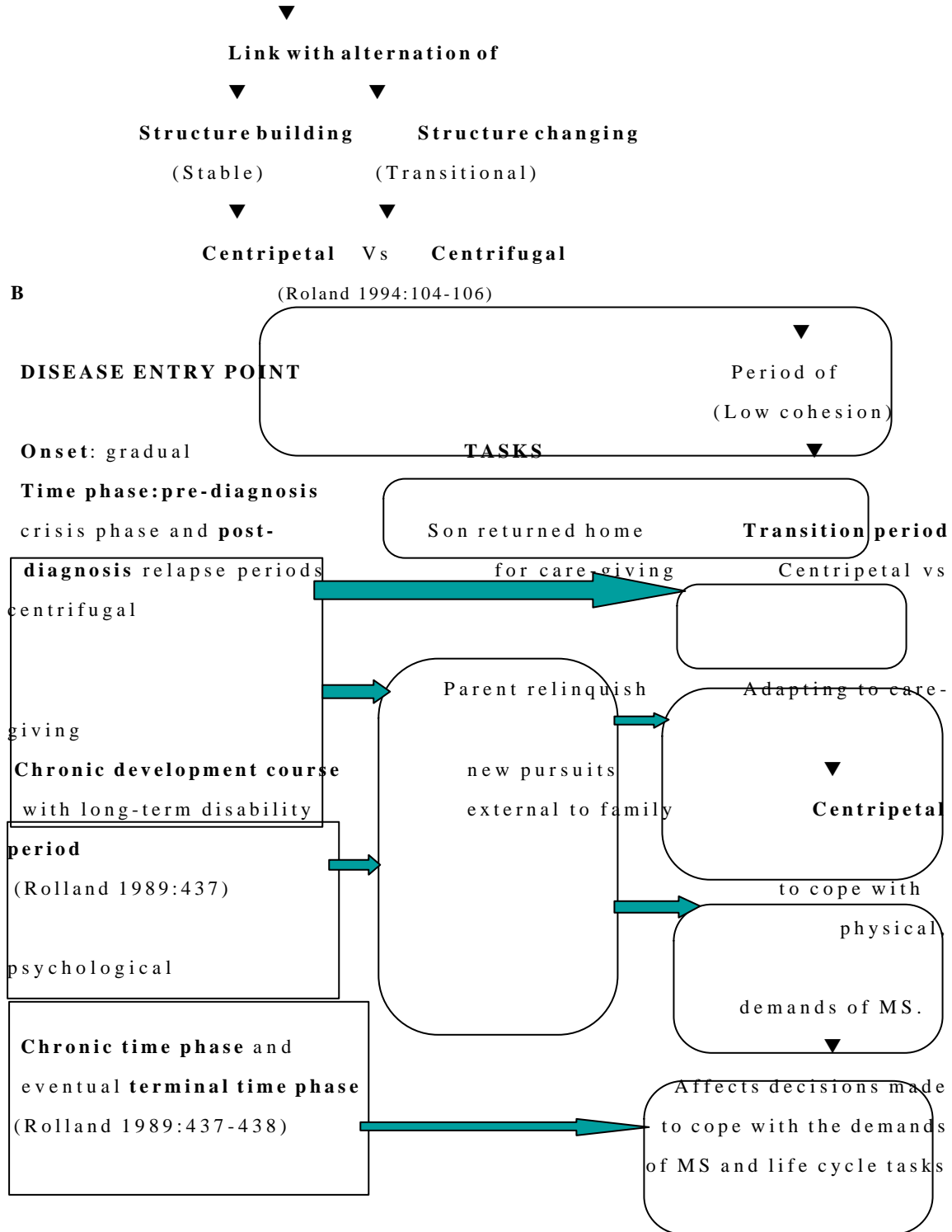
In addition, the adaptation and functionality of the family unit are also influenced minimally or maximally in respect of the specific periods of transition, and whether these occur in the period of centripetal or centrifugal of the individual and family life cycle. Any transition between developmental phases of an illness result in crucial individual and family adaptations to disease and life events.

Rolland (1994:52-53), therefore, compares the similarities between the chronic disease time phases and specific time periods in relation to transitional periods with the life cycle development of human existence or socialisation. An example is the period of transition from childhood to adolescence, where a prolonged period of learning to adjust to and accommodate the related events of life takes place. Thus, insight in a psychosocial understanding of the illness can be gained (Rolland 1994:43). An example of an imaginary family of four will be used to give an idea of the interaction between a chronic disease and the developmental life cycle in figure 3.1 below. The family consists of parents who have recently retired, an elder son who used to live in his own flat and experienced the gradual onset of multiple muscular sclerosis from the age of 22 years, which was diagnosed at 24 years. Another brother of 19 years is studying and lived on the university campus. Diagrammatically the interaction of the unfolding of the disease in the developmental life cycle of this family could be described as follows:

Figure 3.1 The interaction between a disease, individual and family members

> **A   The point of development of the life cycle:** transition to retirement

and a period of early adulthood of both the children (Rolland 1994:104).

▼

Link with alternation of

▼ ▼

Structure building **Structure changing**

(Stable) (Transitional)

▼ ▼

Centripetal Vs **Centrifugal**

B (Roland 1994:104-106)

▼

DISEASE ENTRY POINT Period of

(Low cohesion)

Onset: gradual **TASKS** ▼

Time phase:pre-diagnosis

crisis phase and **post-** Son returned home **Transition period**

diagnosis relapse periods for care-giving Centripetal vs

centrifugal

Parent relinquish Adapting to care-

giving

Chronic development course new pursuits ▼

with long-term disability external to family **Centripetal**

period

(Rolland 1989:437) to cope with

physical

psychological

demands of MS.

▼

Chronic time phase and

eventual **terminal time phase** Affects decisions made

(Rolland 1989:437-438) to cope with the demands

of MS and life cycle tasks

All the above interactions between disease course, time phases and life

cycle events and related developmental tasks will have an impact on the coping skills, organisational structures and teamwork or pulling apart of the family members, depending on the psychological and social demands exerted by the disease interaction with the family life cycle at certain points of the cycle. The above diagram is only an example of the unfolding of a disease in interaction with the life cycle and developmental tasks.

Figure 3.2   An example of the interaction in the psychosocial development of tasks

Adjusting to early **relapsing course** of MS and the **crisis time phase** home

Early MS

father

(Rolland 1989:436)

the

Later MS   (Period of high cohesion)

Adjusting to **chronic developmental course, chronic to terminal transition** **time phase task** (Rolland 1994:23)

Life cycle development put on hold e.g. the youngest son recalled

because of financial stress or the

returns to work. Greater focus on

internal structures of teamwork and coping skills of individual and family.

Alternation between **stable** and

Alternation between **centripetal and centrifugal** periods of high/low cohesion

It is this interaction between the time phases and typology of illness that provides a chronic disease psychosocial-developmental model. Rolland (1989:440) considers that the time phases "...can be considered broad developmental periods in the natural history of chronic disease". It is the interaction with the disease course that unfolds into the drama of human life. Ambitious plans of a mother, for instance, may be put on hold to

accommodate the situation of a pre-school child who is asthmatic. The mother may give up her employment to remain at home in case the child has an asthma attack.

Rolland (1989, 1993, 1994) proceeds to refer to family-systems in relation to chronic disease, but I will only refer to some ideas from family-systems thinking in the next section on a model for mobility disability.

The main points that I will use from Rolland's (1989, 1993, 1994) ideas of chronic diseases, but in relation to mobility impairment, are as follows:

1) because of mobility impairment's prolonged nature it can be classified as different from acute medical conditions, and

2) there is interaction between the biological and psychosocial dimensions

3.6.2 An unfolding narrative of mobility impairment

I note that Rolland (1989:434) considers chronic disease in relation to the individual and family members. I, however, will refer to the course and time phases in association with mobility impairment and the interaction with the personal *narrative* of the individual living with mobility impairment and the family narrative in relation to the *narrative* of social and political life of a society. It means that, instead of developmental family system theory a *narrative* theory perspective will be discussed.

It is noteworthy that Rolland's (1989, 1993, 1994) psychosocial model for chronic illness addresses not only the disease, but also the context of the collective, that is the family. In a sense chronic disease, individual and family members are addressed in the context of a sense of belonging. It assumes that the individual belongs to a family. In chapter two it was discussed that members of a society interact reciprocally and share

narrative accounts with one another. The stories of the collective become "entangled with one another" and the shaping of both personal and collective identity occur.

In a similar way the metaphor of mobility impairment as a member of the family may be understood as including mobility impairment as an ongoing experience with the individual, family members and significant others. The interaction between mobility impairment and individual, family and significant others result in certain biological and psychosocial developments. The advantage of connecting narrative identity theory to the above idea is that the function of narrative is to disclose actors and actions of a story. It can enable a holistic understanding of living with mobility impairment as narrative has the power to disclose what is going on in the experience of living with mobility impairment, and also disclose how the individual, different family members and significant others respond to the physical, emotional and practical demands of the disability. The relation of the theories of psychosocial development of chronic disease of Rolland (1989, 1993, 1994) and narrative theory and narrative identity of Ricoeur (1992, 1995) is important.

The relevance is that narrative can disclose the sufferers in the story of living with a mobility disability and facilitates the possibility of action to be taken and moral assessment of such actions which can help to facilitate a collective identity and strengthen personal identity.

How then can narrative meaning be integrated into a model of mobility impairment? The aim is to bridge the gap between the biological language of the biomedical model and the social model. In doing so, I propose what I call an unfolding of the narrative of mobility impairment. It is proposed that the prolonged nature of mobility impairment can give rise to temporal narrative events.

These temporal events can be connected to give an understanding of the whole biological dimension of mobility impairment. Next, the interaction of the unfolding narrative of mobility impairment with the different phases of the life span, or life cycle, of the individual, family and significant others gives rise to temporal narrative events that can be pieced together. It forms a whole story of the interaction between mobility impairment and the emotional and practical demands on the individual, family and significant others. Finally, the demands and practical tasks and associated decisions made can have consequences for the social, political, economic and religious dimensions of life or the external environment of the individual and family.

The unfolding narrative of life with mobility impairment can be likened to a folded Persian carpet that, as it unfolds bit by bit, reveals portions of its pattern that are part of the whole pattern. It can, however, only be seen as a whole once it is completely unfolded. In the same way mobility impairment exposes its biological or bodily patterns, as these unfold, in connection to the events of living day by day with mobility impairment. These narrative plots, when connected, unfold the whole narrative of living with mobility impairment.

The connection, therefore, between the unfolding narrative course of the biological dimension of mobility impairment when linked to the time phases, will enable the consideration of mobility impairments in relation to narratives of the unfolding biological and psychosocial narrative of life. This means that: 1) the different types of mobility impairments are entangled with other narratives of life; 2) the individual's life-story with the mobility impairment is linked to a pre- and post-disability life; 3) the family members also have life-stories connected to pre- and post-disability life; 4) the society in which the individual and family live, has narratives of social and political dimensions of life in relation to mobility impairment.

The relevance of these narratives of human life and mobility impairment is that they are entangled with each other with prime consequences that may be life-changing in a positive or negative way for all involved. How then do I propose to describe the process of linking the biological dimension of mobility impairment and the psychosocial dimensions of living with being mobility disadvantaged?

Through the use of ideas from Rolland's (1989, 1993, 1994) developmental course and time phases of chronic diseases, the aim is to describe mobility impairment in a way that is inclusive of bodily, environmental and cultural factors related to activities and participation. The importance of the relationship of bodily impairment, environmental and cultural factors was discussed in chapter three. Thoughts from the ICF's (WHO 2001) criteria for classification in terms of capacity and performance in relation to activity, activity limitation, and participation or participation restriction will, therefore, be intertwined in the discussion.

Thus, because mobility impairment has many types of disabilities associated with it, it may be grouped according to differences and similarities of its biological "story" that unfolds through different narrative phases of the individual's, family's and significant others' interaction of life. Mobility impairment can, therefore, be conceptualised over time and over an unfolding narrative of the biological course relating to chronic diseases, aging or post-trauma. There are differences and commonalities to be found over the prolonged narratives of living with mobility impairment.

Elderly frail people, for example, are mobility disabled, but their circumstances are different from those of people who are quadriplegic. The frail elderly may be restricted in mobility for a number of reasons, such as bodily weakness, chronic disease or even senility (Koenig 1994:25). The quadriplegic is usually restricted to a wheelchair because of tetraplegia, but different people have a different extent of restriction in mobility. A person

with tetraplegia, for instance, at thoracic one level has greater mobility than someone who is permanently traumatised at cervical four/five level, yet all are mobility impaired in some way or other. It therefore allows for the uniqueness of the individual, the uniqueness of the family unit life-style.

Of interest is what Fennell (2000) calls a four-phase model for treating the chronically ill person, which is also a systems approach to chronic disease. The four phases she refers to are crisis, stabilisation, resolution and integration. Although Fennell (2000) claims that the four-phase model considers the body and mind of the person and the family, friends, clinicians, colleagues at work and the community, I find it fairly restricted to the importance of medical treatment for chronic disease. The point, however, that is made that chronically ill persons never leave the phases and that the process of maintaining themselves in integration of the illness is relevant because it suggests an ongoing process of illness. I also prefer the use of the expression stabilisation or stabilising in the second form of the course phase because it expresses the rehabilitating period of the condition.

Accordingly, the unfolding biological narrative of mobility impairment that I consider consists of the events: onset, course and incapacitation.

3.6.2.1 The unfolding mobility impairment phases

a) The onset phase of mobility impairment

The onset of an acquired mobility impairment may be gradual. Multiple sclerosis, frailty and paresis are examples of gradual restrictions in mobility. Koenig (1994:24), for example, points out that physical functions decline because of aging. However, the onset may also be sudden, as in acquired quadriplegia or paraplegia after trauma to the spinal cord or a stroke.

The difference between the two types of onset is that gradual onset may give time to adjust, but because of the protracted nature it may be stressful since it is a slow and ongoing loss of mobility. Sudden onset is without warning, with the result that all is thrown into a rush of changes and losses almost simultaneously with no time to prepare for adjustments (Rolland 1993:449).

b) The course phase

Three general forms or episodes may be considered: that of progressive, constant or stabilised and relapsing or unstable.

i) Progressive form

The progressive form of the course refers to conditions that are progressive in nature, such as Alzheimer's disease and frailty, which are ongoing in nature. This means continual care-giving and loss of independence is usual. Arthritis may, for instance, progress with the loss of different kinds of functions that have an impact on family structures of organisation. Koenig (1994:29) notes that relatives caring for the frail aging person are often overwhelmed with responsibilities because of the progressive physical losses and restriction of mobility.

ii) Stabilising form

During the stabilising form of the biological narrative, the situation stabilises and grants the opportunity to constitute better functional actions of care-giving and adaptation to the condition causing the mobility impairment. Examples of this are amputees, stroke victims, paraplegics and quadriplegics. After a period of rehabilitation, life is more stable and predictable over a reasonable time span. It means that individuals with mobility disabilities and their significant others can form a workable routine

around the elderly disabled person or chronic disease or post- trauma impairment. It also means that sometimes the temporality of this form of the course may result in fear of relapses or more loss as a constant reminder hanging over the individual and family (Fennell 2000; Rolland 1993:450).

iii) Relapsing/episodic form

The disease or condition may have periods of relapsing or destabilising for different reasons. Chronic illnesses, such as multiple sclerosis, arthritis and reoccurrence of a stroke, are examples. However, paraplegia and quadriplegia have related conditions that can have the same effect of destabilising the individual and family structures of organisation and relationships. O'Day, Dautel and Scheer (2002:42), for example, point out that pressure sores, urinary tract infections and pulmonary problems are part of life for paraplegics and quadriplegics. These conditions can influence the stability of these people's lives.

Moreover, what must be noted is that the unfolding biological narrative with its different time-related episodes have implications for the person, family and significant others. If a quadriplegic develops bedsores, for example, this results in the routine of home care being destabilised because of the need to manage the bedsores, which changes the normal daily routine. It means greater liaison with the health-care institution and the ramifications that go with it, such as transport problems, time- consuming visits to the hospital and adhering to medical care-management control. It can also destabilise the social situation because it may mean that the individual and the care-givers are more isolated from their community for prolonged periods.

However, transition between the forms of the course events of mobility impairments may occur, but re-adjustments to these transitions may or may not be made by the individual and family. The more frequent the exchange between the three forms, the greater will be the impact on individuals and their significant others.

c) Incapacitation phase

The incapacitation phase applies to the outcome of the disease progress, such as cancer or AIDS, which is terminal. It also applies to conditions that do not result in a shortened life span, but result in permanent incapacitation, which may be stabilised incapacitation or ongoing incapacitation. An example of stabilised incapacitation is paraplegia and quadriplegia where, after a certain period, the extent of the loss of body function is established and remains the same.

Ongoing incapacitation is, for example, found in multiple sclerosis where the individual may experience episodic relapses of the disease with increased incapacitation. The events of incapacitation constitute the period during which the individual and family must come to terms with losses. Changes of the role expectations of family members occur, loss in role status expectation results and the family's structures and its social structures endure losses. In other words, there are psychosocial consequences.

Rolland's (1989, 1993) notion of the three time phases or periods will be dealt with in the next section. I, however, refer to the time phases as the unfolding of living with mobility impairment in relation to certain periods or time-related phases.

3.6.2.2 Unfolding psychosocial time-related phases

These time-related phases are directly connected to the biological dimension of mobility impairment in relation to the sociological and psychological narratives of life. How does this happen? Three time-related episodes are considered, namely the time-phases of crisis, chronic adaptation and losses. These time-related episodes in the unfolding psychosocial narratives of mobility impairment , therefore, cannot be seen as separate from the unfolding biological narrative of mobility impairment.

a) The crisis time-related phase

This period extends from the time of presentation of mobility restrictions, but with the cause of the problem not known, to when the problem has been diagnosed. This refers mainly to chronic illness. However, in traumatic spinal cord experiences and frailty because of aging the period lasts from the onset events to the time of diagnosis.

During this period the individual and family have different tasks to accomplish. Especially in acquired mobility impairment, the family must learn during this period to deal with disease symptoms and/or bodily changes and incapacitation. It means learning to deal with the health-care institution and related treatment with its time-consuming demands that invade family life. Included in the drama of living with mobility impairment are stressors attached to finding meaning for what has happened. Grieving losses and the invasion of pre-trauma or pre-illness or pre-aging identity, to mention a few, are stressors that can be experienced (Rolland 1993:452). A sense of continuity or loss of continuity between past and present needs to be dealt with during this period.

Whether the onset event is gradual or sudden will have an impact on how

the individual and the family manage the psychosocial crises that occur and how they reorganise disrupted family routines and adjust to the bodily changes, routine changes and demands that occur. A gradual onset may give the individual and significant others the chance to adapt more easily because of the expanded period, but it may cause increased stress because there may be a lengthy period of anxiety before diagnosis is achieved. The element of not knowing is stressful. A person with multiple sclerosis, for instance, may experience a lengthy crisis period because of the difficulty of diagnosing the symptoms over an extended time. The stress of not knowing why something is wrong while constantly interacting with medical professionals can create anxiety and insecurity for the individual and family members.

However, a sudden onset, such as immediate paralysis, may throw the individual and significant others into greater chaos and difficulty in working toward goals for reorganisation to adjust to the changes that have occurred. An example of this is when the father of a family has an accident that results in quadriplegia. Sudden role expectation changes occur within the family in addition to the anxiety about loss of employment and finances, among other losses.

The point to be made is that, alongside the biological dimension, changes of functional tasks intrude into the lives of the person who is mobility impaired and the immediate family that are emotionally distressing and can have an impact on all members socially. An example is when isolation occurs because of increased business with reorganising family structures of care-giving.

b) The chronic adaptation time-related phase

This period is the day-to-day living with the biological outcome of the disease, aging process or permanent damage. It is also the period where

there are greater links between biological and psychosocial constructs of life. It is usually the phase in which the individual and family come to terms with permanent changes, incapacitation, organisational necessities and future goals of managing the changes brought about by the aging process, chronic disease or trauma (Rolland 1993:149-152).

The chronic adaptation period can be short or lengthy depending on the biological interaction of disease, post-trauma damage or aging, with the individual, family and significant others. Quadriplegics and paraplegics will, for instance, possibly experience a longer stablising period once they have gone through the crisis period of rehabilitation in the health-care institution. Possibly, for them the chronic re-adjustment period will be prolonged because of the huge adjustments to be made in their lives not only during the period of rehabilitation during hospitalisation, but also on returning home.

Moreover, the changes influence the individual and family, because they have to re-adjust from a home and social life that they previously assumed to be normal life to a seemingly abnormal way of living. The conflict between pre-disease, pre-aging, or pre-trauma and the post-morbid state can be intense. The tension between the expectation prevalent in society about what is normal and the situation of living with mobility impairment can create conflicting emotions for the family.

The added isolation from the community, especially during the re-adjustment period, can result in unresolved conflict within the family unit. The clarity of identity, based on pre-morbid remembrance, may become uncertain because of role changes that can make identifying with their communities difficult. Loss of role status as breadwinner has every possibility of changing how the family will identify with its social communities in future.

c) The time-related phase of losses

During this period the family must come to terms with loss because of death or permanent loss of mobility. It presents episodes of resolving unfinished business and mourning. It also has to do with the resumption of family life in some form of normality, either beyond death or living with the constant reminder of the loss of bodily function (Rolland 1989:442-443).

Frail elderly disabled persons, for example, because of the constant threat of severe pulmonary infections, may die. The family needs to come to terms with the possibility of loss through death. After death the family's organisational structures are disrupted, because of funeral arrangements and the ramification of a member of the family dying. After this the family must resume normal daily life.

However, the paraplegic, quadriplegic or stroke victim, for instance, needs to individually come to terms with loss of body functions. Also, they need to come to terms with loss in relation to being a member of a family and a member of a collective society. Thus, grieving and mourning characterise this period.

In conclusion of this section, I note that the linking of the biological and psychosocial worlds provide a framework of common themes or narrative plots that influence the individual, family and social environments. The main narrative plots present are: disruption to the family routine organisational structures, which results in changes in role and status, relationship problems arising from unresolved conflict among family members, losses occurring along the unfolding course of mobility impairment, such as loss of independence, mobility and finances, as well as isolation.

3.7 CONCLUSION

Now that there is a way of linking the biological narrative with the psychosocial narrative of mobility impairment, a broader understanding of what living with mobility impairment is about is possible. It gives a link between the biological and psychosocial worlds. It allows for a language to consider the narrative links between mobility impairment, the individual with mobility restrictions, the family, significant others and their social, political and religious narratives.

Consequently the next section of tracing a narrative path of people who are disadvantaged in mobility through an empirical study is considered. So far it has been discussed how the biological language can be connected to the psychosocial narratives of life with mobility impairment. In a previous section of this chapter the biomedical and social models of disability were discussed, but only a few references were made to the South African scene. In the next chapter I intend to recount narratives of three people who are mobility impaired that will give some idea of the experiences of living with mobility impairment in South Africa. Although no universal or even regional claims are made in this research, the unfolding stories of the participants will reflect some perspectives of experiences with mobility impairment.

154