

**DISABILITY IN SOUTH AFRICA: A THEOLOGICAL AND
SOCIO-ECONOMIC PERSPECTIVE**

by

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Declaration

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Abstract

The United Nations (UN) declared the period 1983 to 1992 the “Decade of Disabled Persons”, and introduced the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. The Rules demonstrate a strong commitment to upholding human rights and provide guidance for policy formulation to improve the lives of persons with disabilities through their equal participation and maximizing their welfare.

There is no consensus on a definition and measurement of disability (Altman, 2001; Mitra 2005:7). The study used the medical, social, and theological models to explore the theoretical, conceptual and theological meaning of living with disabilities; examine the respondents’ perceptions of the church’s influence on their spirituality and daily lives; describe the respondents’ socio-economic conditions with particular attention to civic participation, discrimination, employment, education and health, and make recommendations, based on the findings, to inform policy on people with disabilities in South Africa.

The researcher adopted a qualitative and quantitative approach in the study. The population consisted of parents or caregivers to minor and adult children with varying degrees of disabilities, adults with physical disabilities, and family members with disabled persons. Data was collected by means of informal and semi-structured interviews, focus group discussions, and observation.

The main barriers to participation were that the respondents did not feel well enough to participate owing to their disabilities; lack of money; lack of confidence, and the attitudes of others either in the community, at work or at service points.

Choice and control in the respondents’ lives was established to be an important aspect of wellbeing and life satisfaction. The respondents who felt they had a choice were satisfied with the services they received. The respondents with mental health conditions reported the least positive experiences and outcomes. Many of the barriers they reported related to their lack of confidence and the attitudes of others in their communities.

The study was limited to a relatively small sample of respondents in the greater Cape Town area in the Western Cape, comprising only Evangelical Christians. Consequently, the findings cannot be generalised to all areas of the country and all the Christian churches.

Keywords: Accessibility; barriers; church; disability; impairment; theology

Table of Contents

CHAPTER 1: Orientation to the study	1
1.1 INTRODUCTION.....	1
1.2 RATIONALE FOR THE STUDY.....	2
1.3 RESEARCH PROBLEM.....	3
1.4 PURPOSE OF THE STUDY.....	4
1.5 THEORETICAL FRAMEWORK.....	5
1.6 LITERATURE REVIEW.....	7
1.7 RESEARCH DESIGN AND METHODOLOGY.....	7
1.7.1 POPULATION AND SAMPLE.....	8
1.7.2 DATA COLLECTION AND ANALYSIS.....	9
1.8 ETHICAL CONSIDERATIONS.....	9
1.9 DEFINITIONS OF TERMS	9
1.10 OUTLINE OF THE STUDY.....	11
CHAPTER 2: Conceptual and theoretical framework.....	12
2.1 INTRODUCTION.....	12
2.2 DEFINITION AND CLASSIFICATION OF DISABILITY	12
2.2 CAUSES OF DISABILITY	14
2.4 THEOLOGY OF DISABILITY	16
2.5 THEORETICAL MODELS OF DISABILITY	19
2.5.1 Medical	19
2.5.2 Social.....	21
2.5.3 Theological	22
2.6 POLICY ON DISABILITY	23
2.6.1 South African disability policy.....	23
2.6.2 International initiatives.....	27

CHAPTER 3: Research design and methodology	32
3.1 INTRODUCTION	32
3.2 PURPOSE OF THE STUDY	32
3.3 RESEARCH DESIGN AND METHODOLOGY	32
3.4 RESEARCH POPULATION	33
3.5 SAMPLE AND SAMPLING	33
3.6 DATA COLLECTION.....	34
3.6.1 Questionnaire.....	34
3.6.2 Interviews	34
3.6.3 Focus group discussions	35
3.7 VALIDITY AND RELIABILITY	35
3.8 DATA ANALYSIS	35
3.9 ETHICAL CONSIDERATIONS	36
CHAPTER 4: Disability and the Church.....	37
4.1 INTRODUCTION	37
4.2 DISABILITY AND THE CHURCH	37
4.3 CONGREGANTS' PERCEPTIONS OF THE CHURCH.....	40
4.3.1 Inclusion and accessibility	40
4.3.2 Ministry and service	43
CHAPTER 5: Socio-economic conditions of the disabled.....	49
5.1 INTRODUCTION	49
5.2 RESPONDENTS' PROFILE	49
5.3 TYPE AND EFFECTS OF IMPAIRMENT.....	50
5.4 CIVIC PARTICIPATION AND SOCIAL NETWORKS.....	53
5.4.1 Isolation and contact with others	53
5.4.2 Sources of emotional support	54
5.4.3 Social activities	55

5.4.4 Social engagement with groups.....	57
5.5 PERCEPTIONS AND EXPERIENCE OF DISCRIMINATION.....	58
5.5.1 Disability in relation to the social model.....	59
5.5.2 Experience of discrimination	60
5.5.2.1 Disability-related discrimination	61
5.5.2.2 Difficulties accessing goods and services.....	62
5.6 EMPLOYMENT	63
5.6.1 Working status	63
5.6.2 Working and out-of-work respondents.....	63
5.6.3 Barriers to employment	66
5.6.4 Attitudes to work.....	68
5.7 EDUCATION	69
5.8 HEALTH AND WELL-BEING.....	70
5.8.1 Quality of life	71
5.8.2 Barriers to accessing health care services	72
5.8.3 Information and advice on health	73
5.7 CONCLUSION	73
CHAPTER 6: Conclusions and recommendations	75
6.1 INTRODUCTION	75
6.2 PURPOSE OF THE STUDY	75
6.3 FINDINGS.....	75
6.4 RECOMMENDATIONS	77
6.5 FURTHER RESEARCH	80
6.6 LIMITATIONS.....	81
Bibliography.....	82
Appendix A: Questionnaire	88
Appendix B: Letter of ethics clearance	97

List of Tables

Table 1 Respondents' age and sex (n=460).....	50
Table 2 Respondents' impairment and age (n = 460).....	51
Table 3 Respondents' number of impairments (n=460)	52
Table 4 Frequency of respondents' contact with people outside the household (n=370).....	54
Table 5 Respondents' view of the impact of their impairment on their daily life (n=460) (%) ...	59
Table 6 Respondents' types of discrimination experienced (n=208)	61
Table 7 Last time respondents were in paid work (those not currently working) (n=345)	64
Table 8 Respondents' perceptions of privacy and dignity (n= 379).....	72

List of Figures

Figure 1 Disability-poverty cycle	30
Figure 2 Last time respondents not currently working were in paid work by age (n=345).....	65
Figure 3 Proportion of respondents who agree with statements about work (n=148).....	68
Figure 4 Whether respondent would like to participate in more education or training, or do any courses by age (n=460)	70

CHAPTER 1: Orientation to the study

1.1 INTRODUCTION

The United Nations (UN) declared the period 1983 to 1992 the “Decade of Disabled Persons”, and introduced the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*¹. The Rules demonstrate a strong commitment to upholding human rights and provide guidance for policy formulation to improve the lives of persons with disabilities through their equal participation and maximizing their welfare.

There is no consensus on a definition and measurement of the controversial and complex phenomenon of disability (Altman, 2001; Mitra 2005:7). Different conceptual models have been developed for definitional purposes, including the charity, medical and social models (Altman, 2001; Pfeiffer, 2001; Campbell, 2001). The charity model views persons with disabilities as elements of pity, and therefore to be helped by welfare approaches (Coleridge 1993). The medical model considers disability a problem of the individual directly caused by a disease, an injury, or some health condition, and requiring medical care in the form of treatment and rehabilitation. Individuals with any impairment are considered disabled, where “impairment” is used for their condition, irrespective of whether the individuals experience limitations in their activities. The medical model is often opposed to the social model, which views disability purely as a social construct where the problems of the disabled are either caused or exacerbated by the society in which they live (Mitra, 2005:8).

The theological perspective of disability is based largely on two fundamental but divergent aspects: the creation of humans in the image of God and the linking of disability to divine punishment for sins. Both these aspects have played a fundamental role in advocating for the rights of the disabled whilst exacerbating discrimination against people with disabilities. However, the chief concern in the theology of disability

¹UN General Assembly resolution 37/52: World Programme of Action Concerning Disabled Persons. Available on: <http://www.un.org/disabilities/default.asp?id=23> (last accessed: 20 June, 2010)

should be what it means to talk about the image of God in relation to persons with disability

In an effort to influence policy on persons with disabilities, a broader approach to understanding disability has prompted research into the consequences of disability on individuals with particular emphasis on their environment, cause and prevention as opposed to cure. Most notable of the probable consequences are that disabilities can reduce these persons' chances of obtaining employment, impede their attempts at self-employment in the informal sector, impose medical and other costs that they would not otherwise have to bear, and exclusion from the productive economy (Aliber 2003:482).

To overcome the definitional problems associated with measuring disability as a straightforward and objective entity, Schneider, Claassens, Kimmie, Morgan, Naicker, Roberts and McLaren (1999) suggest a subjective approach where a disability is determined by the person experiencing it. For the purpose of this study, disability will be defined as a limitation in one or more activities of an individual's daily life. Such activities include seeing, hearing, communication and locomotion.

1.2 RATIONALE FOR THE STUDY

In South Africa, structural and moral discrimination prevents children and adults with disabilities from exercising the same rights as other members of society. While South Africa has a relatively generous social security system for a developing country — including a means-tested non-contributory disability grants² for those incapacitated to

² According to the Black Sash, From 1 April 2011, the maximum amount of Older Person's Disability Grant was R1 140 per month and to be eligible for a Disability Grant, the applicant must:

- have a medical assessment which is no less than three months old which confirms they have a disability in terms of the Social Assistance Act; and
- be between 18 and 59 years old; and
- have assets and income that qualify them for being 'in need' (see means test below).

They will not qualify if they refuse to undergo medical treatment or do any work that they could do; or are cared for by an institution wholly funded by the state – e.g. an old age home, psychiatric hospital, prison, or a treatment centre.

work, old-age pension and child support grants for the care-givers of children — poverty is rife and many are either unable to access these grants (Seekings, 2005; Nattrass 2006a). At the same time, poverty is rife among the disabled and the disability social safety nets are either inadequate or non-existent. Little has been achieved in including people with disabilities in the development process, and it appears that this is partly due to a lack of a holistic approach to disability policy formulation and negligence by civil society.

Interventions to equalise opportunities for the disabled in South Africa have not reached all who deserve them. According to Nattrass (2006a), many of the most vulnerable have been left out, either due to their ignorance of the existence of such interventions or because these interventions have not spread to all parts of the country, especially rural areas. Some interventions appear to be aimed at cost-effectiveness rather than needs-based. The main problems hindering efforts at equalization are politicking and the fact that most interventions are not research-based. This motivated the researcher to undertake this study.

1.3 RESEARCH PROBLEM

Although exceptional amongst middle-income countries, the South African welfare system has done little to increase participation of the disabled in the development process (Nattrass, 2006a) and while the Disability Grant system (DG) has grown rapidly in recent years, many deserving people have been left out of the system due to the ‘means-test’ and age restrictions³ for grant recipients as well as being inaccessible in

In terms of being ‘in need’, both the assets and income of the applicant and their spouse are assessed through a *means test* to see if they qualify. For 2011, the asset threshold (maximum value of what they own) was R752 400 for a single person and R1, 504, 800 for married people. And the income threshold was a maximum of R3 740 a month for a single person (R44 880 per year); and R7 480 a month for married people (R89 760 per year).

Available on: http://www.blacksash.org.za/index.php?option=com_content&view=article&id=891&Itemid=178
[Last accessed: 24 January, 2012]

³ In order to qualify for the DG, an applicant must be “owing to his or her physical or mental disability, unfit to obtain by virtue of any service, employment, or profession the means needed to enable him or her to provide for his

some parts of the country (Mitra, 2009). As such poverty has persisted among the disabled. Even with increased efforts at participation in policy making for the disabled (Kleintjes, Lund, Swartz, Flisher, 2010), structural and social barriers have meant that the disabled perform far worse in terms of other socio-economic indicators such as, education, employment and access to essential services (Loeb, Eide, Jelsma, ka Toni & Maart, 2008). Additionally, while Christianity teaches that all people (or mankind) are created in the image of God which is reassuring to a disabled person who might experience discrimination from society, it is still arguable that the Christian faith has contributed positively and negatively to the constructions of disability present in society and their participation (Njoroge, 2005; McNair & Sancez, 2007). In a time when the Christian church's role in social development is under increasing scrutiny, it is important that researchers extend this line of inquiry to all level of social life. One avenue that is beginning to develop is the relationship between disability and the Christian church and fellowship.

1.4 PURPOSE OF THE STUDY

In light of the situation analysed above, the purpose of this particular study was to

- Explore and determine the theoretical, conceptual and theological meaning of living with disabilities in South Africa.
- Examine the relationship between the church and its disabled congregants with regards to inclusion, accessibility, ministry and service as well as to understand how this relationship has influenced the spirituality and daily lives of these congregants.
- Analyse the socio-economic conditions of disabled people in South Africa with particular attention to civic participation and discrimination as well as access to employment, education and health and other essential services.

or her maintenance.” Applicants must be age 18 to 64 for males and 18 to 59 for females. (the Social Assistance Act (Act 59 of 1992/Act 13 of 2004)).

- Make recommendations, based on the findings, to inform policy and scholarship on issues of living with disabilities in South Africa.

1.5 THEORETICAL FRAMEWORK

The medical, social, and theological models of disability and the relationship between disability and poverty formed the theoretical framework of the study. These models were chosen because they could help in solving most of the definitional problems and the gaps in policy on disability. The researcher was of the opinion that policy defines disability in terms of its medical or social manifestation separately, without considering the two models as complementing each other.

In the medical model, disability is considered a problem directly caused by disease, injury or other health condition. The intervention required is medical care in the form of treatment and rehabilitation (Mitra 2005:7). The medical model regards individuals with impairments as disabled, where “impairment” is used for individuals’ condition, irrespective of whether they experience limitations in their daily life. This is often the basis for designing interventions and welfare programmes (the charity model) mainly focused on cure. Therefore in the model, disability is regarded predominantly as a health and welfare issue with the view that welfare institutions should be conduits for interventions.

In the social model, disability is not an attribute of the individual, but is created by the environment in which the individual lives (Mitra, 2005; McNair & Sancez, 2007). Therefore, social change is the fundamental intervention in this regard. At the political level, disability becomes a human rights issue especially when interest groups challenge the status quo and call for recognition, equal rights and/or elimination of barriers to participation. The social model suggests the existence of a complex form of institutional discrimination, which leads to a collective disadvantage of the disabled manifested in such things as the built environment, institutional arrangements and education systems which do not cater for diversity (Mitra, 2005:8-12).

Regarding poverty and disability, the disabled have a higher propensity for poverty because of institutional, environmental and attitudinal discrimination. They may face this from birth or from the time of their disablement onwards. In institutional discrimination, established laws, social customs or practices systematically marginalize disabled people whilst shared attitudes, values and beliefs influence discrimination against the disabled.

The relationship between poverty and disability can be seen from the birth of a disabled child or the disablement of a child at a certain stage in life. These children will need more care and may not be considered to have the potential to be self-supporting in the future. Given the limitations in resources, it may be difficult to provide the required care for them and they may be less likely to attend school due to perceived coping problems or stigmatization. With their future compromised, they are more likely to inherit poverty later.

Some aspects of the theological model seem to portray people with disabilities as weak, needing care and not so clean. Fast (2011) alludes to the New Testament in support of this argument in relation to the connection between sin and disability. She refers to the first three chapters of the Gospel of Mark where the disabled is referred to as the man with an unclean spirit (1:23), a leper (1:40), a paralyzed man (2:3), and a man with a withered hand (3:1). Also, in Mark 2:10–12 according to Fast, Jesus tells the paralytic: *“But so you may know that the Son of Man has authority on earth to forgive sins, I say to you, stand up, take your mat and go to your home.”* The man then stands up, walks out and all are amazed and glorify God (*Ibid*, 418). Further arguments related to this observation include Moltmann (1998) who argues that the disabled are regarded as not being equal to others and hence not fully human. According to Eiesland (1994:147), the church justifies this view from different theological perspectives such as the interpretation of disability as a punishment for their own or their parents’ sin; a consequence of lack of faith, or a sign of demonic activity and moral failure.

According to Reynolds (2008) the inherent conservative structures in the Christian church still inhibit progressive perspectives of disability thereby leading to “pastoral

counselling to the disabled designed to address the presumed causes of their punishment”. At the same time, however, the scriptures and the church also advocate for human rights, which is important for the disabled to live with a certain level of freedom and fairness. For example, man’s creation in the image of God (Gen 1:26, 27), and the Lord promising comfort to Zion, salvation forever and never-ending deliverance (Is 51:4-6).

1.6 LITERATURE REVIEW

The researcher conducted a literature review on disability, and theories on and approaches to disability in order to familiarise himself with existing material and research on the topic. The literature review covered books, journals, reports and Christian scriptures.

1.7 RESEARCH DESIGN AND METHODOLOGY

The researcher adopted a qualitative and quantitative approach in the study. A qualitative approach was selected because the study wished to determine the respondents’ views on disability. The essence of qualitative research is a belief that multiple realities exist and thus create meaning for individuals studied. Individuals who participate in social actions come to know and understand phenomena through these interactions. The qualitative approach enabled the researcher to examine the observable and learned patterns of behaviour, explore the social or human problems, build a complex, holistic picture, and conduct the study in a natural setting (Creswell, 1998).

Quantitative research employs numbers and statistical methods and is based on numerical measurements of specific aspects of phenomena (Murray 2003: 2). The study wished to measure the extent of the respondents’ disability (moderate or severe) and examine their experiences in terms of burdens of daily life, the nature and impact of the present interventions, and their views on interventions required to improve their lives.

In this study, the researcher's immersion came naturally for two reasons. Firstly, the researcher is living with disability and maintains regular contact with other disabled people in a strong informal network. Secondly, the researcher is spiritually a practising evangelical Christian. The researcher was thus immersed in and well positioned to observe the general disability landscape in South Africa and the behaviours of the un-disabled towards the disabled.

The researcher's immersion was supplemented by informal discussions with academics knowledgeable on disability; health care workers; community and church leaders, and local and central government officials. The discussions focused on issues affecting the welfare of the disabled.

1.7.1 POPULATION AND SAMPLE

The population for the study consisted of parents or caregivers to minor and adult children with varying degrees of disabilities, adults with physical disabilities, and family members with disabled persons.

The participants were located mainly through a snow-balling exercise. The respondents were recruited from places of worship, universities, homes for the disabled, and their own homes around the greater Cape Town area in the Western Cape Province. Wherever possible, the interviewed participants were asked to identify others they thought could be included in the survey (i.e., other households where disabled persons lived or other disabled individuals they knew). To be included in the study, participants had to: (1) have a disability or have first-hand experience of caring for a disabled person; (2) be evangelical Christian spiritual believers (at least in their opinions), and (3) attend church with some level of regularity.

1.7.2 DATA COLLECTION AND ANALYSIS

Data was collected by means of informal and semi-structured interviews, focus group discussions, and observation. Data analysis began at the same time as data collection and involved classifying, categorizing and coding qualitative and quantitative data to enable computer analysis for statistical construction. Quantitative data was analysed using SPSS and excel computer programs and the results were presented in percentages, diagrams and tables.

1.8 ETHICAL CONSIDERATIONS

Ethics deals with matters of right and wrong. *Collins English Dictionary* (1991:533) defines ethics as “a social, religious, or civil code of behaviour considered correct, esp. that of a particular group, profession, or individual”. In this study, the researcher observed the following ethical considerations:

- **Permission.** Permission to conduct the study was obtained in writing from the University of Stellenbosch
- **Confidentiality and anonymity.** The researcher assured the participants that all the information gathered would be treated sensitively and confidentially and the identities and interests of all participants protected.
- **Informed consent.** The researcher informed the participants that participation in the study was voluntary, without any form of coercion and that they had the right to withdraw from the study at any stage and for whatever reason.

1.9 DEFINITIONS OF TERMS

For the purposes of this study, the following terms were used as defined below.

- Accessibility: Accessibility is a general term used to describe the degree to which a product, device, service, or environment is available to as many people as possible. It can also be viewed as the "ability to access" and benefit from some system or entity⁴
- Barriers: A barrier may be something immaterial that obstructs or impedes such as intolerance or physical such as a wall or fence (Free online Dictionary)⁵
- Church: According to Catholic encyclopaedia, (citing Bellarmine, De Eccl., III, ii, 9) church is defined as "A body of men united together by the profession of the same Christian Faith, and by participation in the same sacraments, under the governance of lawful pastors, more especially of the Roman Pontiff, the sole vicar of Christ on earth."⁶ In this respect, 'men' refers to 'human beings' regardless of their race, sex or age.
- Disability: "A disability is a condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term is used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment mental illness, and various types of chronic disease"⁷
- Impairment: Impairment may be defined as "any abnormality of, partial or complete loss of, or loss of the function of, a body part, organ, or system." (The Free Dictionary)⁸
- Theology: "theology is a belief system that is built upon intellectually and emotionally held commitments concerning God and man" (Bible.org)⁹. Also the term 'man' in this definition refers to all human beings.

⁴ Wikipedia: <http://en.wikipedia.org/wiki/Accessibility> (Accessed 14 June, 2010)

⁵ On: <http://www.thefreedictionary.com/barrier> (Accessed 14 June, 2010)

⁶ On <http://www.newadvent.org/cathen/03744a.htm> (Accessed 14 June, 2010)

⁷ On: <http://www.disabled-world.com/disability/types/#ixzz1ZR91N6fA> (Accessed 14 June, 2010)

⁸ On: <http://medical-dictionary.thefreedictionary.com/impairment> (Accessed 14 June, 2010)

⁹ On: <http://bible.org/article/what-theology> (Accessed 14 June, 2010)

1.10 OUTLINE OF THE STUDY

Chapter 1 presents an orientation to the study.

Chapter 2 discusses the literature review conducted for the study.

Chapter 3 describes the research design and methodology.

Chapter 4 discusses the results of the empirical investigation.

Chapter 5 concludes the study and presents the synopsis of findings and recommendations.

CHAPTER 2: Conceptual and theoretical framework

2.1 INTRODUCTION

This chapter puts the concept and the dynamics of disability into perspective using available literature. Under the chapter, the definitions, classification and causes of disability are provided as well as the theology of disability as argued by various writers. This is followed by theoretical perspectives of disability in terms of the theology and sociology of disability, and the vicious circle of poverty and disability.

2.2 DEFINITION AND CLASSIFICATION OF DISABILITY

There is no consensus on a definition and classification of disability. However, various authors and institutions have often defined this phenomenon based to the context and purpose for which the definition is meant. Scholars have been at loggerhead over defining disability *as a social problem*, rather than a medical problem (Reindal, 2010) but it seems that the world bodies are getting closer to a universally accepted definition.

As far as their progress is concerned, two things have taken place. In 1999 the World Health Organization (WHO) published the *International classification of impairments, disabilities and handicaps* to provide a unified and standard language for the description of human functioning and disability as an important element of health. This classification of functioning is based on the individual and society levels of life, and includes a list of environmental factors that may have an impact on these aspects (WHO, 1999). The UN Convention on the Rights of Persons with Disabilities also debated the definition of disability, and the final draft will soon be submitted to the UN General Assembly for

approval¹⁰. According to Leonardi, Bickenbach, Ustun, Kostanjsek, Chatterji (2006), the WHO was mandated to produce a world report on disability and rehabilitation to collate the best evidence about the prevalence, distribution, and trends of disability and recommend action.

According to Elwan (1999:2), definitional issues underlie some if not most of the difficulties when attempting disability statistical analysis while the same issues are encountered in medical and genetic discussion (Cox-White & Boxall, 2009) and on the social side of things, inclusive education needs are also affected by definitional issues (Reindal, 2008). These issues also make it difficult to understand the conceptual questions shaping the efforts of those working on disability and its related fields which, has made it more imperative than ever to find an all-inclusive acceptable definition. Nonetheless, differences in classification and definition persist across time and space especially based on culture and political agendas of states. Schneider *et al* (1999) regard the phenomenon of disability as relative because impairments considered disabling to some may not be so to others. For example, some countries classify certain mental and psychological conditions as disabling while others do not hence which according to Elwan (1999) has led to huge gaps in policy response across countries. Even the attitudes towards disability differ considerable across time and space in that what some cultures consider disabling may not be deemed so in others (Harris-White 1996; Webb-Mitchell, 1996).

It seems then that a subjective assessment of disability may be more problem solving. However this is still problematic to the outsider such as a disability legislator or an educator in that disability is intrinsically difficult to observe and requires subjective assessment by the afflicted and verification by members of the disabled person's social setting (Yeo & Moore, 2003). To enable the subjective assessment according to

¹⁰ United Nations Enable. Eighth session of the ad hoc committee on a comprehensive and integral international convention on protection and promotion of the rights and dignity of persons with disabilities. <http://www.un.org/esa/socdev/enable/rights/ahc8.htm> (Aug 14- 15, 2006) (accessed June 05, 2009)

Reynolds (2008), behavioural, cultural and political views have to be combined especially since the afflicted is not always the policy make.

Webb-Mitchell (1996:126) defines a disability as “whatever a particular group of people defines as a disability” and therefore, every disabling condition is a cultural invention or social construction rather than a personal or private problem. Furthermore, with regards to the cultural issues, Varenne and McDermott (1998) found in their ethnographic study of the cultural constructs of American public schools that the source of disability is society rather than the individual who is different. Varenne and McDermott (1998) argue that the definition should be based on how society treats the disabled other than what they can and cannot do. They argue that during policy discussions, “the subject shifts from *them* to *us*, from what is wrong with *them* to what is wrong with the culture that evolved a disabled separate to the rest of society” (*Ibid*, 144).

There are also effects of language in which case some terms used to refer to the person with a disability may be construed as disabling or inappropriate in some societies. According to Blair and Davidson (2003:72), the language used to describe persons as disabled, handicapped, impaired, challenged and retarded, or even in a more seemingly positive light as differently-abled or special-needs people, is crucial in the construction of the broader discourse that in turn comes to be experienced as social reality by those being described.

2.2 CAUSES OF DISABILITY

There are many causes of disability as observed in available literature. However, Doyal (1983:8) emphasises that classifying the causes of disability is not a straightforward affair because it is embedded in a mixture of contributing and causal factors. For example, Elwan (1999) links disability to poverty because most of the immediate causes of disability relate to people’s well-being and can be or have been eradicated by improving their living conditions especially through advances in economic growth and human development. Also the causes vary across countries as Helander (1995) notes that the cause structure of disability in the developing countries varies markedly from that in the developed world. Elwan (1999) maintains that regardless of the classification, the

proportion of disability caused by communicable, maternal and prenatal diseases and injuries in developing countries is much higher than in developed countries. The reason for this is arguably the fact that all these causes can be eradicated with an improvement in the health system as well as making the health system accessible to all. This argument provides the most believable linkage between disability and poverty (Elwan, 1999:47).

Helander (1995:24) stresses that it is possible to prevent all these causes of disability to a greater or lesser extent. Regarding the health-related causes, prevention programmes need to be implemented mainly through immunization programmes. For example, a great deal of progress has been made towards eradicating poliomyelitis and measles in many parts of the world including the developing world. This has had a direct and noticeable effect on the prevalence of disability among the population. According to Helander (1995:24), global vaccine coverage for poliomyelitis and measles was 78% at the end of 1994. Communicable eye diseases, such as river blindness and trachoma have been largely reduced, while insufficient resources are available to deal with non-communicable eye diseases, such as glaucoma and cataracts (Elwan 1999). Helander (1995:24) points out that nutritional deficiencies are rapidly reducing because of large-scale interventions but progress on preventing chronic non-communicable diseases, accidents, and mental illnesses will require greater effort than currently in place. In the developed world, the largest proportion of disability is due to non-communicable diseases. In 1971 the greatest single cause of impairment in adults in Britain was arthritis (Harris, Cox & Smith 1971:59). In 1980, the three leading disabling conditions of British children were mental sub-normality (35%), cerebral palsy (15.2%), and 13.8% Spina Bifida and hydrocephalus (Baldwin & Glendinning 1981:122).

In 1980, the major causes of disability among children were inadequate nutrition of mothers and children, including vitamin deficiencies; abnormal pre-natal and or peri-natal events; infectious diseases; accidents; environmental pollution, and impairment of unknown origin (UNICEF 1980:12). Contrariwise, in a study of fifteen low and middle income countries conducted between 2005 to 2006 by Gottlieb, Maenner, Cappa &

Durkin (2009), nutritional deficiency were found to be the most influential causes of disability in child.

During the 1980s the main disabling communicable diseases included poliomyelitis, trachoma, onchocerciasis (river blindness) and leprosy (Doyal 1983:8). HIV/AIDS has since been added to these. UNAIDS (2007:3) estimates that more than 33 million people including two million children are infected with HIV/AIDS worldwide, a proportion of whom are suffering from varying degrees of disability, and nearly 14 million people have died from AIDS-related causes since the epidemic began. Other notable causes include malaria and measles as major non-trauma causes of disability in children while trauma causes include landmines and automobile accidents (Eunson, 1999). The spread of trachoma as well as of polio and schistosomiasis in developing countries is widely related to lack of adequate sanitation and, in turn, considered a poverty-related cause of disability (Khan & Durkin, 1995).

Nutrition and mental retardation have been seen as influential especially in child disability (UNICEF, 1998). Moreover, child malnutrition is linked to impaired intellectual development to child malnutrition (UNICEF, 1998).

2.4 THEOLOGY OF DISABILITY

Fast (2011), Reynolds (2008) and Moltmann (1998) highlight the theological perspectives of disability as a behavioural versus spiritual consideration by unravelling the meaning of the *Image of God* (Gen 1:26, 27) in relation to disability.

The basic thesis of the “creation of man in image of God” in the context of disability follows from the scriptures which say that God created the first humans in his own image, in other words, man is created in the likeness of God (Gen 1:26-30). Although humans were created to be God-like, they are now sinful and unlike God in their morality (Rom. 3:10, 23). Nevertheless, they retain God's image (Gen. 9:6; Jam. 3:9) because there is always a potential to reform.

Two Christian themes have significant implications for theological perspectives on disability, namely *imago dei* and incarnation, and are related to the concept of body theology. Body theology draws on the inherent goodness and dignity of humanity (West, 2004). Yet all forms of disability, defect, and impairment or perceived abnormality tend to be ignorantly viewed as the result of original sin, either directly or indirectly. However, as observed by Creamer (1995) the tenet of creation in the image of God tends to encourage a higher, more dignified assessment of the human condition by virtue of the divine identity. Thus, even though the originally pure image is blemished by sin, it nonetheless remains.

Although the human body exists with varying degrees of imperfection, to be divine humans should perceive one another as persons of infinite value to God and to one another. With this in mind, Moltmann-Wendel (1995:36) questions whether the human body is a good creation of God.

The incarnation of God in the person of Jesus Christ is viewed as the cornerstone of the Christian gospel. According to Moltmann-Wendel (1995), the human Jesus in the Gospel of Mark shows very marked human reactions, "...which have been retouched with great skill in the later Gospels". Jesus is said to be annoyed with the disciples (Mk 8:17f; 9:19) and angry with the Pharisees (Mk 3:5). He sighs (Mk 8:12); welcomes children not just as teaching illustrations but also as equals and worthy of the kingdom of God (Mk 9:36; 10:16), and shows compassion (Mk 1:41). These images show Jesus as a functional human being, needing company and tenderness, but also capable of passion and anger. In the Gospel of Mark, Jesus has a body and a human soul and is portrayed as normal but still divine. It is from this body - and not from his will, his head or his spirit - that the energies which heal the woman with the issue of blood emanate (5:30) (Moltmann-Wendel, 1995:46).

Eiesland (1994), Creamer (1995) and Black (1996) call for a redefinition of the symbols for God and Jesus Christ that reflect the experience of humanity. Their views reflect liberation theology compared to other views that concentrate mainly on practical aspects.

Eiesland (1994) calls for the symbol of Jesus Christ as the “disabled God” to be reoriented in that people with disabilities gain access to the world of religious symbolism, particularly the symbol of Christ on the cross, wounded, living and dying in weakness and disability. Eiesland also emphasises that in his resurrected form, according to scripture, the symbol of Jesus retains his wounds. Creamer (1995:32) believes that just as Jesus was resurrected with his wounds, people with disabilities will retain their disabilities even in heaven.

Creamer (1995:33) argues that if human disabilities are taken as signs of being physically broken, and thus an indicator of spiritual brokenness, what can the kingdom of God hold for them? Does salvation require humans to become something other than what they are? Since there is a promise that “we will all be ‘whole’ in heaven”, does that mean the disabled will not have their disabilities, yet disability is a central part of who they are? This would imply that one cannot be whole without it.

Black (1996:34) agrees with Eiesland and Creamer that “wholeness” need not involve “cure”, but must involve a realization of interdependence with God and, for that matter, all the universe. According to Black (1996:34), human life is interconnected and interdependent so that what one does affects the lives of others and the earth itself. Thus, the “cause” of disabilities (and all suffering, natural disaster, and social injustice) arises from this interconnection of the material universe and not from God or sin, as traditional Christian belief posits. Based on the doctrine of interdependence, Black (1996:34) proposes a “homiletic of healing” by addressing five disabilities (blindness, deafness, paralysis, leprosy and chronic illness, and mental illness) as depicted in the healing stories of the Gospels.

With regards to access for the disabled, Wilke (1980) highlights the attitudinal barriers that contribute to physical and architectural barriers, which discourage and even prohibit persons with disabilities from fully accessing the community of faith. Wilke invites faith congregations to consider the special needs of people with disabilities and to bear in mind that they also have exceptional abilities. In the same regard, Webb-Mitchell (1996) addresses issues of social avoidance, historical and theological understanding, as well

as inclusion and integration of persons with disabilities. He offers inclusive perspectives of the Church and the contributions of people with disabilities to society with the church as sanctuary. This highlights the importance of acceptance within the community as an alternative to a society that is generally hostile to perceived abnormality and the Church working as a conduit for social responsibility of congregations in the broader context of community (Webb-Mitchell 1996:51)

Govig (1999) discusses the practical issues of ministry with families coping with mental illness, while offering concise pastoral theology for understanding, mediating, and advocating with and for families seeking Christian fellowship with congregations. Newman and Tada (1993) explore the roles of pastors and volunteers with regard to people with disabilities and list useful resources for clergy in their work with people with disabilities.

2.5 THEORETICAL MODELS OF DISABILITY

Attempts to define disability in terms of its medical or social manifestation, without considering the two models as complementary, have sometimes led to controversial policy formulation. As such, the argument that disability should be defined as “whatever a particular group of people defines as a disability” (Webb-Mitchell, 1996:126) seems proper. In other words, every disabling condition is seen as a cultural or social construction rather than as a personal or private problem. This study examined the medical, social, and theological models of disability.

2.5.1 Medical

The basic thesis of the medical model of disability is that; a person’s functional limitations (impairments) are the root cause of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure (Crow, 2010). In the medical model, disability is considered a problem of the individual that is directly caused by a disease, an injury, or some health condition. Medical care is the only intervention required for such anomalies and takes the form of treatment and rehabilitation (Mitra,

2005:7). In the medical model, individuals with impairments are considered disabled, and “impairment” is the term used for their condition, irrespective of whether they experience limitations in their daily life.

Within the framework of development intervention, the medical model of disability has been extended to include a charity dimension. The medical model considers disability as predominantly a health and welfare issue and welfare institutions are conduits for interventions. Also, the disabled are largely incapacitated, unable to adequately help themselves and hence needy. Therefore, interventions focus on the inability of individuals to perform their functions due to their physical or emotional nature and/or caused by war and violence, poverty, failure of medical devices, unhealthy lifestyles, accidents, and environmental considerations. Little attention is given to what the ‘disabled’ can offer themselves and the larger society in which they live. For this reason, the medical model of disability is considered patronizing (Shakespeare, 2002:19-21)

The medical model may be also be the basis for exclusion of the disabled. Perceived exclusion and segregation of the medically disabled, led organizations to design patronizing welfare programmes (the charity model) as well as ways to cure the afflicted in the hope that their afflictions would be eradicated permanently (Yeo & Moore 2003:582). These welfare programmes are mainly geared to the provision of hand-outs and free treatment to the afflicted as the necessary interventions.

The medical model was developed on the assumption that disabled people were hated or feared due to their afflictions and the onus rested on the non-disabled to provide treatment and alternatives to begging in order to create a semblance of normality in the lives of the disabled. The downside to such an approach is that interventions were designed and provided by people who did not know what it really felt like to be disabled. Therefore, people with disabilities seldom had any say in the shaping of the interventions that affected them.

2.5.2 Social

In the social model, disability is not an attribute of the individuals, but it is created by the environment in which they live (Mitra, 2005:7). Therefore, social change becomes the most fundamental intervention in this regard. For example, a person with a disability may fail to find a job not because of his/her inability to work, but because of the inaccessibility of the workplace. At the political level, disability becomes a human rights issue because state and civil society realize that there has been little recognition of disabled people having equal rights or of the barriers they face.

The model suggests that a complex form of institutional discrimination abides which leads to a collective disadvantage to the disabled. This discrimination is manifest in such things as the built environment (e.g., buildings which are not user-friendly to the disabled), institutional arrangements which design patronizing and inadequate policies, and the education system which does not cater for diversity (ordinary schools are not equipped to deal with disabled people consequently special schools are required for them which, in itself, is a subtle form of discrimination).

Therefore, the social model attributes disability to the shortcomings of society in respect of disability which compromises the capabilities of people with disabilities. Another dimension to the social model of disability is the capabilities approach. This approach focuses on individuals' ability to pursue their goals regardless of the resources at their disposal. Sen (1999:14) points out that a disabled person may have more resources than one who is not disabled, but may have less chance (capabilities) of engaging those resources to attain his/her objectives. In other words, even if a person has more income, he/she may require even more to accomplish the same objectives as another non-disabled person. For example, a disabled individual may earn a higher absolute salary than another individual who is not disabled. However, a large percentage of the disabled individual's salary may go to expenses associated with his/her disability (such as higher medical costs, wheelchair and/or other custom-made equipment that maybe required in his/her daily life; a non-disabled individual may not require any of these). This leaves a small percentage to be spent on other areas of life.

Like the capabilities approach, the social model of disability is concerned with evaluating an individual's advantage in terms of actual ability to achieve variable functioning as part of life. Therefore, the appropriate interventions lie in societal interaction as opposed to how much or what society can do for the disabled. Consequently, as notes by (2010:10), Mainstream explanations of the social model have centred on impairment as the cause of the experiences and disadvantage of the disabled, and impairment as the focus of intervention.

2.5.3 Theological

The theological perspective of disability cuts between the social and medical models as it relates to both the body (impairment) and social construct (attitudes) of the disabled. In relation to the social construct of people with disabilities, the theological model holds that the disabled are weak and in need of care, and therefore objects for charity. Furthermore, with regards to the body (or the imperfections thereof), Moltmann, (1998:101) argues that the church views the disabled as not on equal footing as the rest and hence not fully human. This observation is supported by Eiesland (1994:20), who notes that the church justifies this unequal treatment from different theological perspectives such as the interpretation of disability as a punishment for sin of the disabled person or their parents, or disability being a consequence of lack of faith or a sign of demonic activity and moral failure. For example,

Jesus found him in the temple and told him “Now you are well: stop sinning or something even worse may happen to you” (Jn 5:14).

Reynolds (2008:17) states that other scripture passages speak of Jesus' ministry as one of healing and not curing, such as the man with leprosy who implores Jesus to clean him so that he can be restored to his community (Mk 1:40-45) and where Jesus meets the paralytic and forgives him (Mk 2:1-12).

Such passages are interpreted to the detriment of people with disabilities and often serve to weaken their social standing. However, in an effort to lessen this injustice, the church engaged its charitable institutions to provide assistance and support to people with

disabilities. With the advent of new theological interpretations, an action towards people with disability has shifted from charity to recognition and equalization of opportunities (Moltmann 1998). Reynolds (2008:24) maintains that despite this, the inherent conservative structures in the church still inhibit progressive perspectives of disability thereby leading to “pastoral counselling” to the disabled designed to address the presumed causes of their punishment.

Modern humanistic ideologies encourage people to assert themselves for common causes (Eiesland, 1994:23). This is related to the fundamentally hopeful, yet patronizing, theological perspective that mankind was created in the image of God. Hopeful in that each human is equal and deserves to be equally treated and respected whilst patronizing in that humans should be perfect since they are created in the image of God and therefore failure to reach such expected perfection may lead to prejudice (Eiesland, 1994:23).

Other pointers to human rights for people with disabilities highlighted in the theological model relating to mankind’s creation in the image of God are reflected in Isaiah 51:4-6 that “a teaching will go out from me and my justice for a light to the peoples. I will bring near my deliverance swiftly ... my salvation will be forever, and my deliverance will never be ended”; Galatians 2:6 that “God shows no partiality”, and in Psalm 12:5 that because “the poor are despoiled, because the needy groan, I will now rise up, says the Lord”.

The concept of “helplessness” reverberates throughout Scripture. Moreover, the call for intervention seems to be directed towards those with power and authority. However, society has been identified in this respect as the perpetuator of this helplessness. Therefore, in addition to the pastoral view of disability regarding incarnation, the theological model also takes social and medical constructions of disability into consideration.

2.6 POLICY ON DISABILITY

2.6.1 South African disability policy

There a number of principles which underpin South Africa’s policy on disability as put contemplated by the national Department of Social Development (DSD). These are meant

to guide and inform the mainstreaming of Disability in the development and implementation of all policies, strategies and the integrated service delivery programmes of the Department, throughout all provinces of our country¹¹.

Firstly, there is right to self-representation. People with Disabilities have the right to represent themselves in processes and structures of decision-making on issues that affect them. In situations where they cannot represent themselves, they have the right to nominate a person or a body of persons to represent themselves. The principle of the self-representation may be threatened by the market economy which emphasises profit on top of everything else. The threat to the principle of accessibility may result from the lack of strong economic regulations that would otherwise force the providers of goods and services to comply. Also, people in rural areas are likely to be left behind as many these adaptations are seen as luxuries by some.

There are also the principles of full inclusion, equality and participation in mainstream society. This can be summed up as 'accessibility'. The link between lack of access and exclusion is quite strong and without which, other rights become but lip service. For example: the right to employment becomes meaningless in the absence of public transport that is easily accessible to people with disabilities because they will not be able to access the employment opportunities. Tools of accessibility may be as simple as folding ramps and wide doors in buses for wheel-chair users or as complex as the absence of sign language interpreters for television news to aid people with hearing impairments. The designs of building, development of school curricula, neighbourhood developments and road side signs should adhere to this principle of accessibility for the disabled and even new technology like cell phones and computers. The level of compliance of the goods and services providers presents the gaps in this respect.

¹¹ Disability Policy and Services Guide. Available on: <http://www.etu.org.za/toolbox/docs/government/dps.html#key>

Last accessed: 20 September, 2011

The right to a strong support system is an important principle. While other support systems include, Disabled People's Organisations (DPO's); Non-Governmental Organisations that work with issues of disability and social services; Community Based Organisations (CBO's); social workers; medical and psychological health practitioners and the broader community are vital, the family is the most important support system in meeting the needs of people with disabilities. These support systems are the tools for things like counselling, help with assistive devices, and dealing with prejudices and social stigma. The capacity of these support systems to deliver is mainly reliant on availability of resources. Poverty in households makes families less able to meet the needs of their disabled members.

Since there are various types or categories of disability, each of which results in special needs, the disabled should have the right to access the services in a manner that addresses their level and type disabilities. For example, a person who uses a wheelchair needs a ramp and wider door space, to gain access to buildings; a person who is deaf, or lives with a hearing impairment needs sign language interpreters or hearing devices to hear. The services must be appropriate and relevant to the type of disability that one is addressing and must be accessible to the intended target group or beneficiary.

In line with the principles of social integration, it is imperative that interventions focus on the abilities of the people with disabilities and on the barriers that they experience, to make full integration into society possible. For example, the provision of a social grant to a person who uses a wheelchair, may be responsive to some of the person's needs; but the grant does not in any way provide the person with access to a day hospital or shopping mall in the community that he/she lives in, if the mall has not been equipped with accessible ramps for wheels chairs.

There is also the Batho Pele ("People first") movement is respect of consumer protection and services' rights. People with disabilities should be assured good customer services, as contained in the Batho Pele principles that drive government service to the people. This should entail respect, empathy and an effort to assist the client, in this respect, the disabled client.

As a direct result of policy, the government implemented a disability grant system. This is provided under the Social Assistance Act (Act 59 of 1992/Act 13 of 2004) which provides that individuals are eligible for a Disability Grant (DG) if they pass a means-test and if, as a result of mental or physical disability, they are unable to provide for themselves through employment or professional activity (Nattrass, 2006a; Mitra, 2009). The grant is designed for working-aged adults (18 to 64 for males and 18 to 59 for females) and excludes those who are in principle capable of working regardless of the level and type of their disability. In addition, the DG is a non-contributory.

Disability grant recipients may receive an additional grant if they require personal assistance or personal care (Nattrass, 2006b). In addition, there is a means-tested care dependency grant (CDG) which provides support to families with disabled children under the age of 18. Although this grant is relatively generous, the means-test and targeting people of a certain age have been found to be problematic practices.

While these principles are proper in terms of improving the lives and rights of people with disabilities, there are gaps and problems inherent in the system which threatens the objectives for which they are meant. The first problem is unawareness of the availability of services and other tools of support by the intended beneficiary. Many disabled people may not be aware of the services available to them in their communities. Poverty and inadequacy of resources adds to the exclusion of people with disabilities. For example, poverty in households makes the family a weaker support system as family members are unable to adequately provide for their disabled member. Also government's budgetary problems undermine service delivery.

The general awareness of disability problems and needs leaves a lot to be desired. Society is to a larger extent ignorant about issues of disability. This has led to the persistence of discrimination, poor service delivery and inadequate structural adaptations. It is also not known to what extent other government departments are committed to upholding the principles above because the success of the disability policy depends of inter-organizational and multi-lateral cooperation. The level of adherence of the business sector to these principles is also compromised by inadequate business

regulations. As such, there is always a risk of profiteering at the expense of neglecting the needs of the disable.

2.6.2 International initiatives

Several international initiatives have been developed to improve the lives and restore the dignity of the disabled people, including the International Labour Organization (ILO) *Vocational Rehabilitation and Employment (Disabled Persons) Convention (No. 159) and Recommendation (No. 168)* (Elwan 1999; Harris-White 1996:4).

In the UN's *Standard Rules of the Equalization of Opportunities for Persons with Disabilities*, the term "equalization of opportunities" refers to the process by which social systems and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities. The principle of equal rights implies that the needs of every individual are of equal importance, therefore those needs must be made the basis for social planning and resources used to ensure that every individual has an equal opportunity for participation (UN General Assembly 1996).

Yeo and Moore (2003:584) argue that when persons with disabilities achieve equal rights, they should also have equal obligations. With these rights in place, societies should raise their expectations of persons with disabilities. An effort should be made to assist persons with disabilities to assume their full responsibility as members of society (Yeo & Moore 2003:585).

In many lower-income countries, publicly funded programmes, and even those funded largely by employers, cannot be adopted by those outside the formal labour market. Disabled people in agrarian societies and urban dwellers in the informal sector have to rely on themselves, their families and communities (Elwan 1999). Even where the state provides rehabilitation and other essential services, many potential recipients fail to access them (Helander 1995). Prevention is always more important than cure in cases where disability is caused by communicable diseases. Moreover, Elwan (1999:32) points out that there are indications that there "is still a great deal of scope for preventing or alleviating disability through relatively simple interventions".

In the case of public transfer programmes, in developing countries, the 1990s have seen a shift from universal benefits to highly targeted transfers. Publicly funded transfers that are specifically focused on the poor with disabilities and their households are scarce at best and completely non-existent in many developing countries at worst. Such transfers are more common in countries where persons with disabilities organize themselves into groups with a common goal such as the Disabled People South Africa (DPSA) (Mji, MacLachlan, Melling-Williams & Gcaza (2009).

Some developing countries have disability-targeted subsidies in the form of in-kind transfers for food, clothing or housing. For example, a food stamp scheme in Jamaica; also in India, persons with disabilities receive assistive devices free of charge or at a 50% discount in monthly income is below a prescribed limit (Mitra, 2005). Although persons with disabilities have sometimes been considered part of a broader eligible vulnerable group, targeted in-kind transfers such as food stamps and assistive devices have been very hard for them to obtain (Cornia & Stewart, 1995).

Disability targeting has advantages and disadvantages. First, it is assumed that disability targeted transfers would increase the welfare of persons with disabilities as well as that of their care-givers who are predominantly women, with positive externalities on children's health and human capital (Duflo 2000; Mitra, 2009). Secondly as a disadvantage, these transfers may promote dependence especially when they are overemphasized at the expense of other empowering interventions like promoting skills development for disabled persons and streamlining institutional arrangements. Disability is also beset with an inexplicable increase in costs due to fraud, with the benefits going to those who are not deserving of them (Nattrass 2006a).

As a solution, Mitra (2005:20) suggests community-based targeting as a simpler way to implement disability targeting. This is due to the high cost of disability targeting, the complexity of a disability eligibility test, and also the fact that the community may be in a better position than programme administrators to determine an individual's inability to work due to a particular impairment. However, social exclusion of persons with disabilities in some communities may minimize the reach of community-based targeting.

2.7 POVERTY AND DISABILITY

Disabled people have a higher chance for poverty because of institutional, environmental and attitudinal discrimination. This can be faced from birth or the moment of disablement onward (Loeb *et al.*, 2008). Under institutional discrimination, established laws, social customs or practices systematically marginalize disabled people. In addition, widely shared attitudes, values and beliefs influence discrimination against the disabled. It should also be noted that some discrimination happens involuntarily. That is, discrimination can occur, even when the individuals who carry out the activities of the institution do things with good intentions

The birth of a disabled child or the disablement of a child often has poverty implications for that child throughout life. Such a child needs more care and may not be considered to have the potential to support him or herself in the future. Where there are limited resources either at the micro or macro level it may be difficult to provide the required care for that child. Yeo and Moore (2003:573) found that it is common for some people to consider it “economically irresponsible to give an equal share to a disabled child who is perceived as unlikely to be able to provide for the family in the future”. Disabled children are less likely to attend school because parents choose to keep them at home for fear of not coping, wasting resources or stigmatization. The future of such children is compromised hence they are more likely to live in poverty.

Children who are born with a disability or develop one are often excluded from educational, social and political institutions as well as social contacts. This minimizes their chances of developing their skills, self-esteem, and ability to assert themselves in society as adults. All this coupled with recurrent poor health and physical conditions can greatly or completely reduce their income-generating opportunities. Without high levels of support, they live in abject conditions thereby leading to further exclusion. Figure 2.1 represents a model of disability and poverty and illustrates why disabled people experience high rates of poverty.

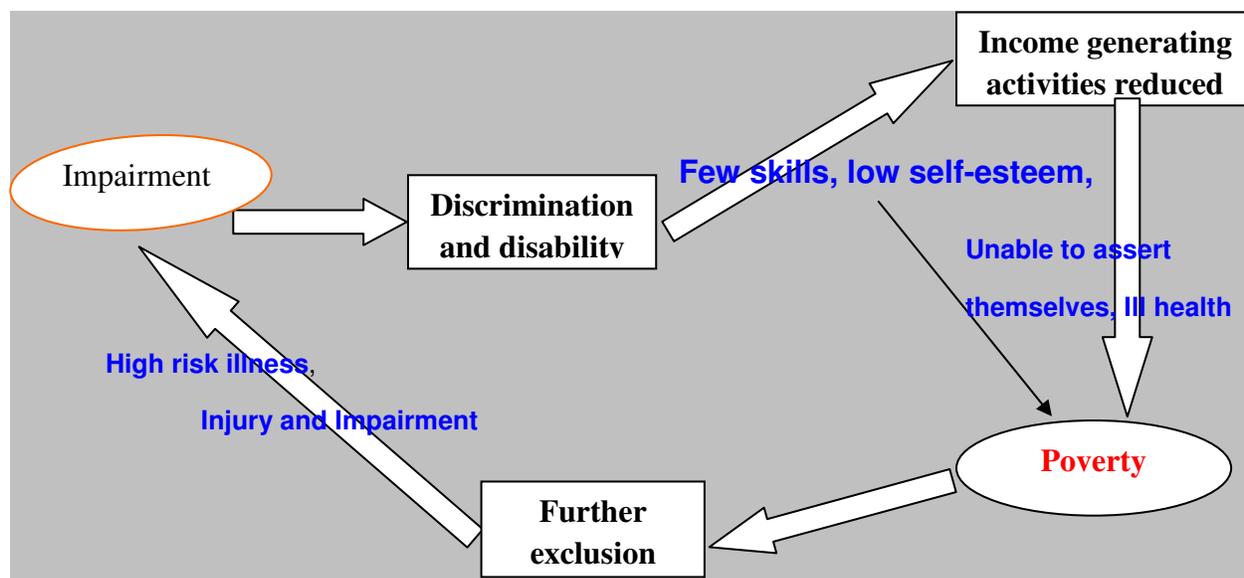


Figure 1 Disability-poverty cycle
Adapted from Yeo (2001)

Figure 1 indicates that disability begets poverty, while poverty begets disability which becomes a generational vicious circle. Regardless of the starting point (poverty or impairment), one or both conditions are likely to be perpetuated.

If impairment is taken to be the starting point, individuals born with an impairment (disabled) are likely to face discrimination, which will deter them from acquiring valuable skills thereby reducing their chances of engagement in the labour market. As such, income generating opportunities are reduced which is a direct link to poverty (firstly income poverty, which may result in other aspects of poverty). Due to poverty, people's self-esteem is reduced, they may experience poor health due to inability to access medical services or good nutrition, and they may find it hard to acquire skills because education/training is expensive. At this point, poverty begets poverty with a higher risk of further exclusion, debilitating illnesses, injury and therefore impairment.

Disability has the potential to extend generational poverty, since being individuals' disability may render them disadvantaged and unable to acquire the resources required to compete favourably in life. As they make the transition into adulthood and start their own family, there is a likelihood that the family will subsist on very limited resources given

all the barriers faced by the disabled. Inability to pay for the education and skills necessary to enter the labour force, may translate into the children remaining poor.

Elwan (1999) emphasises that the relation between poverty and disability has been called a “two-way relationship/vicious circle” since disability adds to the risk of poverty and conditions of poverty increase the risk of disability. The result of the cycle of poverty and disability is that people with disabilities are usually amongst the poorest of the poor (DFID 2000:2). Nevertheless this should not be taken to mean that all persons with disabilities are poor, but this vicious circle does indicate that people with disabilities are more likely to be poor than their non-disabled counterparts.

CHAPTER 3: Research design and methodology

3.1 INTRODUCTION

This chapter describes the research design and methodology including the population, sample, data collection and analysis, and the data-collection instruments.

3.2 PURPOSE OF THE STUDY

The purpose of the study was to

- Explore and determine the theoretical, conceptual and theological meaning of living with disabilities in South Africa.
- Examine the relationship between the church and its disabled congregants with regards to inclusion, accessibility, ministry and service as well as to understand how this relationship has influenced the spirituality and daily lives of these congregants.
- Analyse the socio-economic conditions of disabled people in South Africa with particular attention to civic participation and discrimination as well as access to employment, education and health and other essential services.
- Make recommendations, based on the findings, in order to inform policy and scholarship on issues of living with disabilities in South Africa.

3.3 RESEARCH DESIGN AND METHODOLOGY

The researcher adopted a qualitative and quantitative approach in the study. A qualitative approach enabled the researcher to determine the respondents' views on disability. Quantitative research employs numbers and statistical methods and is based on numerical measurements of specific aspects of phenomenon under study. The study

wished to measure the extent of the respondents' disability (moderate or severe) and examine their experiences in terms of burdens of daily life, the nature and impact of the present interventions, and their views on interventions required to improve their lives. The medical, social, and theological models of disability and the relationship between disability and poverty formed the theoretical framework of the study. These models were chosen because they could help in solving most of the definitional problems and the gaps in policy on disability. The researcher was of the opinion that policy defines disability in terms of its medical or social manifestation separately, without considering the two models as complementing each other.

3.4 RESEARCH POPULATION

This study based its investigation on the residents of the greater Cape Town area in the Western Cape Province. The population for the study were evangelical Christian believers who were disabled or parents and care givers of disabled.

3.5 SAMPLE AND SAMPLING

A sample is a portion of the population selected by a researcher to represent the entire population. Participants were recruited through contact with church leaders and disability ministry. The study employed the snow-ball sampling method to identify potential participants. As a point of departure, participants were asked to consider the following:

- Your experiences with disability on a personal level and from the viewpoint of being a family member.
- How disability has affected your spiritual views and your spiritual life on a personal level and as a member of your family.
- How faith has influenced or impacted on your way of dealing with disability.

- How the church has influenced your beliefs about and response to disability.

3.6 DATA COLLECTION

Data was collected by means of questionnaires, informal and semi-structured interviews, focus group discussions, and observation.

3.6.1 Questionnaire

Questionnaires and interviews are the easiest and most effective methods when the objective of the study is to find out what people believe or think. The purpose of asking questions is to find out what is going on in people's heads; that is, their perceptions, attitudes, beliefs, feelings, motives, plans, and past events. The researcher developed a structured questionnaire, consisting of open-ended and closed questions, and administered 460 questionnaires. The questions covered the following areas: demographic information; the activities that define the level of disability; activity limitation to identify number of limitations as well as classify the respondents in terms of their level of disability as moderate or severe; access to facilities, the ease of using the built environment, integration, and their views on the four target areas of equalization: accessibility, education, employment and social security.

3.6.2 Interviews

Thirty (30) participants were interviewed: 13 were parents or caregivers of minor and adult children with a variety of physical and/or intellectual disabilities; nine adults with physical disabilities and eight other participants, primarily family members. The parents ranged in age from 29 to 60 years. The adults with disabilities ranged in age from 20 to 70 years. Seven of the adults were disabled at birth or very early in life, while two became disabled during their adulthood. Most of the parents and some of the adults with disabilities were married. The participants lived in lower to middle economic income neighbourhoods of greater Cape Town. All the participants shared three relevant

characteristics for the study: (1) they lived with disability or cared for disabled persons, (2) were evangelical Christian spiritual believers and (3) attended church fairly regularly.

3.6.3 Focus group discussions

Focus group discussions were held with thirty (30) participants. These were stratified according to their responsibilities (i.e., as disabled themselves, parents of disabled children, or care givers) and extent of disability (in the case of the disabled participants). The participants included 13 parents or caregivers of minor and adult children with varying degrees of disabilities, nine adults with physical disabilities, and eight family members with disabled persons. The subject of the focus group discussions was disability and the Christian church with specific attention to the following themes: experiences with disability on a personal level and/or from the viewpoint of being a family member; the effect of disability on one's spiritual life; faith and dealing with disability; the church and its response to disability. These themes were intended to gauge the respondents' perceptions of the church's views and treatment of disability and the disabled.

3.7 VALIDITY AND RELIABILITY

The quality of research and research instruments is determined by their validity and reliability. Validity is refers to the degree to which data-collection instruments measure what they are supposed to measure. Reliability refers to how consistently the instrument measures the attribute it is designed to measure. Therefore, if the instrument is reliable, the results will be the same each time the test is repeated.

3.8 DATA ANALYSIS

Data analysis began at the same time as data collection and involved classifying, categorizing and coding qualitative and quantitative data to enable computer analysis for statistical construction. Quantitative data was analysed using the SPSS and Excel computer programs and presented the results in percentages, diagrams and tables.

With regards to the qualitative data, the information generated by focus groups was analyzed by listening to the recorded sessions and reviewing notes taken during the session and documenting the results under the different themes. In some case, statements of individual groups participating in the focus groups were coded together to investigate similarities and differences. The responses garnered from the semi-structure interview were coded and responses to open-ended questions were grouped under the various themes.

3.9 ETHICAL CONSIDERATIONS

Ethics deals with matters of right and wrong. *Collins English Dictionary* (1991:533) defines ethics as “a social, religious, or civil code of behaviour considered correct, esp. that of a particular group, profession, or individual”. In this study, the researcher observed the following ethical considerations:

- **Permission.** Permission to conduct the study was obtained in writing from the University of Stellenbosch.
- **Confidentiality and anonymity.** The researcher assured the participants that all the information gathered would be treated sensitively and confidentially and the identities and interests of all participants protected.
- **Informed consent.** The researcher informed the participants that participation in the study was voluntary, without any form of coercion and that they had the right to withdraw from the study at any stage and for whatever reason.

CHAPTER 4: Disability and the Church

4.1 INTRODUCTION

This chapter discusses the relationship between the church and its disabled congregants. It first presents a brief contextual background to this relationship which will facilitate an understanding of the congregants' perceptions and experience of the church in the following section. These perceptions specifically relate to inclusion; accessibility; ministry and service. The chapter reports findings from (1) a document analysis (particularly scriptures and other scholarly literature) and (2) focus group discussions.

4.2 DISABILITY AND THE CHURCH

People have always searched for meaning and purpose in life. Believers have asked questions like: If God loves me, and I was created in his image, why am I disabled? Why do I suffer? What is the meaning of disability for my life and that of my family: is it due to sin or was there a mistake at my creation? What did my ancestors do for me to deserve this? Why me or why my own? If I pray for healing, and it does not happen, does it mean I am faithless? What does my church or pastor say about these issues? Where can I find healing and answers?

According to Wilke (1980) disabled and non-disabled persons alike need a biblical foundation in order to establish meaning for issues surrounding disability. Blair & Davidson (1993) maintain that without such issues clearly articulated biblically fellowship between the disabled and non-disabled will suffer because societal attitudes and stigma in the world will become reflected in the church.

Interpretive problems with Old and New Testament passages and historical attitudes for disability are often the root of confusion on a biblical perspective. This results in failure to find sense in the judgment of God, the adequacy of faith, and miraculous healing. Scripture has been used to support a view that disability comes from sin and represents inadequacy and imperfection. Wilke (1980) refers to John (9:1-3) as an example of such an assumption and Jesus' response to them:

“...as He passed by, He saw a man blind from birth.... His disciples asked Him, saying, “Rabbi, who sinned, this man or his parents, that he should be born blind?” Jesus answered, “It was neither that this man sinned, nor his parents; but it was in order that the works of God might be displayed in him.”

Gourgey (1995:2) states that it would be “cruel” to accept that God made the man blind for the purpose of using him to demonstrate God’s work in his life. However, Jesus does not say whether or not God created the man’s disability or allowed it to happen to him; only that God uses the man’s blindness for His purpose and that it is not due to sin.

It also becomes important to question the role of God in disability. Psalm 139:13-15 says that God sees our bodies and knows us, even before we are born: “For Thou didst form my inward parts; Thou didst weave me in my mother’s womb. I will give thanks to Thee, for I am fearfully and wonderfully made; Wonderful are Thy works, and my soul knows it very well. My frame was not hidden from Thee, when I was made in secret, and skilfully wrought in the depths of the earth.”

The implication of this is that God not only sees us but He decides what forms our bodies take. On a certain level, it may be easier to accept that God allows disability than to consider that God creates disability or wants us to be disabled. If mankind accepts this, it becomes a problem for humans to accept God as “good” thereby creating a spiritual dilemma. This is how suffering and disability reduces one’s faith. Pailin (1992:39) states that “either God cannot or God will not put an end to pointless suffering in the world. If God cannot end it, then God is not all-powerful – and, it is assumed, a

being that is not all-powerful is not authentically 'God'. If, on the other hand, God will not end suffering, then God is not wholly benevolent."

The bible provides an ethical perspective vital for understanding the role and actions of the Christian church as one that influences the spiritual experiences of people with disabilities and their families. Behind this ethical perspective are these two imperatives: a Christian is to love God first and to love his/her neighbour as him/herself (Matthew 22:37-40). The church has an ethical biblical imperative for ministry to others; that is, Christians' service to one another (Romans 12:10-13). Radmacher (1997) points out that while the Holy Spirit gives spiritual gifts or special abilities to Christians for the purpose of building up the church and managing ministry, there are "spiritual responsibilities" that they have to contend with. Vanderzee (1993:43) states that although the church as a social institution has always cared for the infirm, the poor, and the aged, attitudinal barriers still abound. Eiesland (1994) states that the disabled are viewed with pity and charity by the rest at best, and/or with scorn at worst.

It appears that people within and outside the church may see people with disabilities as different, not the same as others. While Gourgey (1994:70) maintains that religion itself "sometimes appears to deliver a double message. On the one hand, it offers us the language of inclusiveness ...; we may detect other messages, suggesting that disabled people constitute a separate and perhaps unreachable group..." Pailin (1992) emphasises that if we believe that people are made in God's image, all people deserve respect and honour. According to Grenz (1997:258), a person's value cannot be graded according to the extent of his/her contribution to human existence. Therefore, we can never dictate the value of any human life but are to value one another and ourselves as God does.

Christians have a duty to uphold social justice for people with disabilities and their families. People's and institutions' ethical obligations emanate not from inherent individual rights, but from the community of Christ in which believers are members. Nevertheless, how can we still say that they are all members, when we are the ones that pick out a few to discriminate against? Grenz (1997) argues that Jesus is the basis

for moral behaviour (Col 1:10, 2:6, 3:23-24). As God loves us unfailingly, we are to love others within and outside the church. Christians have an ethical biblical imperative to serve one another (Gal 5:13) without exception and without prejudice (Grenz, 1997).

4.3 CONGREGANTS' PERCEPTIONS OF THE CHURCH

For this section, unstructured interviews and focus group discussions with 30 respondents were conducted. This section presents the respondents' perceptions and experience of the church, especially with regard to inclusion, accessibility, ministry and service and how the church has affected them both socially and spiritually.

4.3.1 Inclusion and accessibility

The respondents stated that church leaders have a duty to lead congregational efforts to reach out to people with disabilities. They maintained that inclusion in the church extends beyond not being able to reach or access the church premises, voice an opinion at a church meeting, or the church having access ramps for wheelchairs. It has a deeper dimension in respect of attitudes and perceptions.

The respondents emphasized attitudinal accessibility, which is a mental and emotional willingness to minister both to and with people affected by disability. Although they admitted that disability may contribute to fear and avoidance by those who do not share their experience, they believe that selfless service to one another is the solution. According to the respondents,

Most of the churches that say they're disability accessible just mean they have a wheelchair ramp and that they have a separate toilet for the disabled. But really as far as I am concerned, that is not what it means by "disabled accessible". They need to have someone who is in charge of disabled people's affairs. Often parents have to do everything when they bring their disabled kids to church. I go to this church because I like the preaching, but I have failed to find the right church to handle my son's disability. Now he stays home crying because he can't go to church yet all his friends at school do, his friends think he is not church material because of his condition.

At our church we do not have an elevator up to my daughter's Sunday school room, which is upstairs. Every Sunday I have to carry her up to the second floor and ask

somebody else to carry up the wheelchair. Every time I fear what would happen if there is a fire and she can't get down from there. It is very hard on me and a big issue. She is not the only one in a wheelchair to attend this church. I used to see other people but they don't come anymore. Maybe they got tired, because they had to do the same thing I do, and decided it was not worth the trouble.

The respondents generally felt that someone in the church should be responsible for facilitating inclusion of people with disabilities. Parish nurses or other health care professionals might be ideally suited to do this, but any of the able-bodied members could play that role. The respondents added that some parents struggled to meet their children's daily needs at home and sometimes failed to attend church because of this, especially when the church's physical structure presented accessibility problems.

The respondents believe that support to people with disabilities and their families includes an ability to know what to do, along with sensitivity as well as sensibility, awareness and acceptance of these families. Some congregants noted the common perception by both church staff and the congregation that people with ordinary skills cannot meet the needs of these families.

It's about compassion. It's not just talking or feeling sorry. It is hard and a real sacrifice! God helps people to do this. Very few people are willing to do this. People are so occupied with their own problems. Maybe their problems would diminish if they would step up to the plate and try to help another human being who needs help.

Some respondents were of the opinion that a self-centred focus embedded in people's cultures makes it difficult for people to believe they can assist their own families, much less someone with a disability. Another respondent described disappointment and frustration at not being able to find assistance for her autistic son at church Sunday school. The respondent stressed that special skills to accommodate children with disabilities are usually not required, but people's willingness to serve others is a general problem and is not limited to families with disabled members. As the respondents said,

If one is not prepared to extend a helping hand to one of one's close family, how is he or she going to help a stranger just because the stranger has a special need – they may say "I'm not able to take care of my own family, how can I possibly help somebody else,

with a special need?" That's often what our mindset is today. I think that's why a lot of families with the disabled feel isolated; and that nobody's really caring for them. Some even end up being neglected by some family members.

I don't usually ask help from others, let alone the church, this was the first time I actually asked for help. I needed help and I failed to get it, God! Don't these people have compassion?

Some of the respondents stated that an inadequate biblical foundation for achieving meaning in disability promoted spiritual movement away from God and the church. For example, according to one respondent his lack of a biblical foundation for understanding disability allowed the devil to tempt him years earlier with a belief that God was punishing him through failure to heal his daughter. Biblical teachings in the area of disability and healing would provide a foundation for understanding why God does not always heal, and help to alleviate suffering. A physically disabled respondent attested to movement away from God for similar reasons. According to the respondents,

I would have favoured to have somebody tell me, instead of me having to read in a book that my child is the way he is, because God did it or allowed it to happen to him.

The bible hardly says anything about disability, because I've never heard anyone preaching anything about it...maybe I am wrong, I wonder what Jesus said about disability.

Now that makes it very difficult even for Christians to rectify that and to justify disability within their minds. If the pastor never says anything about disabled people then I may be right in believing that Jesus never addressed the issue. I know and believe that he healed the disabled. But then what? Are they special; are they different? Has any preacher tried to back that up? I don't think so. . . When I read the bible, it doesn't help me to back that up either.

One respondent stated that issues surrounding people with disabilities in the church were neglected for a number of reasons:

The whole issue is neglected, probably for a combination of reasons. It appears to me like the pain and grief when somebody is dying. Everybody assumes the dying person doesn't want to talk about it. The dying person assumes the other people don't want to talk about it. So they don't talk about it. So no one knows or understands what the real situation is.

In contrast, one respondent remarked that his prior biblical background prepared him for such an event (his child's disability). Only three participants recalled having heard a pastoral sermon that specifically addressed the issue of disabilities.

4.3.2 Ministry and service

The respondents expressed a need for church ministry and service in two areas: (1) efforts to promote a theological understanding of the meaning of disability and the meaning of God's work in "us", and (2) religious support that addresses day-to-day needs. They felt that an inadequate scriptural foundation related to disability hinders functional adaptation to associated spiritual challenges. Despite complaints about theological misunderstanding on topics surrounding disability, the respondents' spiritual beliefs gave meaning to their experiences. The respondents emphasised a need for scriptural teaching that addresses disability and other issues related to disability. Both parents and adults with disabilities maintain that the church should initiate this kind of effort and reach out more, engage in direct discussion on issues surrounding disability. This engagement should take the form of teaching from the pulpit, small group discussions, and individual and family follow-up visits for those affected by disability as well as home prayers for those in distress. One respondent suggested that children with disabilities need opportunities to grasp the theological meaning for disability apart from their parents. However, most of the respondents were of the opinion that it was unlikely that families would be keen to ask for this kind of assistance, particularly as it has not been available, and the majority did not expect the church to minister to them in this way.

One respondent with disability was concerned that once people in the church have been taught about those with disabilities, they will think that they understand, "but actually they don't understand and they just leave it there". A further concern was that discussing disabilities would mostly point out differences rather than similarities between disabled and non-disabled persons.

Other respondents, however, believe that the church should openly address disability and accompanying issues, sufficient faith, miraculous healing, and suffering from a scriptural perspective so that church leaders and congregations alike get a theological meaning of disability. They maintained that this would help bring hope and instil faith in those who through frustration turn away from the church. This would require church leaders to reconsider their historical and traditional positions which are devoid of the theology of disability. The respondents maintained that the church deliberately fails to embrace “progressive existence”. While people affected by disability report needs common to others, disability may demand special consideration for religious support. The respondents wished to see that the church periodically inquired into the needs of people affected by disability and also made that a special agenda in their ministry. As one respondent explained:

I think that what is needed more than anything is the church coming to us and asking what they can do to help because it would be hard for us to tell them what to do. And maybe to offer to take once in a while, so that the rest of family can be able to do together other things we couldn't do while we are looking after her. We are forever asking for help from people just to keep an eye on her while we do other things, which is hard because people have even started keeping away from us in case I might bother them babysitting our daughter. The church can give her a good environment to develop and a new experience other than being with the babysitter or inside the house all the time.

The respondents also described social isolation related to disability. For example:

People with disabilities appear different than those who are not. But they're just like us. The only thing that separates us from them is physical needs that may not even last. That need is so vital to them that at that time, their lives depend on it. That need dominates their overall existence. They can't get relief without that need being solved. If one can find a way as a church minister through the church to be with them as people, just like everyone else and recognize the vulnerability of their spirits because of that need, you can truly understand the importance of spiritual inclusion.

According to the respondents, the physical needs are a continuing need for which there is no relief. The respondents felt that unless people address needs that extend beyond the spiritual, they will fail to minister to people as Jesus intended. Some respondents

recommended specialized counselling support for families affected by disability. None of the respondents felt that pastors were equipped to provide that kind of counselling to families on issues surrounding disability. As one respondent put it, “Most pastors can go to families and talk to them about dying, but they seldom talk about living with disability”. The respondent added that churches should join together with NGOs with qualified personnel to provide qualified counsellors who are sensitive to disability issues because

I see a lot of families breaking up because of the child who is disabled . . . The blame has to be put somewhere. They either put it on each other, or they put it on God. This is eroding faith.

Establishing meaning for disability and finding a way to avoid blame for a child with disabilities appear essential to family harmony. Every interventional effort in families affected by disability needs to include all members (including fathers and siblings) with the help of community because providing for that “need” requires a concerted effort. On-going support and health counselling to families affected by disability is also required.

Families affected by disability should be empowered to share their expertise and resources with one another and the congregation whenever possible. Several of the respondents agreed that one of the best ways to help meet people’s needs is for churches to create a family networking mechanism especially through small groups. Some respondents admitted that churches may not have the resources to meet people’s physical needs, but reiterated that they are aptly positioned to meet spiritual needs, and through appropriate referral to NGOs and/or social service agencies and networking with other parents could assist the families.

All the respondents agreed that inclusion of persons with disabilities in the church involved attitudinal, architectural, and communication accessibility. They also suggested several reasons for an apparent under-representation of people with disabilities in church, such as excessive care-giving stress and churches unprepared to integrate the disabled into the congregation. They stated that church staff and congregations

frequently make assumptions about the needs of the disabled because of their lack of knowledge and understanding of disability. Some respondents said that reaching out to people with disabilities is open to perceived risks for churches including concerns about loss of able-bodied members and financial costs associated with altering or creating physical accessibility. According to one respondent:

A lot of pastors are afraid of losing their congregation, so bringing in the disabled may lead to that. They are worried of what may happen as the disabled population increases in their churches. Some would think; sitting next to a person who's maybe leaning on your new suit and perhaps slobbering a little bit, in the same pew, may probably be a deterrent to some people. Most pastors are in it for the money. Even though they preach, it's still a business. You have to have numbers to make it worthwhile. A full church of disabled people will not appeal to them...

While the respondents called for ministry to the people, they also emphasised ministry by the people. They believe that people with disabilities and their families should try to speak out whenever possible for others like them. They should also teach church leaders and the congregation about disabilities because they have direct experience, and this would help to generate sensitivity and awareness among people who have had no experience with disability:

There is likely to be some resistance to embracing people with disabilities. Not all churches will be open to the idea of "strange looking" people sitting next to them as they pray. This is partially because they will have to make changes to their facility which will be a cost to them whilst, some people don't want to be identified with people who are different from them. People fear new untested experiences. Many people haven't been around people with disabilities, so they don't know how to respond. It is that fear that discourages people from embracing others...they would rather stay as far away from them as possible and just pity them.

The respondents said that although the church is called "the church of God", some are continually shut out because they are different. They are viewed as burdens draining the limited resources, yet these are God's resources provided for all mankind to be used communally.

Blair and Davidson (1993:18) find that “the able-bodied world is not usually intentionally rude or insensitive to the disabled; it is simply unaware of the physical and emotional difficulties involved”. Merrick (1994:39-45) points out that disability is “an issue that we do not ‘feel’ until we ‘own’ it; when it happens to us or one of our loved ones”. According to Purves (1993:90), God not only wants people in, God has done something to get people in. Consequently, anything that restricts people from belonging fully to the fellowship of faith is a sin against the generosity of God.

People with disabilities and families who do not feel that their spiritual or vital needs are being met are less likely to be involved in the church. They may blame God for disability out of anger and frustration when they do not have a theological basis for doing otherwise. It is usually brought on by a lack of help, the feeling that they are alone, and had done something to deserve it. If difference in creation is not acceptable, if disability results from sin, or if God has not healed the disabled because they fall short in their belief, their anger against God and the church becomes justified. If emotional conflicts continue at church, if the church does not practise attitudinal and physical accessibility, families will withhold their involvement in the church. Webb-Mitchell (1994:101) states that “until our church buildings, worship, and Christian religious education programs are made inviting, accessible, and open to all who wish to enter and join in the life of a church, there is little chance that people with disabilities will be seen or heard from there . . . They will be more angry and bitter than ever.”

A spiritual belief as a stabilizing dynamism for people with disabilities and their families was a major theme of this study and the participants confirmed that this influenced how they live. Nevertheless, this does not diminish the spiritual challenge in establishing meaning for disability nor does it reduce confusion which people have about disability, sin, God’s judgment and healing. People who feel vulnerable often need something to hold on and think of the church as a pillar of support. According to Govig (1989:4), the church must present “a theology that addresses disability, suffering, sin and healing. It is not enough to preach ‘death’ and possible resurrection; it is equally necessary to preach ‘life’ and ‘living’.”

Eiesland (1994:74) states that in order for “the Christian church to stop doing harm and energize their efforts to be a body of justice . . . A theology of disability must be made a visible, integral, and ordinary part of the Christian life and our theological reflections on that life.” As long as disability is addressed in relation to sin, suffering or charitable action, it will be seen primarily as a fate to be avoided, a tragedy to be explained rather than an ordinary life to be lived fully and harmoniously. Eiesland (1994:75) adds further that as long as disability “is unaddressed theologically or addressed only as a ‘special interest perspective’, the Christian church will continue to propagate a double-minded stance that holds up the disabled as objects of ministry and adulation for overcoming the very barriers that the church has helped to construct”.

According to Govig (1989:5), inclusion of people with disabilities in the church requires recognition of habits and attitudes that inhibit our acceptance of the population as other than blemished persons. Religious beliefs provide meaning for disability, assistance to cope with difficulties, and solace. Although disability creates difficulty and distress, there is a real and full life behind it all, which can be physically and spiritually productive. Behind all the physical and psychological boundaries, many find their disability or that of their family members a blessing. There is a profound need to create increased opportunities for mutual fellowship and service by disabled and non-disabled persons because love of God and one another (Mt 22:37-40) lies at the heart of a biblical ethical perspective for the church’s relationship with all people. According to Webb-Mitchell (1994), the Church is still struggling with the mere acceptance of people with disabling conditions, let alone working on the task of worshipping, living, and learning from them”. Therefore, a lot of work still needs to be done to ensure equality, full inclusion, and understanding what it means to be disabled and how important the disabled are in the kingdom of God.

CHAPTER 5: Socio-economic conditions of the disabled

5.1 INTRODUCTION

This chapter presents a descriptive analysis of the socio-economic conditions of disabled people. It first presents the profile of the questionnaire survey sample, and proceeds with issues related to civic participation and discrimination, employment, education and health. For this analysis, a questionnaire survey with 460 respondents was conducted and for triangulation purposes, this was supplemented by semi-structured interviews. The respondents were located mainly through a snowballing exercise where the interviewed disabled people were asked if they knew of any other people who could be included in the survey. The respondents were recruited from places of worship, universities, and homes for the disabled and in their homes around the Western Cape.

5.2 RESPONDENTS' PROFILE

The respondents were disabled people of age 16–64. Of the respondents, 59% lived in two-adult households; 25% lived with children under 16 years of age; 20% lived alone, and 20% lived in multiple-adult households.

The types of impairment experienced varied by age, with the likelihood of having a physical, visual or hearing impairment increasing with age. Younger people were more likely to have a mental health condition

Of the 460 respondents, 62% had a single impairment; 23% had two impairments, and 9% had three or more impairments. Multiple impairments increased with age.

Of the 460 respondents, 51% said they had acquired their impairment, condition or disability before the age of 16 (including 3% who had the impairment since birth); 32% had acquired the impairment between the ages of 16 and 50, and 16% after 65 years of age.

Regarding the area of substantial difficulty, of the respondents, 57% reported mobility; 53% reported lifting, carrying or moving objects, and 22% reported no substantial difficulty with any of the areas asked about. A further 15% indicated that they had at some time been diagnosed with some debilitating disease. This finding indicated that some respondents had had an illness, disability or impairment in the past but did not have one at the time of the survey, while others had neither a current nor a past illness, but were included in the survey for another reason such as having been diagnosed with a disease that could or had impaired them.

Table 4.1 presents the respondents' sex and age. Of the respondents, 47% were over 45; 46% were male and 54% were female.

Table 1 Respondents' age and sex (n=460)

		% Respondents
Sex	Male	46
	Female	54
Age	16-24	4
	25-34	7
	35-44	10
	45-54	14
	55-64	18
	65+	47

5.3 TYPE AND EFFECTS OF IMPAIRMENT

The respondents were asked to describe their current and past conditions, number of impairments and age of onset of their disabilities. All the impairments need to have lasted for a year or more and have a substantial effect on their day-to-day activities.

Of the 460 respondents, 93% had a current impairment, or a debilitating illness that adversely affected their daily activities; 10% had a past disability, illness or impairment, whilst 3% reported not having a past or current disability, illness or impairment. These respondents were included in the study because of a functional impairment or because

they had never been diagnosed with a major debilitating illness which might qualify them for disability welfare. Such diseases include cancer, multiple sclerosis or HIV/AIDS.

The respondents were asked about the nature of their illness, impairment or disability and to describe all the types of impairment they had (see Table 4.2). Of the respondents, 66% had physical impairments; 12% had visual impairments; 11% had progressive, or fluctuating conditions; 10% had mental health conditions, and 1% had learning disabilities.

Table 2 Respondents' impairment and age (n = 460)

	% of participants	Age 16-34 (%)	Age 35-54 (%)	Age 55-64 (%)	Age 65+ (%)
Physical impairment	66	47	64	68	71
Hearing impairment	15	4	6	11	32
Visual impairment	12	7	8	12	20
Progressive, fluctuating condition	11	6	11	12	12
Mental health condition	10	23	19	6	4
Learning difficulties	2	8	3	1	1
Other	20	18	17	22	20
None of the above	6	7	7	7	5
N		460			

There was some variation in the nature of impairment by age. The likelihood of having a physical, visual or hearing impairment increased with age while 23% of the respondents aged 16-34 had a mental health condition. This implies that some disabilities are either behaviour related or come with age. For example, the high prevalence of mentally

disabled persons at a younger age may be associated with substance abuse as this is most rife among younger people while physical disabilities may be common among older people due to the wear and tear that comes with age.

Of the 460 respondents, 62% reported having a single impairment and 32% had more than one impairment (see Table 3).

Table 3 Respondents' number of impairments (n=460)

Number of impairments	All respondents (%)	Age 16-34 (%)	Age 35-54 (%)	Age 55-64 (%)	Age 65+
None	6	7	7	7	5
One	62	78	67	64	47
Two	23	11	20	22	33
Three or more	9	4	6	7	14

Of the respondents, 78% of those aged 16-34 and only 47% of those aged 65 or older had one impairment. Conversely, 14% of those aged 65 or over and 4% of those aged 16-34 had three or more impairments .

The respondents were asked if they had any areas of substantial difficulties in their life as a result of health problems or disabilities. This question wished to look at disability beyond the physical because disability is a personal as well as a functional issue.

Of the 460 respondents, (57%) reported that they had difficulty with mobility; (53%) had difficulty with lifting, carrying or moving objects; (21%) had difficulty with manual dexterity; (19%) with physical co-ordination, and (18%) with communication. (22%) reported no areas of substantial difficulty. 13% reported an inability to understand, learn or concentrate while 18 % reported communication difficulties. A number of respondents were able to make multiple responses.

The respondents were asked to indicate the age at which their impairment started to have a substantial effect on their day-to-day activities. Of the respondents, 40% had the impairment, condition or disability since birth, and 31% aged 16-29 and 19% aged 30-39 with mental health conditions indicated that these had started to have a significant impact on their day-to-day activities during early adulthood.

Regarding self-identity, 40% of the respondents preferred to refer to their impairment as a “health problem”, and 26% used the term “disability”, and 19% preferred to use the term ‘impairment’. Some of the respondents noted that they only saw themselves as disabled in certain situations. For example, they were categorised as disabled when it came to claiming benefits such as disability grants, but they did not personally consider themselves disabled in other aspects of their lives.

5.4 CIVIC PARTICIPATION AND SOCIAL NETWORKS

Community engagement is a key element of ‘social capital’, and self-help. Both of these have a great influence in social inclusion in policy. Social capital is important because it is associated with positive outcomes such as better health, higher educational achievement, better employment outcomes and lower crime rates (OECD, 2010).

This section focuses on the respondents’ engagement with the wider community: the social activities they take part in, their involvement in groups and clubs, and the level of contact they have with people outside their home.

5.4.1 Isolation and contact with others

Isolation can have a significant negative impact on quality of life for all segments in society (Victor, Bowling, Bond & Scamble, 2003). In order to assess whether the respondents felt isolated, they were asked to say how often they had contact with other people from outside their household: personally (face-to-face) and by telephone.

Of the 370 respondents who answered the question on isolation and contact, 56% had contact with someone from outside their household at least daily; 36% had daily face-to-face contact and 42% had daily contact by telephone, and 5% seldom had contact with others from outside their households, namely once a month or less often (either face to face or by telephone). There was no difference in their answers between the age groups, men and women, or different impairments. However, slightly more respondents with three or more impairments (6%) reported contact with people from outside their household once a month or less often compared those with fewer than three impairments (4%) (Table 4).

Table 4 Frequency of respondents' contact with people outside the household (n=370)

	Face-to-face contact (%)	Telephone contact (%)
Every day	36	42
2-3 times a week	28	26
At least weekly	21	18
At least monthly	7	5
Less often	6	4
Never	2	4

5.4.2 Sources of emotional support

The respondents were asked who they could turn to for comfort and support if they had a personal crisis. They were asked to mention all the people they would turn to and only 203 participants responded to this question. A small number (two per cent) of respondents said that there was no one to whom they could turn for comfort and support, but this figure was six per cent among people with a mental health condition.

Responses differed depending on the type of household in which the respondent lived. The most common answer given by the respondents who lived with at least one other adult in their household was that they would seek comfort and support from their

spouses (70%). Among the respondents in one-adult households, the most common source of emotional support was a relative from outside the household (73%).

Of the respondents who would seek support from a spouse, 60% were men and 42% were women. The reason for this difference was that fewer of the women lived in a household with other adults.

Of the respondents, only a few would seek comfort or support from sources other than family or friends: 1% would seek support from a voluntary organisation and one per cent would seek comfort and support from their church leaders.

5.4.3 Social activities

The respondents were asked what social activities they had participated in during the last month. Of the 187 respondents who responded, 92% (n= 172) had taken part in at least one of the listed activities, and 90% (n= 155) had taken part in at least one activity outside their home (for example visiting friends or family in their own homes, going shopping, going out for a meal or drink).

Participation was found to be age-related. Of the participating (n=172) respondents, 92% of those aged 16-64 had taken part in activities outside their home; 98% of those aged 16-34 had participated in activities, and 97% of the 16-34s had taken part in at least one activity outside their home. However, 13% of the respondents aged 65 or over had not taken part in any of the listed activities, while 85% of those aged 65 or over had not taken part in any activities outside their home.

There were no significant differences in response based on the nature of the respondents' impairment. However, 86% of the respondents with three or more impairments had participated least in any of the listed activities compared to 93% of those with fewer than three impairments.

Regarding barriers to participation, the respondents were asked what barriers prevented them from participating in more activities. Of the 189 respondents who responded, 75%

of those with three or more impairments said that they did not participate in more social activities because they did not feel strong enough; 48% of those with fewer than three impairments did not participate in more social activities because they often did not feel well enough or else felt too tired to do so.

The main barriers identified by the respondents were accessing places (for example, transport to a venue, access within the venue, availability of disability-friendly facilities); personal circumstances such as lack of money and time; lack of confidence, and attitudinal barriers.

Of the 189 respondents, 19% indicated at least one access barrier that prevented them from undertaking more of the activities they would like to do; 12% stated they need someone to accompany them on the journey to a venue, and 10% indicated difficulties with transport.

Of the respondents, 14% of the younger ones and those with mental health conditions stated lack of confidence as a barrier; 2% indicated attitudinal barriers such as the attitudes of others at the place of participation, and 3% indicated a previous bad experience.

When controlling for age, the differences between the respondents with mental health conditions and the others related to access barriers became less marked. However, the difference is still apparent when considering attitudinal barriers, and in each age group, the respondents with mental health conditions felt more strongly that they faced attitudinal barriers to participating in more social activities.

Of the 189 respondents, 29% said that they did not encounter any barriers to taking part in more social activities or hobbies. Twenty six per cent those aged 65 and over compared to 9% of those aged 16-34 did not encounter any barriers. At the same time, however, older people are less likely than younger people to participate in activities. This might indicate lower expectations among the older respondents in relation to what they feel they should be able to do at their stage of life.

5.4.4 Social engagement with groups

In order to gain insight into the respondents' group social engagement, they were asked about the frequency with which they attended social groups, clubs or places of worship, as well as specifically engagement with groups or clubs for disabled people. The respondents were given a number of examples of the types of engagement of interest, including a spiritual group, social club, sports team, support group, community centre.

Of the 240 respondents who answered the question, 44% (n=105) had ever attended any such groups, and 36% attended once a month or more often; while 20% (n=48) had never attended such groups. Forty two per cent of those aged 65 or over compared to 27% of those 16-34 years old attended a group once a month or more often.

Of the 69 respondents with hearing impairments, 34% (n= 23) attended a group, club or place of worship at least once a week compared to 27% of the others on average.

In addition to enquiring about social engagement in general, the respondents were asked how frequently they made contact with groups for people with the same impairment. Of the 146 respondents, 88% (n= 128) said they never attended or made contact with groups for people with the same impairment; 8% made contact with groups for people with the same impairment once a month or more compared to 36% who had attended other types of groups.

As in the case of participation in activities, the respondents were shown a list of possible barriers and asked which, if any, prevented them from getting more involved with clubs, groups or the local community. Of the 178 respondents, 47% reported that nothing was stopping them from becoming more involved; 50% with three and or more impairments and 27% with one or two impairments indicated not feeling well enough; 18% indicated lack of time; 9% indicated lack of money; 6% indicated lack of confidence; 3% indicated the attitudes of staff or community members, and 2% indicated a previous bad experience.

Ten per cent of disabled people mentioned lack of confidence as a barrier to community involvement, and 8% mentioned the attitudes of staff or other people in their

communities or previous bad experience (4%) Attitudinal barriers were more likely to be mentioned by disabled people aged 16-34 (23 %) and respondents with a mental health condition (34%).

Of the respondents, 23% aged 16-34 and 34% with mental health impairments indicated attitudinal barriers; 9% indicated access problems, including transport or travelling; 2% indicated difficulties getting around in the venue, and 2% indicated lack of suitable toilet facilities.

The relative importance of the perceived barriers varied according to age and impairment. Of the 178 respondents, 33% of those aged 16-34 compared to 17% of those aged 35 or older stated lack of time, and 21% aged 16-34 compared to 8% aged 35 or older stated financial costs of participation. Of the respondents, 46% of those aged 55 and older compared to 30% of those aged 16-54 reported that they did not want to be more involved in clubs, groups or their local community. Of the respondents, 38% with mental health conditions compared to 7% with other impairments stated lack of confidence, while 17% with mental conditions compared to 8% with other impairments indicated cost or lack of money.

5.5 PERCEPTIONS AND EXPERIENCE OF DISCRIMINATION

This section examined how the respondents regarded themselves in relation to the social model of disability, their experience of discrimination, and problems accessing goods and services.

Of the 460 respondents who gave their view on the impact of their disabilities on the daily lives, 55% reported they could not lead a full life because of their impairment; 5% said they could not lead a full life due to their health problem or disability and because attitudes and barriers in society prevented them from doing so, and only 1% could not lead a full life purely because attitudes and barriers in society prevented them from doing so. The respondents thus did not mention their disability as having a role in preventing them from leading a full life. Of the 460 respondents, 6% therefore consciously highlighted the social model of disability.

5.5.1 Disability in relation to the social model

The social model of disability emphasises the ‘disabling barriers’ in society that prevent disabled people from experiencing equality of opportunity with non-disabled people. The social model does not assume that disabled people are all conscious of the social barriers that may disable them, but argues that many disabled people accept inequality as inevitable or natural and personal.

The results of the questionnaire survey (n=460) confirmed that the respondents did not necessarily think about or refer to their impairment in this way, as 8% said that they would prefer to refer to their impairment as “impairment”; 66% preferred the term “health problem” and 26% preferred the term “disability” (see Table 5).

The interest in this context was to understand how the respondents relate impairment and disability. To capture this, the respondents were asked to indicate which of four statements about the impact of individuals’ disabilities applied most to them. In this case “disability” and “impairment” were deliberately not distinguished in order not to assume that the respondents made the distinction.

Table 5 Respondents’ view of the impact of their impairment on their daily life (n=460) (%)

	Total (460)	Age 16- 34 (182)	Age 35- 54 (205)	Age 55+ (73)
My disability has no impact on my ability to lead a full life.	36	40	35	38
I cannot lead a full life due to my disability.	55	39	55	56
I cannot lead a full life due to my disability and because attitudes and barriers in society prevent me from doing so	5	14	7	4
I cannot lead a full life because attitudes and barriers in society prevent me from doing so.	1	5	2	-
Don't know	2	1	1	1

Of the 460 respondents, 55% reported that they could not lead a full life due to their disability, and 36% reported that their disability had no impact on their ability to lead a full life. Six per cent cited attitudinal barriers as impacting on their ability to lead a full life. Of the 182 respondents aged 16-34, 19% said that they could not lead a full life: either because of attitudes and barriers in society (5%) or a combination of their disability (impairment) and social barriers (14%).

Of the respondents with mental health problems, 18% said that they could not lead a full life: either because of attitudes and barriers in society (4%) or a combination of their disability (impairment) and social barriers (14%).

Other significant differences in respondents' perceptions included the following: 77% of those with three or more impairments felt that they could not lead a full life due to their disability compared to 42% of those with fewer than three impairments; 60% of those in lower-income households felt that they could not lead a full life due to their disability compared to 46% of those in higher-income households.

It should be noted that although the respondents were not necessarily aware of the social model, this did not mean that they were not aware of inequality and did not experience discrimination.

5.5.2 Experience of discrimination

The respondents were asked if they felt they had been treated unfairly or discriminated against for any of the reasons listed in Table 6. Of the 208 respondents who answered the question, 25% felt that they had been discriminated against or treated less fairly in at least one of the listed ways; 12% felt that they had been discriminated against or treated less fairly because of their impairment or disability; 11% felt that they had had been discriminated against or treated less fairly because of their age, and 5% felt they had had been discriminated against or treated less fairly for other reasons.

Table 6 Respondents' types of discrimination experienced (n=208)

	% of respondents
Any type of discrimination	25
Because of their impairment or disability	12
Because of their age	11
Because of their gender	4
Because of their ethnic background	2
Because of their religion or faith	1
Other answers	1
None	44

Of the respondents, 6% of the women compared to 1% of the men felt that they had been discriminated against because of their gender. Ten per cent of those aged 65 or over felt that they had experienced any discrimination compared to 31% of those aged 16-34.

Regarding their perceptions of disability discrimination, 35% (n=13) of those with mental health conditions felt that they had been discriminated against because of their impairment compared to 10% of those who did not have mental health conditions.

5.5.2.1 Disability-related discrimination

Of the 25 respondents who felt they had been discriminated against because of their disability, 11 said that it had happened in relation to work or employment (either a job they had, or one they were applying for); 8 of the 25 felt that they had been discriminated against in relation to employment, and 10% of those of working age (aged

16-64) compared to 1% of those aged 65 or older felt that they had been discriminated against because of their disability.

Of the respondents who felt they had experienced disability discrimination, 25% said that this had happened while they were out minding their own business; 19% said this was in relation to benefits; 18% said it happened while they were using public transport, and 13% said it happened when they getting information on something they intended to buy or while trying to buy something.

5.5.2.2 Difficulties accessing goods and services

The respondents were asked if they had ever experienced any difficulties accessing goods or services; for example, problems getting into a supermarket, being offered a lower level of service in banks, or being refused entry at a place of entertainment (n=187). Of the respondents, 68% (n= 127) said that they had experienced at least one of these difficulties.

Of the 127 respondents who experienced difficulties of access, 12% aged 16-55 compared to 7% of those aged 55-64 and 4% of those aged 65 or over said that they had experienced difficulties accessing goods and services.

Of the respondents, 17% with mental health conditions, 13% with progressive impairments, 14% with three or more impairments and 7%with less impairment had experienced difficulties. Of the respondents, 49% experienced difficulties getting into buildings and 41% experienced difficulties getting around buildings.

Some of the respondents had been confronted with relatively extreme difficulties: 60% (n= 76) had been refused entry to premises, 4% had been asked to leave, 3% had been refused service, while 16% had suffered verbal or physical abuse in these situations.

The respondents who had experienced difficulties accessing goods or services were asked if they had been able to use the service since the difficulty occurred. Of the 127 respondents, 30% reported that they had subsequently successfully used the service; 22% had not, and 44% had not tried to use the service again since the difficulty. Among

those who had not attempted to use the service again, 1% said they had not tried to use the service again because of what had happened to them.

The respondents who had experienced difficulties accessing goods or services were asked if, as a result of their experience, they had complained or said something to the provider of the service or their staff, or if someone else had done so on their behalf. Fifty nine per cent (n=75) had not complained or mentioned the difficulty to a member of staff while 33% (n= 42) had made a complaint.

Of the 42 respondents who had complained because of their experience, 40% (17) said that their complaint was settled or dealt with, and 25 said that nothing had happened as a result of their complaint.

5.6 EMPLOYMENT

This section examined aspects of the respondents' employment, in terms of what types of work they do, whether their health problem, impairment or disability impacted on or was perceived to impact on their ability to work, and what support, adaptations and adjustments they need to support their employment. The barriers faced by the respondents who were out of work to get back into work were also examined.

5.6.1 Working status

Of the 460 respondents, 48% were out of work; 17% were not working because they were long-term sick or disabled, 20% were employed, and 3% were self-employed.

Disabled people of working age who had other impairments (51%) were most likely to be in paid work, but only 16% of those with mental health conditions were in paid work. Disabled people with current impairments (39%) and with three or more impairments (22%) were also less likely to be in paid work.

5.6.2 Working and out-of-work respondents

This section examined the working situation of the respondents.

Of the respondents who were in paid work at the time of the study, 24 had a visual impairment, and 26 had a hearing impairment. Of the respondents who were working, 64% worked full-time, 43% worked in the informal sector, and 57% had formal jobs.

Of the 460 respondents, 75% (n= 345) were not in paid work at the time of the survey while, 65% (n= 224) of those who were not working at the time of the study said that they had been in paid employment in the past.

Table 7 shows when the respondents who were not currently working were last in paid work. Of the respondents, 84% had not had paid work for more than two years.

Table 7 Last time respondents were in paid work (those not currently working) (n=345)

	All (%)	Age 16-64 (%)	Age 16-34 (%)	Age 35-54 (%)	Age 55-64 (%)	Age 65 or over (%)
Never had paid work	7	9	33	5	3	4
In the past 2 years	9	17	21	18	10	1
2-10 years ago	24	38	35	37	33	6
More than 10 years ago	60	35	10	40	54	88

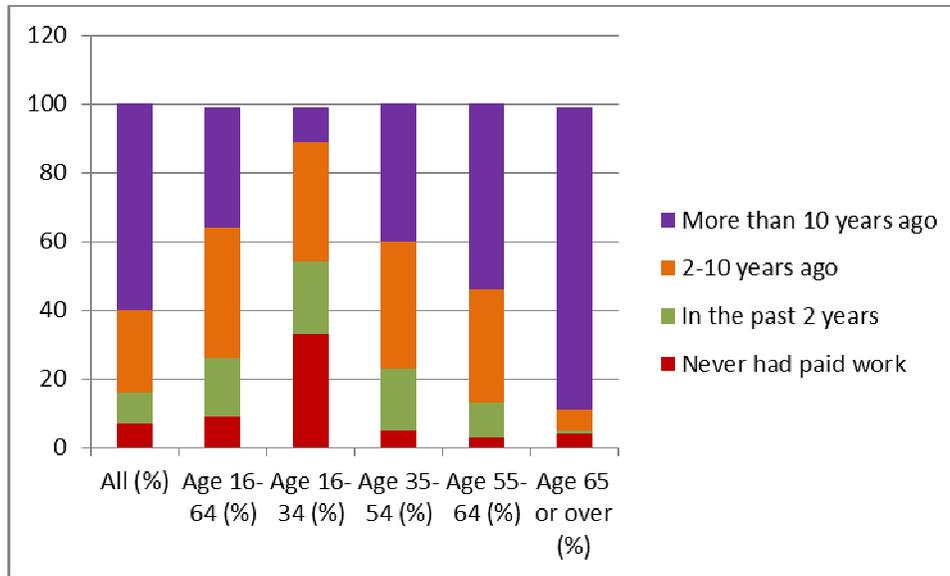


Figure 2 Last time respondents not currently working were in paid work by age (n=345)

The respondents who could potentially be in the labour market (those under the age of 65 who were not retired and not currently working) were asked what prevented them from getting a job. Of these respondents, 42% stated that they were unable to cope with work at the moment; 59% had mental health conditions, and 9% mentioned health reasons such as not feeling well enough. This meant that 50% who could be in the employment market said that they are not working for reasons related to their impairment.

Of the 345 respondents, 17% of the respondents aged 16-34 said that they were not working because they thought they did not have the skills required to get a job. This would appear to indicate that the respondents who were not currently working would benefit from training to enable them to enter or return to employment.

Regarding the reasons why the respondents who could potentially be in the job market were not working, 7% said there was no work; 6% said they were too old to get a job (16% of those were over 55), and 15% cited inability to cope with work.

The respondents who could potentially be in the labour market were asked about the likely impact of learning on their ability to get back into paid work. Those undertaking

learning activities at the time of the study felt fairly positive about the likely impact of learning on their employment prospects, as 57% agreed that a course or class would help them get back into work or find a job.

Those not undertaking activities were less positive about the impact of learning on their prospects, as only 31% agreed that a course or class would help them get back into work.

5.6.3 Barriers to employment

This section examined the respondents' expectations in relation to employment by investigating the barriers they faced getting into paid work. The respondents who could potentially be in work (of working age who were not retired and not currently working) were asked to comment on how their impairment had impacted on their ability to do paid work (n=232).

Of these respondents, 77% of those with three or more impairments compared to 39% of those with fewer than three impairments indicated that they were unable to work because of their impairment.

Of the respondents, 42% with mental health conditions reported that their impairment had made them unable to work and 30% with physical impairments reported that their impairment had limited the kind of work they could do.

Regarding how their impairment had affected the kind of paid work they could or might have been able to do, 42% indicated that their impairment made them unable to work full-time, and 30% said their impairment made it difficult for them to do heavy physical work or lifting; 21% said that their impairment meant that they needed to be off sick for long periods of time, and 20% said that they needed to take time off work at short notice.

Most of the barriers to work identified related to the need for support or understanding from colleagues (for example, flexible working hours, flexibility to take time off sick, need to manage stress, need to take breaks). Of the respondents, 6% said that they

would need support to do the job and 5% indicated special aids or adaptations. It therefore appears that for jobs which do not entail physical work or heavy lifting, several of the respondents felt that they could undertake paid work if reasonable adjustments were made.

The study also wished to assess whether respondents had ever had to leave a job for reasons connected with their impairment. All the respondents who had ever worked and whose impairment had started to have a significant impact on their activities while they were still of working age were asked to comment. Of the respondents, 67% reported that they had not needed to leave work for any reasons connected with their impairment, but 33% had had to do so. Of the respondents, 53% with mental health conditions said they had had to leave a job for a reason connected with their impairment; 14% said that they had been advised to resign by a medical professional, and 3% had been advised to leave by someone else.

The respondents were asked about support, adjustments or adaptations that may have helped them to stay in work. Of the respondents, 50% indicated that they could have stayed if their employers had been more supportive and understanding; 29% said support and understanding from colleagues would have enabled them to stay in work; 33% indicated that they could have stayed if the working hours were flexible; 26% indicated that changes in their job or working schedules would have enabled them to stay in work, while only 9% said they would have needed aids or adaptations to enable them to stay in work.

The majority (92%) of the respondents who believed they could have stayed in work if support, adaptations or adjustments had been made said that they were not offered any of these.

There are also perceptions of discrimination when applying for jobs. As well as experiencing discrimination while in work, disabled people may also experience discrimination related to their impairment when applying for jobs. All those who had been disabled while of working age were asked if they had ever applied for a job and

not got it because of their impairment. Of the respondents said this had happened to them, 10% felt that they had definitely not got a job they had applied for because of their impairment, and 5% thought that this had probably happened.

Of the respondents who felt that they had not got a job for which they had applied because of their impairment, 23% were men aged under 55; 18% had mental health conditions, and 63% said that it had discouraged them from applying for other jobs.

5.6.4 Attitudes to work

The respondents who were working expressed positive views about work and how it contributed to their lives. Some of the respondents who could potentially enter the labour force (of working age and not retired, but not in work) were also positive (see Figure 3).

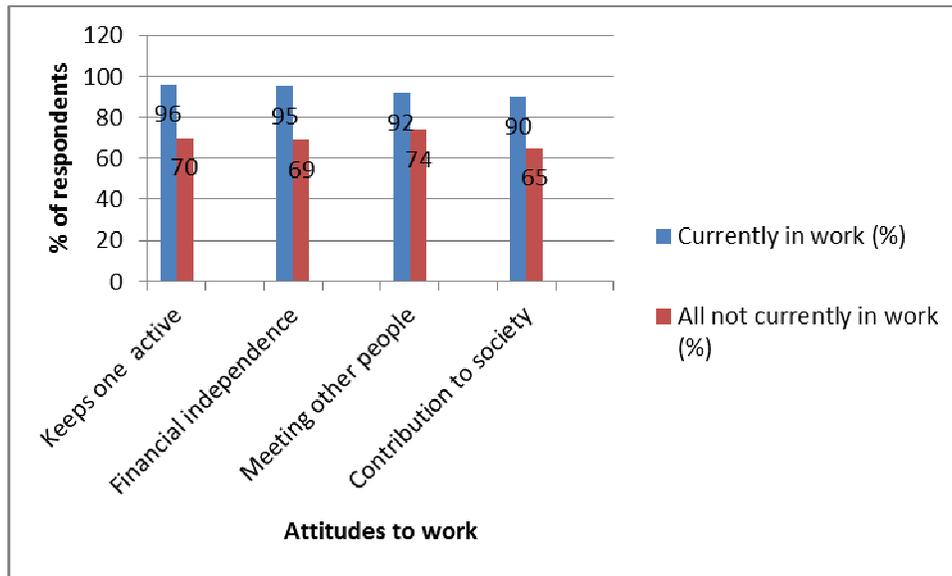


Figure 3 Proportion of respondents who agree with statements about work (n=148)

The respondents were asked to indicate agreement/disagreement with statements related to the impact of work on financial independence, keeping people active, making a contribution to society and meeting other people.

Of the 148 who responded to the question, 85% of men compared to 73% of women agreed strongly that work gave them financial independence. In addition, 98% aged 55-64 compared to 84% aged 16-34 agreed that work enabled them to meet people. Fourteen per cent of the non-working respondents who were younger than 55 compared to 8% of those older than 55 also recognised the benefits of work

Of the respondents who were working, 63% aged 16-34 and 51% in manual labour compared to 36% aged 35 and older saw work as only a means of earning a living.

5.7 EDUCATION

This section explored the respondents' education history and achievements, including types of schools they attended, their attitudes to their experiences generally, barriers to learning, overall attitudes to learning, and their aspirations for the future.

Of the 460 respondents, 27% who were disabled at school and 14% whose impairment started to impact on their activities at age 16 or later described their experience of school as bad; 53% of those disabled at school compared to 64% of those who were not disabled at school did not think that their experience of school had prepared them well for the future. Only 15% were in full-time education at the time of the study; 51% aged 16-34 compared to 24% aged 65 or over had any educational qualifications

Of the 460 respondents, 23% of those who were working and 20% of those in households with a higher monthly income were taking part in learning at the time of the study.

Of the respondents who were not taking part in any learning, 47% indicated that they would like to do so; 30% wanted to participate in learning but they did not feel well enough to do so, could not afford the cost, or did not have time because of family commitments, while 72% were not interested in participating in any course or training. However, 22% wanted to participate in education or training (see Figure 4.)

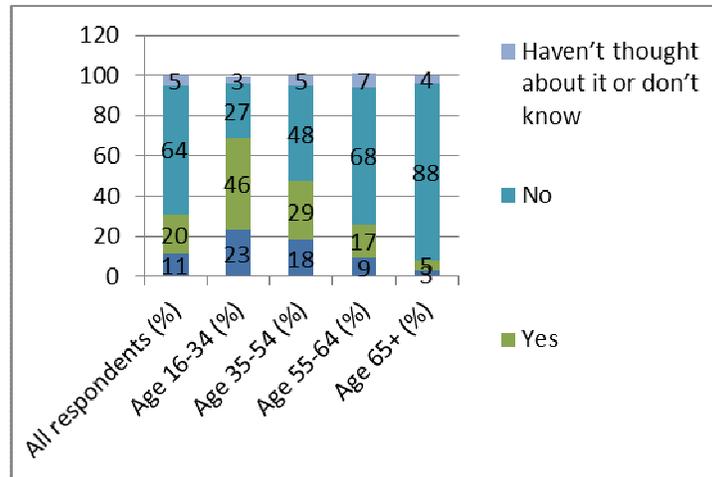


Figure 4 Whether respondent would like to participate in more education or training, or do any courses by age (n=460)

Of the respondents who were involved in learning activities at the time of the study, 78% did it because they enjoyed it; 63% agreed that their course or training kept them active, while 40% of those who were not currently learning thought they would enjoy it.

5.8 HEALTH AND WELL-BEING

This section examined how the respondents viewed their health and general well-being, their use of health services, and their attitudes to health care services and the information they provide (n=411).

Of the 411 respondents who responded to this section, 49% described their life as a whole as good; 4% said that it could not be better; 19% said it was very good, and 28% said it was good, and 30% described their lives as all right and at least one in ten who said it was bad. Of the respondents with a mental health condition 27% described their lives as bad.

The respondents indicated that they had enough privacy and were treated with dignity and respect than to say that they had enough control over what happens in their lives, or that they had done the things they wanted to do. Dissatisfaction was highest among

younger people, those living alone, or those who had mental health conditions. Dissatisfaction was also higher than average among respondents on lower incomes or who were not working.

Of the respondents, 13% of those aged 16-34 and 17% of those aged 35-54 compared to 8% of those aged 55-64 and 5% of those aged 65 or over described their lives as bad.

Contact with other people is often used as a key determinant of happiness. Of the respondents, 30% who never saw any relatives or adults who did not live in the household, 26% who lived in single person non-pensioner households, and 19% who saw people outside their homes less often than monthly described their lives as bad. At the same time, 7% who saw someone every day described their lives as good.

There was also a relationship between satisfaction with one's life and working status and household income. Of the respondents, 72% who were working compared to 55% who were not working said that their lives were good.

5.8.1 Quality of life

This section explored the respondents' perceptions of their own quality of life, in areas of choice, control, privacy and whether they felt they were treated with dignity and respect (n=379). Of the respondents, 12% said they had always and 37% said they had usually done the things they wanted to do in life while 4% felt that they had never done the things they wanted to in life.

Of the respondents, 64% felt that they always or usually had enough control over their lives or what happens in their lives. Regarding control, 76% of those aged 65 or over compared to 55% of those aged 16-34, and 50% of those in households with monthly incomes of less than R4 500 compared to 64% of those with household incomes of R4 500 to R9 000 felt they always or usually had enough control,.

Only 36% of respondents with mental health conditions felt that they always or usually had enough control and privacy in their lives.

Table 8 Respondents' perceptions of privacy and dignity (n= 379)

	Have enough privacy in my life (%)	I am treated with dignity and respect (%)
Always	46	43
Usually	39	43
Sometimes	7	9
Not very often	5	3
Never	2	1
Don't know	2	0

5.8.2 Barriers to accessing health care services

The respondents were asked about their general health over the last 12 months (n=460). Of the respondents, 18% described their health as good; 42% reported that it was fairly good, and 40% reported not good. Of the 460 respondents, 55% and 57% with mental health conditions and progressive disability conditions respectively described their health as not good.

Of the respondents, 51% indicated that they had not encountered any barriers that had made it harder for them to access health services. Men were less likely than women to report having experienced barriers (43% of men and 54% of women). In addition, respondents aged 65 or over (55%) were less likely to have experienced barriers than younger respondents (59% of 16–34 age bracket and 52% of 35–54 age group).

Regarding barriers to access, 24% of the respondents mentioned at least one access barrier to effectively using health services; 15% stated difficulties with transport; 14% stated distance to the nearest health care services, and 12% stated requiring someone to accompany them.

Of the sampled respondents, 10% of those under 54 years of age mentioned a lack of confidence as a barrier to making effective use of health services compared to 4% aged 55 or older, and 25% with mental health conditions mentioned confidence as a barrier.

5.8.3 Information and advice on health

Of the 460 respondents, 80% indicated that they were satisfied with the information and advice they received from health care professionals about their disability; 9% were dissatisfied with the information and advice they got. Among the respondents, satisfaction with information increased with their age: 86% of those aged 65 or over compared to 72% of those aged 16-34 said that they were satisfied.

The respondents who were dissatisfied with the information and advice received were asked to indicate why. Of those respondents, 41% said that the information was not detailed enough; 29% said that they were not given enough information about what they could do to help themselves, and 27% said that the health care professional involved was not sympathetic, there was no information available, or they could not understand the information.

The majority of the respondents (80%) preferred to go to a hospital for information about their impairment; 39% preferred to get information from a specialist practitioner such as a specialist doctor or nurse at a private hospital, and 9% indicated that they would ask their friends or family for information.

Of the respondents, 20% of those with a mental health condition preferred to get information about their disability from a specialised therapist while 57% of the respondents (57%) preferred charities or organisations relevant to their impairment and support groups as a source of information.

5.7 CONCLUSION

This chapter discussed the data analysis and interpretation. The results were presented in percentages, tables and diagrams. Barriers to participate in employment, learning, social activities and their local communities were analysed. The main barriers included not feeling well enough to participate owing to their disabilities, lack of money; lack of

confidence, and the attitudes of others in the communities, at work or at service points. The importance of choice and control in disabled people's lives was established to be an important aspect of wellbeing and life satisfaction. The respondents with mental health conditions reported the least positive experiences and outcomes, especially related to their lack of confidence and the attitudes of others in their communities.

Although the respondents did not allude to the social model of disability, many of the barriers described in the study are generally consistent with the social model, and this indicates a lot still needs to be done to achieve equality for people with disabilities in South Africa.

CHAPTER 6: Conclusions and recommendations

6.1 INTRODUCTION

This chapter concludes the study, provides a synopsis of the findings and limitations of the study, and makes recommendations for practice and further study.

6.2 PURPOSE OF THE STUDY

The purpose of the study was to

- Explore and determine the theoretical, conceptual and theological meaning of living with disabilities.
- Examine disabled persons' perceptions of the church's influence on their spirituality and daily lives.
- Describe the socio-economic conditions of disabled people in South Africa with particular attention to civic participation, discrimination, employment, education and health.
- Make recommendations, based on the findings, to inform policy on people with disabilities in South Africa.

6.3 FINDINGS

The findings suggested that disability creates unique challenges that may necessitate pastoral care by church leaders and congregations. People with disabilities should provide leadership about the needs and resources of the population, rather than to rely on others to speak for them.

The study found a need for action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution to society.

There is a need to propagate up-to-date information on available programmes and services to persons with disabilities, their families and the general public.

The main barrier to participation was that the respondents did not feel well enough to participate owing to their disabilities. Other barriers included lack of money, lack of confidence and the attitudes of others either in the community, at work or at service points.

The importance of choice and control in disabled people's lives was established to be an important aspect of wellbeing and life satisfaction. Satisfaction with the level of choice in the respondents' lives was relatively high and those who felt they had a choice were satisfied with the service they received.

The respondents with mental health conditions reported the least positive experiences and outcomes. Many of the barriers they reported related to their lack of confidence and the attitudes of others in their communities.

With regards to the Church's relationship with its disabled congregants, it seems to suggest that; the church still liberates some while others feel neglected. The church itself is free and responds to people with disabilities but up to a certain degree which indicates that not all are accommodated. Structural impediments loomed large in the discussions. Stigmatizing texts in light of the Gospel of Jesus Christ were rife although debates still exist as to whether the gospel has suffered from misinterpretation. The embarrassing history of discrimination against people who live with disabilities seem to have kept some away. The congregants also challenged the church to be free of the negative influences of the culture of not moving away from its past in order to embrace new challenges. All in all, the general outlook is that people still consider the Church as the main place refuge in times of trouble and the trust is still there.

6.4 RECOMMENDATIONS

Based on the findings, the researcher makes the following recommendations for practice and further research.

The study found a need for action to raise awareness about persons with disabilities, their rights, their needs, their potential and their contribution to society. It is recommended that the National Departments of Health, Social Development, and Public Service and Administration collaborate to introduce local and national information campaigns and programmes on persons with disabilities and available programmes and services to persons with disabilities and their families. The programmes should emphasise that persons with disabilities are citizens with the same rights and obligations as others, and reflect the principle of full participation and equality.

It is recommended that local and national Departments of Health ensure the provision of effective medical care to persons with disabilities; introduce programmes run by multidisciplinary health care teams for early detection, assessment and treatment of impairment. Community health care and social workers should be trained in early detection of impairments, the provision of primary assistance and referral to appropriate professional services, as well as provide advice and counselling to the disabled and their family members. This might assist in the prevention, reduction or elimination of disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organizations for persons with disabilities at the planning and evaluation level.

It is recommended that local and national Departments of Social Development streamline the social security system to eradicate complete dependency on social grants. In doing so, the available social security programmes should provide incentives for persons with disabilities to seek employment in order to establish or re-establish their income-earning capacity. The disability grant should be maintained for as long as

the disabling conditions remain, but in a manner that does not discourage persons with disabilities from seeking employment.

It is recommended that partnerships be established with the private sector to encourage enterprises to include disability issues in all aspects of their activity including raising levels of awareness, recruitment, raising equity for business (similar to Black Economic Empowerment [BEE]) and effecting work adaptations.

It is recommended that rehabilitation programmes and services be developed for persons with disabilities in order for them to reach and sustain their potential levels of independence and functioning. Such programmes should be based on individual needs and foster the principles of full participation and equality. Programmes should include a wide range of activities, such as basic skills training to improve or compensate for an affected function, counselling for the disabled and their families, developing self-reliance mechanisms, and other services such as assessment and guidance.

There is a need to ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily lives and to exercise their rights. It is recommended that the Department of health ensure the provision of assistive devices and equipment and personal assistance, according to the needs of persons with disabilities. All persons with disabilities who need assistive devices should be able to have access to them. In rehabilitation programmes for the provision of assistive devices and equipment, the design, durability and the gender and age-appropriateness of assistive devices and equipment should be taken into consideration.

It is recommended that personal assistance programmes for the disabled should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way the programmes are delivered.

Accessibility is of paramount importance in the process of the equalization of opportunities in all aspects of society. For persons with disabilities, policy should be implemented to make the physical environment accessible. Standards and guidelines

should be introduced to ensure accessibility to housing, buildings, public transport services and other means of transportation, streets and other public places.

Concerning education, there is a need to recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. It is recommended that the Departments of Education, Social Development and Economic Development and Planning ensure that the education of persons with disabilities is an integral part of the educational system. National educational planning, curriculum development and academic institutions' organization should include education for persons with disabilities. Adequate accessibility and support services for people with disabilities need to be available at all education institutions.

Organizations for persons with disabilities should be involved in the education process at all levels. Educational provision for persons with disabilities should be encouraged in mainstream rather than special schools. Education policy should make provision for curriculum flexibility, additions and adaptations; ensure on-going teacher training and support, and the education and the community-based programmes should be integrated to complement each other to encourage communities to use and develop their resources to provide local education to persons with disabilities.

With regard to employment, people with disabilities should have equal opportunities for productive and gainful employment in the labour market. Obstacles to employment of people with disabilities should be removed by providing for vocational training, reserved or designated employment, making loans or grants available for small business, and encouraging employers to make reasonable adjustments to accommodate persons with disabilities.

On the spiritual side, religious authorities should include information on disability in religious education programmes. With regard to the church, there is a need for pastoral preaching to focus more on life than death because this is empowering and gives hope to those who are frustrated with their lives. There is also the need to realize that people

with impairments or disabilities, even as individuals, are creative, relational and open to receiving love and to loving others in a variety of ways. Hence, people with disabilities, are also individually image-bearers of God, as much as anybody else, not only in the collective sense. As such, the scriptural interpretation that prescribes to 'normalcy' should be avoided.

Also, it is essential that all forms of the worship, mass and, or celebrations be completely accessible to persons with disabilities, since spiritual tie that binds the Christian community together. The church should reawaken the old tradition of taking mass to those who are frail and incapable to seeking it. Home and hospital visits are essential as these have an empowering component which brings hope. To exclude members of the parish from these celebrations of the life of the Church, even by not taking initiative, is to deny the reality of that community. Accessibility involves far more than physical alterations to Church buildings. Realistic provision must be made for persons with disabilities to participate fully in all liturgical celebrations such as the sacraments of reconciliation, confirmation, and anointing of the sick. Even an effort should be made to invite disable to perform Church duties.

6.5 FURTHER RESEARCH

It is recommended that further research be done on the following topics:

- The living conditions of persons with disabilities in rural and urban areas
- The needs of families with disabled children
- A comparison of the Roman Catholic, Methodist and Evangelical Christian theological perspective of disability
- The occupational needs of people with disabilities

6.6 LIMITATIONS

The study was limited to a relatively small sample of respondents, in one area (the greater Cape Town area in the Western Cape), and only Evangelical Christians were interviewed. Consequently, the findings cannot be generalised to all areas of the country and all the Christian churches.

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Appendix A: Questionnaire

Thank you for offering to take part in this interview. Your participation is entirely voluntary and the information collected will be used strictly for academic research purposes. **All information provided is strictly confidential, and neither you or any other participating individuals will be identified in any reports.**

1. Do you consider yourself to have a disability or long term health condition (*which has lasted at least 12 months or that is likely to last at least 12 months*) and affects your day-to-day activities?

Yes

No

2. If NO to 1 above, are you a relative, Parent or care-giver of someone with a long term health condition or disability which affects their day-to-day activities?

Yes

No

3. If YES to 2 above, please indicate: Relative; parent; Care-giver

4. Please indicate the nature of the disability and provide details as relevant?

Mobility (physical disability) _____

Mental health difficulty

Blind/partially sighted _____

Progressive disability/chronic illness (e.g. Cancer)

- Deaf/hearing loss
- Learning disability
- Multiple disabilities _____
- Other _____

5. Number of disabilities the person has _____

6. Gender of the person with the disability? _____

7. Age of the disabled person _____

8. Is the disabled person in school or in some form of formal learning?

- Yes
- No

9. If NO, would the disabled person like to be in school?

- Yes
- No

10. If YES, what reason is stopping the disabled person from being in school

11. State educational level of the disabled _____

12. Is the disabled employed?

Yes

No

13. If YES above, nature of employment (indicate position)

Permanent _____

Casual _____

14. If NO, and yet of working age, indicate why the disabled person is not working.

15. Number of people living with the disabled person _____

16. Is the disabled person the head of the household?

Yes

No

17. If NO in 13 above, what is the relationship between the disabled person and the head of the household?

Child to head

Grandchild

Marital partner

Parent of head

Grandparent of head

Other _____

18. Provide the household monthly income of the household in which the disabled person is a member _____

19. Have you or the disabled person on whose behalf you answer been disabled since birth?

Yes

No

20. If NO above, how long has the person been disabled? _____

21. If NO in 15 above, at what age did the person's present disabilities begin _____

22. If NO in 15 above, did the person experience a prior disability before the present disabilities _____

23. Which health services has the disabled person used or visited

.....
.....
.....

24. In relation to the services detailed in question 17, please indicate if they were easy to find, clear directions and easy to access.

Location YES / NO

Car parking YES / NO

Transport YES / NO

Access ramps and Rails YES / NO

Lifts YES / NO

Opening Hours YES / NO

Other (please specify) YES / NO

25. If you have answered *NO* to any of the above, please provide some brief information.

26. Please indicate the resources that were made available to improve access for the disabled and to support their needs in the local area? (*indicate as many as you can think of*)

27. If the disabled person is in employment, indicate the resources that were made available to improve access for the disabled and to support their needs at work? (where none exists, write No)_____

28. If not satisfied or No to above, please give details of what would have helped you to have better access _____

29. If the disabled person is in school, indicate the resources that were made available to improve access for the disabled and to support their needs at school? (write No where non exists)_____

30. If not satisfied or No to above, please give details of what would have helped you to have better access _____

31. Do you find public transport in your area to be disabled friendly?

Yes

No

32. Have you ever been excluded from something that you wanted to do because of your disability? (e.g., a job, a social activity, a party)

Yes

No

33. If YES to above, please give details of the activity

34. Has the disabled person been part of any of the following social engagements during the course of his/her disability? (indicate how often e.g., weekly, monthly...)

Spiritual group _____

Social club _____

Sports team _____

Support group _____

Community centre _____

Other (specify) _____

35. Consider the possible barriers to participation and choose which one if any, would prevent you, or prevents you from taking part in the activities mentioned above as well as others you might want to be part of.

Lack of money/ high cost of participation

Lack of time

My disability / I don't feel well enough

I lack the confidence to do so

Bad attitude from other members of staff

Accessibility issues (specify) _____

Other (specify) _____

36. Consider the nature and extent of your disability how it affects your day-to-day life. Then choose which of the following statements is true to you.

My disability has no impact on my ability to lead a full life

I cannot lead a full life due to my disability

I cannot lead a full life due to my disability and because attitudes and barriers in society prevent me from doing so

I cannot lead a full life because attitudes and barriers in society prevent me from doing so

Don't know/ No comment

37. Do you think that any of the following has created any additional barriers to accessing services? *If so, indicate which one.*

- Race,
- Gender
- Age
- Religion/faith
- My disability
- Non
- Other (specify) _____

38. How does the disabled person consider his/her life as a whole today?

- Very good,
- Good
- Alright
- Bad
- Very bad

39. Does the disabled person think that he/she is treated with dignity and respect? Consider the options below.

- Always
- Usually
- Sometimes
- Not very often
- Never
- Don't know

40. How satisfied is the disabled person with the advice and information from health professional about their disability?

- Very satisfied
- Satisfied
- Not satisfied
- Very dissatisfied
- No information at all

41. Where would the disabled person want to go for information on his/her health?

- Hospital
- Specialist practitioner
- Friend/ relative
- Other (specify) _____

42. Please provide any other comment you consider important with regards to your disability and access to services, social interaction and other important issues.

Appendix B: Letter of ethics clearance



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

21 June 2011

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Reference No. 502/2011

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Mr P Mdluli

LETTER OF ETHICS CLEARANCE

With regards to your application, I would like to inform you that the project, *Disability in South Africa: A Theological and socio-economic perspective*, has been approved on condition that:

1. The researcher/s remain within the procedures and protocols indicated in the proposal;
2. The researcher/s stay within the boundaries of applicable national legislation, institutional guidelines, and applicable standards of scientific rigor that are followed within this field of study and that
3. Any substantive changes to this research project should be brought to the attention of the Ethics Committee with a view to obtain ethical clearance for it.

We wish you success with your research activities.

Best regards



Sidney Engelbrecht
MR SF ENGELBRECHT

Secretary: Research Ethics Committee: Human Research (Humanoria)

